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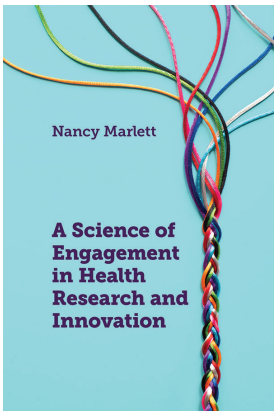

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

Nancy Marlett

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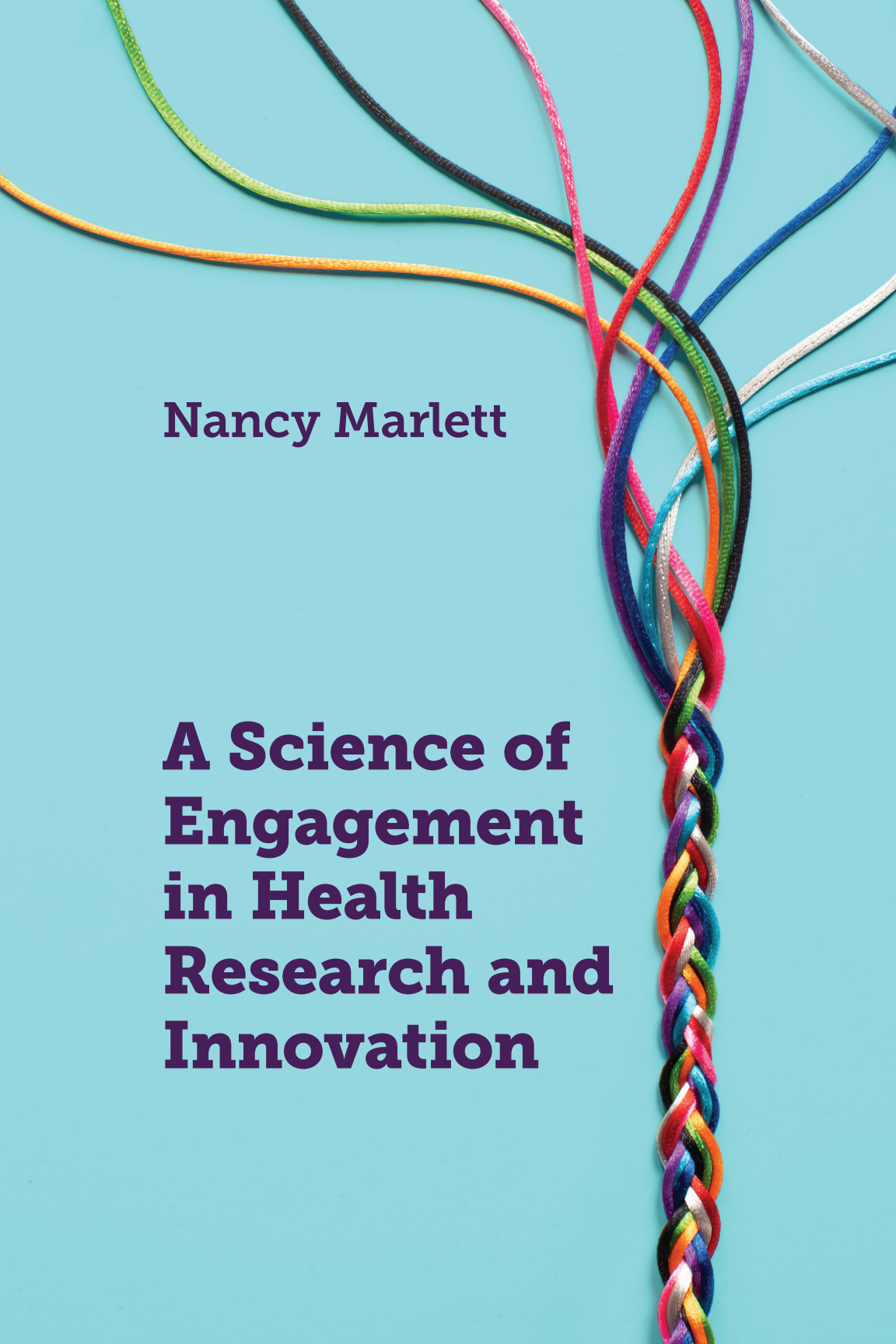

Nancy Marlett

A Science of Engagement in Health Research and Innovation

Chronicling Dr. Marlett's distinguished career, this book is a richly described compilation of accessible resources for those interested in centring "patient" voices in health research and innovation. Through this book, readers—theorists, methodologists, practitioners, educators, students, and patients—find abundant points of entry through which to step into the conversation in a way that best fits their background and goals. Vivid historical accounts help readers locate their own experiences in relation to how discourses and corresponding practices have been advanced as well as challenged. Exemplar patient-driven initiatives are described and innovations to research design and data analysis are illustrated. A multitude of plain language tables and thought-provoking discussion questions add to the demystifying of research processes. This book has something for everyone seeking a world in which power and privilege can be more equally shared.

—Dr. Bonnie Lashewicz and Dr. Meaghan Edwards,
Community Rehabilitation & Disability Studies,
Department of Community Health Sciences,
Cumming School of Medicine, University of Calgary

A SCIENCE OF ENGAGEMENT

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Contents

List of Abbreviations

AAPS	Association for Advancing Participatory Science
AbSPORU	Alberta's Strategies for Patient-Oriented Research Support Unit
AFI	Adaptive Functioning Index
AHS	Alberta Health Services
CAIL	Calgary Association of Independent Living
CBPR	community-based participatory research
CCD	Canadian Coalition of the Disabled
CFHI	Canadian Foundation of Health Improvement
CGT	classical grounded theory
CQI	continuous quality improvement
CS	citizen science
EDI	equity, diversity, and inclusion
GRR	generalized resistance resources
HIMSS	Healthcare Information and Management Systems Society
HQCA	Health Quality Council of Alberta
IAP2	International Association of Public Participation
ICU	intensive care units
IoT	internet of things
JEDI	justice through equity, diversity, and inclusion
KT	knowledge translation
LOI	letter of intent
MAF	motivation to avoid failure
MAS	motive to approach success
NAADAC	National Association for Alcoholism and Drug Abuse Counselors
NIED	National Initiative for Eating Disorders
OCAP	ownership, control, access, and possession
OIS	open innovation in science
PaCER	Patient and Community Engagement Research
PAN	Patient Advisors Network
Pan	Pacific Aids Network
PAR	participatory action research
PCN	primary care network
PCORI	Patient-Centered Outcomes Research Institute
PI	principal investigator
POR	patient-oriented research
PRA	participant research associate
PREM	patient-reported experience measures

PRR	program resistance resources
PWLE	people with lived experience
RRI	responsible research and innovation
SCN	Strategic Clinical Networks
SoC	sense of coherence
SPOR	Strategies for Patient-Oriented Research
TAIL	Tell, Ask, Involve, and Lead
TQM	total quality management
U3A	University of the Third Age
XD	experience design

Acknowledgements

Writing alone during the pandemic lockdown and retirement was new and uncomfortable, but I enjoyed the chance to think about the people who influenced this book. Family has been my constant support: my parents Bill, Mary, and Ethel; sister Jan; Chet, my first husband and co-parent of Paul (Christina) and Dinou (Dan). Our grandchildren, Tia, Zoe, and Oakley; and Heather, my partner and colleague through forty years of struggling to make a difference. At each bump along the way, family encouraged, sighed, and then set to work offering ideas, help, and welcome distractions. They have shared the load and celebrated the achievements.

The researchers and projects that directly informed the development of the science of engagement (SoE) are as follows:

- **Lakeshore Psychiatric Hospital,** during a time of deinstitutionalization in the late 1960s, was the site of psychological innovation: Drs. Dick Steffy and Ron Bond and psychologists Joan Hart and Marg Craw introduced a first Canadian token economy and awakened my passion for data, observing patients and staff to understand underlying relationships and power. I was then asked to develop a realistic work-training program that deepened my understanding of reward systems as treatment and how realistic experience motivated patients. Dr. Hy Day at York University supported this work and introduced me to vocational programs in communities and the international vocational rehabilitation community.
- **Community development, program development, and community rehabilitation as a psychologist and consultant in Canada and internationally.** I moved to Calgary, working independently as a psychologist and working with the diversity and challenges of community alternatives: from families caring for profoundly handicapped babies, troubled youth to seniors and palliative care; provincial and national government policies related to handicapped children's services, legal guardianship, technical aids, assured income; community development and large scale disability census and co-design of treatment and supports for community agencies.
- **Vecova** (formally Vocational and Rehabilitation Research Institute) is an innovative institute of the University of Calgary as part of Canada's Centennial commitment to establishing innovative community alternatives to institutions for persons with developmental disabilities. The leadership team of Roy Brown

and Dan McKerriker from the UK and Trudy Carlisle, along with Reg Peters and Anne Hughson, created many original programs, including the first driving course for developmentally disabled adults, a lab producing medical appliances for an American pharmaceutical company, the first 53-week course for training future rehabilitation personnel for Canada Manpower students in the western provinces, and I completed research and publication of the first strength-based training curriculum and assessment kit co-designed with trainees and staff.

- **The Calgary Association of Independent Living's (CAIL)** Heather MacLean and Muriel Keeling and the members of CAIL forced a sea change in my understanding of consumer-led support programs. This was my first introduction to full co-creation of a peer support program with persons with lived experience of disability that led to an innovative independent brokerage model, where members hired and trained their support staff and managed their service budgets with support from a group of supporters they chose. The members of CAIL were involved in my first experience using stories to identify concerns and goals as part of peer support. The members were also involved in creating the first versions of a disability standpoint theory. Their influence prompted me to study the potential of co-research as a career change.
- **The Open University**, UK, supported a radical PhD thesis that challenged many disciplinary and academic protocols to develop an integrated narrative research method that supported co-design. The co-researchers included: Gerry Kinsella, director of one of the first social enterprises in the UK to prepare persons with disabilities for competitive employment; David Brandon, northern director of Mind programs; Dorothy Birtles of the Prisoner Befriending Scheme as part of the UK Quaker movement; Cicely Saunders founder and director of the modern hospice movement; Henry Three Suns of the Family Services Corporation of the Siksika Nation in Alberta; and Henry Enns, founding member of Disabled Peoples' International. These pioneers of new social movements later were recognized by their governments for their work. They also proved that co-design research with citizens as co-researchers was possible.
- **Kerby Centre**. I acknowledge Dr. Ann Martin Mathews, the national director of the Canadian Institute for Aging for seeing the opportunity to support the translation of my thesis to community-based narrative methods for seniors. The director of the centre and

their Centre of Excellence, Pat Allen, along with Dorothy Dooley and the university team of *Grey Matters* (published in 2010)—Drs. Claudia Emes, Joan Ryan, Penny Jennett, Marianne Rogerson, Mo Watanabe, and Bob Stebbins—mentored six teams of seniors who tested the narrative research methods, in collaboration with eight community agencies that lead to *Grey Matters*, that has become a curriculum for rigorous and participatory community research.

- **Community Rehabilitation and Disability Studies** program at the University of Calgary provided a chance to work with Anne Hughson and Roy Brown to develop the first community rehabilitation and disability studies program in Canada. The interdisciplinary program in five faculties introduced the concept that persons with disabilities and chronic and complex health conditions could be co-developers of a social science based on critical thinking and participatory action research. Our interdisciplinary studies in social work (with Dorothy Badry) and kinesiology (with Claudia Emes, the co-author of *Grey Matters*), and specializations in psychology and medicine, provided the base for work with environmental design, sociology and nursing. When we were invited to move to the Cumming School of Medicine, the following people were instrumental in developing a new and sometimes challenging voice in medicine: Mo Watanabe, Jon Meddings, and Todd Anderson, deans of Medicine; Tom Noseworthy, Brenda Hemmelgarn, and Fiona Clement of Community Health Science; along with William Ghali and Tom Stelfox of the O'Brien Institute.
- **Undergraduate and graduate students** of Disability Studies in Calgary, across Canada at our career ladder colleges and a national early computer-based distance education degree, became champions in challenging institutional barriers and systemic discrimination. I wish to acknowledge the essential contributions and guidance of Svetlana Shklarov and Tamara McCarron, my PhD students who became essential partners in developing and managing teaching and research components, grant development, and publications, providing administrative and personal support.

  Much of the theory adaptation and development of peer research was possible because of collaborative group work by undergraduate and graduate students in courses related to social construction and new directions in community rehabilitation and emancipatory social science. Students conducted detailed narrative analysis of autobiographies of disabled lives and those with health conditions to

identify scripts that led eventually to standpoint theory in healthcare. Other students explored health systems using social problem theory or, more recently, developed proposals to tackle social discriminatory practices using readings from the book manuscript.

- **University of Calgary leadership and administration.** I have been fortunate to be part of the University of Calgary for many, many years, one that acknowledged and encouraged innovation in research, education, and community service. This began at Werklund School of Education with Ian Winchester and Frank Oliver, deans, who, along with Murray Fraser, president, and Joy Calkin, vice-president, supported and rescued many forays into political organizing. In a time when most interdisciplinary programs were short lived, their early support ensured that the program became embedded in an academic culture and supported our early successes as the first university in Canada to use the internet to provide distance education for both undergraduate and graduate education. They paved the way for true transdisciplinary interfaculty collaboration.

  When PaCER became a social enterprise, the administrative and academic infrastructures—from Contracting, Finance, Payroll, and Accounting—were there to find, often circuitous, routes to accommodate new practices that accommodated paying patient researchers according to university scale and an ongoing struggle to understand the value of social enterprise.

PaCER Acknowledgements

- **Intersectoral partnership in health**. Tracy Wasylak of Alberta's Strategic Clinical Networks and Deborah Marshall from the O'Brien Institute of Public Health joined me to become the mothers of PaCER. The three of us formed a creative partnership during the incubation stage, continuing to break new ground in cross-sectional health research as we developed the concept of peer- or patient-led research. They were instrumental in establishing a management team, liaison practices, and ways to handle finance and HR across domains. Tracy and Deb negotiated the transfer of PaCER to Continuing Education and continued to serve on Continuing Education committees to expand academic and health system alliances.

  The PaCER advisory board, led by Dr. John Lacey, guided PaCER during the incubation stage of social enterprise. Without the board's

wide experience and expertise in starting new ventures, PaCER would have remained a pilot project instead of a functioning research contractor and educator. During this time, the PaCER website and the PaCER research hub became part of the university PRISM (https://prism.ucalgary.ca/), a digital archive of the university's intellectual output.

- Continuing Education and the PaCER Advisory Committee. Associate Vice-President Sheila LeBlanc (Continuing Education) stepped up to take on the delivery of the PaCER program as a university program, and she and the Continuing Education teams have enabled the PaCER program to be recognized by the university, offering a university-approved national online training program for non-traditional students. Courses now run two or three times a year and graduates support the Strategic Clinical Networks community health, academic, and clinical teams and the Alberta SPOR unit (Strategies for Patient Oriented Research).

  PaCER graduates have become the pioneers and innovators of peer research and leaders in patient engagement in Canada. Early graduates Jean Miller, Sylvia Teare, Marlyn Gill, Susan Nguyen, and Sandra Zelinsky developed research teams conducting contract research. They became part of the research management team of PaCER and were joined by other graduates who established new teams; Romita Choudhury (Cancer) and Susanna Koczkur (Mental Health), who was also the project manager of the Indigenous contract for PaCER. Eventually they became university contractors who hired peer research assistants for peer research contracts, managed the contracts, reporting to academic leads and team sponsors. They led the way for other PaCER graduates to become peer mentors of training teams, patient advisors, and patient coordinators in healthcare. They published their research with the sponsors and contractors. PaCERs define what can be done and continue to amaze with their ingenuity and persistence in finding openings for peer research in health.

  PaCER research early adopters from the University of Calgary provided the reality check for research done by, with, and for patients. Sixty-four research projects, sponsorships, and contracts in the first eight years of PaCER. The following is a list of a portion of the social enterprise PaCER contract research by academic researchers:

- Knee Osteoarthritis and Self-management and Knowledge (KOASK): Dr. Deborah Marshall University of Calgary
- Cardiac care co-investigators: Dr. Matthew James, Dr. Merril Knudtson, Dr. Colleen Norris
- Centralized intake for rheumatoid arthritis: Dr. Deborah Marshall
- Making It Work Program: Dr. Dianne Mosher
- Patient and family participation in the AHS Seniors Health Strategic Clinical Networks (SCN): Dr. Heather Hanson, Assistant Scientific Director, Seniors Health SCN
- First Nations, Métis, and Inuit rheumatoid arthritis patients: Dr. Cheryl Barnabe
- Advanced care planning within the South Asian community: Dr. Jessica Simon
- Family of youth visiting the emergency department with mental health concerns researchers: Marni Bercov
- Enhancing recovery after surgery: Dr. Leah Gramlich, Dr. Gregg Nelson, University of Alberta
- Engaging patients in breast cancer education: Dr. Romita Choudhury

The Manuscript

At this point I acknowledge those who have contributed to the writing of *A Science of Engagement*. Tamara McCarron contributed material on patient motivation to engage in health research. Cera Cruise contributed student assignments from an undergraduate special project course using material from the early work on the science of engagement. A graduate course in Social Construction in Disability tested an early version of the manuscript as part of the study of changing roles in health care. Finally, the PaCER advisory committee kept me connected to PaCER training and developments in peer research locally and nationally.

I especially acknowledge an unplanned but powerful group of PTSD survivors who agreed to test drive the manuscript from a patient perspective as it evolved. They provided a rare opportunity to share ideas and challenge concepts among equals. Many of their suggestions have made it into print. Their insights convinced me that patients and community members with an interest in health research will become important champions of the emancipatory nature of this new science.

This has been a long journey for the patient and creative staff of the University of Calgary Press: Tariqa Tandon provided the original editing of the manuscript once it was accepted by the Press. She managed to provide consistency in a manuscript that grew and evolved over four years. Director Brian Scrivener, whose vision of open access publishing as a way to democratize science, began with *Grey Matters* and persisted despite the rapid technology transformation of health and healthcare and new social movements devoted to democratizing science. His patience and support, along with editor Helen Hajnoczky and the Manifold wizard, Alison Cobra, have made it possible to achieve the impossible: a manuscript of a new health science in the midst of global health chaos.

Finally, I wish to acknowledge the source of my inspiration and motivation to create a science of engagement. She has been my guide to managing chronic and complex health issues within health systems and the skills needed to meet the challenges of systemic discrimination. She became a colleague in patient-led initiatives, director of Independent Living, co-presenter at courses and conferences. She remains the source of encouragement and support through many obstacles. Heather MacLean, my partner in innovation, and one fine researcher, teacher, and innovator.

This book is dedicated to the memory of Dr. Anne Hughson, colleague and director of Community Rehabilitation and Disability Studies, a fierce advocate for the rights of persons living with disability and a friend. Her input was curtailed by her untimely death, the loss of her critical gaze and humanity is sorely missed by all who had the fortune to work and learn with her.

I most humbly acknowledge the many involved in these last stages fraught with technophobia. The book couldn't have made it to print without the support of family and colleagues and IT folk who found ways for me not to lose documents. Cape Breton is a long way from Calgary, and this last push created an oasis where I could be both focused and alone and reconnect with staff, faculty, and students. Thank you to Valerie, Duaa, and Gunpreet.

Prologue: A Journey of Exploring New Relationships in Health Research

I began this book to share the learnings of a 25-year quest with people trying to have a say in how their health and healthcare experiences could impact health research, policy, planning, and innovation. The backdrop to this journey has been the fierce and ongoing debates about what it means to be a 'patient' in health research that considers patients primarily as data. In such research, patients were selected to ensure consistent outcomes, not told about the research nor why they were selected as subjects, and were advised not to share anything about their experiences. Qualitative research broke free of these rules to acknowledge the importance of authentic patient experiences, to create partnerships with patients in the design of research, and to collect and analyzing data together to produce authentic outcomes to inform healthcare innovation. Patient roles and relationships with health researchers, planners, and innovators began evolving largely because of early advocacy from patient communities, especially those from marginalized groups.

This book tracks the emergence of peer research, done by, with, and for the patients and communities who chose to be co-researchers and patient advisors in health research. It builds on *Grey Matters: A guide to collaborative research with seniors* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/), a research book created in conjunction with seniors who were co-designers of a training approach to senior's led research. Since then, the evolution of peer research methods has continued expanding the scope for patient led research, undertaken by patients in health research and by training programs such as PaCER.

This book begins in Canada, after the Second World War, a time of large systems, institutions and health professionalization. My first career in a large institution brought token economies—paying patients to act normal—first in a back ward of difficult women, and then creating work opportunities for pay

that evolved from one workshop to workshops in all wards, and outside employment and startups in other institutions. Moving to Alberta, I worked as a psychologist, but shifted to a team with a federal grant to start innovative vocational rehabilitation for adults with developmental difficulties. New community support services created the need for university graduates, and I was privileged to design early disability studies degrees programs at the University of Calgary—eventually these degrees moved to the Faculty of Medicine. Creating community-based professions in medicine with groups who had been excluded from health research, such as women, Indigenous people, people with disabilities, and people experiencing poverty, provided a unique opportunity to forefront community expertise and support patient- and community-led research. This led to a partnership with Strategic Clinical Networks, improving the health of Albertans. It also opened the door to federal health grants, and provincial funding to conduct patient engagement in research. *Grey Matters* (Marlett & Emes, 2010), supported peer led research that prepared graduates to conduct co-research with these health grants and projects.

This suggested that we could be a social enterprise to conduct peer research, and we grew fast because we had an entrepreneur guiding our new Patient and Community Engagement business model. We worked with the Strategic Clinical Networks, health research grants, the Community Health Sciences Department, Dr. Deborah Marshall, and community health researchers. Our small social enterprise set the stage for a formal program of studies—PaCER—in the Department of Continuing Education, which took our informal three courses and parlayed them into a university program, training patients and others to conduct peer-led research.

I would like to begin by acknowledging the early health research traditions of patient engagement: participatory action research (PAR), community-based participatory health research (CBPHR), patient-oriented research (POR), and more recently, citizen science (CS). The options of participatory research have grown exponentially across disciplines and research traditions and readers are invited to look at the current fields related to participatory research by Vaughn and Jacquez (2020, https://doi.org/10.35844/001c.13244), who use the IAP2 categories of public participation to consider the current participatory models across disciplines and theoretical models. Nina Wallerstein (https://hsc.unm.edu/directory/wallerstein-nina.html) co-created a standardized POR measures with patients to assess levels of engagement using the same framework and defines a patient as someone who has personal experience of a health issue, or their informal caregivers, including family and friends.

I became a researcher during the civil rights and emancipation movements of the end of the last century. Building on the radical traditions of the Chicago

school and Paulo Freire's emancipatory pedagogy, research and civil action provided the impetus for change in marginalized groups. Early examples of emancipation included community health centers in the United States that gave rise to community health research that explored participatory methods and relationships (Blumenthal, 2011, https://doi.org/10.1016/j.amepre.2010.11.011). The inequities are now defined within the social determinants of health and equity as a result of historic systemic discrimination.

The emancipatory research traditions of PAR and CBPHR have flourished from these early beginnings, providing space for incubating new relationships, methods, and theory on the outskirts of institutional health care, research, and planning. These traditions are evident in the science of engagement (SoE), especially in the peer research job descriptions of the Wellesley Centre and the leadership roles evident in the Pacific Aids Network (PAN) and the Canadian goals and funding of Strategies of Patient Oriented Research.

PAR and CBPHR guided and sustained my continuing work in community development and community rehabilitation. They continue to provide the principles and emancipatory expectations that inform SoE, and the theories and methods that have emerged. This manuscript grew in the belly of academic health research to foster new research roles, relationships, methods, and theory using co-design methods and roles. This led to a university program of studies called PaCER, Patient and Community Engagement Research, that trains people with personal health care experience to conduct co-designed and tested research methods with those that have experiences with similar conditions. Participants take up roles as co-researchers who share data and analysis and have input into the results and how they might be used to make a difference. 'Patients' become leaders and colleagues in research.

POR grew from the need in medical research to create rigorous and standardized measures of patient outcomes for clinical, healthcare effectiveness, as well as health systems research. It is used internationally to contrast, compare, and track patient experience changes in health research. They also include patient engagement as part of their POR mandate. Some POR researchers have begun to include patients in the co-design of POR measures and have patients administer POR surveys to track program and client change. POR data science has generated a strong, reliable, and validated data science to capture patient experience, outcomes, and satisfaction.

CS includes citizens as scientists in academic and professional research. It is beginning to include citizen science to form new relationships with patients as citizens to collect local and personal health data. SoE could support co-design of research methods and training options to bring a patient research voice to CS research teams and conduct citizen-led research. European Citizen

Science 4 Health is gaining strength and scope rapidly in Europe, originating in the Netherlands. Citizen Science 4 Health connects health academics willing to support individuals with identified research questions to conduct personal research and build research networks of patients with common research questions. Leveraging the power of citizen science is expected to support the health and wellbeing goals outlined in Europe framework based on WHO's Triple Billion Targets, creating a healthier and more tenable future for Citizen Science beyond the initial scope of Europe.

SoE seeks ways to collaborate with existing health research platforms to find new ways to support health research as it transforms to recognize the need to foster emancipatory patient roles to adapt to technology.

Acknowledging My Experience That Informs This Journey of Emancipation

During the writing of this manuscript, I discovered that my career as a researcher had been influenced by a birth condition now identified as aphantasia that, in my case this means that I have no visiual memory apart from short lived dreams. Early on my mother realized that I had difficulty with letters and reading, and we set out to learn how to identify what I needed to do to avoid being labelled with a learning disability. Luckily, my family moved often, and I was able to study what teachers did and what they expected. I learned about how education worked with each new school. Apart from reading I was able to learn, challenge ideas, and find new ways of doing things.

My years of observing and understanding how things worked to compensate for not reading, prepared me for an undergraduate interdisciplinary degree where I learned how disciplines worked and researched in social sciences. While I was an outsider in each discipline, I was able to create assignments that I could manage. I was then accepted to a master's program because of my diverse background, and psychology consolidated my knowledge base and research skills. I was then hired as a research assistant in a psychiatric research token economy project and then developed a vocational rehabilitation project to prepare patients to for the hospital that spread to all units.

When I moved to Alberta as an independent psychologist, my career included working with government and community programs at local, provincial, national, and international levels, with all ages and many disabling and health-related conditions. I was hired by a Centennial Research Institute of the University of Calgary, now Vecova, to develop a curriculum based on a person-centred assessment for adults with disabilities—the Adaptive Functioning Index. This experience allowed me to then focus on how to build the capacity of people and communities who were searching for ways to access, inform, and

control the decisions that impacted their lives. I learned that new ideas, while engaging, are risky and prone to being undone unless there is ongoing funding and champions to manage implementation.

I was hired in the early 1970s to use participatory research within disability communities to co-design a curriculum for an innovative, interdisciplinary disability studies program that included the Faculties of Education, Medicine, Kinesiology, Social Work, Nursing, and Continuing Education at the University of Calgary. I was able to use my interdisciplinary research background to work across faculties and communities who motivated us to conduct research that could make a difference. I researched new approaches to legal guardianship, adaptive devices, community health programs, community development, and social enterprise models of employment. We developed new interdisciplinary projects with psychology and environmental design, nursing and social work, and an international curriculum in community-based rehabilitation as part of the International Association for Rehabilitation Counselling. I was privileged to be in a university that valued innovation and transdisciplinary studies, and I enjoyed the freedom to challenge systemic discrimination as part of new social movements related to disability, culture, and economic discrimination.

When our disability studies program moved to the faculty of medicine as part of the Cumming School of Medicine, Community Health Science Department, I realized that health research provided a unique opportunity to change the role of patients in their own health and the health systems they relied on. Then my experience with the Independent Living Centre of Calgary and the international Clubhouse movement intervened. They shattered my assumption that professionals identified and solved problems for persons seeking equity. Their belief in peer support and peer-led communities sent me to do a PhD to explore new social movements in England and Canada. I used grounded theory to co-create and study co-research partnerships in new social movements. This resulted in an integrated narrative methodology and a social contract for research partnership at each step of research.

When I returned, a group of seniors at the Centre of Excellence of the Kerby Centre in Calgary suggested we apply for an innovation grant from the Canadian Institute of Health Research to test the narrative methods from my PhD for a seniors-led peer research model. The results of the four-year study were published as *Grey Matters* (Marlett and Emes, 2010, https://press.ucalgary.ca/books/9781552382516/).

Grey Matters was published as Alberta's Strategic Clinical Networks were looking for innovative ways to train patients to bring a new research approach of patient experience to health transformation. This led to another national innovation grant from Canadian Foundation for Healthcare Improvement (CFHI) to

see if patients could be trained to conduct research that engaged other patients using *Grey Matters* as a curriculum. This Calgary partnership consisted of the Alberta Strategic Clinical Networks, the Cumming School of Medicine at the University of Calgary's Community Health Sciences Department and a small social justice program, Community Rehabilitation and Disability Studies. This steering team supported the project through the incubation years. Graduates joined SCNs and health research teams as advisors and peer researchers.

The Need for a Science of Engagement in Health Research and Innovation

The pace of change is increasing, and, unlike former industrial paradigm shifts, this shift builds on advances in computerization and communications that have led to the combination of physical, digital, and biological technologies. This paradigm shift will impact the roles of patients and professionals and the very nature of who we are, our health, and healthcare. Patient involvement in technology is needed to address the relationships, programs, and treatments of the future. Change won't wait until academic researchers, patients, and communities are ready. We need to prepare patient researchers to co-design, produce, and evaluate outcomes of future health and well-being technologies and health care.

At the global level, we are bombarded by growing wicked problems—pandemics, climate changes, rapid and unfettered technological change, aging institutionalized systems, and civil unrest and a temporary population bulge resulting from post-war births. As with most wicked or intractable problems there is an urgency to find ways to untangle, explain, and take action at local levels where the complexity and challenges can be understood and addressed. The concept of 'local' itself is shifting as patients and online patient groups curate and share their data and discoveries. The Canadian Maple Health Network (getmaple.ca) seems to capture this notion of an online community with real-time doctor visits, links to specialists, local homecare, and diagnostics. Online chronic illness communities are forming that use technology to support treatment options, peer support, and new technology with new forms of professional health facilitators emerging.

Anticipated change will need robust and diverse patient/citizen data systems based on potential futures. Citizen science, social innovation, social enterprise, changemaking (Ashoka), open innovation in science (OIS), responsible research and innovation (RRI) are but a few of the new social movements in science that are attempting to democratize science so that it can respond to future challenges by actively recruiting new partners capable of joining research teams. These forces are transforming and democratizing science to include

citizens, communities, governments, and business as research colleagues and full research partners.

Unfortunately, patients are the only partners currently without a research tradition that captures their experience and expertise. Peer research, as typified by PaCER and other patient-led initiatives, has produced an inductive, adaptive, and engaging methods that produces real-life data co-created with patients. It is located in participatory and action goals and JEDI (justice, equity, diversity, and inclusion) principles. Not only does peer research inform research and innovation, but it is building a literature of how patients and communities can build confidence and capacity for change through co-design and co-production of research that contributes to decision-making and new health relationships.

Democratization of science aims to increase the diversity of partners to increase research relevance, creativity, and improve the rate and effectiveness of innovation and enterprise. Peer research supports practical, relevant, and creative research that will make a difference by creating and validating ideas for innovation. Other factors in democratizing research include the following: consulting with peer researchers with cultural expertise (Indigenous, Black, Gender diversity, and Disability) that can drive authentic peer research; encouraging social enterprise leaders to use peer research in product development; and government policy makers who can look at new forms and relationships as care delivery changes and new policies emerge.

Frank et al. (2020, https://doi.org/10.1007/s11606-019-05436-2) also provides an overview of the four countries that have established patient engagement in research at national levels: Canada, United Kingdom, United States, and Australia.

Format and Use of This Book

You are invited to explore the chapters as they interest you. Each chapter has theory that relate to the topic of the book. Some theories come up in more than one chapter and there is an attempt to include new presentation to respond to the main work of the chapter. Most chapters contain visuals that are included to ground the topics presented.

The book is divided into three sections: Section 1, Tracking foundations lays introduces a proposed science of engagement; Section 2, Engaging, explores existing peer and patient-led research literature, adapts theories related to narrative and salutogenesis (the study of wellness) and presents a compendium of methods tested for use by researchers interested in expanding peer research as part of their research plans. The third section, Possibilities, presents two new theories to deepen the planning, conduct, and analysis of real-life,

storied data, and ends with chapters devoted to the forces for change in health research, planning, and care.

The concept of patients as peer researchers was originally met with skepticism but there is now a body of research done by and with patients that is published to allay this reluctance. You might like to visit Examples of citizen science, changemaking, and peer that are included throughout the book to help understand the scope of peer research. You might also visit PRISM (https://hdl.handle.net/1880/109933) to browse research conducted by patients before you start as a north star of patient-led research.

While the book was initially written for academic researchers, it soon became apparent that the content included ideas from many disciplines. The decision was made to adopt the style of *Grey Matters* that was written for a diverse audience, using a journalistic, narrative style with many examples and links to resources. Formal referencing is included at the end of each chapter.

The University of Calgary Press has been a pioneer in open access publishing (*Grey Matters* was its first open access publication) and an early adopter of an innovative publishing platform, called Manifold, that is dynamic and interactive. Manifold supports health researchers, providers, and planners to connect and learn about the future with patients, citizens, and communities online as they interact with other readers. This brings local, real-life experience to difficult problems. Patients and community members who are advocates and advisors or trained in peer methods are welcome to join any reading group or create their own groups.

The science, theory, and methods will undoubtedly raise some uncomfortable questions and intriguing opportunities. It has been developed to provoke discussion, independent study, and courses in health research.

Outline of the Science of Engagement (SoE) in Health Research and Innovation

The first section is expansive, exploring a broad base of co-research with patients and communities that leads to a proposed emancipatory science of engagement. The second section presents published examples of peer research, theory, and methods for academic researchers that are also applicable for health professionals, students, patients, and citizen groups. The final section introduces new theory and a coherent peer research methodology for academic researchers and social innovators and entrepreneurs. The rapid development of medical technology is setting the stage for a new model of health care that is centered on patients who have sensors to identify obstacles to health in order to avert serious and life-threatening illness. This marks a sea change in current

care where chronic illness dominates health care time and money and patients will finally have a significant role in their health and health care.

Section 1. Tracking the Foundations for a New Emancipatory Health Science

Topics orient and inform students, researchers, innovators, and citizens about the history, research traditions, practice, and science of engagement now and in the near future.

Chapter 1. A Personal Narrative of Social Innovation in Health Research

Emancipatory movements such as civil rights and feminism challenged the balance of power in the latter half of the last century. Shifts in healthcare are tracked through a personal research journey depicting the evolution of roles over the past 50 years, ending with an introduction to the fourth industrial technological revolution.

> *The review team was surprised by how far we have come in only 60 years, but they also found that most of the stories were still being told.*

Chapter 2. Negotiating Co-research

My classical grounded theory PhD developed an integrated narrative methodology with six international founders of new social movements. This showed that co-research could both engage collaborators throughout the research process and produce sound research findings.

> *I think I would take this to the research team I am currently working with.*

Chapter 3. A Social Contract for Engaging Patients in Health Research

This chapter supports researchers and teams who are already or intending to include patients throughout the research cycle from grant writing to implementation. A social contract negotiation tool and a checklist called Acts of Engagement is included.

> *This encourages negotiation of expectations and ways to plan and track engagement.*

Chapter 4. An Emancipatory Health Science of Engagement

A canon for a new science was crafted using the experience of other new emancipatory sciences such as feminist and Indigenous science. It includes principles, philosophy, methodologies, new theory, and applications to promote and sustain innovation, transferability, training, and career opportunities.

> *A novel way to understand peer research from an academic stance while being written in plain English. As patients, we can see the value of innovation while the system may feel somewhat reluctant.*

Section 2. Engaging

An overview of the research that supports a science of engagement. It includes recent publications, salutogenic and narrative theory and methods, along with tested engagement research methods that can be used as part of most health research projects.

Chapter 5. The State of Engaging Patients and Communities

Summaries of recent published research and reports that include motivating patients, international peer research initiatives, peer researcher job descriptions, social impact on health planning teams, blending patient and researcher roles, and peer leadership.

> *The job descriptions were what I needed to understand what I could do as a peer researcher.*

Chapter 6. Salutogenesis as Patient Expertise in Health and Health Research

Salutogenesis provides a coherent picture of patient expertise in searching for wellness despite medical problems. As such it balances the dominant experience theories of illness and the sick role. The process of achieving resilience and sense of coherence informs co-design, data collection, and analysis and suggests action and design thinking.

> *I struggled wrapping my head around the theory, but it lays a foundation for the book and the science.*

Chapter 7. Narrative Theory and Methods in Peer Research

Narrative is the key to an engagement science because of the power of story to support identity, agency, relationships, and change in social institutions. This

chapter explores narrative in peer research to increase social impact through stories as incidents for data collection, analysis, and shared meaning as part of narrative theory.

> *I didn't realize how many ways narrative works in research. It brings people together to find meaning and courage to implement change.*

Chapter 8. Peer Research for Qualitative Researchers

As a compendium of tested methods and strategies, it explores research options for citizen science, peer research as part of academic health research, community-based health research, and patient-led research initiatives. Basic adaptations and new methods are included for data collection, analysis, and interpretation.

> *The Set, Collect, and Reflect model is well broken down so it gives more clarity to how this type of peer research would occur.*

Section 3. Possibilities: New Theory and Options for Future Partnerships

This section increases the potential for evidence-based research by expanding the range of theory and partnerships to deepen analysis and implementation of peer research.

Chapter 9. Patient Perspectives of Health Systems

Systems analysis and system change lead this section by studying examples of system templates that can produce a patient perspective of health systems. Patient and group analysis of their specific health system help focus the choice of research priorities and directions of system change.

> *The diagrams about patient perceptions of the Primary Care Network from a casual user and people with chronic concerns was like a breath of fresh air. The template captures what we so often experience but can't really voice.*

Chapter 10. An Emancipatory Patient Standpoint Theory

This theory began as part of a self-assessment tool. It extends the salutogenesis continuum of health identity to include a vertical axis of agency to reflect the realities of healthcare more closely. It can be used to map current experience and identify goals in research, practice, and social innovation.

The patient and disability standpoint map helped me to map where I have been. The brilliance of this is that, with needed support, almost anyone can use this map and the theory, it is a powerful tool.

Chapter 11. Forces of Change in Health Care, Research, and Planning

A new chapter was needed to address 1) potential changes due to health systems struggling to democratize research, 2) health technologies that are combining to create options that link sensors that alert professionals of early signs of illness that then address concerns, and 3) justice for those facing systemic discrimination through principles that promote equity, diversity and inclusion.

Chapter 12. Possibilities for Peer Research

This final chapter combines the existing methods of peer research with new theory and methods to build bridges between academic research and innovation using design thinking. This is done to promote creative, flexible, relevant, and rapid translation from research to social enterprise of products and services and social innovation in health.

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SECTION 1

Tracking the Foundations for a New Emancipatory Health Science

This section is about the evolution of patient roles in health research that begins in an institution and ends with a science of engagement based on my career in health research. The roles of patients evolve from compliance and institutional control to becoming researchers of patient experience. The next chapter outlines the co-research results of an experimental thesis from international founders of new social movements. The thesis used grounded theory that identified narrative as the essential element of the data collection method for engagement. Chapter three applies the social contract that had emerged in the thesis as an engagement tool that can be used to negotiate goals, roles, and endings of the stages of research from recruitment to publication. Chapter four proposes a science of engagement in health research based on 40 years of collaborating with marginalized groups to explore the nature of emancipatory research.

The evolution began mid-century, as the industrial and military structures of the World Wars were adopted by new social institutions in education, health, justice, welfare, and science. Quantitative and positivist research grew rapidly within these systems, because it provided a quick and verifiable research system to support evidence-based practice. During this time, critical methodology supported emancipatory politics, and citizen health movement were gaining traction with the early social work research of Moreno (1953), to improve the integration of immigrants and marginalized citizens.

Citizens were included in data collection and interpretation of their data, and, in doing so, introduced the importance of data that was action-oriented and made sense to participants.

This was followed by the work of critical sociologists, including the seminal work of Paulo Freire, *Pedagogy of the Oppressed* (its 30th anniversary edition was published in 2000), which introduced a critical analysis of language that turned education into participatory action research and continues to inform emancipatory social science and community-based participatory research.
The science behind these emancipatory methodologies reflects capacity and resilience-based approaches with patients and communities to broaden the

science base into patient engagement in health research. A literature search for 'patient engagement' in research in 2012 yielded 34 hits, and most of these were related to patient-centred care. Today, this same literature search would include patients as advisors, partners, and researchers, as well as apps and technology to engage patients in their own health and healthcare (Nagappan, 2024, https://www.weforum.org/agenda/2024/02/health-tech-healthcare-telangana/). Many new journals have started dealing with patient engagement in research, including:

- *Frontiers in Healthcare Research* (https://www.frontiersin.org/journals/health-services/sections/patient-centered-health-systems and https://frontiersin-healthcare-research.org/index.php/id)
- *Journal of Patient Experience* (https://journals.sagepub.com/home/jpx)
- *The Patient—Patient-Centered Outcomes Research* (https://link.springer.com/journal/40271)
- *Research Involvement and Engagement* (https://researchinvolvement.biomedcentral.com/about)

It is hoped that the development of a science of engagement and the ability to train patients to work with researchers and social entrepreneurs will lead to innovative partnerships to inform this growing research about the emerging roles of patients in health research.

Theoretical Constructs That Inform Research

The following theories are basic ways of thinking about emancipation that guide the chapters in Section 1 and lay the foundations for the rest of the book.

1. Emancipatory Social Science and Intersectionality

Research related to civil rights and justice has been located within critical theory as it relates to emancipatory social science (Wright, 2006, https://www.sscc.wisc.edu/soc/faculty/pages/wright/Published%20writing/New%20Left%20Review%20paper.pdf) and more recently intersectionality (Collins et al., 2021, https://doi.org/10.1057/s41296-021-00490-0) as tools for social change and liberation from systemic discrimination related to race, gender, age, disability, labour, environmental, and economic security. The purpose is to use science to identify and explain the systemic features of oppression with a mandate to use science to create and support the conditions for human flourishing. These calls to action align with participatory action research and more recently the movement to JEDI—justice that is achieved through equity, diversity, and inclusion.

2. Role Theory

Culture within social organizations and everyday activity are socially created and defined (e.g., teenager, patient, customer, churchgoer, expert). Each role is a set of rights, duties, expectations, norms, and behaviours that a person has to face and fulfill. These roles develop into relationships that test boundaries with roles held by those in positions of power. Contested roles exist when values, policies, and procedures change expectations and relationships. We use role theory to focus on the role of the patient or citizen within various systems. In particular, we see a series of patient role changes and predict these roles will continue to change as health systems are impacted by emancipatory social innovations in healthcare and community support. Role theory enables these roles to be studied and supported. This is particularly apparent in Chapter 2, which is a detailed study of how roles are changed as part of new social movements.

3. Postmodern Thinking

Postmodern thinking challenged modern ways of knowing and being. The evolution of systems privileges movement, emergence, and change. This includes the study of social, historical, and cultural contexts according to the realities of individuals, places, and politics that take place in the physical and observable world. Phenomenology and the research of experience are examples of this approach.

4. Phenomenology

A phenomenon is a situation, happening, or experience that is observed. Phenomenology, therefore, is a general philosophical stance that supports research about the world we experience (hear, see, understand, feel). It is also about the language we use to communicate our experience. Engagement through peer research enables us to explore the personal and collective experience of patients. Phenomenology keeps us focused on understanding experience and seeking unheard voices in health research, to broaden our understanding of the diversity of health and healthcare experience (Zydziunaite, 2019, https://www.rsu.lv/sites/default/files/imce/Dokumenti/prezentacijas/vpa_2019/2019_27_04_VZydziunaite_workshop_phenomenology.pdf).

Phenomenology is particularly important when considering patient experience within healthcare systems because healthcare systems seem to be permanent and immutable. Patients with lived experience in health systems are the only resource we have when it comes to research expectations and values that create counter narratives and stories about past, present, and future patient experience.

5. Social Construction and Related Theories

Social construction has been a major influence in emancipatory social science and collective social action. As a philosophy, it suggests that meaning is created through language shared by groups. It began as a radical challenge to objective and rational science by declaring that people were active in shaping the social world rather than simply being acted upon. This means that we are responsible for engaging with others in a way that opens the possibilities of finding common ground and conceiving of shared futures. The tenets included the following:

- Reality is what humans cognitively construct it to be.
- Social constructs include not only language but roles, relationships, social organizations, systems, and policies.
- If social constructs are created, they can be studied, challenged, and changed through the study of social interactions, using various lenses, such as:
    a. Patterns and strategies of interaction;
    b. Power and conflict (critical theory);
    c. Usefulness (pragmatics); and
    d. The study of roles and scripts that people play.

Social construction is both relational and action-based, as evident in the early feminist and civil rights movements and the research that emerged from these early social movements. The power of groups and the moral mandate to act have influenced not only social change, but also postmodern research approaches.

6. Systems Theory

There are a vast number of system approaches. Most professional disciplines have crafted systems theories that organize their practice, ecological, and management beliefs. For this chapter, we use the term 'systems theory' as a focus on social organizations and how they are maintained and challenged by environmental pressures, both internal and external. In this chapter, we use the concept of systems theory in several ways:

- The exercise of power and structure to establish compliance of patients and citizens within health-related systems.
- The changes that occur within social organizations when established patterns are challenged.
- Systemic discrimination that occurs when access to care and the care provided is determined by differences not related to health needs.

Systems theory re-emerges in Section 3, where the focus becomes challenging healthcare systems and a theoretical proposal of a patient perspective of health care systems.

7. Asset-Based Approaches

A major shift in health promotion occurred as the impact of postmodern thinking seeped into healthcare during the latter half of the 20th century. The impact of the shift from deficit to asset foundations are outlined in this 2011 PowerPoint from Glasgow Centre for Population Health (https://www.gcph.co.uk/assets/000/000/189/GCPH_Briefing_Paper_CS9web_original.pdf?1700036392). This has enabled a shift from less-than-effective public campaigns to change the deficit, problem, or behaviours of populations, to engaging with communities to co-design innovative solutions to systemic barriers. The early successes of community-based participatory research became the hallmark of most community health promotion initiatives.

8. Citizen Health Movement

The citizen health movement is included here because it is the healthcare equivalent of engaging patients, families, and communities as co-designers, co-producers, and co-researchers. The citizen health movement aligns with the narrative health and the citizen movement as well. It provides a link between the above theories and healthcare (Doherty & Mendenhall, 2006, https://innovation.umn.edu/citizen-professional-center/wp-content/uploads/sites/66/2020/09/citizenhealth2006.pdf).

The above theories supported new emancipatory social sciences, social justice, and civil rights movements, community-based participatory research and salutogenic strategies that are described throughout the book.

Summary of the Chapters

The first chapter provides a selective, historical review of my research career to demonstrate the evolution of patient roles in healthcare research, beginning with institutionalization and ending with emerging technology-based paradigms that will change the roles of patients significantly.

The second chapter is an article based on my first formal attempt to understand the feasibility and processes of co-research in a grounded theory study of social innovators and the new social movements they fostered. This chapter lays the foundation for a shift to narrative research to support emancipatory and participatory research.

The third chapter is a social contract for engagement, as a compilation of experiences with peer research partnerships. It considers the benefits to both researchers and patients when engagement occurs. Checklists are provided to plan and track the progress of engagement.

The final chapter introduces the emergence of an emancipatory science of patient engagement, focusing on patient experience.

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1

A Personal Narrative of Social Innovations in Health: Research Examples of the Changing Roles of Patients

Highlights

- Evolution of the system from behaviour control of patients in psychiatric institutions to patients as peer researchers and social entrepreneurs
- Personal research narrative of innovation within health systems and the ability of systems to resist change
- The promise of community, self-help, new social movements, and social enterprise health options
- The importance of new research roles for persons with lived expertise during innovation and change as part of digital paradigm shifts that will impact patient roles and healthcare options

Personal Experience with Social Innovation

I was born during the Second World War, as countries struggled to recover from the challenges of two World Wars, a pandemic, and a global economic depression by creating large, evidence-based social institutions. By the 1960s, during my university years, these social institutions were already being challenged by the feminist and civil rights movements, and I marched, protested, and became aware that I, too, was discriminated against within systems, because I couldn't read, or focus, or remember faces for any length of time. In graduate school, I easily learned strange computer languages for large and cumbersome computers. I eagerly spent my first paychecks on the first Mac 128K.

From early experience with social innovation within psychiatric institutions in Ontario, I moved to Alberta. I worked as a contract researcher to government departments, community-based health systems, from home programs for severely handicapped babies to long-term care, policy research for guardianship, developing adaptive aids, and Assured Income for the Severely Handicapped (AISH). I was hired to help develop a university institute for innovative vocational and rehabilitation research, and from there I moved to the University of Calgary to develop a disability studies program (Community Rehabilitation and Disability Studies—CRDS) within the Faculty of Education, based on principles of social justice and community inclusion.

Universities, at that time, were adopting a military internet communication platform, and I was eager to develop distance programs for our new undergraduate and graduate degrees. I eagerly jumped at the chance to create distance online options to reduce costs and travel. This was followed closely by a large community grant to create a Canadian internet presence for persons with disabilities. This seemed logical because so many communication devices were developed and used extensively by persons with disabilities.

Within the university, education and other graduate programs in business, environmental design, and social work banded together to support early online curriculum development and delivery. Because of this, we were able to secure early funding to create laddered degree programs with colleges across Canada and a blended Master of Science degree in disability studies.

When CRDS moved from the Faculty of Education to Medicine, I had the chance to use internet resources to support an equity, diversity, and inclusion (EDI) program that supported community experience for medical students. Small teams of students were led by mentors with lived experiences in the six target marginalized populations that were part of the Canadian medical curriculum: homeless, disabled, Indigenous, considered to be mentally ill, and refugees. One-third of the students felt that they were deeply impacted by their experience, one-third were insulted by being taught by people without academic credentials, and the rest seemed to think it was not important that they know about the lives of people not served by the Faculty of Medicine. I retreated rapidly from trying to influence students and humbly set out to study how to open dialogue between people with lived experience (PWLE) and medical professionals through new research models. This motivated a series of studies to create a patient research voice that would break through the glass ceiling that existed for patients in healthcare.

Social Innovation Impact and Paradigm Shifts

Social innovation and social enterprise are recent extensions of the term 'innovation' that had come to be associated with products, services, and processes that were marketable. Definitions of social innovation were developed to identify new ideas that resolve existing social, cultural, economic, and environmental challenges for the benefit of people and the planet. A social innovation is a personal, social, and systems change that alters the perceptions, behaviours, and structures of individuals, groups, and societies. Even more simply, a social innovation is an idea that works to improve the public good (Centre for Social Innovation, n.d., https://socialinnovation.org/about/our-story-and-impact/). A more recent definition, "change in social relations, involving new ways of doing, organizing and/or knowing" (Haxeltine et al., 2016, p. 19), has been adopted within current theory related to narratives of change, and aligns with Conger's (1974, https://doi.org/10.1111/j.1467-9833.1974.tb00448.x) definition of social innovation that was adapted in my PhD thesis to focus on new ideas and organizations that change the way people see themselves and relate to each other. This implies a focus on changing roles, relationships, and structures within existing systems and, as they transition, in response to shifting societal values.

Table 1.1 introduces the general evolution of systems and systemic challenges addressed in the chapter. It identifies how the roles of patients, professionals, and systems become constricted as systems become inflexible and more powerful through government funding, bureaucratization and specialization, professionalization of care, and finally the medicalization of deviance. Current healthcare systems are protected by the close connection between science and the promise of cure that make the system resistant to change.

The figure provides an overview of reactions to the growth of health systems through the negative impacts, emancipatory forces, and anticipated futures. These are summarized through the experiences of patients, professionals, and the healthcare systems. The figure maps the features of health systems and how they influence people with lived experience, professionals, and the systems.

Table 1.1 *Process of Social Change in Health and Healthcare*

Systematization of Health by	*Negative Impacts on*	*Emancipatory Forces such as*	*Anticipated Futures*
Growth in government funding and control Bureaucratization and specialization Professionalization of healthcare interaction Medicalization of deviance used as access to care Systemic discrimination challenges	**People with lived experience** Loss of control and identity; dependence on professionals **Professionals** Loss of connection, effectiveness, depersonalization, meaning **Health systems** Rising costs; increasing expectations; increasing justification of reduced accessibility; systemic discrimination	**People with lived experience** Peer support; advising health teams; decision-making **Professionals** healthcare partnerships; more community engagement of health professionals **Health systems** Increased patient choice and responsibility; partnerships in care and research; technology advancements in individualized solutions	**People with lived experience** Increased engagement in personal health and healthcare with technology **Professionals** Shifting roles to support technological change; working for patients (individualized funding) **Health systems** Increasing prevention; reduced burden of disease for non-communicable and stress-related disease; more focus on the health of communities

Narratives of Social Innovation

I needed a way to tell this story of change, and my experiences acted as case studies of systems, roles, and relationships, forming a foundation for social change and innovation within health-related systems. And these stories became stories of emerging theory.

In an article updating social innovation, Mason et al. (2015, https://doi.org/10.1093/heapro/dav076) consider how social innovation is manifested as part of health promotion and health equity. This classification has been adapted to describe the stages of the personal narrative.

1. **Service-related social innovations** such as new roles, relationships, new social organizations and institutions, along with an innovative government policy. This, by definition, relates to systems, their rise, and increasing challenges.
2. **Community-based social innovations** that challenge the authority of institutions by creating alternative and inclusive community wellness and support options.
3. **New social movements** or emancipatory networks such as the Black Lives Matter movement, patients international, and the modern hospice movement that were led by those who had recognized and challenged the authority of existing systems.
4. **Innovative forms of social enterprise** that emerged as capitalism became enmeshed in new forms of social innovation. Academic researchers sought ways to turn research advances into commercial products for health and education. With this came the realization that business models could meet social needs. The Ashoka network of university changemakers is an international leader in social entrepreneurship (Ashoka, n.d., https://www.ashoka.org/en-ca). Also included in this is social innovation from a not-for-profit base.
5. **Digital social innovations** in which innovators, users, and communities collaborate to co-create knowledge and solutions for a wide range of social needs at a scale that was unimaginable before the rise of the internet. These digital social innovations have arisen because of the current paradigm shifts in healthcare, health systems and services, and new roles for health professionals and patients.

1. Institutional Service Social Innovations

Healthcare-related institutions for people living with mental illness, developmental disabilities, and wasting diseases began as hospitals and congregate environments that claimed to help patients recover and learn how to exist in society. They soon became long-term institutions based on military, corporate, and industrial systems that grew rapidly, as the goal shifted to removing disruptive or unconventional people from society (D'Antonio, 2011).

By the late 1960s, deinstitutionalization was supported by the promise of cost savings and political pressures to reduce the harms inflicted on patients. New medications were 'on the horizon' to reverse mental illness and enable patients to manage on their own. This did not take into account the devastation of severed family connections, reinforced compliance, and isolation that fostered deviance. These patients became a throwaway generation, living in boarding

houses or on the streets in large cities. Those who had no voice in institutions continued to have no say in the subsequent decisions that impacted their lives.

Token Economies Change Behaviour

The first research narrative captures a moment at the very beginnings of de-institutionalization. The social innovation was operant conditioning using tokens as reinforcements. It fuelled the optimistic belief that even the most difficult of patients could become more acceptable to society. The study took place in a large custodial ward/unit for aggressive and regressed females with an average length of hospitalization of 20 years (Steffy et al., 1969, https://doi.org/10.1177/070674376901400111).

The following is a summary from my research notes.

Very early in the morning, I got on a bus dressed as a young professional and got off at Lakeshore psychiatric hospital. I quickly changed into a 'house dress' and transformed into a quiet, withdrawn patient on a unit for aggressive, regressed mentally ill women. I slipped into my chair as the residents were being showered and dressed to record patient behaviour as a research intern on one of the first token economy projects in Canada. Patients were given coloured poker chips for daily routines and were taught to use the tokens for meals and the small tuck shop. I couldn't resist making small notes on the side of the data sheet that recorded incidents not part of the study, including such as the cluster of nurses worrying about withholding meals when patients didn't earn tokens, the black market in tokens, how dominant patients took tokens as protection money and how I was so easily treated as a patient.

Patients, over time, easily adapted to making their bed, responding to greeting and dressing themselves, in order to pay for their meals and daily treats. Like most token economies, the original behaviour patterns slowly returned when the new expectations were no longer rewarded. However, the power of the research to change behaviour was published and led to other token economies, as the patients were readied to be moved from institutions. The notes and the reflections I made each night on the bus trip home turned out to be my entry into a world of health culture.

This ethnographic view of systems encouraged me to look at research from a patient perspective. They seemed to easily fit into the routine of the ward in order to avoid punishment or removal of privileges. The relationships among patients were covert and based on physical and psychological hierarchies, their relationships with staff a vigilant compliance. These women became my ground zero—people who had no voice, made decisions to obey or refuse to obey based on the level of threat. Operant conditioning worked as long as the reinforcement continued or was transferred into general practice.

My fascination with ward culture was noticed, and I was sent to a psychiatric milieu rehabilitation course at Boston University to learn how to create positive environments within institutional settings. I was able to set up in-house 'research projects' when I returned, to look at ways to prepare patients and staff for deinstitutionalization.

Assessments Change Ward Culture and Roles

My next service innovation was based on the use of the Medfield Rehabilitation Checklist to test a positive, asset-based assessment that would increase the positive culture of a psychiatric ward. The checklist was introduced in a women's ward without any motivators or reinforcements. The Psychotic Reaction Profile (Lorr et al., 1960, https://doi.org/10.1002/1097-4679), a checklist of deviance and psychosis, was introduced to a comparable ward. The staff on each ward assessed the patients once a month and reported on their clients in a staff meeting.

The impact of this simple service innovation was remarkable. Within three months, the staff using the Medfield checklist were more positive and interacted with patients. Further, patients interacted more with each other, they went out of the institution into the community, and family visits increased. On the control ward, staff that used the psychotic reaction profile reported more deviance, but the culture of the ward remained basically the same. One might surmise that the checklist changed the focus, expectations, and role of the staff on the first ward, which provided opportunities to interact positively with their patients. This, in turn, encouraged them to expect more positive activities and more of their patients.

This informal research demonstrated the effectiveness of a positive behaviour checklist that changed the focus of staff attention from deficit and deviance to asset and competence. The role of staff shifted from one of control to encouragement. Patients tried new activities in the community with other patients without staff being present. Positive behaviour checklists reinforce competence as an effective service-based social innovation that changed the way both staff and patients saw themselves and interacted with each other.

Introducing Work Culture in a Psychiatric Hospital

The noticeable change above led to a third innovation, this time to improve the work capacity of patients as part of the politics of deinstitutionalization and community inclusion. I hired a foreman with business experience, and he interviewed and hired patients who were paid according to their work (a form of operant conditioning, based on piece work). Workers were placed in community work sites when they had regained skills and work relationships.

As the concept expanded, other wards started their own workshops and vocational case reviews were started to plan for discharge into employment options. It wasn't long before community and family members joined the meetings and patients were speaking for themselves and the jobs they hoped to find. They had found a voice. However, that voice challenged the culture of psychiatric treatment reviews, and psychiatrists took over the vocational case reviews. The meetings that had been focused on employment were soon incorporated into the regular case conferences. As psychiatric professionals took over, the culture of work returned to a more comfortable culture of occupational therapy.

The success of this innovation was possible because it was, in fact, a social enterprise with the money raised from contracts, providing the incentive pay for the workers and defraying costs to the institution.

2. Community Alternatives as Service-Related Social Innovations

The deinstitutionalization of persons with cognitive delays was a very different story because it was supported by an emancipatory social theory called 'normalization,' which was supported by an active parent movement that led to early and sustainable success. Normalization was perhaps most dramatically articulated by Wolfensberger et al. in *The Principle of Normalization in Human Services* (1972, https://digitalcommons.unmc.edu/wolf_books/1/), alongside feminism and civil rights movements that sought EDI. These early principles are now used to challenge systemic discrimination. This movement led to other emancipatory movements in education, vocational rehabilitation, and community inclusion for seniors and disabled people. Here we focus on the capacity of families and communities to become social innovators of new roles and relationships outside of healthcare systems.

Parent Advocacy for Children Living with Developmental Delays

The parent's movement of the 1960s and '70s created parent support groups, political advocacy, specialized schools, day programs, and workshops. These families created space for their children in society. When those living with cognitive disabilities were discharged during deinstitutionalization, they came to a very different reality. As institutions faded, parent movements grew in power, asserting rights to community inclusion and peer support. The parent's movements had effectively challenged institutionalization and provided alternative community options for families, education, and work. Vecova (2024, https://vecova.ca), then called the Vocational and Rehabilitation Research Institute, at the University of Calgary was one of the 10 centennial projects in Canada that garnered political support in the face of deinstitutionalization. A similar

process was initiated in the United States with the Kennedy Foundation support for university resources to research and support the growing parent movements.

This was a dramatic shift in the roles of developmentally disabled children and adults. They shifted from patient and deficit roles to become children and adults living with their families, with opportunities to learn and contribute to society. The families ignored the roles assigned to their children by medical professionals and created space for social innovation within communities.

Community Capacity Building for Disabled Adults

Because of my experience setting up and researching vocational programs, I was hired as part of the startup team at Vecova to create a culture of capacity from the ground up, through research-informed innovation.

We began by researching asset-based assessments that might raise expectations of staff and trainees to create inclusive vocational, living, and community training and assessments. The assessment process, called the Adaptive Functioning Index (AFI), was created with potential employers, young adults living on their own, trainees of Vecova, and staff. We adopted trainee language to ensure that the assessment was in their voice.

As part of the research and staff training, it was decided to include trainees in completing their own assessments and setting their own goals. When trainees became involved, they were motivated to achieve the goals they set. It was indeed possible to create a culture that challenged the dominant discourse of deficit and incapacity among developmentally handicapped adults. The placement success far exceeded our expectations, and the asset-based culture of capacity and inclusion continues to this day.

As the AFI was sold and used throughout North America, Europe, and Australia, we noticed that staff in traditional programs were reluctant to give up their coveted expert roles as assessors and goal setters. The AFI also came to the attention of funders, who saw it as an ideal way of assessing funding needs, based on the deficit model where the lowest scores received the most funding. In places where this was done, building competence was not profitable and the focus on competence was reduced.

We learned that emancipatory changes in roles and relationships can be profound and lasting when the system is designed to empower those using the service. We also learned that it is difficult to change established staff roles unless they believe that those they work with can and should gain more control over their lives. Funding trumps innovation.

Translating Community-Based Social Innovations to Institutional Systems

Medical Institution for Profoundly Handicapped Children

I was hired in the 1980s to deinstitutionalize a small institution for severely disabled children in Calgary, based on the AFI success at Vecova. We began with a research project to create an assessment for dependent handicapped children to guide staff in creating a family culture with positive expectations for change. This became a social innovation to change attendant roles to parent roles. The family environment within the institution was considered part of the social movement of normalization.

While we were successful in mobilizing and motivating the children and energizing the staff, it collided with a government policy to decentralize government services by building small institutions in small towns to increase rural employment options. Our research, demonstrating that these children could learn and take advantage of a competency-based model, was stopped because it conflicted with their need to believe that severely handicapped children could benefit from being in a small town. However, when the political winds changed, a home-like setting with a family model was created on a portion of land, and the large institution was demolished.

School Curriculum for Profoundly Handicapped Children

The success of the assessment in creating family learning environments with very handicapped children opened the door to the school system, because we showed that these children could learn. I became the chair of a research team developing a novel provincial curriculum for dependent handicapped children that laid out expectations for the new students, classrooms, and teachers based on the previous assessment for dependent handicapped children. This work led me to develop and teach a specialization in special education for profoundly handicapped children through the University of Calgary, to prepare teachers for this new venture. The curriculum was optimistic and hopeful - new teachers expected children to learn and created opportunities for new activities and learning and this, in turn, led to more advanced curriculum goals. This created a belief that all children could learn and changed the views of the education system.

The above experiences, working in partnership with staff, demonstrated that lasting change occurs, and asset-based research can raise expectations and provide opportunities for growth. This is an action-based cycle—as staff expected growth, children (patients) grew and changed, which, in turn, influenced staff to try harder.

We see this when people with Alzheimer's live in community environments, doing their daily chores, interacting with each other, and learning new skills. Community programs are now expected to be inclusive, with adaptations made to enable children, adults, and seniors to be in charge of the choices they make. It is slowly becoming more expected within healthcare settings.

To jump to the future, home healthcare, which developed in the last century to enable seniors with chronic care needs to age in place, is being challenged. Seniors are questioning the introduction of standardized care protocols and digital and telehealth. In order to ensure personalized care, research done by seniors will need to inform new health directions.

3. New Social Movements and Consumer-Led Services

By the 1970s and '80s, the success of Alcoholics Anonymous' twelve-step programs prompted spontaneous self-help groups, where citizen groups informally shared stories and ideas about how to cope with everyday life outside of formal healthcare. These natural relationships heralded the emergence of a collective patient identity, outside of sanctioned health services and facilities. Social support and shared experiences became recognized as important factors of health and well-being. Support groups arose when needed and stopped when the members created more natural friendships. Some self-help groups were encouraged to become agencies, with funding provided by governments and the United Way. Other health-related peer support groups were renamed and reclaimed under the banner of medical psychosocial support (Brown et al., 2004, https://doi.org/10.1111/j.1467-9566.2004.00378.x).

The early self-help groups and disability organizations provided the impetus for consumer advocacy and consumer-led services. Organizations such as Inclusion Canada (https://inclusioncanada.ca), Canadian Association of the Deaf (https://cad-asc.ca), Council of Canadians with Disabilities (http://www.ccdonline.ca/en/), and the international advocacy group Disabled Peoples' International (http://dpi.org/) were early examples of new social movements pioneered by persons with disabilities. Their actions led first to fundraising for community services and research, and eventually to political action and peer support.

During this time, the University of Calgary was initiating an interdisciplinary program (with the Faculties of Education, Social Work, Kinesiology, Nursing, Continuing Education, and Medicine) of research and career development, to prepare professionals to work with persons with disabilities, mental health concerns, and chronic illnesses within community settings and organizations. This program, Community Rehabilitation and Disability Studies, is today located within the Cumming School of Medicine (https://www.ucalgary.

ca/future-students/undergraduate/explore-programs/community-rehabilitation). Faculty members were deeply engaged in new social movements to build the capacity of PWLE and families to advocate for community-based support, full inclusion in society and policy changes. Foundations in emancipatory social science and critical theory changed how we understood the role of PWLE, professions and research in effecting changes in practice and policy. My experience with PWLE and communities convinced me that power is created by groups of people using real-life data and shared meaning to anticipate and activate change. Our work as faculty began with social justice, and we soon adopted the call to challenge and change systems that marginalize through systemic discrimination.

Calgary Association of Independent Living (CAIL)

The Canadian Coalition of the Disabled (CCD) developed the Canadian Association of Independent Living Centres, now called Independent Living Canada (https://www.ilc-vac.ca), who supported disabled citizens to seek and direct their services, and to provide opportunities to help others to become contributing citizens.

The Calgary Association of Independent Living (CAIL) welcomed persons with all disabilities, including those who had been institutionalized for many years. Together, they shared stories and built peer support and independent decision-making about their futures. The director, a graduate of the University of Calgary diploma program, set out to design a consumer-led service that reflected the slogan of the disability rights movement: 'nothing about us without us.' The centre had a strong research foundation and was able to demonstrate the impact of a consumer-led model. The director became an independent service broker that supported members, along with their families and a personal support network, to negotiate an individual service plan that would finance the support services needed to live independently, at any level of disability. The service brokerage model had a strong clinical and research advisory team and produced a number of research projects. Independent service brokerage was a social innovation that was adopted in other countries and is still used today when policy encourages independent living (Marlett, 1988).

CAIL had created a culture of acceptance and service, supported by consumers. The clients identified what they needed and were part of creating the ways to meet their needs. This was my first experience of reversal in roles and relationships. Members who had brokerage contracts were employers of their care providers—they were, in fact, social entrepreneurs. They hired, trained, instructed, and paid their personal staff. Their staff may have been shocked by the reversal but soon came to understand the importance of personal control of care. While individual funding and service brokerage have become accepted

for persons with physical disabilities, the following examples from Marlett and MacLean (1988) depict the impact of these changes in role for those who have multiple cognitive and behavioural disabilities and persons with limited motor and speech:

> LB needed more support than was possible in community services. Through independent service brokerage, he was the first recipient in Alberta of direct payment. With these funds a 'Joshua committee' of parents and friends assisted him to hire and monitor his care providers. He lived in his own apartment with support and was able to attend community activities with support. The difficult behaviours disappeared, and his direct payment decreased and stabilized at a much lower level.
>
> A young mother in the later stages of MS, with only head movement, lived in an auxiliary hospital, but desperately wanted to leave the hospital and live independently. She requested the services of the CAIL service broker, despite the advice of the medical staff. She left after services she required to live independently were costed and funded through service brokerage. An apartment was adapted, and she hired all her staff. She lived many years with natural support, making her own decisions and helping others.

Twenty-eight people were supported using this model, from children to seniors, those in long-term care, institutions, behaviour management programs, and community organizations that could no longer provide service. The brokerage function was later taken over by service providers funded as part of government services.

New roles change the way people see themselves and relate to each other, the very definition of a social innovation. CAIL, run on a shoestring, captured the power of the early feminist and civil rights movements, albeit in a local and restricted manner. It ignited the flame of emancipatory science for me, while challenging my professional view that programs and professionals provided the path to empowerment. Service brokerage philosophy underlies many of the current moves to assured incomes for persons with disabilities that turn clients into social entrepreneurs and purchasers of community services, in stark contrast to the dependence of patients still within the current healthcare system.

The following section presents three major studies related directly to the evolution of peer research and a science of engagement:

- My PhD thesis (Marlett, 1996, https://doi.org/10.21954/ou.ro.0000f617) with seven social innovators of new social movements to test the viability of co-research.
- *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/), a peer research curriculum with seniors researching resilience with seniors.
- Patient and community engagement research (PaCER): A narrative of twin innovations to teach patients peer research as part of healthcare transformation (ongoing).

The common stages of each of the above research projects are summarized in Table 1.2.

Table 1.2 *Evolution of Peer Research Through Three Research Projects*

	New Social Movements (PhD)	***Grey Matters* Seniors' Engagement (CIHR)**	**PaCER Patients as Researchers**
Working Together			
Building trust	Working together as co-researchers	Retired academic mentors	Orientation as preparation
Co-design of research	Classical grounded theory throughout	Full day large group planning in city and rural areas	SET process to identify main concern for research
Negotiating co-production	Give / Get framework	Action teaching with debriefing	Iterative cycles
Data Collection			
Narrative	Integrated narrative methodology	Story template	Use of narrative incidents as data
Individual data	Co-production throughout collection and analysis	Story template from audio tapes	Interview informed story templates
Group data	Not done	Full day focus groups for seniors	Online focus groups

Table 1.2 (*continued*)

	New Social Movements (PhD)	***Grey Matters* Seniors' Engagement (CIHR)**	**PaCER Patients as Researchers**
Theory Building	Root metaphor of innovation for new social movement	Writing group of seniors created general theory of engagement	Grounded theory as explanations of the main concern; some thematic analysis
Dissemination	Within each new social movement; part of conference book	*Grey Matters* as a resource for research with seniors	Academic publications of peer research with research team

Case Studies of Co-research in New Social Movements

My PhD consisted of six case studies of new social movements that changed the way people saw themselves and related to others through new social organizations and movements (Marlett, 1996). Classical grounded theory was chosen as a research methodology because it was suited to the study of innovation.

Gerry Kinsella, a disability rights activist, was the first partner, and the methods we identified were tested and adapted by Dorothy Birtles, who had created a social organization of volunteers, sponsored by the Quakers. The resulting methods were refined and then tested with Cicely Saunders, founder of the modern hospice movement for the dying. These strategies were, in turn, tested with David Brandon, a radical innovator of new roles for citizens living with mental health and developmental disabilities; Henry Enns, who worked at international political levels to challenge systemic discrimination of those with disabilities; and Henry Three Sons, fighting for Indigenous rights for children and families impacted by residential schools.

Gerry Kinsella

Gerry Kinsella, the director of the Greenbank projects (https://www.greenbank.org.uk/about-greenbank/about-us/) in Liverpool, England, saw the need to challenge the systemic discrimination of disabled people as they left school. He created a number of social enterprises, most of them related to new adaptive technologies for work and sports (e.g., competition wheelchairs), and new roles in training and business (e.g., whole food restaurants and businesses). These businesses provided the income to allow Greenbank to challenge medical systems and reinforce emancipatory roles for PWLE. Greenbank College (n.d.,

https://www.greenbankcollege.org.uk) taught employment skills and created employment options and support services that competed with existing professional services.

The new social organizations of Greenbank reinforce a 'give it a go' atmosphere that validates risk-taking, peer mentoring, and personal decision-making. Greenback is considered one of the first social enterprises in the UK. Kinsella bypassed rehabilitation practices to work directly with commercial businesses in creating training modules and hiring disabled graduates. It is a long-term successful social innovation and social enterprise. Peer support, teaching, and mentorship replaced dependent patient roles.

Dorothy Birtles

In later life, Dorothy Birtles became the founder of the British Quaker Prisoner Befriending Scheme. This innovation was a not-for-profit, volunteer-run organization, supported by Quakers International. She studied the brutality of systemic persecution and torture and became the face of non-violence and deep personal connection to prisoners wherever torture was practiced. Quaker letters and cards meant that prisoners felt connected and valued. Social innovation was a deliberate, gentle, and measured challenge to repressive regimes. Within the minefield of international politics and tensions, she found ways to counter the terrorism and systemic violence through oral traditions of sharing stories of everyday life.

The results of these new roles included: prisoners were cherished and connected in spite of their isolation and torture; the Quaker Befrienders used gentle means to advocate and stand up against brutality through sharing their letters with other Quakers and politicians; Dorothy became an activist and changemaker against terrorism from her quiet life and garden shed office. Since then, the Quaker Befriending Scheme has been discontinued. For another example, see Hearman (2016, https://doi.org/10.1080/14672715.2016.1157954).

Dame Cicely Saunders

Dame Cicely Saunders began as a Nightingale nurse, then an almoner or social worker, and finally became a physician and specialist in pain management at the end of her life (Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, n.d., https://www.kcl.ac.uk/cicelysaunders/about-us/cicely-saunders). As an innovative social entrepreneur, Dame Cicely knew that if her vision took money from the health authorities, it would not grow. She vowed not to compete with health systems and independently raised funds for this radical new model of healthcare until it became accepted. The innovative and new forms of caring for the dying were later adopted by health systems.

Patients who had been disregarded because they were dying were encouraged to take up new roles through journalling, preparing their life history for future generations, and to make decisions about their dying. Families, overwhelmed by fear of pain and extreme care needs, had in-home support and the refuge of St. Christopher's Hospice in the final days. Staff who were marginalized in medical institutions gained credibility and value through the science of pain management and the success of hospice.

David Brandon

David Brandon was an impassioned advocate for homeless people and for people with mental health and learning difficulties in the UK. His childhood was brutal, and he lived as a mental health consumer, bringing a unique combination of personal experience and professional expertise to his work and study. David worked the streets, created fledgling consumer-directed services and community development. He was a writer, teacher and academic. He was part of the deinstitutionalization and normalization movement, but from a peer support foundation.

One could say that he deconstructed the power of large service systems that 'bullied defenseless people' in the hope that, if he exposed those in power, they would adopt more humane practices. He saw his role as a changemaker, using personal and volunteer resources as business capital.

He promoted new roles for people that were not defined by their condition, but by their inherent worth. He saw systems and those who ran them as the enemy, but he worked endlessly to bring them to his side. His legacy is great in the north of England, and the memory of his quest for new ways of serving and living together has indeed changed service provision in the UK.

For more information on David Brandon, see Mark Smith's 2006 article (https://infed.org/mobi/david-brandon-homelessness-advocacy-and-mental-health-and-zen-in-the-art-of-helping/).

Henry Enns

Henry was a Canadian human rights activist who was part of the meteoric rise of Disabled Peoples' International (DPI), a grassroots emancipatory movement with strong international political alliances through the World Health Organization (WHO) and national governments. His story captures many emancipatory themes: shared oppressions, coalitions and conflicts within consumer movement, and debates about power. Henry developed rheumatoid arthritis as a teen and spent much time in hospital, where he learned the power of using humour and storytelling against those in power.

DPI acted as a social enterprise funded by national and international sources that supported the drive to change national policy and restrictive

government programs. New roles for persons with disabilities were entrenched in the associations he helped create that spoke to the rights to full citizenship, political responsibility, international support for inclusion of persons with disabilities, and the Independent Living Movement (Independent Living Canada, 2024, https://www.ilc-vac.ca/).

Henry Three Sons

Henry was the last case study. He avoided me for three years because he felt he was not an innovator or a changemaker. He was Blackfoot from the Siksika reserve in Alberta and was an integral part of changing child welfare policy, in response to the Sixties Scoop. From the perspective of innovation, he brought the subtlety of working for change within a large, bureaucratic system while remaining fully part of his culture.

The social innovation was the challenge of Indigenous social work practice to prevent children being adopted by white families. He was a bridge between Elder support of traditional child rearing and the white child welfare system. The systemic threat was at crisis level—the future of Indigenous ways was in jeopardy.

Henry challenged the ontology of modern or Western research that considers knowledge to be the result of individual thought and action. I had assumed that changemaking happened when a person challenged systemic problems and found innovative solutions. Henry considered that knowledge was the domain of the collective—the clan and the nation. Change happened when the collective moved in concert to combine Indigenous ways, innovative use of modern technology, and new bridging roles.

The social innovation for me was a wake-up call. I had imposed my assumption of change on all the case studies. I was forced to return to basic assumptions and create a new, contextualized way to understand truth and theory with each of the social innovators. I learned that social innovation needs to live within the traditions of each movement and community.

His legacy is the Henry Three Sons Child and Youth Society. Advances included support for Indigenous parents to raise healthy children in Indigenous ways. His case study provides an example of the strength of Indigenous culture, bridging between dominant and challenging ways of knowing, being, and influencing.

The stories of these founders are found in the resources at the end of the chapter.

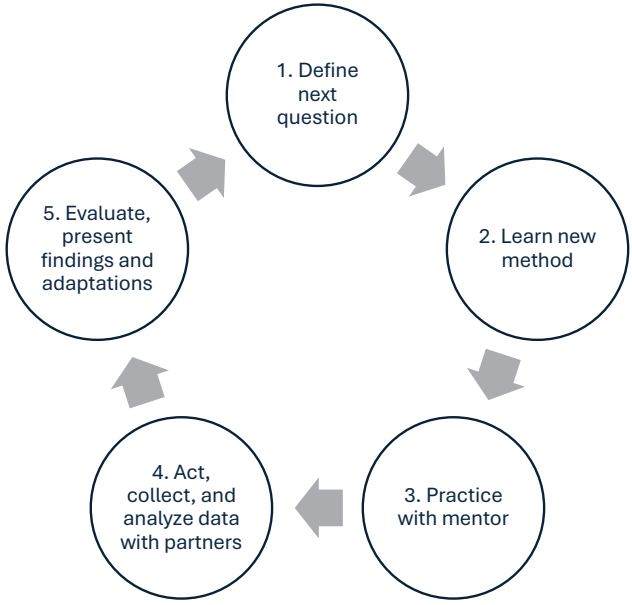
Grey Matters

The second research project was a Catalyst grant from Canadian Institutes of Health Research, to extend the impact of the above co-research thesis of new social movements. We set out to adapt and test the new narrative methods by teaching seniors about peer research. This resulted in a curriculum that included fieldwork, questionnaires, group research, and narrative interviewing that has become a product of peer research methods. The grant consisted of the following stages:

1. A large co-design focus group process with over 100 seniors that identified the model for the research. Retired university researchers supported groups of seniors in researching aspects of resilience as a foundation for testing narrative research methods.
2. Active learning based on participant action research principles. This included a teaching session and practice with the mentor, conducting research with the partner site and sharing results and learnings with the larger group.
3. Each of the methods and the teaching process was hotly debated and modified.
4. A year-long shared writing process used the same action cycle above. Strategies and methods were applied in natural settings as part of the writing process. For example, questionnaires were designed and administered with a seniors' group who wanted to use peer research to design a housing alternative for local seniors.
5. Seniors from the training program joined PhD students studying seniors' resilience to analyze findings from peer research interviews and to support students' research proposals.

Figure 1.1 is the action teaching cycle developed for curriculum development. This has been used in the development of the PaCER courses and in other peer learning situations to operationalize iterative cycles of learning and researching. For full details, refer to page 23 of *Grey Matters* and the Appendix 2 that describes the teaching method in detail.

Figure 1.1 *Participatory Action Research–Informed Inquiry-Based Training*



Note: Adapted with permission (Marlett and Emes, 2010, p. 23).

Seniors are natural researchers—they have learned to watch carefully, take note of powerful people and organizations, and organize for action. The future, in many ways, will be led by today's seniors. They do not want to be placed in institutions, and they have the motivation and capacity to effect change. The power of their research was demonstrated when seniors applied to present their research anonymously and were accepted for the Canadian Conference on Gerontology. All papers were accepted and valued, but the suggestions made by the conference leaders to engage seniors as researchers in future conferences did not materialize.

Shortly after *Grey Matters* was published in 2010, the director of the Kerby Centre was replaced. The Centre of Excellence, that was to be the champion of seniors as peer researchers, was also closed and more traditional programming was initiated. In the months that followed, the lack of a champion to continue this exciting work was the greatest and most sobering learning. Reviews of *Grey Matters* spoke to the potential of peer research, but without a champion to adopt the concept, it became interesting reading and a course resource. Today, there is an active international community of University of the Third Age or

U3A (https://www.u3a.org.uk/), along with the emergence of aging studies programs. With the pending second edition of *Grey Matters*, perhaps this time the Kerby Centre Innovation will move from a resource for students to a new training program for senior peer research.

Twin Innovations in Health Transformation: Strategic Clinical Networks (SCNs) and Patient and Community Engagement Research (PaCER) as Social Enterprises

I was invited, during the early stages of Canada's Strategies for Patient-Oriented Research (SPOR), created by the Canadian Institutes of Health Research (CIHR), to add a patient engagement pillar to Alberta's request for funding. Patients were expected to collaborate in the governance, priority setting, and conduct of research, including summarizing, distributing, sharing, and applying resulting knowledge. This provided an opportunity to assert the potential for patients to take on new roles in health research. This last case study is a narrative about new roles for patients in health transformation that are in keeping with the following publication about researching health together (Shklarov et al., 2017, https://doi.org/10.1111/hex.12591).

The following narrative of social enterprise is based on a collection of writings about PaCER and Alberta's Strategic Clinical Networks (SCNs) written by the founding team: Tracy Wasylak, the administrative director of Alberta's SCNs; Dr. Deborah Marshall, a CIHR research chair and fellow of the O'Brien Institute of Public Health; and me, Nancy Barlett, the originator of the research and training method. This short video was captured from a presentation about the first cohort of students in the PaCER program (Marlett & Penman, 2013, https://www.youtube.com/embed/QX2Z_FeF6UY).

Alberta created a comprehensive and single health system in 2008, and SCNs were formed as engines to drive this transformation. In the SCNs, those who deliver and receive care are equal partners in designing and implementing ways to reduce unwarranted geographic and cultural variation, using evidence and research. The SCN leaders knew that strong patient and community voices were essential when determining priorities and strategies for change, and they were ready to implement radical system changes to make this happen.

When we started, patient advisors were already working on professional and research teams with early indications of increased patient-centred care and research uptake. We soon realized that we were well positioned to develop new roles, relationships, and strategic partnerships because there was the political will to invest in training patients to create research-informed patient advisors.

There are three distinct stories in this narrative of social innovation:

- **Emergence**: This part of the story uses the *Grey Matters* curriculum to teach patients to become members of the SCNs as patient researchers.
- **Survival**: This story shows social enterprise as an alternative way to continue the training after grant funding ceased. It also supported contract peer research partnerships with the SCNs and academic health researchers. Both stories were guided by research and independent evaluation.
- **Coming of age**: The third story captures the collaborative efforts to formalize training within the University of Calgary, create an administrative home, placement options, and contract research with Alberta's Strategies for Patient-Oriented Research (AbSPOR). During this time, I continued to develop the science of engagement in health to support research teams and health systems to sponsor and support peer and community research.

Emergence

This first story captures the development of a training program as part of the Catalyst grant from the Canadian Foundation of Healthcare Improvement (CFHI). We used action-based teaching to test the 'Set, Collect, Reflect' engagement strategy and the curriculum that emerged from *Grey Matters*. The grant funded two full-year internships, and graduates went on to work as patient research advisors with the SCN and national research teams.

It soon became clear that the SCNs, as a receptive social innovation itself, were willing to form a disruptive relationship with patients as colleagues and to use PaCER research to inform and implement change. From previous experience, they knew that putting patients in the centre of a disruptive transformation strategy without support and skills was a risk. PaCER training has helped to minimize these risks through rigorous training in conducting research that engaged patients and communities. These patients became not only advisors and researchers, but also the drivers for changing the culture in the SCNs and research teams. Also unexpected were the leadership roles patients took on and the emergence of their self-identity as change agents.

Survival

Once we had inadvertently created a marketable product that demonstrated the impact of training patients to conduct research using methods co-designed and tested with patients, we were lucky to attract John Lacey, a retired business man, and a support team to help establish a social enterprise within a university environment hoping to use the potential of social enterprise. There were

serious obstacles to operating an enterprise within a university grant structure that had created complex systems that were not able to accommodate the early uptake of innovation or an advisory committee, and a strong partnership with the health system.

PaCER became an early adopter of the language, motivation, and potential of academic social enterprise. In hindsight, had we known about Ashoka, we would have had allies in the uphill struggle of creating a culture of social enterprise within the university.

As our grant funding came to an end, the formal outcomes mapping evaluation and grounded theory research of the key stakeholders indicated that training had been successful in producing peer research capacity within the SCNs. We had created a strong partnership between healthcare, health research, and patient engagement that sparked new ideas, challenges, and opportunities in an environment committed to and able to test new ideas. The lessons we had learned about the viability of the concept now faced the crucible of funding an infrastructure to continue the internship training of emerging peer research teams.

We moved quickly to create a social enterprise to support our training and scale up peer research. We created a business plan and discussed it within the faculty and was assured that, as long as I maintained responsibility for the research, we could experiment to see if the concept was viable. The income sources included training sponsorships and research contracts for peer research services. PaCER became a test case of social entrepreneurship and innovation within our university, as we created new employment, payment, ethics options, and legal, financial, and accounting processes with the university and Alberta Health Services (AHS) infrastructures.

Developing and managing 16 internship teams over seven years along with 24 research projects was taxing without formal infrastructure. We relied on the continued liaison team that founded PaCER, part-time academic and ethics support, and a volunteer management team of PaCER leads. During this time, an advisory board and formal business were established. We earned funds to support research teams and training sponsorships, but not the academic and administrative infrastructure.

As a social enterprise, we learned that researchers were willing to 'buy into' a novel approach of engaging patients in research when they were satisfied that PaCER could manage and oversee the academic integrity and that the cost was reasonable. Direct academic oversight, quality assurance, adherence to legal protocols and ongoing consultation with the university ethics review board ensured that PaCER was seen as a legitimate academic resource. The training and research methods were tested and adapted to ensure lay language and simplified

robust methods. This had added benefits because the results were sound, practical, easily understood and implemented, and were, therefore, publishable.

The main learning from this story was the essential role of the SCNs as the champions of PaCER. Their mandate for evidence-based health change and the ability to implement innovation enabled patient research voices to be included in decisions and future planning. SCNs connected PaCER to other research and quality improvement opportunities, acting as a vehicle to spread innovation and continue support of training.

We moved from the moral imperative of engaging patients to engaging patients as full members of research teams throughout the research cycle. It was becoming more common to be asked to conduct research into troubling and resistant issues that require a deep understanding of how patients make decisions and what matters most to them.

However, we knew the next stage had to be expansion, to respond to demand, both provincially and nationally. A large Indigenous training grant provided the funding to expand. The transition was extremely rapid, and, as with rapid expansion, we lost the capacity to plan, evaluate, and adjust. We needed a predictable product because our contract was high profile and risky. In order to deliver the training by distance around the province, we partnered with the university's Continuing Education unit to create online education and internships.

However, with the politics of working with a large, new population of students throughout the province and a lack of internet capacity, the rubric 'go slow and adapt' was swept away by a rapid change in materials, staffing, demand, and basic processes. In the end, it was successful because of the intense commitment of the staff, board, liaison committee, and particularly the Indigenous graduates.

Unfortunately, when the funding ceased, there was no way to fill in for the infrastructure, and new models were needed to go forward. A partnership among the university, Alberta SCNs, AbSPOR patient engagement unit, and University of Calgary Continuing Education has committed to creating ongoing structures to ensure PaCER sustainability.

Social Enterprise

At this point, we introduce the broader influence of social enterprise, where businesses create social mandates and funding partnerships, charities, or not-for-profit services operating a related business. Some examples include:

- Responsible corporate partnerships to support social needs that have become a feature of corporate culture and marketing addressing mental health, animal welfare, children's help lines, etc.

- Micro-financing of small business in low-income countries and marginalized and Indigenous communities and nations.
- Charities and not-for-profit associations that encourage income generation to support services, such as Goodwill.
- Self-employment for persons with lived experience of disability, retirees, low-income citizens, and veterans as outlined in government policies (Blackburn & Smallbone, 2015).
- Entrepreneurial models where people with disabilities hire and manage their own service provision budgets.

Ashoka changemaker networks combine community innovation and social enterprise—programs devoted to building community-based business opportunities and not-for-profit services and programs. Ashoka (https://www.ashoka.org/en-ca) has become an international network of universities, enterprise fellows and citizen changemakers, leveraging research, experience design support, start-up funding and academic support of Ashoka institutions and student programs. This partnership of academic research and social enterprise has led to a major reconsideration of the innovation at the university level.

In keeping with the social enterprise theme, this manuscript has been crafted to encourage social enterprise in health research and innovation through providing the science, the theory, and the methods to encourage researchers, research teams, social innovators, and social entrepreneurs to promote research done by, with and for patients and communities. To complete this section, we refer to Greenhalgh et al.'s policy paper (2016, https://doi.org/10.1111/1468-0009.12197) on achieving research impact through co-creation in community-based health services and the principles for success. This literature review and case study included many of the topics in this manuscript, from democratic, community-focused, and participatory options, along with innovation topics, including design thinking.

4. Digitizing Health

We begin with a bit of history about innovation, which has always been a part of human life as the major driver of change. The first industrial revolution of mechanization, starting at the end of the 18th century, replaced agriculture as the focus of society. The second industrial revolution was made possible because of new energy sources of electricity, oil, and gas to run automobiles and planes. With this, business soon became the focus of invention and innovation. By the third industrial revolution, computers, electronics, biotechnology, and telecommunications introduced an information age, enabling advances in space exploration and advanced automation (robotics).

The fourth industrial revolution builds on the third but has made quantum leaps because it is defined by the combining of physical, digital, and biological technologies. It unleashes major options for healthcare, such as combining the neural networks with robotic limbs, the internet of things that combine appliance and machine sensors with implanted sensors monitoring a wide range of functions, and implants that track health indicators, which are informing homecare telehealth.

The issues related to data ownership have never been more critical than during the current rush to new technology and decision tools. Teams and companies, from large systems to small community agencies, purchase data sets without understanding the potential biases and dangers and without any way to test the technologies. Apps and data are sold and reused without accountability or oversight. As with most technology, the end users—the patients and the frontline staff—must be ready to question and evaluate. To date, the consumers have been able to make decisions, but as technology is worn or implanted, these decisions become more difficult.

There are many specialists involved in new technology development, particularly algorithm teams using artificial intelligence informed by machine learning. These early teams could avoid many of the high-risk pitfalls inherent in data sets if they were able to use peer research to provide real-life, diversified data that overcomes the sources of systemic discrimination. While this will be costly in the beginning, refitting or decommissioning technology is also costly. If we employ a science of engagement to guide technology and decision-making tools that can be adapted and customized as needed, the eventual goal of having informed and motivated patients while reducing systemic discrimination will be achieved.

The Telegraph newspaper ran an article in 2016 that captures the essence of the emerging digital culture shift that is occurring from a patient perspective (Philips, 2016, https://www.telegraph.co.uk/wellbeing/future-health/fixing-the-holes-in-healthcare/). It represents the first level of transfer of healthcare to patients and community options.

If we include patients trained to engage populations in creating real-life data, the shift to personal control and community options will accelerate. Patients, seniors, and those with disabilities and chronic illness already have the expertise in health systems to become advisors and partners in a new technology future for health and healthcare.

Emancipatory patient movements are percolating, and patients are discovering the power of personal and patient-led research (Williamson, 2008, https://doi.org/10.1111/j.1369-7625.2007.00475.x). Established researchers may still balk at token patient engagement criteria for grant approval, and funders

may still be reluctant to move beyond minimum payment for patient advisors or partners. However, there are examples in citizen science, peer research, and patient-led research where patients are trained (Independent Cancer Patients' Voice, n.d., https://www.independentcancerpatientsvoice.org.uk/voice-science-for-patient-advocates/) or are developing training themselves to research problems on the margins, challenge formal research practices that are discriminatory, and search for research allies to support these new options.

Summary

The journey began with institutional and community innovations and ended in an era being changed by technology. The following are some of the questions you might discuss. Try to use personal experience or a project you are familiar with. Keep in mind the changes in patient and professional roles.

Questions for Discussion

1. How have systems found ways to 'manage' change? Have you seen examples of the waiting game, absorbing new language into existing practice?
2. What are some of the features of successful community-run services? How have pilot or Catalyst projects influenced or threatened new ideas? What is the role of social media in community project success?
3. How can peer research open space for social change, peer support, and community entrepreneurship? What is needed to make space for patient and community expertise?
4. What are the challenges to including technologies in social change and cost effectiveness?
5. How might emancipatory patient movements be supported by peer research and new technologies?
6. How might an experience you have had been different if there was a role for peer input or if the technologies emerging today had been available?

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2

Negotiating Co-research: A Theory and a Method for Empowering Stories

Highlights

- International case studies of new social movements
- Research devoted to finding a way to make co-research work
- Grounded theory research to find theory and a method
- Integrated narrative theory of data collection, analysis, interpretation, and theory
- Case-based or idiographic theory and theory of new social movements

The goal of this chapter is to share the research that led to the emergence of an integrated narrative, grounded theory research method. This was done in partnership with founders of new social movements, as part of my PhD at the Open University in the United Kingdom. This was a case study of six new social movements that enabled the incubation of methodology. Each of the six founders committed to the co-design and co-production of a new research approach suitable for peer research. The resulting method informs grounded theory research to adapt the peer research method of the science of engagement (SoE).

This chapter was first published as partnership research in *Doing Health Promotion Research* (Thurston et al., 1998, out of print). It is adapted here with the permission of the editors. The impetus for the research came from the Calgary Association for Independent Living (CAIL) that introduced me to peer support self-assessment and goal planning as part of action-based research. It helped me understand peer support as a potential model for peer research. In spite of much skepticism from my PhD supervisor and committee, I decided to use co-research where I was a peer in the study because of my work as a social innovator that the co-researchers saw as equal to their work in social innovation.

Research Partnership in Co-research

Co-research introduces new research roles to the study of social innovation, which, according to Conger (1974, https://doi.org/10.1111/j.1467-9833.1974.tb00448.x), is "a new procedure, organization or law that changes the ways in which people relate to themselves or to each other" (p. 26). This study addresses a subset of social change—innovations that influence people's ability to realize personal and group emancipation.

I set out to explore social innovation in ways that would inform traditional power imbalances in research. While conducting the research, I had the opportunity to visit a number of universities to present seminars on my work. I spoke to sociologists, educators, psychologists, and discourse analysts. While most were intrigued by the research, they had strong reactions to the idea of working partnerships with people who were the focus of the research. Reactions were far reaching, from threat to academic freedom if co-researchers were equal partners in the interpretation of data, to the abdication of academic responsibility. On the other hand, feminist researchers I spoke to considered full partnership a fond but elusive dream.

The study took place in several settings in the UK and Canada, with people who had experienced a social change that had an impact on their personal lives. Most co-researchers were involved over a period of three to four years. British partners included Gerry Kinsella, founder of Greenbank College; Dorothy Birtles of the Quaker Prisoner Befriending Scheme; Dame Cicely Saunders, the founder of the modern hospice movement; and David Brandon, Director of Mind UK. Canadian partners included Henry Enns, co-founder of Disabled Peoples' International, and Henry Three Sons from Siksika Family Services Corporation. They and the people involved with their social innovations offered living laboratories of the study.

Through hours of interviews, site visits, and sessions with their families, staff, and clients, they became researchers of their own experience. We were able to document how they, as equal partners, found ways to collect, analyze, and interpret their data. In the process, we uncovered knowledge that was meaningful, both for an academic audience and the new social movements studied. In a way, we lived social innovation, as we explored new partnership roles for both myself and the founders.

I chose to use grounded theory as the general framework for the study because I anticipated that the methods used to study social innovation would have to evolve and expand as the study progressed. After an extensive recruitment and preparation process, we started with a fairly traditional qualitative interviewing approach, using feminist principles and ethnographic processes, which encouraged an open sharing of ideas and reciprocity.

We soon encountered serious difficulties as the transcripts, and the forms of analysis posed barriers to partnership. The founders felt increasingly alienated. Although we spent time together, most of the work was my work trying to figure out how to do co-research. The use of conceptual abstractions as themes distanced the participants from their own material, because many of the themes arose from my background and reading as a psychologist.

When I sat back to analyze what was happening, it seemed that we kept talking because neither I nor the others knew when we were finished. I began to imagine that we were trapped in a force field defined by collecting, analyzing, and interpreting data without a way to stop. My feelings about the search for the meaning were coming close to those of expressed by Rommetveit (1987, https://doi.org/10.1080/00201748708602111) in discussing the plight of the enlightened layperson struggling to make themselves understood within the games of research: "[The participant's] initial pride turning to despair and alienation while I as the scholar of human communication pursued the trade with scientific rigor, formal elegance and academic success within the convenient fiction of joint construction of meaning."

I came face to face with reality, as stated by Gluck and Patai (1991, https://doi.org/10.4324/9780203819371): "Narrators typically are not true partners in the process. Whatever control they exercise during the interview, when they are able to negotiate the terrain, usually ends once the session is completed" (p. 2). Gluck and Patai go on to assert that, although narrators are occasionally consulted prior to publication, the interviewer/scholar maintains control over "the work of framing, presenting, interpreting, analyzing and making the work public" (p. 3). They conclude that feminist scholars contribute to the collectivity of women, but their actual practice has maintained the real separation between narrator and interviewer.

As we discussed the difficulties we were experiencing, it became apparent that the participants had particular strengths related to understanding the nature of partnership research. They had agreed to participate in the study after understanding the scope of the research, their role in negotiating topics, and their role in the use of the material. The participants were high profile people with much to lose, and the topics covered could be potentially damaging—both personally and professionally. They needed assurances that their information would be treated with respect and their ideas not squandered. The first change was to move away from conceptual abstractions and psychology-based theory and agree to base our work within a shared language of everyday experience. We also needed a process whereby we could capitalize on the implicit expectations of our partnership so that we could shift expectations and goals. It seemed logical and natural to consider a social contract that could help us clarify the steps to be taken.

Table 2.1 *A General Social Contract Framework for Co-research*

	Give	**Get**
Co-researcher: content expert	• Information and personal perspective on topic	• Respect and involvement • Useful data that can be shared with others, especially peers and community members
Co-researcher: academic expert	• Values contribution of participant	• Participant information and perspective on the topic.

The contracting process was adapted from a training contract for the Adaptive Functioning Index (Marlett, 1973). It created the opportunity to openly discuss activities, interaction, quality standards, and products and end points. We negotiated next steps and options, instead of being limited to one prescribed research process.

Rather than trying to negotiate a contract for the entire research, we negotiated our roles throughout each task of the research. These tasks occurred within four general and interconnected stages in the research process: data collection, data analysis, interpretation, and theory generation and dissemination. The negotiation at each stage began by defining and agreeing to the tasks at hand. We could then define our respective roles in relation to the specific research task, the anticipated product of each task, and how each of us would know when the process was finished. From this, we could also judge the quality of our work in completing the task and the product that resulted. This was a verbal process, captured on tape, and this is available in the transcripts for reference.

1. Data Collection

Data collection was an easily identified process because most of the co-researchers had been interviewed in the past and were familiar with evaluative research. They were comfortable with the different methods used to collect data in the study—interviews, observations, use of documents—and, thus, the data collection contract held no surprises.

The purpose of the contract, as illustrated in Table 2.2, was to secure relevant and accurate information. In this, the researcher provided the opportunity and means for the participant co-researchers to explore and discover, in order to learn about themselves and the topic. The participants committed to explore and share their experiences and ideas within their limits of trust and safety. I, as a co-researcher with experience in social innovation, contributed when it facilitated and expanded the scope of the data. Any agreements to disclose information were governed by the balance between the benefits and the inherent risks to the participants.

Table 2.2 *A General Social Contract for Data Collection*

	Give	Get
Co-researcher: content expert	• Commitment to explore and disclose information on topic	• Opportunity to be part of research • Opportunity to discuss one's experience • Recognition of experience • Respect and acknowledgement of expertise • Understandable data
Co-researcher: academic expert	• Knowledge about research related to the topic • Willingness to discuss process • Preparation of transcript and data summaries	• Opportunity to explore topic with an expert with direct knowledge • Self-awareness as a researcher

Every effort was made to establish and maintain an informality in collecting data. Co-researchers set the pace and were free to expand on topics or issues that they felt were important. It was common for the co-researchers to ask questions and for me to share my experience and material from my research experience with marginalized groups. The founders were asked to comment on the process and whether they felt safe and comfortable with the information disclosed. If a topic was too sensitive, it was removed, deferred, or approached in alternative ways. In all instances, participants were invited to include others in data collection to explore alternative perspectives. For some co-researchers, this meant the casual involvement of a spouse or family members; for others, formal group interviews with co-workers and the people directly involved in the social invention were arranged. Interviews took place in a location chosen by each participant, usually at the site of the organization. Interviews were taped throughout the entire research process to provide a record of the evolving methods. The final product of the data collection stage was the transcript.

Transcribing our first co-research interviews from taped interviews, field notes, and documents almost derailed the co-research and my thesis. The first transcripts were formal texts that left participants alienated and reluctant to engage in analyzing the transcripts. Similar concerns have been raised by feminist researchers Doucet and Mauthner (2006, https://www.researchgate.net/publication/251770477_FEMINIST_METHODOLOGIES_AND_EPISTEMOLOGY).

Co-researchers felt the words in formal text didn't look like their words and this was embarrassing to them. I had taken their words and ideas and made them mine, as I attempted to impose grammatical structures. The written record seemed barren and alien. All founders felt that I had appropriated their experience, and they were relegated to confirming my record of their lives.

Using Glaser and Strauss's (1967, http://www.sxf.uevora.pt/wp-content/uploads/2013/03/Glaser_1967.pdf) call to experimentation in grounded theory, I spent eight months trying various transcription methods with the co-researchers. I wrote in various styles of texts, prepared short summaries of key points, used various linguistic formulae that translated the spoken word to speech acts, drew annotated pictures of constructs, and, in desperation, I even resorted to writing free verse.

Then, late one night, I plugged in my transcription machine and slowed the speed. I just began typing and lost myself in the unfolding stories. As I listened, I typed and hit the return button each time I heard a pause, for no other reason than that it seemed a sensible way to avoid run-on lines. I typed naturally, often keeping time with the tape recorder, and, after a few hours, I looked at what I had created and smiled. Rather than listening for content and sentences, I listened to the rhythm of the speech and the intonation of the speaker. When I read it back, I suddenly realized that I was listening to the person talking 'text'—the breath, the pause, the hesitation had created speech on paper. The following is a short example of the method for transcribing in which Gerry was talking about bus transport at Greenbank:

> It took 10 minutes to load a trainee
>
> not particularly good on her feet
>
> He (the bus driver) had to use the lift
>
> and I said
>
> are we talking about the same person
>
> she could go up the steps at the side of the bus
>
> (driver) said no she can't
>
> and her mother is adamant that she can't
>
> I said okay, I'll go with you
>
> and I went out

and the parent came out and was about to say my daughter can't do it

and I said

alright Mrs. Jones we don't need you here right now

in a tone that means I don't want you here

it's not a school

this is an exercise that management needs to do

and the kid is bemused as anybody

it could have been one of those tearful experiences

the upshot was that the exercise was completed

she got on the bus.

I've had dozens of these where people assume they can't do things because people tell them they're disabled.

This transcript maintains its conversational character and the integrity of ideas as separate but connected. Without punctuation or a constructed sentence structure, it reads with the rhythm of speech. One of the co-researchers called it research poetry. When the speaker is talking about familiar concepts, long, run-on sentences appear because the speaker doesn't need to think, but when the speaker is concerned or searching for answers, short lines appear. In our transcripts, the visual appearance and the rhythm reflected individual characteristics. When more than one person was included, each person could be identified by the visual footprint of words on the page.

In essence, the story tells itself in the person's own voice. The reader gains what the person is saying in a direct way that doesn't need interpretation or presentation. This maintains respect and reality, and, in doing so, enhances the overall outcome. The connection between memory and the rhythmic patterns seemed to draw in the co-researchers—they could easily locate ideas in text. We could recall the conversations, and, most importantly, each person commented that they could hear themselves in their story. They heard their own rhythm rather than the rhythm imposed by the transcriber who had produced the transcripts.

The problems of written representation have been associated with the power of ownership in research. Written text becomes owned by the researcher instead of belonging to the speaker. This speech transcription shifts power to the narrator.

The speech transcription method is included here because it provided an important breakthrough in the extension of partnership beyond the interview. Transcripts were produced using a technique designed specifically for the study. This created a written representation of oral conversations.

This speech-based procedure for creating transcripts enabled the co-researchers to own their transcripts as part of an ongoing oral interaction. This enabled us to 'play' and engage with the data longer. The social contract of data collection was considered complete when participants saw and felt comfortable with their transcripts.[1]

Listening to recordings and making notes or filling in story templates creates support for the reluctance of grounded theorists to produce transcripts that may inadvertently subtly change the meaning of thoughts in conversation. It also made me more confident in the transparency of the text form of our experience instead of relying on attempting to create written text.

It was interesting that as PaCER shifted to qualitative research using thematic analysis, they also returned to transcribing interviews and focus groups. In the final chapter, we introduce a new integrated narrative science that uses story templates to organize data from recording throughout the stages of research, and this may encourage a return to data that captures real-life experience of co-researchers in ways that reinforce the language used by co-researchers.

2. Analysis

The definition of, and contract for, analysis proved to be the turning point of the study. After much study and discussion, analysis was defined as examining and breaking data into small pieces or incidents for grounded theory constant comparison. In this, the whole story and the elements of the story were considered incidents. Each incident of data was studied to find similarities and to sort the data into categories. The purpose of the contract was to ensure reliability of the information that had been gathered and sorted, to ensure that the elements or

1 *Note*: Not even this simplified speech process was enough to engage seniors from *Grey Matters* (Marlett & Emes, 2010) in transcribing data. They used a story template that enabled them to listen to the tape and insert what was happening in the stories into the story template. This provided a bridge between data collection and the first stage of analysis of taking data apart into pieces or incidents that can be studied for meaning. The story template has since become the basic data format for collecting incidents.

units were complete and correct. Table 2.3 represents the framework for the analysis contract.

Table 2.3 *A Contract to Sort Data Units into Categories*

	Give	**Get**
Co-researcher: content expert	• Verification of correctness and completeness of the data • Agreement on elements in the data, their groupings and order	• Security that information is not distorted or changed • Involvement in data analysis
Co-researcher: academic expert	• Preparing data and templates for analysis • Opportunity to involve participant co-researchers in analysis	• Visibility and verification of the data • Co-researcher perspectives on the connections in the data • Security in the elements and their integrity

After working with the transcripts in the form of whole stories and short word phrases in order to identify concepts, it became clear that the time required became excessive. We agreed that I would take the responsibility to prepare the data into units, so that we sort them into categories. The end product was a collection of incidents sorted into categories with preliminary names from the data.

The search for methods of analysis was a six-month quest to find a collaborative way to work with the transcripts that respected the co-researchers and enabled the analysis to reflect an authentic negotiation of meaning. Conceptual and thematic analysis, life-course analysis, conversational analysis, structure analysis, movement analysis, and antecedent/consequent analysis were all tried, but none fostered the ability to co-research. Each felt like I was retelling their experience in a foreign conceptual language. They felt alienated, abandoned, and frustrated. Eventually, shared stories composed of common experiences were chosen as the foundations of analysis because co-researchers could relate to stories and work with them.

The negotiated contract for analysis was complete when all the relevant information (transcripts, observations from the site visits, interviews with collaborators, and documents) were represented in story units. The initial story chains were constructed using cards enabling the co-researchers, and those they chose to be involved, to see and work with this initial stage of analysis

more easily. The stories were summarized by title, page reference, a summary, and a brief list of incidents of experiences. Participants were invited to add stories that had been missed, combine or separate stories, or delete stories that were not relevant to the topic. It enabled creativity and the notion of playing with experience in the process of ensuring thorough analysis.

The processes were open, concrete, and transparent, and led to productive and comfortable working relationships. Both parties knew what was expected and when the task was complete. Co-researchers had come to feel a certain security in the handling of their stories because they could see and understand each of the steps in the process. They came to believe that their information was respected, that there was a deliberate search for truth and that their stories would not be distorted.

The following section is a summary of some of the more successful methods used with co-researchers in this stage of analyzing their data. The process of sorting and comparing incidents to create categories is considered under interpretation.

Options for Analysis

1. Short Story Summary and Initial Codes of Categories

We began creating notes in the transcripts that identified potential stories in the margins. We named each story (a title) and included a summary of potential themes. We used this process for all data. These stories grew to become chains that created a chronology of stories. Stories from different data sources could be added into the story chain from interviews, groups, and documents. The innovators maintained their ownership of these short stories and story chains. The following is an example of several stories from a story chain of the Greenbank training centre:

- **Debbie comes to Greenbank (field note)**: From a chat with Debbie while writing a European Union report about Greenbank. Professionals had convinced Debbie that she would never work anywhere but in a sheltered environment. However, she came to see herself as a competent and creative worker.
    - *Themes: stigma, labelling, external control, new hope.*

- **Bus and Mrs. Jones (Gerry transcript, p. 16)**: Interview with Gerry and the bus driver. Gerry sidelines a mother who is limiting options for her daughter; Gerry asserts that the daughter will be able to get on the bus.

- *Themes: control of external power, risk, power, power balancing, staff training for expectations, belief and confidence*

- **Crooked eyed joiner (article in newspaper and field note 17)**: General chat in the lunchroom with a group of staff. Gerry noted that a trainee jerks when cutting, not because of physical disability but because he is blind in one eye. The trainee adjusts the angle of the work so he can see and performs well.
    - *Themes: a peer notices problem missed by a professional assessment, native cleverness of peers, staff training, belief and confidence*

Over 90% of the data was included in this type of chronology of stories, which we defined as any temporally and thematically connected series of ideas or incidents. We entered the short story notes onto small cards, to compare each story and to sort into categories of like stories. We worked with the story chains to fill in the gaps, find duplicate or related stories, look for patterns and create analysis for common stories. This process was in keeping with classical grounded theory and necessary for the social contract.

2. Antecedent Consequence Analysis

We experimented with different ways to express the short stories in a more expanded fashion that captured action, direction, and change. The most extensive of these was antecedent/consequence analysis of events to flush out the stories. The following is an example of the analysis of antecedent and consequences in the Bus and Mrs. Jones transcript noted above:

- Implied actors: *Gerry, Mrs. Jones, bus driver, and daughter*
- Condition: *Dispute over time taken to load trainee on the bus triggers Gerry to set up a session to witness the loading process*
- Activity: *Assessment of the loading process to identify parts where difficulty was noticed*
- Tactic: *Interrupt Mrs. Jones before she has a chance to voice her option—change focus to transportation difficulties, not the daughter*
- Consequence:
    - *Daughter is bemused and vulnerable*
    - *Parent is sidelined*
    - *Staff is chastised*
    - *Daughter gets on the bus and is proud of herself*

This analysis was incorporated into the analysis of the story template that consisted of the beginning, middle, and end. The shift to a more simplified format made it easier for novice researchers to understand and use.

Figure 2.1 *Story Template to Record Stories in a Quick, Visible Format from Audio Tapes, Flip Charts, or Observations*

Story Template
Title Researchers Date Project
Context (the who, where, when, and what was happening of the story)
The trigger that starts the story (the action, idea, or event that disrupts the flow)
The plot of the story (and then . . . and then . . . and then) simple steps in the unfolding story 1. 2. 3. 4. 5.
The consequences or ending of the story
What did the teller learn about the topic or her/himself
What did you learn and how does it relate to the concern or question
What next steps are suggested

3. Interpreting Stories: The Search for Meaning

During data collection and analysis, we worked to capture historical truth. Historical truth lies in a story that is recounted by those who have lived it. Historical truth is truth as seen, experienced, and recalled. We had done this

through the honest and comprehensive documentation of actions, events, ideas, and feelings. Now we had to deal with narrative truth wherein the story is true regardless of its historical veracity because of the meaning the story conveys to others (Spense, 1982, https://doi.org/10.1080/21674086.1982.11926984). In the search for narrative truth, the stories were no longer products in and of themselves but were tools in an ongoing interpretive process that used the stories to uncover topic-related information. We defined 'interpretation' as the process of finding relationships between the stories that added to our understanding of the intention, purpose, or impact of the topic.

This following section addresses constant comparison and coding using incidents, which includes stories (small action statements of what's happening) and descriptions of experience (what was it like).

In my experience with quantitative, evaluative, and social action research, the scope of the interpretation was predetermined by the method used. None of these experiences seemed relevant to the work we now faced. While our roles had been different and discrete in the search of historical truth, we were now fellow observers and interpreters, as we moved beyond documenting stories to understanding the topic through stories. We had to create our respective roles and rules of conduct as we went along, as represented in Table 2.4.

Table 2.4 *A Social Contract for Interpretation*

	Give	**Get**
Co-researcher: content expert	• Understanding of context—place, time, actors, history, culture • Increased options for understanding meaning • Seeing commonalities or categories in stories	• Increased understanding through reframing events and experiences • Personal awareness of social innovation • Sorting experience to find common themes
Co-researcher: academic expert	• Process for identifying various perspectives of categories • Recognition of co-researcher's life worlds and impact • Process for making sense of experience	• Contextual and social validity • Fresh insights • Dense categories • Options for theory • Novel process for interpretation

In this contract, we move from stories to categories of stories through a sorting process. There are two goals related to negotiating roles—social validity

and contextual validity. Social validity was enhanced because the process and the product were personally meaningful to the founders of the organizations they created. The contract also framed the tasks of interpretation within our respective experience. Contextual validity was a term that I coined to recognize the underlying meaning inherent in context (historical, social, personal, and cultural). For example, the results of a study of mother/infant interaction would take on particular meaning if the study was conducted in an intensive care nursery and a very different meaning if the study was conducted within the home. When the context is identified, readers have important reference points that ground their understanding.

The tasks involved developing methods that capitalized on the strength and breadth of our combined experience and complementary perspectives. The benefits of partnership during interpretation were great. The co-researchers had an opportunity to reframe their experiences according to a number of perspectives, including their history and their culture. The academic researcher broadens the interpretive base so alternate meanings are recognized and integrated into the final products.

My role included the development of methods and procedures that would engage both of us in a shared search for meaning. The co-researcher's role was to approach each exercise with openness to different perspectives and to identify as many interpretations as possible. We began by discussing what each of us brought to the process of interpretation by looking at our experience with the categories. We also discussed how our shared experience extended the boundaries of possible interpretation to include our combined personal, social, cultural, and historical perspectives. This process also helped me define the potential for generalizing our interpretations.

As we started to work with stories, I was unprepared for the openness, mutuality, and reciprocity that ensued. It was as if the stories had created a familiarity and trust that made it possible to understand our research roles at a new level. The following transcript is taken directly from a tape of the interpretation session, and therefore not presented in the usual transcript format. It is included to identify the partnership that enabled the case study to proceed.

G: *At the beginning, I must confess that you were asking questions and I was wondering if my rabbiting on would give you any information that would be of any use to you at all, and then I stopped doing that very early on. I was constantly thinking about what I'm saying and what meaning it may have to your research. It might have been a botched-up job.*

N: *You know, I don't think researchers realize just how much people do just that –that people are trying to give us what we want. I think that may be the reason why so much research is shit. We never sit down and say "this is the area I'm interested in" and be honest with you. You end up spending your time guessing what my agenda is.*

G: *It's almost like bedpan syndrome. You've been interviewed by so many professionals who are wanting to prove a theory. Not really searching for new stuff by wanting to prove a theory and you see that when somebody's eyes start glittering or their voice changes –it says "yeah, tell me a little more about that" and you think "oh shit, I've got it right haven't I" and then you get the disappointment in their eyes and you think "oh now I've done it." That wasn't happening 'cause I quite enjoyed telling you my stories, to be quite honest.*

N: *There were times when I thought I should be directing it more. I finally thought it's time to just watch where this goes. There were pages where all I got to say was an "um."*

N: *One of the stories that I wanted to interpret with you is a story that happened a long time ago and it will be a challenge to get back into it. I'd like to talk about what roles we might take in this. I'll need to be guided by you.*

G: *OK, lead us into it. There's so much in my mind, let's start with the story and see what comes out.*

(Gerry and Nancy, interpretation tape, 1991)

The short story chronology and the story template identify story-based categories for more detailed analysis and interpretation. The following describes the elements of the story template as used in interpretation.

Title

The title represents an aspect of the story that sets it apart from other stories; the naming of the story is akin to its birth. Story becomes an entity when it has a name that acts as a specific code for the entire story. The title suggests how the story will be recalled, shared, and changed. It, in effect, bridges from story to narrative because of the shared meaning.

We learned that the person or persons who label the story owns the story. Even when I chose words from the transcript that I felt honoured the narrator, my act of naming presented problems. In the beginning, the co-researchers either capitulated and gave the story to me or we engaged in a struggle for power in naming the story. Once we realized the power of ownership, the ensuing naming ceremony developed into a kinship between us.

The title is in fact the theme of the story in most cases and as such titles represent stories as incidents.

Context

This is generally the beginning but can be scattered throughout an interview. It combines the who, what, when, and where of the story. It follows from the much-loved phrase 'once upon a time.' The context sets the stage, outlining what was happening when the story began and the triggers that initiated the story. The context collects the properties and characteristics of the story that are used to understand categories by looking at the common properties. The following is a summary of the properties that are used in interpretation:

- Who is the teller of the story? A young Indigenous woman.
- Where does it happen? A young Indigenous woman in the emergency department.
- When does it happen? A young Indigenous woman in the emergency department in the early morning.
- What's happening? A young Indigenous woman in the emergency department in the early morning having difficulty breathing.

The following example from Greenbank led to an important breakthrough in understanding the importance of place as a context in understanding stories. Over 100 stories from Greenbank were sorted into piles according to where the story took place. Four locations were identified:

- Greenbank, the former special school that was taken over by persons with disabilities to start a training co-op.
- Smithdown, the downtown commercial enterprise that houses shops, a wheelchair factory, and a whole food restaurant.
- Past places such as special schools, hospitals, and in foster care.
- Westfield, the proposed and contested site of expansion and direct competition with professional services. While Westfield failed to materialize, a recreation centre was built instead.

Place or 'where' is just one of the features of story analysis that can lead to categorizing stories and incidents. Categorizing by place was the key in the development of understanding how the environment created consistent psychological spaces that were reinforced by common stories or narratives. It also provided an overall theoretical framework for the social enterprise that was called Greenbank.

The questions related to who, what, where, when, how, and why are not just context, they are a powerful tool in interpreting stories. In grounded theory, which is not narrative by nature, similar tools are called properties—qualities or characteristics. From a narrative analysis perspective, this would relate to the question, 'what is happening here?' This questions the story as an incident, happening, action, or metaphor.

Plot Analysis

The plot consists of actions or incidents, listed in order, from the context to the outcome or consequence. By analyzing the plots of similar stories, it is relatively easy to study what is happening in the story. There are common plots in literary analysis, such as tragedy and comedy. There are also specific tools that capture the overall movement. This represents movement analysis that tracks the conceptual movement from a story template.

Consequence

The consequence demonstrates how the flow of the overall story had altered by the end. It identifies what the person learned (the moral of the story), and how relationships, roles and even organizations seemed changed because of the events of the story. The consequence also includes the 'what next' question, to identify sequence and related stories.

Underlying Scripts or Action Scripts

The following interpretive tool was developed in the student research of autobiographies and is added here as a powerful tool to capture theory. Stories are captured in what became known as script analysis. Categories are described in a short story script that can inform theory.

The context, plot, and consequences can be used to sort stories into underlying scripts. Scripts are, in effect, another way to represent the narrative themes or categories of the research. For example, constructs in grounded theory research are often written as gerunds, or action phrases such as 'looking for safe spaces on the bus.' If the researcher is using narrative methods to complement grounded theory, the following action script can be extracted from the context, plot, and consequence. The movement of the overall story can then be tracked through these script titles.

- The context begins the script with the phrase 'When I . . .' that captures the trigger of the story.
- The plot describes the action or generalized plot through the steps outlined in the story. This begins with the pronoun 'I . . .'
- The consequence, the expected outcome of the script begins with this phrase 'And then I . . .'

The following is an example of a common script used by trainees at Greenbank. Trainees labelled this the 'give it a go' script.

Script title: Give It a Go

> **When I** am afraid because I don't know if I can do what is expected of me.
>
> **I** remember that Gerry and other trainees felt unsure, but they tried.
>
> **And then I** just give it a go and try again and again just to see what happens.

This was a significant script for Greenbank because it removed the role of reward or failure in learning. It introduced a script that allowed trainees to experiment, without the overlay of more traditional approaches that often carry the fear of failure.

The interpretation that emerged from the above transcript about the bus and Ms. Jones and similar stories became narratives or collective stories of the group that set expectations of what might happen and, in the process, explained how to respond to new situations.

For example, a young disabled woman approaches a ramp and a door and is met by a visitor, who offers to help by pushing the chair up the ramp and opening the door. The young woman uses a common tactic of Greenbank and says clearly 'Thank you, but no, I am quite capable of trying this on my own.' She asserts herself and the visitor (in this case, me) is sidelined and bemused.

4. Theory

The definition of theory, a set of ideas that explain practice or experience, includes the tasks of making theory for sharing and comparing results with other theories. There would appear to be three main audiences for theory, depending on the purpose of the research:

1. **The community of academic peers**, who judge and reward the researcher by academic standards. I was concerned about this audience because the final product had to speak to an interdisciplinary academic community that represented often conflicting standards. This paper is an example of an interdisciplinary and multisite academic product.
2. **Practitioners who seek knowledge to improve their practice** and who will judge the theory by its applicability and usefulness. The concepts of empowerment and change are particularly relevant to human service professionals who seek new ideas to keep abreast of changes in technology and policy.
3. **The target population**, who judge the quality of the theory according to its relevance to their personal, social, and economic lives. This audience is represented by people who were impacted by the systemic discrimination they encountered, prior to the new social movements that sought to redress the power imbalances. The stories of each of the new social movements were prepared to recognize both systemic oppression and the empowerment now possible through the new social movements.

The social contract for the research, however, only addresses the target group for each of the case studies. In keeping with this, each case study received a report of the research, with a theory of what was learned about the new social movement and its founder. As such, it is ideographic and specific. There is no expectation that the findings apply to other similar situations.

The social contract for theory was designed for three audiences: usefulness of the theory to those who live the experience; implementation and impact for those interested in improving practice; and theoretical integrity for academic audiences (see Table 2.4).

The negotiation of the theory building process as part of the social contract freed us to interact and explore ideas in an open partnership. Most co-researchers felt they were part of the process; they were not being studied but had embarked upon a joint journey of discovery. The relationship was time limited and governed by the task at hand, but dependent upon us as people, ready to risk and experiment. It seemed natural to see the relationship as a partnership that recognized the sophistication and willingness of participants to be part of social science research. Partnership research provided an opportunity for role empowerment by making role expectations explicit within a process that authenticated the contribution of each of the parties. The improved clarity in the

relationship increased the rigor of the research, opened new options for shared knowledge, and, hopefully, improved the quality of the research product.

We attempted to create an integrated narrative strategy and to understand the role of founders of emancipatory social movements. Examples of the theories are presented below.

An Integrated Narrative Strategy That Is Both Emancipatory and Rigorous

This research was an example of co-research where each partner shared their experience of social innovation. One was the expert of the case being studied and the other a researcher searching to understand the role of the expert in social innovation. The following is a short summary of the narrative strategy or theory of method presented as consecutive research actions.

- **Co-design: Population identifies stories of a social problem that is a priority to the group.** Consult individuals, leaders, and professionals who have experience with the topic to identify categories of concerns and select a general concern or topic for study from the stories they tell.
- **Build trust** in the process through a formal or informal social contract for each step to understand roles, expectations, and when the goal of each step is completed.
- **Use iterative cycles of storytelling** to collect and analyze/explain the social problem to identify possible actions.
- **Explore methods for capturing stories that are compatible with the ways of knowing of co-researchers** (observing, interviewing, documents, and media) that allows co-researchers to tell stories.
- **Organize story incidents**, using recording and notes, to complete story templates.
- **Produce a story chain** of incidents to ensure that all relevant stories are accurate and included.
- **Constantly compare** incidents/stories about experiences, problems, actions, emotions, and thoughts, sorting them into rough categories.
- **Name or code emerging categories** as new data challenges the category and force it to divide or combine with other categories.
- **Test emerging categories** until one emerges as the best explanation of the social problem. This might be a common story that becomes the core category.

- **Arrange all categories into a theory or strategy of action** based on stories that explain the problem. Note: at this point, there is a distinct difference between general qualitative research that is conceptual and action-based narrative research.
- **Share and compare** with dominant narratives of similar social problems.

As the main feature of co-research, narrative builds on the power of story to build and support partnerships in sharing, refining meaning, and sharing the results of research.

An Idiographic Theory of the Role of Founders of New Social Movements

Grounded theory is considered to be substantive but situational. In this study the idiographic or situational theory was the explanation of the founder's role in their social innovation. Each is organized within the context of the situation and the root metaphor or way of thinking of the founder. The following are several examples:

- **The theory of Greenbank** is based on the metaphor of place. Recruits who were disabled came from medical and social institutions that defined both their deficits and needs for care. They came to Greenbank, a place of peer support and mainstream training with the expectation that they would learn new skills and graduate. Graduates either became trainers or moved to mainstream businesses run by Greenbank or other competitive options. There was always a new idea to chase and a program to build.
    - Gerry Kinsella, the founder, was a hero in disability sport who challenged the existing systems that stigmatized disabled people. His root metaphor was the playing coach—he coached staff and trainees alike to take risks, support each other, and aim high. He did this while inspiring trainees through building new facilities and programs, political and business successes, and sports. His way of thinking could be summarized as 'give it a go.' He is the quintessential social entrepreneur.

- **The Quaker Prisoner Befriending Scheme**'s theory is grounded in the teachings of the Quaker movement, specifically, the importance of gaining trust through personal advocacy and passion for a cause. We also learned about the importance of grassroots supporters.

Dorothy's personal mission was to build life-sustaining connections and contributions among volunteer befrienders who committed to share daily experiences with those who have been disappeared (imprisoned without trial) for their beliefs. The theory outlines the power of everyday connection through letter writing when there is no power and almost no hope for liberation. It is here that the power of stories is clear—to connect, inspire, and bring joy in the absence of hope.

  - Dorothy is clear and persistent about the horror of torture that must be faced and studied. Her challenge is simple—when we do nothing, we too share the guilt, brutality, and secrecy of hidden, invalidated people and thus contribute to the potential success of terror.

- **Siksika Nation's traditional child welfare**, based on the metaphor of 'The People.' The context of Henry Three Sun's history and the development of a traditional approach to child welfare provided a chance to learn about what has been called the Sixties Scoop. The innovative combination of Indigenous and white ways provided an opportunity to track the journey from the 1950s to the 1990s that told the story of rapid destruction of traditional values and the eventual reclamation of two-eyed seeing. The stories resonate with colour, sound, symbols, and images. The following theory is presented as a summary marked by decades:
  - 1950s: **the Sundance,** a traditional gathering of the clans to celebrate the harvest through dancing and rituals, while gathering to govern and plan. The colours were yellow for the autumn sun under blue skies, the sounds were the drums and singing.
  - 1960s: **Bad Medicine**. The change is the introduction of alcohol, bars, and loss of ritual and governance. This leads to family breakdown and child isolation. The 'white' government places neglected children into white families. The colours are red and black, the sounds are of loud country music, and the metaphor is the local smoke-filled bar. He is isolated because he is not part of change and turns to Elders for guidance.
  - 1970s: **Silent Funerals**, a cold time of dying and the death of tradition, the family, and community. The colour is cold white of winter, the sound is silence, and the metaphor is the internment of the coffin. Henry's work was to support tribal

members to become Indigenous social workers, in order to reverse the trend of 'scooping children.' These social workers activate the natural supports within clans to refocus on family capacity.

- 1980s: **Briefcases**. Blackfoot negotiators took on the ways of white power brokers to defend and reclaim the rights of Indigenous peoples. Henry speaks about how they studied policy and worked to identify gaps and obstacles to equitable policy and funding. Trusted insiders provided insight into provincial and federal policy. The theme was briefcases and Western business suits with colourful Indigenous emblems, the sounds are the measured sounds of negotiation.
- 1990s: **The Siksika radio station**, the use of Western technology to reclaim traditional communications. This is used not only for sharing stories but community input into planning and governance.

Combining Cases: A Theory of the Role of Innovators in New Social Movements

After all seven cases were completed, I eventually was able to create a combined theory of the role of innovators in new social organizations by conducting a separate analysis of all of the new social movements. It combines the initial role of the founder as both storyteller and activist.

This activist role was embedded within the target population as a trusted ally who challenged the status quo of the dominant system and, thus, was able to make a difference. Their emancipatory stories were shared within the target population and inspired members to imagine what they might have done in the past or might do in the future. This leads to more emancipatory narratives that buttress the new movement's reputation. Not only does it buttress the reputation, it creates a shield against the continued force of dominant discourses of vulnerability, difference, deficit, and deviance.

Over time, a meta narrative emerges that is able to effectively challenge the dominant discourse of society. Examples include the following: dying with dignity and legacy, businesses run by persons with disability, Indigenous support of families, international disability rights that impact not only at the local but national levels. These meta narratives call forth both community support and professional attempts to take over or absorb the innovative features of the organizations related to the new social movements. Many new social

movements are taken over, but the ones that grow and survive share some common features that were apparent in the founders who took part in the study:

- Understanding and skill of storytelling to mobilize new aspirations and roles that challenge dominant discourses of vulnerability, deficit, and marginalization.
- The persistence and energy of the founder to continue to challenge the system and represent the population.
- Organizational skills to enable the new social movements to grow and to become recognized.
- Continuing ability to respond, adapt, and innovate.
- The ability to secure champions who can speak for the movement from the dominant society.
- Remaining alert to sources within the system that are likely to challenge, take over or compete with the movement.
- Use of media, publicity, or publications.

The data from this study continue to inform the development of peer research and social innovation. In particular is the concept of a shield of new roles that protected the members of new social movements from dominant and powerful forces. The majority of the founders were subsequently honoured in their country for their innovation.

Summary

This has been a short summary of case studies chosen to explore the breadth of social innovation and innovators. This was a grounded theory study with two goals: find ways to engage as equals in data collection and analysis, interpretation and theory building, and understand the role of founders in new social organizations.

Story emerged as the framework to enable a variety of methods to engage founders of new social movements as equals. This understanding is the consistent feature of peer research and peer support programs in the disability community and health systems as it emerged through research with seniors and finally with PaCER.

This narrative has enabled work with Indigenous communities and marginalized populations who have strong histories with story and the power of story to bring people together to find meaning in everyday experience and challenge systemic discrimination.

Questions for Discussion

1. What was your understanding of narrative and story prior to reading this chapter?
2. Which cases related to your experience and how did this influence your understanding of the integrated narrative method or the importance of new social movements?
3. Which of the methods used made you uncomfortable, and which might you consider studying in more depth?
4. Are you aware of any new social movements in healthcare or cultural studies including disability and mad studies?

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3

A Social Contract for Patient Research: Negotiating New Patient Roles in Health Research

Much of this chapter is a call to action to provincial and federal health policy who are facing growing overwhelming demand for health care and stretched budgets.

Highlights

- Obstacles to patient engagement
- Engaging patients in all pillars of health research
- Types of health research
- Citizen science levels of engaging citizens as citizen scientists
- Participation levels in health research from a patient perspective
- Social contracting throughout the research cycle
- Resource manual for social contracting through the research cycle

This chapter is written in two stages. The first provides an overview of current pillars, research traditions, participation levels, and social contracting. Then, in the Resources section, there is a manual for co-design of patient engagement to advance your capacity to prepare patients and communities to be active agents in health system transformation.

This chapter was originally written for health researchers and professionals interested in expanding their current patient engagement practices. During pre-print, patient advisors and students found this chapter helped them understand how to promote and encourage new, more collegial partnerships, especially with hard to engage patient populations. This chapter supports the following values for peer and patient-led research in *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/):

- **Equal but different**: The thoughts and beliefs of everyone are equally valid in negotiating research direction, outcomes, and goals.
- **Trust**: Trust is hard to earn and is quickly lost. Actively acknowledging the contributions of each participant leads to greater

understanding and an openness to hear and learn from others. With familiarity and appreciation comes trust.

- **Shared power**: Nobody decides for somebody else. Sharing power comes with the expectation to listen and the freedom to express opinions. Each person and, by association, those they represent grow in confidence and capacity with shared power.
- **Shared work**: To share expertise, there needs to be a willingness to use common language, model, and mentor expertise. Learning to share means time for reflection on the work of research and joint ownership of successes and failures.

The chapter explores the context, existing practices, and new tools for you to locate the type of engagement you currently use or would like to use in four sections:

1. Choose the health research pillar that you are working in, or would like to work in, from the Canadian Institutes of Health Research: Biomedical, Clinical, Health Systems and Population Health). Then
2. Identify the health research methods that you currently use, or would like to use, from quantitative research options (patient-oriented research or behavioural research) or qualitative research options (interpretative, pragmatic, critical theory action). Then
3. Test the levels of citizen science in Citizen Science. Then
4. Consider the level of involvement that would work now or in a new project using adapted levels of engagement based on the IAP2 public participation.

Four Pillars of Canadian Health Research and the Discourse of Professional Communities Associated with Them

The concept of including patients as partners or researchers is not easy for those who are used to more conventional research, where the data is seen to be most objective when collected from naive subjects. However, all research and methods that include patient experience can benefit from including a patient research voice as part of the team. Engagement is a familiar construct in patient-centred care, patient advising in governance, and patient partnership in primary care. The following section is a brief overview of the Canadian pillars of health research from an engagement perspective.

Pillar 1: Biomedical Research

Biomedical research seeks to understand how the human body functions at the molecular, cellular, and organ system levels. Through biomedical research, we develop new therapies and medical devices. The patient's role in biomedical research has been largely limited to providing samples and basic data. There has also been a long history in patient and health associations that are active in fundraising and encouraging patient advisors to become part of biomedical teams. The debates about protection, ownership, and privacy in health research have focused research in quantitative methods such as patient-oriented research (POR), where patient outcomes are standardized to see if goals are being met. Citizen science crowdsourcing in clinical trials is rapidly gaining traction. Concerns about data ownership are also being challenged as patient-controlled health records are curated and shared by patients who decide how to use their data with research projects, specialists, and other patients.

Pillar 2: Clinical Research

Building on the work of biomedical researchers, clinical research seeks to improve the diagnosis and treatment of disease and injury to improve our health and quality of life. Clinical research provides scope for collaboration as clinical trials embrace the new scope and possibilities through citizen science and crowdsourcing data. There is also the recognition that current POR using standardized measures is limited and could benefit from qualitative research to include a patient perspective on outcomes and experience.

Timmerman's (2019, https://doi.org/10.1080/15265161.2019.1619875) article on contributive justice in biomedical research addresses another significant issue for clinical research. She identifies the advantages of participatory research in opening clinical trials to diverse and underrepresented populations to achieve contributive justice. In the process of engaging diverse populations, rigour, and applicability expands. This could lead the way to partnership with underserved populations while ensuring data equity, diversity, and inclusion in clinical trials that reduce systemic discrimination and address social justice in treatment protocols. She also identified specific contributory benefits that reflect the experience for peer researchers and participants: empowerment by allowing citizens to contribute to social well-being, shifting position of dependency to mutual influence and social recognition.

Pillar 3: Health Services Research

Health services research seeks to improve the efficiency and effectiveness of health professionals and healthcare systems through changes to practice and policy. It focuses on the social factors, financing systems, organizational processes, technologies, and personal behaviours that affect our health. Patient engagement has a long history in quality improvement, co-design, health technology assessment, health systems design, and social innovation governance. The advising roles are being extended to include partnerships and opportunities for peer support, community councils, and peer research.

The links to health systems and practices produce leads to the potential for peer research to untangle the threads of systemic discrimination through collaborative frameworks of patient experience related to equity, diversity, and inclusion. This type of research is best conducted through qualitative methods, especially when conducted by peers who have similar experience. Peer research is characterized by the ability to gain the trust of patients and thus to uncover uncomfortable information.

Pillar 4: Population Health Research

Population health research seeks to improve the overall health of different groups of Canadians by better understanding the ways in which social, cultural, environmental, occupational, and economic factors determine our health. The WHO report on participation as a driver of health equity (Francés & La Parra-Casado, 2019, https://iris.who.int/bitstream/handle/10665/324909/9789289054126-eng.pdf) has been advocating that countries include citizens in research to address the need for:

- Empowerment—where citizens and communities take control of their health through health promotion, prevention, and partnerships.
- Engagement—through shared decision-making and healthcare planning, which is a feature of many provincial health councils.
- Co-production—where teams of citizens, professionals, researchers, and administrators become the engines of innovation and social change. We see this in the Strategic Clinical Networks (SCNs) in a number of provinces.

Population health research has been the home of participatory medicine, community-based participatory research, action research. and action science. These developments have begun to open options for peer research and community-led research.

Health Research Options

The following section identifies the challenges and opportunities to expand the scope of health research. We consider both conventional (modern quantitative or positivist) and postmodern options within quantitative and qualitative research. We can begin with a short overview of how the focus of research impacts the type of data collected and analyzed. The type of data being collected within different research traditions also defines expectations and roles of patients and citizens.

Quantitative Research

The basic distinction between quantitative and qualitative is that quantitative research uses numbers and qualitative research uses language. There are, however, many options that use language to create numbers.

POR is an example that uses items of patient experience expressed in words to create scores. The scores are assumed to measure defined characteristics. These quantifiable results link easily to other quantitative measures in health research at all the above levels. The researcher chooses the standardized questionnaire that applies to the patient experience, reflecting the topic of research, and is able to both publish the patient experience results and inform other related research. The challenges relate to the relevance of both the items and the meaning of aggregated scores to the 'class of patients' studied or in general. POR adapts easily to crowdsourcing that is increasingly used to overcome difficulties with recruitment.

Behavioural research, a form of quantitative research emerging from psychology, is also quantitative and deductive, where the unit of data is the behaviour that can be observed. The person researched is defined by their actions, not by who they are. This basic framework is adapted to a wide range of research, from institutional ethnographies to infant communication. Behavioural research dominated psychology during the 20th century and is still a foundation of behavioural management research.

Qualitative Research

This type of research uses language to describe, analyze, and explain experience, values, motivations, and collective meaning. As such, this 'big tent' generic research category is adapted and used within most social sciences, including sociology, anthropology, education, social work, and cultural studies. These disciplines use a social constructivist exploration of self, concepts, roles, relationships, social organizations, and movements. Data collection includes open-ended conversational interviewing from phenomenology, observations,

and critical ethnography. The data are words, images, sounds, and artifacts embedded in language structures.

While subjects can be recruited into standardized experiments where their lives and experiences are the focus of study, it is becoming more common for patients and community members to be included in the design of the research. The role of the researcher also changed dramatically as researchers attempted to take up the identity of the persons being studied, to experience and more fully understand the patient and community perspective. Some became participant observers as conceptual interpreters of experience and language. Regardless of the discipline or methodologies, qualitative researchers are active agents in research. The following is an overview of the qualitative methods most amenable to peer research partnerships.

While most qualitative research relies on highly trained researchers who are embedded in the philosophy and paradigms of particular disciplines or versions of qualitative research, constructivist or interpretive research has influenced the value of collaboration with research participants. Collaboration claims that social values, meaning, structures, and relationships are created and recreated through social interaction within affiliate groups, culture and professional groups, programs, and systems that are best identified in natural conversation.

As the impact of social construction became more pronounced, this method opened new ways for patients and communities to be engaged in qualitative research. This leads to the potential for further involvement in action research. The following are qualitative options that have informed peer research:

Interpretive Research

This uncovers and explains how and why things happen the way they do. Grounded theory, action research, discourse analysis, standpoint research, and ethnography all use specific methods to study and explain reality.

Interpretive research employs iterative and inductive data collection and analysis cycles. Methods include traditional interviews, observations, documents and artifact analysis, systems analysis, case studies, and narratives that can be adapted to maximize engagement.

Interpretive research using peer research by trained patients, communities, and persons from equity-seeking groups often includes direct service staff that can provide parallel real-life experience. This creates the potential to combine staff suggestions for social change with those of persons with lived experience. This is reminiscent of narrative counselling where communities and professionals bear witness to each other's experience and stories in order to come to a common understanding of opportunities for social change.

Pragmatic Research

This shifts the focus of social construction research through a lens of usefulness. It provides methods for solving problems and measuring change using the above methods, but with a focus on expert lived experience.

Pragmatism is about finding what works or could work and draws on co-design and quality improvement experiences. We also see the use of design thinking and social innovation emerging from structured action science that brings the need to understand not only lived experience of patients and communities but the systems, programs, policies, and relationships that structure those experiences. Without both of these perspectives there can be no shared vision for improvement.

Not only is this useful in co-design but also in implementation, where end users and staff are included separately and then work to reach common strategies for improvement.

Critical Theory

Brings focus to the role of power relationships in socially constructed realities. It emanates from critical or Marxist theory and brings a power lens to the research methods mentioned above.

Emancipatory social science uses this critical or power lens to create participatory and action research to challenge the subjugation of groups by entrenched policies, systems, and values. Many academic, culture or population-based programs rely on peer researchers who embody the population under study.

This quick table from the Faculty of Dentistry at McGill University (McGill Qualitative Health Research Group, n.d., https://www.mcgill.ca/mqhrg/resources/what-difference-between-qualitative-and-quantitative-research) contrasts qualitative and quantitative research as part of life studies (medical, dentistry, etc.) for those who are not familiar with the differences.

Action research is a variant of qualitative research that takes quantitative research into emancipatory social science by challenging entrenched and systemic power imbalances. Some examples include action research, participatory action research, community-based participatory research, grounded theory, and emancipatory or critical research from feminist, Indigenous, Black, and disability perspectives. The major shift here is the inclusion of participants as partners in research, building on the early feminist partnerships of women researchers and women seeking to understand how their roles were constrained through patriarchal values. In peer research, the role of the patient is augmented by patients who are trained in patient research.

Biggerstaff (2012, https://www.researchgate.net/publication/236158419_Qualitative_Research_Methods_in_Psychology) gives a list of qualitative research options that have been introduced in the past 50 years.

Levels of Participation as Part of Citizen Science

Citizen science is considered the standard for engaging citizens as citizen scientists. The following continuum reflects the advances made in researching environments, the natural world, climate change, pollution, and more recently health promotion. Health and medical research is added.

1. **Contributive**: The researcher or team recruits citizens to gather local or personal data, but the research is managed by the researcher who shares the findings with the citizen scientists. This is the most common form of co-research in medicine where patients provide data.
2. **Collaborative**: Citizen scientists bring their own data, resources, and abilities to the team, for example, using personal computers or finding and analyzing local specimens. This has been a staple of citizen science that expands resources for collecting and analyzing data.
3. **Co-created**: Citizen scientists suggest a research project or become involved in the design and planning of a study. This is the model of the patient partner advising a researcher or team. It is becoming more popular as large, longitudinal studies develop research collaboratories that join academic research as patients and community members, business, and technology.
4. **Co-produced**: Citizen scientists are involved throughout the study, from design to report writing. This is the model of peer research promoted by community-based participatory research, where citizens act as research assistants who are trained to collect data for the team within hard-to-reach communities.

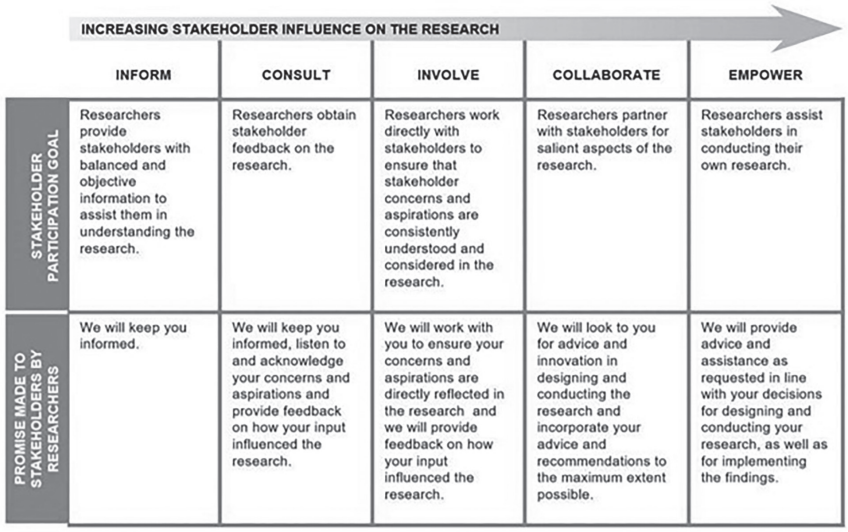
5. **Collegial**: Here the citizen scientist is considered a colleague with the ability to design and conduct their own research with support as needed. They may also create their own products or make policy decisions based on research data. This is the peer research model, where citizen scientists either have research backgrounds or are trained in engagement research. They work as part of the overall project or grant and are given responsibility to conduct a portion of a grant independently, sharing ongoing findings with the team or being contracted by a research team to conduct research to ensure patients are engaged.
6. **Independent or peer-led research**: This consists of research done by communities or patients who either have research expertise or are trained to conduct peer research. They conduct research that is of most concern to them when other options are not available. In medicine, this has been called patient-led research and is growing as patients attempt to address conditions with unknown causes or cures for viruses, contamination, or environmental crises.

This is included here to introduce citizen science as the current option for democratizing science and Open Innovation in Science (OIS) movements. In Europe, citizen science is supported by national and international policies and funding. While other countries encourage citizen science, it is primarily a way to do research that can be done using volunteers. As citizen science moves to include health and medicine, it will need to adopt equity, diversity, and inclusion (EDI) principles with communities that are not able or willing to volunteer. However, the experience gained by academic researchers using citizen science approaches provides workable options for using peer and patient-led research.

From the IAP2 Spectrum of Public Participation to Acts of Engaging with Citizens and Patients as Part of Health Research.

Engagement has been categorized through the levels proposed by the International Association of Public Participation (IAP2). Figure 3.1 presents the most current and straightforward version related to health research from a researcher perspective, as identified by the British Columbia Strategies for Patient-Oriented Research (SPOR). It also includes researcher promises to patients.

Figure 3.1 *Example of IAP2, as Adapted for Healthcare by the BC SPOR Unit*



Tell, Ask, Involve, and Lead (TAIL) resulted during the social enterprise stage of PaCER when sponsors of training and contractors of peer research joined us in creating a way to use the above categories of engagement from a patient perspective to draw up peer research contracts that included all phases of research.

The acts of engagement—Tell, Ask, Involve, and Lead (or TAIL Acts of Engagement)—are used throughout the book to operationalize citizen and community engagement in research. The short definitions are included here and expanded in the resource manual in the Resources section on social contracting throughout the research cycle.

Table 3.1 *The Translation of IAP2 Spectrum as Acts of Engagement*

TAIL category	IAP2 spectrum	Definition of the act of engagement
Tell *The patient's right to know*	**Inform** *Researchers provide information*	Participants in peer research are prepared for their role as advisors on a research team or participant in research studies. They are informed of the purpose and process, what will happen with the information, why they were chosen and what they should know about the research that is being done and their role in it.
Ask *The responsibility to ask questions*	**Consult** *Researchers listen to concerns and share how input informed decisions*	Participants are encouraged to ask questions about the research project, their role, what has been achieved to date and what they will learn from participating as co-researchers. Health researchers learn how to expand the roles of patients in data collection and analysis.
Involve *Negotiating their role and job description*	**Involve and Collaborate** *Researchers seek advice and new ways of working*	This combined level represents the beginning of shared decision-making—understanding their role and the expectations. It is at this stage that negotiation becomes feasible. This represents the goals of current patient engagement.
Lead *Trained peer researchers become colleagues in research*	**Empower** *Researchers empower citizens to make independent decisions*	When citizens and communities become full partners, they take up ownership of the peer process. Ownership also encourages engagement in dissemination, implementation, and innovation

TELL applies to all stages throughout the research cycle. Telling is about effective communication, mostly from researchers to patients based on the rights of the participants. Tell is based on the principles of clear language, relevant information, and transparency about why the information is needed, why participants will need this information, and how the information will be used.

The peer researcher pivots from conventions that withhold information in order to honour their rights as participants. Telling continues throughout research with a mandate to fully prepare participants in advance so they can be ready to contribute as co-researchers. In other words, we are shifting to a creative, collaborative process that begins with peer researchers sharing goals, methods, data collection, analysis, interpretation, and implementation. The following are examples of peer researchers sharing the purpose and intent of the research through narratives.

- A South Asian peer researcher shares her personal story about advanced care directives (tell) at the beginning of a family interview.
- At the end of each focus group, peer researchers share findings and evaluate the process in order to encourage participant co-researchers to share what they have learned about the findings and the process of peer research.

ASK resonates with the IAP2 category of 'consult,' but in peer research, the action of asking is applied throughout the research process. In traditional health research, 'asking' generally relates to the impersonal collection of data about patient outcomes, experience, satisfaction, behaviour, opinions, or decisions. These measures inform clinical trials, experiments, and quality improvement. Asking, in peer research, encourages patients to ask what they can contribute to the research process and their suggestions to make the process more respectful, relevant, and meaningful.

Asking fuels adaptation, which is the engine of engagement. Researchers ask what the participant needs to know to take part, prepare, and feel comfortable and safe during data collection. Co-researchers are encouraged to ask for clarification and ask to discuss how to make expectations clear or more relevant.

- Indigenous peer researchers created a ceremony based on their culture to ground a focus group on cancer prevention that honoured participants and their community practices and ways of knowing.
- Peer researchers asked family members how to present research findings about including families in ICU care.

INCLUDE marks the act of coming together in co-research. When TELL and ASK are part of peer research, the stage is set for inclusive research experiences that are indeed partnerships. This is where 'peer-to-peer' becomes a reality, not only during data collection and analysis, but in planning next steps—who to recruit, how to adapt methods to new populations, how to present findings to new groups. Examples might include:

- At the end of focus groups, findings are shared and suggestions made about next steps and where co-researchers might use their connections and knowledge to identify problem language, politics of inclusion, and initial contacts for data collection.

LEAD relates to the 'empowerment' category in the IAP2 and is seen in patient- and citizen-led research. The peer researcher is trained to design and conduct engagement research about patient experience using a variety of research approaches. These peer researchers use a variety of methods to ensure that patients are involved throughout the research process. Leadership is the end goal of peer research because it holds the promise of a new patient or community research voice that is evidence-based and focused on patient issues.

A Social Contract in Peer Research

Now that you have narrowed your area of interest, your pillar of health research, the research methods you intend to use, the nature of citizen engagement in academic research and levels of participation that might apply, you are ready to apply a social contract negotiation tool, developed in Chapter 2, to frame the relationships between researchers and co-researchers throughout the research cycle. The contract identifies what each partner is able to contribute to the research (give) and what they hope to achieve (get).

The general social contract is a simple give and get process for researchers, citizens, and patients. Once you have looked at the cycle of research, choose a function and consider how you might negotiate a contract that reflects your pillar, research approaches, and roles and level of participation. The following is a generic social contract for any type of research.

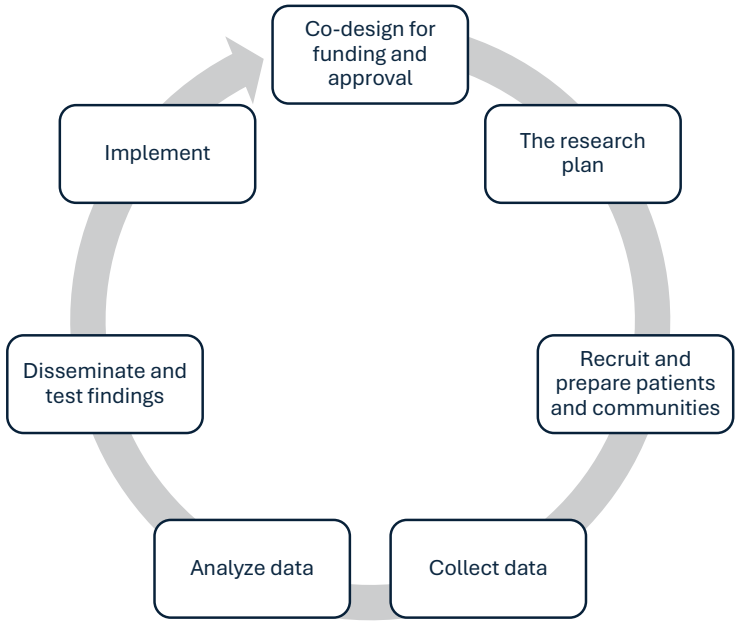
Table 3.2 *A Generic Negotiation Tool for Identifying Roles and Expectations in Research*

	Give	**Get**
Researcher	Including patient and community in research	Relevance and support from a patient and community perspective
Patient advisor, partner, peer researcher	Patient and community perspective about relevance of grant Support letters for grant	Knowledge about research Part of the team with hopes of being part of research

A negotiated contract guides a task or action of the research cycle. The contract provides what each partner expects and is comfortable revealing.

The Social Contract Resource Manual at the end of the chapter identifies the specific expectations in a checklist that evaluates the progress made and changes that might make the process more engaging. It includes detailed examples on grant writing and recruitment through to dissemination and innovation.

Figure 3.2 *Simplified Research Cycle for Research, Quality Improvement*



Co-design for Grant Writing and Approval

Most projects don't include patients until the grant is approved and the focus of the research, the methods, and the analysis is already in place. With Canada's *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (Panel on Research Ethics, 2022, https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2022.html) and it's move to shift to consultation prior to submission, it is possible to conduct co-design with patients and other potential parties such as physicians, healthcare providers, and families. This allows concerns, issues, politics, language, and new patient perspective to be incorporated into grants and ethics proposals. This will ensure that patients have a role and that their concerns and priorities matter.

Table 3.3 identifies a basic overview of roles and expectations of patient and community consultants when applying for grants that should occur within a co-design stage of consultation, prior to writing the grant and ethics proposals.

Table 3.3 *Suggestions for Negotiating Roles and Expectations in Grant Writing*

	Give	**Get**
Researcher	Inclusion of patient and community priorities in grants	Relevance and support from a patient and community perspective
Patient advisor, partner, peer researcher	Relevance of topic and buy-in Support letters for grant	Knowledge about research Part of the team with the intention to be part of research

Summary

How does patient engagement research differ from more traditional methods? The simple answer is that patients can be fully engaged in choosing research questions important to patients, their families, and communities. Patient engagement, in general, refers to helping individuals and groups to appreciate and manage their changing health circumstances with an objective of improving personal and social health in an ethically defensible way.

In order for this to occur, it is essential that patients and communities see themselves as capable of taking more responsibility for their health and healthcare. Unfortunately, many patients rely on the current medical systems that encourage patients to bring their health concerns to professionals for diagnosis and treatment. The anticipated sea change in healthcare cannot occur without creating a patient research voice that demonstrates capacity in identifying problems, making decisions, following and adapting personal healthcare, and

coordinating their chronic and complex conditions. Patients, as part of social media and advances in personal monitoring, are moving in this direction. Now what is needed is a way to increase the patient research voice in health research, to prepare professionals for this emerging paradigm shift and create examples of patient professional partnerships.

Trained peer researchers are capable of making decisions about how to collect and analyze information and how to communicate findings to other patients, professionals, and the public. Patient engagement research (where 'patient' includes the patient, their family, and their community) introduces an important variant on patient engagement and research relationships. It introduces the potential for co-creation of knowledge, wherein all parties share, learn, and benefit from the research process. Participants are equal partners, not anonymous or vulnerable sources of data. Patient researchers come from the culture and experience of health seeking and healthcare, and thereby share understanding with patients. Engagement research, as a new concept with new relationships, offers opportunities to revisit more traditional ethics practices.

Questions for Discussion

1. You might consider an example of a research study you were part of or had read about to try out one of the contracts related to a stage of research that was involved or could have engaged patients more effectively. Consider the steps in engaging and evaluate the engagement that was achieved. How could the engagement have been more effective?
2. Select a stage of research and discuss how you might negotiate a social contract with a research team. If working in a group, take roles as advisors, researchers, clinicians on the team, and peer researchers.

Resources

A Resource Manual for Social Contracting Peer Research with Patients

1. Academic Concerns About Peer Research

Peer Research as Part of Academic and Health Research

Research that claims to represent patient experience from a patient perspective is often met not only with skepticism but also reluctance to include 'lesser' methods. Those who did include patient advisors sought patients who also had experience in healthcare or research who could be trusted to know what was expected—the right patient with the right experience. However, they could not represent the diversity of patient and community voices that are needed to address systemic discrimination in health research.

When the SCNs were being launched, they wanted to introduce patient advisors with research knowledge. Our solution was not to focus on patients with research backgrounds, but train patients for research teams to represent the diversity of their projects. We set out to create research approaches and training programs that could be recognized by health professionals and researchers. Within the first two years of the grant, patients had graduated from the program having designed and completed research projects that demonstrated a new research voice. With the assurance of academic oversight of ethics requirements and academic integrity, early resistance diminished.

Another obstacle was the dependence on standardized measures. The growing concern about democratizing science and JEDI (research justice through equity, diversity, and inclusion) implied need for emancipatory or transformational research. When research is done by, with, and for patients, it creates safe, flexible, and inclusive spaces that foster iterative research, narratives, and collective patient voices that speak of new perspectives and ideas for social change.

Some of the more subtle concerns included the nature of insider/outsider research. Many felt that researchers who were patients could not be objective, because they would lose their perspective as patients, once trained as researchers. While both insider and outsider perspectives are important, it is an asset when there is training on how to use both perspectives in research. Patients, while learning to become peer researchers, confront and deal with their patient and personal biases and perceptions that may interfere with their ability to use insider experience to support their work to capture outsider perspectives. The ability to be both an insider and outsider when needed requires that personal

reflexivity and shared analysis be built into all peer research projects to ensure that peer research teams are 'doing the personal work' to keep insider and outsider roles separate.

One of the benefits of having a flexible insider/outsider presence is to ensure the relevance of research to both academic audiences and field or population audiences. The relevance to the academic audience has been relatively easy to accomplish through the publication of peer reviewed articles done with academic sponsors. The equally important need for a collective patient research voice has been more difficult to achieve. The first step was to create a publication hub (University of Calgary, n.d., https://prism.ucalgary.ca/handle/1880/109933) for research reports and internship papers that were written by patients. This hub also includes direct links to open access peer reviewed articles done in collaboration with the peer researchers and the academic or professional sponsors.

In summary, the introduction has tried to address the benefits, concerns, context, and history of peer research to inform the remainder of the chapter and the development of a social contract for engagement in health research teams.

2. The Players and the Process of Peer Research

Table 3.4 *Patient Roles in Conducting Research*

	Primary role	Role in research	Value (give/get)
Advisors and patient research partners • Honoraria or paid according to advisor scale as a research team partner • All expenses covered	• Patient stakeholder on research team or patient council	• Represents the patient voice as part of the research team • Liaison between peer research and team	• Represent patient voice during research if no peer research is being included • Gains knowledge about research process and roles

Table 3.4 (*continued*)

	Primary role	Role in research	Value (give/get)
Contract peer researchers (lead) • Paid through a separate contract according to research scale	• Contracted to work as a community liaison with research team to explain and support research • Contracted to interview, conduct focus groups or other research elements for the research team	• Negotiates job expectations and scope of work related to data collection, analysis and interpretation • Reports to research team liaison on an ongoing basis • Turns data over to team liaison or reports as contracted	• Provides team access to data sources not accessible through normal means and data from a patient perspective • Access to real-life experience and expertise • Provides connection to new communities of PWLE • Contributes to understanding of peer research • Gains knowledge about team's agenda and approaches
Peer research teams • Parallel research projects • Joint research projects (e.g., patients and front-line staff) • Paid on scale for managing peer research	• Consists of lead and trained peer assistants, advisors or patients recruited by research team and trained by peer team lead	• Lead negotiates scope of contract and hires, trains and oversees other peer research assistants • Sits on a research management team • Manages team providing oversight and support • Prepares regular reports as negotiated	• Opportunity to develop new patient research voice on research team • Dynamic collaborative research sharing • Opportunity for team to experience peer research that is managed and overseen by trained peer leads

The roles in research outlined in Table 3.4 can be manifested in a number of ways. A peer research team generally exists as part of an ongoing research agenda but can also be hired for a specific research project. A peer research team consists of a team lead that manages the project, recruiting trained research assistants and training patient partners or advisors for specific tasks. These tasks are identified in a research contract developed by the team lead and the principal investigator (PI) of the research project. The contract is held and administered by the university or body acting for the university grant. This is then administered through research, finance, legal, and human resources. At the University of Calgary, the PaCER program was considered a social enterprise, and the PaCER leads were considered vendors, responsible for the management and quality of the project. Leads also pay the research assistants and any expenses from the project funds. The PI and the peer research lead met regularly with the sponsoring or contract team.

For example, the HIV/AIDs research that is now linked across the country is not only a strong research foundation but also an action research platform with an online training program devoted to emancipatory and social action and specific data collection options. The women's training program is available to groups looking to increase the competence of their advisors and peer researchers (Kaida et al., 2019, https://doi.org/10.1186/s12954-019-0309-3).

There are other versions being used, and as peer research becomes more diversified, the structures will also need to adapt. For example, health promotion university departments may set aside specific funds to promote peer research. Funding bodies may include peer research as part of grant structures. There is a caution in the challenge to create peer research for the first time, as paying patients as researchers is a new concept and it may take several versions to make it work.

As in any team, the team lead co-ordinates the research tasks. Trained research assistants and the lead conduct interviews, share in focus groups, and conduct shared analysis. The lead writes the final report, in most cases, and often includes team members and patients who have participated.

The PaCER program developed from a need to train patients across a broad spectrum of SCNs. Our initial research began by training patients with arthritis. Through a series of incubator cohorts, the year-long internship in designing and conducting research expanded to become an online university continuing education professional certificate in patient engagement. Patients, community members and university students are sponsored by SCNs, national research teams, and community organizations, health systems, and cultural groups. The year-long online certificate includes an introductory course, a practicum in research methods as part of the co-design of an ethics proposal,

and an internship in peer research conducted by each sponsored team within the cohort.

The extensive research associated with this innovative peer research training program demonstrated that the trained peer and community researchers have become essential in gaining access to new sources of participants and in adapting existing methods to cultural and condition specific needs. The following are some examples of peer led research.

- A peer research team was contracted by the surgery SCN to assess patient reactions to the safe surgery checklist. There was a feeling that patients were uneasy about the checklist. The decision to not include patients in the rollout was controversial, and the SCN asked that we not mention the checklist. Patients from most surgery units in the province were interviewed by phone. All but one felt uneasy, and most importantly, they felt that the staff were not prepared. During the REFLECT focus group, we let patients know about the checklist—most were very upset, and they developed a comprehensive list of recommendations to inform patients and prepare them for the checklist. During the surgery SCN meeting, the first presentation was about the rollout. The staff rollout research identified that patients needed to be more protected from the process because they showed signs of anxiety. When the peer researchers presented their findings and recommendations, you could hear a pin drop. Patient recommendations were adopted, and patients became part of future changes.
- The HIV/AIDs research programs: Canada provides not only a strong research foundation but also an action research platform with an online training program devoted to emancipatory and social action, with specific data collection options. This training is available to any group looking to increase the knowledge of their advisors and peer researchers.
- A Calgary-based PaCER arthritis team had a long-term relationship with a PaCER research team that worked with the PI across numerous research grants and projects, including various types of arthritis, surgery policy development, assistive devices, community online resources for teachers, and Indigenous support. This has been a model for other research projects.
- Wellesley Institute in Toronto (https://www.wellesleyinstitute.com/) is the Canadian leader in urban public health research and has conducted the seminal research in peer research as part of

community-based participatory research (CBPR), investigating how social determinants of health interact with systemic discrimination. Their research demonstrates how community engagement not only builds community capacity but political action and social change.

- The Service User Research Enterprise (SURE UK) (Sweeney, n.d., https://www.kcl.ac.uk/research/sure) undertakes research that examines mental health services from the perspectives of those that use them. Their research demonstrates the impact of service user involvement in research (in terms of process and outcomes) and critically interrogates how service users have changed knowledge production globally.
- Research leads in intensive care units (ICU), acute stroke units and acute cardiac units sponsored research. The ICU had a relationship over several projects and the peer researchers were included in writing grants. The peer team took the lead in developing training and orientation materials for how ICUs could work more effectively with family members. This relationship over six years produced publications and grants with other ICU teams.
- Canadian HIV Women's Sexual and Reproductive Health Cohort Study's (CHIWOS) (https://www.chiwos.ca/) participant research associates (PRAs) have established a strong peer research team and online training. The following summarizes a recent web report of their work and their impact:
    - PRAs conduct research as a way to encourage women living with HIV to voice their opinions, priorities, and experiences, often for the first time. "It has created a strong community of women living with HIV and fighting back against the shadows of isolation, stigma, and discrimination. They are collectively building and contributing to a stronger community to fight for equity" (Kaida et al., 2019, https://doi.org/10.1186/s12954-019-0309-3).

The Cancer Prevention Legacy Fund of Alberta and the Population, Prevention and Indigenous SCN contracted PaCER to train Indigenous community members to conduct cancer prevention research within Indigenous communities. This large project enabled PaCER to hire its first infrastructure supports and put the PaCER curriculum online to be delivered throughout the province and country. Teams completed the training developing research on cancer prevention related to family supports, stories about cancer, and cancer screening

3. Using Social Contracting to Negotiate Expectations and Contributions Throughout the Cycle of Research

Grant writing combines distinct steps:

- Letter of intent (LOI)
- Agenda setting
- Grant development and supporting letters
- Research plan

Ethics Approval

If engagement doesn't start at the very beginning, it remains a token. The patient consultant is left trying to fit into what has already been decided. Patient input is critical when ensuring buy in from participants and the rationale (the 'why now' of the study). Even basic research is being encouraged to include end users in this initial work.

- In a study of acute and life-threatening situations, the team received a grant to identify the types of decisions family members wanted to be part of and how to engage them. At this point, the team approached patient researchers who discovered that families did not want to be part of life saving decisions, but wanted more input as the patient became stable.

The next example describes a large consultation to develop a research grant as part of *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/). It included working with small groups of seniors to set the general purpose and topic. We then recruited retired university researchers to help with a large community consultation to clarify the topic and to create a method for the grant.

- The grant included the concept of resilience identified by seniors, and they were instrumental in writing the LOI and research grant. Retired researchers from the university joined the group once the LOI was approved to help plan the research grant consultation with seniors. The advertising for these events included news coverage, seniors' magazines and newsletters, emails to seniors' groups and the leaders of seniors' activities in the city and rural areas. The most important message of two full-day co-design sessions was that

seniors would take part in designing resilience research that was relevant to them. The research plan was completed and working groups were established at the end of the day, with the retired researchers who had acted as facilitators taking up mentor roles in the groups that were established.

PaCER graduates are often included in the early stages of grant development to provide basic input from other peer studies. Some graduates became research colleagues, available to the team as a natural part of the ongoing quest for grants. In another model, a university research support service in the United States provided a service to researchers by facilitating a consultation with patients who have been trained in research grants (Portalupi et al., 2017, https://doi.org/10.1093/fampra/cmw138).

Many early-stage research teams are nervous about including patients at this stage, because they feel they need to be ready before patients are included. The example below suggests why it is important to include patient consultation early:

- The PaCER team presented findings on models of effective arthritis care at a large grant planning meeting. The PaCER findings were diametrically opposed to recommendations to establish a provincial assessment team to speed up arthritis surgery—the attendees of the planning meeting ended up supporting GLAD, a conservative treatment to avoid surgery.
- A national team planning session on transitions from intensive care units included a PaCER team that had conducted an internship project on transitions from ICU to a step-down ward. There were many patients involved in the planning session, and each working group was able to use the PaCER presentation as a reference for the grant preparation.
- In a recent example, the Post Traumatic Stress Disorders team of the Canadian Institute of Neurosciences, Mental Health and Addiction (INMHA) decided to hold a patient-led planning consensus conference on PTS knowledge gaps. The patients planned all aspects of the conference—they met prior to the larger meeting to get to know each other and their shared interests and skills; they presented at the beginning of each session; discussed the topic with scientists; and fielded questions. The environment in the room shifted from uneasiness to energy with a new openness to discuss difficult issues related to evidence-based treatment with non-traditional populations.

When it comes to grant writing and securing support letters, patients and advisors should be taught about the structure and process of the grant ahead of time, with examples of previous grants. If the team has a consistent patient advisor, partner or peer researcher, ensure that they meet with the new patients and debrief after each writing session. The major problem at this stage is that the discussions can be heated and theoretical, which makes it important to invest in supporting new patients.

There has been a great deal of interest in priority setting processes that bring together patients and families, clinicians and researchers. These are popular as a way of forming a community surrounding the condition and potential grant writers. These provide a list of priorities for research. The following quote from a participant in one such large endeavor speaks to the danger of the priorities being left on the shelf:

- "We spent almost a year working really hard to come up with the five priorities for grants and I checked regularly to see what was being used and now, after 18 months I have seen nothing used or even mentioned. They could just have asked for input."

Patients are often expected to submit letters of support, and a well-crafted letter can spell the difference between a grant attempt and success. The support letters can be the responsibility of an experienced patient advisor or researcher, who can either write letters or support other patients in writing the support letters.

- The common concern for most patients and their families is the constant worry about losing access to needed follow-up tests after treatment. The development of patient or family monitoring tools that can be shared with the specialists through telemedicine will make a big difference in being able to manage stress or fear of relapse.

An increasingly popular process is to invite research teams to present their proposal to the funding committee. Teams often request to have a patient attend. This is difficult when only two team members are funded. We have tried to have patients attend by teleconference, but this is difficult to coordinate. Granting bodies are increasingly involving patients on the funding decision-making committees and this means that more than a checkmark in the patient engagement box will be needed.

Once the grant is approved, patients become part of the implementation plan. At this stage, it is helpful to consult a trained peer researcher, if you have

not included them in the grant writing process. If you do have a consistent advisor, partners, or peer researcher, they should be part of the research implementation team, attending all meetings to ensure that everyone is on the same page. While PaCERs are trained in writing ethics proposals, it is more common for the project leader to write the proposal with a section related to the patient engagement component of the grant. The ethics approval and the implementation plan should be shared with all patient team members.

In summary, Table 3.5 is provided to help ensure that patients are engaged at all levels. Once the grant is approved, it can be used as a quick reference for engagement. It is included as a checklist to guide discussion and can be used in writing final reports about experience engaging patients. Note that the role for patients is filled in for this example to help teams fill in the remaining guides in this chapter.

Table 3.5 *Suggested Acts of Engagement for Grant Writing and Early Project Planning*

Acts of engaging	**Actions to engage patients in grant writing**	**Roles for patients** *(Note: This is an example; this space would be filled in by the research team as part of recording their accountability of engagement)*
Tell	Prepare a script about the grant to use when selecting advisors as consultants for grant writing to include: • Purpose • Time commitment • Roles of patients and community members • Learning opportunities and support	• An experienced patient researcher who is part of the team can create these stories and scripts in the future based on the success achieved
Ask	• Hold sessions with potential advisors to understand the patient and community concerns, and questions about the grant	• These sessions are best conducted by peer researchers, with or without a team member

Table 3.5 (*continued*)

Acts of engaging	Actions to engage patients in grant writing	Roles for patients
Include	• Negotiate roles and expectations of the grant as above • Consider innovative ways to engage that will be noticed in grant decisions	• Note: Research patient engagement strategies that will be noticed as innovative in grants
Lead	• Advisors and peer researchers can be used to canvas / consult with patients and community members about specific grant questions • Write up patient engagement plan as part of grant	• Advisors attended a patient meeting at the clinic to ask for input for the grant questions • Team writes up the engagement plan for the grant

Recruiting and Preparing Patients and Communities for Co-research

Much of the recruitment should have been investigated in the co-design of the grant. The reality is that the era of the poster is long gone with Facebook, blogs, YouTube, and eblasts used extensively in citizen science and health research. The social media script will still need approval. Ethics committees may be uncomfortable with social media, especially when health associations and clinics have their own social media. Recruiting through third-party health professionals generally requires an additional layer of approval.

The risks may be reduced when patient advisors, partners, or peer researchers are involved or in charge of recruitment. The following are some examples of recruitment using peer researchers:

- When usual methods of recruitment didn't work to find people who had undiagnosed knee pain, the PaCER researcher was able to put in a community newsletter a short article about the problems she had with knee pain and why she thought it was important to hear from others. The response was overwhelming.
- A student wanting to connect with families with an autistic child stalled for over six months when recruiting through posters, and teachers failed. One blog post from a parent garnered a large group of families, and the student was able to use the blog posts to announce meetings and share results of her study.

Citizen science provides the chance to work with scientists and to contribute to health research. The principles of citizen science are available online to promote the reasons why citizens are respected and necessary in solving current problems. Crowdsourcing is ideal when large groups are needed, and other social media provide more contact with citizens.

When recruitment of participants for research projects has proven to be costly and difficult, it is a red flag in ethics. It is important to include a number of options for recruitment, and to ensure that you have patients involved in all recruitment plans.

Peer research has uncovered a very different concern—patients often want to be recognized for their contribution. The need to protect personal identity must be balanced by the need to acknowledge the contributions of co-research participants. This debate is clearly acknowledged within citizen science principles that require the contribution of the citizen scientist to be recognized. As more co-research is done in medicine, this debate should go beyond the needs for protection to enable recognition of contributions of participants.

Table 3.6 *Planning and Evaluating Engagement in Recruitment*

Acts of engaging	**Inclusion in the recruitment process**	**Record how patients were engaged in recruitment** *(to be filled in during the project to be part of a patient engagement report)*
Tell	• Patients and community or clinical leaders need to be included in recruitment plans • Peer researchers are effective in recruiting and managing snowball recruiting • Contact peers or community groups who have active social media platforms willing to post the call for participants	

Table 3.6 (*continued*)

Acts of engaging	Inclusion in the recruitment process	Record how patients were engaged in recruitment
Ask	• Hold sessions with above resources to let them ask about the project so that they become informed is asked about the project	
Include	• Community contacts should work on messaging	
Lead	• Peer researchers in community-based participatory research (CBPR) have traditionally been tasked with recruitment as the bridge to the community	

Conducting Peer Research By, With, and For Patients

As a social contract, data collection, data management, analysis, and interpretation are included because of the iterative cycles that require that they occur simultaneously. During this step in research, the role of the researcher refers to the peer research lead, and the patient role refers to the participant in the research. The first step in conducting research is to work out a script to tell participants about the research and their role in the process. The participant often becomes a co-research participant when they become part of the analysis and interpretation of the data that they provide.

It is also possible to train advisors and partners to become part of the research team when the team lead trains them to collect and analyze data. This reflects models in community-based participatory research, where advisors and research partners are trained as data collectors and may also be involved in data management and analysis.

Table 3.7 *Social Contract for Conducting Research: Data Collection, Management, Analysis, and Interpretation*

	Give	**Get**
Peer researcher	• Opportunity to share information to inform research • Methods to ensure verification and security of data • Methods that engage participants in sharing and understanding stories of the main concern or topic of the research • Shared analysis processes that lead to group understanding of and suggestions related to the main concern or topic	• Access to experience and expertise not generally accessible through other methods • Connection to new communities of PWLE • Participant verification of security of data • Collaborative analysis and interpretation of the main concern or question of the research • Verification of collaborative suggestions for social change or innovation
Participant or co-research participant	• Personal experience and expertise related to the topic • Commitment to explore and disclose experience as openly as possible • Verification of correctness and completeness of data • Participate in making sense and finding meaning in shared stories • Contribute to a cohesive explanation of the main concern or research question that leads to solutions or suggestions for social innovation	• Knowledge about how research is conducted • Recognition, respect, and social connection • Contribution to knowledge that directly impacts them • Security in how their data is handled and analyzed • New understanding of personal experience and finding explanations for main concerns studied • Opportunities for future involvement

Table 3.8 of the social contract summarizes the expectations and outcomes of conducting peer research. The role of the participant or co-research participant captures the scope of engagement that ranges from contributing personal experience and expertise to finding new understanding of personal experience, and expertise and explanations of social concerns or questions that lead to suggestions for change and social innovation.

Table 3.8 *Planning and Evaluating Engagement in Conducting Research*

Acts of engaging	**Inclusion in conducting peer research**	**Record how patients were engaged in conducting peer research** *(to be filled in during the project to be part of a patient engagement report)*
Tell	• Clear expectations of roles of participants in data collection, management, analysis and interpretation • Who is sponsoring the project and what will be done with the data and findings • The use of iterative cycles and how participants contribute • Keep sponsors informed about progress	
Ask	• Participants about how the research methods work for them and how the process can be more effective • Sponsors for feedback from field sources	
Include	• Use give/get to establish and review reciprocal roles • Identify innovative aspects and recognize contributions to new methods	
Lead	• Peer researcher shares responsibility with the peer research team and participants	

The Tell aspect of conducting research is controversial but essential, because of the need to prepare participants in advance so that they understand their role and the importance of their experience. The telling process enables you to discuss support that the potential participant might need. While it is fine to include a friend if needed, including family members who have a distinct and important view of research may prove difficult.

- In a focus group about in-home care with chronic illness, a daughter asked to be included in the group. This produced awkward moments when she wanted to share embarrassing information that led the parent to withdraw, and the other participants were left managing her role.
- A family member who wanted to be included in a study of couples and how they dealt with a difficult decision about children was asked to leave when she sided with her daughter about the father.
- A friend from a peer support group was able to help translate what the person was saying in a manner that they had worked out through their friendship.

Regardless of the way data is collected—in person, online, with individuals, groups, and communities—the privacy of the information and the data itself needs to be subject to rigorous management techniques and within strict ethical standards. This training needs to be continually revisited as new techniques are introduced. No matter how informal the data collection method, the participant needs to know that their information will not be shared outside the boundaries agreed to and that they should not disclose or share the data they were part of.

The use of iterative cycles that combine data collection, management, analysis and interpretation enables data collection to be seen as one integrated process, instead of four separate processes. Each step or cycle can be communicated with the sponsor or contractor.

Disseminate Findings

The final sections are covered in more detail. In most studies, the process of research ends when the results are confirmed and the findings are prepared for knowledge translation or uptake. As such, it includes translating research for practitioners, patients, and the public to influence behaviour and attitudes of the population studied. The Canadian Institute for Health Research (CIHR) sees a knowledge user as an individual who is able to use research results to make informed decisions about health policies, programs, and/or practices. This could include patients and family members, health providers, and policy makers.

CIHR has identified two broad approaches to knowledge translation (KT) (CIHR, 2015, https://www.cihr-irsc.gc.ca/e/45321.html):

- Integrated KT (iKT): Potential knowledge users are engaged throughout the research process. This approach should produce

research findings that are more likely to be directly relevant and used by knowledge users.

- End-of-grant KT: When the researcher develops and implements a plan for making potential knowledge-user audiences aware of the knowledge that is gained during a project.

Both forms can involve intensive dissemination activities that tailor the message and medium to a specific audience, and, even further along the spectrum, can involve moving research into practice.

KT research is a very influential area of study that includes health literacy, integrated KT (developmental), communication strategy, motivational research, outcomes, and implementation science. This area of research is often funded separately to ensure that results are shared. It is no longer the last task of a research project, which had been limited to writing an article for publication.

Table 3.9 *Suggested Roles and Expectations in Dissemination of Findings*

Roles	**Inclusion in disseminating research findings**	**Record how patients were engaged in disseminating** *(to be filled in during the project to be part of a patient engagement report)*
Researcher	• Knowledge of the scope and potential routes to dissemination—journals, conferences, professional meetings, health system meetings • Knowledge of cultures of academics and health providers, and the language and formats that are most effective	• Use of appropriate language and terminology to be sensitive to stigmatizing language and concepts • Dissemination with co-researchers, joint presentation, publications with added value of real-life descriptions of methods and findings from a patient or community perspective
Patient advisor, partner, or researcher	• Understanding the scope of theory within the boundaries of the study • Practice validity—how the theory might impact experience and the healthcare system • Face validity of the theory within the target community	• Knowledge of the language and dissemination options for the public, patients, and communities: - Social media - Local and interest newspapers - Magazines

In this area, there are many guides related to the level of language, complexity and even, the use of white space. The more difficult work relates to making sure that the information is relevant to the audience being considered. It is easy to meet all the standards and not connect with the audience. It is important for researchers to include patients and communities who have been included in the study to frame the findings for patients, the public, and communities. This does not mean preparing a presentation and taking it to a group for approval but working through the findings step-by-step.

Patients and communities now have roles as collaborators and contributors in knowledge translation. The following list of potential KT that should include patients indicates the range of activities involved:

- Professional and research publications
- Social media blogs and Facebook pages from research centres
- Health providers
- Governments
- Mass media
- Press releases
- Mailouts
- Fact sheets
- Hotlines
- Displays
- Infographics
- Storyboards
- Presentations

In inductive research, the process is more complex. The information for KT often includes continual modification, based on engaging stakeholders in writing and planning the implications for implementation. At this stage, peer researchers become key, providing access to patients, families, and groups who are part of the KT target.

- In a study of family involvement in the ICU, the patient researchers who had experience in ICU were instrumental in the following KT activities: taking the research finding to groups of families in ICU to discuss what was needed to change practice; forming a provincial committee to create a manual about family engagement in ICU; taking the manual to ICU units for use.

- Wellspring followed a process where members were invited to a focus group to discuss the findings; the board received a draft copy and discussed the findings; a group of oncologists reviewed the findings and at this stage, the team decided to revisit the findings and the subsequent analysis produced a theory that was more substantial and useful within Wellspring. Their current review process can be found on their website: https://wellspring.ca/how-we-help/our-learnings/

Knowledge translation as dissemination or knowledge sharing from a patient engagement perspective is a new feature in KT. Peer researchers and patients are involved in deciding what is important to share with the general public, patients, and healthcare providers, to ensure that the messaging is in their voice.

This is where the most significant obstacles have been apparent. While most research relies on publication in peer reviewed journals and presentations at academic conferences, these must adhere to professional journal and presentation formats. Where patients are part of a team research project, they contribute a portion to the article and it is published within the appropriate academic journal. This is very important as a way to let the research community in that area of specialization know that patients can conduct research and contribute to academic research. However, this means that the impact is also within an academic silo unless there is a keyword in the search to indicate that the article included patient engagement as part of the study.

There are many new journals related to engaging patients in research, but again, these tend to use the expected format for producing articles. PaCER has made significant progress in using the third person plural 'we' to indicate the work was done in collaboration with patients.

There remains a large gap in KT of patient-led research designed for the general public, patients, families, and frontline health providers. One of our first goals was to produce an authentic collective patient research voice in health science, but the struggle continues to be to find a way to share and activate the implications of this new research voice.

In a first attempt to establish an open access voice with full keyword search, the University of Calgary PRISM repository provides curation and dissemination of research, theses, reports, and presentations that are part of the open access search function that also includes journals and books. We have been able to provide links to published works, copies of internship reports, research contract reports, and works in progress. It is our intent to open this to Canadian research teams, graduate student projects, and research conducted by health associations and systems that engage patients in quality improvement and new program development. We intend to support patients to submit their projects

and evaluate submissions for yearly awards for innovation in the science of patient engagement.

- One of the PaCER graduates has been reading the articles and reports and tweeting out summaries and links to the project, encouraging online discussion of feedback through tweets.
- A new faculty member looked up student reports in her area of research to get a basic foundation and connect with the students who had done the work.
- PRISM has also been used as a source of grey literature in scoping reviews.
- News releases of studies done by patients have been included in health organizations and academic departments.

This remains a work in progress—a repository is not the end result but an incubator of research ideas. PRISM will work to support publications derived from research reports and provide links to publications, so that there is a comprehensive and curated resource of ideas to promote patient engagement in research.

Table 3.10 *Partnership in Dissemination*

Acts of engaging	**Inclusion in disseminating findings**	**How patients were engaged in disseminating findings** *(to be filled in during the project to be part of a patient engagement report)*
Tell	• Collaboration in writing reports, publications, presentation requires that peer researchers and advisors are taught about structure and purpose of KT	
Ask	• Peer researchers should be encouraged to read and ask about: - Language used - Stigma - Representing peer research - Peer findings and how to represent individual quotes and share stories	

Table 3.10 (*continued*)

Acts of engaging	Inclusion in disseminating findings	How patients were engaged in disseminating findings
Include	• Share drafts and patient input • Explore options for both professional and public dissemination • Prepare joint presentations and social media	
Lead	• Present findings to patients groups and patient forums of health associations and community groups • Run Instagram and other social media for patient and public audiences	

Implement and Innovate

Implementation is the new frontier and much is to be learned from citizen science, Ashoka changemaking universities, action-based grounded theory, new social movements, and advocacy groups. This is the stage that provided the motivation to begin the study of co-research. It is here that implementation divides into two sections.

The first is to improve the quality of existing services and programs. This has been the focus of the majority of PaCER research, because the work is sponsored by existing organizations within the healthcare system. This sponsored research has developed important social impact practice and policies. A social impact study is needed to follow up the studies completed and analyze new ways of tracking impact. Table 3.11 is a summary of the social impact to date.

The second implementation option is the bridge to social innovation and design thinking that is the focus of Section 3. It moves beyond publication and dissemination to consider how the knowledge gained informs the social organization underlying the description and patterns in the finding. While Section 3 begins with the intent to make a difference, qualitative research often uncovers actionable information.

Table 3.11 *Roles and Expectations in Implementation*

	Give	Get
Researcher	• Clinical researchers and quality improvement are examples of the expectation to implement • Knowledge and links to implementation science • Status to support implementation • Ability to translate research into implementation guidelines	• Validity and usefulness of the research conducted • Proof of impact and credibility for future grants • Ideas for further research • Connections with the field of practice and support for other grants
Patient advisor, partner, or peer researcher	• Motivation is high when peer research becomes 'owned' by the community • Expertise of system in making local and specific changes • Mobilizing local and community networks to support implementation • Face of the project being implemented for press	• Status in community, healthcare systems and research networks when they support implementation • Social contracts within the system and community • Pride of accomplishment

This is the reason that patients become engaged in research. This is why CBPR, PAR, and PaCER, along with grounded theory, are gaining popularity and credibility in health research. People are willing to commit to research that makes a difference. The third section of this book is devoted to this type of action-based research. All the above methods focus on understanding or explaining social problems, issues, or concerns of PWLE and communities. They do this to make a difference in resolving the concerns or finding ways around the conditions that caused the concerns in the first place. Therefore, we and those who employ this type of problem-solving research expect to see an impact.

In the early stages of PaCER, the research was done in conjunction with the concerns raised by the SCNs. This partnership ensured that the research was needed and would be listened to and acted upon.

The more difficult question relates to how research done by patients continues to make a difference. As long as patients are sponsored to become trained, the implementation link is established, making implementation possible. But what of research that is contracted by other bodies that don't have

close linkages to healthcare reform? It is hoped that when this type of research becomes available in other provinces and countries that the bodies associated with healthcare transformation will learn from the successes of the SCNs and research teams to embed patient researchers in their networks.

This raises the issues of payment. While PaCER and other patient researchers are paid to conduct research, they are not paid to be part of the dissemination and implementation teams. To date, this work has been done as a contribution to the contract or the sponsor. In the future, ways to pay for this important patient support of implementation need to be found. Those who know best how to work with patients and communities in implementing findings can motivate stakeholders to consider the changes proposed.

In the advanced care study done with the South Asian communities in Calgary, implementation strategies were developed by community members, faith-based leaders, and community leaders along with the research sponsors. These people came to learn about the peer research that had been done in their community by PaCER researchers from that community. There was lively debate about how to implement the suggestions in implementing advanced care planning. These suggestions covered many aspects not expected.

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4

An Emancipatory Health Science of Engagement: Science with a Moral Mandate

Highlights

- The increasing value of a science of engagement in health research
- Values, goals, and principles of emancipatory science traditions
- Foundations of all new science: philosophy, scope, methodology, and ethics
- Why the science of engagement is relevant: theory development, supporting and sustaining innovation, supporting and challenging current practice, training, and career development

Why Is a Science of Engagement in Health Research and Innovation Needed and Who Is Leading the Charge?

While including citizens in research may seem new, self-taught citizens were scientists long before science became professionalized and affiliated with universities and citizen science was sidelined. While funding reinforced this professional monopoly of science, it didn't take long before there was resistance to the exclusivity of academic research and the barriers between science and society, creating pressure to democratize science and make it more open and relevant to society.

In this chapter we present a proposal for an emancipatory social science that brings practical and action-based patient voices to health crises of high costs, depleted workforce, politicization of health policy, and systemic discrimination. Patients in the middle of the turmoil bring fresh insight to imagining alternatives and preparing for alternative futures and change (Wright, 2009).

A health science that brings new energy and ideas also creates space for inclusive, flexible, and collaborative forms of research to address the problems

at ground level. This recognizes past and present strengths while being open to alternative futures and visions of care. This need for an SoE is supported by new collaborative and open science movements such as citizen science (CS) and open innovation in science (OIS) and community health sciences that support new collaborative health research relationships.

Citizen science attracts academic and professional researchers who are committed to democratizing science by recruiting and working with citizen scientists, civil society, and business to broaden the range and scope of research, to include local wisdom, citizen motivation, and expertise (Strasser et al., 2019, https://doi.org/10.23987/sts.60425). Today this includes not only biological, physical, and natural research to address current crises of degradation of our planet. CS was among the first research platforms to embrace the use of new communication technology (crowdsourcing), physical 3-D printing and distributed analysis technologies. Peer research could be considered citizen science with the difference it trains citizens who are patients to engage other patients in engagement research which aligns with innovation of new forms of treatment and health care delivery.

Open innovation in science (Beck et al., 2022, https://doi.org/10.1080/13662716.2020.1792274) sets out to respond to complex social, environmental, and technical challenges that can't be solved by current linear, disciplinary research. OIS strives to increase creative, collaborative, flexible, and open research approaches by introducing new partners such as business, government, and users of research such as professionals and citizens. OIS began with open access publishing, access to data, and transparent and open review of publications. It now invites debate about initiating and managing knowledge flows across organizational and disciplinary boundaries at all stages of the research and at the individual, team, organization, field, societal, and policy levels.

Deeper interactions between scientists and patients have increased the motivation of scientists to engage in innovation activities (Beck et al., 2022). They recognize the need to prepare new partners to bring their research traditions to new OIS teams. Because of the impact of technology on health, patients with SoE training would be poised to achieve different and potentially more valuable health research (Beck et al., 2022).

The science of engagement could provide the conceptual links between SoE, CS, OIS, and innovation science by introducing collaborative research methodologies designed specifically for patients and citizens.

Community health research pioneers in innovative and emancipatory constructivist research have made significant progress in teaching participatory methods to health researchers and practitioners (Labonte et al., 1999, https://doi.org/10.1093/her/14.1.39). SoE originated within the Community Health

Sciences department at the University of Calgary that combines many forms of research, from big data analytics to personal autoethnographies. It encourages health services research, qualitative research, ethnographic studies, critical research, narrative and participant action research within Indigenous, immigrant, and refugee cultures, and institutional ethnographies of health-related bureaucracies. Community health departments tend to be incubators of emancipatory patient experience research and are supportive of blended methods that combine participant action, critical, narrative, and grounded theory methods within historical roots in feminist and cultural research, community-based participatory research, and narrative traditions.

Community health sciences incubate approaches that are rigorous enough to impact current research directions, while meeting our moral responsibilities to society to produce health systems that promote wellness, compassion, and a creative spirit. During this time of change, we need to form nimble and responsive partnerships that can learn new ways of knowing, while exploring technology-informed forms of care. Artificial intelligence and deep machine learning are already providing support in personal medicine, pragmatic clinical trials, and digital chronic collaboratives, all of which need a strong patient research presence.

This emancipatory science of engagement in health took shape through the study of new sciences: feminist social science (Richardson, 2010, https://doi.org/10.1007/s11229-010-9791-6), Indigenous science (Snively & Corsiglia, 2016, https://pressbooks.bccampus.ca/knowinghome/chapter/chapter-6/), the re-emergence of citizen science (Strasser et al., 2019, https://doi.org/10.23987/sts.60425), sustainability science (Kates, 2016, https://doi.org/10.1002/9781118786352.wbieg0279) and global health sciences. These new sciences intersect through social justice themes and critical theory foundations of disability studies, and are supported by our national Strategy for Patient-Oriented Research (Canadian Institutes of Health Research, 2019, https://cihr-irsc.gc.ca/e/48413.html) and our Strategic Clinical Networks (SCNs), which promote collaborative patient engagement and innovation.

The Pioneers of an Emancipatory Social Science

As an emancipatory social scientist, I have had the benefit of the history and experiences of the pioneers of emancipatory research and action. People with lived experience includes a large, diverse group, experiencing disability, mental health and addictions, aging, disadvantaged or chronic illness, and those experiencing access and equity issues related to Indigeneity, race, gender, religion, and culture. The following taps into the contributions of the pioneers of emancipation in health.

- **Disability**: Persons with a wide range of disabling conditions were among the first to challenge the medicalization of their lives. They became champions of inclusion and rights and, in doing so, innovators of adaptive technologies and emancipatory social organizations. Persons with sensory disabilities founded patient organizations and provided adaptive tools for independent living. Families of people living with developmental disabilities, and their allies, established community services, inclusive education, and individualized funding. Persons with physical disabilities established advocacy and international civil rights, accessibility legislation, and were among the first social entrepreneurs, managing their support staff through individualized funding. PWLE were early inventors and adopters of many of the technologies we commonly use today—from telecommunications to oral transcriptions and robots (Martin, 2012, https://cjnr.archive.mcgill.ca/article/view/2348).
- **Chronic and complex care**: These patients represent the largest segment of healthcare users and, as such, have been involved in projects designed to improve care while reducing costs and more recently to support emancipatory practices. Patients and their families were active in new nursing and paramedic roles, allied health chronic care teams in primary care, and community health programs. In the last few years, new, unified online healthcare models, such as Maple (https://www.getmaple.ca), are providing personal healthcare and wellness support that include physician care, local home care, and specialist services.
- Patients have promoted tools to support each other through social media platforms to curate their own health records, monitor their treatments. Options such as Zamplo (https://www.zamplo.org/) provide technology to curate their data and connect with others and take part in research. A *Globe and Mail* article about the use of technology in healthcare captures the power of patients to use technology to curate their own health and become innovators of digital health futures (Moore, 2021, https://www.theglobeandmail.com/business/article-using-technology-to-put-more-power-in-the-hands-of-patients/).
- **Aging**: Mandatory retirement soon created a discourse of aging that justified terms and labels such as the 'grey tsunami,' 'burdens to society,' and 'decrepitude.' A study of seniors' resilience (Marlett et al., 2010, https://prism.ucalgary.ca/server/api/core/bitstreams/36332647-33ed-48a6-9d89-ad5baa29d96b/content)

demonstrates the depth of their motivation, capacity, and social capital. However, as health technology targets the early identification and prevention of disease, the burden of chronicity and lifestyle conditions will decrease, and the social and economic capital of seniors will be needed to address the dip in working age population as the post-war bubble grows. Already, adaptive devices, robots, and 3-D printing of joints and organs and particularly the internet of things seem set to become commonplace to manage challenges that can't be mitigated by current implants and artificial replacements. Seniors are becoming personal health researchers but will quickly need to gain access to innovation teams who are producing technology targeted to them.

- **Mental health and addictions**: Peer support, social enterprise, neurological, and therapeutic digital technologies in Canada have led the survivors of 'deinstitutionalization' who banded together, adopting recovery models of self-help and starting social enterprises that forced social change. This began with SURE in the UK, and more recently with Canadian Mad studies (Poole et al., 2012, https://doi.org/10.48336/IJDBHR4913). The field of implants for mood disorders highlights the privacy and control issues inherent in many emerging mental health treatments. It is imperative that patient peer research become a permanent feature in digital mental health technique development.
- **Indigenous science:** Participant Action Research (PAR), was forged in low-income countries and has become part of Indigenous science, which is grounded in the land, family, and ancestors. Indigenous science informs education, healing, and environmental stewardship that is becoming recognized during this period of climate disasters and the urgent need to protect our natural world. Most universities now have Indigenous teaching and research capacity, and PaCER research has been informed by numerous Indigenous PaCER teams that reinforce the focus on story, collaboration, and adapting and creating methods to align with customs that are informed by Indigenous ways of knowing. Research led by communities and Elders leads the way to participatory research (Martin, 2012, https://cjnr.archive.mcgill.ca/article/view/2348). The search for recognition and equality will lead to new forms, not only of governance but of healthcare. One reason for this is the strong example is Indigenous research guided by principles of ownership, control, access, and possession (OCAP) that support strong information governance

on the path to First Nations data sovereignty. Recent examples of Indigenous collaborations as part of patient-led research in western Canada are taking back Indigenous ways of knowing and sharing information to promote health and sovereignty of health practices and research.

- **Racial inequality:** Civil rights, race-based and religious stigmatization, systemic discrimination, reconciliation, and anti-stigma approaches in Canada are often minimized. An article by Banting and Thompson (2016, https://politicalsciencenow.com/the-puzzling-persistence-of-racial-inequality-in-canada/) provides a powerful exposé of the factors that challenge our international reputation for tolerance and social equity. The landscape of Canadian inequality is changing, as the dialogue shifts from societies needing to make things right to the recognition of the rights of communities to determine their own relationships within Canada.
- **Economic disadvantages**: The social determinants of health define social disadvantage, but the key factor is poverty. We need to create policies to reduce economic inequality in Canada, particularly policy tools that problematize poverty, target, and alleviate inequality, particularly the urgency of poverty. Those living on the margins of society have often lost motivation to change their lives because, without money, the rest of social determinants drop off the table. This remains a population looking to become equity seekers.

The above list of contributors to emancipatory science is not intended to marginalize the rest of society but to acknowledge that marginalized populations have been the ones in the trenches, borne the brunt of systemic discrimination, and challenged existing practices to find space to flourish. Within each of the above categories, there are movements toward community or peer support workers that demonstrate the power of shared experience in managing complex problems at the local level.

A Canon of a Novel Emancipatory Health Science of Engagement

This section includes the basic framework for a new science, the nature of the science, and finally, the relevance and impact of a new science. We move to a first attempt to conceptualize the elements of this new science. The canon consists of the following criteria, outlined in Table 4.1.

Table 4.1 *Elements of a Canon of Emancipatory Social Science*

1. Basic elements of a new science	
1.1 The goals, values, and principles and philosophy of the science of engagement in health?	
2. Nature of a new health science of engagement	
2.1 The scope of this science?	
2.2 The basic methodology of this science?	
2.3 The ethics particular to this science?	
3. Relevance and impact of a new health science	
3.1 Does this science open the field to new sources of data?	
3.2 How have theories supported the development of this science and does this science produce theory?	
3.3 What makes this science innovative and enable you to sustain innovation and social change?	
3.4 How does this science support research and practice?	
3.5. Does this science produce modifiability and transferability?	
3.6. What are the training opportunities?	
3.7. What are the employment, volunteer, and career options?	

1. Basic Elements of a New Science

1.1 The Overview of Why an Engagement Science

Values, goals, principles, and ethical standards guide research practice and provide the reasons why this is needed. The overarching golden rule of peer research might be researching as you would want to be researched. This does not happen easily, because it challenges the power differentials between researchers and patients. This golden rule of an SoE is captured in the current work of Jer Thorp, *Living in Data: A Citizen's Guide to a Better Information Future* (2021), which informs and invites citizens to become engaged in data and information technology with the question: How do we stop passively inhabiting data and instead become active citizens of it? When we become part of science, we are our data, we understand our data, use our data, and share it to make a difference, and in the process, science is democratized.

This is further supported by the Responsible Research and Innovation (RRI) policy, begun in the EU to align research and innovation to the values,

needs and expectations of society. The current iteration of open innovation in science asserts the need for collaboration with non-traditional researchers such as patients, business, and governments. Most of the 'non-traditional' collaborators bring ways of conducting research to the table. SoE suggests a peer- or patient-led research approach that will facilitate patient research equity with research partners.

1.2 Goals and Principles of the Science of Engagement

The following is a high-level overview of goals and values of science in Canada that sets the tone for peer research.

- **Research that reflects all Canadians** from the perspective of citizens, patients, and communities. This includes not only research about inequities but also research to promote health equality for all.
- **Enhance the common good** to make a difference in health, global health, and the health of the planet.
- **Inform decisions in public policy, systems change, innovation, and applications of knowledge**. Engagement research is designed to promote practical, creative, and realistic social innovation based on input from citizens, patients, and communities.

Citizen health provides an overarching framework to democratize healthcare by engaging citizens as co-producers of health research (Doherty & Mendenhall, 2006, https://doi.org/10.1037/1091-7527.24.3.251). These emancipatory engagement principles apply to most emancipatory social science options and provide a standard of emancipation for health research.

Citizen health research core principles (adapted from Doherty & Mendenall, 2006):

1. The greatest untapped resource for improving healthcare is the knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives.
2. People and communities must be engaged as co-producers of health, healthcare, and health research, not merely as consumers of services.
3. Professionals and researchers can play a catalytic role when they build the capacity of citizens and communities to co-design and produce research to improve and implement new ideas.
4. Citizen-led and co-created initiatives lead to initiatives that are 'owned' or co-owned by citizens. Research led by established programs and citizens cannot share ownership.

5. Local communities must retrieve their own historical, cultural, and religious traditions of health and healing and bring these into dialogue with medical systems.
6. Citizen health and health research initiatives should have a bold vision while working pragmatically on focused, specific projects.

These principles of health care and delivery could also apply to research if it was ready or interested in critical and emancipatory research and peer or patient-led research. This short summary accurately describes the science of engagement as a goal for health research. I would expect that this might concern or embolden readers because it paints the reality of what most would call emancipatory research.

1.3 Values Guiding Partnerships in Research

We begin with the values identified during the *Grey Matters* research. These only come with openness, hard work, trust, and practice. They resulted from iterative discussions about what seniors valued as they learned to become researchers. These values apply as well to PaCER and other emancipatory research movements.

- **Equal but different**: The thoughts and beliefs of everyone are equally valid in negotiating research direction, outcomes, and goals.
- **Trust**: Trust is hard to earn and is quickly lost. Actively acknowledging the contributions of each participant leads to greater understanding and an openness to hear and learn from others. With familiarity and appreciation comes trust.
- **Shared power**: Nobody decides for somebody else. Sharing power comes with the expectation to listen and the freedom to express opinions. Each person and, by association, those they represent grow in confidence and capacity through shared power.
- **Shared work**: To share expertise, there needs to be a willingness to use common language, model, and mentor expertise. Learning to share work necessitates time for reflection on the work of research and joint ownership of successes and failures.

The principles of the international movement of citizen science brings the value of the competencies and contributions of citizens to research. This set of principles were developed in the UK, adapted by the Australian Citizen Science Association and further adapted and shortened for consideration as part of the principles of the SoE in health research. These principles speak to the relationship between academic scientists and citizen/patient scientists.

The Australian Citizen Science Association defines CS as "public participation and collaboration in scientific research with the aim to increase scientific knowledge" (n.d., https://citizenscience.org.au/who-we-are/). These principles have been adapted to focus on what is achieved or valued through conducting citizen science in health research (https://citizenscience.org.au/10-principles-of-citizen-science/).

1. Actively involves citizens in scientific endeavors that generates new knowledge or understanding as contributors, collaborators, or as project leaders. They have a meaningful role in the project.
2. Provides genuine science outcomes such as answering a research question, informing action, or facilitating policy decisions.
3. Benefits science and society through research outputs, widespread evidence to influence policy, and connecting the wider community of science.
4. Develops research questions, methods, gathers and analyzes data, and communicates results that are relevant to the public and science.
5. Engages citizens and populations in how their data are being used and the research, policy or societal outcomes.
6. Increases access to science as a normal part of life.
7. Promotes an open access format and has the potential for data sharing.
8. Acknowledges citizens in project communications, results, and publications.
9. Promotes citizen engagement in communication and evaluation of projects.
10. Promotes the development of legal and ethical practices such as copyright, intellectual property, data sharing agreements, confidentiality, attribution, participant safety and wellbeing, traditional owner consultation, and the environmental impact of any activities.

As well, the European Citizen Science Association (ECSA) (https://www.ecsa.ngo) and the Citizen Science 4 Health Working Group (https://www.ecsa.ngo/working-groups/citizen-science-for-health/) websites both offer valuable resources.

These main principles are suggested as ways to ensure justice for those marginalized by the service systems they rely on. The lack of attention to these principles in research enables systemic discrimination, poor representation of end users in research and care, and costly failures because of inadequate

sampling. While justice is the end goal of emancipatory science, the following values and structures of power reflect imbalances in:

- **Equity**: The lack of equity is highlighted by restrictive criteria for recruitment in health research. When exclusion is built into research recruitment, society in general is compromised.
- **Diversity**: Diversity in recruiting for research leads to essential representation of assets, obstacles, and opportunities for healthcare transformation.
- **Inclusion**: Inclusion brings a sense of belonging that honours differences in voice, perspectives, and experience, leading to a growth mindset that sees everyone as a contributor to social identity and collective action.
- **Access**: JEDI-informed research and practice in medicine often includes an additional principle to reflect a primary obstacle in health care as seen in Indigenous and disability access to timely, appropriate, equal health care that is culturally and conditionally informed.

Further information on JEDI is included in Maureen Metcalf's resource that focuses on JEDI as an antidote for systemic discrimination in healthcare systems (2021, https://www.innovativeleadershipinstitute.com/justice-equity-diversity-and-inclusion-jedi-innovative-health-care-leadership/). It is written for healthcare administrators and staff.

1.4 What Is the Basic Philosophy of This Emancipatory Science?

The philosophy is grounded within social construction traditions that underlie most postmodern emancipatory and critical theory approaches. Social construction asserts that reality is created by interactions of people sharing ideas through language and symbols. There are three main tenets:

- People react in situations according to the meanings they ascribe to those situations.
- Meaning is created and maintained through interaction with others.
- Recognized meaning can be challenged and changed.

This applies to any science that addresses basic issues related to knowledge; what can be known, what are the sources of knowledge and what these sources illuminate. The following philosophy of the new science of engagement in health research is broken down by ontology, epistemology, and methodology.

- **Ontology** (what we can know). Citizen, family, caregiver, and community experience of personal health and healthcare through their experience, knowledge, and expertise is informed by the contextual wisdom of the community or culture from a patient perspective.
- **Epistemology** (how we study experience). We use real-life, in vivo narrative data of what the teller thinks happened, is happening, or could happen that enables detailed shared analysis and interpretation with patients and communities. We use real-life, in vivo narrative data of what the teller thinks happened, is happening, or could happen that enables detailed shared analysis and interpretation with patients and communities.
- **Methodology** (strategies and skills). We do this by training researchers, patients, and community members to engage citizens and communities in participatory, inductive, and narrative methods that are adaptable and flexible.
- **Goal of research.** We do this to explain and analyze health-related concerns identified by citizens and communities in partnership with research, planning, care, and support teams to promote individual and collective empowerment and support innovation in order to improve health and wellness systems and initiate community-based and social enterprise alternatives.

Patients and communities are fundamentally historical and cultural conceptualizations (Lumen Learning, 2016, https://courses.lumenlearning.com/suny-realworldcomm/chapter/8-1-foundations-of-culture-and-identity/) that are not permanent. These have been different, and they change as expectations change and people encounter relationships that enable them to be in control or to be controlled. Peer research data includes stories (incidents of what is happening), context (the who, where, and when) and properties of data (why, why now, and then) that initiate and track these changes.

Patients construct their understanding of health and healthcare through experience, language and interactions with other patients, caregivers, and healthcare providers, all in the context of values and the systems they are part of. The insights of each group are unique and in this context problems and solutions are detected. However, we are not free to believe anything we want about the world if we care about the consequences of acting on those beliefs.

This brings an action or critical focus into play. Our mandate is to influence health transformation through a patient research voice that is separate but recognized as authentic within conventional medical science traditions. Peer

research is generally conducted alongside traditional health or community health research. This includes research about health practice, health systems, and social, cultural, environmental, and population health (pillars 2, 3, and 4 of Canadian health research) (Canadian Institutes of Health Research, 2017, https://cihr-irsc.gc.ca/e/50476.html), and promote methods that are verifiable, accurate, and consistent.

The scope of pillars 3 and 4 expands what we can study from what is happening, to what happened in the past and what could happen in the future. It is here that grounded theory applies. It sets out to study all facets of experience in a careful and scientific way that is grounded in data and tested at each step (iterative) to ensure that the emerging concepts can be defended. This allows us to embrace differences in experience in each person's history, characteristics and connections, and their aspirations. By sharing and analyzing these experiences, it is possible to create a common understanding that recognizes diversity as part of collective experience.

In an emancipatory science, the focus shifts from quantifiable outcomes to a pragmatic, patient perspective of what works and what doesn't, to what might be or who we might become. For more easy-to-read information on research paradigms and philosophy, see "Nada's Island": Resources for Teachers and Students (Salem Abisamra, 2011, https://www.nadasisland.com/doc/paradigms/#1).

2. Nature of a New Health Science of Engagement

In this section, we move from the foundations to the scope, methodology, and ethics of the science of engagement.

2.1. The Scope of Study of This Science

Most of the patient engagement in health research has been focused on understanding patient experience within the systems and programs that provide care in order to identify priority areas for improvement using quantitative POR research, with increasing use of qualitative data.

The scope of research included in this book is included in the introduction to Section 1 of this manuscript, which documents over 50 years of research that provided a unique incubator to increase the potential for social change. In this, we built on health care and traditions that search for wellness, emancipation, prevention, and community health and to find patients who have become 'equal opportunity' health seekers, using healthcare systems as well as complementary, traditional, natural, and even mainstream services.

We encourage readers to visit the PaCER PRISM publication portal for peer research and innovation (University of Calgary, n.d., https://prism.ucalgary.ca/

handle/1880/109933) that is part of the O'Brien Institute for Public Health and Cumming School of Medicine PRISM platform. There you will find early examples of peer research student projects and contract research that speak to the scope of peer research. At this stage, the scope is best summed up by the phrase 'could be.' As in any new conceptual science, scope is determined by its usefulness, and that is yet to be tested fully.

2.2 The Basic Methodology

Peer methodology is the topic of section two that provides details of published research, narrative, and salutogenic theory informed methods and a compendium of engagement methods for qualitative research informed by emancipatory science and critical theory. This methodology section provides the context and foundations for the strategies, methods, and theory that guide not only the process of engagement but how research is conducted, how risk is reduced, and ways to understand what is acceptable within common research standards. The basic qualitative methodology is inductive and iterative and therefore flexible and adaptable in order to focus on priorities for patient populations in order to promote meaningful engagement.

2.3 Foundations of Peer Research

The methodology of peer research and this science of engagement have been co-designed throughout a 50-year research career of finding ways to include citizens in the research that impacts them as a moral right, a way to use research to inform social change, and increase personal agency through building research capacity. The foundations grew from the realization that institutions diminish personal capacity through a focus on deviance and negative control, whereas shifting the focus to positive behaviours and meaningful occupations changed staff behaviour and patient conduct. As a psychologist I used this to build progressive community health alternatives and research adaptive assessments to staff training. I was hired to design a disability studies program that began as affirmative action and soon adopted emancipatory research methods to build capacity of marginalized groups to challenge systemic discrimination. This led to supporting new social movements run by members of equity-seeking programs to provide support and services to their peers. In studying these movements, I realized that qualitative research could be done through co-design and co-research methods. These methods were used to establish research approaches and methods for peer research as part of community and academic research projects and to train students and patients in these methods to bring a research-informed patient voice based on co-designed peer research methods. The PaCER program is the result of this research path that is defined by an engagement strategy of SET, COLLECT, REFLECT, and now INNOVATE, using

a combined qualitative research methodology. These particular methods are Participatory Action Research principles and relationships, narrative data, and grounded theory constant comparison as iterative analysis and interpretation. The nature of this combined peer methodology is part of the final chapter of the book, but the following provides a basic description of the three methods.

- Participatory action research principles: PAR provides the principles and research relationships for the science of engagement and encourages groups to share experience. As action research it allowed us to focus on concerns chosen by patients that they intended to change. I had used PAR throughout most of my career, engaging those relying on social institutions such as education, medicine, and social welfare.
- Narrative data: In new social movements and innovation, stories are analyzed and interpreted to create new collective narratives that focus stories on potential solutions. Narratives are windows on the past; they construct the present and design the future. It is the magic of peer research. The power of narrative enables peers and communities to reclaim their stories as knowledge and examples of expertise.
- Classical grounded analysis: I was trained in quantitative research but found it lacked the nimble creativity needed for the innovative work I seemed to attract. I searched for a qualitative method to study co-research methods and finally discovered classical grounded theory (CGT) that was inductive and, therefore, flexible and adaptive, while being rigorous enough to support a new patient research option. In the beginning, grounded theory was still seen as a challenge to qualitative researchers. Over the intervening years grounded theory constant comparison processes have been taken up by most qualitative researchers who are looking to include inductive approaches and increase the flexibility and rigour of their research.

3. Peer Research Strategy

3.1 The Nature of Data in Peer Research: From Standardization to Diversity

Data has become a commodity to be taken, used and reused, often without the knowledge or permission of the person who provides it. Anonymized digital data is dangerous when it's used in machine learning, as part of AI technology, because existing data sets not aligned with health care conditions have been

used to inform medical algorithms that make decisions about triage, treatment, or research data. While algorithms are important, current machine learning technology can't overcome the biases and gaps that exist in data without clearly understanding where the data came from, how data can be misleading, and how it will impact the decisions made.

This underlines the essential role of peer research as a means to collect real-life data that expands options for healthcare transformation and big data solutions in healthcare. Just as physician records and notes have informed treatment algorithms, so must real-life patient data be part of algorithm design if they hope to remove the white, young, male biases that plague existing data sets. For example, algorithms in triage have used financial data to make treatment decisions, and facial recognition was based on white, male data sets, which marginalizes all other faces. Auditing algorithms to ensure that they reflect the nature and diversity of the issues is a start, but interdisciplinary audit teams will need to include patients to ensure data integrity and accuracy of algorithms going forward. A flipbook called *A Special Power for Good Tech* (Ashoka, 2021, https://issuu.com/ashokachangemakers/docs/goodtech_ashoka2020) opens the debate on technology to draw attention to the downsides of purchasing big data sets in research.

The nature of data captures the difference between traditional health science and emancipatory health science. Traditional quantitative data is discrete, observable, numerical, and can be combined and contrasted to create probabilities of difference in clinical trials. Patient-oriented research (POR) has come from this tradition of measures that represent outcomes, experience, satisfaction, and quality of life that can be combined into 'measurements' (a collection of data elements that stand for a topic of interest). These elements can be sorted into general categories to quantify and predict differences in conditions, treatments and situations and clinical trials. This marks peer research qualitative data as different from qualitative data within most health disciplines that use transcripts to conduct conceptual or thematic analysis of patient experience. This research is deductive or abductive using the language of formal interviews or questionnaires to inform theoretical debates about patient needs, preferences, and outcomes.

Data within a science of engagement is real-life data in all its complexity and diversity. In vivo, or the language of the person or community, is used throughout the processes of capturing data that consist of notes and stories about what is seen, heard, or shared. These narrative data sets are combined to create abstracted, common, and shared experiences to explain the concerns of the target population. As such, it draws upon grounded theory assertions that 'all is data,' and data diversity is needed to understand complex and conflicted

social problems to support innovative ideas. When citizens see their experience as knowledge to be shared and analyzed with others, experience becomes valued as representing patient expertise in healthcare, protocols, and policies. Real-life data captures the process of adapting to lives changed by illness, trauma, and loss, and, in the process, opens real-life options for wellness.

The call for diversity casts the data net widely to tap into unheard voices and reinforce different experiences. Peer research within communities (CBPR) breaks these barriers by giving voice to neglected cultures, to build capacity within their culture-based communities. Attention to data diversity from a patient perspective reflects the democratization and realignment of science, in accordance with the RRI and OIS principles.

3.2 An Engagement Strategy

The overall engagement strategy of peer research emerged during the writing of *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/) research and quickly became the signature of PaCER. It lays the groundwork for peer research, done by, with, and for patients. Figure 4.1 outlines the basics of a peer research engagement strategy as a method of engagement. This provides the structure for research methods that are appropriate for each stage within an inductive approach that plans iterative data collection after each analysis phase. This engagement strategy is used throughout the next sections of the book to organize methods.

Figure 4.1 *Original Engagement Strategy for Peer Research as Part of Peer Research*

During SET, peer researchers and advisors contact patients who have experience in the goal of the research to identify concerns that they feel should be researched and are feasible. The concerns are grouped and taken to a SET co-design team of patient consultants and peer researchers to prioritize the concerns for research and provide advice on recruitment, appropriate language, and political barriers related to the main concern. Co-design creates strong links with the field of study, reduces time and effort in starting the research, and motivates

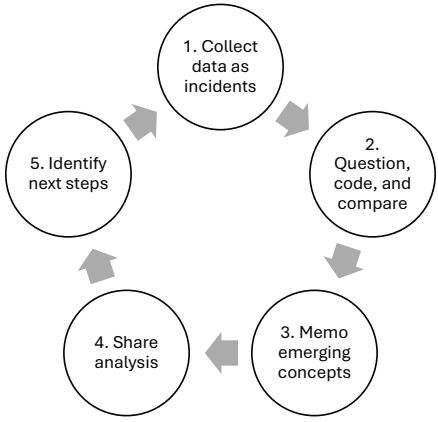
the field to become engaged in recruitment. It also is an ideal way to begin with a strong grounding in the main concern, as the focus for early recruitment for the COLLECT phase.

The SET phase could be considered the open coding process within grounded theory that explores the broad scope of the topic to identify the main concern so that the concern can be explained in order to focus on the best explanation to solving the main concern.

In peer research we benefit from the recent Canadian Tri-Council decision that determined that proposals to contact potential users of research were useful in order to understand their concerns before setting the grant proposal (Panel on Research Ethics, 2022b, https://ethics.gc.ca/eng/policy-politique_tcps2-eptc2_2022.html). This locates SET in the stage of creating proposals for funded research. It has opened the door to patient input in the co-design of all stages of health research.

The COLLECT phase as presented in Figure 4.2 as an adaptable iterative data process. It can be used with most research traditions.

Figure 4.2 *COLLECT Phase as an Adaptable Iterative Data Process*



Note: Iterative cycles of simultaneous data collection and analysis has been adapted from classical grounded theory.

REFLECT is a group process where the original patient SET co-design team return to review findings and co-create a coherent description or explanation of the main concern and solutions from a patient perspective. They also suggest dissemination, implementation, and innovation options. In the future, the REFLECT process could be the bridge between academic research and social enterprise.

The introduction of new forms of data justify the claim to new science. Practical analysis of real-life data is the key to machine learning for artificial intelligence, just as physician patient records enabled more accurate algorithms.

The INNOVATE stage is introduced in the third section to move peer research to the implementation stage.

3.3 Ethical Frameworks for the Science of Engagement.

As with any new science, the concept of ethics is complex. The first component is overseen by someone qualified to submit and supervise ethics protocols within institutional standards. This is relatively simple when the instructor in research courses or the principal investigator covers both oversight of the research and adherence to ethical standards. Without informed oversight and a science of engagement, peer research has tended to become modified to conduct research for academic researchers or projects using the methods of the principal investigator. This was the impetus behind the development of SoE. Until researchers and teams are comfortable with the research methods of peer research, intrigued by the science of engagement, and willing to supervise research and ethics, it may become difficult to meet the potential of peer research. This chapter targets researchers who are willing to experiment with this new approach and to either sponsor formal patient training or create new options that meet their research needs.

There are four levels of ethics to be addressed in this new science:

1. Ethical procedures and standards differ from country to country, and university to university. In Canada, Tri-Council (natural science and engineering, social science and humanities, and health) standards and training are coordinated. All PaCER students must complete Tri-Council online training before they are admitted to the practicum course (Panel on Research Ethics, 2022a, https://tcps2core.ca/welcome).
2. The ethics of engaging patients in health research is covered in Canada at the national and provincial levels through the Strategies for Patient-Oriented Research (SPOR) through online guides and procedures (Canadian Institutes of Health Research, 2020, https://cihr-irsc.gc.ca/e/51910.html). Readers are invited to look at the up-to-date ethics related to engaging patient partners. Peer researchers must abide by these standards.

3. The ethics of engaging patients in health research has been a major topic of discussion because of the complex ethics related to healthcare. Wiggins and Wilbanks (2019, https://doi.org/10.1080/15265161.2019.1619859) provide an example of research related to the outstanding issues being discussed in bioethics about engaging patients in research.
4. An aspirational declaration of personal ethics of peer researchers was co-designed with a seasoned psychologist familiar with professional aspirational ethics by PaCER interns in the second cohort, as a set of declarations to guide their practice (Marlett et al., 2015, https://doi.org/10.1007/s11136-014-0845-y).
5. Perhaps the most important aspect of peer ethics is the formal statement of ethics done by peer researchers at the end of their research and training projects.

Aspirational Ethics of Engaging in Peer Research

In peer research, participants are equal partners, not anonymous sources to be protected. Therefore, peer research invites opportunities to offer a new look at ethics from a fresh perspective that highlights engagement from insider and outsider perspectives.

The following basic values were adapted from the International Declaration of Ethical Principles for Psychology that was current at the time. Dr. Jean Pettifor, the author of this declaration, conducted the ethics of engagement workshops with the second PaCER cohort. The ethics of engagement provide ethical standards to hold student interns and peer researchers accountable.

After this ethic standard is presented, it will be followed by the ethical review of a project by PaCER Interns Wellspring Cancer program in Calgary, Alberta.

Figure 4.3 Personal Ethics of Peer Researchers

Personal Integrity:
Acting openly with honesty and humility, ensuring that self or professional interest does not interfere with acting in the best interests of persons and peoples.

PERs will at all times endeavour to:

- Be transparent, non-judgmental, open, honest and clear in all communications.
- Disclose and negotiate agendas, roles and expectations.
- Use language that can be readily understood.
- Prevent exploitation of persons or groups for personal, professional or financial gain.
- Declare and guard against conflicts of interest.
- Be aware of the impact of power structures on people's ability to speak freely.
- Ensure that others receive credit for their work and contributions.
- Take responsibility for misunderstandings and errors in judgment.
- Know how personal and professional values, attitudes, experiences and social status influence actions, interpretations, choices and recommendations.

Competent and caring research practice:
Our competence is measured by our ability to unleash the competence and capacity of patients to understand their health and health care, make decisions for themselves and to care for themselves and each other.

PERs will at all times endeavour to:

- Work together to be as competent as possible in all research we do.
- Openly negotiate research activities.
- Model engagement in our team work as researchers.
- Constantly evaluate and adapt methods to effectively engage all patients in research.
- Use plain language (e.g., communications, proposals, media, meetings, protocols and reports). Where technical terms are needed, meanings are negotiated, clearly defined and only used when understanding is assured.
- Maximize benefit and minimize risk, offsetting or correcting potential for harm.
- Share ownership of results to honor the contributions of all partners.
- Find ways to share findings openly and in ways that everyone can benefit.

Respectful Relationships:
Grounded in fairness and justice, is our belief in the inherent worth of all.

PERs will at all times endeavour to:

- Share the power of research.
- Seek out, welcome, appreciate and represent diversity of experience and backgrounds.
- Create a comfortable, natural and open atmosphere conducive to sharing personal knowledge and experience.
- Act to affirm that patients are experts in their lives.
- Take time to learn what patients want, need and hope for.
- Follow through with agreed upon goals and expectations.

Contributions to Health and Society:
We come to this work with a commitment to health reform by actively promoting and sharing research with patients and health professionals, planners and researchers.

PERs will conduct our affairs with the highest ethical and professional standards. Our goal is to uncover insights and strategies to encourage the development of social structures and policies that benefit all persons and peoples.

PERs will at all times endeavor to:

- Produce quality research that promotes well-being.
- Protect knowledge from being misused, used incompetently or rendered useless.
- Develop robust and innovative training and research methods that can be used by others.

Ethics Report from Peer Researchers

The last and most effective way of understanding the ethical component of peer research is to hear the deliberation of peer researchers themselves in their peer research roles after their internship research was completed. This group was particularly attuned to the importance of ethics because of their involvement

in developing the ethics of engagement principles with the staff, board, survivor volunteers, and members.

The interns from the final Wellspring report emphasized five issues: the search for quality data, negotiating the engagement process, confidentiality, referencing, and transparency.

They employed several strategies to raise the credibility and trustworthiness of the study and ensure quality data was collected. In patient engagement research methodology the researcher is both an instrument and participant, so great care had to be taken to note any issues that might influence the collection or analysis of data. The interns leveraged this unique position to raise the trustworthiness of the study. Because of the common experience between the patients and researchers, there was a natural trust and openness.

Researchers worked together to examine and discuss the similarities, differences, and patterns within the data, to help eliminate individual researcher bias. Re-examination of source material, including audio recordings, flipcharts, analytical memos, and notes was an essential part of this process. They examined this from different perspectives, and made good use of the PaCER 'reflect' focus group to ensure that the questions and themes were adequate.

The negotiation of engagement boundaries allowed the interns to move from being interested researchers into what they described as a "charmed space where peers were sharing their experience of lives changed by the diagnosis of cancer." This process allowed for the co-creation of knowledge between researchers and patients. The shared understanding was facilitated by the researchers' culture and experience of health seeking and health care. This provided a different quality of research to traditional patient engagement; the latter of which can lead to strategies not well informed by patient perspectives, or even alienate patients. The patient engagement research method allowed access into a private world available to few researchers.

Participants came forward in response to communication from Wellspring and word of mouth. The confidentiality of patients was protected through a separate recording and storing of patient metadata, and the aggregation of potentially identifying markers. Other participant demographic information was not recorded for the study, and all research was carried out in alignment with Wellspring's confidentiality agreement.

The researchers realized that in listening to their participants, they were being invited into their world to understand their reality, and the experiences and difficulties they confronted living with cancer. The research team acknowledged how their input as patients themselves was also a source of data. To maintain transparency, they chose to report comments as referenced to the person saying it, including those of the research team members. Due to the

methodology of patient engagement research, their research voice carried a new and distinct perspective, which asked questions that came directly from patients.

The research team noted that these ethical guidelines are not only important in themselves but also improve the quality of the research, stating that "It is not only about preparing to be ethical but reflecting on how being ethical strengthens the understanding and use of the intrinsic power of research conducted by peers."

4. Relevance and Impact of a New Health Science

This section moves from the practice of science to the impact of science to look at the questions about usefulness of the science, its relationship to existing theory, innovation, modifiability, and options for training and employment. This section will be subject to change as the science is debated and tested.

4.1. Does This Science Open the Field to New Sources of Data?

Changing demographics, costs and the use of technology require new ways of delivering healthcare (e.g., upstream, patient partnerships, computer networks). These new interventions and social organizations need an evidence base that can inform and respond to rapid change. The mandate for any new science is to be innovative and rigorous in exploring new sources of data and data systems, analyses and ways to bring engagement into interpretation and thinking about solutions to problems in ways that bring unheard voices to the forefront. To date, some of these new data sources include:

- Peer-to-peer data analysis using language of the participants instead of theoretical codes; this provides a real-life data set.
- Incidents and 'story' as units of analysis that can be used throughout the research phases.
- The story template replaced transcription and first analysis. Stories can also be taken apart or combined.
- Common or shared stories can be used as data using story as data for secondary analysis.

During participant observations, we created separate observer and participant roles to introduce opportunities for checking reliability of observed data and identifying bias:

- One peer researcher acted as the observer taking notes about actions, relationships, stories.

- A second peer researcher participated in the activity and immediately after wrote a memo about what happened from that perspective.
- The observer and participant shared findings noting differences and similarities and prepared a common report for the rest of the peer research team.
- The observer and participant shared ideas about the process and what they learned.

The following sources of data became common during patient-led research and peer research.

- The use of incidental and opportunistic meetings and events as data collection opportunities created opportunities for natural brainstorming and priority setting.
- Shared analysis with participant co-researchers during SET and COLLECT research activities created opportunities to include personal interpretation and meaning.

These new sources of data led to real-life theory using the concept of working theory as an alternate way of dealing with conceptual theory. It represented a real-life conceptualization of the solution to main concerns of a population that was expected to adapt to new situations or populations. It reinforces the focus on individual differences and meanings held within groups or populations.

4.2. How Have Theories Supported the Development of Science and Does Science Produce Theory?

All new science uses existing theory and methods in the beginning. Existing medical theory relates to the causes of disease, vulnerability, and fallibility. This works well within the first pillar of health, which locates health research in the causes of disease. It also informs clinical trials, treatment systems, and, finally, a catch-all category that includes prevention, promotion, cultures, and communities. Graffigna and Barello (2018, https://doi.org/10.2147/ppa.s145646) provide an example of potential theory within the realm of health science.

If there is to be an emancipatory science of engagement in health, we will need to adapt theory from other fields and create new theories to prompt debate and experimentation. This has been a major focus of the writing of this book, and it has been possible to update a number of theories that have been proposed in earlier publications. Several new theories are also proposed.

All three sections begin with a list of theories that inform the strategies and methods in the subsequent chapters. This was done to provide a theoretical frame for the chapters. Social construction has guided the development and

adaptation of the majority of theories in this book because it enables theory to emerge from the people, activities, and values.

The theories presented in Table 4.2 are included throughout the manuscript. The table presents an overview of the theories used, according to the stages of evolution of peer research. Each of these theories is discussed in detail throughout the book and links are provided here to find those you are interested in.

Table 4.2 *Summary of Major Theories Used in Forming This SoE in Health*

Implementation stage	**The use of existing theory to inform development of methodology and new theory**	**New and adapted theory originating during the evolution of this science**
Stage 1: PhD thesis	• Feminist emancipation theory • Critical and social theory of disability • Narrative theories from the 1980s; Sarbin, Mishler, Polkinghorn, Brenner • Classical grounded theory • Social construction	• Integrated storied theory of research as part of co-research • Give/get negotiation theory for co-research • Theory of new social organizations • Integrated narrative data
Stage 2: *Grey Matters* (2010) teaching engagement research methods to seniors and co-writing the resulting theories	• Participatory action research; emancipation theory • Inquiry-based learning theory • Social problem theory • 7 Cs of motivations for conducting research	• SET COLLECT REFLECT as an engagement strategy • Engagement in peer research • Resilience as social capital
Stage 3: PaCER research	• Salutogenesis quickly became the foundational theory, applied as a theory of patient expertise • Narrative theory • Social innovation and social enterprise theory	• From public participation to the acts of engagement; tell, ask, include, and lead (TAIL) • Ethics of engagement • New roles for patients in health research
Implementation stage	**The use of existing theory to inform development of methodology and new theory**	**New and adapted theory originating during the evolution of this science**

Table 4.2 (*continued*)

Stage 4: Making a difference as a bridge between academic research and design thinking innovation	• Citizen science • Feminist, Indigenous, race, standpoint theories • Emancipatory social science	• Health systems from a patient perspective • Participatory action grounded theory • A new patient standpoint theory • Bridging from research to innovation in health • Integrated narrative science

4.3. What Makes This Science Innovative and Able to Sustain Innovation and Social Change?

The new role of peer researcher becomes a bridge between unheard populations and health research, and between conventional and emancipatory social sciences. In the process, it opens the door to innovation and social enterprise to take innovative research findings to commercialization and social innovation.

PaCER began as a Catalyst grant to test the feasibility of peer research, and social enterprise seemed the best alternative for PaCER after the initial Catalyst grant ran out. We were able to do this because of partnerships with the SCNs, skilled PaCERs, colleagues, and the Cumming School of Medicine resources and innovative business advisors. Research projects provided a way to attract researchers who were interested in training and employing peer researchers. These early adopters covered the basic costs of training and paying patients to work on research projects. This also allowed us to introduce and incubate new methods to solve patient-identified problems with the contracting research team.

4.4. How Does This Research Support and Challenge Current Practice?

The main changes in current patient engagement practices have come from the graduates of the training program who go on to become researchers, advisors, patient engagement facilitators, or coordinators in health systems. They bring a unique blend of advocacy, engagement skills, research expertise, project management, and leadership skills. They worked alongside research teams, SCNs, health associations, and professional bodies, clinics, and regional health authorities. They are employed as patient research leads and coordinators on provincial and national team grants. In these roles, they conduct research about current practice and bring fresh insight to patient perspectives about changes needed and recommendations for change.

The first two years of PaCER had Catalyst funding from the Canadian Institutes of Health Innovation that covered basic infrastructure to test the training program. The five internship projects broke ground as the Strategic Clinical Networks began. Peer research graduates were able to change patient roles by understanding, explaining, and suggesting changes to current practice from a research perspective. The following represent the funded projects of PaCER as part of innovation funding. They are included in a summary of the innovation projects as part of the resources for the book.

- Family practice management of undiagnosed arthritic pain.
- The processes of waiting for hip replacement.
- Community support for surgery after care for immigrant populations.
- The need for ways to understanding patient experience in chronic and complex health systems.
- The documentation of what works and how, in a community-based cancer wellness centre.

The first social enterprise research contracts that were negotiated after the grant funding ceased, were influential in informing policies for end-of-life care for families, the impact of the safe surgery checklist on patient feelings of security about their surgery, the development of community models of prevention to reduce surgery for arthritis and Indigenous rheumatology, and online support for teachers with chronic arthritic conditions. In each of these, current practices and future options were influenced by peer research.

Training contracts also acted as social enterprises because of the sponsorship model to cover tuition. The first contracts led to published research on how youth concussion impacted the use of sensory deprivation; support for parents of stillborn babies; losing identity when diagnosed with mental health concerns; trauma of parents and their children who take their children to the emergency rooms for mental health concerns.

The most recent projects included four Indigenous projects related to cancer prevention along with mental health support during dialysis, and three projects related to inflammatory bowel disease. Each project was done in collaboration with health systems, national research teams, community agencies, and professional organizations. Check PaCER projects on the PRISM platform (https://prism.ucalgary.ca/home) or the PaCER team projects page (https://www.ucalgary.ca/patient-community-engagement-research/research/pacer-team-projects).

The impact of peer research on practice has been demonstrated through three independent evaluations of PaCER as a social enterprise. The first evaluated the outcomes of the Catalyst grant and noted the following:

- Graduates designed and completed ethics proposals and group research projects, including writing final reports from a patient perspective. Most joined the SCNs or health related committees.
- This work was published as a grounded theory that outlined the process of merging patient and researcher identities.
- Key stakeholders and researchers who were affiliated with the grant originally expressed serious concerns about the wisdom of teaching patients to be researchers. The follow up interviews recognized that value of peer research and anticipated future developments.
- The partnership proved successful in promoting innovation and new roles for patients as leaders in engagement and research.

The second evaluation was conducted by the Alberta health research team and analyzed by the O'Brien Institute of Public Health. This was done two years after the social enterprise was established, and it led to significant changes in curriculum that shifted from experiential learning to course structures.

- Students were looking for more structure instead of the year-long internship.
- The lack of infrastructure created uncertainty in funding, expectations, and reporting.
- While the researchers who had used the training and research services were intrigued and would recommend the service to others, they too noted the lack of infrastructure.

The third evaluation was conducted by the research liaison team representing the SCN's, Health Researchers and Disability Studies, using the Canadian Academy of Health Sciences criteria of social impact in health research after a course structure had been established (CAHS, n.d., https://cahs-acss.ca/making-an-impact-a-preferred-framework-and-indicators-to-measure-returns-on-investment-in-health-research/). The innovative partnership when twinned with the SCNs achieved an impact in three of the five categories indicated by the CAHS impact evaluation of health research that were possible given the short tenure of the PaCER program.

- Advancing knowledge through creating and sharing research done by and for patients, about peer research and relationships with

researchers, healthcare providers, and planning. This is evident in the PaCER/PRISM publishing hub projects and links to publications.

- Building capacity of patients to take up new roles in health research, care, and planning and the capacity of researchers, planners, and administrators to work alongside patients to create a new patient research voice. This is evident in the success of graduates.
- Informing health decisions and healthcare as patients and the products of their work have impacted practice and policy making.

4.5. Modifiability and Transferability

Modifiability is inherent in peer research. One of the features of this science is that it responds to and adapts to cultures, conditions, and contexts of participants and communities. The essence of the engagement strategy for peer research is its ability to work alongside health research pillars.

Transferability has been apparent within the scope of the province's Strategic Clinical Networks and through national teams who support training and research within their provincial organizations. Publications of research projects and the publication of this book will hopefully spawn debate and collaboration, to spread the concepts of this science to new places, systems, professions, and patient engagement initiatives.

4.6 What Are the Training Opportunities?

Original concerns voiced by health researchers and funders in the early development of peer research included the following general concerns that are common before training leads to new patient research roles.

- Patients are not capable of understanding clinical health research.
- Patien-experience research is already being done by health professionals who are skilled in what patients need and what patients experience.
- Training patients is not equivalent to health research training through university graduate courses.

The following phases of co-design of training acted as an incubator to test the feasibility of patients being trained as researchers that provided the foundation for training opportunities.

- The first two cohorts were funded to test if it was possible to train patients using the *Grey Matters* curriculum. A year-long internship was designed as an experiential co-designed learning process that

moved through the skills associated with being a researcher and patient at the same time, using the SET COLLECT REFLECT.

- The first year-long cohorts continued to revise and strengthen the curriculum associated with the experiential model. This was evaluated and the training moved to a three-course training program. The first course focused on the fundamentals of peer research ending with a research ethics proposal. The second course focused on the skills needed to conduct research. And the third (two-course equivalent) included conducting research with academic oversight of an internship to conduct their research after ethics approval.
- As the training program became known and graduates were in demand to conduct contracted peer research, the courses were modified based on the feedback from contractors. This led to social enterprise models of both training and conducting research.
- When a large Indigenous grant overwhelmed the existing social enterprise model, the training moved to the department of Continuing Education, who were able to adapt the curriculum for distance education. PaCER is now a university-recognized career diploma that still operates on a sponsorship model but is considering individual tuition.
- The current PaCER program includes up to four online classes a year, each with three to five sponsorships.

Originally the only other training option was the European Patients Academy on Therapeutic Innovation (EUPATI, n.d., https://eupati.eu) to create a research methodology and training program to enable patients and community members to conduct patient technology-based research. Given the escalating importance of technology in healthcare, it may be possible to encourage EUPATI fellows to learn research approaches to engage patients and communities in academic and innovation research. The open courses of EUPATI would also enrich the research and development foundations of academic and innovation research in ways that would expand PaCER graduate capacity to work as part of innovation and implementation teams related to technology.

EUPATI has updated their online courses to encourage open access courses for patients, patient organizations, health researchers, and healthcare providers. They are also available for general interest and certification for those who officially enrol in courses and pass an online test. This provides a strong educational platform about medical innovation and development. It is accessible worldwide, providing up-to-date information so that patients are prepared

to become engaged in research and development. Graduates of the training become EUPATI fellows and are matched with projects to represent patients from an informed perspective. New courses in digital devices and digital health will ensure that the digital transformation of healthcare includes informed patient input.

Most national health authorities now have courses to promote patient involvement in health research, based on short courses for patients to learn advising and partnership skills. Many now also provide training support for graduate students in healthcare-related programs. For example, the Canadian National Training Entity, as part of the national Strategies for Patient-Oriented Research, has created a national training platform for patient-oriented research (Canadian Institutes of Health Research, 2021, https://www.canada.ca/en/institutes-health-research/news/2021/06/government-of-canada-creates-national-training-platform-for-patient-oriented-research.html). The UK initiated a national patient engagement in health research and healthcare program and has been a leader in evaluating the impact in healthcare (Russell et al., 2020, https://doi.org/10.1186/s40900-020-00239-w). The Rand Corporation continues to support patient and public involvement in research (Ball et al., 2019, https://www.rand.org/pubs/research_reports/RR2678.html) and provides a basic guide to working with patient advisors and partners. This has done much to create common language and values for patient and public engagement. See also *A Researcher's Guide to Patient and Public Involvement* (Turk et al., 2017).

The development of the science of engagement draws specifically on the following training examples.

1. *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/): Research and curriculum that is referenced as part of this manuscript describes the development of a curriculum for seniors and others with lived experience related to health and community well-being. This has been used as a curriculum as part of the PaCER program.
2. PaCER curriculum development and incubation led to the PaCER program of studies, offered as a distance professional certificate by Continuing Education. This is basically an internship to teach patients how to conduct peer research, as part of research teams, as contract research or as patient partners with researchers interested in increasing a patient research voice. See also Alberta SPOR Support Unit (AbSPORU) for more training opportunities (https://absporu.ca/patient-engagement/pacer/).

3. The peer research documents of the Wellesley Institute (Roche et al., 2010, https://www.wellesleyinstitute.com/publications/peer-research-in-action/) provide an important look at the roles of community members as co-researchers and the management of peer research. The peer research job descriptions (in Chapter 2.5) are included directly, because they provide a common set of responsibilities and language while planning and managing peer research.
4. The *Peer Worker Support Project* (Howard, 2015, https://www.cahr-acrv.ca/wp-content/uploads/2012/12/Peer-Worker-Support-Project-Final-Report.pdf) is an important research report on the training needs of peer support workers in British Columbia Canada involved in research, healthcare, and community support to help them negotiate personal and work boundaries. While not specific to peer research, this resource provides in-depth guidelines for those projects navigating the bridge between rigorous research and community capacity. This aligns with the PaCER practice of hiring PaCER leads who manage a peer research team of peer research assistants. Leads and academics support and plan together.
5. Changemaker courses are available in most countries through universities, colleges, and schools, as part of the Ashoka international network of fellows, who are social entrepreneurs (see First Book, n.d., https://firstbook.org/solutions/time-for-change/). These credit courses build community capacity through social enterprise models and design thinking innovation. Ashoka also is a modern example of open innovation in science that builds community, government and business capacity. They are leaders in a future that is more community focused.
6. Citizen science has been largely a science platform for researchers who teach citizens to conduct specific research tasks as part of their research projects. The European Citizen Science Academy training platform (https://moodle.eu-citizen.science), however, includes a large range of courses for researchers and citizens. The inclusion of citizen led research in emerging CS projects may lead to joint ventures for CS and SoE.

As the science of engagement helps to provide a foundation for peer and community research, the options for education and training will hopefully expand and diversify.

4.7. Employment and Business Opportunities

The employment of patient researchers means payment or compensation for taking part in research. From the very beginning of PaCER, graduates were paid comparable wages as research leads and research assistants. This created, and still creates much debate about paying patients who are usually expected to be willing to work as volunteers as patient advisors.

This is a minefield that includes university research financing, provincial and national grant regulations, innovation funding criteria, and venture capital. It is beyond the scope of this book to explore all the avenues, because payment options are ephemeral and situation specific. Until health research grants include criteria for paying peer researchers and peer mentors, along with budget guidance, each project will have to create its own solutions.

The payment of patient advisors and partners is tenuous, with some paying by the hour (ranging from $10 to $50 per hour). Other projects pay honoraria plus expenses. Any payment might conflict with assured income regulations that set limits for income and are difficult to change. Managing payment for part-time peer research assistants is draconian, and pay may be deducted from their benefit allowances or they may be considered no longer eligible. Patients who, by nature of their condition, are unable to work full-time but are willing to use their expertise to improve healthcare systems face serious obstacles because they can't continue if payment is involved. The decision for patients with chronic and declining health presents too many risks. We need the expertise of these patients, but more often, they choose not to stay involved because of the increased stress about losing basic incomes or allowances.

This is even more problematic with contract peer research. PaCER became a social enterprise when the initial grant ran out and there was a demand for peer research. The original payment plan enabled people to plan their working time, but the wages were determined by existing pay scales for trained research leads and research assistants within the university.

Our internal guidelines were $40 per hour for lead researchers and $20 for research assistants. After many approaches to payment, the final solution with PaCER meant that lead researchers became vendors (contractors) who paid all salaries and expenses related to the contract. The solution for research mentors has included sessional or course-specific teaching assistant variations.

Regardless of the patient role, social enterprise contracts within academic settings need to be carefully considered to ensure that overhead costs are included as well as salary ranges. As the scope of research expands in citizen health science and Ashoka changemaking, social innovation and social enterprise initiatives may be needed, and the payment of patients and community members will need to be addressed.

The power of social enterprise is that projects begin with the expectation that they will become economically viable. These may also use the following payment guidelines:

1. **A participant** in research brings lived experience and willingness to share this experience as part of research processes. Payment can be by honoraria, expenses, or negotiated pay schedules.
2. **An advisor** brings patient experience or community context to the research team. Some projects use negotiated payments that range from $20 to $50 per hour for specific responsibilities. The research team provides research training as required, and if the advisor is expected to have research or team skills, this should be recognized.
3. **A research partner** is trained, either through specialized programs of study (the national curriculum, HIV training, PaCER) and/or by the research team to take part in specific research activities as part of grants, projects, and funded research. Payment seems to be related solely to the project's ability to pay partners as part of grants for a part of social enterprise development and business development.
4. **A peer research assistant** is formally trained in engagement research methods and is hired to conduct specific research functions as part of research grants and projects, with oversight by academic researchers. In a social enterprise, the research assistant would be part of the innovation team and the business development.
5. **A peer researcher** is formally trained in engagement research methods and project management in order to co-design, conduct, and manage research as part of an academic team. In a social enterprise such as PaCER, the research lead is considered an independent project manager with the responsibility to hire and oversee peer research projects. In the future, these peer research teams would be trained to support both citizen science projects and social enterprise.

The classification of citizens, patients, and community members is based on the current range of options. This categorization also attempts to respond to the issues related to payment. The issues of payment, compensation, and honoraria are beyond the scope of this science, although the move to recognize patient expertise is inevitable.

Although this is still nascent, there are strong indications that the science and peer researchers trained in this science will lead to a variety of career opportunities related to patient engagement and contributions to health

reform. We end this chapter with several examples of emerging or existing careers that are available.

This science will be of use in existing patient engagement initiatives such as patient-oriented and patient-engaged research projects where peer researchers lead and peer research assistants are employed to conduct POR interviews. Citizen organizations interested in health are growing in Canada and internationally. Health promotion and health services units in universities and Ashoka programs are expanding patient engagement opportunities for those trained in peer research and peer support.

In addition, as this book unfolded, it became clear that in health there are two forgotten populations, not one. While patients have been the clear focus, frontline and community support staff—from physicians and nurses to personal support workers and teachers—have been identified as peers as well. Some of the most impactful research we conducted included physicians researching physician experience, in conjunction with patients researching patient experience. We also see graduate PaCER researchers who are academics now using peer research to train patients to work as colleagues.

The science of engagement provides opportunities for researchers to consider ways to include patients and community members as colleagues in research. The issues of employment of trained peer researchers rests with those able to learn about, support and pay for peer research.

Summary

A science of engagement has been proposed to enable a broad range of researchers, planners, providers, and patients to see patient engagement as more than a moral imperative. It is offered to encourage vigorous debate, study, and, hopefully, challenge and change.

You might begin this study by choosing one of the sections that is most relevant to your current work and consider how having a science framework might inform your thoughts or practice. Each element of the theory is covered in detail in the chapters. You might link to the chapters that whet your appetite for innovative partnerships with patients and communities. Whatever your preference, the following questions might help guide your decisions.

Questions for Discussion

1. What individual and community resources do you have access to currently and how might they become engaged? E.g., 'expert patients,' advisors, or researchers who also identify as patients.

2. Do you have an existing team that is interested in engaging patients and communities in your research? Survey their interests in studying chapters or sections and set up some preliminary study groups to apply the chapter to your situation. Explore how to introduce ideas and options for experimenting with ideas. The publication platform is designed to interact with the author or representatives of peer research training.
3. Do you have students who can commit time to projects as part of their training or volunteering? How might they become part of a design team?
4. What funds do you have access to if you want to train some of the patients and community members to become peer researchers?
5. Connect with AbSPOR Patient Engagement or Continuing Education to explore training options and how to contract projects.

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SECTION 2

Engaging: Best Practice of Peer Research

Section 2, Engaging, explores the current literature, players, and practices that inform patient engagement underlying the science of engagement introduced in Chapter 4.

This introduction sets out to provide the context of our current understanding of emancipatory and critical research that engages citizens to encourage research important to patients, facilitate and conduct research that is done to make a difference in health research, care, and planning. We look at the international perspective, critical and emancipatory health research.

These chapters have been prepared for researchers, innovators, patients, and students interested in exploring new patient research voices to expand the democracy and transparency of their research. The intent of this section is to provide a peer research foundation for sponsors of patients in programs such as PaCER and options for researchers and students interested in working with patients as co-researchers in their personal or team research.

International Anti–Oppression and Emancipation Movements That Underlie Peer Research and Engagement

The move to engage populations and citizens in health has been led by the World Health Organization, as seen in their strategic direction for patient and community engagement outlined in their global strategy interim report.

Empowerment: Wherein people and communities take control of their health through health promotion, prevention, and health partnerships. Canada was an early pioneer of health promotion, both in creating international health promotion approaches as seen in the Ottawa Charter for Health Promotion (WHO, 1986, https://www.who.int/teams/health-promotion/enhanced-wellbeing/first-global-conference) and community-based participatory research.

Engagement: Promotes the need for communities and citizens to share decision-making and healthcare planning. This has been the focus of most public participation initiatives. Engagement science and peer research provides support for advisors and teams involved in decision-making and planning for effective and engaging care.

Co-production: This includes stable partnerships between citizens, planners, healthcare providers, and researchers, and is a long-term goal for most countries. It is here that we will see the most dramatic shifts in healthcare. While this goal is not yet part of policy, apart from the European Union Citizen Science support, many of our first graduates have created ongoing collegial relationships with research and planning teams. It is hoped that as more national research teams sponsor training, these long-term relationships will become a feature of the Canadian health landscape.

The concepts of the above goals of empowerment, engagement, and co-production began with Freire's (2000) pedagogy of the oppressed in low-income countries, and evolved to current critical consciousness theories supporting marginalized or oppressed people's analysis of societal inequities and their motivation and actions to redress such inequities (Diemer et al., 2016, https://doi.org/10.1111/cdep.12193). WHO was an early adopter of emancipatory approaches of pedagogy of oppression. The focus on oppression expanded and aligned with critical theory to promote freedom from systemic discrimination all too common in health, welfare, economic, and legal institutions. JEDI-A: Justice through equity, diversity, and inclusion (now including access rights for disability and Indigenous populations) is a recent affirmative action movement.

Emancipatory Movements in Health

Women, Black, Disabled, and Indigenous people challenge discrimination in developed countries, which produced transformative research, community development research, and social rights movements. Citizen health versions of critical pedagogy emerged in the health landscape with core principles that still apply today, as the move to emancipate patients becomes a reality. The following learnings from citizen healthcare (Doherty & Mendenhall, 2006, https://doi.org/10.1037/1091-7527.24.3.251) relate to the emancipation in research.

The following is an overview of the players in this patient engagement health space.

The current interest in emancipation of patients is perhaps best articulated by Charlotte Williamson (2008, https://doi.org/10.1111/j.1369-7625.2007.00475.x), who traces the growth of emancipatory actions of patients from the late 1950s to current challenges to systemic discrimination. Although the movement is fractured and still evolving, the goal of British activists is

not to diminish healthcare systems but to make the system a better place for everyone, by working toward principles of respect, information, access, choice, shared decision-making, safety, and equity.

An example of community-based citizen science in New Zealand (Metcalfe & Style, 2019, https://doi.org/10.1080/15265161.2019.1619874) demonstrates an emancipatory cultural partnership recognizes the validity of Indigenous science as part of national ethical health research. It clearly identifies the value of extended relationships that combine both robust scientific research within the STEMM (science, technology, engineering, mathematics, and medicine) in community capacity building and the co-production of patient-researcher partnerships in research and policy.

The inclusion of Indigenous ethics and conventional bioethics is a novel approach that could inform countries that have developed separate Indigenous ethics. New Zealand's experience includes epistemological diversity that builds on constant negotiation about ownership of data. This is necessary for democratization of science but, in the process, creates innovative ways of doing and thinking for scientists. These learnings are not only important for community research, but also academic research partnerships that strive to conduct action research that can empower all partners.

International Research Models of Participation and Engagement in Citizen Science

The renaissance of citizen science grew from participatory action research (PAR) and the third industrial revolution of computing power and communications networks. It coincided with the move among governmental research funders to include research about real-life problems to have greater impact and increase the relevance of science to the public. The widespread and rapid uptake of internet social media spawned new research networks, crowdsourcing data collection, and online groups that dramatically changed the nature of recruitment and data collection. Dispersed computing power enabled big data projects to operate more efficiently. The following are the engagement change makers in citizen science.

Citizen Science Research Models

Table S2.1, adapted from Strasser et al. (2019, https://doi.org/10.23987/sts.60425) focuses on an international review of participatory or engagement models in research that have been identified in the last decade as part of citizen science. The International Association of Public Participation (IAP2), a leader in public participation since the early 1990s has also been included. Community-based participatory research has not been included in most citizen science approaches

but actively engages communities in identifying and contributing to participatory action research to solve common community problems. Michel Duke's (2020, https://doi.org/10.1093/acrefore/9780190854584.013.225) overview of CBPR provides a broad overview of the range of this participatory research movement. This model is introduced here to consider early research models and again in the last chapter to ground discussion on bridging between health research and innovation. It is used here to introduce the range of citizen roles that are possible in citizen science. This table returns at the end of the book to explore how these roles build bridges between research and innovation.

Table S2.1 *Methods of Engaging Citizens in Research*

Locus of power Bonney et al., 2009 (designed by scientists)	**Ladder of participation** Shirk et al., 2012	**Levels of participation** Haklay, 2013	**Epistemic practices** Strasser et al., 2019	**Spectrum of public participation** International Association for Public Participation (https://www.iap2.org/mpage/Home)
Contributory projects Citizens or patients contribute data	**Contractual** Scientists conduct a scientific investigation and share the report or results with citizens	**Crowdsourcing of data** Citizens contribute local sightings, measures, personal data	**Sensing** Contributions include recording the events seen, heard, experienced	**Informing** Provide balanced and objective information in a timely manner for citizens
Collaborative projects Citizens bring their own resources to the study	**Contributory** Citizens are asked to collect and contribute data and samples for research	**Distributed intelligence** Citizens as interpreters of existing or emerging data using personal computing power	**Computing** Use personal computers to increase computational power	**Consult** Obtain public feedback on analysis, alternatives, and decisions

Table S2.1 (*continued*)

Co-created projects Some members of the public are actively involved in most, if not all, of the scientific process	**Collaborative** Citizens assist scientists in developing a study, collecting and analyzing data for shared research goals	**Participatory science** Participation in problem definition and data collection	**Analyzing** Aspects of large data sets and secondary analysis	**Involve** Work with the public to make sure that concerns and aspirations are understood and considered
Co-produced projects Members of the public are actively involved throughout the project design and implementation	**Co-create** Citizens develop a study and work with input from scientists to address a question of interest or an issue of concern	**Extreme citizen science** Involved in problem definition, data collection and analysis	**Self-reporting** Through crowdsourcing or collecting experience data	**Collaborate** Partner with the public in each aspect of the decision-making
Peer research Citizens are trained to engage other citizens in research about their priority	**Collegial** Independently conduct research, as part of a research team		**Making, creating, inventing** Producing new products using new technology such as 3D printing	**Empower** To place final decision-making in the hands of the public

Note: adapted from Strasser et al., 2019

Bonney et al. (2009, https://files.eric.ed.gov/fulltext/ED519688.pdf) provides a comprehensive description of the way researchers view citizen involvement in projects, beginning with the most common role of patients as data contributors in quantitative health research. In the second collaborative level, citizens are included in refining the research focus, analysis and dissemination. At the co-creation level, we see the goal of authentic and fulsome engagement, where citizens are engaged throughout the research process.

In Shirk et al.'s (2012, http://dx.doi.org/10.5751/ES-04705-170229) ladder, the first two rungs of the ladder are like Bonney's and in the third, collaborative level, citizens assist throughout research with shared goals. By the fourth rung, citizen scientists are developing and conducting parallel research of interest or concern to citizens with input and support of the scientists.

- The Dutch personal health research foundation, 'My Data, Our Health' encourages and supports citizens to conduct research on their health condition and share their results on an open platform. This is an example of Shirk's final step, where citizens are seen as colleagues who independently conduct research independently or as part of the research team.
- This parallel research model is emerging where government patient-engagement funding (e.g., SPOR) is set aside for patients to suggest research ideas, and funding is provided to hire a research team to conduct the research with the patient lead. (Gajic, 2022, https://unityhealth.to/2022/09/patient-led-research/)
- Some teams have supported citizens to conduct their own research that may or may not be integrated into the final research report.
- The other version is the PaCER model of engagement (https://www.ucalgary.ca/patient-community-engagement-research), where the peer researchers are trained in engagement methods, sponsored by research teams, to conduct research about a common concern from a patient perspective.
- The Patient Led Research Hub (https://plrh.org) has become a powerful independent research approach where researchers who share common concerns work together to conduct research and publish results.

Haklay (2013) and Woolley et al. (2013, https://doi.org/10.1186/s12910-016-0117-1) introduce levels of participation within web-based, crowdsourced citizen science. This work is grounded in collective intelligence that emerges in crowdsourcing because of the potential for large, distributed data sets. They posit that four criteria are necessary—independent contributors, diversity of opinion, decentralization, and a way to aggregate the results. The levels reflect not steps to engagement but the type of data collection, beginning with crowdsourcing at the sensing level, where citizens contribute specifically defined data. Distributing the conceptual and analytic skills of citizens using their computers follows, and it is not until the third level that citizens participate in research design. They do include a final step, which implies that some of the web community of citizen scientists are engaged as partners in technology.

Strasser et al. (2019, https://doi.org/10.23987/sts.60425) provide a practical set of functions that can be done by citizens, from sensing, computing, analyzing, self-reporting, and making (innovating products and processes).

These models inform options for engaged health research, from clinical trials to narrative research, and set goals for engagement in health research.

Both PaCER and community-based participatory research (Zimmerman, 2020) are represented in the highest levels of the table.

Summary of the Chapters

In keeping with emancipatory goals, the key feature is the ability to create research that is participatory, natural, creative, and action oriented. Chapter 5 provides an overview of patient engagement through published articles. Chapter 6 introduces salutogenesis as a theory of patient expertise creating a culture of competence. Chapter 7 explores the history, theory, and methods of narrative research. And finally, Chapter 8 is a researcher's guide to including engagement methods as part of qualitative research.

All chapters are aligned with the importance of an engagement strategy that ensures co-research from a patient-selected main concern to reflection on finding and planning for the future. The goal is to suggest a large number of tested qualitative methods and theories adapted to support patient engagement in research in order for researchers and students to experiment with these methods.

Resources

Peer Research Projects Done by Peer Researchers

The PaCER hub is an open access repository in the PRISM database at the University of Calgary (https://prism.ucalgary.ca/handle/1880/109933). This was established to provide an open access and dialogue for patient-led research. The goal is to encourage peer research projects and research that meet the criteria of being done by, with, and for patients. It was intended to become an international hub of patient and peer research, allowing those with an interest in peer research to share their ideas and their research.

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5

Published Research About Engaging Patients in Health Research

Highlights

- Motivations of patients to engage
- Patient engagement in health at the global and international level
- Acts of engagement
- International research that is democratizing science
- Peer researcher job descriptions
- Peer researchers impacting health transformation teams
- Blending patient and researcher roles
- Peer leadership

Chapter 5 includes published articles and reports describing patient engagement in research. We begin where it all starts, with the motivation of patients to engage in research as a co-design team. We then consider the three main research approaches represented by community-based participatory health research, citizen science, and PaCER, a formal training program devoted to peer research by, with, and for patients.

The next two topics address roles and relationships in health research, beginning with a comparison between community-based participatory research, citizen science, and peer research. These are the most common participatory action approaches. This is followed by job descriptions of peer research—advising, research assistant, and peer researchers—that is a combination of the Wellesley Institute research, the AIDS community health, and PaCER.

This is then followed by a summary of a grounded theory article that uncovered the process of merging patient and researcher roles during innovation funding through the Canadian Foundation of Healthcare Improvement (CFHI). Patients trained in peer research and related leadership roles have

become the pioneers of this new social movement of patients as partners in healthcare transformation.

The end of this chapter describes four leadership areas that arose from the early incubation period: mentoring and teaching other patients as mentors, advisors, and research assistants; support and liaison, being the bridge between research teams and patient groups; managing organizing teams and overseeing projects; and, reporting, including working with teams on grants, ethics proposals, social media, and articles.

Motivation to Engage: The First Step in Successful Engagement

This research was done in partial fulfillment of a PhD in Community Health Sciences by Tamara McCarron (2019, http://hdl.handle.net/1880/110238). The research is an example of co-research, as three patients who were trained in peer research and experienced patient advisors were included in all phases of the research, including a scoping review, interviewing patients, developing the questionnaire about values that drive motivation, analyzing data, planning and conducting regional workshops to validate the results with patient advisors and professionals in the field of patient engagement. They were also involved in reviewing the final dissertation and were present at the PhD defence.

The scoping review represented the first phase of the PhD thesis (McCarron et al., 2020, https://doi.org/10.1186/s13643-019-0994-8). Patient co-investigators were involved in co-developing the questions which guided the review, developed the search terms, reviewed titles and the abstract for inclusion, full text review, data extraction, and synthesis. This study advanced our understanding of how health systems invested in building the capacity and ability of patients/family members to participate in research and healthcare decision-making. We discovered that the evidence base to advance patient engagement was largely absent.

The survey represented the second phase of the PhD thesis (https://doi.org/10.1111/hex.12942). Patient co-investigators were involved in patient and family interviews, which were used to inform the survey tool, developing and reviewing the survey tool, piloting the tool and sharing the survey within their networks. This study advanced our understanding of why patients and family members are motivated to engage in health system decision making. When you understand why people are motivated to do the kind of activities they do, such as being a patient advisor, you can build programs that are not only meaningful but are also sustainable.

The final study provided additional insight and understanding to the results of the survey and resulted in a final framework that describes how to support and sustain patient and family engagement (McCarron et al., 2020, https://doi.org/10.1111/hex.13054). Patient co-investigators were involved in developing the community workshops, facilitating the workshops, and collecting/analyzing workshop data. The co-investigators were involved in the design and validation of the patient and family engagement framework.

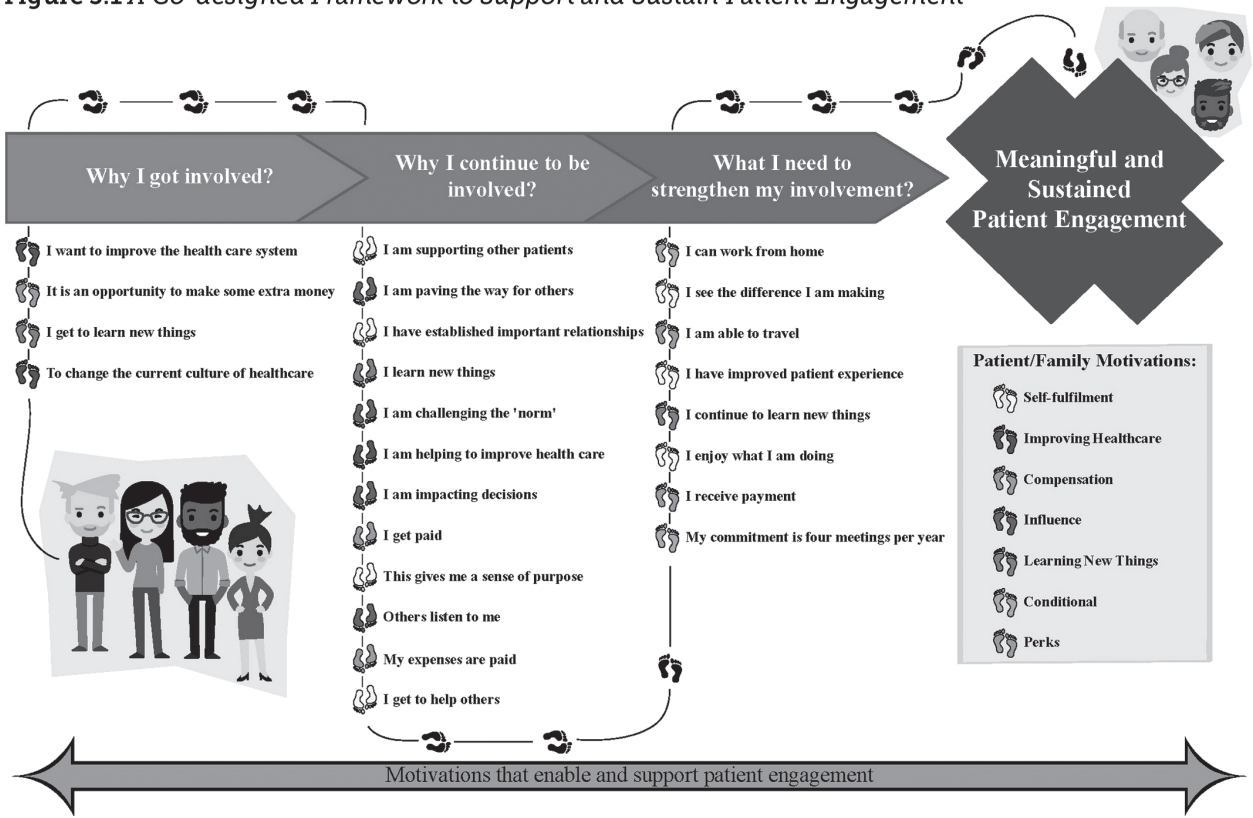
The results of this study, as presented above, mark the first-time that the motivations of patients to become involved in volunteering or becoming peer researchers has been done using established value frameworks from organizational management. The many facets of the study and the large numbers of patients involved in both the questionnaire across the province and health sectors has produced a tool for recruitment of patient volunteers, for retaining and deepening their engagement, and for sustaining their involvement. These values speak to several key motivators that manifest in different patterns during recruitment, retention or continuing to be involved, and sustaining and growing as part of being involved.

- **Self-fulfillment**: An **emotional motivation** that focuses on an individual's desire to find purpose, do something meaningful and establish productive and rewarding connections. It is rooted in a sense of obligation and driven by the desire for the gratification provided by the opportunity itself, such as participating in an activity to help others.
- **Improving healthcare**: A **functional motivation,** where individuals are motivated to make healthcare better, either because they had a good or bad experience themselves, or they want the healthcare system to perform to the best of its ability, so all individuals receive the same care.
- **Compensation**: A **functional motivation**, driven by the desire to satisfy a need, in this case being paid. Individuals motivated by compensation are seeking to fulfill a financial need (removing barriers to participation) or the need to be recognized by others (being paid is an acknowledgement of the patient/family member's contribution as a partner).
- **Learning new things**: An **epistemic motivation**, driven by the need of an opportunity to provide novelty, to arouse curiosity, or to gain knowledge. Individuals motivated by learning have the desire for more knowledge and self-improvement, achieved by the novelty of new roles for patients.

- **Conditionality**: An example of a **social motivation,** contingent on the specific situation faced by the individual. This motivation enhances the choice, to participate or not, by increasing the perceived value to the individual. For example, this motivation was achieved when participants could participate in opportunities that were flexible and convenient to their schedules. Since these were unique to each situation, having multiple opportunities for people to get involved would satisfy individuals who are motivated by this value.
- **Influence**: A **social motivation**, described as an individual's ability to impact decisions, feel that they are being heard and considered as a partner by other healthcare professionals. This motivation is further enhanced when an individual's perspective is acknowledged and valued by senior health professionals and others who can effect change. This motivation is satisfied in the realm of power and status. It depends on the membership of the group and how individuals measure their status in relation to others within that group.
- **Perks**: An example of a **social motivation** that is associated with the symbolic meaning (and prestige) of being a patient advisor and member of the team. This value is realized when individuals are asked to attend conferences and events, requiring expense reimbursement for travel and registration fees, are associated with the prestige associated with attending or presenting at conferences, and get recognition for the work done.

The theory emerging from the research is captured in Figure 5.1, a user-friendly diagram that engages both patients and professionals.

Figure 5.1 *A Co-designed Framework to Support and Sustain Patient Engagement*



Note: McCarron et al., 2020.

Additional work describing how we co-designed strategies to support patient partners during a scoping review and how you can use the motivational framework described above can be found from in McCarron et al. (2021, https://doi.org/10.1186/s40900-021-00272-3).

Three Main Models of Peer Research in Citizen Science, Community-Based Health Research, and Peer Research

The development of partnership roles in healthcare has been difficult because of the longstanding power differentials between patients and healthcare professionals and researchers. However, in research, it may be possible to establish new, more productive relationships by conducting research in more collaborative ways that focus on the roles of patients within healthcare, from a position of strength and expertise. It must be noted that Table 5.1 does not include patient-led research, which is growing rapidly as researchers who are patients conduct research to share their experience and expertise and answer the research questions that are not being addressed by traditional research. It also doesn't include the personal health research networks of 'My Data, Our Health,' where patients share their personal data and research findings online.

Table 5.1 contrasts three distinct established approaches that engage citizens and persons with lived experience (PWLE) in research. The similarities are startling, given the different contexts and histories of the initiatives. All are emancipatory in nature in that they include citizens in research to build better relationships between health populations and scientists through research that is inclusive and meaningful.

In the case of community-based participatory research, the goal is to build community capacity and political strength to research their concern and build leadership. Citizen science is the powerhouse of democratization of science that connects citizens and scientists in attacking the major environmental and social problems facing society. The science of engagement supports all forms of peer and community research to transform healthcare and democratize health research. This SoE is based on models that have emerged in co-research with new social movements, peer research with seniors, and the Patient and Community Engagement Research training program in Alberta.

Table 5.1 *Contrasting Peer Researcher Roles in Community-Based Participatory Research, Citizen Science, and the Science of Engagement*

Community-based participatory research (CPBR) (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2951933/)	**Citizen science** (www.citizenscience.org.au)	**Science of Engagement (SoE)** (This manuscript)
Community members advise and are hired to conduct specific tasks in research that is co-designed	Citizens may act as contributors, collaborators, or as project leaders, and have a meaningful role in the project	Includes PWLE, patient advisors, participants, and trained peer researchers
Citizens work as part of research teams and are mentored in the skills needed for CBPR	Citizens bring their interests, skills, and assets to the projects; training may include data collection, analysis, and presentation	Formal research training is available for PWLE and researchers through SPOR, PaCER, and other training initiatives
Begins with and builds on strengths and resources within the community.	Projects actively involve citizens in official scientific endeavors that generate new knowledge and understanding	Promotes the engagement of PWLE in health research, quality improvement and social enterprise
Facilitates collaborative, equitable partnerships that are empowering and power-sharing in all phases of research.	Provides benefits to both science and society, including learning opportunities, personal enjoyment, social benefits, the publication of research outputs, contributing to scientific evidence that can influence policy; connects the wider community with science	Promotes meaningful engagement through all stages of research from co-design to implementation; the goal is to impact roles, relationships, programs, systems, and policy through evidence-based collective patient research voices

Table 5.2 (*continued*)

Community-based participatory research (CPBR)	Citizen science	Science of Engagement (SoE)
Promotes co-learning and capacity building among all partners involved	Citizen scientists may participate in various stages of the scientific process, which may include developing research questions, designing methods, gathering and analyzing data, and communicating results as well as creating innovative technology and health products	Formal training options: 1. Foundations curriculum for patients and researchers 2 Theory and methods of patient engagement in research done by patients 3. Internship in participatory grounded theory
Integrates and creates a balance between knowledge generation and action for mutual benefit of all partners	Provides greater opportunity for public engagement and participation, increasing accessibility of science in society	Graduate peer researchers work with research teams to co-design and conduct peer research as part of research agendas; graduates can also support training as mentors
Disseminates findings to all partners	Project data and meta-data from projects are made publicly available and results are published in an open-access format	Reports are available online and research publications are produced with team members and peer researchers

This table suggests synergistic approaches working to the same end with very similar values and methods. The following sections of the chapter provide examples of research that apply to all three options. Peer research, developed within a health system, is actually a variant of citizen science that includes an engagement methodology and training in conducting research.

Job Descriptions of Peer Research

The most common definition of peer research is a participatory research method in which people with lived experiences of the issues being studied take part in co-designing, directing, and conducting the research. The role of the peer researcher becomes a bridge between citizens as part of the population of interest and a research team. This bridging function is not new in community-based

health research. In Canada, the AIDS research in Ontario and later in the Pacific AIDS Education and Training Community (https://paetc.org) have demonstrated the value of training AIDS community members to provide the bridge between research teams by conducting research within the community and sharing results, planning direction, and implementation with research teams.

Because patient engagement in health research is expected by most granting bodies, patient advisors and partners are increasing. In their article with the Wellesley Institute of Toronto, Roche et al. (2010, https://www.wellesleyinstitute.com/publications/peer-research-in-action/) present a clear and detailed picture of the options, strengths, and challenges of peer research. Its methods of engagement have proven the importance of peer researchers within the communities they work with. PaCER, Wellesley, and the HIV peer research training programs are examples of how community-based participatory research supports emancipatory research.

The following are the three most common styles in peer research, as identified by research at the Wellesley Institute in Toronto. We have used their basic structure and content to acknowledge their seminal role in moving peer research forward. It also includes models used by the PaCER program and the peer research conducted in AIDS communities.

The Advisory Model

The most common understanding of peer involvement is as a patient advisor, partner, or stakeholder on steering or advisory committees. This comes from a long history in civic participation where citizens held positions on committees, providing a grassroots citizen voice, along with service providers, advocates, local officials, and charities. The advisory roles on these committees range from the opportunity to tell motivational personal stories to being included in decision-making.

The role of an advisor needs to be clearly negotiated and recognized with opportunities to learn and develop. It is wise to have more than one advisor on a committee, and they need to be prepared and debriefed after engaging to ensure that they develop the skills to participate and contribute the perspective they represent. There are many ways that informed advisors can contribute to the design, recruitment, interpretation, and implementation of research. In the European Union, patients are trained in clinical trials to become advisors on research teams. In the UK, cancer survivors provide training in cancer-related research to support researchers and as advisors on teams. In Canada, the national curriculum developed by the national Strategies for Patient-Oriented Research (SPOR) unit is adapted and administered by most provincial SPOR

units, to acquaint patients with Canadian health research and opportunities to volunteer as advisors on research teams, funding committees, and policy development.

In health, there has been a long history of choosing a health professional, researcher, or family member who is also a patient to act as advisors. These advisors wear two hats, bringing both their peer connection and their professional understanding. While this professionalization of the right patient is a comfortable arrangement for committees, the experience of patients is filtered through a professional experience perspective that continues to marginalize many patient and community voices.

In some seniors' advisory groups or research teams, there is a tendency to hire a skilled patient as a consultant that is paid to represent patient input when required. Advisors on planning and funding teams are often trained in the skills required to participate as an equal. For example, on funding committees, advisors are instructed on how to read proposals and the expectations of the advisor. In planning committees, there are support groups or training sessions to learn planning processes, criteria, and how to contribute to the discussions and decision-making. Many advisors come to the advising role with high motivation and willingness to contribute but lose interest if they become a token once their story has been told.

The Contract Model

Peer researchers are often contracted or invited to provide specific research services. For example, in citizen science, citizens may be recruited to record local data, collect data, analyze data, be part of reviewing, or disseminating findings. Historically, citizen scientists do this not for a salary, but because it is an interest or a vocation. Examples such as the bird counts, water testing, monitoring symptoms, analyzing large data banks, and providing input into civic implementation strategies are done because of the intrinsic value of being part of the research. In community-based research and health research, there is a growing interest in recruiting people with lived experience to use their connections within their peer community to recruit, test surveys, collect data, respond to findings, and suggest ways to engage the population in the findings. These can be seen as consultations or research assistant roles.

In the PaCER professional certificate, the first of three courses trains patients and community members to be involved as advisors or patient partners, conduct patient-focused co-design, provide research support as interviewers, and facilitate focus group discussions as part of data collection. When I was a contractor of research, detailed job descriptions were created in response to the specific interest of research and healthcare teams to engage a researcher that

could connect with the population to recruit and collect data. This method is often used by the Alberta SPOR patient engagement platform.

In community-based participatory research, training is provided as part of participatory research, the specific research methods, ethics, and data management are included. Service providers are often recruited as research employees to train community members. This is similar to the pairings used by McMaster University's Public and Patient Engagement program (https://ppe.mcmaster.ca) that trains health students to work with patients to interview research participants.

There is a debate about what to teach and how to train research employees or contractors who are patients or community members. The Strategies for Patient-Oriented Research (https://cihr-irsc.gc.ca/e/51465.html) through the Canadian Institute of Health Research provides a series of training opportunities, including introduction to Canada's health science pillars, the basics of patient engagement, and how to work within health research.

The majority of peers employed in research are trained and mentored within the parameters of the research project and gain experience from the diversity of projects that they contribute to. The PaCER training program teaches the approaches and methods of patient engagement and ethics for those wanting to sit on research, healthcare, or clinical teams.

There are also researchers and graduate students who identify with a community of persons with lived experience (PWLE). They may be looking for ways to combine their background as a health professional with an interest in peer research methods. These researchers operate with the advantage of the status and training in research and the lived experience that enables them to use the techniques in this book to train patients to become peer researchers. In my experience as an academic, I have noticed that disability studies is richly endowed with effective researchers who also identify with patients or allies of patients, and the same synergy enriches other equity-seeking university programs.

Peer Research Partner or Peer Researcher

The Wellesley peer researcher model involves members of target communities as partners from the very beginning, training them to conduct the research, do the analysis, co-write together, and co-present. One project reflected the culmination of peers' long-term activism around mental health issues. While not easy to achieve, success takes many forms. Some peer researchers have grown into leadership roles, while others have introduced new ways to work as bridges between academics and service providers. Wellesley has produced a seminal report on peer research job descriptions and practice (Roche et al., 2010, https://www.wellesleyinstitute.com/publications/peer-research-in-action/).

True research partnership means that everyone—peer researchers, academics, and service providers—works together to refine the nature of each partner's goals for the project, as well as their personal and professional needs and the risks each group faces.

In community-based participatory research, some come with career-building goals, others with advocacy and credibility goals. The process of research is reframed and strengthened by the partnerships among community members, academics, and agency staff. In PaCER, similar relationships are formed—some work as part of PaCER teams and as contract research assistants, some become team leaders, working with national teams to design and conduct patient-engaged research as part of the ongoing team's agenda, while others work directly with researchers and support their academic agendas. Regardless of what these new innovative roles are, they are adding to the growing repertoire of social innovation in partnered peer research.

Peer and Patient-Led Research

Patients have been actively researching their own conditions and treatments, especially with access to medical information, internet searching, and the ability to meet 'others like me.' We introduce the growth of the quantified self movement in the last chapters as the precursor to personal health research. Peer research is, in some ways, similar to patient-led research (PLR). As Vayena et al. (2016, http://dx.doi.org/10.1136/medethics-2015-102663) state, the goal is producing generalizable health knowledge. PLR is distinctive in being initiated and conducted by the participants themselves, often using the tools of online social media. In their exploration of PLR ethics, they offer a number of specific standards and oversight policies to provide "material support for PLR, incorporating its outputs into the body of scientific knowledge and translating those outputs into practice" (p. 217). While all peer research and PLR would be considered a form of citizen science, and therefore invited to adhere to the principles of citizen science, the authors also include a number of specific ethical considerations that could apply to both peer research and PLR.

It has long been expected by those working as part of emancipatory patient movements to support an independent patient research voice (Williamson, 2008, https://doi.org/10.1111/j.1369-7625.2007.00475.x). Examples of this are emerging as peer-led research manuals for youth (e.g., National Coordinating Centre for Public Engagement, n.d., https://www.publicengagement.ac.uk/learn-others/case-studies/communicating-partnership-participatory-design-young-people) and in published articles in medical journals (e.g., McCorkell et al., 2021, https://doi.org/10.1097/PR9.0000000000000913) about the patient led research that pioneered the acceptance of long COVID as a

legitimate diagnosis for research. This marks the next step in open innovation in science (Beck et al., 2022, https://doi.org/10.1080/13662716.2020.1792274). The science of engagement creates a platform for groups considering forming patient-led research and peer research. It supports the value of independent research voices which is similar but, to date, has been conducted in collaboration with academic research teams.

Becoming Part of the Team: Twin Innovations in Collaboration

The following is a summary of the outcomes mapping and grounded theory study that informed a Catalyst grant through the Canadian Institute of Health Improvement to advance knowledge about the feasibility of training patients as peer research partners for the Alberta Strategic Clinical Networks (SCNs). The research consisted of a detailed outcomes mapping (Shklarov et al., 2017, https://doi.org/10.1111/hex.12591) that included the key stakeholders, interviews with SCN researchers and planners before and after the project, and a grounded theory study of the emergence of a patient researcher role. In the process, five studies were completed by patients. Patients were recruited onto the SCNs as patient research partners. The emerging core concept 'becoming part of the team,' is summarized below from a patient and a SCN perspective using quotes from that publication where appropriate

Knowledgeable, Competent, and Assertive Partners

- **Legitimate role at the table:** The training produced skilled patient researchers.
    - From an SCN executive: "*They aren't speaking for themselves—they can speak from a much larger body that is different than we, as providers or researchers have. We just have our own narrow window.*"

- **Competence and empowerment:**
    - From a PaCER intern: *"I can see myself actually being able to apply the appropriate research techniques which would have been absolutely outside my expertise five months ago."*
    - From a senior planner: "*When you sit down with people who are your peers, in peer research, you identify with them. Who is out there really doing this kind of research and understanding them . . . letting decision makers learn how to hear the experience of people?*"

- **Conduit to underrepresented voices:** It is not just access to other voices, but that the voices are interpreted by them.
    - From a patient: *"Patients are absent from data analysis. If we provide that aspect to it, we will enrich the decision-making process."*

- **Co-creating knowledge**: PaCER peer-to-peer approaches are effective in allowing people to discover, share, and co-create new knowledge.
    - From a patient researcher: *"Throughout the process, my own beliefs and experiences have changed as I have shared other people's stories . . . common experiences and individual variations combine."*

Impact on Professional Research Leaders and Partners

- **Patient researchers as equal partners**: While they were cautiously optimistic, they spoke of partnership: *"For me, this was a kind of a foreign concept, because I am a health services researcher and we hadn't engaged patients in this way before, and it led me to believe that this is a completely new science."*
- **Impact on team functioning**: *"It's just so helpful to have a patient right there in the middle, saying 'this is what patients feel,' and this is a much larger voice at the table. . . . It gets us on track much faster, building a better system. It stops some of the arguing among the different disciplines about which is the direction we should go. The information is different from the academic or administrator or healthcare provider, and I find it often is a much more balanced perspective that some of the rest of us have."*
- **A balancing of power:** *"I would find it difficult now not to have them in the room. It would be for me a real missing piece, and for other people who haven't experienced that, they don't know what they're missing—they don't know what they don't have."*

The Last Word from a Director of the SCN

- *"If you wait for the system to be ready, if you do preliminary training and preparation beforehand, it will never happen. There is something about engagement that means you **engage**. And this is certainly one of the things we've learned, I have certainly learned a huge amount. Thank God we started this kind of work before our research project was over, because we wouldn't have understood what engagement with organizations means. We have to keep finding new ways to engage."*

The description of the impact of a patient researcher role as a partner and leader set the stage for future training of patients. The PaCER program of studies is now an official professional certificate recognized by the University of Calgary and delivered online through Continuing Education.

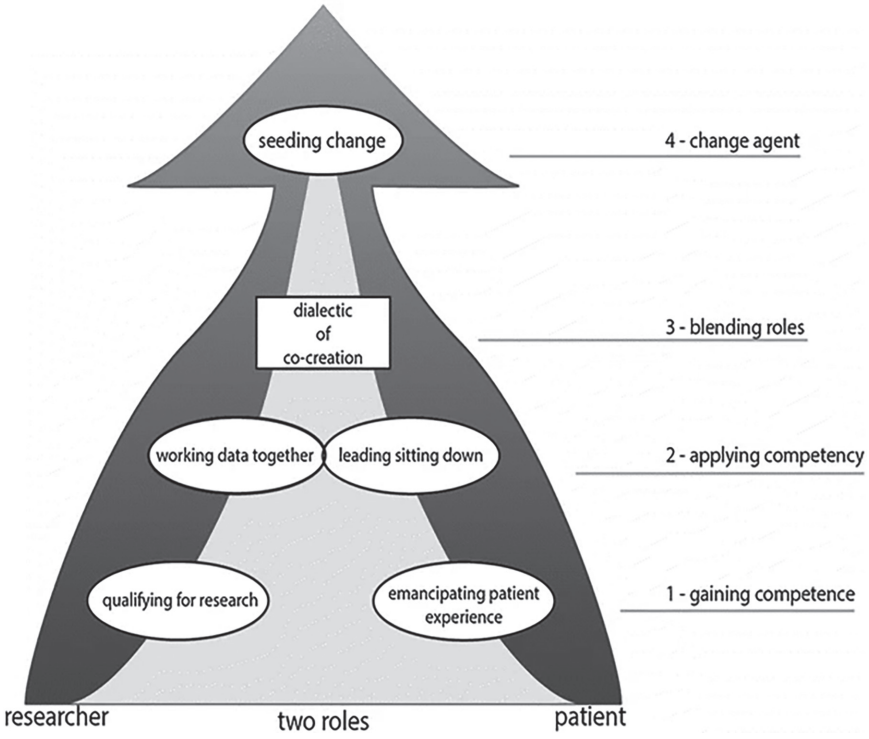
A Dialectic Merging of Patient and Researcher Roles

This section refers to Marlett et al.'s (2015, https://doi.org/10.1007/s11136-014-0845-y) New Roles for Patients model of patient engagement research and is included with the permission of the ISOQOL journal (https://www.isoqol.org). This study was funded by Healthcare Excellence Canada (https://www.healthcareexcellence.ca/), a new organization in 2021, amalgamated from the Canadian Foundation for Healthcare Improvement and the Canadian Patient Safety Institute.

Patients who completed the first two PaCER internships were extremely diverse, in terms of education level (from high school to PhD), cultural background (immigrant experience, homelessness, seniors), employment (employed full- or part-time, receiving disability benefits, or retired), age (from 30 to 75), and gender (17 women and four men).

Figure 5.2 is a theoretical model of the dialectic of co-creation and the emergence of a patient researcher role (Marlett et al., 2015). This next section has been summarized from the article with the permission of the journal.

Figure 5.2 *Theoretical Model of the Dialectic of Co-creation in the Emergence of a Patient Engagement Researcher Role*



Note: Source: Marlett et al. (2015, https://doi.org/10.1007/s11136-014-0845-y), reproduced with permission.

The main categories represented in this diagram describe how patient and researcher roles remain distinct in the first two levels, gaining competence and applying competencies. These roles then merge during the third level, and this leads to a new fourth role as change agent in healthcare transformation.

Gaining Competence

The first level describes the early training phase of gaining competence. As a peer, you are learning who you are as a patient, uncovering biases and triggers, and finding ways to contain these, while understanding how to use your experience to engage others. As a researcher, you are learning the craft of engagement research. In the first two levels, the roles remain distinct.

Applying Competencies

At the second level, the roles remain distinct, as you apply the skills you are learning in the practicum course, which provides opportunity to consult with a wide range of consultants, patients, clinicians, community resources, web chat rooms, resources, and community leaders. You learn about the politics of engaging, as you shift your role to accommodate the person or resource you are meeting. As a patient, you learn to research sitting down, a metaphor for learning how to engage as a peer. Emancipating a patient role is perhaps the hardest, because, no matter what your background or experience, everyone lives with habitual reactions driven by expectation, values, and roles. Emancipation requires not only self-reflection, but it also involves being in situations where you are confronted with your patient self, time and again, to get to know it and contain it.

If you've been an advisor, your story has been your experience, and you have learned to capitalize on this story to help researchers and health providers see healthcare through a patient lens. If you are coming from an aging studies, disability studies, or mad studies lens, you are coming with an emancipatory and critical theoretical framework that surrounds your patient experience. If this is new territory for you, you likely have not had the opportunity to use your patient experience as a source of strength and knowledge, and it may be a challenge to get to know your patient self not as misfortune but as an asset.

If you are coming from a caregiver or parent perspective, the role of supporter creates a set of helping values that are difficult to let go. In three of the internship projects, family members who wanted to become peer researchers consistently tried to help, inform, or guide those with patient experiences. Trained family members and carers could, however, produce a specialty team, in the same way that mental health or cancer families are trained to support other families.

The hardest to manage are situations where students have patient experience that they do not want to discuss or reveal. Peer research is almost impossible when personal experience is off limits. Regardless of the reason, you need to face your default patient self with gentleness and honesty, so that you can use it without being pulled off course. There will always be risks in this work, but you can learn to stop, park, and reset in order to use your experience to listen and engage openly.

Patients are not unique in seeing the world through their experience and training; anyone working in research needs to understand how professional or official roles impact research. Through training, you learn what to watch for and how to use your past experience as a deliberate and conscious tool, instead of being held hostage to your beliefs. This means giving up claims of objectivity,

replacing them with transparency and reflexivity, and working to understand and make clear your actions, values, and experiences.

Before we close this category of self awareness, all researchers are prone to narrowed focus because of their training. Each discipline works to inculcate students with theories that explain reality and methods that focus attention on what is considered important and part of the discipline. Disciplinary research training is like any apprenticeship that prepares trainees for specific roles that define the scope and power of the discipline.

Patients who defined themselves by their diagnostic categories and symptoms became interns learning to master patient experience research and, in the process, came to see their day-to-day experiences as valuable. In mastering engagement methods, they learned to use personal experience to help others share their experience.

Researching Sitting Down

The next step in achieving new roles as patient researchers is to 'learn to research while sitting down.' This allows you to become an equal partner in co-research. In peer research, you don't rely on status; you listen and self-disclose as a companion. The need to lead is manifest in small ways, sitting at the head of the table, standing in a focus group, holding a clipboard—all these small clues are noticed by participants.

This peer research role is an unfamiliar role for participants, and they will continue to act as a 'research subject' unless you let them know, in advance, that this is peer-to-peer research. They need to be prepared to expect that they are a peer with important experience and expertise that could make a difference. The term 'co-researcher' is often used instead of 'participant' to level the research balance and promote working together as equals.

Gaining Research Competence

All students see themselves at a disadvantage. Those without research training feel that they will never learn to become a researcher. Those with research training face an even larger obstacle—unlearning what they have learned about how to conduct research. The biggest obstacle for all students is the eagerness to understand the co-researchers' condition and their illness trajectory. Not only is that inappropriate in peer-to-peer research, but it reinforces the vulnerability and dependence of patients and the medical definition of patient experience. Patients are consultants, peers, or co-researchers, and as soon as you set the stage as a health professional, you lose your peer status.

While being open and curious identifies your stance in engagement, co-design allows you to practice a neutral stance as a student, learning and being able

to demonstrate research skills with your sponsor or field supervisor, patients, clinicians, community leaders, and family members. Consultation implies that you are looking for experience and expertise to inform your research.

Analyzing Data Together

This last competence in becoming a peer researcher is called 'analyzing data together.' When you are actually conducting research with a group of peers who are fully engaged in analyzing data, the new role of patient researcher finally makes sense. Peer researchers and your participant co-researchers become one group, trying to make sense of the data. You discover the thrill of sharing stories and finding collective meaning together. Until this happens, the concept of being a patient and researcher exists consecutively, not in tandem.

You begin to realize the challenge of being insiders and outsiders. As peers you are insiders, you share common experiences; but you are now also outsiders as you plan, guide the process, and figure out what is being learned. You have the advantage of having a basic mental map of the topic, and this enables you to anticipate and respond more comfortably with participants. This is often the level of the patient partner.

Blending Roles: The Dialectic as Roles Merge

During the internship where students become interns, student identity as patients with authority and researchers with credibility was established. The core category of the dialectic of co-creation emerged.

The acts of engagement captured their aspirations in their declaration of professional conduct in this new profession. This combined role became entrenched through the ethics process and in conducting their research. The final report was presented and shared with the SCNs. They began to see themselves through the eyes of other researchers and health professionals, and slowly came to define themselves as peer researchers skilled in patient engagement. The value of belonging to a professional, powerful group that accepted them as a new research team member enabled them to take up their new identity as a peer researcher to others. Chapter 2, which was developed during the time of this study, helped define a peer researcher who used their patient status as a tool to build safe, engaged, and productive research environments.

Agents of Change

By seeing ideas and opportunities for engagement in their roles as research-informed patient advisors in the SCNs, graduates are part of the process of seeding change. Trained peer researchers have become competent in speaking

in a collective patient voice that informs decisions and invites health professionals and researchers to design and implement research that includes patient perspectives.

The above theoretical model provides a glimpse into the process of merging two distinct roles of peer and researcher and, in the process, unleashes a force for change. There were two findings that challenged traditional research wisdom. The first was the evolution and emancipation of patient experience, which challenged the labels we use to define our patient lives. Reliance on medical categorization may actually be holding back deeper understanding of health and healthcare experience. The second was the essential activity of analyzing together. Analysis has long been the 'glass ceiling' in participatory and qualitative research. As evident in the Domecq et al. (2014, https://doi.org/10.1186/1472-6963-14-89) study, data analysis, interpretation, and knowledge translation have been absent in most patient engagement projects.

We knew from the *Grey Matters* research that even if seniors advised on the research question, contributed data, and reviewed findings, they felt that the research still belonged to the researchers if the data chain was broken during analysis. As a result, analysis in patient-engaged research is structured to foster shared analysis and decision-making, to promote shared ownership of results and a high level of commitment.

Overcoming Barriers

Patient-engaged research is hampered by beliefs that patients are too emotionally involved; they will lose their patient status and become professional; or that it will cost too much for uncertain outcomes. We demonstrated that with a concrete curriculum and practical training, patients are capable of contributing to discussions, collaborating to find solutions, and impacting the healthcare system. Staniszewska et al. (2012, https://doi.org/10.2165/11597150-000000000-00000) provide concrete evidence of these facts.

This theoretical model of the new role for patient research may inform other potential patient roles. Patients have been hired or volunteer to advocate or guide other patients through treatment processes, and they are paid to scale as researchers and assistants. Graduates of the PaCER program work as patient coordinators, clinic assistants, research assistants, and a range of contract positions.

Patient Leadership Roles in Promoting Engagement

The following roles were identified by the PaCER management team, based on their experience as lead researchers. Students and interns should have the opportunity to act in four key roles or tasks. This process of defining leadership is an important part of building effective teams, and this is but one method used to help teams learn to appreciate the competencies of the members while supporting team members in practising and gaining confidence in roles they have not experienced.

These roles will cover the four aspects of activities: mentoring, supporting, managing, and reporting. These roles represent leadership in research contracts. PaCER research teams, upon graduation, are expected to become leaders either in patient engagement generally or in research, so it is important that all interns can try these roles during their training. Students generally begin by choosing a familiar role in the practicum course and then take up roles that they aspire to in the internship. For example, a student may come with natural managing skills but would like to learn to be able to write reports.

This section also outlines the types of leadership required as part of independent, patient-led research.

1. **Mentoring**: This intern works with the instructor to ensure the team gains competencies related to the concepts, theories, and methods of the PaCER curriculum. This role relates directly to the engagement skill of telling or teaching team members during training and participant co-researchers when conducting research.
    - Goal: Making sure that the team and participants are competent and understand what is expected.

2. **Supporting/connecting:** This intern connects and arranges group meetings and contacts with field supervisors and their sponsor. This role relates directly to social connections that are needed in both training and research.
    - Goal: Ensuring everyone has the social structures and communication strategies for open and transparent communication.

3. **Managing**: This intern manages the group process of completing the assignment, working with the group to assign tasks, ensure people understand what is expected and the time requirements.
    - Goal: Team and participants have the structures and support to achieve expectations, while being flexible and adaptable.

4. **Reporting**: This intern involves the team in discussing, writing, and submitting assignments in conjunction with the team manager. It requires taking a leadership role of representing the work of the group in a manner that demonstrates the work done and the results achieved.
    - Goal: Assignments are submitted as reflecting shared understanding of the concepts while meeting assignment expectations.

Each student is expected to assess their own strengths and challenges within each of the roles, with the support of the instructor. It is not expected that each student must take each role, and students may pair up to take on leadership roles, if numbers permit.

Teams create a compact that outlines their roles and responsibilities and how to handle situations based on the above. It may be useful to discuss personal learning and working styles when creating the compact.

Summary

This chapter includes many ways to understand the scope of engagement in health research. The goal of the chapter was to summarize research about engagement that was part of the co-design of the early stages PaCER. This was important because PaCER marked the first time that trained engagement researchers were hired to conduct peer research, in collaboration with research teams and health transformation networks.

Questions for Discussion

1. What are your motivations for being involved in the research you are currently involved in? How has this informed your understanding of volunteers and peer researchers?
2. What peer researcher roles (advisor, contract or peer researcher) would you hope to see in your future? Where are current patient roles located?
3. Looking at your team, are the reactions of researchers in the twin innovation close to your experience?
4. Where are you or those you work with located in the research of blending patient and researcher roles?
5. What are the patient leadership roles identified in your study?
6. Is there room in your project for patient-led research?

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6

Salutogenesis as Patient Expertise in Health and Healthcare: Patients Reclaim Their Health in Healthcare

Highlights

- Health promotion theory at personal, program, and societal levels
- Patient experience informed by salutogenesis
- How the decision to face stressors refocuses personal, program, and social resources
- Sense of coherence as a theory of patient expertise in healthcare
- How salutogenesis informs emancipatory and democratic health research

Salutogenesis is not commonly understood in Canada and the United States but has been a major force for change in health and management in many other countries, as noted in *The Handbook of Salutogenesis*, a major collaboration of current theory, research and practice (Mittelmark et al., 2017b, https://www.ncbi.nlm.nih.gov/books/NBK435831/). The theory was first published by Antonovsky (1979), and came to my attention while writing *Grey Matters*, and focused on the feasibility of teaching seniors and patients to conduct qualitative narrative research with their peers. Following the publication of *Grey Matters*, we offered a graduate seminar course in seniors' resilience that included seniors who had been co-authors in *Grey Matters* and graduate students. Dr. Shklarov, a Russian physician with a PhD in rehabilitation studies who worked with *Grey Matters* and PaCER, introduced us to salutogenesis. It affirmed that patient agency in everyday interactions with inevitable health-related stressors build resistance resources. Learning to understand, manage, and build resources that promote well-being and confidence, extend the scope and opportunities to study what can be learned from personal and care provision. As such, salutogenesis is the companion to pathogenesis, the search for the causes and cures related to illness and the deficits that lead to studying the vulnerabilities and

fallibility caused by illness and loss. We realized that salutogenes is not only informed patient engagement but professional practice. Both approaches are needed, and peer research uses action-based narrative methods to explain concerns in order to find pragmatic solutions in systems dominated by pathogenic approaches.

During the early stages of PaCER we found that salutogenesis can be used to guide research co-design to prioritize a main concern that relates to stressors at personal, program, and policy levels. Peer research methodologies explain these concerns or stressors to find the best resources and solutions to counteract or solve the main concern. This is the purpose of action-based research, supported by salutogenesis that encourages peers to share and analyse stories to make a difference. In short, peer research fosters the expertise of searching for health and well-being in the midst of attending to illness and medicalized care that directly aligns with the following description of salutogenesis:

> Patients choose to face stressors by calling on program or generalized resources to build wellness capacity and, in the process, develop a sense of coherence, resilience and confidence. In health, patients develop "a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable. In addition, there is a high probability that things will work out as well as can reasonably be expected" (Antonovsky, 1979, p. 10).

This chapter is not a retelling of Antonovsky's theory of salutogenesis but a response to his challenge to use salutogenesis to explore how it informs new ways of seeing healthcare and research to bridge between current medical health theory and theory that celebrates the expertise of patients. Salutogenesis has supported the purpose of peer research—uncovering and analyzing stories that can inform healthcare solutions hard to solve problems as part of the stages of illness, treatment options, healthcare professionals, transitions, and discharge. What we have learned is that extended experience within health systems can build patient expertise to face the stressors patients and families encounter, strengthening existing resources and building new ones to handle care, relationships, programs, transitions, and policies.

A patient reviewer of the manuscript noted the salutogenic approach of Headstrong, a youth leadership initiative of the Mental Health Commission of Canada (n.d., https://openingminds.org/training/headstrong/). It champions mental wellness through online school programs that challenge stereotypical thinking about mental health and inspire a positive focus on youth leadership. They use school-based teaching using real-life recovery stories, discussions,

and action planning initiatives that highlight self-care, resilience and positive mental health skills within a community based, peer-led support model.

Antonovsky, the architect of the theory, saw in the strength and health of survivors of the Holocaust a theory of health that changed illness, trauma, and loss from the enemy of health to being a natural and ubiquitous part of living. It is this personal life strategy that becomes an emancipatory bulwark of healing and empowerment against the challenges we all face.

Salutogenic theory is an elegant description of the complex but essential search for health and well-being. The central feature revolves around a way of thinking that focuses on a sense of coherence and a developmental model challenging stressors and building resources as young children through to preparing to die (Fries, 2020, https://doi.org/10.1057/s41285-019-00103-2). The key is the assertion that people have choices. They can adopt an illness-based approach that locates stressors as a threat or they can see health-related stressors as an opportunity to build self-knowledge and resilience. The most used feature of salutogenesis is the measure of a sense of coherence that is grounded in three distinct characteristics: comprehension, or our understanding and access to information and trusted guides; manageability, or how we manage and explore coping strategies; and meaning, or how we are motivated to face life with purpose, finding meaning along the way.

Background and Theory

Aaron Antonovsky was an Israeli-American medical sociologist who became intrigued by the resilience of Holocaust survivors who were thriving in their old age, despite their horrible experiences as children. He thus became a champion of including wellness as part of a continuum of health. As such, it offers a health-based theory for everyone, not just those who have been labeled sick or deficient.

The salutogenic approach is reflected in recent public health frameworks, beginning with the Ottawa Charter (Public Health Agency of Canada, 2017, https://www.canada.ca/en/public-health/services/health-promotion/population-health/ottawa-charter-health-promotion-international-conference-on-health-promotion.html) which states, "Health promotion is the process of enabling people to increase control over, and to improve, their health" (p. 1). The Charter views people as active agents rather than just 'victims' of disease. It shifts agency from professional interventions to the capacity of populations. People marginalized by systemic discrimination are recognized as holding assets and knowledge that can be harnessed to create health promoting environments. More recent articles reinforce the links between salutogenesis and health promotion (García-Moya & Morgan, 2016, https://doi.org/10.1093/heapro/daw008). Health promotion asserts that deep, personal ways of being,

thinking, and acting lead to a feeling of inner trust that taps into our ways of knowing about healing. This is connected not only to personal health but Indigenous and planetary health movements that can show the way to be present and connected to healing not only people but the planet.

Salutogenesis is a dynamic theory, calling upon personal and program resources called 'generalized resistance resources' (GRR) that are aligned with the social determinants of health, such as education and employment, which help people resist or combat stressors. This has been expanded here to also include program-specific resistance resources such as safe refuge, writing about experience, and programs built around a salutogenic construct. Individual or specific resistance resources such as a pet or a talent for observing are also possible.

The second general process is the development of a sense of coherence that evolves as people build resilience through challenging stress experiences. This helped understand resilience from a seniors' perspective.

The stress seniors had faced during the World Wars and the Great Depression did not diminish them—it made them stronger and more resilient. For example, the loss of male family members increased the opportunities of children, women, and seniors to take up important roles in the family and the economy. The result was the importance of struggling to build resilience. Seniors worried that today's youth were disadvantaged because they did not have opportunities to face adversity and overcome their fear and anticipation of stress.

Salutogenesis was first introduced in the later stages of *Grey Matters* (Marlett & Emes, 2010) and our early studies in PaCER. By sharing concerns, seniors took control by working to explain these concerns to 'make a difference.' Some examples included figuring out the need for a personal pathway through chronic illness, building capacity of families to discuss end of life options rather than leaving decisions to the head of household in South Asian communities, looking for stories of overcoming cancer to counteract the omnipresent wasting and death presence of cancer in Indigenous communities.

Salutogenesis aligns with action research using grounded theory methods that focus on explaining main concerns in order to uncover positive changes in patient roles, relationships, and social organizations. Patient experience research does not stop with discrete experiences of direct care. Salutogenic-based methods open research to shared patient expertise in the search for wellness during and following care.

While peer research often starts with concerns about social problems and systemic barriers, the goal is to explain what is happening to reframe or resolve the concern from a patient perspective. Looking for and prioritizing stressors

as social problems marked the co-design or SET stage. During data collection and analysis, grounded theory analysis explored how stressors worked and how resources resisted the force of stressors. As categories were identified during interpretation, salutogenesis helped most projects ensure that the interpretations were comprehensive and patient-centric.

The anticipated changes as part of the fourth industrial revolution point to salutogenesis to increase patient expertise about preventing ill health, promoting positive health, and managing ongoing health. This shouts of the need for salutogenic action research done by patients and community members in co-design, academic research (citizen science), and in all forms of social innovation and social enterprise (Ashoka). This needs to occur at three distinct salutogenic levels: the study of personal (micro) levels of change; meso levels of programs and treatments; and macro levels of policy and society.

Salutogenesis is present throughout this emancipatory science of engagement and all sections of the book, because it focuses on the empowerment potential that is often missed. It underlies the shift from traditional patient experience categories of fear, vulnerability, loss, and dependence to patient expertise of being in control of information and resources, coping and adapting to challenges, and finding meaning and social connections. This alternative voice often surprised sponsors or those encountering peer research for the first time. This is the long view of health, a narrative-informed patient view to complement a professional view of a suffering patient experience within healthcare.

In Section 2 of the book, we look to salutogenesis theory to guide co-design, conducting research and making sense of experience. In Section 3, we shift to the expertise of patients and communities to make a difference. This is because making a difference is not only about how technology and innovation can reduce the burden of illness; it is also about increasing opportunities for patients to be part of innovations in care. The fourth industrial revolution in health aims to move healthcare upstream, where the patient will be responsible for detecting problems earlier, deciding on technologies to maintain health, reducing risk of future illness and monitoring health status. Salutogenesis is a theory to inform how to build these new healthcare practices.

The Basics of Salutogenesis in the Asset-Based Study of Health Experience

The area of patient experience is complex, tied to theoretical and epistemological debates about who owns and curates patient experience, the methods and measures used, and how patient experience informs research and practice. A good example of this is Rowland and Kuper (2017, https://doi.org/10.1007/s10459-017-9777-y), who noted that patient experience was constructed

through the prevailing ideological systems of a particular moment in time and politics. From their article we see a clear example of patient experience from the perspective of nursing within hospital settings. It provides insight of vulnerability, embodied experience of being overwhelmed, and physical fallibility (the way the body asserts itself). In this view:

- Patients are objectified, rendered voiceless.
- Times when patients are most vulnerable help us to understand what is important to them so that we can respond appropriately and imagine how to improve care.
- Embodied experience of physical dominance, fallibility, and vulnerability focuses on the experience of the body within the role of patient.

The following definitions of patient experience have been slightly adapted from the Beryl Institute for Patient Experience (n.d., https://theberylinstitute.org) to demonstrate the current view of patient experience as it relates to informing healthcare more generally:

- Patient experience encompasses the range of interactions that patients have with the healthcare system, including their care from health plans and from doctors, nurses, and staff in hospitals, physician practices, and other healthcare facilities. As an integral component of healthcare quality, patient experience includes several aspects of healthcare delivery that patients value highly when they seek and receive care, such as getting timely appointments, easy access to information, and good communication with healthcare providers.

These common definitions are information that is considered essential for effective, efficient, and sustainable healthcare. These examples lead to methods and measures called patient-oriented research (POR). Standardized, patient experience measures create quantified patient experience, outcomes, and satisfaction data for 'big data' research that compares treatments, systems, and populations.[1] POR focuses on target behaviors identified by healthcare professionals

1 For those not familiar with these POR approaches, the Agency for Clinical Innovation (https://aci.health.nsw.gov.au/statewide-programs/prms/about) provides a very quick overview of PowerPoints from the New South Wales Agency for Clinical Innovation. Those interested in the development of our Canadian Strategies for Patient-Oriented Research should look into Ball et al. (2019, https://www.rand.org/pubs/research_reports/RR2678.html).

and health systems analysts that provide guidance to improve health outcomes and more efficient and effective care. As such, they are important measures in health research.

This manuscript, however, is devoted to a patient perspective—how they see their health and healthcare and the problems they consider worth investigating. In President Obama's call to support precision medicine's potential, the mission was to enable all Americans to make the best health decisions, and this would mean that they were able to securely access and analyze their own health data. This was indicative of the expanding need to include patient-generated and patient-owned data.

Recent developments within CIHR and Patient-Centered Outcomes Research Institute (PCORI) (https://www.pcori.org) recognize that it is not enough to measure patient experience, satisfaction, outcomes, needs, and preferences. CIHR, in the Strategies for Patient-Oriented Research section of their website (https://cihr-irsc.gc.ca/e/48413.html), and PCORI are now including the need to recognize the expertise of patients and to engage them throughout health research and healthcare. CIHR set three principles for POR:

- Patients are seen as experts.
- All research is solely directed by patient needs.
- Patients are equal collaborators within the healthcare team.

Table 6.1 summarizes the main differences of pathogenesis and salutogenesis that inform a patient perspective in health research. Pathogenesis, the search for the causes of ill health that includes all biomedical, medical, and health system health research. The features of salutogenesis are in keeping with emancipatory social science, citizen health, changemaking, and participatory action research, including community-based participatory research and patient and community engagement research.

Note that the differences present options not conflict. Even though they represent opposite ends of a continuum of health, both options are needed. Our findings support that a salutogenesis approach applies throughout all aspects of healthcare, particularly in those areas most impacted by stress and lifestyle conditions that include a large portion of healthcare costs.

Table 6.1 *Comparing Pathogenic and Salutogenic Approaches to Health Research*

Pathogenesis	**Salutogenesis**
Biomedical ill health	**Physical and mental wellness**
Evidence based research (about patients)	Context-based, system-focused paradigms for patients
Avoiding a problem	Realizing potential
Reactive	Proactive
Assumes we are inherently healthy	Assumes we are inherently flawed
Idealistic	Realistic
Condition-specific quantitative research	Citizen- and community-centred qualitative research
Health professionals are the experts	Patients, families, and community are the experts

We can now look at the elements of salutogenesis as they relate to academic peer research and peer research. Table 6.2 includes not only the elements of salutogenesis but the roles of citizens.

Table 6.2 *The Role of Salutogenesis in Qualitative Peer Research and Social Innovation*

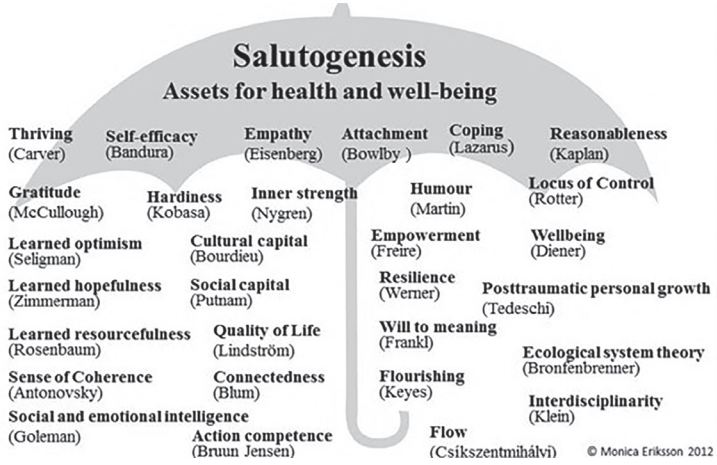
Elements of Salutogenesis	**Academic Peer Research**	**Peer Research**
• Stress is ubiquitous and natural, and therefore provides opportunities to face stress	• Stress is to be avoided or reduced by treatment and pharmaceuticals	• Citizens often hold beliefs that stressors are resolved by experts • Peer research provides examples of how patients and communities have capacity to manage stressors
• Resistance resources exist at all levels	• Research targets the most appropriate level to answer research questions • Includes practice, policy, and program information about resources	• Gaps in generalized resistance resources bring communities together to act • Gaps in program resistance resources are studied in program evaluation

Table 6.2 (*continued*)

Elements of Salutogenesis	Academic Peer Research	Peer Research
• Opportunities to challenge stressors are essential to survival, growth, and confidence	• Stress is considered a personal characteristic • Reducing stress is the role of professionals, programs, and policy	• Resources to confront stressors are most effective when personal or offered within or by the community (social enterprise)
• Sense of coherence is a global measure of confidence and resilience	• Sense of coherence is a measure of confidence and resilience to test the impact of practices and programs	• Sense of coherence scales are used to measure capacity development at personal, project, and social levels
• Overall focus	• Patient expertise in interpretation	• Social impact of change

Salutogenesis has become the umbrella for asset-based psychology. Find the positive health or asset-based theories that you have used and find those that relate to your future goals. Most closely aligned theories are resilience, empowerment, coping, self-efficacy, and the theories related to optimism, hope, and resourcefulness.

Figure 6.1 *Salutogenic Models of Positive Health*



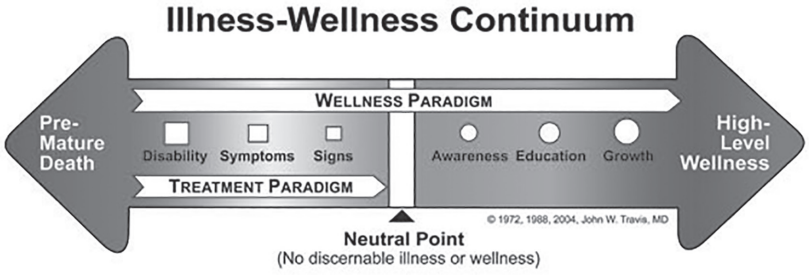
Note: Source: Eriksson, 2012

Salutogenesis is one of the most comprehensive asset-based theories, and it informs many other theories and constructs that have been used in explaining the experiences related to health and healthcare. Can you locate the constructs that you have used to guide your practice or research? Where is it located in relation to salutogenesis?

The Nature of Health Experience

Figure 6.2 introduces a related wellness continuum that grounds patient experience that leads to valuing engagement and expertise. It has been called a continuum of health that depicts a state of disequilibrium caused by health-related stressors in the form of pathogens, illness, loss, and trauma. The end is called 'dis-ease' in salutogenesis and represented here as the outcome—premature death. The other end of 'ease' or a sense of confidence and optimism relates to a high level of wellness that is not determined by the lack of stressors. Figure 6.2 represents a full spectrum of patient experience that will be our reference point throughout the rest of this chapter.

Figure 6.2 *Salutogenesis in Everyday Use That Aligns with the Salutogenesis/Pathogenesis Continuum*



Note: Illness-Wellness Continuum as conceived by J. W. Travis (2004). Reproduced here with permission. (Source: The Wellspring, 2018, http://www.thewellspring.com/wellspring/introduction-to-wellness/357/key-concept-1-the-illnesswellness-continuum.cfm.html)

The pathogenic or biomedical approach is represented by the left treatment side. This treatment paradigm includes stages related to way stations of signs, symptoms, and then disability, ending at premature death, which has dominated health research. The final result of medicine is noted by the treatment paradigm that aims at reduced symptoms and recovery. This more familiar or dominant discourse of health calls upon professional expertise to counteract the vulnerability of patients in the face of threats or stressors, which are considered threats to health.

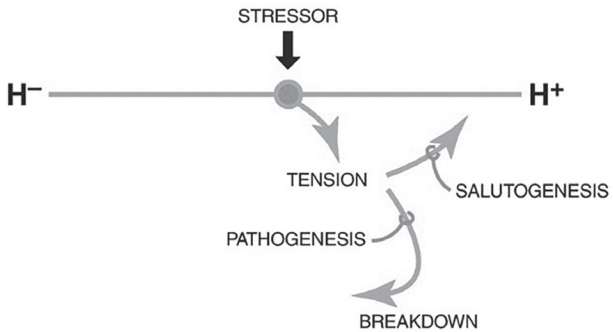
The right side of the diagram could be considered the salutogenesis, psychosocial, and environmental approach that focuses more on wellness and healthy living. This side provides the health promotion side of salutogenesis with way stations supporting health promotion and citizen health movements of awareness, education, and growth. The wellness paradigm here stretches throughout the entire length of the continuum, ending in high-level wellness as the end result of living until a healthy death.

There are several additional features of this diagram. The first being that while it is a continuum from dis-ease (premature death) to ease (high-level wellness), it also captures the dichotomous history of medicine. This dichotomy was based on the long-held belief that medicine becomes activated when healthy people are attacked by stressors. They are in danger of being damaged either acutely, repeatedly, or fatally if they do not receive medical attention. This implies people who are not ill are healthy and that health is not the responsibility of medicine until there is a diagnosis. It is an either/or situation. People easily adopt this dichotomy. When they are diagnosed, they relate to that diagnosis. No matter how steady their recovery or how skilled they are, their identity holds on to that label.

We can now focus on how salutogenesis denies that this dichotomy exists and instead posits that life itself is always in a state of flux, with health-related stressors a natural part of living. Stressors are not only present, they are also essential if we are to learn how to figure out how to cope and create a personal identity of resilience.

We can see this dynamic in an original diagram (Figure 6.3) that is often used as the act of salutogenesis.

Figure 6.3 *The Options of Salutogenesis and Pathogenesis That Arise from a Stressor*

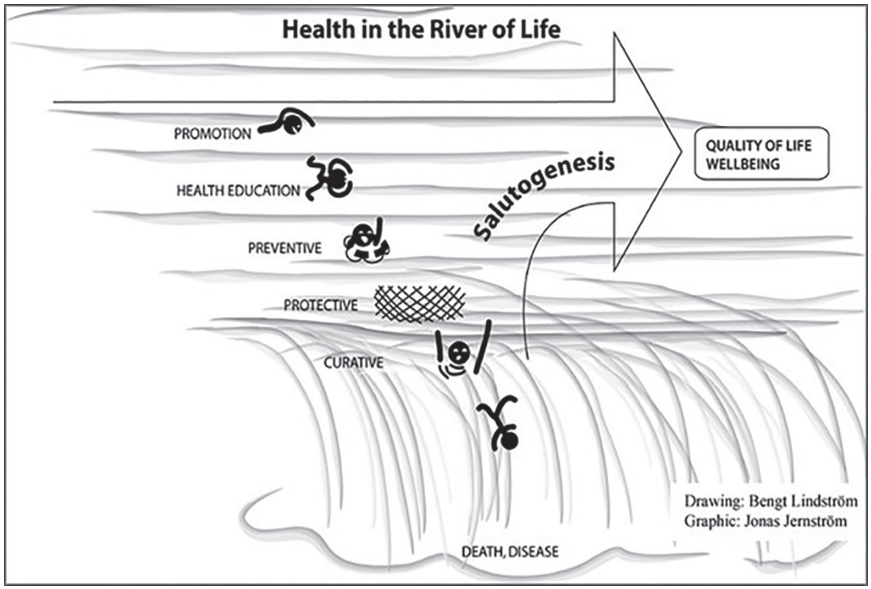


Note: Graphic by Bengt Lindström, Monica Eriksson, Peter Wikström (Lindström & Eriksson, 2010). Published with permission from Folkhälsan Research Center, Helsinki.

While this has been called a health continuum, it depicts the state of disequilibrium caused by health-related stressors in the form pathogens, illness, loss, and trauma. One end is represented as a simple H+ or 'ease' that results from a salutogenic gaze, reflecting a sense of confidence and optimism. This relates to a high level of wellness that is not determined by the lack of stressors. The other end, H- relates to the concept of 'dis-ease' as part of pathogenesis that leads to further breakdown. This diagram represents patient agency in choosing their role in their health and healthcare. In our PaCER research, however, there was a blurring of direction—at times patients focused on the dis-ease culture of healthcare while looking for an overall movement to salutogenesis. They saw this diagram as encompassing the deepening sense of coherence that results through working to build comprehension, manageability, and meaning. They saw the stressor as leading to tension, which can be understood from two perspectives: pathogenesis that leads to a breakdown unless health professionals intervene from the negative side of the diagram to overcome the negative outcome of the stressors; or salutogenesis that leads to a positive experience of growth through learning about stressors and using resistance resources to find ways to manage the impact and become more motivated to continue to see stressors as opportunities to increase personal and program resources.

Figure 6.4 depicts interventions when viewed as stages of illness using the metaphor of a river that eventually reaches a waterfall of premature death. The river in the diagram begins with health promotion, which averts the stressor and continues as the impact of the stressor increases until medical symptoms present the waterfall as a crisis with dire outcomes. Current healthcare tends to wait until symptoms of a health condition are recognizable and patients tend to wait, hoping that the pain is temporary.

Figure 6.4 *Stages of Health and Health Experience; Upstream Focus of Salutogenesis*



Note: "Health in the River of Life." Drawing by Bengt Lindström, graphic by Jonas Jernström.

This is a picture of expected stages of health that reflects the 1970s when the early signs of illness could be picked up during the 'annual checkup' as part of family medicine. Unfortunately, annual checkups were cut from primary care in a move to reduce costs in Canada and the United States. Countries who adopted salutogenic practices have had more success in maintaining a preventive and upstream medicine approach because they are more likely to see prevention as an accepted part of healthcare. This enables doctors to identify illness early and to treat illness proactively as part of health promotion. This is best done with an informed public who expects to be proactive in their personal health care.

A good example of salutogenenic practice would be cardiovascular medicine. As upstream or prevention and promotion approaches are taking hold in heart health initiatives, cardiovascular medicine itself is adopting a more holistic view that it is more effective in preventing heart disease instead of heroically treating advanced heart problems. In some countries, prevention is incentivised in primary care, and screening for heart health is becoming a regular practice.

It is also interesting to revisit the waterfall analogy from the perspective of the fourth industrial revolution that is the topic of Section 3, Possibilities. Here, the equation shifts dramatically from evident symptoms as the call to action. The advances in technology-based sensors, particularly when combined with artificial intelligence and machine learning, will dramatically change the nature of promotion and prevention.

I would like to use an example of a colleague who uses wearable technology to study gait in runners. The patterns detected in the strides and rhythms of runners can be used not only to improve performance but also to detect very early signs of potential strain and stress. These early signs can be used to notify the runner of early signs of stress that can be corrected and, thus, eliminate serious problems before they arise.

With increased wearables and implanted sensors, early signs of stressors can be caught and steps taken to remedy the emerging problem well before the need for curative medicine is reached. This is especially true with lifestyle-related chronic conditions, such as diabetes, where early detection can trigger early kidney and related organ support and supplementation.

While salutogenesis is more familiar in health promotion theory, it is important to note that the search for health extends throughout the illness side of the continuum. This became very apparent in the early PaCER studies. Patient expertise was not just about their illness, loss, and trauma. Instead, it was about what they had learned in their search for wellness in the face of problems and decline. This period in the development of PaCER had the feeling of new territory waiting to be discovered.

To understand patient experience, we now look at salutogenesis and two key psychological processes that impact how health events are experienced and processed. The first is the interaction of resistance resources and stressors as part of developing a sense of coherence through active engagement to resolve the impact of stressors by using existing resources or creating new program resources. The second is the use of a salutogenetic approach as a personal worldview that has utility in measuring change in resilience and confidence. For purposes of this emancipatory science, we focus on the study of stressors and resistance resources as targets of research. We do this to deepen our understanding of patient experience and, more importantly, on how patients develop expertise that has not been recognized or used in health research done by and with patients.

Ubiquitous Stressors and Dynamic Resistance Resources

Stressors

Stressors, or the situations that cause stress to the body and mind, are a natural part of life that unbalances or disrupts our sense of health and may herald disease. Antonovsky saw these ubiquitous incidents as instigators of resilience and confidence. Medicine, on the other hand, considers stressors as pathogens to be avoided and controlled. When we pathologize stress, we increase the negative impact and increase the damage. That is to say that the degree of 'dis-ease' increases when the person becomes trapped in the anxiety of the stress.

The following scenarios about emotional intelligence provide perhaps unintended examples of how seeing stress as negative increases anxiety and, therefore, is to be avoided or eliminated. I have also contrasted a salutogenic approach to the same situations.

Situation 1

"If you're unable to manage your emotions, you are probably not managing your stress either. This can lead to serious health problems. Uncontrolled stress raises blood pressure, suppresses the immune system, increases the risk of heart attacks and strokes, contributes to infertility, and speeds up the aging process. The first step to improving emotional intelligence is to learn how to manage stress." (Segal et al., 2024, https://www.helpguide.org/articles/mental-health/emotional-intelligence-eq.htm)

Notice how 'stress' introduces added levels of problems.

Salutogenesis alternative:

Identify the stressors that you are facing and figure out how it works. Is that stress something within you, a stress about your relationships, your work or other activities, your healthcare, or about a restriction imposed upon you by rules or policy? Then name that stress and think about what resources or help you can call upon to 'resist' that stress. Share your ideas with others who have also had to face this stress or with those you trust. Share your analysis with your health care professionals and look for ways to use this experience to learn new ways of handling stress.

Situation 2

"Uncontrolled emotions and stress can also impact your mental health, making you vulnerable to anxiety and depression. If you are unable

to understand, get comfortable with, or manage your emotions, you'll also struggle to form strong relationships. This in turn can leave you feeling lonely and isolated and further exacerbate any mental health problems." (Segal et al., 2024)

Salutogenesis alternative:
As you identify the stressors that make you anxious and you work out how to deal with each new stressor, you become stronger. You will develop new ways of coping with stress and, in the process, come to feel less alone and more able to help yourself and others.

How Stressors Work

From a salutogenic perspective, we modify and reframe our stressors as we encounter new situations and develop new resources that have the power to help us resist the impact of these stressors. In research, we make stressors visible by studying overt stress through observations, studying documents, and collecting data according to current stressful situations using patient stories to find common solutions. Table 6.3 is an example of a formal classification of stressors that relate to salutogenic theory.

Table 6.3 *Common Categories of Stressors*

Stressor	Examples
Situation-specific stressor	Lack of a computer, lack of transportation to get to appointments, no boots for winter
Individual physical and psychological stressors	Toxins, pathogens, genetic abnormalities as well as personal characteristics and medical conditions
Psychosocial stressors	Loss, grief, fear, accidents, horrors of history, unfilled goals, fear of aggression
Organizational stressors	Unbalanced power structures, restrictive roles, unequal relationships, unrealistic expectations, lack of goals or exit criteria
Societal-level stressor	Discriminatory health and social policies, institutionalization and incarceration, economic collapse, climate change, civil unrest
Lack of social determinants of health	Housing, safe environment, employment, education

Mapping Stressors

Stressors are difficult to observe directly, but they can be identified by observing the program or policy resources that are created to address the impact of stressors. By asking a mapping question such as "what personal, social, program, or policy stressors are being targeted by the program activities or policies?" it is possible to use the general stressor categories listed above to analyse how that stressor was challenged. Like most salutogenic tools, the researcher is encouraged to be specific about how stressors work to create opportunities for learning about stressors and gaining new skills that are specific to the culture, program, or population. The following example that was used in a course on salutogenesis demonstrates the nature of stressors, by moving from left to right.

Table 6.4 *A Mapping Sentence Tracking the Relationships Between Resources and Stressors*

The specific stressor (insert here) is an example of a . . .	**General stressor category** (select)		**A person**		**An established resistance resource**	And thus: diminishes combats controls avoids adapts accepts reframes to resolve the impact of the stressor
	physical		in a healthy relationship		a physical resource	
	psychological		in a family		an educational resource	
	psychosocial	that impacts a	in a friendship	that activates	primary care resources	
	program		with a condition		professional intervention	
	systemic		as part of a population		community support and inclusion	
	policy		as part of a community		peer support	
	social determinant of health		as a unique individual		advocacy	

As an example, when analyzing the stories observed as part of the research to understand the salutogenic nature of the programs at Calgary Wellspring,

we noted that there were no overt observations of stressors. In discussing this among the peer research team and the staff, we wondered if the program was instead focused on overcoming the impact of stressors.

We asked the question: "If this story is about a resource, what are the stressors it is resisting?" We worked through the above tool to capture the personal, program, and generalized resources that were observed and then analyzed these stressors using the above mapping sentence. These categories were further confirmed by a focus group of Wellspring members. We then used the identified stressors when creating the final theory of what works and how in a cancer wellness centre, as evident in the table below. This is an example of how salutogenesis works to provide data about both stressors and resistance resources.

The following sequence provides the Wellspring example of the use of a mapping sentence to understand stressors addressed in the programs and activities observed during peer research at Wellspring Calgary:

> PaCER interns were collecting stories about the mandate of their research to identify and categorize how Wellspring provided salutogenic resources to manage and motivate resistance resources to address the ubiquitous stressors of cancer. They used an early form of the mapping sentence above to identify the nature of the stressor and the steps taken to reduce the impact of the stressor. This basic analysis can ground the analysis of who is impacted by the stressor and then what type of resistance resource speaks to options for resolving the stressor.

Students in particular benefit from mapping sentences because it provides a way to analyze the nature of specific stressors, what groups or individuals are impacted, and the resistance resources that produce outcomes that are salutogenic. Table 6.5 was created by their work.

The three main categories below—fear, loss and emotions—captured the stressors identified in the narrative analysis of stories. The analysis of the stories and these stressors were used to inform the action-oriented theory of what worked and how at Wellspring. Mapping stressors to identity provides a standardized analytic tool when working with salutogenesis.

Table 6.5 *Stressors Identified in the Mapping Sentence Process*

Stressors Are Recognized & Identified		
FEAR (of)	LOSS (of)	EMOTIONS
Death	Energy	Shock of diagnosis
Being taken over by cancer	Independence	Uncertainty
Stigma, being different	No place to be yourself	Depression, sadness
Pain	Self	Guilt about getting cancer
Taking risks	Expectation of what you expected death to be	Guilt about impacting others
Thinking ahead	Connectedness, friends, work	Constant vigilance and anxiety
	Comfort in roles	
	Ability to contribute	

Stressors can also be categorized into three broad categories when working with communities or teams where there is general consensus of stressors that are common and the ability of resources to meet the challenges of common stressors:

- Chronic stressors (e.g., a disability)
- Main life events (e.g., death of a family member)
- Daily hassles (e.g., an argument at work)

The mapping sentence helps to manage the essential link between stressors and resources in academic qualitative research, action research, citizen science, community-based participatory research, and social enterprise.

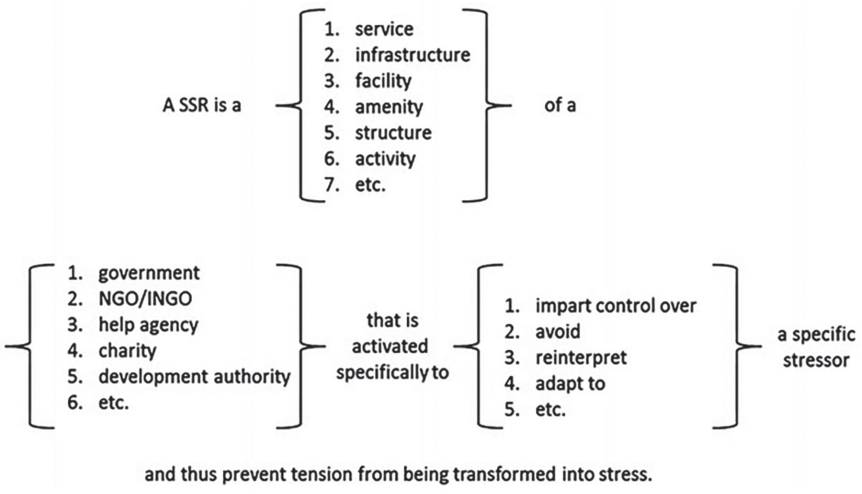
When learning to use stressors in health research, it is important that we, as researchers, consider our own experience with stressors. We need to consider what we had been taught or how we were reinforced or punished for talking about stress. Stress in biomedical medicine tends to be a characteristic of the patient, but in real life, stress operates at all levels, as seen in the mapping sentence. This is important because it will sensitize us to the stressors that emerge from systemic discrimination and chronic untreated health-related problems. When preparing a mapping sentence with the population you are working with, be sure to notice how we deal with common stressors that manifest according to our disciplines and professional experience. Also important to salutogenic research are the hidden contexts that define cultural or program-based experience of stressors. We tend to pathologize individual stressors while considering program or treatment stressors as a natural part of doing business.

When training peer researchers, the study of stressors can be initiated using categories that begin at the individual level and progress to policy levels, depending on the ecology of the programs or policies related to the topic being studied. You can brainstorm the resources at each level and define stressors from individual to system and societal levels. This can then be used to identify potential or actual resources that are available at each level. This is an excellent exercise to build solidarity and an understanding of how stressors and resources are rich sources of data at all levels and how they relate to each other.

Mapping Resistance Resources

We now shift from the concept of mapping sentences to understand the impact of stressors to how to understand how resistance resources manage stressors at all socioeconomic levels. The mapping sentence in Figure 6.5 is a general format that can be adapted at individual, program and system levels. It is the theoretical version of the mapping sentence above. The program specific resource in the diagram below, that can be used to capture how resources impact specific stressors. This is particularly useful with peer research within social organizations that create new roles, relationships and resources to increase a sense of coherence.

Figure 6.5 *Mapping Sentence for Program-Specific Resources*



Note: Source: Mittelmark et al. (2017a, https://www.ncbi.nlm.nih.gov/books/NBK435842/)

The example above shows the type of mapping sentences used during the Wellspring study as described in the PaCER final report.

> When we returned to our data, we were able to uncover stressors by analyzing the program specific resources that were in place to counteract stressors that might arise. We shared the stressors we had discovered with members to confirm that indeed these were stressors. The following is one example. The sentence read: "The book of remembrance is a material characteristic of Wellspring as a peer community cancer wellness centre that is intended to neutralize the fear of dying by honoring members' lives."

The mapping sentence, as above, provided a way to use what we observed (the program resources being used by patients) to uncover the stressors involved that were difficult to see or hear. The following is an example of program resistance resources (PRR) in the study of Wellspring. This demonstrates how the analysis process of mapping sentences makes properties and themes visible. In Wellspring, these PRR fell into two general categories, 'a place to go' and 'give it a go.'

> **'A place to go'** identifies the program-specific resources that work at Wellspring:
>
> - **Sanctuary**: The building is the antithesis of a hospital or clinic, yet not a home or place of work.
> - **Sharing energy**: Many different opportunities to experiment with and practise physical, emotional, and spiritual energy programs and therapies. An essential antidote to the crushing loss of energy from cancer treatments.
> - **Humour and joy**: Provide a respite from the vigilance, fears, and stress and a chance to learn how to be happy again.
> - **Mortality and the silent presence of death**: Provides a chance to adapt and lessen the tension about dying. The natural presence of death becomes a resource for life.
>
> **'Give it a go'** describes how the resources are manifested through the actions of members:
>
> - **Accepting**: Accepting myself by being in a safe space and learning from others like me. This is where I can take my hat off.

- **Encouraging**: Reducing self blame through learning to encourage others and myself to try new things and make small steps to change.
- **Contribution**: We support each other and share tasks, and there comes a time to become a volunteer at Wellspring.
- **Self worth:** We achieve self worth; building new lives takes time and effort.

The beauty of the mapping sentence process is that it can be created at the individual, program, and generalized levels. Individual resistance resources are specific to individuals, a part of their arsenal of resisting the impact of stressors, such as fear of pets, opioid addiction, overeating, and accessing treatment. Program-specific resources are those developed by programs to serve the needs of a situational set of stressors, such as integrating children with health needs into regular classrooms and cancer wellness programs or clubhouse models for adults with mental health concerns. Generalized resources, on the other hand, are just that—they include social determinants of health such as access to after care, improving employment options, and basic health literacy in immigrant populations.

Using Stressors and Resources in Research and Practice

The materials presented above are based on the first level of understanding salutogenesis—the study of stressors and resistance resources, and the interactions between them. These processes were used during the interpretation sessions to increase our ability to understand and make sense of how Wellspring, as a peer-led support centre, worked. We were then able to work with members and the board to explore this unseen aspect of the program. In research, we can focus on reducing stress and deficits through building resources or we can study our practice to build patient and community capacity.

Building a salutogenic orientation in healthcare is very difficult, because most patients in primary and even continuing care seldom become part of health-based programming within the healthcare system. This means that they seldom can meet with others who share their experience or to think about their experience as knowledge that could be important to themselves and other patients. Emancipatory research can only be effective when patients and communities have the opportunity to share their stories of both the stressors involved in their healthcare and the resistance resources they experience, or could experience if the stressors were identified, studied with others, and subjected to research such as mapping sentences to analyze and overcome the impact of stressors at personal, program, and system levels.

If you have the option of introducing peer research and can study patient experience from their perspective, you build a window into experience that can be shared with staff and patients. This can be used to build patient and community capacity to foster collective action, which may include identifying the sources of power and systems that keep groups dependent and compliant. Peer research findings can be made available to patients and families who might otherwise be isolated.

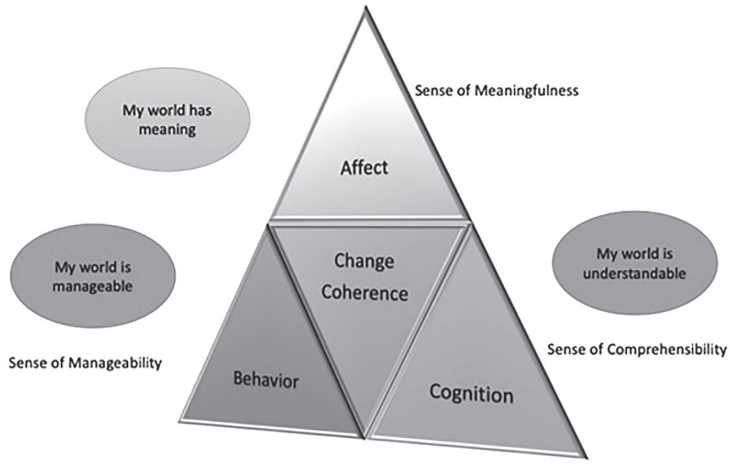
Building a Sense of Coherence

Now that we have some understanding of stressors and resources, we can move to the basic action of salutogenesis—building a sense of coherence (SoC). We begin with the idea that exposure to stressors is part of being alive. We can either choose to face a stressor or succumb to it and give it over to others who are professional to handle it. That is not to say that this provides an either/or decision. Both ends of the continuum need to be engaged. Salutogenesis creates a positive alternative to creating research related to patient experience. A stressor creates tension and disequilibrium that presents both options—confront the stress (salutogenesis) or consider the stressor as an illness for experts to figure out and resolve. In this section, we look at how salutogenesis moves the person toward health and wellness. We face each new stressor as a motivating tension that we can respond to. The response might move research toward salutogenesis or pathogenesis. In peer research we have noticed that this is not an either/or decision, but an organic and dynamic dance of healthcare that includes both clinical pathways and capacity-building pathways.

Sense of Coherence (SoC)

Figure 6.6 presents SoC as a conceptual combination of factors for change, confidence, and resilience. This diagram will guide the next section through the three elements of the triangle.

Figure 6.6 *The Basics of Salutogenesis as an Asset-Based Study of Health Experience*

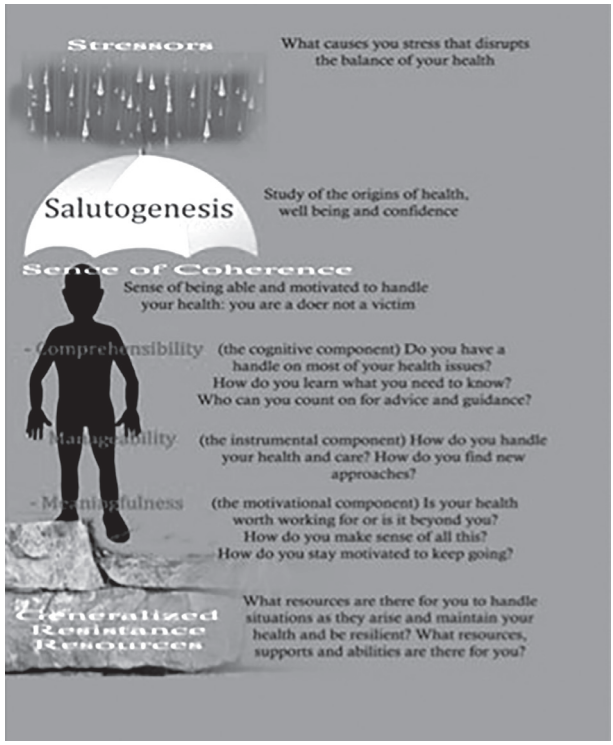


Note: accessed Nov 2021, internet diagrams of Sense of Coherence, no longer available

A definition of sense of coherence takes some time to digest. To begin, SoC is a general, pervasive, enduring, and dynamic feeling of confidence. This takes some time to unpack. First, SoC does not act externally so that you can see and measure it; it acts internally and influences action and readies our thinking toward positive action. This begins with our sense that action is possible because we have confidence, based on meeting and successfully challenging or reframing stressors in the past. It produces a feeling of safety, confidence, and resilience that life makes sense and it is possible to be healthy, in spite of health problems. This worldview suggests what can be known or done in the world, and, more importantly, how it can be known and done (Erikkson, 2016, https://www.ncbi.nlm.nih.gov/books/NBK435812/).

A strong SoC makes it possible to be flexible and creative in meeting challenges, whereas a weak SoC leaves people with emotional responses (avoidance, depression) and rigid coping strategies that most likely will defer to reliance on healthcare providers. If a person believes there is no reason to persist, survive, and confront challenges, then that person will not be motivated to move forward. Figure 6.7 is my amateur diagram, developed to depict salutogenesis as a person in action. A strong SoC suggests that individuals possess resources (such as social support and ego identity) that enable the person to cope with various kinds of stressful life events.

Figure 6.7 *Concept of Salutogenesis and How It Works*



This diagram begins with stressors that are as common as rain falling upon a hapless human. Fortunately, that person is standing on a resource platform that could help the person stay steady and resist the force of the raining stressors. The SoC is depicted as the umbrella that acts to help the person to stay dry enough to move forward to take the next steps. The three elements of SoC are internalized within the person.

A Conversation in Peer Research About the Three Properties of SoC

The following three properties of SoC enable us to take action:

1. When one's internal and external environments are structured, predictable, and can be understood. This is called **comprehensibility**.
2. When resources are available to cope with challenges. This is called **manageability**.

3. When demands and challenges are worthy of investment and engagement, and, in the process, gain meaning and purpose. This is called **meaningfulness.**
(adapted from Antonovsky, 1979)

These three properties can be measured in a simple SoC scale. While the three properties overlap in the analysis of the assessment tool, the three categories remain intact in practice. Eriksson and Lindström (2005, https://doi.org/10.1136/jech.2003.018085) provide a study of the validity of Antonovsky's SoC scale.

The following questions have been created for use in conversations as part of per research. These conversations are based on the situations that encourage the characteristics of comprehensibility, manageability, and meaning and are useful when exploring SoC within a narrative framework.

Comprehensibility: The Cognitive Skills That Help You Figure Things Out

Comprehensibility is the belief that things happen in an orderly and predictable fashion. This develops a sense that you can understand events in your life and reasonably predict what will happen in the future. This is the cognitive component of SoC. You have a better chance to be healthy when you:

- feel life is basically predictable—feel 'together';
- feel ready for what might happen in unfamiliar situations;
- understand how your body works;
- appreciate your environments; and
- understand your relationships.

You might have the following conversations about comprehensibility:

- *Can you understand most things, or do things in your life blindside you?*
- *Do you have a handle on your situation?*
- *How do you learn what you need to know to go forward?*
- *Do you know people you can count on to give you advice?*

Comprehension is the most widely understood aspect in healthcare. The following are some of the ways that comprehension is included in healthcare.

Patient education: SoC encourages a shift in focus from health literacy to patient agency, as part of patient education. Healthcare educators teach patients the information that healthcare professionals need them to know (the treatment and expected outcomes) to reduce patient anxiety. However, a study of patient education done by a PaCER team as a research contract, identified that patients generally want to know who they can contact when they are unsure of what the process is going to be like, how it will change their life and the resources they will need rather than the information that nurses and social workers might suggest (Choudhury et al., 2020, https://doi.org/10.1177/0017896920911690).

Information age medicine: While patients are provided approved information by healthcare professionals, this is only one perspective of the information available. One can also learn from peers who have been through the process and experts from around the world. It is possible to be misled and to spend money on products that promise impact without any evidence. In the near future, information age medicine will have to provide more detailed information that is relevant to patients about what the results mean for lifestyle and prognosis. It will create artificial intelligence of treatment options developed using thousands of cases.

Artificial intelligence (AI): As machine learning continues to improve, information on choices will provide expected outcomes and when to contact professionals. AI will mean that, if patients choose, they can use AI to treat themselves without the support and advice of their health professionals. To capitalize on this aspect of SoC, we need to provide stories to help patients and families understand how to use this new information and connect effectively with the doctor. The gap between what is known and what is safe and reasonable will need to be addressed directly in the near future, and it needs to be done with patient input.

Manageability: The Instrumental Component of Using Your Resources to Cope

This is the belief that you have the skills or ability, support, help, or resources necessary to take care of your personal health. It also means that your personal health is manageable and within your control. You have a better chance to be healthy when you:

- know that there are resources to help you;
- believe you have a right to seek them;
- understand and access resources; and
- believe you are capable of putting together a plan to understand and 'manage' things.

Conversations you might have:

- *Who do you call on to give you advice (family, faith, professionals, friends)?*
- *When have you had to try a new way to manage things?*
- *How do you know that you will be able to handle things that come up?*

We see examples of manageability in evidence-based medicine protocols. These condition-specific care plans are standardized as tools to ensure compliance. Healthcare fits patients into protocols and expects patients to follow these protocols. However, patients who have been coping and managing chronic and complex conditions are the ideal life experts in customizing and adapting care plans from a patient perspective.

Some of the advances in current healthcare related to increasing patient capacity to manage their healthcare include the following:

> **Buddy systems**: These pair new patients with experienced patients who are familiar with protocols and can support patients and families learn how to safely adapt or modify them. In similar ways, peer mentors in training research methods help those learning research skills to practice and apply skills and interpretation.
>
> **Wearables**: These track and interpret health data for patients during daily activities and health routines. These have become commonplace aids tracking steps, sleep, health indicators, and diabetes data. These will continue as medical technologies

specific to conditions greatly increase patient roles in coping with their health concerns. The current personal use, or use by insurance companies and patient data collectors, have pushed health upstream with incentives. Citizens are using data to become more engaged in their health and monitoring healthcare.

Adaptive technologies and implants: These are changing not only how we live but how we see ourselves. When adaptations are customized for user control, biomedical technologies from robots, exoskeletons, pacemaker implants, and a wide range of adaptive technologies increase independence and productive life years. The changes focus on coping but also connect us to resources automatically such as physicians, technicians, and emergency interventions.

Meaningfulness: Motivation and Purpose to Engage in Your Health and Healthcare

This belief is related to the feeling that health is important and worth the effort. This promotes the motivation to engage with your health and healthcare. You have a better chance to be healthy when you:

- are you prepared to make the effort to understand your health and health care;
- are motivated to take care of yourself and others;
- have a purpose in life; and
- are part of community or group that you contribute to.

Conversations you might have:

- *What makes your life worth living?*
- *Is it worth putting the effort into handling the problems that arise?*
- *How do you make sense of 'all this'?*
- *How do you stay motivated?*

Meaningfulness is a low priority in healthcare, although purpose and contribution are major factors in extended life years (whether people live or die after health diagnosis and treatment). An informal study by Statistics Canada included the SoC questionnaire in their study of a representative sample of Canadians, and it demonstrated that this short measure was a top-tier indicator of extended life years. Meaning and motivation denote a 'grey zone' of

health research that is addressed after 'accepted methods' fail or as part of the domain of traditional or cultural health practices.

While medical science informs discrete causes of illness, this reliance on discovering causes to find a cure or remediation has a number of significant drawbacks. We lose our belief that we can understand what makes us well or ill. If there is no identifiable cause, there is no treatment, and the person lies outside the perimeter of medicine. People expect science-based medicine to identify their problems and experts are responsible for making us well. Finally, people who have not made sense of their conditions have little appreciation or commitment to citizen roles in personal health, health of our communities, or global or planetary health.

We see this in the popularity of complementary and traditional medicine, which seems to reflect our personal values and philosophical foundations. Alternative and traditional medicine practices represent the need for a foundation of meaning about health. From the time of Hippocrates, there have been practical theories that explain health and the reason for illness. The boundary between modern scientific medicine and alternative and traditional medicine is increasingly blurred, as citizens search for ways to understand health and illness. It may be difficult to bridge the gap between efficient care to meaningful care.

The concept of meaning during an increasing reliance on digital technology must be addressed. If technologies are seen as an extension of the health systems through prescribing technologies that are standardized, we will see the perception of external control increase. Consequently, the goal of a patient-centric or controlled health will not be reached. Emancipatory goals can only be reached when patients are informed, data savvy, knowledgeable, and motivated, and this can only happen when they believe that they are seen as worthy of control and capable of using technology.

To understand future issues related to sense of coherence, you might look up Hochwälder (2019, https://doi.org/10.1177/2158244019846687).

Using Salutogenesis in Health Research and Practice

While salutogenesis is gaining traction in health promotion and prevention, as well as in program development and architecture, it is also a way to introduce asset-based approaches within medicine, and throughout all systems of health and well-being. To accomplish this, health research could include emancipatory peer research to include a salutogenic perspective as part of research teams. As systems are reconfigured, it is suggested that health systems might add salutogenesis to future planning resources. It is particularly important that healthcare practices should not undermine a person's SoC. Treatment should

instead attempt to support patient resilience by acknowledging patient research that identifies stressors as main concerns of populations to be understood in order to find personal and condition specific resources to assist patients, families, and communities to confront and learn from health-related interventions.

From a research perspective, we have seen how salutogenesis broadens the scope of research dramatically. It increases the scope of co-design studies by exploring stressors and resources and ensuring that the three aspects of SoC are explored. During research, these same concepts help categorize data and add to theory development. The many aspects of salutogenesis provide models for theory building in health.

Technology is becoming a new form of generalized resistance resource that will have great impact on how patients are able to cope with the stress of systems change and the reconfiguration of patient roles.

Summary

This chapter addresses the difference between individual measures of patient experience that reflect specific healthcare processes and patient expertise that informs social change and organizational concerns. The need to study patient experience and expertise from a positive or salutogenic perspective does not diminish the importance of a pathogenic model. Salutogenesis, however, is the most comprehensive and adaptable theory of citizen science and change-making. It has proven its capacity to guide and challenge peer research, while providing a theory base for patients and communities. This simplified version has been adapted to serve both academic and design thinking research and is relatively easy for patients to understand. The challenge may be selling this concept to researchers who see a salutogenic focus on asset-based research as outside of their remit to improve health care.

Questions for Discussion

The theory of salutogenesis provides a conceptual framework for understanding patient expertise. It involves the conscious decision of patients to challenge stressors by using existing resources and building new ones. We have identified several ways that salutogenesis can be used in peer research that suggest it is a theory not only for engagement but for action and social change.

The following questions may facilitate group discussion about using salutogenesis in peer research:

1. What theory do you use in your research or professional practice? Briefly describe so that others may share in your experience.

2. Where are you on the social ecology of health systems—the personal, program, or systems levels? Can you work with others to create an ecology of systems to define where your research or practice might fall?
3. What were the main aspects of salutogenesis that you found challenging and why?
4. Where do your clients or research participants gather on the continuum of health practices diagram?
5. How do you see using salutogenesis in your training?

Resources

Discourse Analysis: Using Salutogenesis as Part of Design Thinking

This section was created for Section 3 but is included here because it demonstrates a method for learning and using salutogenic theory to understand patient experience and inform qualitative peer methodology. This example has been contributed by Cera Cruise, a senior student in the Community Rehabilitation and Disability program. Her topic relates to citizens suffering from moral injury. Feel free to explore this data and analysis now or wait until you have completed Chapter 9 on systems theory.

This example is part of a salutogenic discourse analysis of a proposal for design thinking–informed innovation to address moral injury of frontline health workers.

The application of a salutogenic lens gave my proposed design thinking–informed innovation a measure of self-described patient progress and broke down the components of resilience, so that my innovation could be individualized to target the specific needs of patients. The aim of my innovation was to strengthen the SoC of patients using PRRs to assist patients in developing their senses of meaningfulness, comprehensibility, and manageability, in response to the stressor of a moral injury. Engaging in the salutogenic analysis gave me a more comprehensive understanding of what the stressors were, what resources were available to patients, and where gaps in treatment lay.

This excerpt of a casebook identifies online resources as part of three stages of healthcare: treatment and diagnosis; community inclusion; and peer and natural supports. In each resource, the student selected quotes that referred to stressors and generalized or program-specific resources and conducted a discourse analysis to identify the roles of patients and professionals.

Table 6.6 *Excerpt of a Casebook Identifying Online Resources as Part of Three Stages of Healthcare*

Data: Treatment and diagnosis (Nuckols, n.d., https://www.naadac.org/assets/2416/cardwell_nuckols_treatingmoral.pdf)	**Analysis**
"Many veterans were presenting with difficulties that were not sufficiently addressed in the fear and extinction-based frame that underlies exposure."	Resource: There's a recognized community of individuals facing similar stressors.
"They have seen the darkness within them and within the world, and it weighs heavily upon them."	Stressor: Resources need to be created to shine light on the darkness. The quote also shows that there is a lack of sense of meaningfulness about the incident.
"Mistake the foe for a friend, and perhaps die…Mistake a friend for a foe and die inwardly."	Stressor: All sense of coherence is gone, the individual with moral injury is regarded as the living dead.
"Spiritual healing results in worldview changes."	Resource: There is recognized potential for a sense of meaningfulness to be created out of the morally injurious situation, thus changing the worldview of the patient.
Summary: The patients being described in this system lack, from the perspective of a professional, a sense of coherence, thus explaining their ill-being. Using a salutogenic framework, professionals could prompt patients to share the meaningfulness and create a sense of manageability about the morally injurious incident in an honest fashion (i.e., not just giving the 'right' answers so that the professional can 'cure' them). From there, patients could share their resilience resources and work with the professional to build upon those resources.	

Table 6.6 (*continued*)

Data: Community inclusion Sources: Whole Health Medicine Institute, 2020, https://courses.wholehealthmedicineinstitute.com/whmi-whole-health-studies-course-202036086740 Rankin, n.d., https://lissarankin.com/doctors-are-suffering-from-moral-injury-whats-the-solution/ (Founder of WHMI)	**Analysis**
"Our courses, workshops, and training are designed to help you understand and apply a whole body medicine approach in your life and in your practice. We support practitioners in building a thriving healing practice."	Sense of manageability is created by knowing resources are available to support healthcare providers.
"The all-powerful mind can control your reality, and all you have to do is learn to harness it."	Resource: Healthcare practitioners already have the tools they need to change their reality. This program allows them to develop GRRs necessary to respond to the stressors that are created by the healthcare system.
"WHMI brings a deep and direct understanding of the body-mind-spirit continuum to physicians, nurses, health experts, and healthcare providers. We believe that this understanding is critical for complete and sustained healing and growth, and necessary to reveal the untapped resources and potential of your body."	Sense of comprehensibility is developed about the body-mind-spirit continuum so that healthcare providers have a deeper knowledge both of the causes of their moral injury and what they can do to resolve the internal anguish created by the injury.
Summary: Resources are contingent on participation in the program, which may have financial or time-related barriers (and therefore lack a sense of manageability). The main strategy of the program is to create a sense of comprehensibility for healthcare providers about what it means to heal others beyond just the physical.	

Table 6.6 (*continued*)

Data: Peer and natural support Source: Project Trauma Support, n.d., https://projecttraumasupport.com/peer-support-group/ (no longer active)	**Analysis**
"By the end of the cohort, I could talk about the deaths and still have joy in my heart. I am no longer in a nightmare. We have all gained knowledge on how to deal with our brains when all the negative tries to come in. To top it off, I have gained nine brothers who I know would be there for me whenever I need them. Nine warriors who shared all their sadness, only to have it all taken away together. By loving each other and helping each other tackle the darkness. It feels so amazing to have the old me back, ready to live, ready to dream, ready for tomorrow."	Resource of supportive individuals and control over negative thoughts/ stressors. A sense of meaningfulness and manageability has been created for the individual.
"I feel like taking care of myself is worth it. I better understand some of the barriers that were built in at a young age that are no longer useful to me."	Manageability and meaningfulness are ascribed to life by the individual. They recognize that some of their resistance resources are no longer useful.
"The groups are a fellowship of members who share their experience, strength and hope with each other."	Resource: Peers who accept each other. They contribute to a sense of meaningfulness in that new relationships and strengths are created.
Summary: Sharing their knowledge with those at risk of moral injury before injury occurs could give members of the group a sense of meaningfulness out of their experiences. It would also assist in creating resistance resources for others.	

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7

Narrative as Data Science: Turning Stories into Real-Life Data

Highlights

- The power of story in identity, community building, education, social innovation, and health-related community business
- Stories, narratives, and metanarratives
- Narrative in medicine
- Using narratives for building trust, research priorities, data collection, interpretation, and implementation
- Discourse analysis of stories in autobiography
- A narrative data science

While seeking to test the feasibility of co-research in Chapter 2, we discovered that narrative methods unleash the power of stories as reservoirs of experiences and expertise that are essential to peer research. Stories allowed us to explore existing theory and create a storied method for co-design, data collection, analysis, interpretation, and innovation. Consistent use of story identifies and explains shared concerns and explores potential solutions and actions that are meaningful to patients and communities. The challenge has been how to make narrative meaningful to health professionals and researchers who favour itemized, standardized, and aggregated evidence.

The chapter begins with Rita Charon (2001, https://doi.org/10.1001/jama.286.15.1897), a pioneer in narrative medicine, who has been instrumental in calling attention to medicine's need to find more humble, respectful ways to see health from a contextualized, patient's perspective. A narrative gaze invites healthcare into an intersubjective dance, populated by patients, healthcare providers, and families in their relationships. This opens the door to using stories to explore present and past experience along with possible futures as suggested by Duncan Campbell (2015, https://onthewards.org/bother-listening-patients/).

While coded language and siloed health publications protect power and professionalism in research, there is the growing pressure to democratize science by making room for voices of those who live with, care for, and support patients and their families. Patients are the only new partners in open innovation in science (OIS) initiatives that don't have an existing research methodology or understanding of science. It is therefore important to consider the need for narrative research methods, especially those that have been co-designed and tested with them. Narrative, in this time of new social media platforms that are familiar to patients, can and should be part of how we gather and understand data that is relevant to patients and the public.[1]

Medical sociology and psychology already have adopted narrative, and this chapter could not have been written without the inspiration of researchers who experienced health concerns and used narrative. Using dual roles to explore how direct experience enriches and informs scholarship. Dr. Art Frank, a sociologist at the University of Calgary, wrote about his experience with cancer in *The Wounded Storyteller* (2013), which encouraged academics to explore narrative. Kay Redfield Jamison, author of the autobiography *An Unquiet Mind* (1997), produces academic and popular books that brought new light to bipolar disorder through a patient lens. New research directions such as narratives of change (Wittmayer et al., 2015, http://www.transit-socialinnovation.eu/content/original/Book%20covers/Local%20PDFs/181%20TRANSIT_WorkingPaper4_Narratives%20of%20Change_Wittmayer%20et%20al_October2015_2.pdf) and narrative foresight (Finkler & Leon, 2019, https://doi.org/10.22323/2.18050202) provide democratic, participatory, and action research perspectives and structures to address the surge of potential of narrative approaches in citizen and personal science.[2] This work informs the creating of a theory of engagement in this book.

A Peer Research Approach to Narrative

People tend to lose their personal stories when confronted with serious illness. As patients, they quickly become socialized to new stories about who they are now, as 'the patient.' They view their new identity through clinical and illness

1 Take some time to visit/revisit Chapter 2, which chronicles the development of an integrated narrative methodology for co-design and co-production of health research with participant co-researchers.

2 Before beginning this chapter, you might take time to link to "Losing Our Stories" presentation in PRISM (Koczker et al., 2015, http://hdl.handle.net/1880/109949) that explores the insidious loss of personal stories and identity when people become part of the mental health system. Look at the results and discussion as an example of how compliance and becoming your diagnosis was challenged by a common story of reconnecting.

stories and language that reinforce standardized labels and practices about their new identity. These patient stories are adopted and embodied because they open the door to the clinical pathways that define expectations, roles, relationships, and life goals. People see themselves as their diagnosis and healthcare roles. This loss of personal stories not only changes the content of stories, but the characteristics of stories also change.

Patient stories lose their individuality and singularity as they become absorbed in their care pathways. Peer research reclaims the importance of patient perspective as an active participant in the decisions about what they experience or would hope to achieve. The use of stories as data reclaims a patient voice that makes these authentic health research partnerships possible by describing a patient perspective of main concerns that invites engagement in potential solutions. Stories can be full stories or fragments of stories, using research methods that incorporate personal and shared stories, metaphors, songs, pictures, films, advertisements, or common slang or sayings, in person or online.

New practices emerging from artificial intelligence and machine learning identify patterns and make decisions but require data from real-life patient perspectives. Just as physician narratives and notes made significant advancements when added to machine learning, so too will direct patient experience data increase the power and usefulness of machine learning about patient experience. The final result will be patient-informed algorithms for treatment options. This movement is enhanced through examples such as Zamplo https://www.zamplo.org that are creating platforms that combine online research, patient access to research to data platforms and treatment options while opening the gates to patient networks.

Strengths of Narrative

The following summarizes some of the reasons why stories are essential to research about patient experience.

- Stories make sense of illnesses with links to healing.
- When you listen to a story, you process the action as if you were the actor and this increases memory.
- Stories look back, process the present, and forecast options of what could be or should be.
- Stories start in chaos, and in the telling and retelling make sense out of confusion.
- Stories can make ideas that are complex seem doable.
- Stories are windows into traditions and cultures that are hard to access.
- Finally, stories are subversive; they expose official stories and, in doing so, counter dependence, vulnerability narratives.

The Role of the Researcher in Narrative Research

We begin this section with a discussion about the basic shifts in researcher roles that are necessary when the decision is made to engage patients and communities in research using narrative methods. My PhD study began in the midst of fierce debates over appropriate roles for citizens in participant or partnership research as part of civil rights movements. For example, in *Women's Words* (Gluck & Patai, 1991, https://doi.org/10.4324/9780203819371), Etter-Lewis stated that women should tell their own interpreted stories, while in the next chapter, Katherine Borlan, a folklorist, cautioned that researchers needed to maintain responsibility for research integrity by re-telling community stories through an academic lens. Mishler (1996) used the term 'critical research' to challenge researchers to enhance the opportunities for those studied to gain awareness and improve their status. Mishler, in the same text, suggested a continuum of shared interpretation strategies in narrative research:

1. The researcher analyzes and interprets narratives on their own, with no contact after data collection.
2. The researcher has the subject verify the transcripts.
3. The researcher completes the project and shows it to the subjects for verification.
4. There are opportunities for separate roles for narrators and narrative researchers.
5. The researcher and the subject enter into an ongoing dialectic about meaning and arrive at a joint product.
6. The researcher is the scribe representing stories told.

None of these accurately reflected the nature of our roles at the beginning of the original research to test the feasibility of co-production, but our research relationship grew into partnerships, which reflected point number five above. The partnership was built on a shared commitment to move beyond the moral imperative of engagement, to learn how to create a relationship at all stages that would combine rigour, experience, and meaning for both me and the co-researchers. Within these relationships, peer research is seen as an interaction controlled by role expectations. If the roles are not discussed openly, participants are left to construct their own roles as narrators, telling stories based on their assumptions about what the researcher was looking to find.

Experience with peer research reinforced the need to include a process of negotiating roles and expectations as outlined in Chapter 3. I needed to be clear about why I was committed to the research, what co-researchers could expect of me, and how we would handle challenges. This also included what

co-researchers wanted to know about why they had been chosen, disclose how they saw themselves, and their concerns and hopes in light of the risks, costs, and potential benefits. Without this foundation, there are risks for each party, left to guess about what was adequate when they were finished and what the results meant.

In Canada, we see this through the powerful participatory and action research done by trained peer researchers within the HIV/AIDS community (PAN, n.d., https://paninbc.ca). In narrative methods, roles of peer researchers and participant co-researchers are more easily balanced. The natural peer partnership between researchers and participants significantly reduces the ethical and scientific challenge of imposing theory on vulnerable populations. At the most fundamental level, enabling stories of role expectations to be shared enables peer research to use stories to share ideas and concerns.

This reflects narrative therapy where the person is encouraged to explore different endings to entrenched problematic stories. In peer research the same is true when peers share stories and, in the process, come to understand the problems and possible alternative outcomes.

How Narrative Improves Health Research and Care

Stories impact not only our ability to process information, but how to use and remember stories (Zak, 2013, https://greatergood.berkeley.edu/article/item/how_stories_change_brain). The innate or hard-wired biological power of stories works as follows. When your brain detects the beginning of a story, the auditory cortex becomes active. Then the left temporal cortex, the language cortex, becomes engaged and filters out complex and distracting language to focus on the story. By the time the frontal and parietal cortices become involved, we are literally engaged with what's happening in the story as neurons respond as if we were enacting the story in person.

As we hear stories they are translated into personal ideas and experiences in the brain. This process is called 'neural coupling,' where experience told in the story is mirrored by the same experience in the listener's brain. Speaker-listener neural coupling underlies successful communication. Emotionally charged stories release the neurotransmitter dopamine that ensures that memories remain relevant and accessible. These neurological patterns have spawned new transdisciplinary research and science used in business and marketing, social change at the organizational and political levels, education, and therapy, but it has not penetrated the shields around health research.

We see the evolution of narrative in health research beginning in 2014, when the *Lancet* called attention to qualitative research to broaden the scope of health research and to become more cultural, humanistic, and holistic. The

increasing presence of wellness theories, such as salutogenesis, honed interest in narrative research to capture personal stories of success. The World Health Organization (WHO) Health Evidence Network produced a report on the cultural contexts of health and the use of narrative research in the health sector (Greenhalgh, 2016, https://www.ncbi.nlm.nih.gov/books/NBK391070/). This report focused on how qualitative evidence from narratives has been deployed in the health sector and to what effect. Within the scope of policy and planning, the report highlighted strengths and limitations of using narrative to identify shared values and meaning related to culture in the following:

- Individual accounts of illness.
- Case study narratives of health organizations and systems.
- Cultural narratives where stories are embedded in master narratives of disadvantaged or displaced communities.
- Policy discourses that drive action.
- Shared narratives.

The report concluded, "In recent years, researchers have recognized both the ethical and the scientific challenges of imposing their own research framing (e.g., a particular theoretical lens) on the voices of the vulnerable" (Greenhalgh, 2016, para. 9). They suggest that phenomenology, co-design approaches, and community-based participatory research open opportunities to employ naturally occurring narratives and online communities, broadening the options to include narrative in health research.

There is increasing support for narrative research as an adjunct to quantitative research to support patient-oriented research and policy evaluation and innovation. Data storytelling (Nugit, n.d., https://www.nugit.co/what-is-data-storytelling/) has been called the last 10 feet of research, where it creates a coherent and compelling narrative to share data results.

Levels and Types of Stories as They Relate to Health Research

There are three commonly understood types of stories that operate at the personal, group, and societal or organizational level.

This section describes how personal stories take on the power of community narratives when they are shared. These narratives then grow into master or metanarratives or discourses that challenge dominant professional and institutional discourse. The research of my thesis revealed three significant levels: personal stories, narratives, and metanarratives or discourse. This is depicted in the following example.

> Henry Enns, a founder of Disabled People's International, connected with groups of disabled people around the globe by encouraging sharing personal stories of the challenges of living with disabilities. These painful and embarrassing stories, when shared in groups, led first to dark humour and then to the realization that the challenges were not about their personal or group inadequacies but about the common lack of institutional planning to make access to funding, buildings, and services a priority. Personal stories led to shared and compared stories that identified stories with meaning for the group. These then led to stories about power, oppression, and emancipation.

Stories: The Level of the Individual, Personal Accounts of Events

The term 'story' has ancient roots in most languages, most frequently, a form of 'historia' to describe a form or way of sharing experience: a tale, information, stained-glass windows.

> *A story is a report, description, account or a telling,*
>
> *either true or imagined,*
>
> *of an event, incident, occurrence or something that happened, is happening or could happen*
>
> *that has not been widely known or previously told.*

In most northern countries, a story includes a beginning that sets the context of the story, the plot or sequence of the events, and an ending that indicates the impact and consequence of the story. This provides a framework for collecting, transcribing, and interpreting stories. This structure presents stories as data for analysis that can be shared, compared, and combined with other stories. Mishler cautions that our "attempts to validate people's intentions or personal truth inserts our theories into personal stories. Traditional research practices often obscure relationships . . . and disrupt the individual's attempts to make sense of what is happening to them and around them" (Mishler, 1986, p. 120).

I realized that it was impossible for me to represent the life world of a co-researcher during my thesis. My interpretation of a co-researcher's personal stories coloured my understanding of what was happening. I learned that the story in vivo, in the person's own voice, provided direct insight into possible

categories, priorities, codes, and possibilities for using the same basic story to convey many meanings depending on the intention and outcomes expected.

A young man with AIDS may tell or interpret stories from the perspective of gay men as a group, a person with terminal illness, a young person living on fixed incomes with ongoing needs for support, a person stigmatized and alone, or someone living in a large city. He may share much in common with each of the groups he represents. In peer research, the peer connection creates the context (type of group above) and the co-researcher contributes within this shared view of the world. He is clear about himself as a producer of knowledge within the shared context.

Narratives: Stories of Shared Meaning in the Group or Community

The meaning of narrative comes from the Greek 'gnare' or meaning. Narratives are the way human existence is rendered meaningful to others. Stories take on value and meaning as they are shared and repeated in different contexts, with different people, for different purposes. Stories become narratives of expertise and potential futures.

A peer research focus group comes together to share common experiences and in the process the group creates narratives of their collective understandings. The process of sharing, analyzing and interpreting individual stories develops narratives in research in the same way people who share common experiences create narratives that create collective understandings of their fears and concerns, experience, and aspirations. They connect the past to the future through shared stories in the present.

Narratives are triggers of action research, they identify common concerns, explain what is happening, and explore alternative outcomes and actions to challenge dominant restrictive discourse. The following story from my time at Greenbank demonstrates this.

I was working with the founder of Greenbank to code data in a story about professionals who tried to take over Greenbank and move Gerry to 'disabled jobs' within Greenbank. I had named the story 'Carpet Bagging' because they were opportunists looking to take over. He was very offended by my assumption that he was considered weak because he was disabled and countered with the titles of 'Playing Coach' and 'Taking Back Power.' After much debate, we agreed that the meaning in the story was 'Expect Takeover Attempts by Those in Power.' The eventual title spoke of a relationship wherein innovators needed to expect takeover bids and be prepared. It was not a threat but a fact of doing business, as social innovation threatens those in power.

The above discussion created new meaning and made future analysis lively and collaborative. In the end what mattered was that the title (the code for the story) had changed to bring action and power to the overall storyline of Greenbank. It demonstrated how important it was to clarify the meaning of individual stories to make room for potential change narratives.

The seniors in the *Grey Matters* study (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/) were motivated to confront geriatric and gerontological narratives of loss, 'downhill slide,' decrepitude, and burden of care. They were looking to challenge these healthcare narratives, and in their research, they found narratives of strength through common stories of expertise and knowledge, not deficit and loss. Their stories spoke of the importance of family and community strength during war and depression that prepared them to be resilient, resourceful, and political. These narratives were slogans of emancipation and defined who they were and could be in society. They feared for young people who lacked opportunities to test their abilities and build resilience. These findings seemed to challenge geriatric and gerontology professionals when presented at conferences.

Narratives also create the impetus to change in healthcare practice. Charon's 2017 work on narrative medicine motivates physicians who are interested in making a difference to restore medicine to a more holistic and humane partnership with patients. She does this by sharing common stories of relationships, insight and foresight

To summarize, emancipatory narratives tend to capture the struggle to overcome prejudice or marginalization, and in the process, these narratives challenge the power of accepted professional or political discourse. A narrative is a story with a purpose—it conveys something new or different from the expected patient story. Collective stories suggest new roles and relationships in the way we see ourselves and relate to each other.

Master Narrative or Metanarrative: Using Emancipatory Narratives to Challenge Systemic Discrimination

The story of Terry Fox and the Run for the Cure became an example of a Canadian metanarrative. He courageously challenged cancer by running across Canada, and in the end, cancer won. His story of courage in the face of a common enemy spurred generations of Canadians to run for the cure. This discourse is seldom understood in countries where only winning counts. We all need heroes, especially those heroes that are part of us—imperfect, struggling, but with determination and focus. We want people to look up to those who are like us.

Master narratives operate at the organizational and societal level to define, share, and hold power. These master narratives become dominant discourses

when they justify political control through policy and procedures that restrict the independent action of those who fall within their authority. The power held by experts and the systems that support them became a target of early emancipatory social science that studied the language of the power holders to lay bare the means of oppression. Discourse analysis became the tool of critical theory and emancipatory science to understand metanarratives, especially in academic programs such as feminist, racist, Indigenous, and disability studies that are devoted to social change. They use action research to confront power through new ways of doing, organizing, framing, and knowing through narratives and metaphors that reinforce innovation and action.

To date, health systems have been relatively immune to these challenges because their power holds the promise of access to life-saving information and care. Early emancipatory narratives in health identify why change is needed by unpacking the systemic forces supporting dependence and marginalization. They also locate who has the power and how change can be promoted. This is the message of Chapters 9 and 10 of Section 3, which is about systemic analyses of healthcare discourse from two perspectives: systemic discrimination and collective empowerment. They create alternate realities by challenging the norms, values, and beliefs of the dominant discourse and, in the process, devise alternative futures and the social innovations for change that focus on the use of narratives as community development practice (De Fina & Georgakopoulou, 2008, https://doi.org/10.1177/1468794106093634).

These emancipatory and change narratives move the question from 'what is' to 'what if' to 'what might happen next' (Wittmayer et al., 2015, http://www.transitsocialinnovation.eu/content/original/Book%20covers/Local%20PDFs/181%20TRANSIT_WorkingPaper4_Narratives%20of%20Change_Wittmayer%20et%20al_October2015_2.pdf). Individual stories of both oppression and empowerment, when shared, become narratives, and these narratives motivate change and become master narratives that challenge oppression and incite collective actions.

Narrative Data Methods Support Social Change Using Peer Research

I was privileged to be able to teach narrative therapy to graduate students, and it informed my approach to teaching and emancipatory science. Narrative therapy revolutionized psychotherapy just as narrative medicine revolutionized clinical practice by encouraging new stories and productive scripts to build courage, curiosity, and competence.

All social innovators in the new social movements study used narratives to disrupt stigmatizing master narratives by using their experience as examples of new stories of liberation and emancipation. Henry Three Suns used Native wisdom traditions to inform Indigenous child welfare; Gerry Kinsella adapted the root metaphor of David and Goliath to challenge systemic discrimination of persons with disabilities; and Dame Cicely Saunders used Christian liberation theology to frame stories of dignity in dying. The integrated narrative co-design and research methods then informed peer research methods.

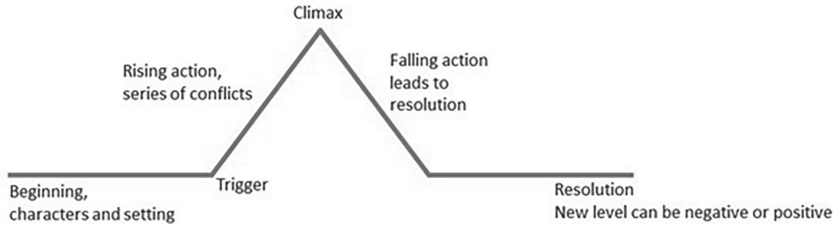
- Peer research with seniors championed narrative focus groups and interviewing methods that consolidated the importance of sharing stories in peer research. At the same time, I was teaching the use of stories in social construction to find common scripts in autobiographies that reconstructed identity after illness and disability.
- During co-design of PaCER peer research, patients shared stories to understand problems and find solutions. This was surprising to the early research teams who partnered with us, because they had believed that patients experience mainly vulnerability, loss, trauma, and deficit. They had not heard a different patient perspective of problem solving and wellness that promotes stories of experience, expertise, strength, insight, and problem-solving competence.

The Elements and Nature of Stories

In peer research, we search for methods that promote iterative data collection, analysis, and interpretation to create a more streamlined and simplified approach. Narrative data promoted both participatory practices and constant comparison. Narratives generally follow two basic patterns.

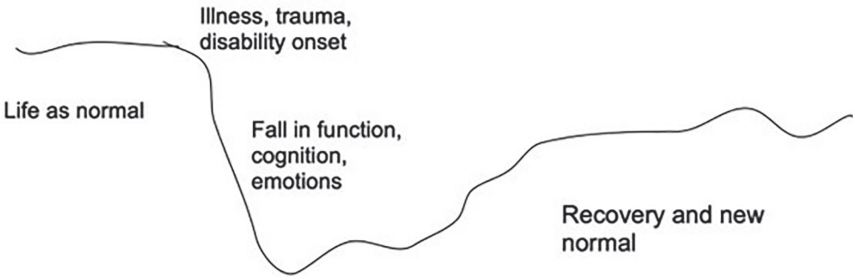
The first is the traditional wide upside-down V that begins at the bottom left with the setting of the story (the who, what, when, and where). The trigger starts the story and as the line goes up, we see the conflict or problem (the trigger that starts the story) and then the rising action. At the top of the V, the climax explains or resolves the trigger, and we have the falling action and the moral lessons learned to return to normal or a new normal at the bottom right. In healthcare the climax tends to focus on healthcare intervention.

Figure 7.1 *Typical Pattern of Stories*



In health research, we tend to see an upside-down V. A story begins with a line that depicts everyday life, then a downward slope that depicts the experience of health problems. The slope can be gradual or steep, smooth or rocky, but most frequently it levels out as the person begins an upward climb to a resolution. That can include rehabilitation, a new normal, or even finding themself in an improved situation.

Figure 7.2 *Anticipated Pattern of Health-Related Personal Health Journey*

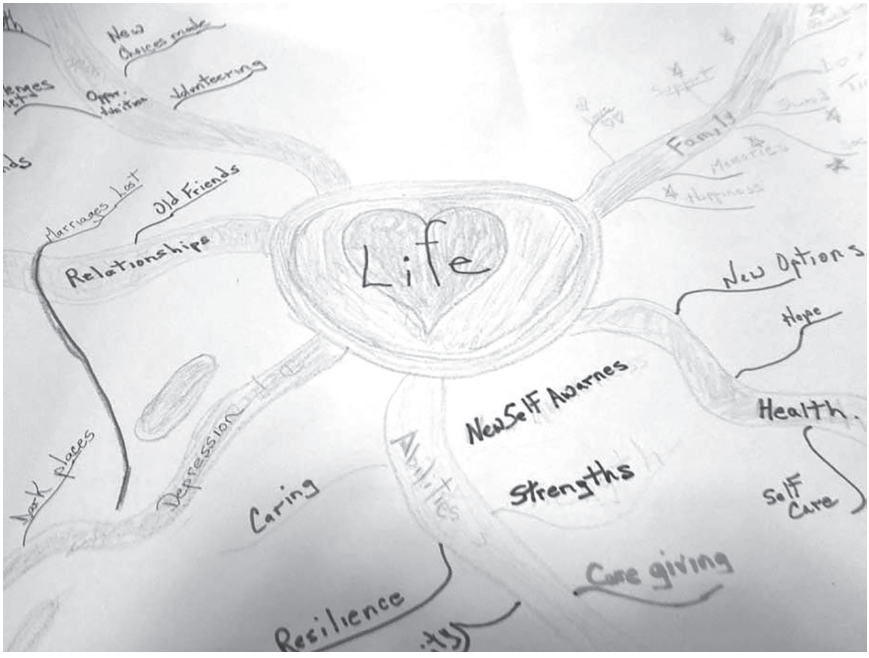


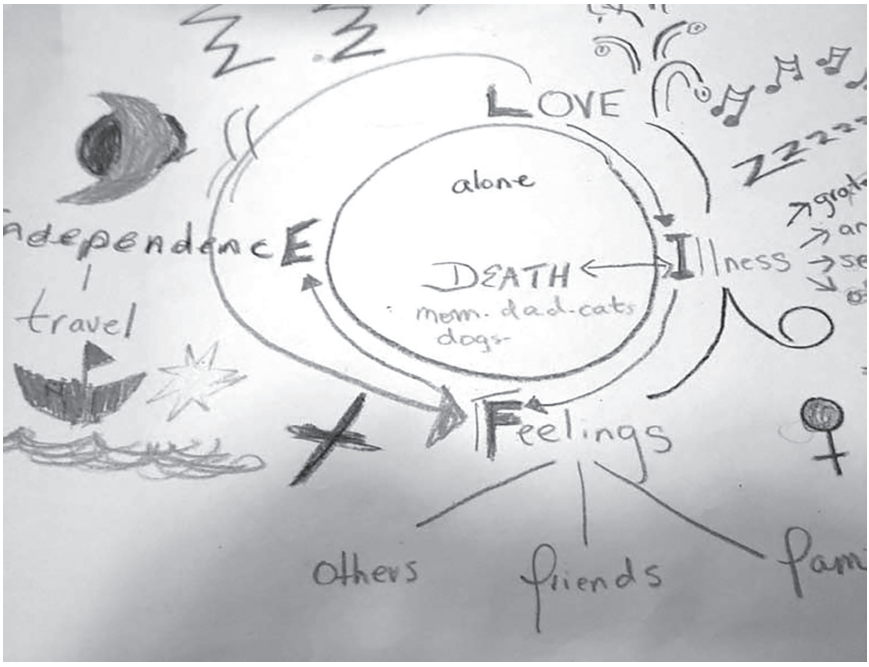
This storyline reflects the dominant story of healthcare that begins with the experience of a patient during the onset of illness, trauma, and loss. When told by healthcare professionals, it is assumed that the patient will engage professionals during this time, who will then diagnose the underlying problem, slow the fall, and provide treatment to recover. The subtext of this healthcare story is one of patient vulnerability and fallibility and the ability of professionals to respond to patient needs and guide them to the new normal.

This does not include those with conditions that arise early in childhood, where the journey has not established a base. Here the goal of the journey is an uphill climb over time, the journey from the bottom of the above figure.

Figure 7.3 is presented to offer a very different picture of a patient story, done by a group of patients living with chronic illness. The story itself was difficult to find because most of the co-researchers and peer researchers involved in the research were at different stages and had different healthcare pathways. The final storyline or theory called upon what had happened, what was happening, and what might happen in a sequence of substories. This created a very powerful storyline of the hidden pathways through chronic illness. The patient story is here presented as a poster that aligns with the clinical story and professional opportunities for engaging patients.

Figure 7.3 *Hidden Pathways Through Chronic Illness*





Hidden Pathways	Patients' voices	Related clinical activities	How health professionals can engage patients
Alien Land	*"[I feared] anger would grasp me and I could easily get stuck in my box."*	Diagnosis	Offer opportunities to ask questions and make connections
Searching for Answers	*"My long days in hospital were spent trying* to *understand this beast that was in front of us. I was convinced that if we educated ourselves about our opponent, we would outsmart him."*	Health promotion, tertiary prevention (lifestyle changes)	Education, validate patient choices

On Your Own	*"This illness is my journey, now that I am on my own. I will be my own counselor and take it into my own hands."*	Clinician's position: "This is the best I can do."	Listen without promises
Searching for Meaning	*"Too often we are overly focused on us. Helping and working with others ... gets us out, moving, thinking and contributing to a more dynamic self"*	Adapt and customize treatment to patient values	Discuss values and obstacles to meeting them
Presenting a New Self	*"I go to counselling ... for advice on how to deal with other people. Because very often it's not how I deal with my disease, it's how other people deal with my disease."*	Follow up	Share health monitoring with patients (patient generated data)
Not the Boss of Me	*"I am the expert of me. [I told my doctor], 'You do not understand! You aren't dealing with the illness!'"*	Co-led team	Work with the patient and other team members

Note: Credit: Zelinsky, S., Marlett, N., & Shklarov, S. (n.d.), Hidden pathways diagram. Source: Banerjee et al., 2013, http://hdl.handle.net/1880/109953.

This theory creates a series of hidden pathways, with each stop along the way a chapter of regaining control of a chronic condition. The dynamic feature of the patient pathways is the dynamic representation of increasingly autonomous destinations as chronic conditions, health, and relationships change. This patient research of chronic conditions creates new options to support shared decision-making between patients and health providers as indicated in Figure 7.3.

Peer research storytelling in a group captures the ability to respond to past, present, and future storied destinations. At the end of each interview or research group, participant co-researchers are invited to identify and analyze the stories that were told with the peer researchers. This ensures that stories

are complete and bring new meaning to what co-researchers have learned from telling the stories. It is also possible to apply the properties (the who, what, where, and when) to inform the nature of their journey: the places, the type of professional providing care, a contact with a peer in the situation, a similar feeling, a strategy.

Common Types of Stories from Peer Research

This leads to looking at the types of stories that are told in peer-to-peer settings:

- Health-related survival stories, where the threat is identified and attempts made.
- Esteem stories, where overcoming health problems are celebrated.
- Personal growth, where the opportunities and challenges lead to the capacity to try new things.
- Action or adventure stories about a quest to find an answer, take control, be a different you.
- Mystery stories, where you and others look for answers.
- Comedies, where threats and low self-esteem are challenged by unexpected positive experiences.
- Journey stories that track stages in recovery or acceptance of disability or death.
- Teaching stories that describe how new ideas and skills can be achieved.

Elements of Stories Told by Patients for Patients

We now look to the similar structures of stories as used in research. Stories are composed of major elements: the title, context, the incidents, plot, consequences, and meaning. These elements form the basis of the story format used in most narrative research.

The **title** of the story names (codes) the story that has meaning to the teller of the story (in vivo code). Titles often change when stories are shared, and in the end the title of the story acts as a major theme of what happened, is happening, or could happen.

The **context** includes properties that define the nature of the story, the actors, the places, the social situation. Properties are identified by who, where, when, and other questions that categorize stories.

The **plot**, the movement of the story is a sequential accounting for the actions of a single story, but elements of the plot may become known from other

stories and thus can be used in several plots. This allows for detailed understanding of the movements within the trajectory of the story through the focus on properties of how, why, and then.

The term **incident** can refer to short abstractions of actions that include actors, actions, and outcomes. These incidents provide a bridge between grounded theory and more traditional thematic analysis. Grounded theory, especially participatory grounded theory, is adept in using and comparing incidents that can be analyzed using properties of narrative.

The **ending, consequence, outcome, or moral** of the story marks the end of a story. It tells what has been learned in the telling of the story and may suggest the beginning of the next story. The ending marks at least a partial resolution of the situation that triggered the story as indicated in the diagrams of story frameworks above.

Narrative peer research uses a **standard story template** to explore a story's properties during data collection, managing data, data analysis and interpretation, and theory. The template promotes iterative story presentations that evolve from personal stories to shared/collective stories that act as narratives. The format remains the same, but the nature of the incidents evolve from personal to collective stories and, in peer research, to scripts for action that challenge systemic discrimination, policy triggers, or social innovation.

The following is an example from Indigenous co-researcher Henry Three Suns. He is talking about how sports and competition allowed reserve students to learn how white society worked.

The first transcription is typical of many transcripts here, presented using a transcription that captures the speech rhythm that reinforces the intention and meaning by starting a new line with each pause in speech rather than traditional transcriptions that force grammatical structures onto oral data.

> *We were exposed to other schools in high school*
>
> *Mostly white schools*
>
> *In sports and the like*
>
> *And we were led to believe that you could be as good as the other person*
>
> *And we won a lot of high school matches*
>
> *And to prove to ourselves that we could do well*

One of the prides of my life is the provincial basketball championship

We won

That was an accomplishment

You get appreciation from the province and the family.

(Henry Three Suns; Marlett, 1996 thesis data)

Notice how the following list is presented as incidents of the above content that occurred as Henry and I discussed his initial story. The language used is Henry's but reflects an initial analysis of what the story contributed to his work.

In high school we got to know white kids

Coaches said we could be as good as them

We won many high school games

We won the provincial basketball championship

I was proud of our success

The province and our families appreciated our achievements.

These incidents could then be sorted into different categories of 'learning about white society,' 'competing in sport,' and 'new ways of being together.' In the final theory, these incidents led to a category of 'Indian Briefcases,' which spoke of a time when Blackfoot members who had learned about white ways began to negotiate with those in power. His grandmother laughed as he tried to work with white officials, saying "you just have to use white people to practice on until you can figure it out."

In later narrative peer research with seniors, the peer researchers used the template while listening to the tapes to fill in the story template, which avoided full-text transcripts. This made it easy to record incidents within the template and allowed them to compare the stories using the templates to combine and rename stories as they were shared.

The value of the use of incidents as individual units of analysis is that they can be detected and recorded directly as focus group, interviews, and observations stories. The incidents can be written verbatim during data collection and then shortened during analysis and interpretation. Incidents are easily

recognized by participants but remain private when reported in categories and quotes that are recognized both by participants and effective in oral presentations and publications.

Metaphors Act as Stories to Explore Meaning

There are five main types of the figurative language—metaphors, similes, personification, hyperbole, and symbolism—that provide ways to understand meaning within stories. Metaphors are the most commonly used tool by citizens and were common as patients struggled to explain their experiences and their expertise. They represent meaning and values when there are few words to explain what is happening. Metaphors can suggest actions, feelings, outcomes, or expectations, and are treated as incidents. "My body was limp like a rag doll after the accident," or "I felt warmth, like sunshine that sinks into me."

Root metaphors are used to find a way to make sense of how our lives are changing. "Life is like weather," "I think like a computer," "I seem to have become my electric wheelchair." Root metaphors can introduce shifts in understanding over time. "I remember my childhood as a time of sunshine and clear skies," or "I can only try to avoid the hurricanes of my bipolar life." In this way, metaphors are windows to worldviews that lie beneath the surface of competing worldviews, which might stifle or negate possible change. These worldviews are often held in our most protected and often unconscious levels of thought.

Common metaphors are often captured in slogans and sayings. "Black lives matter," "nothing about us without us," or "ban the bomb." They are found on plaques, social media, graffiti, and are particularly useful online or in health settings. They often capture the goal, the outcome, or the expectations of marginalized people.

Metaphors provide the data for deep analysis and questioning during research and the participant co-researchers should be invited to explain the metaphors they use in relation to the research being done. Metaphors uncover sources of institutional bias and examples of unexpected success.

Emerging Directions in Narrative Analysis Suggest a Framework for an Integrated Narrative Science in Peer Research

This section attempts to locate the use of narrative in peer research compared to an exciting narrative framework for qualitative narrative research by Roest et al. (2021, https://doi.org/10.1186/s12910-021-00691-7). The original four quadrant process proposes a four-step narrative analysis to guide research projects.

- The first cycle of analysis is **in vivo coding** to capture incidents within stories. This relates to the use of the story template in peer research to locate incidents within the context, plot, and consequence of stories. In vivo coding is the first level of analysis of data collected during observations, interviews, focus groups, and online patient self-help platforms. The structure of the template enables analysis to move through all four cycles as stories are combined and divided as concepts are identified.
- The second cycle of analysis employs features to **interrogate incidents**. In peer research features are related to properties used in classical grounded theory, but the intent and outcome is similar. Peer research focuses on properties that relate to each stage of the research:
    - SET: Co-design of the main concern, properties of who, where, what happened, and what then. These help categorize concerns for prioritizing the focus of the proposal.
    - COLLECT: Iterative data collection and analysis to inform the main concern to search for possible solutions. Properties include who, what, where, when, why, and why now, then.
    - REFLECT: Choosing the best solution to the main concern that is feasible and important to patients using properties. Properties include how the story relates to the main concern, why it works, what is anticipated if it was implemented, and who would implement it and how.
    - INNOVATE: The properties now shift to implementation, such as who will conduct the design of the solution, what is needed to ensure it is EDI compliant, who will pay for the solution, how will costs be covered.

- The third cycle of analysis relates to context of the analysis, by consolidating themes through the various forms of data collection and analyses. In peer research, constant comparison is inductive in that the findings of each step decides the direction needed to extend or challenge the findings until a best solution from a patient perspective is found for the main concern of the research. The equivalent analysis in peer research begins with COLLECT and continues through REFLECT and INNOVATE in an attempt to tell the story of the iterative process and how each step informed the final solution.

- The fourth cycle of the Roest cycle is the synthesis in light of the research question and what has been learned about the methods and the research findings. This cycle in peer research takes place early in the process as the peer research team becomes part of the sponsored research team, sharing emerging findings and challenges. As the REFLECT process identifies how the research informs a patient perspective of a solution to the identified main concern, there is an opportunity to reflect on the narrative data processes informing the research and how it builds bridges to implementation from a patient perspective.

The above exploration of peer research and the qualitative narrative analysis methodology of Roest highlights the shared importance of in vivo incidents and the use of features or properties as analytic tools to interrogate incidents and stories to capture what has happened, is happening, and what could happen. It solidifies the action nature of peer research that focuses on patient concerns and solutions. It also highlights the use of a standardized template to facilitate analysis in peer research that also maintains the integrity of stories to support the evolution of in vivo codes as part of iterative analysis.

In the final chapter, it was finally possible to complete a narrative form of analysis that maintains the integrity of the story as data, method, and theory throughout the engagement strategy of SET-COLLECT-REFLECT. It has not yet been tested, but it builds levels of analysis by using story properties from individual stories of personal concerns that captures the power of story. The next stage encourages sharing stories through the power of narrative to capture concepts that have meaning at the level of the group. The final stage uses past concerns, the current understandings, and potential action-based stories that aspire to suggest potential solutions as the collective expertise of patients who are willing to share stories to make a difference.

The End Goal of Narrative

"Sharing stories to make a difference" was first coined by an Indigenous community researcher as a way to define what PaCER research meant to her community.

The end goal of narrative is to produce stories that are so powerful that they hold narrative truth. For example, the following tale by Dame Cicely Saunders, founder of the modern hospice movement, is an example of a challenge to the existing health discourse for dying patients. In an infectious and gentle manner, the challenge is implied, not shouted. The medical discourse of loss, fallibility, and dependence is challenged through a simple story:

> *Always I remember Helen's laughter. She had a delicious sense of the ridiculous, and especially of the ridiculousness of her own crippled body. She neither pitied it nor hated it—there it was and, like everything else in life, could be laughed at. From behind the curtains came muffled giggles from the nurses, from the bathroom came quite uncontrollable laughter.* (Cicely Saunders, 1988)

Helen's story challenges most of the stereotypes of severely disabled people—the lack of respect for their condition, the sadness of disability, objectivity and non-involvement of staff. This one small story undermines medical, professional, and charity discourses about disability. Stories such as these challenge prevailing oppressive discourse by presenting a very different story of joy and friendship that clashes with what might be approved.

Shared stories often tell about the strengths of patients and communities, in contrast to the weaknesses implied by the dominant medical discourses. For example, those who were part of the new social movements thesis had been defined by political and professional labels or experiences—patients, disabled, prisoners, Aboriginal peoples, that defined how they were distinct from general society. Collective stories as narratives and metanarratives of emancipation are about challenging power, risk. This enables us to combine individual and collective strength to achieve collective action. The following two collective stories are examples:

> *There is a great deal of camaraderie among disabled people*
>
> *Telling stories and laughing at themselves*
>
> *I don't think that really happened until the grassroots movement got off the ground*
>
> *When the professionals were involved*
>
> *You just didn't tell jokes about how crazy it was to be in a wheelchair*
>
> *But now we tell all kinds of stories*
>
> *Even jokes about sexual feelings*
>
> *The professionals thought it disgusting*
>
> *That created a certain sense of community*

Of bonding among the group by challenging professionals

(Henry Enns, Disabled Peoples' International; Marlett, 1996)

All story types have the potential to be emancipatory when they share themes of personal competence, purpose, or contribution. It is about finding and sharing inner authority and finding our preferred roles. This empowerment shines in the comment from Debbie (D), a trainee and apprentice trainer at Greenbank training centre in Liverpool, UK.

N (Nancy). Did you find a difference between the disabled and non-disabled staff when you first came to Greenbank?

D. Yeah. I didn't trust anyone who was able bodied.

N. Are you like that still now that you're becoming staff?

D. I'm less likely not to trust anyone but I'm not blind anymore

When Gerry says 'come on you, you can do that', I know now that he's pushing it

You know, I think he's not exactly me

He may be close

Like what I can do in a chair

The disability and the handicap

But he's not a woman and doesn't have the same problems

(Debbie, Greenbank; Marlett, 1996)

Advances in Narrative as Part of Innovation

The use of stories in innovation needs stories of what might happen, what could or should happen. These are the stories of anticipated and hoped-for futures. If you are interested in this field, recent developments in narratives of change provide exciting ways to use this chapter to understand social innovation by identifying hoped for, anticipated, and feared futures (Wittmayer et al., 2019, https://doi.org/10.1016/j.futures.2019.06.005). The narrative approach above can also be used in design thinking. There are already many narrative or

storied methods being used for user story mapping, projects defined by stories and standardized epic story formats to track progress during prototype testing in design thinking.

Stories and narrative analysis continue to evolve in health research as this manuscript expands to include social innovation in health. New narrative opportunities in design thinking can also be used in qualitative and peer research. These methods are expanded in Chapter 11.

Summary

Stories are the way people share experiences of health and healthcare. Patients with direct experience across settings, transitions, professionals, levels of care, and organizational structures are able to study and share stories of expertise and hope for futures that lead to narratives of change. The ending to a peer research story becomes a practical theory that is useful and meaningful for patients, the public, health systems, and health research.

We realized that the use of narrative methods overcame many of the obstacles that made classical grounded theory seem difficult, lengthy, highly conceptual, and open-ended. The systematic use of stories challenged these assumptions. The major question is perhaps not if patients can conduct classical grounded theory, but if classical grounded theory analysis and practice benefit when simplified through the use of a narrative methodology. Just as Glaser and Strauss (1967) predicted, grounded theory can be done effectively by those without extensive disciplinary training, and we came to believe that the use of narrative made grounded theory even more plausible as a force for social change. Stories and their analysis provide the link between classical grounded theory and the science of engagement.

Questions for Discussion

1. Select one of your favourite stories about a health-related incident. Think about how it began as a story and may have informed narrative or metanarratives that you now hold. Share your findings with others.
2. Write your personal experience in a story template and, if you are intrigued, conduct a basic narrative analysis using the set of questions to identify properties.
3. What obstacles do you see in using narrative in the research you have been involved with? Where do these obstacles come from and how could narrative be adapted to support inclusion?

4. What similarities do you see between narrative medicine and peer research? Have you encountered narrative medicine or therapy in your training or practice?

Resources

- For those interested in a practical guide to the use of narrative, this lay report by Mitchell and Egudo (2003, https://apps.dtic.mil/sti/pdfs/ADA421725.pdf) is short and comprehensive. This can be used as an extra resource that is designed for frontline workers.
- Narrative foresight becomes necessary when creating narratives for social change, as explored by Wittmayer et al. (2019, https://doi.org/10.1016/j.futures.2019.06.005).
- There are other practical reasons for health researchers to engage patients in peer research using narrative. At the foundational level, narrative methods have made inroads in quality improvement research (Greenhalgh et al., 2005, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1744090/pdf/v014p00443.pdf), and there is an increase in patient experience collections that capture personal and family stories:
    - "Why Study Narrative?" (Greenhalgh & Hurwitz, 1999, https://doi.org/10.1136/bmj.318.7175.48)
    - "Database of patients' experiences (DIPEx): A multi-media approach to sharing experiences and information" (Herxheimer, et al., 2000, https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(00)02174-7/abstract)
    - For an example of how medical facilities are incorporating social media into their online resources, see Sunnybrook Hospital's Video Library (n.d., https://sunnybrook.ca/content/?page=youtube-video-library)

1. Narrative Analysis of Autobiographies: An Example

The following case book summarizes the elements of student research done on over 100 autobiographies to learn how to analyze citizen stories to understand the process of personal growth and resilience due to illness and loss.

Table 7.1

Summary of the Elements of Student Research on Autobiographies

Topic	Variable	Data collected and analyzed
1. The stories		
	Title for the story	The title represents the story. It often includes the words of the storyteller. The title stands for the action and results of the story.
	The trigger of the story that disrupts the equilibrium	Loss, challenges, unexpected support, threat to income. *It was my first day and I was excited to wear my new shoes to school.* *Betty had been admitted again because her weight had dropped to 87 pounds.*
	The context of the story, the characters	*When I started grade one, my mother walked me to school to make sure no one would make fun of me.* *Betty, on her 21st birthday, is sitting in her bleak hospital room with her dad, thinking that this may be her last birthday.*
	The plot	List of incidents recorded as what happened.
	The consequence of the plot	The outcomes, changes in direction and role.
Topic	**Variable**	**Data collected and analyzed**

Table 7.1 (*continued*)

2. Discourse analysis of the stories selected		Unpacking the language of the author
	The tone of the language	Emotional, descriptive, abstract, professional, advocacy. Look for
	Pronouns used	The social structure and scope of the story. 'I' is considered to indicate agency, whereas 'me' is considered to be passive. 'We' is an indicator of connection, 'he,' 'she,' and 'they' are active, whereas 'him,' 'her,' and 'them' are passive.
	Active and passive verbs	Study of agency, location of the agency (locus of control).
	Metaphors and figurative language	Finding the root metaphors in the text. A plant metaphor is considered an indicator of growth, and therefore suggested agency. Black dogs are seen as a sign of being controlled by negative influences.
	Developing simple scripts	When (the trigger) *When I am in a crowd of people I don't know.* I (summary of the plot) *I try to close in and get to the edge.* Then (the consequence) *I can figure out how to get away.*
3. Interpretation		Summary of what the student had learned about patient experience from the analysis and how the scripts depicted the trajectory of personal experience.

2. Narrative Analysis Used to Uncover the Social Reconstruction of Self After Health and Disabling Condition

The author of this excerpt was a student in the narrative analysis class. It has been revised to remove any identifying information.

Table 7.2 *Story Analysis Workbook*

Story Analysis Workbook Inquiry into scripts of recovery and resilience: An inquiry is a structured set of questions leading to novel and personal answers. Learners own their knowledge and gain confidence in their critical-thinking capacity.
Reference for Autobiography: Roney, L. (1999). *Sweet invisible body: Reflections on a life with diabetes.* New York: Henry Holt and Company, LLC.
Short 200-word book report: Lisa Roney writes of how being diagnosed with diabetes at age twelve has affected her life. She describes the constant attention diabetics must pay to diet, exercise, and the constant balance of high and low blood sugar. She voices how diabetes infiltrates all aspects of her life. Through her autobiography, Roney hopes to reach out to other diabetics, inform others about the implication of a chronic disease and also validate her own story. Her struggle and life experiences lead her from a young girl trying to be brave to a defiant teenager challenging authority, a college student pretending diabetes doesn't exist, a battered lover defined by diabetes, and then her having found her place as a writer. Throughout the book, Roney knows that her experiences and choices have brought her to where she is, but as is the case throughout much of her narrative, she finds it hard to break out of the control she requires in order to risk any of herself to others. Through her uninhibited recounting of her life, Roney exposes herself, provides an intimate look into the world of a person with diabetes and provides hope for others.
Data collection: Chronological story chain. Each story is summarized as a Story that is a comprehensive incident recounting a story with intent, context, what happened and the consequence
1. Title: Grandpa's moral story (pp. 5–7) Description: Grandpa tells the story of how his brother Russell lost the tips of his fingers to a young Lisa, who hears the moral of perseverance and overcoming horrible events.

Table 7.2 (*continued*)

2. Title: Hershey haze (pp. 18–24) Description: Vaguely aware that she is not well, but too tired to do anything about it, 12-year-old Lisa waits for her mother to come home and return the doctor's call, which confirms that she does have diabetes.
3. Title: Able to take care of yourself (pp. 26–31) Description: Lisa finally learns to inject herself by practicing on a candy striper first.
4. Title: It's okay, I'm brave (pp. 44–46) Description: Lisa's rolling veins cause problems for a nurse who tries to take her blood, but fails and cries due to the pain she has caused Lisa, who tells her, "It's okay. Really."
5. Title: Out of lines (pp. 50–53) Description: Unfairly made to do lines, Lisa copies out an excerpt about strict teachers really being afraid; this earns her more lines that she uses to continue her protest.
6. Title: Role reversal (pp. 62–64) Description: While they are hiking, Lisa's brother, who usually looks out for her on hikes, becomes dehydrated and needs Lisa to take care of him.
7. Title: Soda of hope (pp. 69–72) Description: Coming home from a high school trip to Mexico, Lisa is falling into insulin shock from lack of food and is saved by the sodas that all the Mexicans hoping to cross the border had to sell before they found work.
8. Title: Just a drunk tourist (pp. 85–90) Description: Traveling alone in Venice, after hiking, Lisa shares drinks with Australian women and her glucose drops. Too proud to ask for help, she stumbles around Venice, humiliated by others' reactions to her condition, until she finds her hotel.
9. Title: Allies in a train of normals (pp. 91–93) Description: Lisa is embarrassed about testing her blood in a train car, until the elderly man across from her turns out to be a diabetic as well.
10. Title: Mary's Marvelous Diner: Everyone welcome (pp. 97–104) Description: Mary's Diner was a safe haven for college students to work, where staff and customers alike were comfortable regardless of their shortcomings and Lisa could work and not feel set apart.
11. Title: Cheater, cheater, ice cream eater (pp. 125–128) Description: While visiting her uncle and aunt, who constantly monitor her eating, Lisa sneaks some ice cream while her aunt is out, and is caught by her cousin whom she perceives as disgusted by her behaviour.
12. Title: Running with indifferent rose (pp. 154–156) Description: Lisa's new exercise partner continually changes plans and shows no regard for the structure Lisa needs to regulate her diabetes, so she decides to exercise alone once more.

Table 7.2 (*continued*)

13. Title: Fear of blindness is blinding (pp. 165–168) Description: While proofreading for a law firm, Lisa experiences visual problems related to hyperglycemia and reflects that fearing blindness misled her into art studies rather than following her passion for writing.
14. Title: Learning by lightning (pp. 174–177) Description: One of her favourite teaching moments - during a storm her students were restless so she abandoned her plan and just let the students write while she felt the power of language.
15. Title: Practically perfect Panos (pp. 202–211) Description: Panos accepted her diabetes and created a want for monogamy in Lisa, but they had little in common and he disagreed on the nature of fidelity, eventually giving her an STI.
16. Title: Bill destroys belief (pp. 212–219) Description: Long-term relationship with Bill, who cheated uninhibitedly, lied and raped her, leaves Lisa jaded and wondering if her diabetes made her think she had to put up with this kind of treatment.
17. Title: Trapped, fighting and paralyzed (pp. 242–248) Description: Lisa describes recurring nightmares where a sniper holds her hostage and she won't escape alive, and others where she is rushed by a man who never hurts her but she cannot move, and ones when she yells at people in her life that she is angry within waking life but can't communicate with.
18. Title: Cheating Craig for control (pp. 266–267) Description: A new roommate already found to take her place, Lisa's planned move falls through. Craig offers to work it out together, but Lisa's name is on the lease and she refuses to leave.
19. Title: Cassie is witnessed (pp. 279–283) Description: Lisa's cat Cassie is diagnosed with diabetes, and as she gets worse, her life is worth fighting for, from Lisa's perspective. When she passes away, Lisa takes comfort in the fact that Cassie was known and thus lived fully.
20. Title: Safe and loved with Sally (pp. 292–295) Description: After four years alone, Lisa lives with a roommate again and is worried Sally will start to hate her, but Sally regards Lisa's quirks with affection.

Choose five key stories from the trajectory above and repeat the following analyses for each story. Copy the templates for each story.

Table 7.3 *Sample Analysis of Plot and Structure of Key Stories*

Sample analysis of plot and structure of key stories
Able to take care of yourself (this is the title of the story) The beginning. The context (the who, when, where) Lisa, as a teenager in hospital with diabetes is faced with learning how to inject herself before she can leave the hospital. The nurses and her family try everything.
The middle: The plot (what happened in clear, concrete steps)
1. Lisa's mom went to an American Diabetes Association support group meeting where one mother spoke of her teenage daughter who still refused to give herself injections.
2. Her mom tells her that she is not leaving the hospital until she can give herself her own shot.
3. Lisa practices on oranges but struggles with the idea of self-mutilation and of something "alien invading the body."
4. Every nurse on the floor tries a different tactic, but after days, patience is wearing thin.
5. Finally, a candy striper cuts the deal that Lisa can try it on her first if she does it on herself immediately after.
The ending: Lisa does the needle on the candy striper and then finds it much easier to do it on herself than on someone else.

Table 7.4 *Sample Discourse Analysis of Language in Key Stories*

Sample discourse analysis of language in key stories—abbreviated Select a passage from each story that captures the emotion or movement of the story.
1. Underline individual words that jump out and write them down here. Read your words aloud and write about the nature of the words, what they tell you about the author (who is the author here – victim, colleague, expert, etc. and how do the words generate sympathy, justify anger, etc). Look at the familiarity of the words, how they fit together, are they concrete or abstract, raw or sophisticated, strong or gentle, intimate or aloof. Airy, braced, warm, jerks, dim, rivulet, frightened, tensed, hurting, flesh, recoiled, squeezed, scarlet, imprints, bruises, swelled, angry, puncture, relief. The nature of the words is one of battle. She starts out bracing herself, frightened. Then there is the attack – hurting, flesh – and the retreat – recoiled. The aftermath is told – squeezed, scarlet, imprints, bruises, swelled, angry, puncture – and the final verdict is passed – relief. In this story, Lisa is a warrior on trial. She is being put to the test in a battle of wills. Her unwillingness to break the integrity of her skin and the need to permeate that barrier so she can learn to take care of herself are in conflict. She knows she must overcome her willingness and the generals are present to witness her battle and judge her bravery. The words she uses are strong and very sensual. This highlights the emotional as well as physical struggle she is experiencing.
2. Circle pronouns as connections and indicators of agency. Count the number of each type of pronoun and comment on who each pronoun (I, we, they, she, it, etc.) represents. Me, my: 6 times – represents Lisa I: 9 times – represents Lisa *The story shifts from me/my to I after Lisa has gotten the needle in and can now take it out.* Her, she, and herself: 8 times – represents the candy striper Everyone: 1 time – represents her parents and a floor nurse

Table 7.4 (*continued*)

3. Record verbs as indicators of agency. Are these verbs active or passive? Indicate agency for verbs as indicated: Technique – evaded – Lisa (the technique is in control) active Lisa – braced – side of my right hand (she is mobilizing her hand) active Lisa – planted – needle (using different mediums, first her hand and now the needle, she is acting upon the candy striper) active Giving the needle – take – time (In the story the wording is "This seemed to take forever…") active Dim – going – vision (This verb is passive) Sweat – running down – back (she has no control over her body) active Candy striper – sucked – air (awareness of the candy striper acting is established) active Candy striper – tensed – her arm (though this verb is active, it goes on to say in spite of herself – implying that she was not in control of her actions) Lisa – hurting – candy striper (Lisa is now the one acting directly upon the candy striper) active Lisa – pulled – syringe (there is a shift back to the medium of the needle) active Lisa – recoiled – herself (Lisa withdraws herself, now that she is finished the needle her focus is once again on her own body) active Lisa – squeezed – her left hand (Looking at the candy stripers arm after, Lisa again looks at the effects of the medium between her and the candy striper, in this case her hand) active Lisa – withdraw – needle (still the candy striper is not mentioned – the needle is) active Bruise – swelled – candy stripers arm (The actual wording does not mention the candy striper here, but the angry puncture wound) active Though the author is using very active and vivid verbs here, her role in the affair is very passive. She is rarely in control of the events that are happening beyond her own body. It is her hand that grips the arm and the needle, but her role in puncturing the candy striper's flesh is minimalized through the prominent role that the needle takes on.
4. Purpose / motivation for telling this story at this point in the book. Look to changes in power, establishing new roles, etc. This is one of the first instances where Lisa really talks about losing control. She has just been diagnosed, but previously was vague about what was happening to her. Now that she knows that she has diabetes, suddenly she is powerless. Whether or not she wants to invade her body with a needle is irrelevant – if she wants to live, if she wants to leave the hospital, she must overcome that barrier. This is where her battle with diabetes begins.

Table 7.4 (*continued*)

5. Sample metaphor analysis Read the autobiography to find mention of metaphors. Often metaphors are implied and hidden. Metaphors often point to ideas of concern, strong emotion or confusion.
Metaphor
"The state of the weather seems comparable to my blood sugar levels – some days it makes exercise outdoors impossible, but most of the time it's just something to take into consideration." (p. 149).
"I envisioned a silent monster always after me with an eraser; some days it didn't make much progress, but others I would be going home with barely more than my toenails. During the evening and night, my real self would regenerate, but if I had been erased down to my toes that particular day, then I might have to go in to work the next morning still missing my head or my hands. That gave the eraser demon a jump start and the cycle might go through a horrible phase where I couldn't restore myself and so hardly knew myself, barely felt that I existed." (p. 168).
Is there an underlying root metaphor to the book? For example, does the person use weather, plants, animals, machines, places as the underlying metaphor and how does it shift during the course of the book.

3. Playing Out Scripts

This exercise creates a space to think about the final step in understanding personal truth—the wisdom that the person has to offer from their journey through disability and health concerns.

While people tell individual and unique stories, they do so with recognizable underlying scripts that provide the structures for what roles they play and what they expect of others. Once you have identified common scripts in your text, take these scripts back to the data set of 20 stories to see which stories are told from these common scripts. Identify other scripts in your 20 stories. If possible, take your script discoveries to other stories in your autobiography to find other scripts.

As you begin to understand the purpose of the script (agency and self-regard) you can begin to understand the path taken by the author in finding meaning through adversity.

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8

Emancipatory Methods That Engage: A Resource for Qualitative Researchers

Highlights

- Characteristics of peer research as part of a science of engagement in health research
- Discussion of the foundations of data collection, data management, analysis, and interpretation
- Quality indicators of peer research

The goal of this chapter exists within the context of making a difference in the lives of patients who are marginalized and stigmatized by the health systems trying to provide inclusive care for all those who need it. It could be called emancipatory because the patients and citizens most impacted by the need for change are involved in learning about problems in order to find solutions. This builds on qualitative research, especially community and population health research that have pioneered applied, pragmatic approaches to find workable solutions on behalf of society.

Peer research by, with, and for patients and communities is a significant next step to seeing that patients who want to learn the skills to conduct robust research and the researchers who are interested in using peer research now have access to a science of engagement replete with historical foundations, best practices, a growing literature, adapted theory and new theoretical proposals, and ethical frameworks and practices. It is written to speak directly to academics, researchers, and health professionals. As it was being written, I asked patients and students to read it, and they decided it was written for them as well. This confirmed the growing realization that peer research as part of a science of engagement needs to be accessible and understandable for anyone interested in emancipatory outcomes.

It relates directly to existing responsible research and innovation (RRI), open innovation in science (OIS) research teams, personal health research, and patient-led research roles, which are poised to move the change indicator in health from patient perspectives. Movements such as citizen science and Ashoka changemaking, along with established participatory action research (PAR) and community-based participatory research (CBPR) will hopefully find a science to support their efforts to democratize science. Emancipation increases responsible and relevant outcomes that lead to focused, nimble, and creative innovation in response to healthcare reform and dramatic paradigm shifts in health and healthcare.

While most methods included are qualitative in nature, they also work well in partnership with quantitative and evaluative methods. Links are provided to extend information about methods for group discussion and teaching purposes. Provincial and national patient groups, charities with patient engagement partners, groups of citizens who advise, and healthcare, along with Patient Advisors Networks (https://www.patientadvisors.ca/) who are interested in peer research, might use this chapter to explore the potential to promote peer research as part of their advising and partnership roles in health research. The format is designed to inform grant writing and co-design while incorporating engagement methods into existing teaching and research agendas and teams.

Professionally trained researchers and students who identify as a patient or person with lived experience (PWLE) may find this chapter particularly useful in their personal research or in training patients as collaborators in their research. Teams of health researchers may be interested in sponsoring or supporting patients to become trained peer researchers through existing community-based or patient-engaged research training programs and courses such as Wellesley Institute in Toronto and the Patient and Community Engagement Research certificate at the University of Calgary.

This chapter extends the current health research landscape and the descriptions of field work, interviewing, questionnaires, focus groups, and narrative research that are included in the companion book, *Grey Matters: A Guide to Collaborative Research with Seniors* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/). Also included is a section outlining how researchers and community groups might develop methods to address questions that are important to them and to provide input into developing health research courses and new community-based health options.

Characteristics of Peer Research

One can understand why people are initially puzzled by the concept of patients trained to conduct research. The power imbalances in health are protected by patients and communities who fear loss of their healthcare providers if they question their care. Peer research is not about challenging existing research or care but reinforces the wisdom of patients in explaining concerns from a unique patient perspective that leads to suggestions for action. In doing so, it provides a competent patient research voice about general practices and policies. Patients are ready to be part of improving healthcare and ensuring healthcare sustainability and are ready to advocate for and use their experience and expertise to become involved. It is important, therefore, to look at the common characteristics of peer and patient-led research.

To ensure patient research reliability, the methods included here were tested and modified as part of research projects and grants, with community and health system programs, students, and as part of professional workshops and presentations. This includes the *Grey Matters* publication of research methods and over 85 co-designed research grants and contracts. The methods here represent the scope of methods that become part of a blended methodology in the final chapter of this book. Here we focus on emancipatory methods that can be used in a wide range of research, including qualitative, quantitative, and action methods to inform both theory and action.

We thank especially the researchers and mentors who were early adopters in both *Grey Matters* and PaCER and were willing to try new methods to overcome challenges of engaging patients in research. It seems appropriate to begin this chapter with an example of peer research that captures the character of peer and community research. This is a community-based peer project titled "Understanding Advanced Care Planning Within the South Asian Community."

Four trained PaCER researchers from South Asian countries were contracted by an advanced care planning (ACP) grant to identify the readiness of South Asian communities to become part of an ACP initiative with Alberta Health Services (AHS). Each PaCER was from a different faith community, and all were women. As women, they conducted a women's focus group to identify the obstacles and opportunities for conducting this research. The peer researchers, the project principal investigator, and PaCER academics then met to discuss the need for a culturally appropriate data collection strategy for families and for the researchers within the South Asian communities.

We decided that any research involving end-of-life care should be done within families because the traditions surrounding death were generally led by the head of the family and each family member would also want to be involved.

A modified family research method was created to meet cultural protocols. The recruitment of families included a careful description of the ACP process and how the research method would meet cultural and language needs.

Each research event involved two peer researchers—one in traditional dress, the other in western dress. They met the family in their home and brought along tea and treats. The lead researcher (the one from the same faith community) outlined the process with the family, asking if everyone felt comfortable and, in the process, introduced herself and why she and her family felt that advanced care planning was important—a personal family story.

Adaptations were negotiated, if needed. Once the head of house had negotiated changes and set out how all members would have a chance to speak, there was a narrative conversation about the concept of ACP. Confusion and conflict with traditions were also discussed. All members—from grandparents to children—contributed. Other methods were not needed, as the data from families in all four faith traditions created very detailed discussions about family goals, the process of dying, and advanced care planning from all generations present.

The results were compiled and analyzed after each family gathering and shared with the team to plan next steps. The PaCER academic staff and peer researchers met regularly to provide support and discuss any ethical or methodological findings. As we neared the REFLECT consultation, it became clear that the topic had generated a great deal of interest in the community and a radio invitation was issued for a feast and a chance to be involved in the research findings.

The morning session consisted of the peer researchers and co-researchers who had participated in the research to discuss the research findings and plan for the afternoon session. The noon feast included faith-based and community leaders, community members, and health providers, along with the sponsors. In the afternoon, the results from the group sessions in the morning were presented to the group, with active discussion and answering the main questions.

Highlights included a leader in the community who spoke for many, indicated his appreciation for the chance to be involved. He suggested that if AHS wanted an advanced care plan done, why not leave it at the doctor's office on a computer that they could fill out and update as needed. An Elder spoke quietly to say that she felt that everyone was familiar with computers and they could discuss it amongst themselves. A doctor rose to say she could help and then a faith leader suggested that they could hold discussions after services to show their support.

The family method produced deep and rich information. The results contributed to the team's implementation plans and were published (Biondo et al., 2017, https://doi.org/10.1111/hex.12531/). The full report is available in PRISM (https://hdl.handle.net/1880/109933).

The following table introduces us to the basic characteristics of peer research to set the stage for this chapter that highlights how peer research differs from most general qualitative research.

Table 8.1 *Characteristics of Peer Research and More Traditional Research Methods*

Characteristic	Peer research	Qualitative research
Emancipatory	The overall goal is to build citizen capacity to engage in research about personal health and healthcare that makes a difference to patient roles in health care practice and planning.	To conduct research to understand and support patient vulnerabilities and to inform care providers and systems how best to support care and the interests of patients.
Salutogenic	To understand the salutogenic search for health and well-being to build capacity for resilience, confidence and well-being.	To understand the pathogenic nature of patient experience to understand how to address vulnerability and fallibility of illness and loss to improve outcomes.
Inductive / deductive	Inductive, iterative data collection, analysis, and interpretation with patients and communities. Each new step builds on and tests the accrued findings.	Deductive process—data collection completed and then analyzed and interpreted to test hypotheses. Increasing use of grounded theory for iterative data cycles.
Adaptable	Methods for data collection and analysis are adapted for in iterative cycles to ensure that methods engage population and topic appropriately and effectively.	Standard questions and data collection procedures for computer analysis. Semi structured interviews have some leeway.
Use of narrative	Narrative values and methods permeate all aspects of peer research from identifying the concern or topic to disseminating findings.	Selective use of narrative in data collection and some narrative analysis.
Data	In-vivo data of incidents are compared to form real life categories. In-vivo codes reinforces co design features of participation with co research participants.	Results of standardized questionnaires and interview questions are analysed at the end of the research to inform theory and practice.

Table 8.1 (*continued*)

Characteristic	Peer research	Qualitative research
Orientation	Action: What happened, what happened next, what could happen. Focus on a main concern of the population to find what action can be taken.	Descriptive: What was it like, how did you feel? Using thematic analysis to describe common categories of experience.
Group research	Open, extended conversations, small working groups and focus groups. Methods encourage creativity and consensus.	Groups follow scripted questions and processes.
Participation from the lens of citizen science	Citizen scientists are supported to engage in data collection, analysis and are valued for their local and personal knowledge.	Participants engage in data collection and may include analysis and dissemination. Results of the study may be shared.

Emancipatory Stance

To call research emancipatory is to align the purpose and methods of research with a mandate to reduce obstacles that reduce patient and community capacity to flourish and, instead, increase the possibility of becoming key stakeholders in their own health and healthcare. Why is an emancipatory social science needed at this particular time? The simple answer is that emancipatory research provides a local and real-life way of addressing what are considered 'wicked problems' in healthcare. Wicked problems are social, cultural, or institutional problems that pose often insurmountable challenges to aging systems, as indicated in the following healthcare resources:

- "Wicked Problems and a 'Wicked' Solution" (Walls, 2018, https://doi.org/10.1186/s12992-018-0353-x)
- *CREATE WISDOM: Wicked Problems in Healthcare* (UI Health, n.d., https://uihealth.uic.edu/research-clinical-trials/create-wisdom/create-wisdom-wicked-problems-in-healthcare/)

Peer and community research is pragmatic and focused on real-life, local health problems that are of concern to a specific population and to conduct research at the local level that provides opportunities to tackle wicked problems such as systemic racism and discrimination, obesity, and environmental toxins in management contexts. Emancipation has been supported by computerized

medical information platforms and patient portals that enable patients to collect and analyze their own data and share data with others. Online patient portals also develop connections and networks of patients who share common concerns and open new channels for patient-informed and supported research such as Patients Like Me (https://www.patientslikeme.com), where patients have become active in drawing attention to problems in the medical grey zone of 'no known medical cause or cure' (for example, see Callard & Perego, 2021, https://doi.org/10.1016/j.socscimed.2020.113426). 'My Data, Our Health' personal health networks are becoming popular in countries that support citizen science, where patients share and discuss their personal research about their health challenges.

Zamplo is a trend-setting breakthrough that fosters patient emancipation as a person-centred connected health platform, which "is designed to place the person at the centre while remotely capturing patient-reported outcomes and wearable data to provide valuable real-world insights into treatment efficacy and patient experiences. It helps identify adverse events, provides patients support, and empowers individuals to manage their care themselves" (Zamplo, n.d., https://www.zamplo.org/) It will empower people with the resources, knowledge and tools needed to understand their health information. Individuals can connect meaningfully with the wisdom of a global health community by sharing and working with caregivers, peers, patient advocates, researchers and health professionals to make the best possible decisions based on individual goals.

Salutogenic

Patients seldom realize that their experience with health problems and health systems is, in fact, knowledge that grows as they face the stressors associated with ill health and seeking wellness. This knowledge encourages interactions with health professionals and health systems. Salutogenesis is the study of the process of managing stressors by using and building personal, program, and system resources and resilience skills that includes cognitive skills that build confidence that stressors can be challenged and managed, and that it is worthwhile making an effort to face health-related challenges. It is asset based and a metric for ensuring that explanations lead to potential solutions. This contrasts with problem-focused pathogenesis that is the dominant discourse in health research. As technology influences our human bodies, salutogenesis will become even more essential if patients are to become active in technology development and implementation.

Inductive Approaches

Most health research is done within deductive research methodologies that test a research question by collecting data using a consistent method. When all data is collected, it is analyzed, often with computer analysis to confirm (or not) the hypotheses. Results are related to the original question.

Inductive approaches are common in emancipatory research, participatory action research, grounded theory research, and peer research, which use iterative cycles of data collection to gradually move closer to a best solution to a main concern of a local population. Researchers have more flexibility to test ideas with new co-researchers or in using forms of data collection based on the information found in the data. This is important in engaging patients because it provides a flexible, simple process to ensure engagement of groups by tailoring data collection methods to the needs and culture of diverse populations. Every time data is collected, it is analyzed by asking questions such as: What is happening here? What caused this to happen? What was the outcome? What should we study next (planning)? Inductive methods lead to rich interpretation in a short period of time because data collection and analysis is focused. This also means that research needs fewer participants and is less costly.

Inclusive

Peer research relies on the ability to reach out to populations that are not being heard because they have either given up or, more likely, because they are considered outside of the scope of standardized studies. For example, research with young people with sport-related concussions was difficult because so many people felt that they were responsible for the injured youth and tried to protect them from taking part in a study that might prove stressful. Indigenous focus groups were conducted with ceremony. Women researchers conducting research in Muslim communities required careful planning and adherence to gendered relationships. The need for peer research training will increase as we address the need to create bridges between marginalized populations and mainstream research. Inductive research is essential in laying the foundation for a flexible and adaptable research methodology of the future.

As peer research is adopted by innovation and social enterprise teams, adaptation, especially in the prototype development and testing stage, will be essential. Good design thinking is about learning about the potential diversity and being able to adapt to new populations.

Narrative

Stories are hardwired into the human brain to understand the problems of the past and dream stories of better futures. Narratives of change are becoming more popular in emancipatory research and implementation science. The use of a consistent story template helps peer researchers and participant co-researchers see stories as a legitimate form of data and knowledge as they evolve throughout the research cycle from a common concern, understanding why problems exist and how they work to open the door to narrative futures and forecasting solutions. Design thinking also uses story formats throughout to produce rich and flexible data focused on processes that solve problems.

The use of a story template helps peer researchers and participant co-researchers see stories as a legitimate form of data and knowledge that can be interrogated using standard narrative properties such as 'what is happening,' 'why now,' and 'then what' to understand how problems work in order to find potential solutions. Finally, stories, used as part of innovation and marketing research, shows that implementation strategies that include a vision conveyed through stories have maximum impact and increase uptake (Davidson, 2017, https://doi.org/10.1057/palcomms.2017.93).

In Vivo Data and Coding

The co-researched social innovation study (Chapter 2) faced the so-called glass ceiling of analysis when I used disciplinary concepts, language, and theories when coding data. The co-researchers felt sidelined because they did not share my academic language or culture. When we used the titles of stories as category names, we were able to re-engage in shared analysis. I realized that categorizing data held insidious assumptions that separated participants from academics, and I used grounded theory to find ways around this chasm between conceptual and real-life analysis. Step by step, study by study, throughout *Grey Matters* and PaCER we studied alternatives to test new approaches that could compensate for this lack of academic conceptualizing using discipline-focused theory. Community-based participatory research (CBPR) and participatory action research (PAR) use plain, in vivo language of everyday life to contextualize experience that reflects local culture and organizational structures. The language of peer research may not be conceptual from a disciplinary or theoretical foundation, but it does lead to deep, action-oriented categories of real-life experience. The following titles of peer research are examples of in vivo theories:

- 'Losing our stories,' that speaks to how medical language takes over during mental health crises

- 'Out in the cold without a clue,' after asking for physician help with lower-back pain
- 'Hiding undiagnosed arthritic pain'

Grey Matters and PaCER have found that the use of stories and plain language has been well received when publishing in professional journals. Peer research data has been re-analyzed by professional and academic researchers who use different languages but come to similar results.

Action Orientation

An action orientation is the hallmark of emancipatory social science of social problems in order to inform collective action. Through 40 years conducting and teaching about emancipatory research, I found the common question of participants was, 'Will this make a difference?' Participatory and action research was, for a long time, considered non-academic because the research addressed population concerns to explain, resolve, or reframe the concern. I encountered this skepticism from my PhD committee and even from colleagues who felt that action research was not objective because there was a 'political' goal.

However, the engagement strategy of PaCER—SET-COLLECT-REFLECT-INNOVATE—caught the imagination of the research community in Calgary. In team meetings, people seemed comfortable with the simplicity and pragmatism of a research strategy that consulted with citizens about the main concern or topic in order to co-design the research proposal (SET); engaged citizens in collecting and analyzing data (COLLECT); and brought the co-design team together to consider the best solution to address the main concern (REFLECT).

Group Focused

Group research was first proposed by seniors in the *Grey Matters* Catalyst grant. They wanted to create a focus group method that provided time to understand the topic, share stories and discuss common concerns. The resulting method takes more time and promotes crosstalk while creating shared meaning. These group sessions create common goals and ownership of the findings. It is perhaps the most effective peer method, producing not only data but shared meaning informed by in-depth collective stories that produce not only explanations of the main concern but the best and most feasible solutions.

Little did we realize that the magic of working in groups would unleash the power of improvisation. As groups shared stories about the present and the past, the interaction sparked new aspirational stories of change, foresight, and solutions. It is doubtful that improvisation exists without open discussion among diverse participants. These groups seemed to rely on the freedom and

crosstalk that builds trust and a common mission to make meaning of diverse experiences.

Group research is used to set priorities, collect a broad range of stories to inform the development of categories, reflect, and contribute to findings that suggest actions based on the findings. The SET consultation team captures the energy of connecting with the community to weigh options and choose their focus and the methods for the study and prepare them to engage in the research. COLLECT groups provide a rapid way to collect, analyze and plan next steps using group formats to reach diverse groups and perspectives. This is especially useful with small online groups. REFLECT re-engages the SET team to respond to findings, next steps, and action.

Participation from a Lens of Co-creation

The principles and relationships of participatory action research reinforce co-creation. Today, the terminology for engagement revolves around a number of 'co's, which compete for engagement space: co-creation, co-design, co-production, co-research. The following is a short summary of these definitions, with a summary of their use and those they engage with.

Co-creation appeared first and with a long history in innovation through design thinking. It grew from the early days of capitalism, when companies were looking for new products to entice consumers to buy. Customers and inventors were welcomed and encouraged to 'co-create' new products and services. The field of design thinking grew rapidly, and professional innovators moved quickly to take the lead. These include using social media, online communities, workshops, discussion groups, or in-depth interviews. Verleye's (2015, https://doi.org/10.1108/JOSM-09-2014-0254) research on the co-creation experience clarifies not only the history and practice of co-creation, but the motivations of customers and inventors engaged in designing products and services.

Peer research emancipation is co-creation with patients and communities who are co-researchers throughout the research process, from co-design through to analyzing data and finding ways to understand common concerns in order to co-create solutions and co-design implementation strategies.

Choosing Models of Participation for Citizen Science and Peer Research

In concluding this first section, we return to the levels of citizen science to describe the range of co-research related to the engagement of patients and communities in research. The basic approach is simple. Academics, mostly in the natural and environmental sciences, recruit citizens to collect data, analyze

data, or even conduct research. Many of the projects are ongoing and become collaborations that are networks of researchers and citizen scientists enhancing and extending the reach and relevance of their research.

In the introduction to Section 2, there is a comprehensive table outlining the five levels of the four most common citizen science approaches. It also includes the International Association of Public Participation (IAP2), which is a commonly used guide to engagement in governance and academic projects. The following is a summary of levels of engagement in citizen science that may help researchers identify the level of engagement they aspire to.

People involved in all forms of collaborative research feel they are part of it, commit to using the information, and support uptake. In the future, the preparation to become a co-research participant might include some basic online stories and the use of peer research reports. Co-researchers are motivated to become part of dissemination, implementation, and uptake.

Options Related to Peer Research and Citizen Science

This is an extensive collection of engagement methods following using the peer research engagement strategy.

- Co-design or SET that identifies the topic of the research from a patient perspective.
- Collecting data or COLLECT using interviewing, group research, field work and participant observation, and mining unstructured public data.
- Data management COLLECT.
- Data analysis that includes content and thematic analysis, narrative analysis, discourse. and framework analysis COLLECT.
- Interpretation using the categories above to connect to levels of theory and implementation REFLECT.

Co-design or SET

SET is the equivalent of the open coding in classical grounded theory that takes place in academic research prior to the ethics proposal. It sets the focus of the project within the context of the systems, politics, and values that impact the patient experience from their perspective. SET can be done by a trained patient researcher, a small team of patient advisors supported by a patient researcher, or an academic lead familiar with peer research who supports patients and community members. The goal is to collect and categorize a number of potential

research ideas that reflect the main concerns of patients or communities as an informal consultation. Some examples include the following:

- Consultation with experienced patients and community members through informal consultations in person or online.
- Online chat groups of all kinds to identify the concerns of the population within the topic of the research.
- Websites related to the general topic to identify program goals and gather consumer comments.
- Grey literature related to political, policy, advocacy groups.
- Practice protocols related to the topic.
- Reading and analyzing patient experience articles from open access journals.

Depending on the resources available and the time, choose from the above options. Keep the information about options for research using a simple story template, so that everyone is consistent in presenting topics of concern. When you have a range of concern options identified, write each on a poster that can be shared in person or online. If you are working as part of a research team, share the posters with them ahead of time.

A SET co-design team of patients and citizens meets to discuss and prioritize the options. The team can be drawn from your consultations or from an independent collection of patients and community members. This in-person or online group discusses the categories, weighing not only what is most important but also what is feasible and impactful. Once one or two concerns are identified, they are prepared for the team (the grant development team or early-stage research team). The report includes politics related to recruitment, advocacy, and community inclusions; the ethics related to engagement and equity, diversity, and inclusion; and suggestions related to methods. This is then discussed and included as part of the grant or implementation plan.

Collecting Data

The specific methods for collecting data are presented separately, although in peer research, data collection is combined with analysis because of the links to classical grounded theory iterative cycles. Iterative data collection is a cycle of data collection, analysis, memoing, and shared analysis, but for this discussion of qualitative methods for peer research, the elements of the cycles are separated.

Table 8.2 describes the four basic ways to collect data in peer research: individual interviews, group research, field work, and mining public and unstructured data. This figure summarizes the data sources, the use of stories, and how to track data collected using basic field notes. This is done to lead into the next section that locates and describes these methods within the engagement strategies.

Table 8.2 *Methods and Purpose of a Peer Research Engagement Strategy*

4 WAYS TO COLLECT DATA IN RESEARCH				
	Individual interviews	**Groups**	**Community-level field work**	**Public data**
Definition	Open interviews that invite stories of experience	Sharing experiences Creating common experiences and strategies	Observing interactions and actions within social situations Visiting people and noting community resources	Online searching and analysis wof publicly available data *(not subject to ethics restriction)*
Data sources	Audio tape Process recording Notes taken during interview	Flip chart notes Audio tape Process recording	Process recording Notes on observations Notes about conversations	Program descriptions Chat groups Policy
Data units	Words, phrases or sentences, that capture action or incidents, stories	Flip chart notes of incidents (what happened) Stories	Incidents as actions, behaviours, interactions, environment details Can be stories	Analysis of descriptions and data provided online
Stories as unit of analysis	Notes can be taken within a story template Can listen to audio tape and transcribe segments	Note individual stories around emerging common category or theme	Observations can be compared, told and recorded into a story format	User comments are stories, as are slogans, goals of programs, policies, and role descriptions

Table 8.2 (*continued*)

	Individual interviews	Groups	Community-level field work	Public data
Field notes as data	Notes taken to capture the nature and findings of the interview	Notes taken capturing the incidents that can be combined as group stories	Notes describe the social environmental, interactions and outcomes	Online data is data Discourse analysis can be used to identify power differentials

The next sections follow up with specific details about the data collection methods summarized above.

Interviewing

The initial study of interviewing for peer research took place with seniors who were taught open-ended, semi-structured, and standardized questionnaires. While seniors felt secure with structured and standardized interviews, they were disappointed with the results that were difficult to apply to their research with partner agencies and were difficult to interpret beyond counting the number of responses. The scope provided by open interviewing was more difficult to analyze but provided useful information that could be applied to their research.

Citizen science interviews often employ structured or semi-structured interviews that ensure that the citizen scientist collects the data needed for the academic research protocol. In this situation the data is collected in ways that allow for computer input and analysis. Even formal interviewing requires training in being able to engage patients and communities in the interviews. For more information on types of standard interviews that have been developed by seniors refer to the "Interviews and Questionnaires" chapter of *Grey Matters* (Marlett & Emes, 2010, https://prism.ucalgary.ca/server/api/core/bitstreams/b7ccdd45-80bd-467f-9f1e-d610823efd22/content).

Peer research interviews are more likely to be open, narrative conversations about specific experiences. A peer researcher uses their own personal stories to enable the participant to feel comfortable sharing their personal stories when it is appropriate. This is difficult for an academic to do because they seldom share life experiences with participants. In peer interviews, participants are prepared ahead of time so that they know the topic and that the topic was chosen by patients. The peer researcher generally has personal experience with the topic of concern. The purpose is to collect stories about what happened to them, and what could or should have happened.

You begin with an open and curious stance, inviting the participant to share their experience of the topic or main concern. You learn to listen to and capture stories by taking short notes of incidents that are story fragments about the topic. Incidents and story data are entered on the story templates during the interview, or you can wait to use the template later from notes or audio or video recordings.

The skill lies in creating a conversation of equals, interested in exploring experiences about a common concern or topic. You show interest in learning more about what happened and, as in a conversation, by prompting to hear more elements of the story. Stories lead to other stories on the topic and open up questions about what happened and why.

The nature of narrative conversations invites the telling of whole stories. Whole stories provide space for exploring meaning. The peer researcher is curious and interested, but avoids any reinforcements such as 'good,' 'oh my,' or 'me too.' These reinforcing statements lead the participant to think that they are answering an implied question, and they will search for the right answer or struggle to figure out what is expected in an answer. Learn to allow time for people to think. If you feel you need to provide support, a gentle prompt related to the story often works. This is where the story properties come in; you could ask 'who,' 'where,' and 'when' questions but try to avoid 'why' questions until the whole story is revealed.

The problem is that the use of standardized questions is often reinforced by ethics committees who see questions as a way of ensuring that research stays within safe boundaries. In medicine, patients are so socialized to being asked questions by professionals that the response is automatic, strong, and visceral: What is the right answer? What will happen if I don't answer correctly? Why is this being asked? What will happen if I answer the wrong way? How do I answer without criticizing my healthcare provider? Who will find out what I have said? These are not idle concerns. Patients spend a great deal of time and energy anticipating questions about their health and how to answer them, and they bring these expectations with them when they come to research. This is why the story format, while it may seem awkward in a health context, provides openings to explore explanations and solutions without triggering uncertainty about how to respond.

It is often useful to tell a story so that the co-researcher knows about the format and expectations.

At the end of a narrative interview, you celebrate the stories as important knowledge about the research topic by asking what the narrator has learned by telling the story and what they feel they have learned about themselves and the topic. In summary, a narrative interview is not a series of questions but an

integrated and meaningful conversation that leaves participants engaged and acknowledged.

Group Research as Data Collection

The group research method was created by seniors who were fed up with focus groups that lasted an hour and asked members to respond to set questions with no opportunity for crosstalk. The results were seldom shared and when they were, they didn't know how to respond. The full curriculum for groups can be found in *Grey Matters*, Chapter 5 and Appendices 4 and 5 (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/). The power of the group is also embedded in SET and REFLECT consultations that guide the choice of research topic at the beginning of the research and consolidating findings at the end to reinforce that peer research is guided by patients.

Group research is the magic ingredient in peer research. Groups ground engagement and consolidate a conversational sharing of stories to create common stories. Peer research aligns with JEDI principles of justice, equity, diversity, and inclusion. In particular, the diversity of peer research groups seems to foster common stories that are more powerful because of the diversity of experience. The following are examples of group research.

In a three-country study of women immigrants with suspected cancer, the SET and COLLECT group were conducted in Russian, Portuguese and Arabic languages, and when the stories of the three groups were combined after the REFLECT stage, the commonalities stunned us all. All women felt Canadian physicians were more clinical and less supportive, especially when it came to physical testing and conversing about feelings about cancer. The diversity reinforced a common immigrant discourse in spite of very different backgrounds and care experience.

Similarly, in an advanced care planning study in South Asian communities of Calgary, the initial data collection included a peer researcher from one of the four faith and ethnic communities and, as the results were discussed, the similarities led to powerful recommendations that were shared by all four traditions.

A final example is of Indigenous cancer prevention studies that included two treaty-based nations, an urban mixed Indigenous group and a Métis community. The data of each of the groups reflected their different cultures and traditions but each had similar concerns about the lack of cancer survival stories that led to hiding early cancer signs. The lack of stories of hope increased the devastation when patients were separated from their families for late-stage cancer treatments that reinforced the notion that cancer meant death.

As the use of JEDI becomes more ingrained in peer research, group research will become more involved in justice because the diverse groups will provide equity, diversity and inclusion examples of experience. Explanations of concerns and common solutions benefit from the ability to study a diversity of ideas that generate an almost improvisational energy during group sessions. The more diversity, the deeper the data possibilities. Group energy builds not only results but shared ownership of the stories. Some of the most exciting results have occurred when the groups work to reconcile differences. As the group negotiates a common story that reflects the diversity of the group, it generates space to explore new explanations and solutions.

The following identifies the data collection aspects of groups from *Grey Matters*. Many peer researchers like to work as a three-person team who take on the following duties.

- **Facilitation** is done 'sitting down' to be seen as a group member. Facilitation starts the conversation and supports and redirects conversation when the group stalls. This is not a leadership position—it follows participatory action research principles that state all group members are equal and bring differing but valued contributions. The facilitator might say nothing for an hour when the openness and respect for ideas and diversity is evident.
- **Flip charts** are created by the flip chart recorder, who stands up so that everyone can see as the data is recorded when the group is in person. The recorder records using a visible chat function when working online. Either way, the flip chart pages become the group data record. The flip chart person records conversation in small incident units. The names of contributing members are not included, unless the group requests that they be noted. The flip chart person is responsible for the integrity of the data, checking to make sure that the incident notes on the flip chart are accurate. This person also identifies when incident notes are turning into stories. These stories may be recorded on separate flip charts to allow groups to think in stories. The flip charts of stories are used for group analysis at the end of the day.
- The use of flip charts is more complex unless there is the ability to send data to each participant when a topic or story is completed. Each participant still has to scroll through the data instead of being able to see all the data at once.

- **Process recording** is done by a team member trained in recording what is happening in short incident notes. This is not a recording of content, but the nature of the conversation, ideas that resonate or separate the group, and the emotional connections that grow as part of the process. This provides the context and relationships within the group.

Groups are often involved in co-research analysis that informs important research decisions—SET: choosing the main concern or topic for the research; COLLECT: comparing categories to find the core category that explains the main concern; and REFLECT: confirming the findings and suggesting solutions and next steps. The afternoon ends with a summary and reflections on what they have learned about themselves and the topic, and what they think might be needed next and how they can help. The day ends with a short evaluation of the day and the process with invitations for next steps.

Focus groups create not only a consistent collaborative research environment but also motivation to continue to be involved in other peer research and often an interest in becoming a peer researcher.

Fieldwork and Participant Observation

Observing and taking notes is an essential skill, not only for fieldwork or ethnographic study, but because it highlights what the observer considers important to help unpack biases. These skills are essential for interviewing and group work, or any situation where information is collected by observers. Fieldwork is used at the SET stage of consultation with key informants and visits to community and clinical resources (Marlett & Emes, 2010, https://prism.ucalgary.ca/server/api/core/bitstreams/b7ccdd45-80bd-467f-9f1e-d610823efd22/content). The ability to observe and take short notes about possible concerns that might become research topics, ensures that those being observed don't feel that they are being researched. This is important because research per se must occur after ethics is approved.

In data collection, we focus on 'participant observation,' which typically means that one person participates and observes at the same time. In peer research, observation is taught in pairs so that they can share notes and discuss the impact of personal values on what people look for and record. The goal is to establish inter-rater reliability, which is achieved when observers are aware of their personal biases and expectations and can focus on what is happening instead of what they expect to happen. This takes time to achieve but is easier when one person observes and records as the event unfolds, and the other person participates in the event and records after the session. This allows the

participant and observer to compare their observations from two perspectives. This exercise teaches about research and the need to be open and not be drawn into looking at action through biased eyes.

This method was developed as part of a PaCER internship research project at Wellspring Calgary. The SET consultation identified that the best and least intrusive option for gathering data of classes and groups for cancer survivors was to observe activities and casual groups. The research team, whose members were from Wellspring, and the academic supervisor worked together to create a way for one person to observe and record while maintaining a discrete distance. The other person took part in the group and recorded their experience after the activity was completed. This is an example of adapting data collection methods to suit the nature of the community setting.

Participant observation is also the most difficult process to get approved in healthcare settings. Staff are often uneasy about patients watching healthcare being delivered. While it may be difficult to gain access, observations in clinical and community settings come with the expectation that the writeup of the observation is shared with the staff to discuss findings and to share the summary with any staff who are interested.

Shadowing doctors is often used to enable students to see first-hand the roles they aspire to. A similar process occurred when students in the PaCER program were able to act as research assistants in a peer research project in an intensive care unit (ICU). Their experience led them to choose to research about the transfer from the ICU to the step downward. Shadowing is an excellent way to study reactions in hospital or clinical settings, and sometimes the best way to achieve this is to arrange for a patient, who has permission, to observe their care and record what they experienced.

Mining Unstructured Public Data Sources and Artifacts

There is an explosion of publicly accessible information, personal beliefs, opinions, and experiences through the internet and related social media platforms. It opens new meaning to the grounded theory contention that 'all is data.' These new and widely available data sources are unorganized and require careful attention to ensure data quality, especially reliability. Data mining is not new in marketing, public opinion, and values research, and with more interest in citizen science, these new forms of data will become more a part of more formal co-design and research.

Some of the public sources of information include the following:

- Interactive news publications, customer generated online comments.
- Social media platforms such as Facebook, LinkedIn, Reddit, etc.
- Video streaming websites like YouTube and photo sharing platforms like Instagram and Flickr.
- Medical records and health chat rooms such as HealthfulChat (https://www.healthfulchat.org/), Patients Like Me (https://www.patientslikeme.com), Health Experiences (https://www.phc.ox.ac.uk/research/research-themes/patient-experience), and Health Talk (https://healthtalk.org), along with an increasing array of professionally led open chat discussions.
- Personal research platforms, such as My Data, Our Health in Holland, are opening new opportunities to access how patients understand the issues related to their health concerns. As these are translated, it will build opportunities to share personal health research results across countries.

These data sources require the use of peer researchers familiar with internet practices, because they have more expertise in assessing data quality, reliability, and soundness of online data. Accessing these data sources may also require the assistance of those familiar with the target online resources. Online resources may be a good place to begin co-design, because the use of media platforms for data collection is a growing field and it doesn't require ethics approval. The use of crowdsourcing has been used to access simple, low-tech, inexpensive solutions to fight COVID-19 (Ramamurti, 2020, https://hbr.org/2020/10/global-crowdsourcing-can-help-the-u-s-beat-the-pandemic). The use of online technology in citizen science is informing all levels of data from individual protein folding online competitions to artificial intelligence networks that are informing national COVID-19 planning teams. Clinical studies are adopting crowdsources to extend sample diversity and hard-to-reach populations.

Data Management

All data collected needs to be managed and protected. Table 8.3 is a short summary of some of the options that have been proven successful in peer research. Each management approach requires training and oversight to ensure that data is held in secure storage according to ethical standards. Each of the data management options have assets and obstacles in peer research and some adaptations are included.

Table 8.3 *Six Ways of Managing Data for Sorting and Categorizing*

Data	Asset	Obstacle	Adaptation
Audio and video recordings	A permanent record of the data collection event as a reference for all other data management tools	Privacy issues: These records must be secure at all times, which makes it difficult for teams to share the recorded data	Audio and video recordings can be held temporarily while transcripts or incident lists are being prepared Some sponsors request audio recordings, but this can prove dangerous as the participants can be recognized. Avoid it if possible Quotes can be accessed and depersonalized as needed
Full transcripts	Most qualitative research uses full transcripts for quotes Peer research tends not to use full transcripts, except during training to listen without bias	Time consuming Computer transcription needs careful editing Participants are often uncomfortable with full transcripts	Use audio and flip chart notes to take short notes and identify those areas most related to the topic Use full transcripts of sections that may be used for quotes
Speech rhythm transcripts	Connection to participant Fast and easy to transcribe Speech rhythm reinforces memory	Novel approach may be foreign to qualitative researchers	Speech transcripts often mirror incident notes in story transcripts Use as text backup of audio tapes
Short incident notes of 'what's happening' or 'what's it like'	Consistent format for all data collection methods Includes unstructured and social media data	Qualitative researchers may still require transcripts	Begin using short incident notes as part of SET focus groups to build competence in using short incident notes in other data collection methods

Table 8.3 (*continued*)

Data	Asset	Obstacle	Adaptation
Story template that includes the context of the research, the steps in the plot and the consequences of the story	Template can be used in all data collection Templates are used for both incident analysis and story analysis Provides common format for data management	Shifting templates as individual stories become group stories	Templates can be used during data collection Story templates can be used with participants when sharing stories and when analyzing stories at the end of COLLECT interviews
Framework templates	Each team member can enter their data directly from recordings into a case/concept framework template	The use of a framework may encourage quick analysis without consultation	When the basic framework is known, it helps identify options for co-design topics and main concerns

Whenever possible, students and new researchers should ensure that there are audio recordings of their work so that they can refer to them to relive their experiences, evaluate their style, and think about how to interview better. It also helps to learn, to listen, and record in short incident notes or story templates.

The speech transcript was introduced in Chapter 2 as a way of capturing the patient voice with the rhythm of speech. Also in Chapter 2, there are numerous examples of speech transcripts that produce a natural speech rhythm, which improves memory and connection. Reading speech transcripts produces a feeling of hearing the person tell the story. This method is useful in reports developed for patients and communities and has been accepted in peer reviewed journals. A short example of a speech transcript might be:

When I am in a new group

fear strikes

I tend to attach myself to someone who looks friendly

I can then follow their lead until I feel safe.

Short incident notes and stories are the preferred method of managing data in grounded theory research and other participatory and inductive research methods. They can be collected or produced on incident cards to increase the

ability to sort and compare incident notes during constant comparison. It is easy to take pictures of the cards in a category for data tracking. Notes can also be added on the back of cards. I have tried to do this using online organizers and would encourage their use if using cards seems low tech.

Narrative data collection using story templates can be produced during data collection from short notes or by listening to audio recordings. When seniors found it difficult to transcribe data or take short notes, they suggested using the story templates to manage data. It was easier to use the story templates, filling in the spaces as they listened to the tape repeatedly. It also has the benefit of identifying gaps in data collection. It is common that the storyteller misses important information that describes the initial context or in the consequence of the story. Many participants enjoy seeing the story being recorded on the templates as it takes shape, and have commented that it makes the story real to them and valued by the researcher.

The framework method for data management creates a structure at the beginning of data collection to enable researchers to enter their data quickly and compare entries to build analysis structures. There are computer software options to move through the stages from initial categorizations to final reporting. This framework research by Gale et al. (2013, https://doi.org/10.1186/1471-2288-13-117) is an excellent source of framework analysis in policy research.

As a tool in peer research, frameworks organize and manage data into a consistent matrix consisting of columns organized by basic themes that can be redefined. The rows represent cases in framework analysis. The cases are organized according to the structure of the research such as different researchers in a team, different disciplines in a team, programs according to focus, stage in treatment, funding formats, etc. The resulting matrix reflects the unique needs of the research.

Data Analysis

Data analysis is the process of taking data apart into pieces that can be questioned and sorted into similar categories, then recombining these pieces of data to capture new meaning about the topic. Constant comparison of incidents leads to coding or naming the categories that represent the collective meaning. In peer research, categories are named by the actions or descriptions of what is happening. Qualitative research in general is more descriptive of what the experience of the incident was like. Peer research analysis is encouraged to remain grounded in in vivo language and codes for categories to ensure that the research remains in a patient voice and captures patient experience.

Note that statistical analysis is not included in the list of peer research options, although there are computerized thematic analysis tools that are easy

to use that could be adopted by peer researchers. Scoping reviews are also not included, although McCarron et al. (2020, https://doi.org/10.1111/hex.13054) worked with three collaborating patients to conduct a scoping review of patient motivation for interviewing. There are several articles published with the patient collaborators relating to the possibilities of training patient colleagues to conduct a variety of research methods. Refer to Chapter 5 for more details.

Table 8.4 outlines the major data analysis techniques used in peer research. In raw data, the units chosen and the codes of potential categories all use the same language.

Table 8.4 *Analysis Methods Applicable to Peer Research*

Type	Focus	Example	Assets	Difficulties	Adaptations
Content and thematic analysis	Comparing data to sort into descriptive or emotion category codes	Challenges with food for patients with Inflammatory Bowel Disease	Descriptive data Many computer options available Variety of coding schemes	Academic traditions use theoretical codes that may not be meaningful to patients	When thematic analysis is used in peer research, real life codes can be used throughout
Classical grounded theory analysis	Identifying and explaining main concerns of populations Theory is generated directly from data.	Peer resources in community-based support programs	Rigorous, structured analysis	Focus on conceptual categories	Use of story as 'incident' or unit of analysis Use of in-vivo, real life codes for categories
Narrative	How people form and share meaning through stories.	Losing our stories when diagnosed in a mental health system.	Common unit of analysis for all data collection Properties of stories inform interpretation.	Not widely accepted in academic journals.	Common story template and analysis format makes it easy to teach and share ideas not related to research, per se.

Table 8.4 (*continued*)

Type	Focus	Example	Assets	Difficulties	Adaptations
Discourse and systems analysis	The study of language to find meaning and power in relationships and systems	Analysis of online program descriptions to identify the role of patients and their agency related to their health	Focus for systems analysis at all levels Easy to teach and access through social media	Can be threatening to systems	Use of analysis of language at all levels from policy to the patient/ provider interaction
Framework analysis	Organize and manage early findings of team members	Contrasts themes across specific programs in an organization	Rows (cases) and themes enable early and summative data to be analyzed quickly	Mostly used in descriptive categories and requires oversight to ensure common reporting	Excellent for shared analysis of peer research teams, where each member analyzes a theme

Content and Thematic Analysis

The majority of qualitative health research uses content and thematic computer analysis where data is sorted using pre-established category codes created by the researcher. Most current computer analyses allow for the emergence of other categories. Computer content analysis of social media has become popular in quantifying patterns and categories of values, preferences, and expectations. There is a broad range of content analysis software (solutions for public and unstructured text data in chats, comment sections, news, blogs, and social media platforms). One example is Intellspot (Valcheva, n.d., https://www.intellspot.com/content-analysis-software/).

Peer research methods for general qualitative studies have used content analysis but may be challenged by theoretical coding processes that require advanced academic training and experience.

Regardless of the process or the type of data, content or thematic analysis builds bridges between talk and meaning. Whether that meaning is presented in descriptions of experience, stories, strategies or new ways of doing things, the goal is to use data to confirm or uncover meaning.

Classical Grounded Theory Analysis

While classical grounded theory was the research method used during the innovation and incubations stages of peer research, Holton and Walsh's (2016)

book, *Classic Grounded Theory: Applications with Qualitative and Quantitative Data*, provided a modern take on classical grounded theory as a method that can be used with many research traditions. This book is recommended for those who have not used grounded theory previously because it is applicable across many disciplines and research traditions.

Classical grounded theory has been adopted widely as a part of qualitative research analysis to increase rigour and concept development. The analysis tools used most widely by qualitative researchers are iterative analysis cycles, open coding, and constant comparison of data. Iterative analysis not only ensures focus but also increases the potential for unplanned concepts and theory to emerge.

Classical grounded theory analysis consists of creating short incident notes from whatever data collection method is being used. Whatever the data, the first analysis question is: 'What is happening here?' A more traditional question, if you are focusing on early abstraction of concepts, would be: 'If this is my data, what am I studying?' Analysis exists as part of constant comparison of the incidents that lead to categories and eventually theory. These categories are named or coded according to the shared meanings of the incidents included in the sorted categories. If the new incidents don't find a home in any of the categories, a new category is created and named. Categories are expected to divide or combine through this process to refine their relevance to the main concern of the study. Throughout this process, the definition of the main concern or topic is being refined, and one category is selected that best explains the underlying structure of the main concern or topic.

The Holton and Walsh book was instrumental when combining classical grounded theory with participatory action research principles of the peer research's engagement strategy.

- SET: An open coding process that collects and categorizes concerns of a population. The analysis of open coding iterative cycles, as part of a classical grounded theory study, is done after ethics approval. More recently, in peer research, the mandate to empower citizens in the selection of the research topic opened opportunities to use open consultations with patients, community and clinical services, and online platforms to create categories of concerns prior to ethics and this has streamlined the identification of the topic of study as a common concern of the population involved.
- COLLECT: This includes iterative cycles devoted to collecting, analyzing, memoing, and planning next steps in the research process. This is done to focus on explaining the main concern

to find solutions. In peer research, the iterative cycle includes similar functions of collecting, analyzing, and memoing that are the functions of an individual peer researcher who analyzes their particular data collection events. However, the individual analyses are shared with a peer research team to combine and challenge emerging categories in order to plan the next cycle. This ensures both theoretical sensitivity and increased rigour that comes with interrogating emerging categories as a group.

- REFLECT: This includes interpretation and theory building. Theory is pragmatic, and it consists of a core category that best explains the main concern. This core category also coordinates other categories in finding solutions to the main concern. In peer research, the best choices are presented to a REFLECT focus group, which confirms or modifies the choices from the iterative data collection and analysis cycles. Selective coding identifies the core category. This enables patients to confirm the findings and to be involved in identifying solutions and options.

Grounded theory analysis is ideal in new areas of research, conflicted or confused social organizations, or in tracking social innovation, because it adapts easily to unexpected information. Grounded theory is particularly effective within organizations where the roles and relationships are the focus of study.

Narrative Analysis

Stories are the currency of communication, and they are the foundation of data analysis in peer research. Narrative focuses on the ways in which people create and use stories to interpret and explain daily life and world views. As such, narrative analysis includes a wide range of options, depending on the profession or discipline. Anthropology and ethnography gravitated early to use stories to capture knowledge about people, their culture, and adaptations. Sociology and nursing produced ways to analyze the content of stories, and psychology specialized in ways to understand how people form meaning in their lives through narratives. In general, narrative analysis helps make sense of past experience. It organizes our current experiences and uncovers the values, expectations, and structures that lead us to share stories with others to create common stories and narratives. Narratives of change and forecasting narratives focus on the anticipated futures that emerge from story analysis.

The narrative analysis as part of peer research is based on collecting data incidents that are analyzed initially using story templates. These templates organize data according to the context of the story, applying the questions about

story properties - the who, what, where, when and how - to probe for ways to categorize data. The steps, or plot of the story, provides the strategy, or expected process of the story. The consequence includes the expectations, outcomes and impact of the story. In addition to the story, a range of narrative functions are identified including metaphors, mottos and slogans, roles, and values.

The early analyst focuses on the apparent questions—the who, where, why and how—but as they gain confidence, they become attuned to the subtle nuances of individual difference and style. Narrative analysis aligns with grounded theory because both are looking for explanations of what is happening in the data. In narrative, the question 'what is happening here' leads naturally to the properties of the story: who was involved and what actions were in play. When asking how the story unfolds, we are looking at the dynamics of the movement that unpacks the power of using the story in analysis of the entire incident (why did this occur), flow (why did this happen next), the highs and lows. The individual elements of the story are also used to tease out the subtle actions, shifts in focus and meaning. The story invites the analyst to repeat—what is actually happening here and why? This iterative process leads to a main story or script that best describes the main concern of the research. It is also possible to use the main story to confirm related thematic analyses. The goal of the narrative is to provide real life data of actions in the past and propose actions for the future that are understandable to patients, healthcare professionals, the general public, and policy makers.

Discourse Analysis

Discourse analysis focuses on analyzing language, especially the language of power and the powerful. Direct access to speech acts as data that identify pronouns, verbs, metaphors, and role descriptions. There is an example of discourse analysis of stories in autobiographies in the Resources section of this chapter. Discourse has been particularly useful in emancipatory research because language and the structures of language uncover both sources and impacts of systemic discrimination and therefore study sources of power and wealth or privilege that can be used to confront power.

The use of JEDI principles provides a framework for classifying language used to promote systemic power tropes that produce access to justice, equity, diversity, and inclusion within the study of policy and practice in health systems. Discourse analysis of systemic discrimination using these principles is now a viable option because of public access to social media documents, program and policy statements, and advertising. Critical theory research uses discourse analysis to detect power imbalance and systemic obstacles. Discourse analysis also identifies personal roles in organizations, professional relationships, and

business practices that protect power through structures and policy that can be employed as a secondary analysis after the initial analysis is complete.

Framework Analysis

Framework analysis provides an early stage of analysis throughout, regardless of research methods used. The engagement stages highlight the use of framework analysis in peer research.

- SET: Co-design team of patient researchers can enter preliminary data about the potential topics or problems for research. These can be entered by the team members as possible topics or social problems for co-design. This framework matrix could replace the current use of posters of possible topics for research for a SET co-design team to prioritize. The matrix could also be used in rating each topic or problem during the SET focus group.
- COLLECT: During data analysis, the framework template could initially be used to record data at each iteration, and then it could be used to redefine cells according to the level of theme and subthemes. In action research, the template could be used to identify various ways that data inform or explain the social problem of the research.
- REFLECT: The co-design team of patient consultants could use a framework template to summarize categories related to the topic or to portray the explanation of the main concern, based on the core category and properties such as sequence, actors, location, and funding.

It would be interesting to test the acceptability of framework analysis beyond the ability to organize and present data and findings. While it is effective in identifying similarities and differences in an easy-to-understand format for shared discussions, the eventual quality of the interpretation or theory is yet to be tested.

Framework analysis increases the scope of analysis. Tremblay et al. (2017, https://doi.org/10.1002/ajcp.12142) introduce a number of frameworks in community participatory research, a framework analysis process using in vivo codes in a study of patient experience in emergency care. The article provides a step-by-step approach to framework analysis although it is not called a formal framework analysis because the actors are not included.

The following is a peer research example of a similar process of abstraction. Note that peer research is generally simplified to include fewer steps.

[Direct quote—transcribed with natural breaks with in vivo incidents.]

As I noticed changes in the way people reacted to me,

it became important to be more like everyone else

Being normal is impossible

It always leaves me feeling alone

I always expect to fail.

Incident

I feel alone and expect to fail when I try to be normal

In Vivo Category Codes

I don't belong

Trying to fit in

Expecting to fail

Interpretation

At this stage, interpretation options tend to blend. Interpretation is the act of explaining, reframing or otherwise understanding the meaning of a main concern, phenomenon, or practice. It uncovers the underlying structures in what people do and say. The term 'interpretation' exists at the level of categories, pragmatic, explanatory, and conceptual theory. As such, it includes qualitative interpretation of themes and classical grounded theory that includes explanations of the concern and potential solutions. Because inductive analysis consists of constant comparison and memoing, interpretation occurs throughout the peer research process when using grounded theory as part of a blended methodology.

Interpretation is practised by peer researchers and participant co-researchers at the end of each data event, by individual peer researchers, by the peer research team and by the REFLECT team that consists of peer researchers and consultants from SET or COLLECT phases.

Memoing is the act of documenting what you are noticing, the patterns and questions that emerge. A memoing trail of meaning becomes the thread of interpretation as you develop a sensitivity to ideas that are emerging. In peer research, memoing is considered a personal and private chance to create your own conceptualizing style. This personal memoing occurs prior to sharing analysis with the peer research team so that each person is prepared and more confident in planning next steps.

I have noticed that, while not an official characteristic of peer research, inductive research itself develops a finely tuned sense of pragmatic theory. While becoming immersed in the data and analysis, peer researchers become tuned to underlying concepts and potential directions for sampling and adapting methods. The following is an example of a team approach to promote individual conceptualizing.

A large team of student interns held a day-long focus group, and each person analyzed a portion of the flip charts. Each intern wrote memos about the categories that were emerging and what interested them most. While personal memoing is considered a personal and private process in grounded theory, it prepares each intern to take part in shared analysis.

During shared analysis, the first intern presented a category they had identified from a sample of incidents and why the category was of interest to them. The intern then facilitated a group discussion about the category and invited other team members to contribute data to that category. Each team member had a chance to present a new category or a change to an existing category. This version of shared analysis provides a learning process for personal conceptualizing and shared decision-making. It is made possible as part of peer research because of the use of in vivo and real-life coding that focuses on what is happening instead of relying on emerging academic concepts.

Once there is an initial plan for how the categories work with the main concern or topic, a REFLECT focus group is convened. This consultation includes mainly patients and community members who were involved in the SET research. They work with the findings from a patient perspective. They challenge categories and their relationship to find a coherent presentation that explains, resolves or describes the findings. The REFLECT group then discusses the potential impact and suggestions for implementation or innovation. These lead to discussions about how to present the findings, potential audiences, and

opportunities to try out the findings. The session ends with an evaluation of the research process.

Because interpretation is not a separate process, we come back to the analysis frameworks that were used throughout to describe the process and expected outcomes.

Thematic Interpretation

The final stage of thematic analysis is a process of consolidating main themes and the hierarchies of subthemes. Quotes are generally incorporated into the structure to capture patient voices. This often leads to discussion of each thematic hierarchy.

Grounded Theory Interpretation

Grounded theory as action-based research arrives at the end stage as part of iterative cycles that support analysis and memoing of the emerging explanations of the main concern and resolution of that concern. The focus on the main concern and individual memoing that supports shared analysis builds momentum toward a consolidated picture of what is happening to create and sustain the main concern. The essence is a simple and actionable pattern that leads to specific recommendations for action backed by evidence.

Narrative Interpretation

Narrative interpretation provides a way of conceptualizing findings within a story framework. Because narrative supports all forms of data collection and analysis, it can augment any stage of the interpretation processes. One of the interpretation tools identified during narrative analysis of autobiographies by undergraduate and graduate students who used story templates throughout their class research is presented below.

Autobiographies were eventually analyzed using an abstracted script template that captures the context, plot, and consequence of a category. The context is abstracted using the property of 'when,' which identifies the setting from the person's perspective, and as such it begins the template with the 'I' pronoun. The plot is reduced to the fundamental action that describes the property of 'how.' The consequence captures personal life story changes, beginning with the 'and then' property.

[Direct quote—transcribed with natural breaks.]

I noticed changes in the way people reacted to me

It became important to be more like everyone else

Being normal is impossible

Eventually it left me feeling alone

Always expecting to fail

Potential Script or Interpretation

When people notice the change in my condition

I try to fit in

And when it doesn't work, I feel more alone and a failure

The benefit of these simple scripts is that they are easily understood and tracked by researchers and participants during and after research. Scripts can be combined and structured into a final interpretive scheme. Action scripts also focus recommendations for prototype testing and implementation. This method of interpretation is expanded in Chapter 10: Standpoint Theory.

Discourse Interpretation

Discourse analysis results from the investigation of language to uncover sources and supports of entrenched power. It uncovers pragmatic and systemic theory about the influence of power at the level of relationships, organizations, or society. This opens a power-based debate about why actions and relationships occur the way they do. A power-based interpretation can be applied at all stages of analysis and interpretation where you are searching for agency, both internal and external, to understand how actions happen and why people take up the roles they do. In Section 3, discourse analysis is used in Chapter 10 to locate the sources of power that patients experience within the health systems they use.

Framework Interpretation

Like discourse analysis, framework analysis is a secondary tool that opens avenues for discussing interpretations.

Quality Indicators of Peer Research Partnership

Measuring Quality in Peer Research

Quality indicators can be considered from a number of perspectives. The peer research method adopted a classical grounded theory analysis to provide a consistent, focused, and robust method of analysis and interpretation. The key to grounded theory quality lies in the process of iterative data collection and analysis through constant comparison, memoing, and planning next steps. This is the benefit of grounded theory standards that ensure that measuring and testing theory is built into the research fabric.

The quality indicators for grounded theory research include four practical criteria. A fifth category, engagement, is added for peer research.

- **Fit**: The final theory fits with the original main concern and the data.
- **Work**: The theory does what it is intended to do; in other words, it works to inform the underlying structure of what people do and say.
- **Relevant**: It is useful for those who share the same concern; it makes sense.
- **Modifiability**: The theory can be applied and modified for different populations and different concerns.
- **Engagement**: This category was added for peer and community research to identify how patients and community members were engaged in the research and how the results can be used in engaging other groups and communities.

The following criteria were developed at the end of the *Grey Matters* project to formalize how peer research was different from qualitative research:

- **Real-life language:** All communications, including proposals, interactions, meetings with stakeholders and media, research methods, and protocols, reports, and articles use language that is understood by all. Concepts may become abstracted but retain real-life experience examples.
- **Representation**: The various voices in your project are clearly recognized and documented. Representation is a negotiated process. The methods for achieving partnership at each stage of the research—from creating the research agenda to presenting findings—are negotiated through a process of mutual agreement (cf. Chapter 3).

- **Relevance**: The process and results should signal a change in the practices of research. Begin by reviewing the following principles of collaborative research with each person who joins your team. These set the expectations of how all researchers and participants will be included in the process:
    - **Equal but different:** The thoughts and beliefs of all participants about the shared questions and issues are equally valid. Everyone from the grant holders, project coordinators, peer researchers, co-research participants, and volunteers need to accept that each person will have a say.
    - **Trust:** Trust is hard to earn and is quickly lost. Actively acknowledging the contributions of participants leads to greater understanding and an openness to hear and learn from the voice of others.
    - **Shared power:** Nobody decides for somebody else. Sharing power starts with the expectation to listen and the freedom to express opinion. Each person learns from others and grows in their own confidence and capacity. The team lead and committees need to ensure that there is a consensus process in place for meetings and a process to make decisions between meetings. This requires a strong team lead that summarizes information and data for discussion, sets meetings, writes minutes and emails, and maintains open logs of progress. If the participants are going to own the results, they must feel they own the process.
    - **Shared work:** To share expertise, there needs to be a willingness to use common language, and model and mentor unfamiliar activities. Learning to share requires time for reflection on the process and joint ownership of successes and failures. Working together includes the glamorous tasks of planning and committee work, but also the tasks of clearing up, making tea, and taking the heat for missing deadlines. It may be just as hard for an academic to learn to chat with a potential participant over tea as it is for a senior to analyze data. Neither task is exclusive in collaborative research.

Are We Doing It Right or Is It Any Good?

We end this long and detailed chapter with a comment made by JW from the *Grey Matters* project, who summarized the thoughts of her research team of

seniors: "It may be easy to learn how to do the research but then, how do we know if we are doing it right or if it is any good? These words resonate with most research innovation" (Marlett & Emes, 2010, p. 25).

JW has a good point—wanting to do research isn't enough; it is necessary to know the standards used to judge good research, so that there is confidence in the quality of the work. The standards for judging quantitative or experimental research (experiments with numbers) are widely accepted. Reliability in quantitative research means that the findings can be replicated by others who use the same procedures.

The following are commonly accepted standards for qualitative research. The criteria of quality in grounded theory includes clear measures of clear links between the concern, data, and findings (fit). Does the theory work for the reader, is it relevant or make sense to people with similar experience, and is it flexible enough to be useful for similar concerns or problems?

Credibility

Are the results believable from the perspective of the participants in the research? Would a patient or a member of a marginalized group who was cruising the internet have faith in what you are presenting? This includes faith in the question, the methods, and the findings. This is where peer research has the edge over most academic researchers. If the research is designed and conducted by patients, the results should speak to patients.

When patient's use research done by other patients, they will likely be surprised that peer research exists, but as they respond to the concern identified, the explanation of the concern, and the suggested actions to make a difference in their language, they are likely to resonate with the process used and be intrigued by the results. Because peer research uses the pronoun 'we' in articles, researchers are building a relationship not only with the patient participants but with other patients who are concerned about similar problems.

Transferability

When a researcher talks about findings or writes an article, they need to think carefully about how other people or programs might translate the findings to their situation. To accomplish transferability, the researcher starts by carefully describing the 'who,' 'where,' 'how,' 'what,' and 'when' of the research, so that the reader can understand the research and how it relates to their own situation.

It will take some time to establish a patient research voice in academic publications, so it is important to foster other ways to write and speak about peer researchers in other venues that patients read. This initially might include

health associations related to the research, seniors magazines such as *Zoomer*, or publication hubs for peer research like the PRISM/PaCER hub.

Dependability

This is a confirmation of how carefully the research was done, what problems arose, and how the changes made affected the study and the results. Dependable research is transparent, meaning that nothing is hidden. Sometimes, standardizing the process increases dependability but can decrease credibility. As JW, one of our researchers, commented when administering their standardized questions: "We felt good that we had a standardized questionnaire and that we were doing the questionnaire the right way, but the answers were boring and left a lot of questions unanswered" (Marlett & Emes, 2010, p. 86).

Objectivity

Academics are most likely to use this objectivity standard against research done by patients and communities. They may feel that peer researchers are biased and tempted to distort the information to reflect what they want to find. Research is not about proving the researchers' thoughts and knowledge but about looking at every event or piece of information as if it were happening for the first time. Objectivity means that every observation is open to question. Every researcher, regardless of age, must struggle to avoid having their biases affect their observations. Research can range from a very simple observation to a very complex investigation, but regardless of the size or complexity, all research is a process of discovery.

In this chapter, we have attempted to provide a broad overview of how health researchers and healthcare providers can understand and support peer research. The following quote is from two of the authors of *Grey Matters* in their field notes:

"It would have been so easy to take the data and to write it up as an academic, the data spoke to the theories that I was interested in. It was a hard decision. In the end, perhaps there is a place for both, research that speaks to theory and research that speaks to everyday life. The ideal would be to have both goals possible in the same method; at least it's something to work toward."

Summary

This chapter explored the basics of peer research methods in a variety of health-related research options to extend patient engagement. Those wishing to become peer researchers may also understand why peer research is different from other forms of qualitative research.

This chapter completes the second section, combining the findings of a number of research projects. As such, it provides the background for PaCER training for those health researchers wanting to include patients in their research plans and research teams and thinking about hiring trained patients to augment existing or proposed grants. It is also provided for researchers who have either taken PaCER training or worked through the companion *Grey Matters* and this manuscript, and who are willing to experiment with training the patients and communities they work with to develop their own version of peer research.

Research students and researchers who identify with a patient or community population might use this chapter to hone their personal research skills. It is hoped that teams who are working with peer researchers may consider new ventures to create new models of peer research. This chapter is, above all, intended to incite experimentation and sharing of engagement methods. It is not a manual but a set of ideas from 30 years of experimenting with engagement methods.

The next section uses the methods and theories of Section 2 to extend peer research to support social innovation and social enterprise to bring patients and communities into the transformation in health that is 'just over the hill.'

Questions for Discussion

1. Have you used methods similar to these as part of your research? If so, how have peer research methods differed, if at all?
2. What methods seem to capture your ideas about peer and community research?
3. What obstacles do you see in adapting these peer methods to your patient engagement practice?
4. How might you incorporate peer research into your future plans?

Resources

The following process is one summary of a research method using the stages presented throughout this chapter. It captures a single iterative cycle of data collection, analysis, interpretation, and planning the next cycle.

Table 8.5 *Iterative Cycle of Data Collection, Analysis, Interpretation, and Planning*

Collect your data	Prepare to listen and look for incidents in the data you are about to collect. Incidents are actions (stories), and elements of stories and indicators of actions (metaphors, strategies). Coding occurs at the category level as incidents refine, challenge, or support the category code. As new data is captured as incidents (using cards or computer programs), question the incident using the standard questions and make notes on how the answers deepen your understanding of the incident and be prepared to compare with other incidents or categories.
Question, code, and constantly compare incidents	**Question** each incident, in turn, to learn how it relates to your main concerns and what ideas it brings to your analysis. Based on your questioning, refine each incident to reflect the answers to your questions. 'Rehearsing children' might change to incident codes 'rehearsing children for the social worker visit,' 'rehearsing children-vulnerability,' or 'rehearsing children to be allies.' **Constantly compare** each incident to the incidents within categories of other incident codes, and from this sorting process, you form categories that share the same meanings and/or properties. As categories form, you compare new incidents to the emerging categories. You continue to ask questions of the contents of each category to test its strength in making sense of the main concern and how the category could be used to resolve or find solutions to the main concern. Categories are flexible and combine and divide as new incident codes are added. When the **core category,** that best category that you have identified, you compare each remaining category to the core category and to each other to find the pattern of categories that make up your working theory.

Table 8.5 (*continued*)

Memo about emerging categories	Write field notes about the methods and findings each time you collect data. Memo as questions arise about connections and ideas about emerging theory. If you are sharing analysis with your teammates, you might follow one category throughout the analysis to learn about how categories evolve or dissolve. As you come close to the core category, focus on which category seems to stand out and how your category might relate to or challenge that emerging category as theory. Continue to memo selectively about which category best seems to explain the main concern and is the foundation of your theory.
Shared analysis, with the researcher team and the principal investigator	This is an opportunity for each team member to present and be questioned about one of their categories. Initially, each person presents and works with the team to collect and consolidate any incidents or concepts that fit with their category. Each person has at least one category to work with. When you are selecting the core category, each person presents what they consider to be the best category until consensus is reached. Each person then presents how their personal category relates to the core category. During this shared analysis, the team also divides up the remaining categories and each team member works with that category to prepare a poster for REFLECT.
Disseminating research findings	Next steps allow the team and the principal investigator to decide how to disseminate the results from the Reflect focus group paying attention to the consumer targets, academic teams, publication.

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SECTION 3

Pivoting to Possibilities: New Emancipatory Theory and Methods for Peer Research and Innovation

So far, the book has been about the foundations of a new emancipatory science of engagement that supports new research roles for patients in academic research that includes co-design with patients and health researchers to adapt theory and methods for qualitative researchers and patients. I had intended to use the last section, Pivoting to Possibilities, to introduce new theories and consolidate a peer research methodology. However, the landscape of health research outside of academic health research has changed dramatically with pressure to democratize health research, respond to health technology advances, and systemic discrimination. During this time, patients and communities have taken advantage of these forces to use and create personal health data and use this data to share data with other patients, locate treatment options, connect to research opportunities to use their own data and augment their understanding of their health issues. The need for the book suddenly made sense.

We begin this chapter by returning to the basic dichotomy of health research and emancipatory research to identify the reality that opposites, in the case of health transformation and planning, can and have worked together to produce research that includes both quantitative and emancipatory science. Both are desperately needed during this time of crises in our aging health and research systems, from new challenges such as climate change, civil unrest, the polarization of society into camps unwilling to communicate, and a growing rejection of science. Emancipatory research may provide ways to bring localized communities together to understand local issues and work together to conduct research to make a difference. The ability of communities to focus on local concerns has been cited as a way to address wicked problems that have no alternative solutions and, as we encounter strong forces for change, we will need to include patient voices to move forward. Emancipatory peer research is an example of localized research focused on patient concerns in health research and planning that bring new patient research voices to health research and planning.

Democratization of Health Research and Planning

This force combines initiatives that have come from within existing health systems and policy. Responsible Research and Innovation (RRI) and the Open Innovation in Science (OIS) (Beck et al., 2021, https://doi.org/10.1080/14479338.2021.1999248) movements and citizen science are examples of international movements to democratize science to create more lean, creative, and flexible research models that respond to the rapid changes in healthcare and research. These changes emerge from within health systems, government policy, and funding structures. Participatory health science movements such as citizen science (CS) provides a way to include users and patients as citizen scientists who collect data as part of academic research grants and projects. Citizen roles focus on extending the scope of research and are governed by engagement principles. The emergence of community science as participatory science is making significant emancipatory moves to support communities to identify research to address pressing needs and conduct research to make a difference. These are possible because of volunteers who are motivated to support change and learn new skills. PaCER and other emerging patient training models are in effect citizen science but have focused on training and co-designing methods to bring a unique and emancipatory citizen science voice to health research. Many of the graduates continue to volunteer and others are paid to conduct research as part of health research and planning teams.

Democratizing science began by including patients and other stakeholders in health research teams to bring new perspectives to research. Emancipation theory began with Freire's participatory action theory as part of critical education of the poor in South America. The move to democratize science also includes ways to include an authentic patient research voice to inform current research practice. The concept of emancipation of patients was first promoted by Charlette Williamson (2008, https://doi.org/10.1111/j.1369-7625.2007.00475.x), who laid the foundation for a theory of patient emancipation within health systems and research in the UK and led the way to public and patient involvement in health and social care at all levels in the UK to counter harmful experiences and systemic discrimination in healthcare and research.

Health Technologies

Health technology migrated from the third industrial revolution, which saw the adoption of single innovation technologies such as computers and online communication, to the fourth industrial revolution, which combines these single technologies with digital, physical, and biological technologies. While thousands of new health technologies are created every year, we are focusing

on technologies that relate to patient engagement in personal health and health care. This includes devices that diagnose, prevent, monitor, and alleviate suffering. One example is precision medicine and personalized medicine that combine technology with biological systems and organisms. Patients already use smart phones that are becoming hand-held laboratories, smart contact lenses have been developed to test blood sugar, and Kardia heart monitors analyze and share information between patients and physicians. The list is large and has the effect of creating new roles for patients to coordinate diagnostic and monitoring devices that produce real-time data for patients to use and share with care providers. Artificial intelligence (AI) provides real-time data to detect early signs of health conditions and tools to improve diagnostic and therapeutic accuracy.

Increasingly, technology uses early detection and preventive care to reduce chronic and stress-related conditions in order to promote wellness options for patients to live longer and better. This is not to say that there are not serious obstacles inherent in healthcare that uses costly technologies that may increase the gap for those unable or not familiar with technology. In my reading of this opportunity, it comes down to making technology literacy and personal health care part of all educational programs and insurance packages (Bhatia, 2021, https://doi.org/10.1177/0972063421995025).

JEDI Principles Challenge Systemic Discrimination in Health Care and Research

The adoption of JEDI principles in Canadian academic institutions and many health authorities has been a conceptual leap into emancipatory science, systems reform, and social innovation. The link between JEDI, the emancipatory theory of Paulo Freire, and digital literacy is clearly outlined by Tygel and Kirsch (2016, https://openjournals.uwaterloo.ca/index.php/JoCI/article/view/3279/4304).

While adherence to JEDI principles is expected to improve existing systems, it will also promote the need for peer research bridges between health research and equity-seeking groups. Emancipatory peer research is able to produce real-life data from diverse and unheard populations. Readers are encouraged to access the EDI toolkit, which provides a guide to implementing JEDI in health systems (Equity & Inclusion Office, n.d., https://equity.ubc.ca/resources/activating-inclusion-toolkit/).

JEDI also acknowledges the importance of group identity in understanding the value of real-life narrative data that captures the context, structure, language, and outcomes of identity as part of the experience. SoE reinforces emancipatory theory and social identity in these final chapters by providing

new theory to encourage patients and their allies to identify and analyze systems from their unique perspectives and to show how language can be used to understand the intersection of patient identity and agency in health care and research situations, policies, and practices.

Theories and Models That Inform 'Possibilities'

The following resources underlie the social change, theory, and methods of the future. The resources from the introductions to sections 1 and 2 are also relevant.

Emancipation, Liberation, and Empowerment Theories

These theoretical models recognize the capacity of patient researchers to challenge systemic discrimination to achieve equality. Salutogenesis provided the foundation for the search for positive outcomes, and this focus is expanded in this section to include a patient perspective of health systems along with a standpoint theory that extends salutogenesis to include the influence of agency within healthcare.

Peer research provides a way for patients to be part of the digital revolution by bringing patient voices to the table. The current practice of emancipation is described by Tygel and Kirsch (2016, https://openjournals.uwaterloo.ca/index.php/JoCI/article/view/3279/4304) as the modern equivalent of emancipatory research in a time of technological change.

The most recent conceptualization of emancipatory theories in relationship to patients can be found in Gibson et al. (2012, https://doi.org/10.1177/1363459312438563), which describes the complexity of distilling theory related to patients in public engagement initiatives in Great Britain. It appears to be the most comprehensive, for those interested.

Design Thinking for Innovation

The industrial revolution, after the Second World War, created a need for new products to fuel innovation and economic recovery. During this time, customers were encouraged to propose innovative products, and they were able to work with designers and engineers to develop products. Over time, 'innovators' who employed design thinking became professionalized. The roles of customers were formalized into group discussions and activities, and their roles were reduced. Innovation professionals now define the landscape, and end users are called in for specific functions. The creativity of designers supports the economic value of market research. There have been several cycles that bring more attention to real-life experience and problem solving with end users, and the

current design thinking process that is used in the next section re-establishes an essential engagement for end users, in this case patients and family members.

Increasingly countries are supporting innovation by providing funding. The particular practice of experience design (XD) is a holistic design approach where the designers are considered to be holistic problem solvers dealing with the ecosystem of the brand or issue being investigated. It focuses on engagement of people and, therefore, employs a more narrative style, based on satisfaction, using all senses and 3- or even 4-dimensional data. Chapter 12 introduces ways to combine experience design and academic research, but from the perspective of patients and seniors. They are the main targets of user design and should be key stakeholders throughout the design process to meet the need for new patient/user data systems for research and digital literacy for seniors as life expectancy increases. There are interesting calls to overcome poor user interface and to use deeper engagement strategies as reliance on technology increases.

Early in PaCER, an Indigenous community worker took the training and was able to identify the common links between PaCER and Indigenous ways of knowing. There have been six Indigenous cohorts in PaCER to date, and these have not only been grounded in their Indigenous values, but Indigenous values have also resonated with many of the research teams.

We have attempted to introduce the importance of new partners and ways of thinking as we shift to a method tailored to address the links between peer research, culture, academic research, citizen science, design thinking, and social change.

Discourse Analysis

Meaning and memory arise from ongoing conversations, at all levels of society, that enable people and communities to develop a sense of identity. If we are to study roles and relationships as a way to understand systems, we need to have a way to study interactions. Discourse analysis is just that—the analysis of language in all its forms, including speech of professionals, documents, protocols, research papers, procedural manuals, and increasingly, social media. The language and how it is used helps us understand how we make sense of the world. Systems themselves create a series of guidelines that are written as policy and procedure. In effect, these proclamations are the storylines identifying what is expected, how service and support will be delivered and paid for, and how service will be evaluated. From this, we can deduce the formal, systems-approved roles of patients and professionals. In this final section there are examples of discourse analysis of health documents and communications to understand how systems influence patient identity.

The integrated narrative science proposed in Chapter 12 ensures that data collected as stories continue through analysis and interpretation in order to preserve language and the properties of language as in grounded theory.

Systems Theory and Patient Identity

Systems theory is the study of the impact of systems on patient identity and agency as part of their experience of professional expectations and relationships, policies, programs, and resources. Systems theory creates space for topics of peer research that are identified by patients, citizens, and communities. This includes the impact of the official systems that are used by patients, along with related services and systems of health and well-being that are outside of traditional systems. The topic research would be created through a co-design process involving patients, clinical and community values, and resources.

For example, when looking at ongoing support for young adults with inflammatory bowel disease (IBD) and their relationship to food, the system from a patient perspective might include the IBD specialist, the clinic nutritionist, the primary care network diet specialist, the naturopath and a holistic nutritionist, a store specializing in special diets, and friends who are living with IBD who are available through personal videos, blogs, and online communities.

Summary of Chapters

New Theory of Patient's Perspective of Health Systems

Chapter 9 introduces a theory-based tool to engage patients, programs, and relationships in constructing a health system specific to particular experience and needs. This is important because what we call the health system confuses and threatens citizens in its complexity, which then leaves the impression that it is all powerful and cannot be changed.

The matrix includes levels, from medical science to mainstream support, in four elements: medical system, personal system, healthcare focus, and technology. The tool creates a visual representation for patients, programs, care providers, navigators, administrators, and planners. This assists in identifying gaps, areas of concern, and community and commercial options when conducting co-design consultations. It also focuses attention on the level and type of support, care, and intervention that relate to the main concern of the study. This is an attempt to concretize the sources of systemic discrimination so that they can be analyzed more clearly.

New Patient Standpoint Theory

In Chapter 10, a patient standpoint theory is necessary because of the complexity of health systems. It provides a step toward making a difference because it identifies current status or standpoint and the goal for change. This standpoint employs the salutogenic bipolar axes related to patient identity and adds a vertical axis representing agency. It deviates from the 2-dimensional feminist standpoint theory to create a 4-dimensional grid that guides co-design, analysis, and prototypes of solutions through four psychological social environments and four transitions.

The theory also incorporates transitions between the four psychological spaces that help patients and allies consider options for change. This simple and colourful visual tool can be easily used with individuals, groups, professionals, and researchers to explore the power of understanding how identity and agency create messages of competence, crisis and change, learned helplessness and refuge, and belonging and acceptance. It helps professionals and allies understand that these psychological states are real, that their dominant psychological state of competence gets in the way of those who live within different realities, and the transitions from these realities may have unexpected consequences. For example, Bob has been stuck in learned helplessness and his teacher has decided that it is important for him to stop blaming others and take more control of his actions. If Bob tries to take control, it will push him through defenses and into crisis. A better solution would be to improve his self identity by finding a sense of belonging.

The most advanced move to peer research and full research collaborations have emerged as part of Indigenous nationhood and the ability to form equitable relationships with Indigenous nations. In this regard, the UN declaration on Indigenous nationhood has created international alliances of Indigenous nations and academic units. In Canada, two-eyed seeing, as articulated by Jeffery et al. (2021), and in other countries with strong Indigenous traditions such as Australia, New Zealand, South Africa, and the United States, there have been dramatic shifts in a data system to recognize data and ownership of results through the lens of sovereignty. One project in particular depicts the results of over 20 years of collaboration to create a partnership based on two equal nations (Brunger & Wall, 2016, https://doi.org/10.1177/1049732316649158).

We have much to learn from these early Indigenous pioneers of authentic research partnerships. Siksika Nation in Alberta was the home of Henry Three Suns, and, as part of the co-design of new social movements case studies, fractured many of the original epistemological beliefs that I had. The value systems of the Siksika Nation embraced the primacy of the land, collectivity of community, and ancestors as essential elements of the cosmology. These

were in stark contrast to assumptions of place and individuals grounded in the present and future as values of Western and European nations. This contrast fractured the study and sent me back to each of the other co-researchers to test out how their basic values informed their co-research experience. There were many changes made that brought depth to the emerging theory to reflect their understanding of individuality and collectivity, the past and the present, and their role in change.

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9

Patient Perspectives of Health Systems

> *You cannot understand a system until you try to change it.*
> (Lewin, 1951)

Highlights

- Evolution of health systems in Canada
- Discovering ways to depict health systems from patient perspectives
- Using a patient perspective of health systems to explore patient roles and opportunities for change
- Analyzing systems using crowdsourcing, narrative, and discourse analysis
- Examples of emancipatory systems from seniors, social enterprise, etc.

I have always been intrigued by the influence systems have in our daily lives. This interest began in the 1960s, first on a closed ward for women with complex behaviours, and then as the director of a psychiatric vocational training program for patients hoping to find employment. The power of changing routines that impact the nature of experience couldn't be denied as women behaved as expected to gain access to their meals and treats. I moved to Alberta and joined a social innovation that trained people with disabilities for employment and worked with community rehabilitation programs across ages and conditions.

When I was hired to develop the community rehabilitation and disability program of studies at the University of Calgary and later hired as a faculty member, I turned to social construction to study and influence the power of systems on individuals, emerging community programs, and access to health, social care, and employment (Marlett, 2021; also reproduced in the Resources section of this chapter). My intrigue with systems motivated my research in education, healthcare, long-term care, welfare, guardianship, and social service

systems. All shared hierarchical structures of staffing and decision-making, professionalization, low-paid frontline staff, and rigid criteria related to client expectations and access to resources. Access to care depended upon adherence to expectations.

This chapter proposes a different look at systems from a client/patient perspective. It combines subsystems and includes systems that exist outside of the formal health systems. The goal is to provide a template that can be used by patients and shared with service providers and researchers to understand systems as constellations of services and supports from a patient perspective. This theory enables individuals and groups to use information about health systems to guide the specific systems they use, both inside formal systems and within community options.

Evolution of Healthcare Systems

In order to understand current healthcare and the potential futures of health systems, let's look at how health systems became so large and entrenched supported by health research. After the Second World War, societies around the world struggled to reestablish social order and looked to the dominant industrial and military systems as models. Healthcare grew through industrial models, adopting reliance on evidence, influenced by Japan's industrial model that was based on extreme evidence-based statistics. This evidence foundation became known as continuous quality improvement (CQI) or total quality management (TQM). These provided the scientific, statistical foundations, clear authority hierarchies, and evidence-based decisions that supported standardized care protocols.

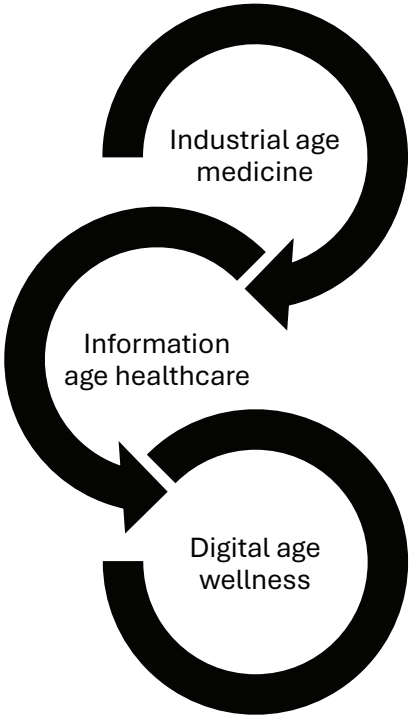
As industrial age medicine and medical science merged to create strong science-based health systems, the resulting model justified government funding and control, along with the development of health professions to maintain the institutional structures. Professions, supported by science and secure funding, produced medical evidence-based definitions of service and standardized interactions between citizens and professionals. In this process, deviance became formalized as a criterion of eligibility, along with 'due process' to control deviance.

By the second half of the century, citizens and new social movements reacted against the impact of large, standardized health systems as they experienced increasingly restrictive systems and lost identity, control, and independence. Professionals experienced a loss of autonomy in their practice, depersonalization, and loss of effectiveness as protocols were adapted to be done by less expensive and less qualified staff. Governments, who saw costs and expectations rise, then sought to reduce costs by privatization, downloading care to families and less expensive care providers, while tightening eligibility criteria.

During this time design thinking, social enterprise and innovation, and citizen science responded to advances in information technology and computing. Artificial intelligence and machine learning began addressing issues that had normally been part of health systems. In particular, health technologies were being designed outside of health systems to respond to profound societal changes within our entrenched health systems. If we are to make a difference to existing healthcare and research systems, we need to look outside of health systems to patients and communities, new action research models, and flexible and nimble change strategies. Regardless, the future seems poised to become more democratized with complementary, traditional, and community-based health. Health systems from a patient perspective include services both within and outside of the existing healthcare systems.

Figure 9.1 attempts to depict the nature of the healthcare system transformation.

Figure 9.1 *Anticipated Change from Industrial to Information to Digital Medicine*



Information age or digital healthcare provided the impetus for the beginning of the PaCER program. Patients who responded to our recruitment were eager to use their newfound online information to improve their health and the healthcare system. They were early adopters of digital wellness that includes our ability to prevent or lessen the burden of many chronic and stress-related conditions.

We also need to address the growing wicked problems in healthcare and research, which includes natural aging of systems and healthcare and stakeholders that reify complexity, competition, and bureaucratic barriers. Wicked solutions, on the other hand, are more likely to be found in localized initiatives that focus on specific concerns that reduce complexity, and peer research is a natural example of a local or self-contained research model. Luckily, health research already operates at the level of localized health conditions and services based on age, pathways, and types of service communities that come together with shared experience and knowledge. At this level it's possible to use JEDI principles to categorize systemic obstacles in research. Increasingly, research grants include more support for diversity and inclusion to support goals of open innovation in science (OIS), responsible research and innovation (RRI) that promote research that is democratic, creative, and nimble.

PaCER training has the advantage of working with diverse, local, and targeted health research grants, sponsored by research teams interested in patient perspectives on clearly defined, local concerns. For example, one PaCER class included families with experience with intensive care, another with recent immigrant women with early-stage cancer, and another with patients with chronic kidney disease. In this environment PaCER students conduct patient experience research related to the topic of their research learning about equity, diversity, and inclusion and common challenges in access to healthcare. Democratizing research is best done by including communities, patients, and citizens as partners from co-design to healthcare implementation.

Health-related citizen groups, such as Imagine Citizens (https://imaginecitizens.ca/), are involved in collective citizen research. The largest collective patient voice is the International Alliance of National Patient Involvement in Research, which includes partners such as INVOLVE UK (https://www.nihr.ac.uk/health-and-care-professionals/engagement-and-participation-in-research/involve-patients.htm), PCORI USA (https://www.pcori.org), SPOR Canada (https://cihr-irsc.gc.ca/e/41204.html) and Consumers Health Forum Australia (https://chf.org.au), that support recruitment into research studies and increasingly support patient, clinician, and patient researcher collaborations. Independent peer-led research is gaining a foothold in establishing a patient research voice outside of traditional health research grants.

Other key actors in gender, race, culture, and age-based movements rely on shared wisdom and collective action to challenge systemic discrimination in health practice and policy. Women's, Indigenous, disability, race, and aging studies academic programs have been able to create emancipatory research voices based in critical theory foundations that support the need for change and support localized research. Ashoka changemaking social enterprise (https://www.ashoka.org/en-ca) provides a different perspective, in that the engagement for change begins when citizens come together with innovators to share experience, ideas, and potential for change.

Perhaps the most significant force for systemic change in health research is emerging with a dramatic challenge to the way research is funded and conducted. Luna is an American data-sharing platform for rare conditions and diseases founded by families frustrated by the lack of research or treatments, which has become a public benefit corporation (National Academy of Medicine, 2022, https://doi.org/10.17226/27107). The corporation has changed the roles of patients and families from anonymous research subjects to partners of discovery. The corporation is funded by biotechnology companies and venture capital organizations to provide better ongoing connections between research participants and researchers and give participants direct control over how their data are used. This includes ownership shares with cash dividends.

A Canadian social enterprise started from the urgent need to locate cancer research opportunities to extend the life of a cancer patient, Zamplo, with Alberta Cancer Foundation support, empowers individuals with the knowledge and tools to curating their real-world data (Zamplo, n.d., https://www.zamplo.org/). Zamplo Research connects researchers to patients and caregivers and supports online research opportunities.

The options for new patient-centred research partnerships are growing rapidly. Many patients have found ways to become agents in detection, decision-making, treatment, and ongoing monitoring both inside health systems and as part of the large network of complementary health providers. These patients could easily transform into citizen scientists, from early detection to technology driven treatments. This may seem like a brave new world scenario, but monitoring and treatment implants are already in early stages with non-communicable diseases and stress-related health problems that should include patients as part of innovation teams. Patients in Alberta already have access to digital health records and reports. Every day new technologies to monitor symptoms, diet, and exercise come on the open market. They use their access to internet health information to learn about medical conditions online and connect with the networks of other patients with similar issues.

In this chapter, we propose that health systems benefit from investing in building capacity for peer research that informs research on existing practice and innovation. Patients can be engaged through chronic care hubs that are becoming dynamic, engaged platforms that encourage patient sharing and patient control of monitored and patient-provided data. This combines the formal evidence-based goals of health and emancipation of patients who could use the science of engagement to become peer research–informed chronic care supporters for in-home care. Unlike academic research, the focus of new models uses innovation research models that are nimble and able to change as needs and technology change. Most of these initiatives begin with the expectation that new options will include community and patient participants.

The following section introduces alternative views of health systems that were used to design a theoretical model for the last section, which describes health systems from four perspectives.

Alternate Views of Health Systems

The concept of healthcare based on real-life experience can help patients, communities, and health professionals create new views of a health system. This is already happening online, with organizations such as Maple (https://www.getmaple.ca/) and chronic care online health hubs. Maple has evolved into a health system to provide acute, chronic, and specialist care support to remote and marginalized populations and fill the gaps in our provincial health systems. They may include existing professionals and new options such as nurse practitioners, paramedics, and health technology assistants along with peer health navigators and peer support. The online health networks and condition-specific care hubs provide alternatives to more formal systems. This is where the potential of information and digital age medicine currently resides. These new paradigms encourage us to move beyond industrial age medicine, where the system provides for the health of patients, and information age medicine where access to information is open to patients, to digital health, and to new forms of health systems that include community options.

We now look at social-ecological system frameworks that have informed the study of how systems impact seniors or PWLE living with conditions such as mental health, disability, and a range of acute and chronic health conditions. My first exposure to social ecologies emerged while working in Russia and Japan, where I was part of developing community options to extend existing health systems. Most recently, social ecologies of health systems have been used as part of a consultation to identify how patients see their primary care health systems done with the Health Quality Council of Alberta (HQCA) and a design thinking course for senior undergraduates and graduates as part of disability

studies. The final model presented a template to identify systems patients use, or could use, to deal with their health concerns as part of peer research.

This chapter now moves to the social ecology of healthcare and research systems that patients and their families rely on in the attempt to explore how emancipatory science and the unique contextual factors patients encounter in their use of health systems add to the science of engagement. In this, patient health is not quantified or permanent but includes how to extend patient expertise and the capacity of patients and communities to be part of healthcare transformation. The SMART framework in Saskatchewan is a courageous combination of citizen science and participatory research that reflects the direction of the emancipatory science of engagement in health research and innovation (Katapally, 2019, https://doi.org/10.2196/14056).

The forerunners of all emancipatory movements in health are the disciplines and advocacy-based professions that began with women's studies, race studies, Indigenous studies, and disability, aging, and mad studies. These new disciplines are defined by critical theory and focus on changing policy and programs to foster role equity through challenging systemic discrimination and labels. These new programs and services shift from remediating deficits to fostering capacity and rights of patients as stakeholders. These pioneers are fundamentally challenging historical and economic power imbalances in healthcare to lessen systemic discrimination as part of existing health systems.

Increasingly, health and rehabilitation professionals begin their journey as undergraduates in cultural studies programs, learning the foundations of critical thinking. They become more comfortable working in contested spaces, with the ability to create synthesis from multiple standpoints. They are creating innovative communities with peer-based and consumer-driven options within health. Existing rehabilitation professionals are also migrating into community-based wellness and rehabilitation services.

A Peer-Led Investigation of Primary Care Systems from a Patient Perspective

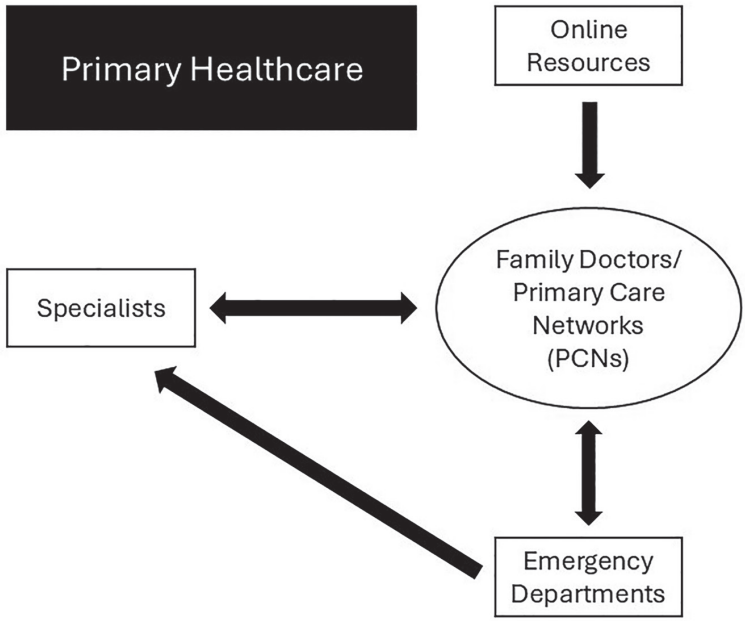
This consultation was carried out by the PaCER program at the University of Calgary for the Health Quality Council of Alberta (https://hqca.ca). The goal was to provide an independent snapshot (map) of the primary care network (PCN) systems from a patient perspective. Patients were recruited from three key groups within primary care—seniors, occasional users, and patients living with chronic and complex conditions. These representatives were recruited from five provincial patient organizations and included urban, small-town, and rural Albertans, a balance of age and gender, with diversity in cultural backgrounds. Patients, PaCER peer facilitators and recorders, HQCA staff, and a

film crew were involved. The film and the information gathered and analyzed were prepared as the introduction to a provincial primary care consultation that would consider future directions from a patient perspective.

Each participant was asked to contribute up to five recent health incidents that required attention, along with the options they considered to address them. Over 240 incidents were identified, and a surprisingly clear picture emerged about their use of health systems at the primary care level. The resources were compiled and categorized as system maps from a patient perspective that identified how patients saw the systems they considered part of their specific health system.

Figure 9.2 represents primary care from the perspective of occasional users. Their health system aligned with the primary care system. They saw primary care with two main connections: the primary care network and specialists. They also recognized their personal use of online resources and emergency departments. This simplified notion of a primary care system reflects a common understanding of most occasional users.

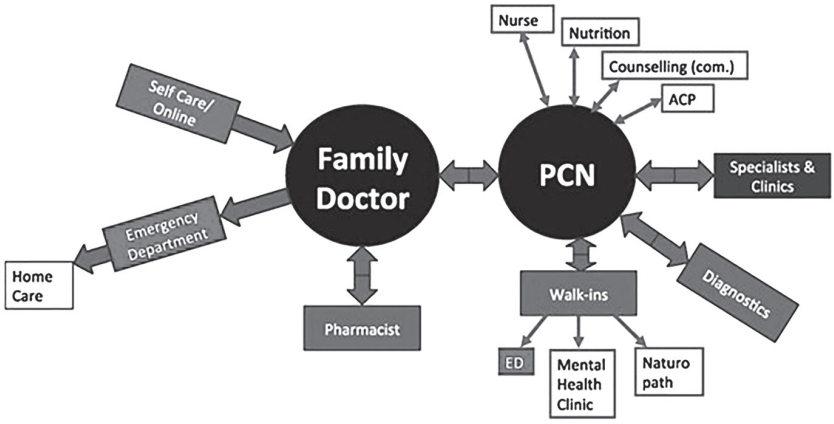
Figure 9.2 *Primary Healthcare from the Perspective of Occasional Users*



Next, in Figure 9.3, we shift to the complexity of the primary healthcare system from a senior's perspective that is grounded by a 'family doctor' as the centre of their health system, along with the doctor's nurse or alternate who provides access to other services. These include ongoing nursing support, nutrition, specialists, diagnostics, and other services. The PCN plays a much smaller role.

The doctor links to the emergency department or hospital for urgent and transitions to services such as home care. There is also an interesting connection between walk-in clinics that suggested links to complementary care and mental health supports.

Figure 9.3 *Primary Care from the Perspective of Seniors*

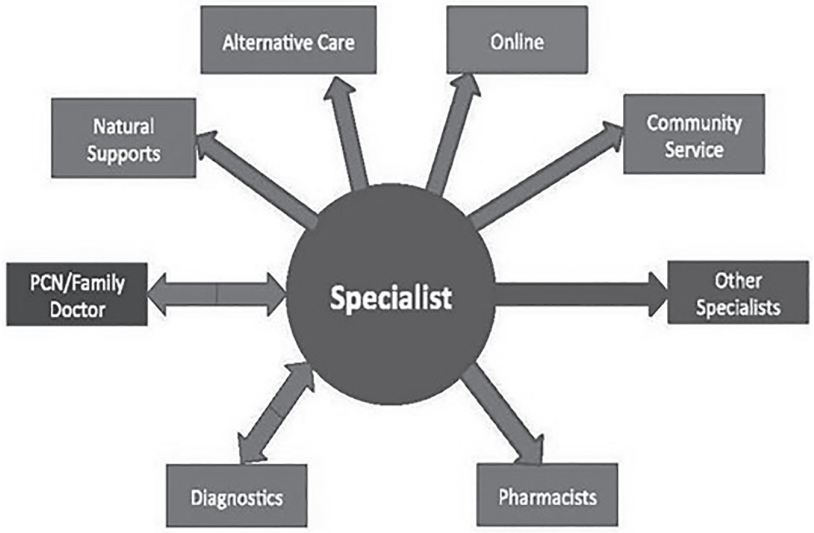


The role of the emergency department was of particular interest as a community resource, especially in rural areas. In addition to handling emergency care and their natural links to hospital services, doctors seem to provide access to specialists, private clinics, and community resources. The link to the emergency department seemed particularly strong, and this mirrored a similar trend in other primary care diagrams as part of this workshop that reflected the after-hours 811 calls.

In Figure 9.4, we see primary care for patients with ongoing chronic and complex healthcare needs. Here, the primary role of the family doctor is replaced by the specialist or specialty clinic. Many of the incident cards spoke of specialist care that was not part of hospital care, but also not part of the PCN. Specialist connections included medical specialists, pharmacists, allied health (private physiotherapy, diagnostics), and complementary health

providers (naturopaths, chiropractors, massage therapy, counsellors, dentists). Natural support included self-help groups such as AA and church programs. Community services included mental health and community rehabilitation agencies for groups such as those with brain injury and strokes, persons with disabilities, and the Alzheimer's Society. This foretells the chronic care hubs that are emerging outside of traditional healthcare.

Figure 9.4 *Perceived Role of Specialists Within Primary Care*



The flow between the PCNs and medical specialties is reciprocal, but participants saw the specialist system as mirroring the role of the doctor. The specialist system is more simplified than other systems and most patients noted that they would prefer that specialists provided more primary care functions rather than going back to their family doctor for referrals.

This report is available in the Resources section of this chapter.

Most of the studies completed with peer research through PaCER are located within existing healthcare systems and some innovative systems designed to overcome systemic barriers. We now pivot to specific examples of how to open the discussion of healthcare systems that have led to significant changes in healthcare delivery. We begin with an early example in Russia that introduced the need for a simple tool to help psychiatrists understand how community mental health might be introduced as part of Russian psychiatric care.

A Community Mental Health System in Russia

I came to understand the power of systems during the collaborative efforts of Community Rehabilitation and Disability Studies (CRDS) at the University of Calgary and the Russian Institute of Psychiatry. The goal of this 10-year collaboration was to expand the Russian mental health system from a reliance on large institutions and to develop community options. This also involved a consumer-led community mental health program called Fountain House (https://www.fountainhouse.org/) that was similar to Clubhouse in Canada (https://clubhousecanada.org/). These three systems: psychiatric institutions, community health professionals and support for Fountain House marked a significant system change for Russian psychiatry (Disability Rehabilitation, n.d., https://www.ijdcr.ca).

In effect, we were introducing social innovation by co-designing a community mental health system. Russian patient members of Fountain House and a family movement were our allies in Russia, and members of our Clubhouse acted as mentors and hosts of the visiting Russian team for each Russia-Canada visit. These patient mentors met the Russian team at the airport, settled them in their accommodations, took them to each session, and acted as their guides and instructors. The Russian team was initially reluctant to be reliant on 'patients,' but soon came to appreciate the capacity of the mentors and the partnerships they formed. It was a powerful tool in readjusting the distinct power differentials that existed in psychiatry in Russia by challenging Russian beliefs about the role of patients as recipients of care for permanent disability.

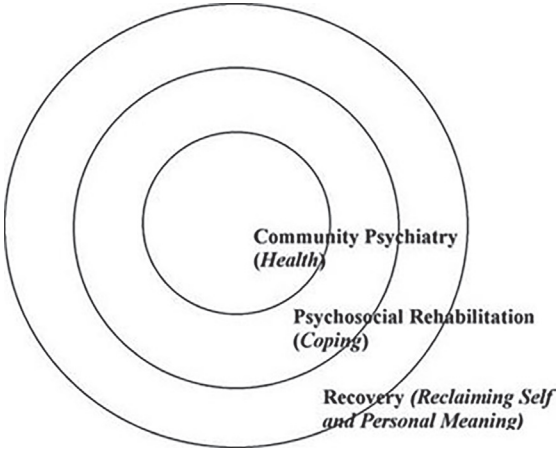
I was responsible for opening a debate about healthcare systems in mental health. We began with our shared focus on science and research. During two weeks of sessions with psychiatrists from across Russia, we discussed common social problems for citizens with mental health concerns—from employment, physical activity, housing, family support, and legal and political issues that were conflated with institutional psychiatry.

During the first few days, all situations produced a common response—refer to the hospital psychiatrist. Carefully, we created hypothetical services and supports that could be created within the community to be offered by other professionals. It was difficult, but as the psychiatrists became involved in a co-design process, they began to see that there could be alternatives to psychiatric hospitals.

The simple tool in Figure 9.5 allowed the participants to experiment with community-based psychosocial subsystems. The outer rim captured the goal of Fountain House, a community mental health recovery system with the goal of reclaiming self and personal meaning as part of an integrated system of peer support. By the end of the sessions, we had created a simple system for

community mental health, consisting of three concentric circles. The article was published in Russian, and the teams met regularly to develop community resources and training programs for psychosocial rehabilitation.

Figure 9.5 *Russian Community Mental Health Template for Creating Community-Based Psychosocial Services*



- The centre combined science and community psychiatry, which was synonymous with all psychiatric support inside and outside of the large institutions (and most often located in the institutions). Psychiatrists were the main professionals, looking after medical interventions, family support, employment, and funding.
- The psychosocial circle represented a separation of medical psychiatry and new professions such as social work and community rehabilitation specialists in work, living, leisure, and physical therapies. This ring was extremely hard to conceptualize because few professional traditions or psychosocial training programs existed apart from psychiatry. This was called a coping circle.
- The outer circle represented recovery, based on the principles of Fountain House about reclaiming useful roles in society and sharing the development of personal meaning through peer support.

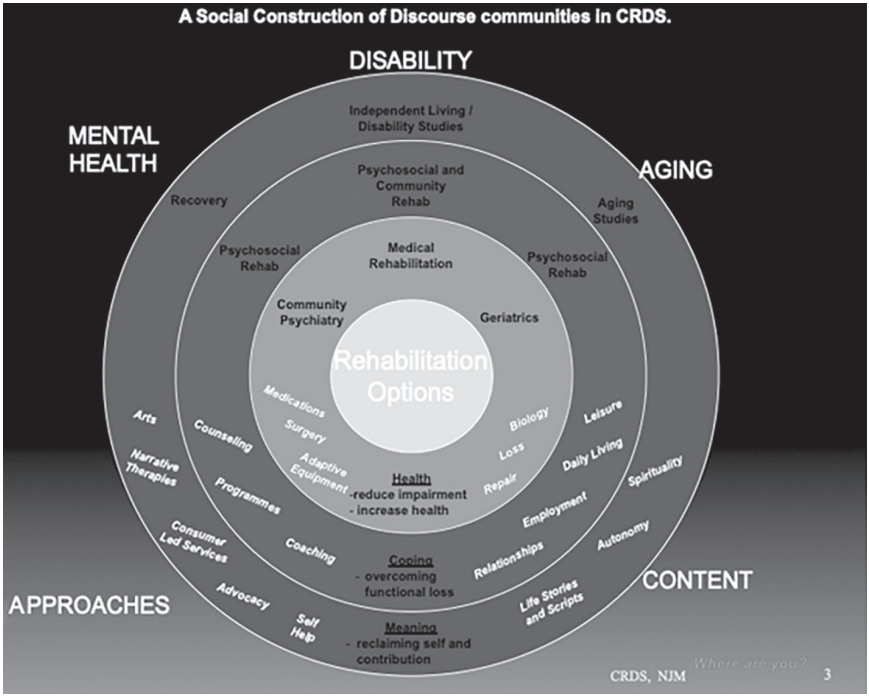
This simple tool was used to develop models for teaching in my home faculty and publications. It has been used with quality improvement, community-based participatory research, peer research, discourse analysis, and program evaluations.

Disability, Aging, and Mental Health Studies

Figure 9.6 is a template of a social ecology of health systems, created as part of the study of health systems related to disability studies programs. The disability section includes:

- Medical rehabilitation that includes diagnosis and treatment, primary care, specialists, and emergency departments in order to reduce impairment and support health of disabled persons, seniors, and those living with mental health challenges.
- Psychosocial and community rehabilitation therapies and clinics, including many complementary options to remediate health-related problems to improve coping skills and the ability to function.
- Independent living and disability/aging and mad studies focus on peer and natural supports and mainstream services, to find meaning and reclaim productive roles that make a difference in their lives.

Figure 9.6 *Health and Healthcare Systems in Disability, Aging, and Mental Health*

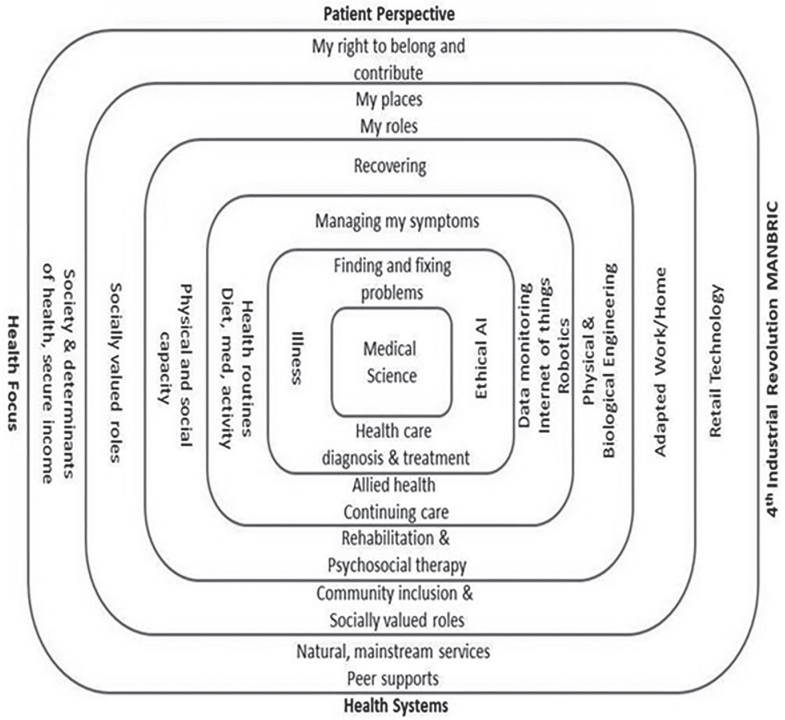


While this was developed specifically for disability, aging, and mental health systems, it can also be applied to systems such as hospitals, acute, long-term, chronic, palliative and primary care. The template can be used to support researchers, both academic and peer researchers, looking to learn about the systems when beginning an action-oriented research project. It can be adapted to identify policies, programs, procedures and relationships for any group or community.

A General Template for Patient Perspectives of Healthcare Systems

The template in Figure 9.7 grew from an attempt to consolidate options identified by students in disability studies, that include medical, nursing, disability studies, and education students. Much of the input came from reviewing Grey Matters and PaCER research projects.

Figure 9.7 *A Patient Perspective of Health Systems*



The Science of Medicine: Biomedical

Science systems have been the driver for health transformation and technology innovations, but new patterns of innovation are also emerging, notably social enterprise initiatives that come from community needs and maker spaces that bring together citizens with diverse talents and interests to create technologies such as 3-D printing to solve pressing problems. This would also include emerging science platforms that include patients and researchers as partners such as PaCER. Science seemed to be a common starting point for all four sides. The following looks at health systems form a patient perspective that draws on the other three sides of the visual theoretical system.

Finding and Fixing Health Problems

Illness focus, healthcare, diagnosis, and treatment using ethical AI technology.

The patient name for this first ring is a practical, almost mechanical view of illness. Healthcare diagnosis and treatment translates science into practice from a health system perspective. In Canada, diagnosis and treatment rests within primary care, with links to specialists and hospitals. It is a pluralistic system of public healthcare delivery, quarterbacked by group physician practices. This operates within the *Canada Health Act* principles with provincial single-payer agreements (Hutchison et al., 2011, https://doi.org/10.1111/j.1468-0009.2011.00628.x). Patients seldom understand the intricacy or politics of federal agreements and provincial healthcare delivery, or how these create obstacles to social change.

Increasingly, when a patient engages with primary care or emergency departments with a 'magic bullet' condition (i.e., an identifiable cause and an approved treatment), the health system can operate with almost big box efficiency. This level of healthcare seems to attract new players because many of the functions of primary care are accessible online. For example, Walmart health clinics provide primary, urgent, senior, behavioural health and dentistry services as an example of a growing global movement to standardize care for routine healthcare needs outside of our current primary care networks. In Canada provincial health plans work with online health providers such as Maple to fill gaps in primary care as an almost automated primary health system for common health issues. These online options could threaten the viability of the 'family doctor,' who is a local ally and advisor throughout life instead of a one-stop shop for existing health problems.

The role of primary care physicians and specialists are changing dramatically with the advent of artificial intelligence and machine learning that enables

collection and analysis of digitized data from a wide array of new sensing and tracking devices, computerized tests, and records. Advanced and personalized algorithms and protocols will become available to patients and a variety of healthcare providers, changing the diagnosis and treatment paradigm currently in place. This suggests that the connection to a primary care practice and staff may be lessened.

Medical professionals are already preparing for these new developments. New information specialists are being prepared to work with patients to help them understand and make decisions based on accessible health data and patient-owned and patient-generated data (Heath, 2022, https://www.techtarget.com/patientengagement/feature/Digital-Health-Literacy-Why-Its-Important-and-How-to-Improve-It). Patients need to prepare to take advantage of these new directions in patient-managed care as healthcare systems transform. Patients can now curate their own health information, share it with treatment options, research opportunities, and connect with others with similar problems to share ideas and combine resources using provincial health platforms and emerging data platforms such as Zamplo. In many ways, new patient-driven ways to use personal data have the markings of incubator spaces that are driven not by systemic problems but opportunities for inclusion in self-care and management. But these new options will only increase the care divide unless using healthcare technology becomes a recognized curriculum in our schools and communities.

Patients are not alone in recognizing the power of deep medicine, private clinics, pharmacies, and new consumer hubs that are using the streamlined diagnostic treatment links to create new options for healthcare of common and chronic health concerns. The issue of ownership of information at this level is hotly contested among health systems, diagnostic systems, patients, governments, pharmacies, and insurance companies, and patients may be included in ownership debates. Whatever the outcome, the increasing patient access and ownership of their personal health data are likely not to be reversed.

In summary, primary care is the first system to be impacted by the fourth industrial revolution and will lead change throughout health systems.

Managing My Symptoms

Allied health continuing care as part of primary care, with a focus on health routines of diet, medication, and activity using data monitoring, the internet of things, and robotics.

Allied health professionals are part of the primary-care health system, especially the support for rural and marginalized groups. These multidisciplinary

teams include health management nurses, clinical pharmacists, mental health professionals, social workers, dieticians, and others as identified by the population being served. These professionals cover a range of healthcare supports under the umbrella of tertiary (symptom management/rehabilitation) prevention (Institute for Work & Health, Toronto, 2015, https://www.iwh.on.ca/what-researchers-mean-by/primary-secondary-and-tertiary-prevention). Patients in these chronic care systems learn to tell new patient stories about themselves. As they are socialized to use new language and routines of clinic protocols, they see themselves defined by their condition and the allied health professionals they rely on. The rising costs associated with chronic care have fast-tracked wearables, implanted sensors, and personalized robots that will alert care providers of concerns as they arise. AI analysis supports online digital interventions that assess and address needs. At this stage, the future of an internet of things (devices) is moving quickly, and the eventual destinations and outcomes are anyone's guess.

As the aging population increases the need for chronic care, it is important to seriously consider what is happening in the United States that is poised to face competition from retail health providers such as Walmart, Amazon, and big box pharmacies such as CVS Pharmacy to manage the current models of primary and continuing care healthcare systems and corporations. I have included a link to a recent Forbes report that looks at the current cracks in primary and continuing care (Pearl, 2022, https://www.forbes.com/sites/robertpearl/2022/10/10/amazon-cvs-walmart-are-playing-healthcares-long-game/?sh=1f138fa978f6). These models that are vertically integrated, focused on efficiencies, and supporting customer loyalty and professional development may not reflect our Canadian vision of healthcare but they do present uncomfortable options.

The other alternative model to ongoing professional care teams is the Independent Living Centres (https://www.ilc-vac.ca/core-programs) and the Clubhouse (https://clubhousecanada.org/about/) models that provide peer support and peer-directed services in many Canadian cities as part of international movements. These two provided much of my training in peer-run services and they were active in developing both research methods and theoretical models of peer research as part of this book.

There is also growing popularity and effective use of online peer support groups for a range of chronic conditions that range from groups run by professionals, structured peer-led self-management training, peer coaches to online support. In the meantime, projects such as the Wellesley Centre in Toronto, the HIV/ AIDS communities across Canada, and peer research such as PaCER provide examples of how to capture the experience of people in their own voices.

How relevant are these chronic care models to the science of engagement in health research and innovation? From the health system perspective, health professionals are not trained to engage patients in peer support, education, or co-design of programs. The focus of most allied health ventures in peer support includes selecting and training peers to work as assistants to professionals, but it has been hard for professionals to delegate peer support to existing peer support programs that already exist. This is particularly common when working with marginalized populations such as those dealing with addictions, poverty, and mental health issues that have low access to or uptake of health system services.

Peer support programs run by peers are perhaps the best agents of peer research. They understand local community strengths and interests and often take up participatory action research to inform their mission, activities, and advocacy. It would be my hope that funding options for PaCER might be found to provide peer research training for these associations. It is also possible that peer support programs could use the science of engagement to create their own model of peer research.

Recovering

The site of recovering physical and social capacity that has been aligned with physical technology and recent biological engineering.

The recovering ring is similar to the previous one but is about the personal search to find a new normal in everyday life through adapting or regaining everyday skills and relationships. It remains a deficit-based approach that relies on assessing functioning and creating ways to reduce deficits or to re-establish former skills as part of emerging roles and responsibilities. Physical rehabilitation (physiotherapy, occupational rehabilitation, and speech therapy) focus on regaining function and competence. Social rehabilitation considers emotional, cognitive, and social skills. These two approaches are often merged to reduce the lasting impact of illness, accidents, and trauma.

Cancer treatment provides an excellent example. More cancer patients become cancer survivors as new treatments reduce mortality rates. However, the impact of treatments and the fear of recurrence leave many incapacitated. Cancer specialists have created a major psychosocial or rehabilitation response to support survivors. This is significant because this response occurs simultaneously within the medical system (Mikkelsen et al., 2007, https://doi.org/10.1080/02813430802295610) and within community services (e.g., Wellspring Cancer Support, n.d., https://wellspring.ca).

These two service options are significantly different. Psychosocial rehabilitation tends to be funded by the hospital cancer systems and uses professional interventions and health professionals. Community, patient-run options such as Wellspring Cancer Support Alberta (https://wellspring.ca/alberta/) are more aligned with the next two subsystems, community inclusion and peer support. The main difference is funding and costs; formal programs cost more and are government funded, while community supports such as Wellspring rely on fundraising but are less expensive because of the use of volunteers and peer support.

Psychosocial teams, unlike allied health teams, tend to be interdisciplinary, where each professional is more independent because they are less dependent on medical compliance and oversight. Most teams have a common focus (e.g., mental health counselling clinics, physiotherapy clinics, or head injury programs). Their means of funding is variable, including combinations of provincial health, health insurance, health associations, or fee for services. Therapy is more likely to be connected to health funding when they use approved medical protocols. These protocols reinforce status among professionals who may be paid on different scales. There is the risk of creating a ghetto of 'ancillary' professionals not formally recognized who are seen as assistants that are supervised by approved healthcare professionals.

Patient roles reflect their perceived deficits—they work to adapt to each therapist they work with. They speak their language and aspire to the goals of their treatments. Patients often feel anxious about leaving these supportive programs. The role of peer support in many of these programs face similar problems as noted with allied health teams. Peer support tends to be a program, with supporters trained and supervised to act as assistants carrying out program protocols. There is little room for natural peer support, unless connecting with clients is encouraged outside of program activities. In some situations, peer support is discouraged because it may distract patients from the approved—and funded—programs.

Therapy programs are a breeding ground for physical and biological engineering of assistive aids that can be funded by government allocations. The rapidity and scope of the innovations emerging at the intersection of biological and physical functions will be heightened by the addition of new digital technologies, which enable computer-assisted movement and communication. Technologies such as virtual reality and gamification are increasingly used in psychiatric and physical rehabilitation.

My Places and Roles: Community Inclusion

This site focuses on the rights of inclusion and adherence to socially valued roles of work, volunteering, family, and leisure with the aid of adapted routines and technology.

Community inclusion is the first of the systems not controlled or funded by provincial health budgets. Funding is provided by provincial community services, health charities, United Way, and a variety of foundations. The concept of community services began from the early adult training and employment services for the blind after the First World War and the Halifax explosion in 1917. Community inclusion began through the developmental disability family movements of the 1950s. Special schools were established to prevent institutionalization of young children who grew up and into sheltered workshops, to allow people with disabilities to 'go to work.' Early sheltered workshops were soon replaced by training and employment options that taught age-appropriate employment skills. These, and all other community inclusion options, are not considered to be part of the healthcare system, per se, and staff are not considered health professionals.

Community support is considered essential to achieving health for persons living with disabling conditions, including many related to chronic health conditions. Most staff working in this area are trained to support PWLE with a variety of conditions at colleges and universities. In a community-inclusion system, programs specialize in everyday roles and relationships, including those in employment, living together, and integrated social, artistic, and sport opportunities. It is also true that adults in integrated programs find companionship, peer support, and accomplishment. Regardless, staff in this outer ring of systems see themselves as allies in achieving integration and providing support when obstacles arise.

There is a growing movement to support integrated schools, workplaces, and leisure that reduce the stigma and isolation of PWLE. This will be accelerated as technology and assistive and communication devices related to mobility, employment, and living at home become widely available. As the burden of illness and disability is reduced through early intervention and technical adaptations, we will see a dramatic extension of productive life years for everyone. The tenor of community inclusion and support will shift as former clients become employees to meet the projected employment gaps.

My Right to Belong and Contribute as a Citizen

This final ring reflects health supports not part of the official health system that are used by all citizens to achieve good health. This includes technologies available to everyone who can afford them

At this final level, patients are more interested in being able to find supports that everyone uses—activity and heart rhythm technologies, sugar monitors, massage therapy, physiotherapy, a scooter instead of a wheelchair—and as technology improves in mobility and other assistive devices, seniors, patients, and persons with disabilities will continue to be a growing market sector. It is here that the issues of inequity are challenged.

We now come to the end goal of an emancipatory health system from a patient perspective that is grounded in equity, social justice, and emancipation. It is, at this outer ring, that the focus of health shifts from 'cure' and 'fitting in' to the right to belong and thrive because we are enough just as we are. To begin, we must understand how JEDI principles can be embedded in organizations, civic systems and society. The following definition of equity summarizes this final ring of the diagram:

> Equity is fair treatment, access, opportunity, and advancement for all people, while at the same time striving to identify and eliminate barriers that have prevented the full participation of some groups. In order to improve equity, we must increase justice and fairness within the procedures and processes of institutions or systems, as well as their distribution of resources. Tackling equity issues requires an understanding of the root causes of outcome disparities within our society. (Minow, 2021, https://doi.org/10.1162/ajle_a_00019)

It is here that we focus and work toward what an inclusive society might be like. Patients and communities align with innovative consumer services, new political allies, peer support initiatives, and mainstream services. This system, if it is to be called a system, also includes web chat rooms, peer support groups, along with citizen science research and open science. We also find community innovation and social enterprises being led by citizens and PWLE.

At this final stage we return to an early pioneer in this work of justice through inclusion, the international Clubhouse movement that grew from the Fountain House movement in the late 1940s by a group of six patients who met in an institution to share stories and find new ways to deal with the challenges of discharge. They knew that they needed to find housing, meaningful work and relationships and ways to handle the challenges of fluctuating mental

health. Today Clubhouse is still a social enterprise (Clubhouse International, n.d., https://clubhouse-intl.org/what-we-do/overview/) that has created an alternative to psychosocial rehabilitation clinics and programs. The success of Clubhouse has replaced many psychosocial and community inclusion mental health programs, and, in many jurisdictions internationally, these peer support programs receive government funding to promote community inclusion. Like most health-based social innovations, Clubhouse changed as health dollars were funneled to these effective recovery membership centres. With the legitimization of funding, Clubhouse became a sought-after employment option for mental health professionals.

Many new social movements operate in this space. They are strengths based, building patient and PWLE capacity to take up work, the arts, sports, and peer support using their skills and talents. These programs are natural sites for collective action, capacity building, and problem-solving.

Voices of Men (http://www.voicesofmen.org) is a one-man show that performs for mixed gender and single-sex groups as part of the men's social movement to reduce sexual assault, domestic violence, and sexual harassment. It uses humour and male celebrity voices to show that men can be both part of the problem and part of the solution.

A social movement called The Phoenix (https://thephoenix.org/movement), started by Ashoka Fellow Scott Strode, is a national network of volunteer-led programs battling isolation. Participating in The Phoenix's activities, from rock climbing to yoga, gives individuals activities to occupy their time and achievements to help those fighting addictions build a sense of themselves as capable and strong. This constitutes a psychological bedrock and a new community, which helps build lasting recovery.

Disability and mental health, aging and Indigenous studies were the first health-related groups to evolve through the above continuum from conventional healthcare, psychosocial and community inclusion. They were also the first to move toward peer and membership-based support. It is no longer an issue of 'fitting in' but the right to belong. If we focus on fitting in, the emphasis is on the deficits of the person who must be trained to be more 'normal.' The right to belong asserts that everyone has the right to be a member of society, and the focus is on making society accessible and inclusive.

University programs that promote emancipatory social science align with a social ecology based on JEDI principles and the study of systemic discrimination. Ashoka changemaking is a major contributor to this space, using academic resources and changemaking fellows to work with communities to co-design and implement social enterprise. Universities, schools, and community action groups that support emancipatory social research involve groups in analyzing their own challenges in order to confront sources of long held marginalization.

This space is more than a site of innovation and social rights. As a site for social enterprise, it has the potential to address the major obstacle to community development—how to pay for the innovative services developed. It is here that I introduce an alternative to grants. It is individualized funding through service brokerage that puts funds in the hands of families and patients to purchase the services and supports they need. Without a monetary system such as this, which is currently evident in assured incomes for veterans, persons with significant disabilities, and handicapped children's allowances, there will continue to be a charity ethic to promote the right to live in the community. Without the right to purchase and evaluate needed services, there is no equity. In completing this section, I acknowledge that the Independent Living Resource Centre of Calgary that took me in and helped me understand the essential difference between the support of a consumer led community and the role of professionals in changing the direction of my commitment to social justice and inclusion.

An Example of How the Above Health System Tool Might Play Out for Seniors

This example is informed by *Grey Matters* data, building on research done with participating systems that seniors use.

Geriatrics level is informed by the science of aging as the biomedical treatment of conditions related to aging. It is the practice related to biological decline, with treatment being informed by biological markers. For example, a study of resilience might look for resilience genes, or how people who are resilient are different from those who are not, according to some characteristics like adrenal functioning, health status, or depression. The language deals with slowing loss or decline and is home to metaphors such as 'the grey tsunami.' Some refer to this domain as reverse development, as assessments use age markers. While essential, many seniors feel defined by the degree of loss.

Recovery, psychosocial, or gerontological level of healthcare and research is devoted to 'reducing the problems of aging,' and tends to be found mostly in professions such as social work, nursing, rehabilitation, and psychology. Gerontology is the scientific study of the bio-psychosocial phenomena associated with old age and aging. These professions bring their disciplinary gaze to seniors' experiences so that professionals and policymakers can be more effective in providing services and policies. Gerontology research also uses patient-reported experience measures (PREMs) and patient-oriented research (POR) and standardized data measures as well as qualitative research to describe common reactions to the aging process. Seniors who come into contract with psychosocial rehabilitation learn to see themselves through the lens of the therapists they are referred to. These therapists not only provide adaptations, they are also

the gatekeepers to needed assistive devices. Most seniors learn quickly to work within the boundaries of the therapy and to compartmentalize their lives to fit.

My place, community inclusion, focuses on aging studies, which is a relatively new field. This emerging field of study is related to healthy aging and was the foundation for the *Grey Matters* project. Here, the focus shifts to tapping into the expertise of seniors (values, beliefs, language, media) and the politics of aging. In many ways, this new area is like women's and disability studies, although the academic roles of seniors have yet to be widely accepted in universities.

This research is closest to the interests of seniors. It clearly states that aging is not an illness or disability, nor is it a problem. Aging happens to everyone, and, like any other stage of life, becoming older has advantages as well as challenges. Aging studies would place the 'problem' not with individuals but with society that tends to use age as an excuse to marginalize older people because they are seen as being less productive once they reach 'a certain age.' With the loss of status and place in their communities, seniors often lose connections, struggle on fixed incomes, and become overwhelmed with the illnesses of idleness.

Patient experience in aging studies is considered from a patient perspective and joins a host of other traditions including health professionals who write as autobiographical ethnographers about their experience as patients. COVID-19 has brought awareness to the systemic discrimination of seniors who live in congregate care. It was interesting that the battle cry came not from seniors' advocacy groups but from medical staff and researchers. There is a long way to go, beginning with changes in each of the levels within the systems as seen by patients.

The focus on critical theory and social justice fuels the last level in seniors' health systems.

My right to belong is represented by seniors' advocacy, action groups, and peer support that includes the adoption of universal design and mainstream services. The normalization of accessible architecture and assistive devices (designer scooters and easy to use kitchen utensils) that are used by everyone was the motivation behind the *Grey Matters* research on resilience and demonstrates that seniors can be agents of their own lives and support the lives of others.

It is now easier to identify problems faced by patients and PWLE in achieving the roles they aspire to and the relationships that may promote or constrain these aspirations. Dramatic changes in professional roles are possible when, as a group, they decide to adopt other ways of working that promote confidence and personal agency in those they serve.

You are invited to create the template in your area of research or practice, and to use this to consider potential ways of increasing patient involvement

with their own health and healthcare. This understanding of current and potential roles will help define the patient experience research needed to be done.

In the last few years I have been privileged to be part of a family initiative to support the 96 year old matriarch to stay at home and take part in all decisions about care, travel, meals, engagement. To facilitate this, the daughter devised a data system to focus on the many co-morbidities so that everyone, contributed to record data and discuss this openly in house and with her input and with her doctor. It was a privilege to see what a beautiful life and death could be when her role was to be heard and loved.

An Example of a Social Enterprise That Aims to Promote 'My Right to Belong and Contribute'

One of the best-known social enterprises in the UK, Greenbank College (https://www.greenbankcollege.org.uk), began as a challenge to existing health-based institutional services for physically disabled youth in Liverpool. The existing system consisted of an institutional residence built for polio survivors, nurse-run group homes, and education provided through the institution. Decisions about treatment and future occupations were made by staff. It was a benign system that socialized young people to become patients dependent upon the healthcare system when they grew up.

Gerry Kinsella, a polio survivor and the founder of Greenbank, led a campaign to raise funds to buy the original institution and started a college with apprentice-style training and employment options. He received European Union funding and began to expand in direct competition to sheltered workshops. I spent time at Greenbank as part of a study of social innovation, and together we studied the programs—a prosperous training college, an athletic wheelchair company for competitive sports, a competitive recreation program, and a whole food restaurant. They had, in effect, created a parallel system to the expected health system for physically disabled youth. The following is a sample of the roles and relationships within the system of Greenbank projects above.

Others control my health—diagnosis and treatment: past places included institutions, group homes, workshops, and nursing and home care routines. The 'patient' experiences were marked by negative self-concept and excessive external control by care staff and systems. The data captured themes of vulnerability, fallibility, risk, protection, control, anger, and despair.

My place—community inclusion: The Greenbank site included a variety of training programs. Experience here was identified by concepts such as accepting, curiosity, self-help, receptiveness, and affection. Experience was marked by a positive self-image, with positive external support of peers. The themes spoke of exploring, 'give it a go,' and peer support that created new roles as students, learners, risk takers, and part of the peer community.

My right to belong: Smithdown was the mainstream competitive business site. It included the wheelchair manufacturing company, a whole food restaurant, and a consignment store. The experiences were clearly identified—competent, independent, willing to risk. The new environment and expectations created new roles as citizens and employees

Research Potential of Systems from a Patient Perspective

This last section suggests some research methods not covered in sections one and two that are more appropriate for research focused on making a difference within health systems. They relate more to the need to identify and explain systems blockages and understanding patient experience from their perspective. These systems and related methods will be integrated in the research options in Chapter 11 that combine the methods from Sections 1 and 2 with new work to prepare to bridge between academic research and design thinking of social innovation and social enterprise.

Crowdsourcing

As health research adopts citizen science as a bridge between academic research and social innovation/enterprise, online research options such as crowdsourcing reinforce the needed ability to reach diverse populations to address JEDI requirements in specific health systems. The first round of research might include the request to identify the health systems or services that a specific population uses, and these could be plotted on a system template, as presented in this chapter. A template that reflects the health use or lack of access could then be sent back to the online participants with options to include stories about the systems that work well, why the systems are used, and stories about the gaps, conflicts, and lack of access. A third round of online crowdsourcing might select several systems and ask participants to vote for the one that should be addressed first in research. From there, crowdsourcing could build on the existing online populations to conduct more detailed research.

Narrative Analysis

Narrative methods have been used in peer research to solicit stories of personal experiences in health systems as part of research to explain the blockages in these systems from a patient perspective. We now extend this to discussing how peer research might inform social innovation to resolve or reframe existing problems in health systems. In looking back over the reports and projects in the PaCER PRISM hub, I was surprised to see how many of the suggestions

related directly to systems blockages and the subsequent creation of new roles, relationships, and programs.

The process of identifying blockages begins with co-design, where the main concerns of patients are identified from a number of perspectives using online and in-person consulting as in the following examples.

- In a recent research internship related to young people with inflammatory bowel disease, two teams came up with topics related to their relationships with food. The group identified an interesting finding. Patients initially were looking for professional support in managing unpredictable reactions to food. After conducting their study, they had a new understanding of the blocks in the system and patient experience. They realized that it was important for patients to find their own way to develop a healthy relationship with food. They suggested that professionals needed to support patients after diagnosis and provide resources for how patients manage their food through unpredictable reactions, changes in diet, and family traditions. This required a mixture of patient expertise and professional support.
- In an early study that was to identify appropriate wait times for hip surgery, peer research discovered that patients were most interested in what they could do while waiting for surgery, in order to be prepared. Their research identified serious system blockages, which included unnecessary appointments that took many months to sort out and the lack of information about what they could do to prepare for successful surgery and recovery. Their experience before surgery was a mix of frustrating appointments that did not prepare for surgery and a lack of ideas for exercise, diet, and reading. Their research had a major impact on subsequent tools to prepare for surgery, driven by patient input and analysis.

Discourse Analysis of Systems

Discourse analysis is likely the most effective tool in social innovation because it lays bare the obstacles to emancipation and progress through the language used by those in power. Those who struggle for power study the language of those in power, while those in power seem unaware of the impact of the language they use (McCauley, 2013). Relational-cultural theory provides a theory base to using groups to build strong motivation for action.

Discourse analysis can be part of co-design or data analysis. Online resources are ideal for this work because they are the forward-facing representation of systems that describe the services and programs provided. The following is

a simplified discourse analysis process that quickly identifies distinctions between different systems in the concentric circles, which can be done by students or peer researchers:

- Who is the author and what is their relationship to the reader or the patient? For example, what authority or power is in play:
    - Expert, colleague, victim, ally/advocate, scientist, professional, program director

- Language cues that identify power imbalances
    - Pronouns: Who is the 'I,' 'she,' 'we?' Identify if the patient is being acted upon—'me,' 'her,' 'them'—or is an agent— 'I,' 'we,' 'they.'
    - Verbs: Are there signs of patients deciding, acting, and making progress, or are the verbs a sign of being acted upon?
    - General tone of language: Identify the type of language being used. Is it professional language, colloquial or collective language, or inspirational and goal-focused language?

- From the above, you can identify roles in the text, what is expected of each, what is the power balance, what happens if the patient doesn't play the roles expected, and what does the person gain from playing this role.

Summary

This chapter looked at health systems from a patient perspective to uncover obstacles within the current system. We introduced a patient perspective of a health system that incorporates not only funded and established illness care, but a continuum of care that includes wellness and equity. This is important because of JEDI principles of diversity and inclusion that underlies the systemic barriers to culturally and population-based care.

This made it possible to consider the forces of innovation and how they relate to a patient and community view of health and health equity as a foundation for making changes in our current healthcare systems. In this chapter, we also begin to introduce new research methods that can build patient and community awareness of the tools of innovation that are designed with them in mind. These will be presented in the following chapters.

Questions for Discussion

1. Where did you find yourself on the systems maps introduced in this chapter?
2. How would the templates work as part of your research or peer support work?

Resources

Use of Discourse Analysis to Understand Different Healthcare Options for Moral Injury

The following is a group process designed to teach systems analysis using the template and a simple group casebook in an undergraduate course in innovation in health research. Each person chooses a subsystem from the template, locates a website or document about that subsystem, and then uses a simplified discourse analysis to identify roles of patients and professionals that identify identity and agency (power and making decisions).

One of the students in the course agreed to share her work. One aspect of the case study is included in each of the chapters in Section 3.

Table 9.1 *Innovations in Health Casebook*

Innovations in Health Casebook

Systems thinking and discourse analysis

This assignment begins with three analyses using new and adapted theories related to patient experience and design thinking:

1. Systemic analysis of patient and disability roles in health and wellness systems.
2. Salutogenesis, building patient expertise and resilience in health through understanding patient experience.
3. Standpoint theory, building capacity for changing patient roles and then pivoting to more creative work, based on the first three days of analysis.
4. Choosing a social innovation using information science options that will empower patients.
5. Preparing a protocol for a low-risk innovation protocol.

Health systems: patient and disability roles and agency
Resources: Greenbank website and articles, peer research example, systems theory

The first framework that influenced the design of my moral injury social innovation was using a discourse analysis to understand how systems and institutions, defined as a collection of shared understandings that constrain and prescribe actions, impact the presence of moral injury. Viewing systems from a patient perspective revealed weaknesses of the traditional treatment and diagnosis system that prevented patients from becoming well. It also prevented healthcare professionals from fulfilling their duties, while revealing the elements of community inclusion and peer and natural support systems that support patients in their journey to well-being.

See below for a demonstration of discourse analysis for the three systems introduced above.

Table 9.2 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis (Nuckols, n.d., https://www.naadac.org/assets/2416/cardwell_nuckols_treatingmoral.pdf)	**Analysis**
"If one cannot accommodate or assimilate the event within existing schemas about self and others, guilt will be experienced, as well as shame and anxiety about the personal consequences."	The patient is to blame for their inability to assimilate the morally injurious event.
"Shame is associated with a wide variety of psychological problems, including depression and PTSD, as well as physiological changes including an increase in harmful cytokines and proteins that promote inflammation and cortisol."	The patient is something to be studied rather than a whole person—their actions are not a natural reaction to a personally horrifying event, but a chemical consequence of shame.
Professionals must "develop a knowledge of the exact nature, conditions, issues, environment, locations of the veteran's theatre of operation."	Professionals are responsible for knowing every minute detail of the morally injurious event.
Summary: The presentation is written for professionals, not patients. The patient is unconsciously at fault for their illness and professionals change the way they view the morally injurious event, so that shame and maladaptive coping strategies lessen or cease. Treatment cannot happen unless the patient wants to engage with the professional, and it is the professional who decides when amends to the morally injurious act are too much. The professional is active while the patient is passive, within the article.	

Table 9.3 *Peer and Natural Support Analysis*

Data: Peer and natural support ***Project Trauma Support*** https://projecttraumasupport.com/	**Analysis**
"The purpose of the groups are not to exchange war stories, so details of traumatic incidents are not shared. Instead, the meetings are intended to help members weave a new story of hope and healing."	Members of the group assist each other in creating new narratives. Power is horizontal rather than vertical.
"For me, the peer support group is a safe place I can go once a week and be with other first responders who truly understand what I'm going through. I can be honest and not feel judged. I can shed a tear and not feel weak."	Members feel empowered by the group; there is no fear of shame or pressure to share every detail of their morally injurious event. They remain in control.
Summary: Those who are a part of the group are seen by peers as warriors. By taking the initiative to attend meetings, the individual is doing something that their peers consider to be good, and they can actively help others who are experiencing a similar injury. The role of each member is to support others.	

My involvement with health systems began with large institutions for mental health and disabilities. These removed citizens that made the general population uncomfortable by claiming to care for their needs. I learned quickly about the dominance of hierarchy within these settings that extended not only to staff but stigmatization of patients. As an academic, I worked to understand how systems created restrictions for those they served, with seniors in long-term care, disabled citizens in community workshops, and profoundly handicapped children and youth in custodial institutions.

I also worked to create new systems that tried to reverse restrictions on the following: legal guardianship; communications technology for disabled persons; new community mental health options in Russia and North America, including Mexico; independent living in England and Canada; professional curriculums for teachers of profoundly handicapped and community disability studies; and community mental health workers.

As an academic, I studied systems from the perspective of an upstart social justice program that seemed destined to challenge established practices, and through all of this I became convinced of the following findings.

Findings

In the deficit-based diagnosis and treatment system, the patient is passive and responsible for changing their worldview to correct the deficit. This is guided by a professional who decides when acts of making amends are sufficient or insufficient, thus decreasing the patient's agency. The relationship dynamic is about conformity with the professionals deciding when the patient graduates from being ill to not ill.

The example of a community inclusion system, the Whole Health Medicine Institute, acts against the hegemonic medical system by training healthcare providers to understand health holistically. Healthcare providers enrolled in the Institute have more agency than patients in the treatment and diagnosis system but are still acted upon by the program. To be successfully treated, one must adopt the ethos of the program.

Supporting others can facilitate new self-narratives. The peer support system changes the role of patients from morally corrupt individuals to people who can help others and make meaning out of their experiences. Peers understand the unique factors that lead to moral transgressions and create a non-judgmental environment through which parties can redefine themselves. Power is horizontal rather than vertical, and the dynamic is one of relationships and learning.

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10

An Emancipatory Patient Standpoint Theory: Stories Tell Us Who We Are and Who We Want to Be

Highlights

- Standpoint in everyday decisions
- Feminist standpoint and JEDI principles
- Discovering a patient standpoint as part of making a difference
- Patient standpoint map

As I began writing this book, I realized that the combined patient and researcher roles in peer research resonated with the early dual roles of feminist researchers. Feminist standpoint theory helped me understand the impact on people as they were recruited into patient roles within health systems, just as women were/are recruited into roles by patriarchal systems.

The most dramatic similarity with feminist standpoint theory was the call for research to begin with the experiences within systems. In this I was lucky because of my foundation within disability, aging, and mental health communities that were early leaders of emancipatory movements that challenged health system restrictions and achieved significant success.

PaCER peer research development was fortunate because several health professionals, Jean Miller and Sylvia Teare, were also patients who were part of the first research cohort. They were able to define the distinct difference between patient experience research done by professionals and that done by patients. Jean Miller, an academic nurse who was part of the first cohort of patient researchers, tells her story on YouTube (PaCER, 2017, https://www.youtube.com/watch?v=bR6VnjwupjM). The unique partnership between trained peer researchers and participant co-researchers was able to tap into the social structures of healthcare and the political forces that were present and not apparent to professionals.

This chapter attempts to 'stand on' standpoint theory to prepare a simple emancipatory tool that combines the analysis of systems in Chapter 9 with an emancipatory extension of salutogenesis (Chapter 6) to inform a standpoint theory that enables patients to identify the impact of their experience in their health systems.

A standpoint theory can help identify program and policy characteristics and obstacles to patient ownership of their health and healthcare. It is also useful for communities and patients looking to find alternative ways of dealing with systemic discrimination. As such, it enables people, students, patients, and communities to look at options for change and innovation in existing health systems while supporting innovative community and consumer options.

The theory was incubated through community peer support groups, my thesis, student discourse analysis of autobiographies, and study of *Grey Matters* and PaCER research. Like salutogenesis, it offers an asset-based alternative to the deficit or dependence focus of most healthcare research. The theory is a pragmatic strategy using a map of key psychological spaces in health systems. The following are responses to the patient standpoint theory.

- *The powerful thing for me is that it isn't about being 'positive' in the face of something cruel and terrible, it's about being real and assertive, to have a life in your own hands when so much of the power can be taken away by treatment, illness and even sympathy.* (PWLE reviewer of the chapter)
- *Patients who participate in peer research respond to the safety of a peer-to-peer approach to share their stories. Our group said that 'Telling stories to someone who is like me adds to my knowledge about who I am, and what I know.' In group sessions, participants listen to others and respond with their own stories, and all gain power and control of new knowledge about their lives.* (A note attached to a peer research report by a peer researcher)
- *Through being co-research participants, they describe, explain, or evaluate healthcare experience. Through their efforts, they become knowledgeable agents in their own right rather than the source of information that is held by others. Peer research comes from and focuses on questions that would not otherwise get asked.*

Feminist Foundations of Standpoint Theory

Feminist standpoint theory arose from sharing real-life stories to create a collective identity. In doing so, the feminist scholars legitimized everyday

experiences of women. They created a movement that challenged the male patriarchy, which assumed that women's aspirations were misplaced and their problems were seen as a weakness of nature or character faults (see Borland, 2020, https://www.britannica.com/topic/standpoint-theory).

A patient standpoint theory begins with the basics of feminist standpoint theory that identify and analyze the systemic obstacles in healthcare. A patient standpoint supports emancipatory social science by combining the two key dimensions of empowerment identified in the co-design of peer research: identity and agency. Throughout, it addresses how we are recruited into dependent patient roles and the potential to change these roles to become stakeholders in our own health and healthcare.

The term 'standpoint' in everyday language refers to the stance, perspective, or point of view each of us take about issues, opportunities, and challenges. We likely have more than one standpoint at any one time, depending on what we are doing. These values, beliefs and expectations generally evolve from our history and current circumstances. These standpoints, or life scripts, develop early in childhood, based on family expectations, and they branch out as we encounter and are socialized by the schools we attend, our faith, work, sports, professional training, healthcare, and friendships.

For example, a student in Community Rehabilitation and Disability Studies at the University of Calgary might introduce a case study assignment with the statement: I take a social justice standpoint in that I look to the sources of power that render persons with disabilities subjugated. Nursing students might approach the same case study quite differently: As a nursing student, I would be looking for the impact that disability has on overall health and, in particular, the nursing services that might be required. If I were a business student, I might take a standpoint that enables me to investigate the case study from a cost-effective perspective.

Most of us are not even aware that we make choices and decisions using the values and expectations of family, schools, faith, and work. Feminist standpoint theory linked experience and everyday experience of being a woman (Hartsock, 1998; Heyes, 2002, https://doi.org/10.1353/hyp.2002.0033).

Standpoint theory takes this everyday understanding of roles, relationships, and systems one step further. Marxist theory, said to be the beginning of standpoint theory, encouraged workers to understand and challenge the forces of capitalism. Modern standpoint theory is also grounded in a collective consciousness or identity as the first step to emancipation. By sharing their experience, women recognize the dominant and systemic forces that have shaped the scope and boundaries of their lives. Patriarchal systems, not personal inadequacy, hold women in support roles. Subjugation is the result of

systemic, economic, and social discrimination. Collective understanding of the forces that constrain women creates a collective energy to challenge power imbalances.

Women researchers are also mothers and daughters, and they understand that knowledge generated as peers creates a perspective of women as told by women (Hartsock, 1998). The researchers and academics who were part of the early feminist movement created disruptive feminist research to legitimize the importance of sharing and researching everyday experience through stories. These narratives, in many ways, are like the narrative research methods that evolved in the development of peer health research.

The publication and dissemination of research informed women's experience and called out awareness of systemic patriarchal forces. These courageous women researchers and academics were both insiders and outsiders on a very basic level. They shared the discrimination of all women and also that of women scholars in academic patriarchal systems. They published research about women's oppression to support the need for social change. "We looked both from the outside in and from the inside out . . .we understood both" (hooks, 1984, p. xvii). In turn, the feminist political movement used these publications to motivate women to construct a collective reality to challenge stereotypes of their lives, their potential, and their power (Brown et al., 2004, https://doi.org/10.1111/j.1467-9566.2004.00378.x).

Downing and Roush (1985, https://doi.org/10.1177/0011000085134013) provide an early example of a standpoint theory about women's experience, moving from a passive acceptance of sexism to a greater understanding of the ways in which sexism has affected their lives. The summary of the four points of their work depicts four stages of emancipation:

1. **Passive acceptance** of traditional gender roles and the belief that traditional gender roles are acceptable.
2. **Revelation**, when women question traditional gender roles and how they may have supported these roles.
3. **Synthesis**, when women reject traditional gender roles and judge men on a more individual basis.
4. **Active commitment** sees collective action and a commitment to social change. Women and men are different yet equal.

Finally, Table 10.1 depicts the similarities and differences of feminist standpoint and a proposed patient standpoint theory. This table was adapted from principles and practices of current feminist science to contrast established practices of feminist standpoint theory and early indications of a patient and disability standpoint theory.

Table 10.1 *Feminist Standpoint and Patient Standpoint Characteristics Contrasted*

Feminist standpoint theory	Patient standpoint theory
Study of the production of knowledge and the practices of power.	Study of the production of patient roles within systemic power practices of medicine.
Female identity is defined mainly at birth.	Patient identity is defined by the systems they rely on. These change as health status changes.
Women in diverse cultures are further defined by social determinants.	Patients are further marginalized by gender, poverty, culture, and other social determinants
Women share everyday experience to produce a collective-research-informed voice.	Patients seldom share everyday patient experience. Peer research produces a collective-research-informed voice.
Knowledge owned by women through their natural connections and affiliations.	Knowledge is accessed by patients through social media and access to digital medical information and their interactions with their medical contacts.
Challenge patriarchal values and dominant discourse.	Challenge the impact of labels and protocols that reduce personal values and preferences.
Oppositional conscience names the sources of oppression as a call to action.	Systemic vulnerabilities identified by JEDI are named as a call to action.
Social action to achieve equity and equality, through targeted social movements.	Call to create social action within healthcare through research and alliances.
Range of methods within a critical theory and epistemology of emancipation.	Critical theory and engagement research strategies to draw attention to the need for change.
A political strategy to name and confront sources of patriarchal power.	Political alliances within health transformation teams to increase collective patient voices. Social entrepreneurship alliances to create innovative alternatives.

This comparison highlights the obstacles patients face to increase their control over their health and healthcare. The shaded cells identify the key differences that had to be considered when creating a patient standpoint theory. The first and most difficult is the lack of a consistent patient cohort. Most standpoint theory relates to identifiable groups where the difference is stable and lifelong, such as gender, race, immigration status, or Indigenous heritage. Patients,

however, are defined by their conditions and the services they use. They interact with individualized treatment models that seldom include opportunities to connect with patient peers during their care. Knowledge about health conditions tends to be organized by health professionals, and there is little opportunity for sharing experiences and concerns among patients that might create a shared identity.

Social media and chat rooms have done much to overcome this gap in patient knowledge and identity, and these new connections triggered patient engagement networks. This is nascent, as citizen action groups and health associations are just realizing the importance of patient action, and there are few political avenues to voice concerns and suggestions for change. The examples below from patients who were reviewing this manuscript, however, reflect emancipation.

- *In reading this chapter, I reflect on patriarchal and colonial views on women and other cultures and how they relate to my health conditions. I sometimes feel my present journey is counterintuitive to how I was raised. I'm now examining the matriarchal way in my own culture, the roles we played, and how they were erased by colonialism. I've always felt I was in two worlds, not quite in one, not quite in the other, but then I learned about the concept of two-eyed seeing and I was able to reconcile things and feel stronger in my beliefs as they evolved, and we joke about Big Aunty Energy.* (Patient reviewer of the manuscript)
- *I know as a dialysis patient in my 40s, social media opened up my world to people like me, and, in turn, to patient engagement opportunities.* (Member reviewer of this chapter)

Patient identity is not stable, even for those with substantial and ongoing contact with the health system. Currently, the first goal of emancipatory theory is to recognize and acknowledge a patient's right and ability to question and make decisions about personal health and healthcare. Patients then can identify the systemic practices that reduce or obstruct the ability to notice, call out and challenge these obstacles by seeking out opportunities to share experience with other patients. This is where peer research exists. It enables patients to share their knowledge of systemic discrimination and look for ways to make these known. How to make this knowledge available to others is the last step in the process to a patient standpoint theory.

A Patient and Disability Standpoint Theory

This section draws on parallel research projects. The Calgary Association for Independent Living research supported an informal grounded theory project to explore how members could analyze everyday stories to understand the obstacles they faced and set goals that mattered to them. At the same time, undergraduate and graduate students conducted class research as part of a social construction of disability courses in disability studies. They used a casebook-based narrative analysis to uncover how patient roles were constructed and how they reconstructed patient stories to find a new normal. A number of ideas emerged from student-driven narrative and discourse analysis that was interfaced with real-life peer support experience of telling stories in peer support group sessions. More recently, versions of this chapter about standpoint theory were used in courses related to social innovation and design thinking.

Standpoint theory works with other standpoint theories, salutogenesis, JEDI goals, and the principles and methods of the science of engagement and citizen science to achieve a new understanding of the potential of peer research to support new roles for patients in research, healthcare, and new health technologies.

We start with Jean Baker Miller's (1976) feminist standpoint definition, adapted as a patient standpoint theory:

> *Patients, who are in a subordinate position within a health system, observe and learn what is expected by the system and professionals to navigate the system. Their dependent position is what motivates them to study the system. This perspective is an advantage, and patients with chronic illnesses or disabilities who become adept at learning what professionals need and want to hear use this knowledge to retain or regain control.*

This aligns with the basic theory of salutogenesis, which affirms that

> *patients make choices to use stressors of health systems to build and refine personal, program, and generalized resources and, in the process, develop a sense of coherence using their understanding of their health conditions and their ability to manage stressors to find meaning that builds resilience, confidence, and expertise.*

Standpoint, salutogenesis, and systems theories were not part of the early development of PaCER. These theories gained importance during the development of the science of engagement and the role of peer research in health research and innovation. Standpoint theory evolved as a tool to set goals in

personal well-being and program settings where it speaks to the interaction of identity and agency within programs, policies, and systems. Standpoint builds empowerment through new social roles that address justice, equity, diversity, and inclusion (JEDI) principles that reflect standpoint theory, citizen science, and peer research that should be an essential tool in future health systems and the transformation of current systems.

These situations can be identified by simple narrative analysis of patient and PWLE stories to uncover identity and agency. Through PaCER research, we discovered that when systems support new roles for patients and persons with disabilities, change happens. This innovative partnership created peer research that was listened to by the healthcare system. The SoE and new peer research options may help to guide professional and public interest in patient involvement to achieve health transformation. The following are some examples from the PaCER/PRISM hub at the University of Calgary (https://prism.ucalgary.ca).

- Patients were initially excluded from information about the safe surgery checklist, a tool to improve surgery outcomes adopted by most provinces. Patients were confused by the questions in the survey and this led to stress at a critical time before surgery. The peer research that uncovered this was instrumental in patients being informed as part of the checklist protocol that significantly changed the role of patients in surgery and allowed them to participate in the protocols that impacted the overall compliance with the protocol.
- An arthritis study included both peer and physician researchers as part of a co-research team to develop a patient management app for knee osteoarthritis that met the needs of both physicians and patients.
- Patient input into one-day breast surgery intervention noted significant patient suggestions for more patient-centred education, focusing on preparing for surgery and aftercare.
- Current socialization practices in mental health override patient stories and relationships, and when the findings were shared with professionals, they were more aware of the impact of losing personal stories in their new patient identity.
- A peer research study of parents who deliver still babies showed that they needed to connect with their newly born child and mourn loss in natural ways. This helped professionals respond differently after delivery.

Most health problems occur within health systems that are not aware of the impact their roles, language, practices, and policies have on patients. I tried popular polar archetypes such as Eysenck's introversion (1952), but few included the social ecology of the categories. The following patient standpoint theory was developed so that patients, healthcare providers, researchers, developers, and funders could visualize the patient journey through healthcare systems based on the two characteristics of identity (as a patient) and agency (within the health system).

I had been intrigued by self-assessment and personality theory early in my career, so I selected two current theories: Atkinson's (1974) motivational theory (motive to approach success and avoid failure) and Rotter's internal and external locus of control (1966, https://doi.org/10.1037/h0092976). A current application of Rotter's locus of control addresses the concept of agency or locus of control (Tyler et al., 2020, https://doi.org/10.26686/wgtn.12956984.v1).

The eventual format to create a concept map of patient experience in health systems evolved into a cartesian map informed by these two theories. The quadrants evolved to include four psychological spaces created by the intersection of a horizontal axes of:

- self-regard or identity informed by theories related not only to feeling good and being motivated to approach success approach or avoid failure; and
- internal and external locus of control that denotes personal control and control by external agents and systems.

During an extended series of workshops and peer support sessions, participants chose a story of their experience and identified where the story was located on the grid by plotting where it was located on the horizontal identity grid and the vertical grid of internal and external control. They then proceeded to where on the grid they would like to reach by plotting how they would like to feel (horizontal) and the control they would like to have (agency). This was the inception of standpoint theory as a tool that could be considered a standpoint that included both identity (horizontal) and agency (vertical) directions. Refer to the following YouTube video for a quick lesson on plotting coordinates on a grid (Mathispower4u, 2009, https://www.youtube.com/watch?v=s7NKLWXkEEE).

Staff and members of CAIL were recruited to experiment with the first primitive grids. Members made statements or told short stories about their experiences that were important to them, and they helped each other to plot their stories on a four-quadrant map as a way to analyze how it made them feel.

- First they considered the horizontal axis and identified where their story was located along the axis of feeling good or feeling bad. It was not necessary to use numbers. They just estimated the distance from the neutral centre to the end of the horizontal coordinates. The questions might be: 'How do I feel about myself when I tell that story?' 'Do I feel good about myself or bad about myself?' 'How good?' They used the centre as a transition point where you 'feel just ok,' and the right end is 'better than you have ever felt' and the left side is 'feeling really bad about myself.'
- They then considered where the story was located along the vertical axis that asked the question: 'Where am I? Am I in control of this, or are others in control (internal/external locus of control axis)?' If the 'welfare system rules are in control, how much control do they have along the up and down axis?'
- They then made a mark based on the horizontal and vertical positions. This mark ended up in one of the quadrants that identified where they felt they were at the time of the story in terms of their identity (good or bad) and agency (internal and external locus of control).

They now knew where they stood when the story unfolded. They could then discuss how they felt with language about feelings and their hopes for being in control. They were supporting each other in telling and thinking about their stories. For example:

- When that happened, I was feeling good and in control of what happened (positive identity and internal control)
- When that happened, I was really messed up and I should have known better (internal control and negative identity)
- When that happened, I was not happy with myself, but it was because I was stuck in that group home that wouldn't listen to me (negative identity and external control)
- When that happened, I knew I was doing the best I could and the guys there support me so that I can count on them (positive identity and external locus of control)

This created a natural communication and planning tool for people to understand how their experience made them feel and how much control was in their hands or in the hands of others. The tool also suggested that it might be possible to have control over what happened to them. It was not long before we realized

that this small self-assessment tool was also able to identify the nature of the environments that people lived in.

- Pete had spent most of his childhood in a behavioural unit. When asked about the unit, he was clear when using the tool: *They made me feel like shit, they always noticed how I screwed up, it was like they had shit radar.*
    - This clearly defined feeling bad and not in control; 'they' were in control.

- Joan, talking about living on her own for the first time: *I have my cat and I'm learning to cook, I decide when I go to bed and what I eat for breakfast.*
    - In a situation of being in control and feeling good about herself.

- Megan, talking about her weight in a hospital setting: *I try everything I know to lose weight, but no matter how hard I try I look fat and ugly.*
    - In control and feeling bad about herself.

- Tony, about playing wheelchair basketball: *I was so lucky to meet Jim, I'm now part of the ball team and my life has turned around.*
    - Lucky to be part of a team supported by others and doing well. The team is external control that brings comfort and a positive identity.

This helps people think dynamically about identity and agency that changes with experience. For example, *I am not always a loser who screws up; yesterday I saw a person drop her scarf and I ran to get it and gave it to her.* People on their own or discussing experience with their peers make meaning that challenges the labels they use to describe themselves.

This tool soon became a power for personal change. Individuals could share experiences that were disempowering. They could identify how they wanted to change in a natural environment with peers. We could also use this at the program level. We could see how our expectations and structures created positive and negative roles and relationships. We could also build personal agency (internal locus of control) and self regard (the good-bad axis) by creating different expectations within the program. It was a clear representation of peer support.

> *J was a physically disabled woman who was overweight. She was quite worried about her size and wanted to lose weight, but she*

came from a large family and the only times she was invited to visit was for family meals. Her mother was proud of her cooking and cooked very traditional high-calorie food. She said she felt very bad about her weight and that she placed herself at the negative end of the horizontal axis. However, when she considered the vertical axis, she placed herself as in control, but as she talked about this, she felt she couldn't miss her family meals, and her mother would be very insistent that she ate her food. While this did not change her behaviour with her family, she clearly understood the external force that her family and her mother exerted. J knew she could make the hard decision to take control, and this realization meant that the decision was hers.

The above story was included because it captures what happens when people are trusted to evaluate their own situations, identify possible goals, and then weigh the options. As an emerging standpoint map or grid, it was shared in community settings, practicums, and classes on social construction and capacity building, along with conference presentations and professional meetings with educators, nurses, and psychologists. As these groups experimented with the standpoint grid, the nature of the grid shifted and responded to the different applications.

As I was writing the science of engagement and reviewing both *Grey Matters* and PaCER research projects, I realized that this simple grid was not only a good tool for peer support, but it was, in fact, a standpoint theory to explain the nature of patient and disability experience in the systems they were part of.

A Patient Standpoint Theory

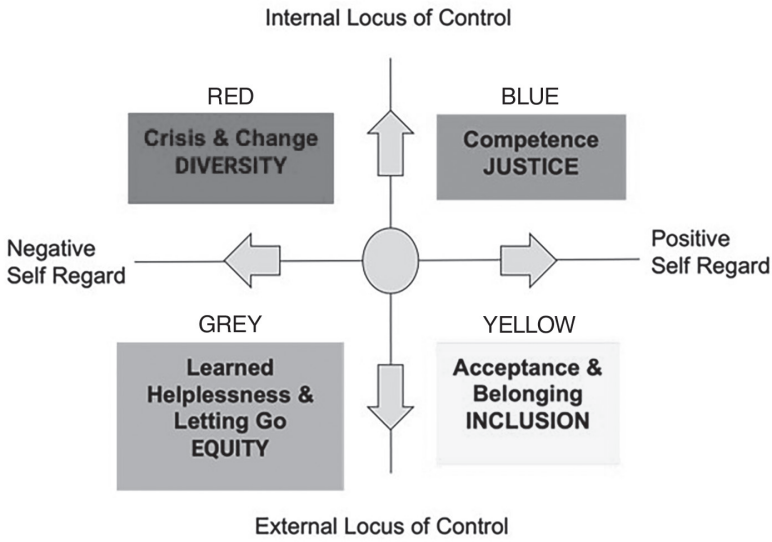
Most standpoint theories start with the process of sharing stories of capacity and oppression that identify strengths and the obstacles that are part of their experiences in systems and relationships that define who they are and what they do to live the life they expect to live. Sharing stories leads to analysis of obstacles and this then leads to identifying ways to resolve the inequalities and collective action to achieve these goals. The standpoint-informed theories use data from real-life experiences to understand and categorize the nature of the oppression and stages of emancipation.

This section deals with patient standpoint theory from a patient perspective that recognizes the complexity and dependence of patient roles in health systems. It also celebrates the power of narrative peer research to challenge

existing barriers to achieve justice for patients and communities and make systems and policies more equitable, inclusive, and diverse.

Figure 10.1 is a basic four-quadrant map with concepts of identity and agency that evolved during workshops with persons with disabilities, seniors, patients, and health and education professionals who were invited to describe their personal healthcare and well-being experiences with healthcare systems and health research. This was done to co design a way to represent healthcare and research characteristics that produced a map with two axes that eventually produced four psychological spaces and four transitions between spaces.

Figure 10.1 *Basic Structure of a Patient Standpoint Map*



Note: Map is based on positive and negative self-regard poles and internal and external locus of control poles. Also included are the related JEDI principles in capital letters.

The map represents the basic four-quadrant grid with the themes and colours negotiated during consultations and tested during the narrative analysis of autobiographies of patients done by students. The quadrant labels can be adapted to reflect specific situations. Each axis can be adapted, by changing the axis labels of identity and agency.

- The horizontal axis represents a positive and negative pole, the poles can also be named good, bad; happy, sad; pain-free, overwhelmed with pain; upbeat, depressed; even the ease, dis-ease continuum of salutogenesis. The horizontal axis represents the balance obtained when a positive or salutogenic theme is added to the focus on illness and trauma.
- The vertical axis represents agency with labels such as: internal or external control of the person's actions; supportive, restrictive experiences; individual or collective agency. This axis of agency is new in health experience research, which has focused on negative or weakened patient characteristics of vulnerability, fallibility, and loss. It brings a salutogenic element to medical research.

When dealing with external control in health situations, there seem to be a number of debates. For example, when overwhelmed with pain or loss that places people in the negative side of the grid, the source of control and power is two-fold. The external control can be supportive and facilitate positive self-regard, or it can be negative and increase avoidance of failure or helplessness. When it is negative, it relates to the JEDI principle of equity and captures the essence of the loss of essential personal or group power.

External control that takes away agency is difficult for patients with complex healthcare needs who may, for a short time, need to let go and let others help or make the decisions when faced with intractable pain and loss. Those who brought this to light felt that it was a conscious decision to prioritize what they could or wanted to be in control of. For them, it was not a learned helplessness but a willing suspension of being in charge for a period of time. A reviewer spoke of having to abide by funding regulations to meet basic needs, even though they restricted her freedom and ability to contribute to her advocacy work. This led to the realization that all quadrants had both positive and negative attributes. For example, 'competence' can be destructive when it leads to burnout. 'Crisis' is also the motivation to change. 'Learned helplessness' can be seen as needed refuge, while 'acceptance and belonging' is both a positive thing and can lead to dependence. This brought new meaning to analysis.

A patient standpoint theory needs to accommodate many layers of power and complexity to represent and benefit from an emancipatory science in systems that are both essential and restrictive. This is one of the intriguing ways that theory opens the door to layered and nuanced experiences and decision-making in healthcare.

Four psychological spaces were identified by analyzing stories told by patients, using concepts of identity and agency. These stories can be captured as

part of peer research from narrative analysis or through discourse analysis of public documents and online social media of programs and policies. An example of using standpoint theory to inform discourse analysis of public documents is included in the Resources section as part of a university course on innovation using the science of engagement theory to analyze systemic discrimination to identify solutions identified by patients.

As you read about each psychological space of the standpoint map, consider how it might be used during co-design or SET to identify a main concern or priority for peer research. Consider also how you might recognize identity and agency, the criteria you might use to compare stories and themes during COLLECT data collection and analysis. Finally, consider how standpoint theory might map themes and categories that relate to the explanation of the main concern of research and point to the potential solutions as part of REFLECT.

Blue: The Competence Quadrant

Table 10.2 *Blue Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Blue—capacity and competence Feeling good and in control Motivated to achieve success (MAS)	Develops where there is positive reward and opportunities to develop resilience Achievement leads to expectations of success	The exaggerated need to achieve and to test oneself Dependence on individual strength The constant need to prove oneself Type-A personality	Look at me Bring it on Learn before acting Don't sweat the small stuff Put it on a schedule Just do it I know I can

The blue quadrant was the first psychological space identified in the study of autobiographies, partly because most autobiographies begin with a chapter about what life was like before the accident, illness, or loss. This represents their anticipated life story and sets the stage for the changes that come with the onset of a disability or health condition.

Blue stories aligned with Atkinson and Litwin's (1960) achievement motivational theory that captures the early work of McLelland on the basic motive to approach success (MAS). This includes the expectation and probability of succeeding. The MAS appears to be associated with the behavioural activation system, positive emotionality, and extraversion that combine in an approach temperament (Elliot & Murayama, 2008, https://doi.

org/10.1037/0022-0663.100.3.613). Many of us live our entire life in this quadrant, living our anticipated life guided by our scripts. It is difficult to realize that this is only one reality, if we have never experienced anything else.

Everyone doesn't have a history of success or a motivation to achieve. Standpoint theory helped professionals realize that their way of seeing the world as a blue standpoint might inadvertently restrict the potential for their students and clients to understand their own place in standpoint and their option to change their identity and agency through finding ways to celebrate their identity and search for ways to take more responsibility.

Living the success of a life expected can present long-term consequences when serious setbacks occur later in life when you have had little chance of building resilience. The concept of errorless learning that was once popular in special education actually harmed children who had experienced failure and had learned to focus on avoiding failure. When faced with a teacher's expectations of mastery, because of errorless learning, children are locked into a struggle between staying safe by avoiding failure. Teachers who expect all children to be able to succeed are soon surprised and disappointed when children who don't respond the way they expect them to. They see these children as not motivated, lazy, and disruptive.

Resilience as Social Capital

In the senior's study of resilience, one of the key findings was the worry that young people don't have opportunities to risk and to fail, and that they will never learn how to be resilient. Seniors had all experienced deprivation and loss as part of two World Wars and the Great Depression. They felt that their childhood experiences had produced a social capital of resilience that could be shared with others as a gift of achievement.

The blue quadrant is important when analyzing programs and policies, because it represents the dominant quadrant of many who are health professionals. It is not uncommon for online program descriptions to be written as if clients were motivated primarily by success, even though the language used to describe patients and clients reflect the goal of compliance—"the good patient."

Red: The Crisis and Change Quadrant

Table 10.3 *Red Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Red—crisis and change High motivation to act to change an untenable situation Feeling responsible for being unwell or in pain	Caught in a negative situation and believing that it is your fault Feeling overwhelmed by the problem Temporary high anxiety, loss of positive self-regard due to illness, negative self-regard, identity and feelings Loss of control in new traumatic or medical situation Survivor guilt	Constant and pervasive tension can lead to dangerous choices and motivations Anger at oneself and others because of fear and hypervigilance about loss	Must get back to normal I need to learn about this problem Naming ceremony Shaming and blaming I know I can How could I do this I must have done something to cause this Anorexia—I hate my body; I can change it by not eating Post traumatic stress—I must control the uncontrollable I must keep control no matter what the cost

The red quadrant is extremely complex and stressful—it is a crisis. The patient considers themself responsible or at fault. It is a double jeopardy situation. This quadrant captures the power of pathogenesis and the challenge of personal agency for a serious problem. We make decisions to stay in control, often in threatening situations that preclude control. The red or 'crisis' space most often comes without warning—accidents, trauma, sudden onset infections, or disease. It is also primarily a temporary space, as people struggle to maintain some control during the onset of problems. This is a high-energy quadrant of crisis with high motivation to return to the blue quadrant. The power of personal threat makes people feel desperate but can also motivate patients to change. They have the option of becoming involved in the technology innovations that are emerging. Access to medical information has made it possible for people to understand their conditions, share experiences, and gain confidence and

motivation to find solutions, or build self-management skills to monitor and manage their healthcare.

Stories in this quadrant were hard to identify in autobiographies because stories are about blame and shame and are relatively short lived. The breakthrough to understanding this quadrant came with a group of undergraduate students studying autobiographies about eating disorders. Not only did they read autobiographies, but they also dove into deep-web anorexia chat rooms to learn more about the RED quadrant. The students also were motivated by the Mental Health Commission of Canada's report that year that had declared anorexia to be the most serious mental illness issue, because of the high rate of suicide. The National Initiative for Eating Disorders (NIED) identified that the mortality rate associated with anorexia nervosa is 12 times greater than ALL other causes of death combined for 15- to 24-year-olds (NIED, 2020, https://www.nied.ca/eating-disorders-in-canada).

The first level of analysis done by students dealt with the inherent danger of being in a negative RED space (the fear of being overweight) without a way to leave the negative space. Students noted that girls and boys who were trapped in a negative space, with an 'overweight' impression of their appearance, withdrew from school, work, and family relationships and many joined deep internet chat groups that promoted losing weight and suicide.

While suicide is a way out, the majority of people in the red quadrant use the motivation to change. The following examples are offered from personal experience and student presentations.

- **Too close to home**. I had been asked to teach the quadrant map to a class of special education teachers by a colleague. She took part in the class discussion until we reached the red quadrant. She slowly moved to the back of the class and crossed her arms. I quickly ended the class and went to her to find out what was wrong. Her husband had lost his job in the downturn of the oil and gas boom. He was a senior executive, used to power and control, and considered that he should be able to overcome this unexpected setback. He spent months analyzing the firing, working on strategies to convince companies that they needed him, looking for comparable jobs, and selling off luxuries. Finally, he seemed to lose hope, became depressed and was found dead by suicide. She was angry with me for not telling her about the dangers of feeling responsible during a sudden change in identity. She felt that if she had known this she could have intervened and prevented his suicide.

- **Yvette's metaphor of an alien land.** This metaphor comes from a PaCER student's contribution to their final report on hidden pathways of chronic illness. It describes the initial impact of adult-onset, life-threatening illness, such as cancer, Huntington's chorea and ALS, as well as conditions considered to be without hope. This is a segment in "Hidden Pathways to Chronic Illness" (Banerjee et al. 2013, http://hdl.handle.net/1880/109953) that captures the impact of negative news over which you have no control:

> You and your family have been away on vacation for two weeks and return to your farm in southeastern Alberta. The sight that awaits you is shocking and surreal. The entire landscape that was once flourishing with undulating green grain fields around the farm is now nothing but fields of pale brown earth with short straw stubble everywhere. As you drive up the driveway toward your home, you are more shocked. The house and outbuildings look starkly naked as there is not a shred of colour visible where the trees, shrubs, and garden that had been lovingly planted. All that remains is a moonscape with some tree skeletons standing in the brown earth and the carcasses of hordes of grasshoppers. This scenario might be similar to those confronted with serious illnesses. Life proceeded as normal, and then one day a huge, foreign landscape was before them.

Most patient experience research does not focus on this quadrant because there seems to be an assumption that the cure for the anxiety and stress of health concerns is to align with professionals who understand how to manage these situations. This is in part due to the individualized nature of healthcare—there are few options for connecting with patients who could provide support for self-help and how to make decisions about care. The fear of losing medical support is often just too great for individuals who would like to be engaged in their healthcare; it is easier to turn control over to professionals.

Grey: The Learned Helplessness and Letting Go Quadrant

This represents a common quadrant in patient experience studies. It is the psychological space that occurs when people feel vulnerable, fallible and lost that supports the need for professional care. Unfortunately, it also has the potential to create long-term dependencies, as people rearrange their lives around the healthcare they rely on.

Table 10.4 *Grey Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Grey—learned helplessness Negative self-regard but it's not my fault History of failure or rejection leads to a motivation to avoid failure (MAF) Grey is also the quadrant of deliberate acquiescence of control when serious or chronic conditions become too onerous to manage. This requires further study.	Giving up control in a negative situation reduces anxiety (move from RED) Externalizing fault and power Compliance with authority Oppressed by stigma and external control through rules and punishment A history in these situations can be hard to change because they perpetuate expectations of inadequacy	People are misperceived as unmotivated, aggressive and difficult when trying to avoid being seen Avoiding failure takes a lot of energy and vigilance This is a quadrant of loss and holding ground. Blaming others, the system, fate, poor health Extended periods of compliance can cause people to withdraw and give up	Don't expect much of me; I'm sick (disabled, etc.), I used to, but now . . . They have it in for me It wasn't worth doing anyway Nobody cares I work all the time just to keep out of sight If only . . .

Grey is the second most identifiable psychological space and is the polar opposite (diagonal) to the blue space of 'competence.' Grey captures Atkinson's motive to avoid failure (MAF) that is the opposite to motive to approach success (MAS, in the opposite blue psychological space). MAF is defined as a relatively stable personality disposition to avoid and anticipate negative impact of failure outcomes. It is the stable response to loss of control of chronic conditions that are often defined in terms of shame, embarrassment, humiliation, and loss of status and esteem (Elliot & Murayama, 2008, https://doi.org/10.1037/0022-0663.100.3.613). This avoidance is seen in the stories of experience of many of the clients and patients who had experienced failure, stigma, loss, and despair. This history results in little control over the probability of failure or success. The MAF may be associated with behavioural inhibition systems and a learned avoidance temperament (Elliot, 2008).

The title of this quadrant, 'learned helplessness,' which was the original work of Roald Nygård (1969, https://doi.org/10.1080/0031383690130112) was adopted during the early stages of development of this standpoint theory during work with the Independent Living Centre of Calgary. It conveys the

systemic discrimination of bureaucracies and educational systems that fostered loss of confidence and reliance on professionals.

This is often interpreted as disruption, low motivation, and avoidance, all of which reinforce the continued need for external control. Teachers often use programs based on positive reinforcement to try to promote achievement, but unfortunately, positive reinforcement often increases anxiety and the need to avoid potential failure.

However, people who have complex and severe medical conditions can see the term 'learned helplessness' as giving up. Learned helplessness also failed to recognize that there are times when the pain is just too great, the loss too hard to ignore. During these times, patients need to unplug and let others take over, to retreat and recover, at least for a while. Therefore, 'refuge,' a new name for this reality was added to the GREY quadrant that doesn't diminish those who end up in this psychological space either as respite or because financial security or access to needed treatment force them to comply with external demands.

The following examples provide dramatic grey situations.

Naming Terrorism

The following excerpts from Dorothy Birtles, the founder of the Quaker prisoner befriending scheme where Quakers became pen pals with victims of terror in prisons. As a co-researcher, she provided examples of extreme external control in a situation that is fraught with death and pain. Both external locus of control and a certainty of torture and death are dramatic and, sadly, still current. Dorothy begins:

> Violence and torture are so highly successful
>
> We need to be shaking in our boots
>
> The pictures, smuggled out from a prisoner are excruciatingly painful
>
> These guards are trained to bring these people to their knees
>
> The lowest possible level of human experience
>
> The sexual things are not there by accident
>
> It's beyond sadism as such
>
> Getting pleasure from terror and pain . . .

This small gentlewoman fiercely believed that all societies are capable of unspeakable terror, but it needs to be faced, studied, and countered. The personal contact through letters, lessened the impact of terror and brought a sense of refuge with each new letter.

Those who end up in GREY because they can no longer fight the systems they rely on represent the need for a standpoint theory to name and challenge systemic discrimination and punitive social policy that restricts personal choice and ignores personal values. It is here that extreme JEDI action is needed.

Yellow: Quadrant of Belonging and Acceptance

Table 10.5 *Yellow Quadrant Psychological Space*

Standpoint	The starting place	Potential concerns	Scripts
Yellow—belonging and acceptance Feeling good within a collective psychological space that matters to me New normal	Peer support—finding others like me and adopting the ways of the group Finding attachment among family and friends Spiritual and personal meaning	Vocational and insurance professionals often see patients who don't return to former employment levels as malingering, unmotivated, settling for less, not living up to potential Individuals may become dependent on the support that is provided and may lose motivation to regain more personal control.	Fitting in Sanctuary/peace New expectations My place is here God guides my path

This quadrant has had a low profile in an economically oriented economy where everyone is expected to contribute to production and wealth. It also provides psychological space for living with a purpose beyond employment. This has been a choice for many living with disabilities and chronic health conditions. The patient and citizen engagement movements rely on people who volunteer to make a difference because working full-time may not be possible. Funding sources for basic life and disability necessities use policies that restrict earning and even discourage volunteering as a means of controlling funding.

The yellow quadrant is most uncomfortable for professionals whose work is to ensure that people return to productive employment after injuries or illness. In the past, rehabilitation for adults was focused on vocational rehabilitation that used employment statistics to justify rehabilitation professions and programs as a way to reduce disability benefits.

As a rehabilitation professional, I didn't understand this quadrant because I worked in work-training programs, but I came to understand that yellow was an end goal for many of the people I worked with. I began to worry about my own lack of experience of belonging and acceptance because my life was so filled with work. The yellow quadrant is more than an alternative to employment—it is a space to gain strength and acceptance. It is the space of peer support. It is a realistic goal for standpoint theory. It is here where identifying with 'others like me' can lead to wellness.

That said, yellow is a psychological space relegated to 'othering' those who are defined within charity or as non-productive discourse. The science of engagement will hopefully take up the challenges of contributing without pay to support research in these important and neglected spaces. The following examples are from comments made by reviewers or students developing or using standpoint theory.

- **Balancing a yellow life**. This new normal is where I'm at and happy, and even find that many in my team support me not working so I have the flexibility of volunteering and peer support. However, it's a big thing that I struggle with, knowing that I'm doing the right thing for my physical and emotional health while society as a whole believes that somehow I don't have value or am taking advantage of the system or am lazy, just because my new normal is better for me.
- **Professionals see acceptance and belonging as malingering**. Workers compensation and disability insurance professionals, at a presentation about the standpoint grid, were quite happy to name the quadrants and consider the implications for working with clients in the first three quadrants, but the last quadrant was met with hostility and anger. They felt that a standpoint needed to be about going the full way, not taking advantage of the system, malingering or challenging long-term treatment goals. While I had never related to this quadrant easily, likely because I had worked as a vocational counsellor, I was shocked into reconsidering the value of living a life that had purpose.

This quadrant provides a safe path back to blue, and a standpoint from this quadrant that provides a peer foundation for support groups and a standpoint

that is invoked when those with serious conditions search for meaning to accept their new normal. It is here where identity with others like me can lead to wellness.

A Route Map to Get from One Psychological Space to Another

Standpoint and systems theories were not part of the early development of PaCER. These theories gained importance as the science of engagement and the role of peer research in health research was recognized as a means of addressing systemic discrimination and achieving JEDI principles in healthcare and research. Standpoint also works as a tool in personal and program level where it speaks to the interaction of identity and agency within programs, policies, and systems.

We had learned that autobiographical stories often start in one quadrant, often the blue or 'competence' quadrant and end up in other quadrants, and often ending back in 'competence' or in 'acceptance.' As students continued to map autobiographical stories, we noticed common movement patterns.

These basic movement patterns provided new focus in creating a standpoint map that included transitions from one quadrant to another, and another, and another.

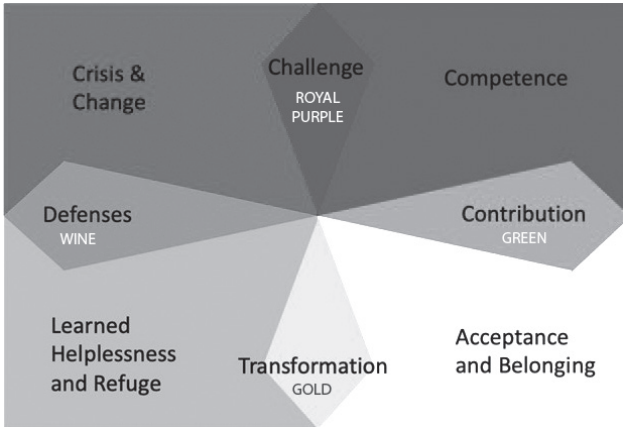
- The movement between BLUE and RED combines the colours to represent the PURPLE 'challenge' transition that sees the experiences associated with illness and disability as challenges to be conquered. It captures the energy and essence of regaining agency as the person achieves a new identity and retains personal agency. This space is the foundation script of sociologist Art Frank, author of *The Wounded Storyteller* (2013, (https://press.uchicago.edu/ucp/books/book/chicago/W/bo14674212.html), who sees this movement as a hero script. This also represents most professional discourse in healthcare where patients are rewarded for complying with treatment. This is a purple health discourse about succeeding by following care plans.
- The movement from RED to GREY produces a WINE colour of 'defence' transition that captures resistance and defense mechanisms employed to protect self-identity and personal agency as long as possible. When it is not possible to overcome the challenges of illness and systemic discrimination and loss, this transition shifts to attempts to defend one's identity and agency in the only methods left, giving up control to others to achieve stability through acceptance of loss and moving to the grey quadrant.

- The next transition from GREY to YELLOW produces a GOLD colour and was named 'transformation' because it includes powerful external forces such as spiritual awakening (gold scripts) and the influence of peers, champions, models, or mentors. This captures the power of inclusion and acceptance from the JEDI principles.
- The final movement from YELLOW to BLUE produces a GREEN 'contribution' transition that occurs when people regain enough positive self-regard to become agents again and use their new knowledge of illness and peer support to regain former roles or find new ones or focus on contributing to others. This captures JEDI principles that rely on accepting difference and diversity as one re-enters everyday living and contribution. It is about claiming the right to be included despite differences.

We now have a basic set of four psychological spaces that reflect health-related experiences, and four transition strategies that point to where people want to move and how to get there. The grid had become an active standpoint theory for training health-related students, professionals, and communities seeking to understand peer support. I then returned to the autobiographies to test out the hypotheses generated by the blending of the colours and realized that the quadrants and transitions depicted most patient journeys. In the past four years, I have also been able to explore the ability of this standpoint theory to support interpretation of peer research using peer research included in the PRISM hub and publications of peer research.

The final coloured standpoint theory is presented in Figure 10.2.

Figure 10.2 *Standpoint Theory Map Using Four Psychological Spaces and Four Transition Actions*



The eight psychological spaces of the coloured standpoint theory map represent an emancipatory patient perspective of healthcare experience. It represents the links between changes in identity, health status, agency, and EDI principles that identify the nature of systemic discrimination.

Transitions as Standpoint Stories of Emancipation

This section describes the four transitions that mark strategies to regain control and a sense of wellness. The study of transitions took up a great deal of incubator space and focused study and research.

The 'Royal Purple' Transition from Crisis to Competence

This transition is the most common motivation and the most frequently used strategy to overcome obstacles and return to life as it was before illness and trauma. This is the transition of patient education, of finding answers and new ways of living to regain competence. This is the hero script in Arthur Frank's (2013) work. It is also a dominant male script.

Sometimes, people become addicted to the emotional satisfaction of conquering health problems, and tempt fate by pushing limits to challenge their power. This is a high-energy transition.

If we consider the EDI principle of difference defined by a change in health status, we see that this transition is about reducing differences to become 'normal' and a way back to their 'just' position (justice). It also is the hero script of conquering adversity and loss.

- Deciding to ignore cancer and win the election, Ed was the leader of a political party and had successfully fought cancer. When he realized that the cancer had returned, he made up his mind to work through the cancer, no matter what the result. He and his party worked out many ways around the fatigue and pain, and Ed continued valiantly defying cancer. Shortly after the election, he passed away but had achieved an unprecedented increase in election wins. He died a man of competence, bravery, and determination, and he achieved his goal and died with the memory of his achievement.
- Terry Fox: The Canadian hero decided to use his remaining time to make a difference by running across Canada, in spite of a painful prosthesis and active cancer. His determination to continue despite major obstacles struck a chord in the Canadian spirit of never giving up. His legacy continues as we respond to his challenge to run for the cure as we continue the fight to beat cancer.

The 'Wine' Transition: Defenses Transition from 'Red' to 'Grey'

There are two routes out of crisis and change, and the "wine" transition is not normally tried until the person has tried repeatedly to transition through the 'challenge' transition (i.e., the royal purple back to blue). Naming and understanding the transition between the red (crisis and change) quadrant and the grey (learned helplessness) quadrant was the last transition to be identified. This transition is seldom recorded in autobiographies or shared with others, apart from the despair and the fear of losing control or power. Much of the search to understand the role of defenses came from focus groups recalling their experience in the 'defense' transition. In groups, they were able to share these stories and enjoy the embarrassment and struggle, but they indicated that they would be reluctant to share these experiences in formal interviews or surveys where they might be identified.

Losing control is often seen as a defect and acknowledged infrequently. However, people caught between an untenable situation (red) and helplessness or loss of hope (grey) live in constant turmoil. For many, the potential loss of control (moving from red to grey) is overwhelming, and it took much reanalysis to figure out what was happening.

People who live with blame, shame, and anxiety protect themselves from new uncomfortable realities through defense mechanisms. I include some of the more widely accepted defenses as examples of some of the strategies that were identified to protect personal control over health and healthcare.

- **Repression and denial.** When faced with a diagnosis or prognosis that causes loss and fear, patients protect themselves and their family by tucking the information away and ignoring its existence. Doctors used to encourage families to hide medical information that might be considered too much for the patient to handle. Many families close ranks and don't let others know about a cancer diagnosis—it becomes a family secret. This was a common defense for men who couldn't cope with the thought of not being able to continue to be the head of household. It is also common with cancer, when a person feels that the only way to protect family members is to hide the diagnosis and continue life as is. Some cultures hide or ignore disabilities or illness, for fear of public shame.
- **Projection.** This tends to be used in situations where others are blamed for causing the problems, diverting attention away from personal responsibility. The process of blaming others is used by patients and by family members who become complicit in blaming

others for family problems, that often include blaming the medical system for lack of action or poor treatment practices.

- **Regression.** With chronic and degenerative conditions, it is easy to lessen adult expectations and enable patients to relate as they might have done when they were children. Those with dementia are often encouraged to live in a past they remember, to make their life happier and less stressful. Similar stories are told of developmentally handicapped adults who are encouraged to continue with childlike activities and avoid situations that might become difficult if the adult were expected to live like an adult.
- **Sublimation.** Unacceptable impulses are transformed into socially acceptable interests, turning negative energy into positive outcomes. This is often seen as a mature defense mechanism that can divert feelings of anger, loss, or frustration into physical activities that create opportunities for new identity in adapted sport, leading peer support groups, mentoring, and writing about experiences. This 'defence' mechanism is not just about avoiding loss of control, but it provides a way to establish new forms of competence or new relationships in the quadrant of belonging and provides another way to avoid the grey quadrant.

Defensive strategies that help deal with the anxiety of being caught between 'crisis' and 'learned helplessness' are significant and provide a temporary reprieve between two untenable situations. This category of strategies is difficult to research through autobiographies or traditional qualitative research, because defenses are not generally shared as coping mechanisms.

The 'Gold' Transition: Transformation

This transition is life changing. It is about finding value and connection that enables us to change negative identity to positive identities through the power of inclusion. Transitioning occurs when people connect to a power source that can counteract the forces of marginalization and subjugation. Finding a higher power, reconnecting with cultural traditions, reading an inspiring autobiography, and disability sports are some of these forces. When connecting with peers, patients realize that they are not unique or alone. People find hope that they might also be able to change their situation when they meet others who have been able to make significant changes in their own lives. This sentiment captures the power of the independent living movement, emancipatory theory, and social disability theory.

The stories from disability and adult mental health celebrate peer support through disabled sport and artistic accomplishments. This includes the independent living movement and clubhouse and the many advocacy and emancipatory groups that exist in this space. This is a collective space of role models and peer support of those who have overcome adversity and use their experience and expertise to support others. This psychological transition is particularly important for health-related conditions because healthcare is primarily an individual experience, and this often makes the power of 'belonging' a new experience that is unexpected and emancipatory.

- **Greenbank program.** Most of the applicants to the Greenbank College came from special schools, specialized institutions, family homes, or group homes for the physically disabled. As such, many came from a grey standpoint. Greenbank College was a place of acceptance and belonging, run by people with disabilities. Gerry himself was disabled, coming from childhood polio to challenge the education provided by the institution he lived in. Greenbank College was founded on peer support and challenged the systems that subjugated and controlled the options available to disabled youth. Originally, I thought that Greenbank represented the blue quadrant of competence, but the stories of competence were more in keeping with the social enterprises that were considered separate from Greenbank: community wheelchair industry; whole food restaurant; and a second-hand store that existed during the research connection. Greenbank was, in fact, an example of gold standpoint theory, providing time and opportunity to share personal experiences of being able to challenge the dominant stories of subjugation through their successes in the training college. This was possible because storytelling was encouraged by Gerry and disabled staff members.
- **Wheelchair sports.** Gerry grew up avoiding being in a wheelchair and struggled to get around with canes and callipers. One evening, he attended a wheelchair basketball competition with a friend and became mesmerized by the power, maneuverability, and grace of wheelchairs. He was smitten with a desire to use a wheelchair and to build wheelchairs for racing. He and a disabled colleague, who was an engineer, designed and manufactured high-end racing wheelchairs and used them in fundraising runs.

- **The god scripts.** In one of the narrative analysis classes, I noticed that many students had chosen religious autobiographies. This provided a unique opportunity, and I asked if the students might like to focus on 'god scripts' in their analysis. With autobiographies covering many faiths and cultures, this became a highlight of the year. The scripts had many diverse and contradictory messages, but the essence remained the same: there are things to learn about life from setbacks; there is a purpose in what is happening; you can handle this.

Connecting with a higher power to find meaning is also a common source of transformation. These 'god scripts' can be as simple as "God wouldn't have sent this illness if he thought I couldn't handle it," or as complex as the need to atone for past life sins in order to move to grace in the next life. These higher power scripts are often minimized by professionals who may be uncomfortable talking about someone's higher power.

The 'Green' Transition of Contribution

This transition is about using the expertise, connections, and understanding that comes with long-term conditions or life-changing events. This is also a key transition in standpoint theory, turning knowledge gained through the collective identity of the gold transition into action in the same way that feminist standpoint theory focuses on collective action to build personal competence. The autobiographies and experience working with the patient standpoint grid also identified the option of moving from a collective sense of belonging to individual action. This was part of Indigenous stories that celebrated the retelling of original stories and living within a community with ancestors and the land, while finding ways to use this new traditional strength and wisdom to declare ownership of their lands and expertise related to reparation of land devastated by climate change, industrial pollution, and degradation.

The key to a green transition lies in the expertise gained among peers and communities as part of the yellow quadrant of acceptance and belonging and the willingness to become active in making a difference. There is a large appetite for champions who have experienced a serious health concern, who then write or speak about their experience. Other patients and PWLE use their influence to become involved in advising and research. These generally begin as a volunteer commitment but are no less valued than moving to paid employment.

The other example of this is the growing influence of peer support. There is a growing movement to invest in training and payment of patients who provide support to others. Some examples of peer support workers include the following:

- Peer Support Canada (https://peersupportcanada.ca) that works with the Canadian Mental Health Association to certify peer support workers.
- A scoping review of peer support workers by MacLellan et al., (2015, https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0141122).
- There is a growing interest in citizen science in health and healthcare. Citizen Science for Health (https://www.citizenscienceforhealth.org) is a broker for health research, looking to find engaged patients as citizen scientists in health research.

In summary, the structures and strategies of the above patient standpoint theory will hopefully evolve as it is used and adapted to various situations. Like the challenge of Antonovsky, the originator of salutogenesis, my challenge to readers, is to use and adapt this standpoint theory to health research and, in particular, peer research.

An Application of Standpoint Theory at the Program Level Using Experience of the Case Studies of New Social Movements

In looking back at the case studies, it struck me that the data spoke to the power of standpoint theory.

- **Gerry Kinsella** was a scrapper, fighting the system in defense of others like him. He was the insider with status, because he was a social entrepreneur, earning money as a business to challenge the oppression of the 'professional disability sector.' His standpoint was the blue quadrant as a media sports hero, setting a standard of competence and achievement for his Greenbank team. Originally, I thought that Greenbank was also in the blue quadrant, but Gerry was an agent of transformation, guiding and encouraging young people who had come from the grey quadrant of special schools and medically based programs into Greenbank, a safe, yellow place of acceptance and learning among peers. Eventually, with training, the young people joined competitive, downtown businesses to contribute to the success of Greenbank by working and mentoring new graduates and, eventually, moving into mainstream lives.
- **Dorothy Birtles** was driven by a personal and a spiritual mission as a Quaker. She reached out to those tortured and often killed in prisons because of their political beliefs. With a simple act of kindness,

she connected caring Quakers with prisoners, writing letters of acceptance and belonging, and sharing the stories of prisoners with their extensive Quaker networks. Prisoner's lived in the deep depths of the grey quadrant, without hope or personal control in the midst of torture and extreme brutality. The befriending scheme was the transforming influence (gold) and a source of comfort. Being part of a story that was larger than torture was emancipating. Prisoners experienced an unexpected source of belonging and acceptance within a yellow quadrant formed by sharing letters between the Quakers and prisoners. For the Quaker correspondents, their normal, everyday, blue existence was plunged into the pain and suffering of the red quadrant, but their work brought them to a new competence and sense of control, not in releasing prisoners but through sharing the power of their stories with others.

- **Dame Cicely Saunders**, the founder of the modern hospice movement and St. Christopher's Hospice. Dame Cicely began as a nurse, an almoner, and eventually a physician and a palliative pain specialist. Her books were written for families and patients, and she expected patients who were dying to write their life's legacy story for the family. She expected them to set aside the despair and helplessness imposed on the dying to take up the challenge to live until you die. Patients came to the hospice deep in the grey quadrant with cancer and other terminal conditions that controlled their lives. This was the only example of patients moving from a grey quadrant directly to a blue quadrant, without going through the other transitions. Most patients died in the blue quadrant.
- **Henry Enns and Disabled Peoples' International (DPI).** DPI is an international social movement that captured the emancipatory promise of the women's movement and all its struggles against systemic discrimination. It was founded by disabled people, who resisted the attempts of the World Rehabilitation Association to control them. Henry was the master storyteller and part of an international coup that located their work at the level of the United Nations and the declaration of the rights of disabled people. This new social movement worked in the same fashion that the feminist movement had. Henry and others travelled the world, meeting groups of disabled people and sharing stories of systemic discrimination and the lack of accessibility and services. They also met with the power brokers in each country, challenging their policies and practices, and building the local capacity to continue

the fight. Within standpoint theory, Henry and the DPI team acted as gold agents of hope and transformation, encouraging those living within neglected segments of society without hope or agency. They helped groups come together and build skills, to become agents of change in their own right. They created a positive collective sense of positive self-regard (blue). In many ways, the original DPI group of disabled men acted like the women academics, as insiders able to bridge to power through their negotiation skills.

- **Henry Three Suns and the Siksika Nation**. Henry had become a social worker to create child welfare solutions that honoured the traditions and family values during the infamous scourge of the Sixties Scoop in Canada. However, he refused to see himself as a change agent. His Indigenous spiritual and collective approach to life opened an interesting translation of the grid. He and one of my PhD students who was Indigenous felt that the blue quadrant represented the dominant white culture; the yellow quadrant was Indigenous, with external forces of ancestors, generations to come, the Creator and the land; grey was the loss of their humanity through alcohol and white ways; red represented the pain inflicted by white ideas of power and wealth. This positive yellow collective existence found a way of living and knowing with white society that reflected a green transition. The changes made in the colours reflected the quadrants of the medicine wheel and this was used in teaching Indigenous students of PaCER.

Summary

This chapter has introduced a new standpoint theory for peer research elements of participatory action research, narrative data, and grounded theory analysis. It creates a bridge between the previous chapters and the final chapter about possibilities for using peer research in new ways in the future.

Questions for Discussion

1. Now that we have completed the chapter, I invite you to return to the "Hidden Pathways of Chronic Illness" peer research project (Banerjee et al., 2013, http://hdl.handle.net/1880/109953) and use the grid to locate the paths in the quadrants. Although there is not a 1:1 match, what pathways can you identify that reflect the psychological spaces (quadrants and transitions) identified in this chapter?

2. This chapter introduces a first attempt at a standpoint theory, grounded in the complexity of healthcare systems. Consider a course you have taken that included theory which was emancipatory and choose a theory to compare with the patient standpoint theory described here. What were the strengths and weaknesses of each of the theories, as applied within a healthcare setting?
3. Plot your own journey through the standpoint theory during a stressful stage of your life. What have you learned about your strengths and emancipation? Or, what might you have been able to accomplish had you known about standpoint as a theory?

Resources

Standpoint Theory as a Tool in Design Thinking as Part of the Science of Engagement

The following resource by Cera Cruise, an undergraduate student in Community Rehabilitation and Disability studies, provides an example of how standpoint is useful in choosing potential goals/innovations for design thinking. It demonstrates how online program descriptions can be used to identify location on a standpoint theory.

Using scripts from three of the health systems related to health professionals who experience moral injury—treatment and diagnosis, community inclusion, and peer and natural support—I used standpoint theory to understand the location on the standpoint grid of moral injury patients at the onset of their moral injury in the red quadrant and the treatment, staff, or programs as they attempted to guide patients to healing and acceptance in the yellow quadrant. The 'end destination' of each system was illustrative of what the system defined as patient capabilities or the blue quadrant. However, in the treatment and diagnosis system, patients were not supported in returning to the blue quadrant, while in the community inclusion system supports were given to those who were in the grey quadrant, therefore excluding those in the red quadrant. Finally, the peer support system supported members in all quadrants, but was uniquely able to facilitate a transition from yellow to blue that the other analyzed systems were unable to do.

Table 10.6 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis (Nuckols, n.d., https://www.naadac.org/assets/2416/Cardwell_nuckols_treatingmoral.pdf)	**Analysis**
"Another coping strategy involves letting the incident overly redefine one's self-concept and identity."	Crisis: Locus of control or agency is internal, while self-regard is negative. This places the person in the red quadrant.
"The patient needs to understand that concealment is understandable but maladaptive."	Control: Here seen as personal control by concealing the problem. The professional encourages the patient to take the advice of the professional and transition to the learned helplessness quadrant.
"Ultimately, the expectation is self-forgiveness and the possibility of living a moral life."	There doesn't seem to be an expectation of moving to competence through contribution; acceptance seems to be the final goal of treatment.
Summary: To heal, one must first give up control, and this program requires the patient to develop a sense of positive self-regard in the face of doing something that they currently see as morally reprehensible. It would have been interesting if the treatment system discussed the power of contribution, beyond the fact that amends can be good but within reason. The limit placed on amending acts suggests that the professional remains in control to decide which acts of amendment are too much. The patient, therefore, can't move from acceptance to competence without the professional willingly giving up control. Program and patient capacity could be increased if the transition of contribution was facilitated or encouraged more.	

Table 10.7 *Community Inclusion Analysis*

Data: Community inclusion https://courses.wholehealthmedicineinstitute.com/whmi-whole-health-studies-course-202036086740 https://lissarankin.com/doctors-are-suffering-from-moral-injury-whats-the-solution/	**Analysis**
"I couldn't tolerate the feeling of failing to give my patients the kind of loving, tender, comprehensive whole healthcare I knew they deserved, but I had no idea how I would pay the bills if I left, and after spending 12 years training to become a doctor—and feeling spiritually called to do so—I couldn't imagine what else I'd do. Rock and hard place. Despair. Helplessness."	Control of their circumstances is external and the patient shares that their negative self-regard was placing them in the learned helplessness quadrant.
"We support practitioners in building a thriving healing practice, as we believe this is necessary to provide the material and organizational resources needed to accelerate the reintegration of psychospiritual work into the healing process and the healthcare industry."	Presumes that having a "thriving healing practice" will increase the healthcare provider's self-regard, and that by being more effective at their job, they will (re)gain a sense of competency.
Designed to diagnose and treat what the shamans call "soul loss," this program is meant to heal you by helping your soul take over as the guiding force of your life.	Brings awareness to patients of the importance of spiritual well-being (self-regard), meaning that patients are presumed to be in the crisis and change or learned helplessness quadrants.
Summary: The Whole Health Medicine Institute's aim is to improve the self-regard of healthcare providers, which it presumes is negative. Giving them the tools to be more effective practitioners, the program assumes that this will move them in the competence quadrant. No resources are specifically mentioned for individuals whose moral injury stems from their own actions; rather, the Institute appears to be catered towards those whose moral injury stems from structural violence—the injury created by social institutions. This leads me to infer that the program may be effective for those in the learned helplessness quadrant, but perhaps not the crisis and change quadrant.	

Table 10.8 *Peer and Natural Support Analysis*

Data: Peer and natural support https://projecttraumasupport.com/	**Analysis**
"Pain is nothing more than a sensation of extreme discomfort, meant to alert you to the need for attention. It is not meant to make you hide or withdraw. Its purpose is to focus your attention."	Crisis is recognized as a temporary position in the plot, leading one to infer that a transition is necessary.
The group provides a forum where openness and honesty are admired and encouraged, under an umbrella of assured confidentiality and anonymity.	Acceptance: The group is the external locus of control that admires the patient for their openness and honesty, encouraging the patient to increase their self-regard
"I feel like taking care of myself is worth it."	Competence: patients sees themselves with positive self-regard and realize that taking care of themselves is an active choice.
"We are in a position to walk in the dark suffering that others are feeling and to bring in the light and love we cannot see for ourselves. We cannot and should not be cutting the cords of the collective just to protect ourselves—we are better than that."	Competence: Contributing to others with a similar journey as a necessity. Locus of control is internal, in that it's an individual decision to contribute to others' well-being.
Summary: Patients come to the group in crisis with low self-regard and an internal locus of control. The group allows them to contribute to the healing of others, therefore lessening their locus of control so that it becomes more neutral and less extreme. Coming to a personal place of acceptance is important to group members, and increased opportunities to contribute to society outside of the group could be innovative for patients and allow them to reach a place of competence. Through growth within, the group patients are able to improve their self-regard and transition from crisis to competence. Some control is given up when they join the group, as they follow the group's rules and experience the group's reactions to their story, showing that acceptance is necessary before competence. Contribution is an important patient role and signals that they are in a position to walk in the dark suffering that others are feeling.	

Co-designing an Emancipatory Standpoint Theory

This section is part of my ongoing memo about emancipation. It is included to depict how grounded theory provides a way to support and document inductive reasoning of social change. It is included as a first-person memo.

Intrigue with power in health and healthcare began for me in a psychiatric unit for aggressive and regressed women. As part of a social innovation called 'Token Economies,' we were able to change the behaviours of these women by providing rewards for 'good' and 'productive' behaviours. In the same institution, I was part of challenging dependent roles of patients by introducing a positive checklist that staff had to fill out and report on. We created a workplace within the hospital by creating realistic employment expectations.

I continued to develop self-assessments and community training programs for disabled adults that built a culture of capacity. This led to changes in institutional programs for profoundly handicapped children, new curricula for the children, and training programs for teachers where none had existed in public education. This position led to designing the Community Rehabilitation and Disability Studies program at the University of Calgary, the first of the Canadian Disability Studies programs that was transdisciplinary and focused on creating leaders in community alternatives and advocate for people with disabilities and their families.

These experiences confirmed my belief that new social organizations could change the way people saw themselves and related to each other. Then I was jolted further from my belief in being able to establish ways to empower people by creating new programs. I joined a new social organization for independent living that challenged my assumptions that social change depended upon professional programs and tools. One of our university students was hired to create a program that followed the principles of independent living, including: changing the environment, not the person; a person with a disability can understand the needs of another; and a person with knowledge and power can make their own decisions. The program accepted all people with disabilities, including those who had lived their lives in institutions.

I was so taken aback by the changes in people's lives that I set out to do my PhD to understand more about how to conduct peer research with social innovators in Canada and the United Kingdom. As I was conducting my PhD, my university students took up the challenge to become engaged in research that looked for the ways people reconstructed their lives after illness, loss, trauma, or disabling conditions. We developed methods to analyze autobiographies. The result of all three simultaneous activities created a first version of standpoint theory. All three activities were about emancipation and created

tools and theory to unpack a standpoint theory that explored a very broad and diverse sector of health.

Incubating a Self-Assessment and Goal-Setting Tool

The director of the Independent Living Centre was a student in the Community Rehabilitation and Disability Studies program, who knew of my early work with Vecova and how we had used a simple tool to help people with limited language make basic decisions and express (positive and negative) feelings. She asked me to help find a way for the members of Calgary Association and Disability Studies (CAIL) to make decisions. She felt that they had been so controlled and diminished by their experiences in institutional care that they had difficulty understanding their strengths and what they wanted to accomplish. We introduced the Vecova yardstick, but it was clear that the linear process was too simplistic. Instead, we decided to add a second axis to create a grid system.

Developing a self-assessment tool for peer support as the beginning of standpoint theory, I had been intrigued by self-assessment and personality theory early in my career, so we tried the following popular polar archetypes:

- Eysenck's (1952, 1966) introversion/extroversion polarity and Atkinson's (1974) motivational theory (motive to approach success and avoid failure), covered in Elliot's *Handbook of Approach and Avoidance Motivation* (2008).
- Rotter's internal and external locus of control have been covered in Tyler et al. (2020, https://doi.org/10.26686/wgtn.12956984.v1). The concept of agency or locus of control seemed to work when combined with the basic positive/negative axis of identity and personal self-regard. The intersection of the map axis became a neutral or transition zone of two bipolar opposites.
- The personal construct work of George Kelly (Cherry, 2023, https://www.verywellmind.com/george-kelly-biography-2795498) supported our goal of creating simple grid structures for basic self-assessments. This interest in grid formats has continued and is currently represented through what is referred to as cartesian mapping, used to map constructs against each other. The above grid as a cartesian map was eventually called a patient and disability standpoint map. It consists of a horizontal axis related to feeling good or bad (self-concept, ease/dis-ease in salutogenesis, self-regard, pain) and a vertical axis about locus of control. The quadrants are psychological spaces created by the intersection of self-regard and locus of control.

The process of using this simple grid as a self-assessment tool had a profound impact on my career. In my former work, I had developed a number of standardized tests and surveys, in particular the adaptive functioning index (AFI) (Marlett, 1973) training and assessment tool. It led to trainees assessing themselves according to a standardized instrument that they had been part of creating.

CAIL presented an even more disturbing challenge for me: the role of the test designer and assessor was removed completely.

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11

Forces for Change

The back stretch has proved more challenging than expected. The confluence of the rapid growth of health technologies, JEDI emancipatory principles and the efforts of governments, funding bodies and health research to democratize health science bring new energy and challenges to healthcare and research. The growing impact of our aging healthcare systems and the complex needs of our aging population provide the urgency for us to come together to share not only concerns but bold and novel ideas to prepare for change.

While most countries have established research policies to democratize health science by including new patient and community partners on health research teams, Canada has yet to recognize their competence and the motivation to be part of transformation. Patients have become health and data literate, accessing others who share their issues and connecting with options for international treatments and research opportunities. Writing these last chapters has been both terrifying and exhilarating as I tried to include new options for patient and peer research. This chapter lays the foundation for understanding the forces for change that create new roles for patients in health research and opportunities for researchers to be part of health transformation.

The final chapter had grown to 50-plus pages because of new opportunities, and I finally had to carve out a chapter specifically related to the current and anticipated landscape of health research and to lay the foundation for a methodology based on potential roles for patients as full partners in the transformation of health research.

We begin this new chapter addressing the contrast between current quantitative patient-oriented research (POR) methods and the emergence of pragmatic emancipatory methodologies grounded in critical thinking. We then explore how health technology, democratizing science, and challenges to systemic discrimination are already impacting the landscape of health research. Each of these forces foresee a future where patients are more engaged in their health using available information, health records and personal health research (Maltseva & Lutz, 2018, https://doi.org/10.1016/j.chb.2017.12.006).

New opportunities may also reinforce the current vulnerable, dependent, and outsider roles of patients in healthcare, policy, and research if we do nothing.

Polar Opposites or Co-designers

This work began early in my career as a quantitative health research and program developer that was challenged by equity-seeking influencers in mental health, disability, seniors, and Indigenous communities. International new social movements became co-designers of new research methods to see if there was an alternative way to conduct research within these groups. I was attracted to independent living and international mental health initiatives that were willing to share their skills and practical research ideas. Retired academics and seniors developed *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/) that became a curriculum for community research that supported the co-design of patient and community engaged research as part of health research and innovation. Research teams were open to exploring the involvement of patients and the impact of a patient research voice in health research teams. They tested emerging research methods and approaches. Equity-seeking patients and citizens and their identity-based communities were co-designers in all aspects of this work. The Faculty of Continuing Education of the University of Calgary is now home to the PaCER distance education training program, and the Alberta SPOR patient engagement unit provides an academic and development home.

In this regard, PaCER evolved as a social innovation, a social enterprise, funded research, a curriculum for non-traditional learners at our university, and finally, a science of engagement.

The following table returns to establish the contrasting research methods that became part of the incubation stage of peer research that led to a social enterprise that both trained patients in new emancipatory research methods and employed graduates to conduct patient-led research.

Table 11.1 *Polar Opposites in Evidence-Based and Peer Research Data Approaches*

TOP Box Why does health research need a patient research voice in citizen science?	
Problem-based (pathogenesis)	Solution-focused (salutogenesis)
POR—about patients	Narratives by patients
Deductive and predetermined	Inductive and iterative
Discrete, digitized data	Real-life data
Focus expected change	Focus on past, present, and future
Reduced harm	Emancipation and thriving
Data owned by researchers and pharma	Data is co-created and co-owned

These characteristics of data clearly indicate the difference in the purpose, application, and intended outcomes that would seem to suggest the inability to collaborate in health research. Evidence-based health research sequesters patients by ensuring that there are no connections to individual patient data and patients are not aware of the goal of research. The data is owned by researchers, universities, or pharma. The outcome is predetermined by setting the hypothesis that guides the data at the end of the study, with little room for correcting assumptions or changing the data during trials. The focus of the data is to search for the cause of a problem (pathogenesis) using data about patients as it relates to how the problem responds to the anticipated change. Researchers take this process seriously, and any attempts to change the data, how it is collected, and how it is used is a threat to their ethical standards related to reducing harm.

Now let us look at the data of peer research that begins with the shift from pathogenesis to salutogenesis—the search for well-being, capacity, and resilience that build personal resources to limit the impact of illness, trauma, and loss. This process is guided by inductive and iterative cycles that enable all co-researchers to follow and test new explanations of the main concern and the emergence of potential solutions. If peer research is practised within an emancipatory framework the data is co-created and co-owned by participants involved in the research. The outcome is not determined until the best outcome is identified with suggestions for implementing specific changes that will influence patient roles and relationships in healthcare: the language used, the policies, the systems implicated, and the roles of patients in changing practice. The methods used determine the outcomes and relationships.

The data science of pathogenesis is fixed, powerful, and focused on specific problems. As a methodology, most health research operates on fixed,

standardized deductive procedures that make up normal science expectations of excellence. Knowledge is concrete, data is numeric, and results are quantified and measured and published in a consistent format. Emancipatory peer research on the other hand suggests that the knowledge of patients and communities is accessible and patients can become more capable, confident, and effective in understanding problems in ways that can make a difference.

The proposed data science of peer research is new, creative, pragmatic, and action oriented. It considers knowledge to be what happened, what is happening, and what could happen to build well-being through building personal capacity to learn about, manage, and find meaning from their experiences. Emancipatory research taps into this personal expertise as part of inductive research, combining stories and experience to find ways to change what is happening to create opportunities for patients to benefit and take up new emancipated roles in their health, healthcare, and health research and planning.

The epistemology and worldview of these two approaches could not be more dissimilar in the way experience is studied, just as each sees the roles of patients in different ways with different goals for the outcomes of their efforts and knowledge. We anticipated reluctance about emancipatory approaches and also expected that it might be difficult to publish in evidence-based journals. However, health researchers were open to peer research findings that were novel and creative, and teams and peer researchers were able to publish and influence practice and policy. This sets the stage for PaCER as an incubator and prototype of innovation in health research.

The uptake of PaCER research was only possible because of emerging forces supporting new roles for patients: the initial calls for proposals for SPOR (Strategies for Patient-Oriented Research), the start of the Alberta Strategic Clinical Networks (SCNs) and the publishing of *Grey Matters* as a co-designed curriculum for community research. The synergies created an impetus for change that encouraged established researchers in Alberta to support and train patients to conduct research that engaged patients and communities in research. After the grant was complete, we established a social enterprise within the faculty of medicine with the help of health research and planning teams that sponsored training of their patient advisors and contracted peer research done by the graduates.

The innovation began in a psychiatric institution, explored in community services, co-designed with independent living centres and founders of new social movements, and formally tested with seniors and retired academics. It was guided by a steering team of three: me, Tracy Wasylak, a director with the SCNs, and Deborah Marshall, a health systems researcher. As a social

enterprise, the university and the Faculty of Medicine found ways to support a radical social enterprise within university structures with the sponsorship of the SCNs and health researchers. New training methods, theory, engagement strategies, and a peer research model was co-designed, identifying potential solutions. Meaningful engagement was found to be open and collaborative, iterative and inductive. Engaged research, as it turns out, tends to open opportunities to understand the nature of obstacles within current systems and create innovation opportunities in health research, healthcare, and policy. The forces supporting co-design and innovation laid the foundation for future growth with Alberta SPOR and Continuing Education and a growing number and range of sponsoring health research teams.

Ten years ago, it would have seemed impossible to see emancipatory research done by and with patients as part of health research. The forces for change that are introduced in this chapter bring with them the expectation that future patient roles and relationships in healthcare and research will continue to require a creative, authentic, pragmatic, and action-oriented patient research voice to be ready as health systems transform from a focus on acute and chronic care to prevention and health promotion.

Patient Roles in the Changing Landscape of Health Research

I had expected that each of the forces for change would lead to different patient roles. Little did I expect that the end goals of each force for change required similar relationships with patients. They shared expectations that future patients would aspire to be more active in managing their health in the following ways:

- Health technologies expect to reduce the burden of chronic conditions and stress-related illness that will provide opportunities for transformation to increase prevention and health promotion. Patients will be expected to monitor their health and respond quickly to address conditions through new technologies that reinforce patient involvement in their health.
- JEDI, through challenging systemic discrimination, hopes to provide space for marginalized groups to be respected for their advocacy to access care while bringing important information to healthcare about how their diversity will lead to more comprehensive and shared care for all.

- Citizen science as part of health and health research brings an understanding of participatory science that will include research conducted by non-traditional researchers. The overall impact of democratization will be more options for dealing with diversity and the ability to work with patients in new and emancipatory ways to take advantage of options for prevention and health promotion.

Looking back, PaCER created a participatory and pragmatic patient research role. The teams we worked with were willing to create these new roles for patients as engagement researchers and new roles for participants as valued co-researchers. These roles were dramatically different from current healthcare patient roles and expectations of anonymity and compliance in research. Academic researchers who sponsored or hired peer researchers as part of their research grants commented that peer research brought a new, distinct, and comprehensive perspective to what it meant to be a patient that provided new insights. The data included aspirations and fears as part of living with health conditions, interrogation of systemic discrimination, suggesting solutions from a patient perspective, and health-related policies and practices that reflect patient experience and aspirations.

The explosion of new roles for patients during the past 25 years was unprecedented. New social movements such as independent living centres and quantified self movements of the late 1990s used computers, and communication technology created online connections for equity-seeking groups. Then, as I was focused on co-designing an emancipatory research method for academic research, the landscape of patient engagement in health research changed dramatically. Consequently, in the past four years, I have been looking at other models that engage citizens and patients in health research that might be interested in the SoE.

The new title of Citizen Science in the United States, the Association for Advancement of Participatory Sciences, identifies the potential to expand the roles of volunteer citizen scientists beyond data collection for academic research teams. This is evidenced by the recent moves to community science that recognizes the power and capacities of communities to identify and research issues of concern using emancipatory models to build community competence and capacity. These early examples echo the advances in community-based participatory health science, as pioneers in community engagement. Another influencer, Ashoka (https://www.ashoka.org), is bringing community research to local communities and all education levels through the tagline of 'everyone a changemaker.' Other potential avenues for changing roles are the personal science networks in Holland that support patients, as part of condition specific

networks, to research their own health concerns and share results with others with the support of health-related CS (My Data, Our Health).

We now return to the table of citizen science models of research that were introduced in earlier chapters to support the potential of advanced and comprehensive roles for citizen scientists. These volunteer roles that are supported by academics focus on the traditional academic research in the natural sciences, ecology and climate, and astronomy. More recent examples include history, cognitive science, audiology, psychology, and the quantified self and personal health networks. We now use this table to reflect on the extensive range of citizen science roles, particularly the advanced levels that reflect the concepts of peer research.

Table 11.2 *Models of Engaging Citizens in Research*

Locus of power Bonney et al., 2009 (designed by scientists)	**Ladder of participation** Shirk et al., 2012	**Levels of participation** Haklay, 2013	**Epistemic practices** Strasser et al., 2019	**Spectrum of public participation** International Association for Public Participation (https://www.iap2.org/mpage/Home)
Contributory projects Citizens or patients contribute data	**Contractual** Scientists conduct a scientific investigation and share the report or results with citizens	**Crowdsourcing of data** Citizens contribute local sightings, measures, personal data	**Sensing** Contributions include recording the events seen, heard, experienced	**Inform** Provide balanced and objective information in a timely manner for citizens
Collaborative projects Citizens bring their own resources to the study	**Contributory** Citizens are asked to collect and contribute data and samples for research	**Distributed intelligence** Citizens as interpreters of existing or emerging data using personal computing power	**Computing** Using personal computers to increase computational power	**Consult** Obtain public feedback on analysis, alternatives and decisions

Table 11.2 (*continued*)

Co-created projects Some members of the public are actively involved in most, if not all, of the scientific process	**Collaborative** Citizens assist scientists in developing a study, collecting and analyzing data for shared research goals	**Participatory science** Participation in problem definition and data collection	**Analyzing** Aspects of large data sets and secondary analysis	**Involve** Work with the public to make sure that concerns and aspirations are understood and considered
Co-produced projects Members of the public are actively involved throughout the project design and implementation	**Co-create** Citizens develop a study and work with input from scientists to address a question of interest or an issue of concern	**Extreme citizen science** Involved in problem definition, data collection, and analysis	**Self-reporting** Through crowdsourcing or collecting experience data	**Collaborate** Partner with the public in each aspect of the decision making
Co-research by, with, and for citizens Citizens engage other citizens in research to provide a citizen perspective	**Collegial** Independently conduct research, as part of a research team	**Not included but could identify co-design of methodologies that would support extreme citizen science**	**Making, creating, inventing** Producing new products using new technology such as 3-D printing	**Empower** To place final decision making in the hands of the public

Note: Adapted from Strasser et al. (2019) with the addition of IAP2.

The following represents Peer Research within each of these options.

Table 11.3 *Peer Research as Part of the CS Models*

Peer research provides training in action research	This is peer research, but it doesn't include methodology	Citizens would create a parallel from a citizen perspective	Peer research that aligns with design thinking and human-centred design that could inform this column	Peer research provides the theory and research methods for engaging public input

Peer research is added at the bottom of the table to suggest how it might work with the citizen science methodologies. This table provides an easy way to engage teams, communities, and patients in identifying patient research roles of engagement to entice teams to consider new options for CS. These methods include citizens and communities who conduct traditional methods to extend the scope and reach of research.

Organizations outside of health systems are engaging citizens in their research. I joined US Citizen Science, now the Association for Advancing Participatory Science (AAPS), and found organizations that included patients as partners in studying conditions such as HIV in British Columbia, inner-city poverty initiatives, and breast cancer. More recently I reconnected to Citizen Science for Health in Europe, Public and Patient Involvement in the UK, PCORI in the US, Ashoka and social innovation centres as part of community health and development.

It seemed that as soon as computers and communication devices were available, the door opened to citizens to use these new tools to become personal scientists using self-tracking or self-knowledge through numbers of the quantified self movement. This enabled citizens to use their personal wearable devices to track and conduct research using performance data and to share their research with other citizens. While tracking was possible, analysis and interpretation lacked research literacy, but basic quantitative methods for analyzing data have become part of the growing number of research networks enabling citizens and patients to connect and share their personal research. Online data platforms such as Zamplo (www.zamplo.ca) are examples of data curation sites that support personal research and now include researchers looking for participants and advisors.

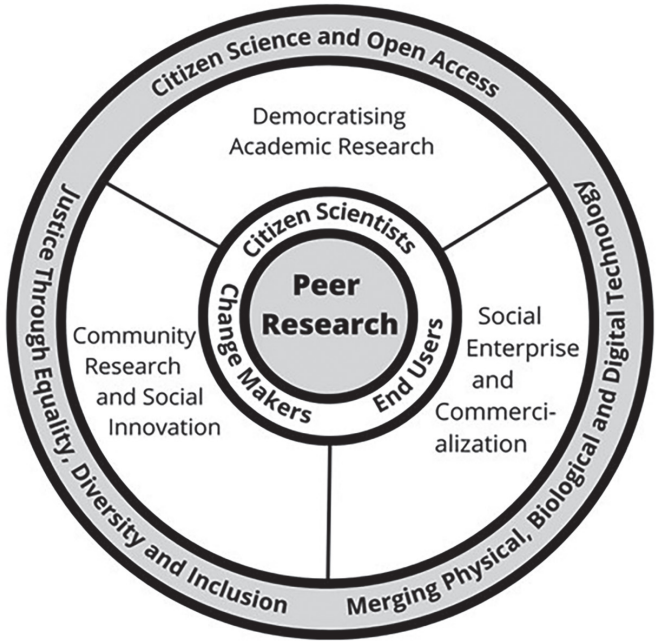
Networks of patients who are also trained researchers have created research hubs to address their common health conditions and concerns and are bringing important research options to health research. The first hub that has long been a leader in patient and public engagement in research began in the UK (Patient Led Research Hub, n.d., www.plrh.org). These hubs are providing new energy to patient experience research by conducting orphan research about issues not being done by traditional research teams. These networks and peer research–trained patients are producing groundbreaking publications, such as the phenomenon of long-haul post-COVID and PaCER research publications (https://prism.ucalgary.ca). Perhaps the most promising recent development is the Citizen Science 4 Health Network of the European Citizen Science Association (ECSA Working Group, n.d., https://www.ecsa.ngo/working-groups/citizen-science-for-health/). The first conference was held in the Netherlands in 2024.

PaCER is a type of CS that trains patients to conduct peer research. It supports new science roles for patients in health systems and health research, the EU citizen science has embraced personal health research networks that will bring new energy and partnerships to the concept of CS as the domain of academic research. It would have seemed impossible to conceive of health research outside of academic oversight and control, but the quality of health data by patients will continue to energize new options for future patient roles in health research.

Forces Changing the Landscape of Healthcare and Research

The following diagram considers three forces for change and innovation that are directly related to establishing new roles for patients: as users of technology and partners in reversing systemic discrimination, and in democratizing health science.

Figure 11.1 *Forces for Change in Health Research, Care, Delivery, and Planning*



Beginning at the centre, **peer research** is research done by citizens who are part of co-research with peer researchers who are 'like them.' It provides an authentic peer research voice as part of health research, care, and policy development. Peer research includes all forms of research done by, with, and for patients that contribute a perspective of not only their experience but also their expertise in navigating diverse health systems. This leads to innovative suggestions for change that will lead to greater patient involvement and control of their personal health, technology, emancipation, and new forms of care.

The first inner ring captures the **roles of patients as part of the forces for change** in health research:

- **Citizen scientists** are recruited by academic research teams to collect local or personal data using research methods overseen by a research team. They have a wide range of citizen research roles, **volunteer data collection, supervising data sites, maker spaces,** including **conducting research** as identified in the above table of CS roles.
- In health technology–based research, patients are **end users** and as such should be involved in design thinking or human-centred design. Patients, and often parents of young children and care staff, are part of **creating the right question** to focus on developing technologies that meet patient needs and actively contributing to **prototype testing**.
- Citizens and patients are **change makers** that collaborate in **JEDI**-related, equity-seeking academic programs and social movements and have challenged the **roles ascribed to them by the systems** they use. Equity-seeking groups are **pioneers** who have co-designed and fostered roles as part of peer-run services such as Independent Living and Clubhouse. They are potential **leaders**, able to identify stigmatizing practices and JEDI solutions in collaboration with the systems that currently minimize them. Many of these formerly marginalized groups are affiliated with university social justice academic programs and could take on roles as **JEDI researchers** and advisors that can bring a patient voice to negotiation and planning teams in universities and health systems.

The large inner spaces represent **each force's goals for improving healthcare**:

- Volunteer **citizen scientists** have long been seen as a force as part of the goal to **democratize academic research**. This volunteer role is highly valued, supporting both national health research policies

of Responsible Research and Innovation (RRI) and the Open Innovation in Science (OIS).

- **Health technology** aspires to reduce the burden of roles related to chronic and stress-related illness. The goal for end users of health technologies is to become part of research related to creating personal and environmental devices to remediate or avoid illness and create new patient roles. A second goal relates to healthcare delivery, which relocates patient care to people's homes and shifts focus to supporting patient roles as managers of their own care.
- **JEDI** principles of justice though equity, diversity, inclusion creates opening for new patient roles as leaders in identifying and collaborating with health researchers to solve entrenched discrimination across silos and systems that lead to restricted recruitment in clinical trials. It also encourages social innovation in community and population health research.

The outer ring identities the **force for change**.

- **Citizen science**: national and local health systems are looking to citizen science, and the emergence of community science, to encourage health research teams that include patients as partners in their research. This agenda reflects international science directions that began as a movement to make research accessible to everyone and ensure that research is relevant to citizens and research teams. There are challenges in opening health research to patient and public involvement, but progress is being made, especially in the EU development of citizen science for health and national health plans such as Canada's SPOR health policy's strategies for patient-oriented research.
- **Health technology:** Merging physical, digital, and biological technologies to create an integrated internet of things (IoT) provides a realistic example already being used in home care and chronic care networks. The ethical management of these systems is yet to be accomplished. Early experimentation on vulnerable and largely unseen patients may seem warranted from economic perspectives but sends an alarm about the urgent need to consider future patient roles, particularly those who are not considered able to make decisions. The growing interest in closed-loop decision-making may jeopardize not only the role of health professionals in monitoring care but how to protect quality of life and the need for compassionate models for end-of-life care.

- **JEDI** at this stage in health research is fragmented and has yet to become part of the challenge to health grants to find ways to address the need for justice in health research, particularly the inclusion and diversity in recruitment. Current clinical research has been hampered by limited selection of equity-seeking populations, especially those who are marginalized and unfortunately their health suffers on the margins. Community-based participatory health research and social justice academic programs in areas such as disability, mental health, Indigenous studies, and race celebrate the strengths and assets of these communities as allies in JEDI.

The Changing Landscape of Health Research and Future Roles of Patients

This section describes the three forces for change as it relates to patient relationships with academic researchers and healthcare options.

Citizen Science and Open Innovation in Science

The first mention of people being involved in conducting research occurred in an MIT technology review in 1989 when community labs were described using citizens who were studying environmental issues. It began as an amateur or volunteer opportunity for citizens to become involved to study personal interests in the natural sciences, media, and information science. It attracted mainly women looking to contribute to science while meeting others and sharing ideas. Space research attracted many men interested in the analysis of space data. While it began to extend the reach of both funded and exploratory research, it has broadened to include school programs to introduce science by learning about science and conducting local research. Local citizen scientists also contribute local data to extend internationally sourced data and provide increasing opportunities to expand the scope of collaboration internationally.

A range of other participatory sciences (participatory action research, community-based participatory health research, and critical research) also support democratization of science by engaging citizens and communities in co-design as co-researchers and in some cases the data and outcomes are owned either jointly or by the communities, as in the First Nations Information Governance Centre's (FNIGC) First Nations Principles of OCAP® (https://fnigc.ca/ocap-training) declaration that includes principles of ownership, control, access, and possession of cultural knowledge, data, and information. This ownership principle states that a community or group owns information collectively in the same way that an individual owns his or her personal

information. While this was difficult for many researchers to process, it has provided an example for other groups struggling to conduct research that is meaningful and essential as part of their identity. OCAP provides interesting options that open dialogue of equals between academic research and communities and has been an important example for emancipatory research initiatives, especially for community science and peer research.

Community science as a participatory science recognizes the interest and capacity of communities to initiate research that is important to them, but it is unlikely that these local communities can achieve the impact that OCAP has produced. For example, Hunter et al. (2023, https://doi.org/10.1002/fee.2635) identified very different attributions at this early stage where citizen science was widely recognized, community science that is community based and initiated by communities with few formal scientists and collaborators. It might be suggested that community science might consider SoE as a foundation for community-based peer research to reinforce the importance of community-led research as a distinct methodology apart from the large variety of citizen science methods currently used by different disciplines as defined by the supervising scientists and their research home. The presence of community science begins to suggest commonalities with personal science networks and peer research that share the need for a code of ethics for research conducted outside of formal research ethics approaches as part of citizen science. Remmers et al. (2023, https://doi.org/10.13137/1825-5167/35356) have created a strong emancipatory approach to ethics in citizen science that is appropriate for personal, peer, and community science as well. The social contracts for research (Chapter 3) could also be used effectively to clarify roles and expectations throughout the research process as citizens and patients are involved in research.

National and international policies to democratize science that include patients and the public in health research seem to consider that current citizen science volunteer roles as primary data collector will remain consistent in academic health research in the future. In my dealings with citizen science in the United States, there were concerns about new roles for patients that could change volunteer roles as data collection if these citizens were to be allowed to conduct research co-designed to be specific to patients. However, the theoretical models of citizen roles include citizens conducting independent research as part of CS teams. There were also concerns expressed about citizens conducting research that academics might feel unable to supervise or use. Hopefully, this science of engagement in health research and innovation will provide a way for teams and their citizen partners to explore peer research.

CS has had a major role in exploring and sharing research approaches because it crosses disciplines. Conferences convened because of the engagement

of citizens in science provide one of the few ways that researchers and citizens from wildly different domains can share ideas. In my first conference I joined in conversations about data analysis with researchers working with frogs, analyzing space data, and worried about pollution in rural areas. One has only to look at the nature of patient roles in the above table to understand why CS continues to lead in testing and advancing new methods for research. For example, CS was an early adopter of crowdsourcing and, along with open innovation in science, is creating theory related to data collection and non-traditional data collection online. Crowdsourcing methods as part of citizen science, has made significant theoretical progress as seen in this recent article by Beck et al. (2024, https://doi.org/10.5334/cstp.691) that identifies five basic models of crowdsourcing that considers the history of communication technologies to get more data and to how to engage groups more effectively and how to manage and analyze the data. The five models formalize the scope of crowdsourcing. While this is an exciting venture that includes more citizens, it seldom engages patients or extends the roles of patients to engage citizens or co-analyze data.

That said, CS seems to attract a very narrow range of citizen scientists, likely because it relies on volunteers who have free time and a desire to use their time to make a difference. This fosters strong connections among citizen scientists but also means that the voices of marginalized populations are seldom present. I noticed that conference goers seemed concerned that these groups were not represented. These marginalized populations provide opportunities for co-research and peer methods that can customize the data to collect, how to collect it, and collaborative ways to analyze data to use research to understand what is happening and potential solutions.

The following table describes a natural history of citizen science in health as a result of health system policies for patient engagement. There are two facets to citizen science. The early response to national policies for patient-oriented research and the historical inclusion of citizens as part of research teams. The shaded sections identify examples.

Table 11.4 *Democratization of Health Science by National and International Health Authorities*

Force for change	Early opportunities	Recognizing potential roles	New patient roles	New organizations and networks
National health and health system policies to include patients and the public in health research to democratize science	CS is identified as a Patient Engagement platform to support national and regional grants and research projects	Teams attract patients with research or professional backgrounds They become part of research teams to collect and analyze with team members	Patients are included in grant writing, reviews, research teams Ethics for CS (EU) Funding for patient-suggested research topics recruits professionals to conduct the research in UK, US, and Canada	Patients curate, conduct, and share personal research online through computer networks (e.g., Zamplo) EU Citizen Science 4 Health network Dutch Personal Health network part of CS
UK first patient engagement platform as part of NIH Canada, US, EU, and Australia are leaders in OIS, RRI, SPOR, and PPI. Early concerns about privacy and ethics	CS is named in RRI and OIS mandates	*Grey Matters* published about seniors conducting narrative research with seniors Training for patients to contribute to academic research: EUPATI and PaCER, HIV/AIDS research networks Patients who are researchers collaborate to conduct research important to their shared concerns as patient-led research	Patients conduct research as part of health research teams Patient-led research hub in UK conducts long-haul research and is published	Ethics for peer and personal research SoE published for emancipatory research

JEDI-A: Justice in Health Through Equity, Diversity, and Inclusion

JEDI emerged in the 1960s as an American affirmative action initiative to ensure fair treatment in the workplace, and it continues to evolve to promote non-discrimination in hiring, employment, and work relationships. More recently, academic institutions provide support for non-discrimination of staff and students with efforts to encourage diversity and inclusion. JEDI appears to resonate in social justice programs related to discrimination and marginalization due to gender, Indigeneity, poverty, and disability. These programs bring their focus on identity to inform JEDI.

JEDI is the newest force to be introduced to health research and brings attention to the policies and practices that restrict inclusion of equity-seeking groups in healthcare, policy, and research. We were invited to move to the Faculty of Medicine with an invitation to introduce opportunities for marginalized groups to be included in health research decisions and promote inclusive models of healthcare. We soon learned that community-based participatory health research pioneered inclusion, equity, and diversity at local levels and communities are included in all stages of research. Within medicine, JEDI-A has begun to suggest the need for professional sensitivity to systemic discrimination in clinical practice and care. Health research has had a lack of diversity and inclusion in clinical trials that have compromised care for marginalized groups. One has only to consider the struggle to include women in clinical trials let alone all other equity-seeking groups. In health this is exacerbated by research and treatment silos that restrict sharing information about how this can be done. The A in JEDI-A stands for access, particularly related to disability, but the lack of appropriate access is common in most systems and for most marginalized groups whether related to identity or medical conditions. JEDI research in health provides a focus, not only for marginalized groups but for studying intersectionality as a factor in medical research (Chase, 2022, https://library.usa.edu/inclusive-intersectional-research).

The importance of using JEDI-A principles to counteract and avoid systemic discrimination in health research marks the recognition that group identity is both a legitimate construct to understand the roles of patients in health research and their access to appropriate healthcare. JEDI, from this perspective, is informed by traditions of symbolic interactionism, critical theory, role theory, Eriksonian psychology, and social identity theory that reinforce the importance of language and interactions as part of identity. Our position of disability studies in the Faculty of Medicine is a case in point. While our undergraduate degree is extremely successful, our graduate program struggles because disability studies does not exist within a research culture of significant

grant opportunities and thus cannot sponsor graduate applicants. This means that few applicants are accepted and those who are accepted are expected to take required medical courses rather than courses in critical theory, social change, prevention and health promotion, and emancipatory research methods. In the future courses in salutogenesis, JEDI, and systemic discrimination in healthcare and research, and the future of healthcare and research, will become essential for all community health and medical students. If the anticipated shift to technology-based care materializes, future graduates will need to be ready to transition to future models of healthcare that will see a focus on new roles for patients, especially as health technologies support the shift from current models to prevention and promotion managed by patients.

Salutogenesis and two new theories of SoE—patient standpoint theory and a patient perspective of health systems—provide opportunities to track patient roles during transition. Salutogenesis is a powerful tool to understand what is needed to shift to the study and introduction of prevention and promotion as part of healthcare and research. While pathogenesis has been the dominant foundation in medicine, positive outcomes that support new patient roles in their health and healthcare are possible, especially when 'health' care incorporates salutogenesis as part of treatments. This enables patients to realize that health problems are ubiquitous and provide opportunities to learn and use the opportunity to become stronger and more adept in managing stressors of everyday living.

The visual representation of how patients create their version of their health systems in Chapter 9 reinforces JEDI principles of inclusion, diversity, and access. This is being reinforced as an aging population requires many supports normally associated with medical systems, and this means that these community and mainstream services will be available as part of person-centred health systems. This simple concept can be used as more healthcare shifts from institutional needs to prevention and promotion.

Patient standpoint theory has been co-designed through many iterations with groups who have been marginalized in their experience of illness and trauma. It is an analytic tool that visually locates experience within four psychological spaces in health systems according to identity and agency. It also includes transition options that can identify options for equity, diversity, and inclusion. In identity-based groups, visual depictions using colour and characteristics support in-depth analysis of difficult health experiences that suggest alternatives for moving from health crises and dependence toward acceptance and competence. It seems an important guide for transition to equity and justice from the culture of health based on difference and dependence.

An example of the importance of working to build more supports that are in the quadrant of belonging and acceptance can be found in the doula movements that originated over 30 years ago to provide support during life transitions, both through the birthing process and support for people at end of life. These movements provide training to offer support during times of uncertainty and change. The doula concept is being picked up as alternative ways to support those living with mental health concerns. These movements, like personal health science, explore positive supports during experiences associated with health services that may inform future emancipatory research methods. Boulton et al. (n.d., https://cumming.ucalgary.ca/sites/default/files/teams/382/RMHD-Powerpoint.pdf) provides an example that research conducted to support alternatives will continue to grow.

These theories relate to emancipatory peer research that, in this respect, are best understood within the PaCER training and research of Indigenous community members who have been able to honour Indigenous ways of knowing and Indigenous science in their peer research. Peer researchers from marginalized communities, even those marginalized by their health conditions, become spokespeople to reduce discrimination and promote emancipation. One of the most effective tools is discourse analysis, which is included at the end of this chapter. This includes analysis of language, relationships, and clear, responsible, recorded action to remedy barriers to justice. Change will be short-lived at best unless all parties related to discrimination are involved.

If those who are impacted because of their social identity are not active agents, they will rely on the system to fix the problems or remain uninformed about efforts to make change. This just reinforces the reliance on professionals to solve their problems and will leave their personal identity more entrenched in compliance and dependence, which will further impact their vulnerability within the system.

This force for change is too new to have a history within healthcare and universities, but the following are potential assets within current universities to support JEDI as a force to impact current practice in health research.

- Education, sociology, nursing and community health emancipatory science projects.
- Equity-seeking social justice academic programs such as disability studies.
- Groups that have had success in working with health research and technology companies to learn from their experience. For example, rare disease research companies are fostered by parents and patients who become partners and pay for their data.

- Guidance of Patient Advisors Networks to work with university equity-seeking programs and identity groups related to health to understand options for collaboration.
- Finding conference venues to introduce JEDI to citizen science.

Health Technologies as a Force for Change

Future technology-based healthcare would improve patient experience and outcomes through sensors that monitor health status, shifting from acute care to prevention and promotion that will change the paradigm of healthcare as technologies move to homes where patients understand and use technologies. These changes are expected by increasing productive life years and general health.

Precision medicine already holds great promise for prevention and public health, by identifying predisposed or high-risk patients for specific conditions and quickly developing treatment and remediation options to reverse or manage potential illness. This is particularly important for non-communicable disease, which accounts for 75 to 80 percent of healthcare costs. This also targets stress-related disease by targeting the source of stress and improving stress management. These two alone would dramatically change the configuration of what we know today as healthcare (Schwab & Davis, 2018).

While the overarching slogan of 'changing who we are' is couched in emancipatory language, the patient voice is secondary at this early stage. It is essential that health research find new ways to create stakeholder roles for patients. Canada's medical system has declared that patients are the most underutilized resource in a digital health reality, but important decisions must be made if patients are to be stakeholders in their future on who owns patient data and who controls technology.

It is not the remit of the science of engagement to study technology per se. However, the MANBRIC rubric of technologies suggest how medical, additive, nano, biological, robotic, information and cognitive technologies might impact not only deficits and illness but enhance our lives (Grinin et al., 2017, https://doi.org/10.1007/978-3-319-49604-7_13). By 2018, the field of technical and biological technology in healthcare produced astounding advances in medical technologies. I take the liberty of including the following resources: a report from the World Economic Forum on health and healthcare in the fourth industrial revolution (Goy et al., 2019, https://www3.weforum.org/docs/WEF__Shaping_the_Future_of_Health_Council_Report.pdf). Healthcare Information and Management Systems Society (HIMSS) is a member-based society committed to reforming the global health ecosystem through the power

of information and technology (HIMSS, n.d., https://www.himss.org/what-we-do-initiatives/accelerate-health), and this second resource from Dassault Systemes (n.d., https://discover.3ds.com/are-you-ready-future-healthcare), *Are you ready for the future of healthcare?*, is typical of innovation in life sciences (health sciences) and demonstrates the parallel universe of healthcare outside of the typical innovation framework.

Technology advances are changing all aspects of society as work, healthcare, and education are redefined, and our very social reality seems likely to change. The ability to combine biological, physical and digital technologies seem particularly poised to transform healthcare as we know it. For example, primary care is migrating to multipurpose pharmacies using the scaling power of artificial intelligence diagnostics. Large delivery companies such as Amazon are investing in new diagnostics to receive, process, and send medications and devices (while being involved in localizing 3-D printing to reduce inventory and travel costs) (CB Insights, 2022, https://www.cbinsights.com/research/report/amazon-disruption-industries/).

Patients today are already more motivated, competent, and ready to move into new stakeholder roles. Patients and citizens are moving ahead to adopt new technologies on their own. We can see this in the response to open access to medical records. While electronic health records are still cumbersome and complex, new online supports allow patients to curate their own health records, to learn how to use their records to seek treatment, research, and peer support options around the world.

Patients will need to be taught to use technology so they can identify emerging threats and support wellness. This learning may occur as part of school curriculum or in the emergence of online training connected to the transition to smart technologies. Health technology coaches are already part of online chronic care networks and hopefully research will identify the benefits for patients and families. Health and healthcare delivery will be present at home, with a greater input of people or patients themselves. This is often referred to as the consumerization of healthcare that will be delivered as a seamless continuum of care, away from the clinic-centric point-of-care model. Broadly defined, the consumerization of healthcare is the trend of individuals asserting more influence and control over their medical and wellness care. To address this, non-traditional companies such as those in the retail, technology, and consumer packaged goods sectors are looking to address consumer and patient needs (UBS, 2020).

However, citizens could remain confined to being compliant end users of technology instead of increasing patient personal control, privacy, and value. There are a few detailed references to increasing patient control through

self-regulating technology, assistive devices, and robots. It is almost impossible to find research and policy about how this might happen and how it will be adopted, let alone the role of patients in all stages of research and innovation. There are major risks to privacy in the use of sensors used in surveillance. We need to guard the use of sensor data without consent if commercialization of health data is not curated and controlled. If cost containment continues to be the driver of innovation, we could see the hard-won advances in consumer or patient control over their personal health and healthcare eroded.

Anticipated change will need robust and diverse patient/citizen methods and data systems based on real-life patient experience that is able to anticipate and respond to change as it evolves. Just as real-life physician data helped guide online care of complex conditions and hard-to-reach patients, the current focus on POR, while standardized and effective in clinical health patient experience research, is not real-life patient experience. Peer research on the other hand can facilitate targeted real-life data that can inform AI and machine learning. Peer research is also compatible with online networks and data security that is ready made to provide in vivo data for machine learning.

The short history of health technology as part of healthcare is presented below.

Table 11.5 *Roles of Patients as Part of Health Technology Innovation and Implementation*

Force for change	Early opportunities	Understanding potential	New patient roles	New networks and methods
Third and fourth industrial revolution in technology	Access to online info and data	Sharing data	New roles for patients emerge	Online personal science networks

Table 11.5 (*continued*)

Force for change	Early opportunities	Understanding potential	New patient roles	New networks and methods
• Computer and communication technology • Personal devices for measuring and tracking performance • Combining physical, digital, and biological technologies • National research policies to democratize science	• Tracking personal health data • Access to health records (ownership of data) • Citizens track data from sensors and apply to health	• Patients curating online access to personal files and records • Share data with peers and researchers • Rare research groups use computer network to share data with each other and research companies • UK—Patient and public involvement in health decision making, sharing research roles	• Support for personal health research roles • Networks of personal scientists • Companies with patients / families as partners • University programs to train peer research roles (PACER) • Patient-led research coalitions conduct research about common concerns	• Citizen Science 4 Health (EU) • Community science as part of citizen science, communities take the lead • International patient-led research groups within universities • Online SoE with engagement methods and supports
• Citizen access to computerized health data and information • Development of personal performance tracking devices • Democratization of science and technology policies in open science and national guidelines	• Quantified self-movement • EUPATI curriculum trains patients to contribute to health technology development • Researchers use crowdsourcing to access data	• Commercialization of health and personal data • PPI in UK moves to health policy using networks	• Patient-led research published • PaCER research published • Computer networks for chronic conditions with new tech support roles	• CS4H conference and international scope • Citizen Science moves to Advancement of Participatory Science to broaden scope • Commercial relationships with patients as partners

These forces for change will hopefully prepare readers to engage in discussions about change. The key would seem to be the need for researchers and patients

to discuss these forces together to be on the lookout for indications of their presence. These forces share visions of a future where the burden of chronic and stress-related illness is lessened, giving way to a future that relies more on early signs and interventions supported by focus on health promotion that become part of education and supported by funding options that enable people to access needed community services and opportunities. They see home-based services and communities willing to build inclusive, diverse, and accessible supports using different mechanisms. Democratization includes patients and communities as co-designers and co-researchers as they respond to change. JEDI focus on removing barriers to change by focusing on justice (emancipation) for citizens that result from sharing equity (power), encouraging diversity and inclusion of those groups who seek equity. Finally, health technology builds new tools to identify and prevent illness while promoting decentralized, home-based care and support that combine technologies and promote patient engagement in their health and healthcare.

Supporting Emancipatory Research

This last section addresses how the science of engagement supports these forces for change. In healthcare and research the idea of democracy embraces inclusion and equality to be heard and respected in decisions about them. It has become clear through the arc of writing this book that past patient roles of compliance in care and exclusion in research will change as a result of democratization.

In this last topic we look at how emancipatory science theory and methods supports all three forces for change.

It has seemed symbolic that these forces for change co-exist with the emancipatory foundations of disability studies and other programs that seek equity for minimized groups. In our early stages we were also early adopters of the internet to deliver both undergraduate and graduate degrees. Disability studies followed feminist and Indigenous studies to bring social justice issues to university campuses, and we hired a technology expert who was disabled to develop courses and a research program. Our program supported the use of technology in vocational rehabilitation, accessible sport, and special Olympics, adaptive technology as part of daily living and environmental accessibility. Our faculty members, students, and graduates have become leaders in emancipatory practice and research. All three forces will need robust and diverse methods and data science based on real-life patient experience to anticipate and respond to change as it evolves.

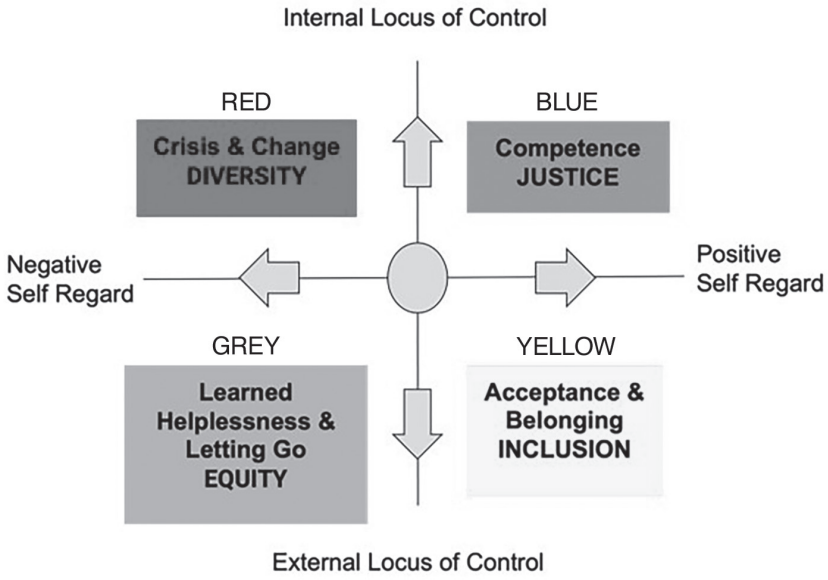
For example, JEDI-A committees could recruit members and community advocates from programs committed to democratizing healthcare and research to inform JEDI teams of specific forms of systemic discrimination and research

methods to find solutions. Discrimination is not equal or the same for each group. This might encourage groups to share methods, information, and ways to work together to support JEDI.

SoE itself has emancipatory theory to inform JEDI: salutogenesis, narrative, health system and patient standpoint theories bring an emancipatory research foundation to JEDI committees.

- Salutogenesis as a theory supporting well-being in the face of medical challenges and relationships, provides a way to balance the strong pathogenic focus in most health research. Clinical work is pathogenic and, in the past, has been complicit in excluding a wide range of potential subjects in clinical trials. Salutogenesis as a comprehensive theory of how patients can learn from difficult experiences and informs the implementation of JEDI principles to create positive outcomes. In particular the stressors associated with systemic discrimination can use mapping sentences to unpack how specific stressors can be analyzed and subjected to resistance resources to resolve the impact of the stressors, especially those related to chronic health stressors.
- Narrative and the power of stories can be used to convey complex ideas related to both current stressors and aspirational solutions, particularly aspirational stories of what might be possible in the future. Narrative is particularly important when unpacking systemic problems that are difficult to analyse through more traditional questionnaires and interviews. The use of story properties such as who, where, when, and why unpack common features of discriminatory acts.
- Patient perspective of health systems encourages groups to create their own understanding of the systems they would like to use, including both formal health systems and those as part of alternative or mainstream options. It may be that groups that have been marginalized have found alternative options that reduce the impact of systemic barriers to health.
- Standpoint theory incorporates the principles of JEDI within the diagram of the psychological spaces related to healthcare and research experience. The following example of an emancipatory theory is presented to demonstrate how theory opens opportunities for innovation, inclusion, and diversity that suggest different and salutogenic approaches to understanding the unintended and unstudied impact of current health systems.

Figure 11.2 *Basic Structure of a Patient Standpoint Map*



Note: Based on positive and negative self-regard poles and internal and external locus of control poles. Also included are the related JEDI principles in capital letters.

This diagram of psychological spaces in healthcare and personal health help identify their primary impact.

- The blue 'competence' quadrant denotes that those who are both in control and feeling competent are more likely to be treated fairly, impartially, and reasonably because they feel in control of their lives and expect to be treated fairly.
- The red 'crisis and change' quadrant is about people becoming different than they were previously because their lives have changed dramatically due to illness, trauma, or loss. They also feel it is somehow their fault that they are different and have two options to reframe their identity: either to see difference as a challenge that can be overcome (move back to blue) that will reinforce their control and acceptance of difference; or to move into the grey quadrant and accept a life without power and control.

- The grey quadrant of 'learned helplessness and letting go' is about the loss of equity or power over their lives. They learn to accept life without power or become motivated to avoid failure.
- The yellow quadrant of 'acceptance and belonging' is about being included and being part of groups that affirm their identity.

This standpoint also includes the transitions between these spaces and the principles they represent. Online chronic illness communities are situated to use this standpoint theory because they have already transitioned through blue and red to grey and are now in a yellow community that encourages them to increase their self-regard. Unlike most current healthcare systems, they are based on peer support instead of personalized care. These groups experiment and learn new skills like using technology to join online communities and to experiment with technologies that can improve their self-concept to support treatment options. Peer support and treatment options challenge the individual nature to support new forms of online chronic care.

Finally, other disciplines have historically supported marginalized groups in their quest to provide support and develop new wellness options. Education faculties have been informed by the *Pedagogy of the Oppressed* of Paulo Freire (2000, original 1970) in creating safe and respectful learning opportunities for students from marginalized groups. The struggles to eliminate harsh punishment and discrimination are common in sociology and ethnography. Nurses, particularly community health nurses, share a commitment to community participatory research and have become advocates for patients within health systems. Environmental designers have been leaders in emancipatory architecture and inclusive community planning.

The following goals of health-related technologies address the emancipation of patients in their health and healthcare as full partners in healthcare transformation from numerous media and research literature.

Patients have much to gain and much to lose depending on our willingness to include them as stakeholders at all stages of digital transformation (Miller, 2016, https://www.telegraph.co.uk/wellbeing/future-health/welcome-to-the-150-club). One would hope that patients have access to smart technology so they can closely monitor themselves. They can have devices that will constantly measure their heart rate, blood pressure, breathing, weight, or activity levels. While there is much rhetoric about patient control, most of the attention is still focused on the doctor-patient relationship. The exception is patient ownership of records, and how this creates conflicted ownership within the healthcare system (Schwab & Davis, 2018).

Next Steps

This chapter has evolved dramatically, and to this end it has become a process of thinking about the social innovation of peer research/design thinking alliances that could have a major impact on healthcare transformation and social enterprise. By capitalizing on the connections of peer research to citizen science, peer research could become an active research partner in OIS and related Responsible Research and Innovation models.

It is speculative, but in innovation the number one rule is to think BIG.

Summary

This chapter was added at the end of the preparations for publication and the amount of material could easily become a book by itself. The major problem I see is that health has been cloistered within systems and silos that make them immune to challenges.

Questions for Discussion

This new chapter opens the door to many discussions and opportunities to include patients and communities in the major healthcare options of transformation as part of medical science, and design thinking. There are many questions that might be asked:

1. Set up a discussion between a peer researcher and traditional health researcher about applying for funding for a topic you are interested in. Switch roles. What questions came up that surprised you?
2. Which patient roles were familiar to you and why? What roles might be difficult for you to take up?
3. Using the table of citizen science roles, which roles are you familiar with? Which ones would you feel comfortable in and which roles would you use in your research? Discuss how these roles of citizen science relate to your understanding of peer research.
4. Have you read publications about citizen science? If not, go to the citizen science journal site and choose one to read.
5. Have you known anyone who has used citizen science in their research? What did they learn during that process? What would they change about the experience?
6. What are the differences between citizen science and the research you have been involved with?

7. Did you read the JEDI toolkit? Does it apply to your work? What could you use in your work?
8. Health technologies are advancing every year. The World Economic Forum hosts several articles about the future of healthcare on their site (https://www.weforum.org/stories/health-and-healthcare-systems/). Read Nagappan (2024, https://www.weforum.org/agenda/2024/02/health-tech-healthcare-telangana/) and Bourla (2025, https://www.weforum.org/stories/2025/01/the-3-megatrends-that-will-shape-the-future-of-health/) and discuss them with a partner or group. How will these advancements impact your work and research?

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12

Emancipatory Methods Inform Social Change and Innovation

A Philosophy of SoE

Preparing for a change that is already taking flight is difficult at the best of times, but in this climate of crisis, the very systems that are needed to plan for change are struggling with crises that threaten the very innovative systems that had made Alberta's evidence-based health planning an international leader in health research innovation. All health systems are struggling to keep existing systems functioning while patients increasingly work outside of health systems to find ways to use technology to conduct their own research. JEDI-A challenges systemic discrimination and works toward justice in health research and healthcare, but without action soon, equity-seeking groups currently marginalized will lose ground in securing appropriate healthcare. We need patients, advocacy groups, and community groups as partners in research and planning to prepare.

Recalibrate What a Science of Engagement Can Provide

The elements of the philosophy of this emancipatory science of engagement shift, in light of the anticipated transition from chronic and stress-related care to prevention and promotion to build patient capacity to take up new roles (**goal of research)** as old roles become less prevalent. It is predicted that future patient roles will have greater control over managing health and healthcare. An emancipatory SoE may support democratizing science through including patients and communities in health research, if JEDI-A challenges systemic discrimination and promotes emancipation for equity-seeking groups and if technology achieves its goal of moving the focus to prevention and promotion with new emancipated roles for patients and citizens.

The **scope** of engagement includes managing technology and a major shift in educating students and citizens for an extended life span and new ways to contribute to society.

Epistemology of human knowledge shifts as the nature, origins, and limits of human knowledge adapts to the unpacking of systemic discrimination, and the very nature of our bodies will shift as technology becomes incorporated in who we are and can become and the inclusion of citizens in research. Narrative and storytelling, marginalized currently, will return as an accepted, effective knowledge foundation that promotes engagement and shared analysis. The iterative nature of peer research will become accepted as co-researchers find solutions to concerns of importance to patients.

The **ontology** of this work is simply that while evidence-based medicine and quantitative and qualitative research are essential in health research, so is the expertise of patients who live with illness, trauma, and loss. Patients rely on access to healthcare and are interested in ensuring that healthcare is effective, secure, and available. They want to contribute to quality healthcare and inclusive research by sharing their experience from their perspectives.

The narrative **methodology** of SoE is emancipatory, co-designed to capture patient experience in healthcare and research from their perspective. They conduct research that is important to them based on what happened and what could have happened to make a difference.

This will take serious commitment from all parties to champion peer research as salutogenic, pragmatic, and action-oriented to facilitate innovation as part of transforming healthcare and funding options. These will include individualized funding for patients and families to secure the supports they need and emerging collaborations of patient-led research, personal health research networks, and especially local, national, and international health agendas to make science open and innovative.

What is required to promote change? The following agents and environments have been identified in *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/) and final PaCER reports for funders.

- Researchers motivated to experiment with new ways to use technologies as part of social innovation, enterprise, and transformation.
- System champions and transformation networks such as Alberta's Strategic Clinical Networks, willing to use policy to build or reframe new systems and support new roles, partners, delivery, and funding approaches. *Note: In the space of preparing this book for publication, the Alberta Government virtually eliminated the Strategic Clinical*

Networks and took political control of health care and research. This loss of a planning network will make the roles of Academic networks even more important to support health research planning.

- Ethical theorists and pragmatists who take up the challenge to ensure adherence to legal and ethical issues such as copyright, data-sharing agreements, confidentiality, reciprocity, traditional owner rights, and the environmental impact of new research options and healthcare delivery. During the time when PaCER was a social enterprise, the university system worked with us to deal with these issues that seemed insurmountable.
- A community- and population-focused culture of health that recognizes the challenges and seeks justice for patients and support for equity, diversity, and inclusion in health research and innovation.
- Trained patients as peer researchers ready to become part of transformation networks and research projects. Our experience found that these trained patient researchers become leaders and can support patient and community change. It almost seems that these graduates are being trained for the anticipated direction of healthcare.
- Action teaching methods where patients and community members co-design and conduct peer research using participatory, narrative, and inductive research approaches.

What Has Been Learned

The characteristics identified in Chapter 8 defined peer research as part of emancipatory research that is co-designed and conducted by citizens who share a common identities defined by them. A co-research process ensures that they are included throughout, that they share their experiences, opinions and creativity safely. They are acknowledged as co-researchers and participate in actions that have the potential to make a difference. The following table introduces us to the basic characteristics of peer research to set the stage for this chapter that highlights how peer research differs from most general qualitative research.

Table 12.1 *Basic Characteristics of Peer Research*

Characteristic	Expectations and Goals	Results
Emancipatory	To build citizen capacity to conduct research about personal health and healthcare that makes a difference to their roles in research, healthcare practice, and planning.	Emancipation occurs when concerns are prioritized, chosen, co-researched. Peer research confirms that change can happen, and patients will benefit.
Salutogenic	To understand the salutogenic search for health and well-being to build capacity for resilience, confidence, and well-being.	Identifying and researching a common concern, open discussion about how to confront it and build positive action and capacity to see that positive change is possible.
Inductive / deductive	Inductive, iterative data collection, analysis, and interpretation with patients and communities. Each new step builds on and tests the accrued findings.	Co-design can't exist without inductive cycles that build co-research expectations and processes.
Adaptable	Methods for data collection and analysis are adapted in iterative cycles to ensure that methods engage populations and topics appropriately and effectively.	Adaptability is an emancipatory principle that confirms that difference is important and must be accommodated in the way research is conducted and so that the data is meaningful to participants.
Use of narrative	Narrative values and methods permeate all aspects of peer research from identifying the concern or topic to disseminating findings.	Narrative was difficult in analysis, but this final chapter proposes a way to use narrative throughout, especially with anticipatory stories of solutions.
Data	In vivo data of incidents are compared to form real-life categories. In vivo codes reinforce co-design features of participation with co-research participants.	In vivo data without the use of in vivo categories reverts to general qualitative themes. Using in vivo properties can maintain narrative data integrity.

Table 12.1 (*continued*)

Characteristic	Expectations and Goals	Results
Orientation	Action: What happened, what happened next, what could happen focuses on a main concern of the population to find what action can be taken.	The action orientation motivates change but only when the research is focused on positive outcomes. Descriptive categories do not promote action orientation.
Group research	Open, extended conversations, small working groups and focus groups. Methods encourage creativity and consensus.	PaCER training employs focus groups during set, collect, and reflect which grounds the research with individual interviews. Online group research has adapted to conversation.

The following summarize the main findings and inform how emancipatory research works.

Salutogenesis / Action / Orientation

Most North American health systems feel that 'health' is about the achievement of health by overcoming illness and disease. Salutogenesis, the search for health and human-centred in response to illness, builds capacity for resilience, confidence, and human-centred. Salutogenesis has been found to be a theory of patient expertise that guides the analysis and eventual solutions to problems. However, in a strange reversal, we discovered that focusing on a common concern as the focus of peer research provided the motivation and shared stories that enabled people to understand how problems worked as a way to design solutions. This led to open discussion about how to confront and build positive action and capacity to meet challenges. Both PAR and grounded theory use this approach to motivate people to find solutions that reflect who they are, what they are facing, and what they need. This becomes the key to action and making a difference.

Interaction of Co-research, Inductive Iterative Research, and an Engagement Strategy Define Action Research

Peer research, an inductive search for solutions for main concerns, is most effective when an engagement strategy is followed. During SET, peer researchers reach out to citizens to collect stories of concerns related to the study. A SET

co-design team of patients prioritize potential topics and advise on the politics and resources needed to conduct research along with recruitment strategies and potential impact. COLLECT is an iterative process with the results of the first set of data informing the next step. Each step moves closer to understanding the concern and how to address it. REFLECT re-engages the SET design team and others interested in discussing the findings to consider potential solutions and next steps to make a difference. As PaCER became more involved in research projects, there seemed to be a possible INNOVATE phase that reflected the involvement of design thinking specialists to prototype test the finding.

Narrative Data and Analysis / In Vivo, Real-Life Language / Meaningful Outcomes

Sharing stories not only activates personal neural and endocrine systems, it also builds collaboration and creativity.

It was expected that stories would also ensure the use of real-life language that reduces reliance on formal academic theory. This enabled peer research to produce results that were practical and relevant to a wide range of audiences. This is the most difficult component for quantitative researchers, who have come from deductive methods and standardized questions. Theory conveyed in real-life language leads to pragmatic, action-focused theory that is meaningful to the general public.

These characteristics reinforce not only the search for new views of health research but also an understanding of what emancipation involves in health research.

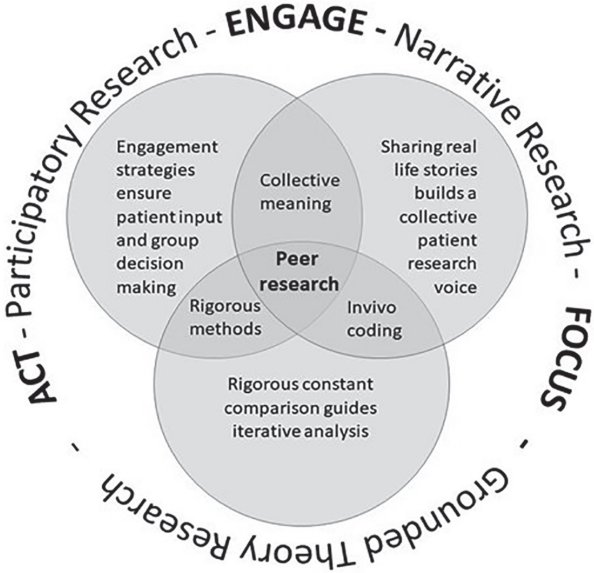
A Blended Peer Research Methodology

The goal of Sections 1 and 2 was to provide options for academic qualitative peer research, and now we formally blend three qualitative research methods to create a blended methodology to involve patient co-researchers throughout all phases of research. It combines and creates research methods that are intended to ensure the inclusion of justice, equity, diversity, inclusion, and access (JEDI-A), to create an emancipatory social science and theory. We begin with an overview of three research traditions that have been most effective in supporting participatory and emancipatory action-based outcomes from the first formal study with innovators of new social movements through to analysis of current research projects. These methods include:

- Applying participatory action research principles and understanding participatory relationships.
- Collecting narrative data to ensure real-life data of real-life solutions.
- Using classical grounded theory to explain concerns of populations to find solutions.

The careful combination of these three traditions produces robust action-based methods for solving systemic problems while supporting innovation. Glaser encouraged experimentation with classical grounded theory methods (Holton & Walsh, 2017), and Figure 12.1 looks to futures informed by both JEDI and health technology. I offer the same challenge to readers—to experiment with the following model.

Figure 12.1 *A Peer Research Combination of Participatory Action Research, Narrative Data Foundations, and Classical Grounded Theory Analysis*



These combinations of three distinct research traditions produced three distinct qualities of peer research—engage, focus, and act—that capture the shared focus between pairs of methods. Secondary analysis of methods looking for evidence of PAR, narrative and grounded theory in combination concluded that combinations were common and theoretically sound. PAR provides both the principles and equity-based relationships that are central to peer research. Grounded theory's iterative nature and analytic rigour are easy to understand and increase confidence in co-researchers. The power of narrative to engage using everyday language and the consistent story structures reinforced the intent to engage, focus, and act.

The overlap between each pair reinforces the integrity of the engagement. PAR principles, when used with narrative data systems, create a depth of collective meaning that can capture cultural nuance and instill creativity. Grounded theory, when using narrative data, opens theory to publicly accessible coding of real-life experience. When participatory values and grounded theory standards are combined, the detailed and consistent analysis enables smaller samples to achieve quality and relevance. Engagement research responds to all three traditions to offer a new voice to health research.

Peer methodology focuses on patient experience of what happened or is happening to explain why and how it happened. It provides the structure to make a difference in what might happen in the future. The inductive nature of peer research as described below enables peer researchers to focus carefully on the concern or topic of research to find simple and direct recommendations for action.

While it is possible to teach patients general qualitative research, the methods are more likely to be deductive, with analysis taking place after data is collected. It was clear, early in the research related to co-design and narrative, that grounded theory or thematic analysis could be done in a participatory way, but it was prone to becoming theoretical and abstract and thus lost common language and meaning. The findings tended to be descriptive and expansive and difficult to translate into clear action. Some trained peer researchers, especially those with qualitative research training, felt it important to use thematic analysis to be recognized by academic researchers, and, as in emancipatory research, researchers are encouraged to adapt methods to the situations they encounter.

Patient research builds patient capacity to be part of social change. Descriptive thematic findings, while often in publications, are not easily translated to social action or social media. Patient research, in an era of rapid technology transformation, needs to be widely understandable and action-oriented if it is to influence innovation. Interestingly, grounded theory is a popular methodology for health administrators because it is easy to understand and

action-oriented. In the end, social change relies on public and policy support, and peer research that is poised to provide clear, pragmatic, focused, and action-oriented research appeals to policy makers.

In summary, participatory action research provides principles that ensure research equity, narrative provides the data platform, and grounded theory provides the focus and iterative analysis methods to ensure rigour. The goal of this combined method is to reinforce citizen science and social enterprise, reach unheard populations, reduce systemic discrimination in health, and support health research and innovation.

The following is a summary of the current understanding of each research tradition as it contributes to making a difference. In introducing each separate method, we look at the history and how it works with the other methods. It also includes how each method informs the science of engagement, changemaking, and citizen science.

Participatory Action Research Principles

We start by revisiting the values of participatory action research that align with peer research as an emancipatory science of engagement. The most obvious is the right to participate so that personal and local knowledge is heard and acted upon. In peer research we acknowledge that methods must adapt to and use cultural ways of knowing and learning to conduct and honour research. When working with equity-seeking groups, the use of language is best left to language speakers who understand the nuances of these groups.

I began using participatory action research with marginalized populations early in my career and adopted its principles to focus my early use of classical grounded theory. Figure 12.2 is a common diagram describing the interaction between participation, action and research that resonates with peer research principles.

Figure 12.2 *The Multiple Linked Facets of Participatory Action Research*

Note: Source: Allen (2016, https://learningforsustainability.net/post/par/). Reproduced with permission.

These principles are now expanded to include the participatory action research model adopted in *Grey Matters* that aligns with JEDI principles. These values are particularly important when dealing with group intersectionality in systemic discrimination related to both healthcare and research. To understand this concept as part of critical disability theory, read the entry in the *Stanford Encyclopedia of Philosophy* (Hall, 2019, https://plato.stanford.edu/entries/disability-critical/).

- **Equity** The research process allows each participant to gain new skills and perspectives that enhance their own abilities and power. The group also gains shared knowledge and capacity by virtue of the use of JEDI principles that are central to emancipatory research within health systems.
- **Diversity** refers to different ways of knowing that capture the value of participatory research with those marginalized and honours cultural ways of knowing and personal knowledge and expertise. This also includes new perspectives that emerge through peer research improvisation. People have different ways of expressing what they know, and in peer research the group is responsible for creating nuanced and collective understandings that incorporate these differences.

- **Inclusion** refers to the processes that ensure that communication is continuous so that participants always know what is going on, what it means, and where the process is taking them. This informed belonging enables groups to welcome different perspectives even if they challenge 'group think.' Inclusion assumes equity within each group.
- **Action** is the result of any participatory project. Action is legitimized here as part of JEDI because the engagement strategy of peer research promotes ownership of the data and findings. Implementation and innovation are the end goal of participatory action research.

The above participatory principles are manifest in co-design where patient consultants review and prioritize concerns during the SET or co-design phase. Co-research participants provide and share storied data and take part in analyzing their own and collective stories in COLLECT. During a REFLECT process, they are involved in reviewing the total findings. The roles peer researchers play depend on the project, how it is related to health research teams, and which streams of research they are part of. Participatory and social justice traditions of identity research are deeply held and treasured; some examples include ceremony in Indigenous research, or working in solidarity with those pathologized for their bodies and minds to refocus on social and environmental barriers or sexual preference as part of gendered research.

Participation is also the common denominator in all the new social organizations devoted to open and collaborative research, especially HIV communities and gender-based alternatives. Most critical research projects speak to the need to include patients as stakeholders or collaborators; citizen science goes so far as to describe ways to include citizens in research, although the uptake of peer research has generally been cautious. This could be linked to the former lack of strategies, engagement, theory, or the adapted methods that would make collaboration of equals possible. Chapters 4, 5, and 8 facilitate some confidence and comfort that a new collective patient research voice in health research and innovation is ready for implementation.

Participation, when combined with narrative, ensures shared meaning. When combined with grounded theory, it supports rigour of iterative data analysis and a focus on action. Grounded theorists have questioned a pairing of PAR and grounded theory, but the goals are the same: making a difference.

Narrative Data Support Both Research and Leadership

The importance of narrative methods was first identified in the new social movements research (Chapters 2 and 3) and was expanded by seniors who

created storytelling focus groups and story templates as part of *Grey Matters*. During the incubation phase of PaCER, it was discovered that the story templates could be used for data collection interviews, focus groups, observations, public data, and art as data. Story templates provided a way to use storied data to connect all phases of research.

Narrative is a comfortable companion to participatory research because storytelling is what people do when they get together to share ideas and solve problems. The combination of narrative and grounded theory is less common, but produces robust real-life data and analysis, based on in vivo or everyday language and concepts. The uncertainty in combining classical grounded theory and narrative existed because classical grounded theory focuses on conceptual analysis, which was not easy for non-traditional learners without disciplinary theory to ground the concepts. This was resolved by Holton and Walsh (2017), who identified units of analysis in classical grounded theory as 'incidents,' which included stories, along with metaphors, story fragments, and alternate forms of stories. This provided support for the use of stories as data and story templates as preliminary analysis.

An example of narrative used in community research occurred in 2013, when Alberta was overwhelmed with unprecedented flooding. Psychology and ethnography researchers used Facebook to gather stories of trauma related to the flood in small towns. The platform produced rich data sources that were then used to analyze the stories told, the storytellers, and the resources they used while supporting the need for citizen experience data as part of climate change. Discussed later in this chapter is a structured story template that PaCER researchers use to collect stories online and also social media stories as research opportunities.

Narrative, when combined with PAR, reinforces the ability to produce shared meaning of diverse populations that increase the ability to include diversity in innovation. When combined with grounded theory, narrative intensifies rigour and the relevance of real-life experience.

Classical Grounded Theory Analysis with Narrative for Innovative Grounded Action

Classical grounded theory shares key action-based features with participatory action research and narratives, providing opportunities to create new data science based on real-life experience. The inductive nature and iterative cycles of data collection, analysis, and interpretation reinforces participation and decision-making at each step. Grounded theory provides a robust data analysis and decision-making protocol that teaches shared analysis and planning at each consecutive cycle.

The use of grounded theory analysis opens avenues for collaboration with qualitative researchers and patient-oriented researchers (POR) who use both quantitative and qualitative methods. Most social sciences, health, and culture studies programs that use emancipatory and critical theory have research traditions that include grounded theory, narrative, and participatory action features that may also be of importance for open innovation in science and crowdsourcing methods.

In closing, I might offer a short summary of peer research as an integrated whole. Participatory action research sets the stage for authentic engagement. Narrative data ensures that real-life data and frameworks inform co-design and analysis. Classical grounded theory guides analysis to ensure each step is focused on explaining the main concern of the population to find solutions using consistent cycles of collection, analysis, reflection, and planning.

The Possibilities of an Extended Narrative Data Science

The use of narrative has been hampered by the lack of options for analyzing stories that take analysis through to interpretation and publication. Qualitative narrative research options include thematic analysis of language, movement analysis of the incidents within stories, developing categories and types of stories, gathering events and from various forms of inquiry to create explanatory story types and strategies. This last section on methods introduces an attempt to consolidate an integrated narrative research method that moves from identifying a research topic, collecting and analyzing data, and ways to share interpretation of stories.

This is important because narrative peer research methodology can support a range of health research options: developing and testing, POR, clinical, intervention and outcomes, and even research grants that include patient experience. This leads to planning research with communities and patient groups along with community participatory projects and grants, citizen science, and the list continues. This is because stories reflect time sequenced real-life experience about what happened, what is currently happening, and perhaps what might happen if things were different. The concern about stories as patient experience is that there is no sequence or path that enables analysis at different stages of research. While most studies use narrative to collect data, the unfolding analysis and interpretations are not included.

Recently I was using PaCER research reports and publications to understand how to provide a logical way to categorize the functions of stories as data, and I discovered that the engagement strategy, along with a new stage of INNOVATE that is introduced in the last section of the book, provided an

easy way to focus stories as data and the analysis options at each stage. The following list uses the peer engagement strategy to tailor narrative methods to the research being done.

The process of storytelling and sharing stories was consistent during the co-design stages of new social movements, *Grey Matters*, and PaCER in the following ways:

- Co-design of the topic (SET) collects stories of potential concerns that are important to patients, communities and frontline staff. These stories are used by a design team of patients to prioritize stories of a main concern as the topic of research.
- During COLLECT, stories are gathered and shared to explain the main concern of co-researchers in order to explore solutions. It is here that other methods of analysis became part of the training program.
- During REFLECT, it seemed easier to revert to thematic analysis to identify themes or categories that described patient experience instead of focusing on solutions. This moved peer research from action research to qualitative research.
- During INNOVATE, stories are already used in design thinking and human-centred design and methodology will be explored in the last section of this final chapter.

I realized that qualitative thematic analysis had been adopted by the PaCER curriculum because it was difficult to analyze stories in a way that promoted descriptive categories to describe patient experience. I decided to see if it was possible to use the story templates to create a consistent narrative methodology that was able to identify a topic of research from a patient perspective, collect and analyse data, and interpret findings within a co-researched emancipatory research approach. This had become possible in part because of the two new theories (patient perspective of health systems and patient standpoint theory) that, along with salutogenesis, provided the impetus for using theory to explore new tools to support analysis, interpretation, and innovation.

This section is divided into three components related to what we know about peer research to date. Each starts with a diagram that sets out the process involved followed by a story template that can be used to guide data collection and analysis.

We begin by considering the utility of the original story template that was created during new social movements and used by *Grey Matters* and PaCER.

Figure 12.3 *Story Template*

Story Template
Title Researchers Date Project
Context (the who, where, when, and what was happening of the story)
The trigger that starts the story (the action, idea, or event that disrupts the flow)
The plot of the story (and then . . . and then . . . and then) simple steps in the unfolding story 1. 2. 3. 4. 5.
The consequences or ending of the story
What did the teller learn about the topic or her/himself
What did you learn and how does it relate to the concern or question
What next steps are suggested

This basic format can be used whenever stories are being collected, but it lacks ways to analyze the data. It is here that we look at how properties, used in grounded theory constant comparison analysis, can provide a way to efficiently explore elements of comparison that do not require themes or categories. It moves peer research from descriptive categories to a deep understanding of process and properties that expose what is happening and then leads to why it is happening and what might be next steps.

The SET

The following figures describe the narrative process for each stage, and each includes a story template that can be adapted to track analysis during each stage of set, collect, and reflect. The first figure, SET, begins the research agenda that collects stories of patient concerns related to the research and the expectation that the topic will prompt stories that suggest future options for change.

Table 12.2 *Use of Narrative During Consolidation of the Topic of Study*

SET: the question/concern
Purpose: Gather potential stories about concerns related to the research topic and select the main concern or topic of peer research.
Collect patient stories about their concerns related to the topic and prepare them for a SET focus group to prioritize and discuss merits.
Prepare a handout about who you are, why you are doing this research, what co-design is, and the participants co-design role in the research to collect stories about the topic and recruit patients to work as a co-design team.
Use story template to collect concerns or topics from a variety of patients about the general topic and categorize stories to create common stories and analyze according to story properties.
Create SET co-design team to prioritize concerns using story templates.
Co-design team helps describe the prioritized what happened, who was involved, where it happens in which system, why is this a priority.

Table 12.2 (*continued*)

Discuss, if feasible: availability of participants, recruiting, political obstacles and sensitivities, language sensitivities, effort involved in reaching participants, costs involved.
Share results with sponsor and plan to use the SET information in the ethics proposal.
Include the story of the research process and the potential outcomes for making a difference as part of the reason for the research ethics proposal.

This process maximizes the level of participation of patients as co-designers during in-person and online recruiting, contacting organizations to support research and ethics approvals. The above process can be modified depending on the nature of the topic and the target population for research. The following simplified story template is designed as the first step in peer research that engages patients and community members in collecting and prioritizing stories of their main concern. This story is then used as part of research grant proposals or an ethics proposal to clarify the SET co-design process.

From the recording or notes of an interview or observation, create the following description of a story related to the topic of the research. If feasible, share this document with the storyteller and record their reactions to the story. At this stage, the narrative is focused on collecting a variety of stories that identify concerns or topics patients feel are important. These stories are then used to select the topic for peer research from a patient perspective as part of the SET focus group or process. This template establishes the language and categories used to describe peer research.

Story Template to Engage Patients in the Topic of Research

Context: Fill in the following information that sets the stage for the story:

1. Sponsoring, planning, research team, or patient-led research, date

2. Student or peer researcher

3. Storyteller: how recruited

4. Focus of the interview (concerns related to the contract or sponsorship topic from a patient perspective)

Story elements using properties of stories:

1. A working title and summary in 40 words or less

2. **When and where did the story happen**: 'When' locates the event in time and 'where' is both the situation and the health systems involved.

3. **Who was involved** (roles not names)

4. **What happened** (including what triggered the story, what then happened and what was the outcome). This is based on your notes and listening to tapes; in this peer research follow grounded theory practice about detailed transcript.

Analysis of the story as part of SET that creates the topic of the study:

1. How is it related to the general topic of research?

2. Why is it important to research this and what might happen if it was researched?

If you're using this for your report, use the following space to track the trajectory of the story as it informs the final results.

COLLECT: Collection and Analysis of Narrative Data

It seems natural to use narrative when collecting data, but it has been more difficult to implement an analysis strategy that maintains the integrity of the story. Data collection is based on identifying incidents of what happened. At this stage, incidents or single acts of occurrences provide the structure for data collection with a sequential, numbered list of experiences. This method was first explored during the new social movements study, formalized during *Grey Matters*, and used at the beginning of PaCER co-design. These single incidents can be analyzed according to grounded theory properties that apply as well to basic narrative analysis. Incidents can also be combined to categorize experience. These properties provide the foundation for analysis of stories. The following describes the steps to use stories as part of both data collection and analysis.

Table 12.3 *Steps of Analysis*

COLLECT AND ANALYZE DATA
Iterative sequence for data/analysis cycles
Each story is analyzed to identify categories according to story properties.
The story template records incidents in sequence with space to analyze the story incidents to focus on the meaning for the main concern and solutions or explaining an innovation.
Co-design strategy recruits participants using the story of the research and uses the 'social contract for co-design' from Chapter 3.
Data /Analysis uses COLLECT story template format of Context: Action / Incidents and Consequences
Analysis 1: Complete the context section of the story template that includes: who (including all actors and their role); a one sentence summary of what happened; where it happened (place and system); and when (what triggered the story)
Analysis 2: Action section: From the list of topics of what happened, list the sequence of incidents, then the resolution of the story.
Analysis 3: Why and then what. The following sequence shifts from past challenges to future possibilities in the script: identify common properties analyze 'why' and 'then what' motivation and obstructions identify surprising outcomes that signify a different outcome, the 'aha' of grounded theory analysis a break the cycle of concern and identifies a potential option for change

Story Template During Data Collection and Analysis

The consistent use of a story format encourages the categorization and the detailed analysis of incidents using grounded theory properties that resonate with storied data. While it is easy to use story templates for data collection, the revised story formats focus on analysis at various stages (SET<COLLECT>REFLECT).

Early in COLLECT data and analysis, the focus is testing a number of data options in order to move to stage two analysis, which uses analysis to consider options for each subsequent data collection and analysis. It has become common when training patients to become peer researchers to focus on one focus group for each set, collect, and reflect with optional individual interviews. However, if working to explain a main concern and a viable solution, it will likely take more than one data collection and analysis cycle. The story template accommodates many options to customize the template to your process.

Story Template for Data Collection and Analysis

This template includes the same stages of context and analysis.

Context: Record the following data in the space provided.

1. A working title and summary in 20 words or less

2. Date and location of data collection

3. Sponsoring planning, research team, or patient-led research

4. Student or peer researcher

5. When and where did the story happen: 'When' locates the event in time and 'where' is both the situation and the health systems involved.

6. Who was involved (roles not names)

Analysis of the story as part of COLLECT using properties of incidents and stories:

Stage 1: Who (roles), where (location and system), and when (what was happening when the story was triggered)

Table 12.4 *Data and Analysis Story Template*

A sequence of incidents as single acts or occurrences	Optional use of this space as: 1. Analysis of each incident; analysis of properties such as why and what then, who, why then, etc. 2. Remove lines below to record analysis by properties, surprising outcomes, potential opening for solutions.
1	
2	
Title/resolution/action script and next stage	

This iterative stage of data collection and analysis process has resulted from co-design opportunities and reading reports from the co-design stage of PaCER. The formalization of analysis is not intended to be prescriptive but to provide opportunities to use a more formal narrative analysis based on the use of properties from grounded theory. Feel free to explore your own properties that more closely reflect your area of study and participants. This approach is one of the possibilities that enable analysis by peer researchers and co-researchers that are not familiar with qualitative analysis or academic theory. The focus remains on the discovery of common stories that explain concerns and their solutions.

REFLECT: Interpreting and Publishing Peer Research

When narrative is consistently used, it is natural to explore aspirational stories and their potential alternative outcomes. This last step has been a keystone moment in consolidating the last piece of the puzzle that moves peer research closer to the original intent to use in vivo language, concepts, and theory throughout the peer research process.

This last stage brings back the original goal of an emancipatory science for peer research. The first obstacles to peer research, identified in the new social movement co-research, identified the need for a narrative foundation to achieve a partnership. The next obstacle arose in the need to focus on action-based research. Then came the challenge to ensure real-life language in data collection and analysis to maintain contact with peer storytelling. To ensure contact with real-life action based on all three stages, we had prepared for moving more effectively to a unified research methodology.

This is a particular challenge during REFLECT that brings the original co-design team of the topic of research together to consider the results and implications. We soon realized that the use of stories in prioritizing the concern for study was important in REFLECT because the use of abstract and descriptive themes broke the link to early SET decisions about what to include and how to do it. To accomplish this, we brought posters of the stories that identified the main concern and posters of the identified solutions. These were used to prioritize the best solution and how to implement the actions suggested. This process when using thematic analysis shifts the focus to abstract categories and away from action that resulted from using thematic analysis during analysis of stories collected during the COLLECT phase.

The following storied alternative completes a storied sequence of research with real-life language and action included.

Table 12.5 *REFLECT*

REFLECT: identifying stories that reflect potential solutions.
Prioritizing stories of the best solutions as pragmatic theory
Explore the nature of concern that identified specific solutions that support patient and equity-seeking group goals
Prepare a package of 1 to 3 of the top choices for stories that explain the main concern and a solution to the main concern. Send to the co-design participants and the sponsor for feedback. Option: Action Scripts: a shorthand way to capture scripts using a common format to summarize the key elements of agency in the face of challenges. It can also be used for novel positive experiences. *When (the trigger that starts the story)* *I (what I do)* *Then (the outcome)*
The REFLECT co-design team prioritizes a solution for action, comparing solutions using appropriate criteria for social innovation of current systems, commercial potential, users, feasibility of change, who pays the cost. For the final choice consider: Relevance to equity-seeking groups and target medical condition Political obstacles and sensitivities Language and marketing Effort involved in reaching users Costs involved
Advise on politics, recruitment strategies, feasibilities, and costs for final reports.
Prepare a final report for co-design participants and general patient groups. Prepare a final report for the research team.

This REFLECT stage could be an action-based alternative to the common practice of combining themes from analysis, interpretation, and preparing findings as reports and publications. The reason for this returns us to the basic premise of peer research and the emancipatory and action-oriented goals of peer research that includes re-engaging the co-design team to evaluate the process, understand the findings, and be part of considering the feasibility criteria for next steps. This has been a defining characteristic of peer research from the first stage of testing the ability to conduct research as peers where those who the target of research set the goal and were part of creating the results.

This sets peer research apart from most qualitative research and citizen science processes that use methods and data and analysis chosen by the academic lead. The story template for the REFLECT focus group is an agenda that includes the stories related to the findings of the research and the action options. The agenda is shared prior to the meeting with goals and expectations for what will be accomplished. It connects to the principles of participatory action research, the narrative data science, and the grounded theory goals of focusing on results that make a difference. This final process motivates participants to learn more and get involved in the next stages of peer research INNOVATION.

Agenda for REFLECT Focus Group in Preparation for Next Stages

Prepare final story templates of chosen stories that explain the main concern and identify solutions to distribute before the meeting with the co-design team and sponsor.

Details of meeting and expectations:

- The original working title of research proposal and the main concern.
- Summary of what happened during the research project.
- List of options for solutions to the main concern or how the social innovation could work.
    - Use either a short summary of why the solution might work or action scripts.

Agenda of work to be done:

- Review of each option according to priorities based on potential impact, patient roles, systemic discrimination reduction, feasibility, cost, and potential focus.
- Choosing the top solution and making any changes to it.
- For the final choice consider:

- Relevance to equity-seeking groups and target medical condition.
- Social innovation or enterprise potential.
- Political obstacles and sensitivities.
- Language for marketing.
- Effort involved in reaching end users.
- Costs involved.

This section has attempted to consider possibilities for future peer research as part of a curriculum for training patients, providing experiential learning for graduate students, research and planning team exploration of emancipatory and JEDI-informed research, and a chance for researchers to consider ways to prepare a research option where patient roles will shift to prevention and promotion.

Peer Research and Innovation

We begin this final topic with the implications of the fourth industrial technology paradigm for patients. We then propose an integrated peer research methodology that can act as a bridge between academic research and design thinking. The new theories, health systems from a patient perspective and patient standpoint, are then incorporated into peer research. With these elements in place, we explore how peer research aligns with experience design to unleash the untapped resources of academic research working together to respond to our changing future.

Technology-Informed Healthcare Opens Doors for Innovation

Here we return to technology because it has the best potential to significantly influence health systems and to open doors to other forces for change, including JEDI and democratizing science. One could consider tech-informed healthcare as increasing community-based and patient-focused care that will keep patients well instead of waiting for problems to mature.

Learning how to use technology needs to move beyond the instructions on packaging as it is currently. This learning may occur as part of school curricula, health technology professionals, or in the emergence of online and community-sponsored training connected to the transition to smart technologies. Health technology coaches are already part of online chronic care networks, and hopefully research will identify the benefits for patients and families. There might also be options for current online data curation platforms and personal

research such as Zamplo (https://www.zamplo.org/), condition-specific patient networks in the Netherlands, and condition-specific patient networks such as Bladder Cancer Canada (https://bladdercancercanada.org/en/about-us/).

This is often referred to as the consumerization of healthcare that will be delivered as a seamless continuum of care, away from the clinic-centric point-of-care model. Broadly defined, the consumerization of healthcare is the trend of individuals asserting more influence and control over their medical and wellness care. To address this, non-traditional companies such as those in the retail, technology, and consumer goods sectors are looking to address consumer and patient needs (UBS, 2020).

Improving Patient Experience as Part of Improving Health Outcomes Through Health-Related Technologies

The following goals of health-related technologies returns to the emancipation of patients in their health and healthcare as full partners in healthcare transformation from numerous media and research literature.

- **Shifting modes of diagnosis and treatment**
  The distinction between diagnosis and treatment may become blurred as health monitoring shifts treatment from pharmaceuticals and direct intervention to early detection and prevention. Biosensors could become a part of human existence, as they scan and transmit information to systems for action or, more likely, regulate messages to citizens about medications, physical activity, and diet. The challenge with healthcare delivery then becomes how the monitoring and regulating functions are organized. This becomes a wholesale reconceptualization of ethics of privacy and control. What will be the role of patients in this new society driven by maximizing health by self-regulating systems? (Grinin et al., 2017, https://doi.org/10.1007/978-3-319-49604-7_13).
- **Shift from acute care to prevention and promotion**. Precision medicine holds great promise for prevention and public health, by identifying predisposed or high-risk patients for specific conditions and quickly developing treatment and remediation options to reverse or manage potential illness. This is particularly important for non-communicable disease, which accounts for 75 to 80 percent of healthcare costs. This also targets stress-related disease by targeting the source of stress and improving stress management. These two alone would dramatically change the configuration of what we know today as healthcare (Schwab & Davis, 2018).

- **Changing the current magic bullet equation** assumes that a diagnosis identifies the treatment model. Biosensors will initiate links with data systems and options for treatment such as the internet of things (IoT) that link all forms of health technology from physical, biological, and digital sources to inform patients and providers about options. This is being investigated by home care and chronic care networks to reduce professional cost. It is essential that health research find new ways to create stakeholder roles for patients (Grinin et al., 2017, https://doi.org/10.1007/978-3-319-49604-7_13).

The above narrative methodology now aligns with the inclusion of citizens in design thinking/human-centred design to complete a peer-derived solution that is able to make a difference. The last section of this chapter creates the bridge between peer research and design of new processes and products. Both peer research and innovation by design begin with identifying the right question to capture the main concern of patients; patients are included in both methods from the beginning of the process through to implementation.

Canada's medical system is realizing that patients are the most underutilized resource in a digital health reality, but important decisions must be made if patients are to be stakeholders in their future on who owns patient data and who controls technology.

1. It has been said by many that the patient is the most underutilized resource in medicine. How can we accelerate the adoption of virtual care and the expanded capability of electronic healthcare records so that patients' time is valued and they are enabled to be more actively engaged in their health and healthcare?
2. How can we ensure that all Canadians have equitable access to new health technologies regardless of their geographic location and their socioeconomic/cultural characteristics?
3. The private sector clearly recognizes the value of connected health data, as evidenced by recent announcements by companies such as Apple and Google. What will it take for Canada's 70 percent publicly funded health sector to expand beyond its siloed legacy data systems and invest in big data and analytics?
4. How can Canada better support innovation and commercialization in the healthcare sector?
5. In an era where health information is being captured and linked across many points of the healthcare system and beyond, who effectively are the owners and stewards of personal health information?

Design Thinking, Human-Centred Design

I began to see design thinking and human-centred design creeping into community health research and realized that the theories related to SoE were applicable to design thinking as well because partnerships with end users of technology is a defining characteristic of design thinking (Abookire et al., 2020, https://doi.org/10.3389/fpubh.2020.00459). For example, design thinking in health technology development involves end users at the beginning of innovation to ensure that the right question is being studied and that end users are engaged during prototype testing that is iterative. The end of Chapter 12 explores the design thinking/SoE research approach not only as part of health technology innovation but as a model that can support patient research roles in JEDI, along with community health science looking to include patient-led research as part of research grants and projects.

Finally, the rapid development of digital health will impact patients in unprecedented ways, and they need to be included in these changes to ensure that data used in machine learning includes diversity and that patient autonomy and privacy is respected in the design and management of new technology. Patients can and should become citizen scientists of their own health-related data and data monitoring, to inform their healthcare decisions, especially as these decisions relate to personal devices and linked IoT. The following suggestions identify where SoE intersects with app development, design thinking, and lean product testing:

- Engage users as stakeholders to maximize consumer input in product and process development.
- Ensure diversity of data and data science to inform machine learning.
- Facilitate patient and community networks to support social innovation and social enterprise that build patient and community support of research and digital literacy.
- Create training in inductive research that includes iterative cycles that are the foundation for both peer research and product development for students and researchers.
- Include stakeholders in the process of identifying who uses, chooses, benefits, and pays for change.
- Use stories of innovation to support grants, team building, recruitment of real users, impact, and marketing.
- Explore individual funding and citizen education that ensures that all citizens have the resources to be part of the next stage of healthcare.

This section draws on the work of Valentine et al. (2017, https://doi.org/10.1080/14606925.2017.1372926), who introduce the use of design thinking for social innovation in healthcare using the Glasgow Public Health model that uses contextually sensitive narrative approaches to focus on community health, diversity, and inclusion. Those working or interested in community health are encouraged to read this foundational study of the need to explore alternative research approaches.

We now take a giant step in suggesting that peer research methods provide the tools to support the natural connections between academic research and innovation represented by design thinking. The analysis of each approach considers strategies, focus, data, and goals. This figure is provided to consider research approaches to understand the alliances according to processes, focus, data and goals related to design thinking.

Table 12.6 *Comparing Qualitative, Grounded Theory, OIS/Citizen Science, Peer Research, and Design Thinking*

	Qualitative research	**Classical grounded theory research**	**Citizen science in an OIS framework**	**Peer research**	**Design thinking**
Description	Description of conceptual themes related to disciplinary theory	Solutions based on explanation of main concern of populations	Inclusion of citizens in collaboration across disciplines, citizens, business, and policymakers	Patient perspectives on solutions to main concerns	Meeting people's needs with what is technologically feasible to create customer value and market opportunity
Research process	Mostly deductive Language-based study of human experience using interviews and surveys to test assertions	Inductive Iterative cycles of data and analysis using constant comparison as theory evolves	Depends on research tradition of collaborators	Inductive Emancipatory and participatory grounded theory of narrative data to explore patient concerns to find solutions	Deductive, inductive, and abductive Exploratory and ongoing explorations of opportunities for change

Table 12.6 (*continued*)

	Qualitative research	**Classical grounded theory research**	**Citizen science in an OIS framework**	**Peer research**	**Design thinking**
Focus	Questions from research, literature locate gaps in knowledge	Open coding refines a main concern of population	Citizen scientists collect local data and are part of crowdsourcing using formal research protocols Emancipatory community science	SET: patients prioritize main concern from consultations with patients and co-design team	Iterative prototype cycles in the context of user needs, marketability, and feasibility
Data	Descriptive data consists of answers to interviews, standardized and open questions	All is data that informs how the main concern works and how to resolve it	Science methods of data collection; many use information technology and social media	Stories of what happened, is happening, or could happen to explain the main concern and solution	Observations, stories, interviews, information diaries, personas
Goal	Themes and theme hierarchies	Core category that best describes the main concern and supporting categories	Data and findings shared with other researchers, policymakers	Solutions to resolve the main concern	User-focused innovations with market value

Each of the approaches above come from very different research traditions, methodologies, and epistemologies, but all aim to understand and solve common real-life problems of communities and citizens. This rich diversity of approaches was included to show creativity in achieving new research partnerships and methods. Peer research is designed to work alongside formal research projects to add an authentic patient voice to the research or planning topic of concern. It also provides a research methodology that is designed specifically for patients, citizens, and communities. It shares many characteristics with

community-based participatory health research and Indigenous science while bringing inductive practices to the more common deductive methods of medicine. Peer research as part of PaCER methodologies has been considered qualitative research that employs grounded theory iterative cycles to ensure that research methods can be adapted to a broad spectrum of participants. This is done to maximize diversity and ensure authentic inclusion that builds patient research equity as part of academic research teams.

We can now look at how SoE supports innovation. The following references provide a quick overview of design thinking in social innovation that is written for community and academic readers.

- The Stanford Social Innovation Institute seems to provide the most widely accepted summary of design thinking that reflects the emancipatory goals of peer research (Brown & Wyatt, 2010, https://doi.org/10.48558/58Z7-3J85).
- The hybrid model combining evidence-based practice and design thinking done by the library services at the University of Alberta is an excellent resource for beginners interested in design thinking (Howard & Davis, 2011, https://doi.org/10.18438/B8TC81).

In this section we propose a short version of the science of engagement for academic research to locate peer research in the realm of social innovation, social enterprise, and commercialization of health (Sebastianski et al., 2015, https://doi.org/10.2147/IEH.S60790). They suggest that publicly funded healthcare systems may reconcile "the tension between delivery of publicly accountable health care services, innovation development, and commercialization" (p. 78).

Patients will be the end users of future healthcare technology and, therefore, should be key stakeholders in the development and implementation of social innovation, social enterprise, and commercialization through peer research partnerships. This is facilitated by a bridge between peer research and design thinking. The bridge enables solutions that explain the main concerns from a patient perspective using peer research to inform design thinking ideation and prototype processes. Peer research could be used to continue to support design thinking, prototyping and implementation or commercialization after completing academic research projects.

Design Thinking Innovation and the Science of Engagement

Peer co-research methodology aligns with the inclusion of citizens in design thinking/human-centred design to find solutions that can make a difference. We now create the bridge between peer research and the design of new

technology and health products. Again, we must begin with identifying the right question to capture the main concern of patients and then include patients from the beginning of the process through to completion. I also notice that some community health research is exploring design thinking and hopefully community researchers might explore peer research.

With the above foundation, this section pivots to design thinking as an "interdisciplinary collaboration that uses designers' creativity and user centred approaches and methods to match people's needs with what is technologically feasible and what a viable business can convert into a customer value and market opportunity" (Brown, 2008, p. 84, https://pubmed.ncbi.nlm.nih.gov/18605031/). This includes not only direct consumer purchasing but adoption by health systems as part of treatment options. Design thinking is characterized by a consistent set of steps that begin with engagement processes with potential consumers of new products and services and a series of steps to identify problems, potential solutions, and iteratively prototype options for social innovation or commercialization.

Design thinking is generally not considered a research method; it is, however, a set of standardized methods that are applied in a systematic scientific manner. We focus mainly on experience design (XD) as a holistic design approach where the designers are holistic problem solvers dealing with the ecosystem of the issue being investigated. It focuses on engagement of people and, therefore, employs a more narrative style, using all senses and multiple levels of data.

University-based Industrial designers and innovators from science backgrounds are trying to find ways to connect with the economic possibilities as new technologies emerge. The movement from individual products to integrated processes such as IoT may provide support for university innovation teams that have university support to bring new ways to focus on experience design, even with an incredibly large commercial sector.

Experience designers appear to have an advantage in the upcoming transformation of health in which value is created on a local level by addressing broader societal issues with all the stakeholders involved (Kleinsmann et al., 2017, https://www.ijdesign.org/index.php/IJDesign/article/view/2771/780). For example, RED, a 'do tank' that uses innovative design to tackle social and economic issues, was set up by the British Design Council in 2004 (Overbeeke & Hummels, 2011, https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/industrial-design). These thoughts are reflected in a recent YouTube video by Tim Brown, one of the leaders of experience design who supports design approaches to foster emancipation (Brown, 2009, https://www.youtube.com/watch?v=UAinLaT42xY).

Design thinking, human-centred design, and innovation are being adopted by science movements that are looking to democratize science to make products and processes relevant and economically sustainable as an antidote to the current commercial structures of the industrial revolution. Health systems increasingly struggle under the pressure of political structures and funding, aging health facilities that struggle under the increasing population of those in need of care that call for programs to finance innovation. Nevertheless, there are signs that new technologies are creeping into the existing structures and new health systems based on greater use of technology that are percolating beneath the surface to provide options for transforming health and healthcare.

The new medical science platforms such as pragmatic clinical trials and precision medicine, the Gates' global health programs in developing countries, and EUPATI, are a sign of political restructuring of health technology. In Europe and are examples of democratic health innovations that support new patient research opportunities. The goal is to infuse existing medical science with flexibility, creativity, quicker uptake, and relevance.

The following is a highly optimistic and hopeful proposal to focus on the urgent need to prepare for inevitable change. It is also important to include a recent project in the EU to canvas commercial innovation companies that identified that most were not using end users as part of their work on health devices and products because they were unsure about the ability of patients to understand the design process. Experience design engages citizens and communities as part of the process, but it has yet to explore training citizens to work with end users to increase and support recruitment, consumer involvement and confidence in prototyping. Considering the significant impact of merging technologies on the lives of patients, it is time to increase the role of end users in design and implementation methods at all levels of health research and innovation.

Citizen science has helped motivate new models, such as maker spaces, where citizens and people from many disciplines come together to solve problems and create solutions for the marketplace. Wiggins & Wilbanks (2019, https://doi.org/10.1080/15265161.2019.1619859) discusses the importance of citizen science in health and biomedical science. Patient engaged research, as seen in Callard and Perego (2021, https://doi.org/10.1016/j.socscimed.2020.113426) is an excellent example of peer-led research in healthcare.

Open innovation in science began with the challenges of academic research cultures and silos that focus on making journal articles accessible to citizens as part of open access. The most recent article (Beck et al., 2022, https://doi.org/10.1080/13662716.2020.1792274) creates the framework that makes it possible for citizen scientists and other key stakeholders to be part of academic research that is government funded.

In a review of literature on citizen involvement in community-based health research, Israel et al. (1998, https://doi.org/10.1146/annurev.publhealth.19.1.173) tracks the movement from positivist research to emancipatory research in health promotion and identifies methods that show promise for co-research. However, apart from the work of the Wellesley Institute related to Peer research in community research (Roche et al., 2010, https://www.wellesleyinstitute.com/publications/peer-research-in-action/), there are few published examples of how to encourage community members to conduct research. The exceptions, used throughout this book, included PaCER research, which trained patients to conduct research with patients and community members; Wellesley Centre at York University, which trained community members to recruit and co-research with institute members; and the HIV training unit at the University of British Columbia, which trained HIV patients as community researchers. The British Columbia SPOR unit hosts a patient voices network to share experiences that relate to planning and health decisions with healthcare partners and health researchers, and it has recently announced interest and preliminary explorations into a patient-initiated research assistance program.

The most advanced move to peer research and full research collaborations have emerged as part of Indigenous nationhood and the ability to form equitable relationships with Indigenous nations. In this regard, the UN declaration on Indigenous nationhood has created international alliances of Indigenous nations and academic units. In Canada, two-eyed seeing, as articulated by Jeffery et al. (2021, https://bcmj.org/articles/two-eyed-seeing-current-approaches-and-discussion-medical-applications), and in other countries with strong Indigenous traditions such as Australia, New Zealand, South Africa, and the United States, there have been dramatic shifts in a data system to recognize data and ownership of results through the lens of sovereignty. One project in particular depicts the results of over 20 years of collaboration to create a partnership based on two equal nations (Brunger & Wall, 2016, https://doi.org/10.1177/1049732316649158).

We have much to learn from these early Indigenous pioneers of authentic research partnerships. Siksika Nation in Alberta was the home of Henry Three Suns, who was part of the co-design of new social movements case studies. He fractured many of the original epistemological beliefs I brought to the new social movement research. The value systems of the Siksika Nation embraced the primacy of the land, collectivity of community, and ancestors as essential elements of the cosmology. These were in stark contrast to assumptions that were grounded in the present and future as values of Western and European nations. This contrast fractured the values and meaning underlying the study and sent me back to each of the other co-researchers to test out how their basic

values informed their co-research experience. There were many changes made that brought depth to the emerging theory to reflect their understanding of individuality and collectivity, the past and the present and their role in change.

Early in PaCER, an Indigenous community worker took the training and was able to identify the common links between PaCER and Indigenous ways of knowing. There have been six Indigenous cohorts in PaCER to date, and these have not only been grounded in their Indigenous values, but Indigenous values have resonated with many of the research teams.

We have attempted to introduce the importance of new partners and ways of thinking as we shift to a method tailored to address the links between peer research, culture, academic research, citizen science, design thinking, and social change.

Peer Methods Meet Design Thinking

This section explores a hybrid peer research approach that uses peer research as a bridge between academic research and design thinking. Peer research, as a method for engaging patients in academic research, can increase the credibility of experience design and human-centred design by using rigorous methods to identify priority concerns of patients and communities. Skilled patient research roles can be introduced to extend current capacity to bring a patient perspective of what needs to change and how to make it happen.

Table 12.7 compares peer research, citizen science, open innovation in science and design thinking as part of social innovation and social enterprise. The table begins with the goal and role of patients and researchers, and then outlines the categories of design thinking, to lay the foundation for discussion of how SoE relates to social change.

The stages of experience design are:

1. Engage and establish empathy with community—aligns with SET
2. Define the problems—aligns with SET
3. Ideate options—combines COLLECT and REFLECT of peer research
4. Test prototypes for feasibility and marketability, which uses end users to test products
5. Test and scale for commercialization

These steps are proposed to open discussion with collaborative researchers and their networks who are interested in cross-sectional research. PaCER and peer research has demonstrated that patients are a reliable source of innovation, and their research shows that concerns and needs can be identified and studied by patients to produce solutions that will be effective and adopted by patients.

The nascent academic, peer research partnerships have the potential to be the bridge between academic communities and greater innovation and commercialization in health.

Table 12.7 *Peer Research as a Bridge Between Academic Research and Design Thinking*

Goal	**Citizen science**	**Peer and patient-led research**	**Design thinking approach to social innovation and enterprise**
	Deductive partnership with citizens to democratize research led by academic researchers.	Inductive research to create a collective patient research voice and innovation led by patients.	Inductive and abductive research to increase market value of innovation, led by innovators, designers, engineers and marketers.
1. Engage and establish empathy with community/ (SET)	Citizen scientist volunteers are engaged as partners. Instrumental empathy is evident in principles of citizen science and the partnerships formed. Community Science brings empathy to citizen science as communities design and conduct research.	Patients and community resources co-design concerns. Engagement throughout research as peer research reinforces empathy and collaboration.	UX Engages to build empathy for researchers so that they can understand consumers (observe and listen).

Table 12.7 (*continued*)

2. Define the problems (SET)	Problems as identified in the research grant. Co-design may be possible if citizens are encouraged to suggest concerns (community science).	The SET co-design team prioritizes problems identified by patients and communities. Provide guidance for research engagement.	Problems identified by designers and end users (or their representatives).
3. Ideate options (COLLECT and REFLECT)	Findings governed by grant. Could be listed as suggestions for action or to answer theory or policy questions.	COLLECT: Iterative cycles to explain problems to identify solutions. REFLECT: Co-design team prioritizes solutions for prototyping.	Focus groups using visual problem solving.
4. Test prototypes for feasibility and marketability	X	Options tested to train patient researchers in follow-up prototype testing.	Iterative cycles to rapidly test prototype versions.
5. Test and scale commercial-ization	X	X	Design thinking cycles involving engineering and marketing specialists. FAIL FAST

While evidence-based medicine tends to be deductive to test for significant effects of hypothetical situations, inductive research uses cycles of explaining problems to find solutions. Experience design cycles of prototyping and field testing include input from end users at each step. In looking at the results of PaCER studies to date, peer research like experience design can use abductive research because both celebrate intuition and creativity in finding solutions and opportunities as part of innovation.

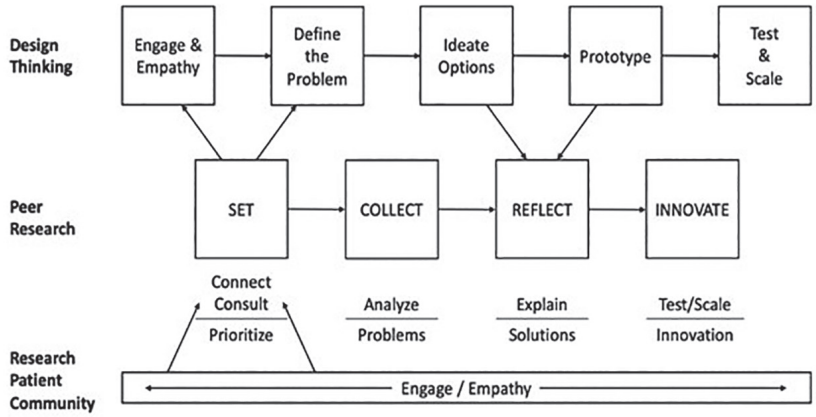
Citizen science opened options for inductive experimentation and observations in the natural world, while maintaining deductive evidence-based protocols and disciplinary frameworks of science. Peer research is a form of citizen science that suggests an opportunity to bring peer co-design approaches into experience design stages of engagement and empathy. This then opens common ground for both peer research and design thinking using iterative cycles of data collection and analysis.

The potential of a parallel framework for peer research and design thinking is captured in Figure 12.4 that provides links between existing design and peer processes.

- The top line represents design thinking stages, the second line represents the engagement strategy for peer research that is extended to reflect the final prototype testing phase. This model suggests that peer research can begin as a companion to academic research that has some expectation of innovative results. The top line represents experience in design thinking.
- The second represents peer research.
- The bottom represents the research processes involved.

Both experience design and peer research are committed to engagement and the resulting empathy. Here empathy is seen as a powerful communication skill of understanding and being aware of what other's experience, which is a way of appreciating and fostering authentic research where end users' views are sought and valued. Peer research would take this perhaps one step further to include end users in decisions about the need for and characteristics of technology.

Figure 12.4 *Hybrid Model of Peer Research and Design Thinking*



This can now be translated into a functional hybrid of peer research and design thinking in the links between the two. This hybrid brings the academic credibility, JEDI focus, publication potential of academic research to design thinking innovation and commercialization. An academic research team could use peer research stages of the new hybrid model to inform an innovation grant that would use the peer research already completed to meet the stages of engagement and empathy, defining the problem, and ideating options. The grant could then focus on using marketing and engineering resources of experience design to set up rapid prototyping, testing, and commercialization. This would complete design thinking, conducted by design thinking specialists in collaboration with an academic research team with peer research that would act as a bridge of patient input throughout.

Peer research could also be started as part of design thinking funding that is interested in conducting peer research to augment aspects of design thinking processes. This could be done to enhance the engagement and empathy stage, to meet JEDI and citizen science principles. This could increase the probability that the product, process, or service is indeed designed in conjunction with patients and citizens. A peer researcher could be hired to design a process in keeping with the expectations of the designer. The methods and theory of the science of engagement can be streamlined to accommodate a combination of design thinking and peer research, using methods and theory from both.

The following sections address design thinking and how science of engagement and peer research might contribute to it. We have adopted the stages of

design thinking, as used in the above figure to structure this section because it extends beyond the current scope of peer research.

Empathy and Engagement

These are the hallmarks of peer research, the science of engagement, and design thinking/experience. Both include the values and experiences of citizens in order to engage authentically and deepen understanding of the real-life struggles and motivation to make a difference. Co-research reinforces not only empathy but also the equity of peers within the research process. In the future, patient identity and control will be transformed through technologies that are preventive, augmentative, and promote wellness and longevity. This also includes JEDI emancipatory principles of equity, diversity, and inclusion that could guide future design options.

Salutogenesis is a theory of patient expertise in how to handle medical and health challenges. It underlies their potential to be engaged in research that aims to improve patient experience. The new theory template of a patient perspective of health systems opens debate about what technologies are included in each of the health systems now in place. Standpoint theory brings the importance of both identity and agency to the design of new products.

Today, in both peer research and design thinking, empathy and engagement include expectations to become familiar with the lived reality of individuals and groups and to learn from people who know first-hand the problems, preferences, and hopes of populations. An example of this using crowdsourcing might include the peer research team creating an online video about who they are and their interest in finding stories about patient concerns related to a research project or innovation. They could introduce a downloadable story template and demonstrate filling it out. The download would include a link to declare the level of their interest in being involved along with the completed story templates. The teller's story could also be told by video, which allows the peer research team to find common goals and expectations of technology that could then be shared with the storytellers.

Engagement is considered part of the SET stage in SoE, and as such, it spans engagement and problem identification of design thinking. The empathy/equity in peer research continues throughout, deliberately including participant co-researchers in data collection and analysis of both the research topic and the eventual solutions for change.

Finally, the basic philosophy of this SoE is framed by cognitive empathy that refers to our ability to identify and understand other people's experiences and reactions. It has been clear that peer research is ideal for achieving cognitive empathy with communities of interest. This is an opportunity to appreciate

and share concerns and negative experiences early in the process. Cognitive empathy requires researchers to ensure the level of diversity and inclusion necessary to achieve equity and justice in future technologies.

Patient standpoint theory is an effective tool for building cognitive empathy among health professionals and citizens involved in research. This new theory enables all parties to analyze patient stories about real-life problems in ways that suggest solutions that relate to potential technologies and how to use them. Also useful in experience design is the ability to use a patient standpoint theory to analyze stories using two axes of identity and agency.

Identity helps define how technology might make people feel good about themselves. Here I am reminded of my work with people who were disabled who would show me a closet or a room of technologies that someone thought they should use. It was not something they wanted or needed or something they would use in public. The axis of agency from avoiding failure to approaching success is seldom used in technology design that focuses on the instrumental value instead of how and why patients use technology. Without an understanding of more than function or cost, technologies will continue to live their lives in closets.

Standpoint theory also breaks through dominant discourses of patient experience of vulnerability to glimpse how health situations and systems impact the identity and agency of patients. Instead of considering patients as vulnerable because of their conditions, the focus shifts to how the systems, relationships, and services impact patient identity as vulnerable and dependent. When citizens are included early in the design process, they are more able to regain confidence and agency to become resilient and competent in their health and healthcare. Co-design and technology can support health promotion and equity in health.

Define Problems

In design thinking, problems are identified through connecting with a subset of the target population. Problems are then identified and discussed by the design team to create statements of the problem from a citizen perspective. This creative process uses stories, games, ice breakers, and focus groups.

This is where peer research differs. The last stage of SET is the convening of a co-design team of patient consultants who prioritize the problems identified by patients and their allies. The priority is identified according to its importance to patients and the potential for change. Concerns are often embedded in healthcare relationships, policy gaps, access to appropriate care in addition to access and exclusion from the services or products needed. There are circumstances when the question for co-design is enmeshed within health systems

that are difficult to identify, and this is where the iterative cycles of peer research come in to clarify the nature and site of the concern.

Analysis of blockages or gaps in health systems has proved difficult using standardized survey measures, mostly because the instruments are written by professional researchers from their research focus. Here we focus on some methods that can be used to identify and analyze concerns:

- Consultations with expert patients, community resources, clinics online or in-person.
- Survey of grey literature and patient experience literature.
- Patient researchers shadow procedures that have been identified as concerning using story templates.
- Open crowdsourcing of solicited stories using a story template or short descriptions of difficulties, gaps, delays.
- Sorting these into categories that can be prioritized using group decision-making or framework analysis.

The problems chosen are written from a citizen or end user perspective, and these become part of the ethics proposal. The co-design team advises on potential recruitment, language and politics to provide a full understanding of the problem chosen. This option could inform complex problems that seem appropriate for technology support or solutions.

Ideate Solutions

In experience design thinking, problem statements from the problem definition stage inform the design team, who typically generate ideas about how to solve the problems, sometimes in collaboration with citizens. This process can also include large brainstorming and creative decision-making collaborations with stakeholders. At this point, engineering and marketing is included, but there is a caution that this detail might limit creativity or criticize ideas prematurely.

In peer research, searching to explain how problems emerged and are perpetuated leads to focusing on understanding the problem in detail in order to effectively uncover solutions that resolve or reframe the concerns. This occurs during the inductive process of COLLECT, which includes iterative cycles of storied data collection and analysis. This process uses individual and group research methods that encourage in-depth and wide-ranging explanations of problems. Groups and individuals are also encouraged to improvise as a way to think about potential solutions.

Grounded theory's constant comparison and iterative analysis supports the search for solutions. Patient stories that are meaningful to patients and

communities are constantly compared and studied to identify similarities and differences to identify common narrative properties (who, when, why, what, how). The use of narrative throughout also ensures that the solutions are real-life solutions to the problems of importance to patients.

The theory of salutogenesis provides a strong asset-based foundation for ideating new solutions. Salutogenesis suggests solutions that build confidence in handling medical problems and provides a structure for ideating solutions in peer research. These include:

- Cognitive actions related to identify and find help and support.
- Coping strategies that build options for managing problems.
- Finding meaning and motivation and a sense of purpose.
- Social connections that build wellness and support.

Standpoint theory suggests the use of patient identity and agency to identify problematic psychological spaces and the nature of the situations. This supports understanding goals and possible options for innovative solutions. This is a new theory that promises to move current analyses to evidence-informed choices for action:

- Challenging health problems to find new ways to overcome them.
- Resisting the loss of agency.
- New relationships and roles that improves one's sense of identity.
- Opportunities to contribute and take control of problems.

These powerful new engagement tools are part of SoE in support of data-informed solutions. Peer research works well within qualitative health research to bring evidence-based collective experience narratives into existing research agendas. It is also able to dive deeply into personal and community-lived experience by including unheard populations in community science. This work could bring informed and innovative patient solutions to design thinking. This is likely the most important contribution to the goal to build bridges. Health problems are entrenched and difficult to understand. Peer research could bring new rigour and detailed analysis to ideas for solving difficult and complex health-related problems in ways that will resonate with patients and lead to technologies that will be accepted by end users.

Develop Rapid Prototyping, Test, and Scale

At this stage, peer research as part of academic research takes a different direction. The action-oriented focus in PaCER research led to dissemination and, in some cases, to implementation studies that arose out of the findings.

One of the founders of PaCER, Dr. Deborah Marshall, sponsored a series of peer research contracts to study new ideas related to knee osteoarthritis (Mackenzie, 2022, https://ucalgary.ca/news/ucalgary-researchers-lead-international-program-develop-value-framework-socioeconomic-impact-living). The findings suggested a patient app that would enable patients to track their symptoms and treatment results, stay in touch with new ideas, and prepare reports for their physicians. These findings were then moved into a collaborative innovation team consisting of patients, family physicians and researchers, and technology innovation specialists.

Design thinking, on the other hand, excels at taking good and needed ideas through fast, low-risk incubation that consists of iterative testing of mock-up digital and physical products in person or online. The development and testing of possible solutions using low impact trials minimizes health risks, and this is essential in health innovation. Testing includes usability, acceptance by the user/patients, and the market variables related to who pays and how much.

The iterative design prototyping practices are similar to the iterative constant comparison cycles of peer research, which might suggest that the peer researchers could become an important feature in design thinking at the rapid prototype stage.

Instead of testing THE solution as part of academic research, design thinking uses a process of incubation that is based in low-risk experimentation cycles within safe test sites. This avoids the academic reluctance or inability to change prototype directions where, if THE solution fails it is considered a failure of the concept.

The ideas of low-risk incubation and modification may hold the answer to the difficulties in the uptake of health research findings. On the other hand, peer models could easily be modified to include prototype testing because the methods are iterative and a natural fit with moving from reflection to testing and marketing. This would extend the process to SET-COLLECT-REFLECT-INNOVATE engagement strategy.

Design thinking is customer- and user-centred, and by introducing peer research and patient-led options, it is possible to include theory-informed direct experience research. This would include a storied approach to interviews, observations, focus groups, collaborations and arts-based projects. The most salient feature, however, is that peer research reinforces engagement and empathy by acknowledging patient expertise in analyzing and interpreting input

throughout design thinking, just as peer research reinforced engagement in academic health sciences.

The rigour of peer research can provide new options for design thinking/social enterprise and citizen science. As a new option that builds research capacity at the personal and community levels, peer research provides ways to build community alliances and partners in social change.

This capacity can be employed by communities as they try to understand systemic barriers in order to influence policy and economic decisions. This can also be used when negotiating with research teams interested in forming RRI and OIS partnerships, citizen science research, and changemaking projects.

Next Steps

The above suggested collaboration could include peer research iterative cycles, supported by a university team with initial ethics approval for implementation. The options for prototype testing would have to be negotiated to include iterative cycles that would or could produce changes to the prototype. The other way to include peer research would be to become part of a design thinking prototype testing team covered by the regulations of innovation funding.

This chapter has evolved dramatically and, to this end, it has become a process of thinking about the social innovation of peer research/design thinking alliances that could have a major impact on healthcare transformation and social enterprise. By capitalizing on the connections of peer research to citizen science, peer research could become an active research partner in OIS and related RRI models.

Summary

This final chapter opens the door to many discussions and opportunities to include patients and communities in the major healthcare options of transformation as part of medical science, and design thinking. There are many questions that might be asked.

Questions for Discussion

1. What would it take to create interest in the science of engagement in health research and innovation in your situation?
2. Is your health research prepared to open conversations with design thinking, and, if a maybe or a yes, how might that conversation be initiated?
3. Is design thinking, social innovation, and social enterprise motivated to explore ways to move academic research ideas closer to innovation? If so, how might the risks be managed?
4. Is it possible to scale up peer research through existing training models in social innovation, social entrepreneurship, or design thinking to create adaptations that would focus on peer research, participatory research, changemaking research, and research as part of social innovation?
5. Are there informal ways to embed peer research engagement strategies and peer research roles in either academic research or design thinking projects that have the interest in training a patient or community member to be a mentor to work with team members to create a customized training program?
6. What would it take to test and scale a PaCER model for design thinking?
7. Are there informal ways to embed peer research engagement strategies and peer research roles in either academic research or design thinking projects that have the interest in training a patient or community member to be a mentor to work with team members to create a customized training program?

Resources

This is the final report of the casebook using design thinking to inform social change. This example summarizes the resources in Chapters 9 and 10, as an example of design thinking for moral injury to inform rapid testing and commercialization.

Social Innovation and Moral Injury: A Design Thinking–Informed Casebook

Cera Cruise
CORE 591
University of Calgary
September 18th, 2020

INTRODUCTION

Design thinking requires the same attributes in its users as is the mission of the Community Rehabilitation and Disability Studies (CRDS) program at the University of Calgary—to instill in its students the empathy with innovation with consumers to challenge mainstream perceptions of ability that separates those who benefit from design thinking from those who do not. Like anything that is human-focused, design thinking is an iterative process and students in the CRDS program are well equipped to adapt their training, both academic and practical, to create social innovations in their field of choice. A focus on social innovation in health reflects a growing consensus that social needs are not being met by current practices within the healthcare system and that patients are a wealth of knowledge to create stronger healthcare systems.

As a fifth-year completing a combined degree in Community Rehabilitation and Political Science, I feel very fortunate to have an opportunity to apply skills I have developed in both fields to create a patient-informed innovation for those with moral injury. Studying political science has taught me how to apply theory and use it as a tool to enhance my understanding of structural inequalities, while the CRDS program has instilled in me the belief that individuals are experts in their own experiences. Therefore, in my mind, solutions ought to come from the bottom-up rather than the top-down. This is the basis of social innovation.

Moral injury is intriguing to me in that it's a deeply personal injury that requires an individualized response—there is no "fix-all" cure. As someone with post-traumatic stress disorder (PTSD), I have empathy with those with moral injury, recognizing that their hurt is significantly different than my own, as the cause of their injury is an internal violation of what it means to be a good person. Everyone wants to think of themselves as good and kind and brave—to have that taken away is to experience a loss of self. Being encouraged to step into the patient's shoes while proposing a social innovation was a huge change for me, as that's something that I'm able to do easily but is usually discouraged in an academic context. Actively reading individual stories allowed me to understand the extent to which moral injury harmed them and to share several

theoretically informed observations in this casebook that could impact how healthcare providers with a moral injury experience recovery.

I looked at three systems that individuals with moral injury potentially act within—treatment and diagnosis, community inclusion, and peer and natural support. The treatment and diagnosis system traditionally takes place in psychiatric settings—the patient comes with a problem and the professional helps them fix it. To understand this system, I used an open-access PowerPoint for professionals, instructing them how to treat moral injury through the National Association for Alcoholism and Drug Abuse Counselors' (NAADAC) website.

The system of community inclusion occurs when disability-specific programs are created within communities. Prior to searching for such programs, I wanted to understand the community itself— moral injury is usually an injury associated with members of the military, but I wanted to look at healthcare providers, due to the extraordinary circumstances they are currently in due to the COVID-19 pandemic. I used Bailey's (2020) online newspaper article, which reported physician's claims of moral injury and then found a career-specific resource currently offered to healthcare providers—the Whole Health Medicine Institute. This qualifies as a community inclusion program because it has specific inclusion criteria, centred on both the feeling of dissatisfaction with the medical system and the profession of the individual. It was created by a physician with a moral injury, and many of the contributors to the program also identify as having a moral injury as a result of their career in the healthcare profession.

Finally, I used a peer support program in Ontario, Project Trauma Support, as an example of the effectiveness of peer support in the hopes that this model could inspire my innovation. Together, the three systems came together to share various perspectives and allow me to observe the impact of power on the human-centred of those with moral injury. From a standpoint theory perspective, individuals with a moral injury in the military are in the crisis and change quadrant—they have negative self-regard and internalize the cause of their injury. In other words, it is their fault the event occurred, and they do not deserve to be well. However, in a brief review of the literature, there is little to be found to point to how healthcare providers differ from members of the military in their experience of moral injuries; it is presumed they experience it the same way. Evidence from Bailey's (2020) article points to physicians recognizing that their actions are limited by external restraints, but that the consequences of these institutional restraints lead to them having a negative self-regard. This set of reactions points to physicians being in the learned helplessness quadrant and, therefore, needing a different set of support from the military members in the crisis and change quadrant.

Patient roles and experiences within each of the three systems were focused on, as power relations can tell us the extent to which a patient is empowered within the system. When creating a social innovation, analyzing the patient's role is crucial to reveal social gaps within the system. Standpoint theory, which combines a salutogenic perspective of well-being with the degree to which an individual feels control of their circumstances is internal or external, acts as an indicator of how effective intervention is. Salutogenesis reconceptualized health as being on a spectrum—the aim of my proposed intervention is to assist the individual to be well, rather than simply 'not ill.' Markers of transition from unwell to well in users of my innovation for healthcare providers with moral injury will be increased self-regard and a lessening sense of needing to control emotions internally. After sharing the findings of my collective analyses, I will share my social innovation proposal to create a story sharing online platform that is intended to create an anonymous community of individuals with moral injury. Potential barriers and theorized motivations of individuals to participate in the innovation will then be discussed, prior to a reflection on the value of a design thinking-based social innovation course.

DAY ONE

Table 12.8 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis https://www.naadac.org/assets/2416/cardwell_nuckols_treatingmoral.pdf	**Analysis**
"If one cannot accommodate or assimilate the event within existing schemas about self and others, guilt will be experienced, as well as shame and anxiety about the personal consequences."	The patient is to blame for their inability to assimilate the morally injurious event.
"Shame is associated with a wide variety of psychological problems, including depression and PTSD, as well as physiological changes including an increase in harmful cytokines and proteins that promote inflammation and cortisol."	The patient is something to be studied rather than a whole person—their actions are not a natural reaction to a personally horrifying event, but a chemical consequence of shame.
Professionals must "develop a knowledge of the exact nature, conditions, issues, environment, locations of the veteran's theatre of operation."	Professionals are responsible for knowing every minute detail of the morally injurious event.

Table 12.8 (*continued*)

Summary: The presentation is written for professionals, not patients. The patient is unconsciously at fault for their illness and professionals change the way they view the morally injurious event, so that shame and maladaptive coping strategies lessen or cease. Treatment cannot happen unless the patient wants to engage with the professional, and it is the professional who decides when amends to the morally injurious act are too much. The professional is active while the patient is passive, within the article.	

Table 12.9 *Community Inclusion Analysis*

Data: Community inclusion ***Whole Health Medicine Institute:*** https://courses.wholehealthmedicineinstitute.com/whmi-whole-health-studies-course-202036086740 https://lissarankin.com/doctors-are-suffering-from-moral-injury-whats-the-solution/ (Founder of WHMI)	**Analysis**
"A place where healthcare providers and those seeking healing could receive a deep and direct understanding of the body-mind-spirit continuum so we could scale this, infiltrate it into public health, and bring real healing to those who need it most."	The Institute teaches healthcare providers an alternative model of health; power is top-down in teaching. Healthcare providers receive knowledge from the Institute.
"The Whole Health Medicine Institute seeks to fill in the gaps. We specialize in educating body-oriented practitioners who have insufficient education in mental, emotional, spiritual, and trauma healing modalities that may help cure otherwise 'incurable,' 'untreatable,' or 'terminal' conditions."	Body-oriented practitioners are lacking in knowledge, and this can lead to their own moral trauma when they are unable to assist their patients. The program fixes this deficit.
Summary: The program is holistic in that it recognizes a salutogenic-type of well-being. The role of healthcare providers is to learn this new understanding and use it to change the healthcare system. Healthcare providers are exclusively allowed in the Institute, thus its categorization as a community inclusion system. By learning a more holistic understanding of health, healthcare providers prevent and treat their moral injury created by the current healthcare system.	

Table 12.10 *Peer and Natural Support Analysis*

Data: Peer and natural support ***Project Team Support*** https://projecttraumasupport.com/	**Analysis**
"The purpose of the groups is not to exchange war stories, so details of traumatic incidents are not shared. Instead, the meetings are intended to help members weave a new story of hope and healing."	Members of the group assist each other in creating new narratives. Power is horizontal rather than vertical.
"For me the peer support group is a safe place I can go once a week and be with other first responders who truly understand what I'm going through. I can be honest and not feel judged. I can shed a tear and not feel weak."	Members feel empowered by the group, there is no fear of shame or pressure to share every detail of their morally injurious event. They remain in control.
Summary: Those who are a part of the group are seen by peers as warriors. By taking the initiative to attend meetings the individual is doing something that their peers consider to be good, and they can actively help others who are experiencing a similar injury. The role of each member is to support others.	

Findings

In the deficit-based diagnosis and treatment system, the patient is passive and responsible for changing their world view to correct the deficit, while being guided by a professional who decides when acts of amendment are sufficient or insufficient, thus decreasing the patient's agency. The relationship dynamic is about conformity, with the professionals probing patients and focused on the achievement of patients graduating from being ill to not-ill. While in the peer system, the patient is also responsible for changing their worldview; it is done both for themselves and to help others who are experiencing similar emotions as a result of moral injury. The example of a community inclusion system, the Whole Health Medicine Institute, acts against the hegemonic medical system by training healthcare providers to understand health holistically. Healthcare providers enrolled in the Institute have more agency than patients in the treatment and diagnosis system but are still acted upon by the program. Countering this model of participation is the peer and natural support system. In the peer system, the power lies with the patient; they decide if they want to share their experiences with others and there is no expectation that they do anything except support others. Supporting others can facilitate new self-narratives. The peer support system changes the role of patients from morally corrupt individuals to

people who can help others and make meaning out of their experiences. Peers understand the unique factors that lead to moral transgressions and create a non-judgmental environment through which parties can redefine themselves. Power is horizontal rather than vertical, and the dynamic is one of relationships and learning.

DAY TWO

Salutogenesis was introduced to us on day two of our block week course and is significant for my innovation in that the application of a salutogenic lens gives my innovation both a measure of self-described patient progress and breaks down components of resilience, so that my innovation can target the specific needs of patients. Rather than aiming for a lack of illness, I hope for patients using my innovation to gain expertise of their own well-being.

A process of salutogenesis is the building of generalized resistance resources (GRRs) to stressors. Challenging a propensity for individuals and medical systems to pathologize stressors, salutogenic theory encourages the development of GRRs to respond to, instead of combating inevitable stressors. Resilience is created when an individual has a variety of GRRs, this results in an internal sense of coherence (SoC): stressors are met as challenges rather than obstacles. The three components of SoC are a sense of meaningfulness, a sense of comprehensibility, and a sense of manageability. A sense of meaningfulness is created when an individual determines that overcoming the stressor is worthwhile and will result in personal spiritual, emotional, or physical gain. Comprehensibility occurs when internal and external environments are understood by the individual to be predictable. Finally, having resources to respond to stressors leads to a sense of manageability. The aim of my innovation is to strengthen the SoC of patients using program resistance resources (PRR) to assist patients in developing their senses of meaningfulness, comprehensibility, and manageability in response to the stressor of a moral injury.

Table 12.11 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis (Nuckols, n.d., https://www.naadac.org/assets/2416/Cardwell_nuckols_treatingmoral.pdf)	**Analysis**
"Many veterans were presenting with difficulties that were not sufficiently addressed in the fear- and extinction-based frame that underlies exposure."	Resource: There's a recognized community of individuals facing similar stressors.
"They have seen the darkness within them and within the world, and it weighs heavily upon them."	Stressor: Resources need to be created to shine light on the darkness. The quote also shows that there is a lack of sense of meaningfulness about the incident.
"Mistake the foe for a friend, and perhaps die . . . Mistake a friend for a foe and die inwardly."	Stressor: All sense of coherence is gone, the individual with moral injury is regarded as the living dead.
"Spiritual healing results in worldview changes."	Resource: There is recognized potential for a sense of meaningfulness to be created out of the morally injurious situation, thus changing the worldview of the patient.
Summary: The patients being described in this system lack, from the perspective of a professional, a sense of coherence, thus explaining their ill-being. Using a salutogenic framework, professionals could prompt patients to share the meaningfulness and create a sense of manageability about the morally injurious incident in an honest fashion (i.e., not just giving the 'right' answers so that the professional can 'cure' them). From there, patients could share their resilience resources and work with the professional to build upon those resources.	

Table 12.12 *Community Inclusion Analysis*

Data: Community inclusion ***Whole Health Medicine Institute***: (https://courses.wholehealthmedicineinstitute.com/whmi-whole-health-studies-course-202036086740) (Rankin, n.d., https://lissarankin.com/doctors-are-suffering-from-moral-injury-whats-the-solution/) (Founder of WHMI)	**Analysis**
"Our courses, workshops, and training are designed to help you understand and apply a Whole Body Medicine approach in your life and in your practice. We support practitioners in building a thriving healing practice."	Sense of manageability is created by knowing resources are available to support healthcare providers.
"The all-powerful mind can control your reality, and all you have to do is learn to harness it."	Resource: Healthcare practitioners already have the tools they need to change their reality; this program allows them to develop GRRs necessary to respond to the stressors that are created by the healthcare system.
"WHMI brings a deep and direct understanding of the body-mind-spirit continuum to physicians, nurses, health experts, and healthcare providers. We believe that this understanding is critical for complete and sustained healing and growth, and necessary to reveal the untapped resources and potential of your body."	Sense of comprehensibility is developed about the body-mind-spirit continuum to that healthcare providers have a deeper knowledge both of the causes of their moral injury and what they can do to resolve the internal anguish created by the injury.
Summary: Resources are contingent on participation in the program, which may have financial or time-related barriers. The main strategy of the program is to create a sense of comprehensibility for healthcare providers about what it means to heal others beyond just physical healing	

Table 12.13 *Peer and Natural Support Analysis*

Data: Peer and natural support ***Project Team Support*** https://projecttraumasupport.com/	**Analysis**
"By the end of the cohort, I could talk about the deaths and still have joy in my heart. I am no longer in a nightmare. We have all gained knowledge on how to deal with our brains when all the negative tries to come in. To top it off, I have gained nine brothers who I know would be there for me whenever I need them. Nine warriors who shared all their sadness, only to have it all taken away together. By loving each other and helping each other tackle the darkness. It feels so amazing to have the old me back, ready to live, ready to dream, ready for tomorrow."	Resource of supportive individuals and control over negative thoughts/ stressors. A sense of meaningfulness and manageability has been created for the individual.
"I feel like taking care of myself is worth it. I better understand some of the barriers that were built in at a young age that are no longer useful to me."	Manageability and meaningfulness are ascribed to life by the individual. They recognize that some of their resistance resources are no longer useful.
"The groups are a fellowship of members who share their experience, strength, and hope with each other."	Resource: Peers who accept each other. They contribute to a sense of meaningfulness in that new relationships and strengths are created.
Summary: Sharing their knowledge with those at risk of moral injury before injury occurs could give members of the group a sense of meaningfulness out of their experiences. It would also assist in creating resistance resources for others.	

Findings

Using a salutogenic lens, I observe that those with a moral injury have very little sense of coherence. If a professional is going to treat a patient and try to assist them in moving out of crisis, creating program resistance resources (PRR) for each of the three components of sense of coherence would be innovative for this population. Professionals in the treatment and diagnosis system understand that healing is a spiritual endeavour, and that little meaning is attributed by those with moral injury to the harmful event. In the community inclusion system, a sense of comprehensibility is encouraged in program participants, and

this sense of comprehensibility is assumed to heal healthcare providers who came to the program when they felt that the medical system was not allowing them to fulfill their moral obligations as healthcare providers. The peer support system aims to create support resources that enhance an individual's sense of manageability by knowing that there are peers who understand what they are experiencing as a result of moral injury. Because shame is such a big component of having a moral injury, having a place where others will not express disgust or anger over one's actions is a significant resource. This finding in particular inspired the creation of my innovation.

DAY THREE

On our third day, the premises of the theories we used the first two days, systems analysis and salutogenesis, came together in the form of patient standpoint theory. Patient standpoint theory comes from Marxist origins and is intended to emancipate patients and assist them in challenging the traditional passive patient role in healthcare systems (Marlett, 2020). Creating a grid, self regard or dis-ease and ease, influenced by a salutogenic understanding of health, are measured on the horizontal axis, while the vertical axis measures agency, referred to as the locus of control. Using scripts from the three systems—treatment and diagnosis, community inclusion, and peer and natural support—used standpoint theory to understand where on the grid patients are at the onset of their moral injury and where on the grid treatment or programs attempt to guide patients towards.

Because life stories are not static, everyone moves from quadrant to quadrant throughout their lives. Where the quadrants overlap—challenge, defensive, transformation, and contribution—is where transitions occur, when one journeys from one quadrant to another. For example, for someone who has a lack of self regard that is highly internalized (i.e., some in the crisis and change quadrant, giving up control and understanding that they cannot control everything will invoke a highly defensive response, as they transition towards learned helplessness). Standpoint theory is a valuable foundation for my innovation because it shows how individuals currently view themselves and what they experience as self regard and agency change.

Table 12.14 *Treatment and Diagnosis Analysis*

Data: Treatment and diagnosis https://www.naadac.org/assets/2416/cardwell_nuckols_treatingmoral.pdf	**Analysis**
"Another coping strategy involves letting the incident overly redefine one's self-concept and identity."	Crisis: Locus of control is internal while self regard is negative.
"Patients need to understand that concealment is understandable but maladaptive."	Control must be given up to move away from the crisis. The professional encourages the patient to transition to the learned helplessness quadrant.
"Ultimately, the expectation is self-forgiveness and the possibility of living a moral life."	There doesn't seem to be an expectation of moving to competence through contribution, acceptance seems to be the final goal of treatment.
Summary: To heal, giving up control is necessary in this program and requires the patient to develop a sense of positive self-regard, in the face of doing something that they currently see as morally reprehensible. It would have been interesting if the treatment system discussed the power of contribution beyond the fact that amends can be good but within reason. The limit placed on amending acts suggests that the professional remains in control to decide which acts of amendment are too much. The patient therefore can't move from acceptance to competence without the professional willingly giving up control. Program and patient capacity could be increased if the transition of contribution was facilitated or encouraged more.	

Table 12.15 *Community Inclusion Analysis*

Data: Community inclusion ***Whole Health Medicine Institute***: https://courses.wholehealthmedicineinstitute.com/whmi-whole-health-studies-course-202036086740 https://lissarankin.com/doctors-are-suffering-from-moral-injury-whats-the-solution/ (Founder of WHMI)	**Analysis**
"I couldn't tolerate the feeling of failing to give my patients the kind of loving, tender, comprehensive Whole healthcare I knew they deserved, but I had no idea how I would pay the bills if I left, and after spending 12 years training to become a doctor—and feeling spiritually called to do so—I couldn't imagine what else I'd do. Rock and hard place. Despair. Helplessness."	Control of their circumstances is external and the patient shares that their negative self-regard was placing them in the learned helplessness quadrant.
"We support practitioners in building a thriving healing practice as we believe this is necessary to provide the material and organizational resources needed to accelerate the reintegration of psychospiritual work into the healing process and the healthcare industry."	Presumes that having a "thriving healing practice" will increase healthcare provider's self regard, and that by being more effective at their job that they will (re)gain a sense of competency.
Designed to diagnose and treat what the shamans call "soul loss," this program is meant to heal you by helping your soul take over as the guiding force of your life	Brings awareness to patients the importance of spiritual wellbeing (self-regard), meaning that patients are presumed to be in the 'crisis and change' or 'learned helplessness' quadrants
Summary: The Whole Health Medicine Institute's aim is to improve the self-regard of healthcare providers, which it presumes is negative. Giving them the tools to be more effective practitioners, the program assumes that this will move them in the competence quadrant. No resources are specifically mentioned for individuals whose moral injury stems from their own actions; rather, the Institute appears to be catered towards those whose moral injury stems from structural violence – the injury created by social institutions. This leads me to infer that the program may be effective for those in the learned helplessness quadrant, but perhaps not the crisis and change quadrant.	

Table 12.16 *Peer and Natural Support Analysis*

Data: Peer and natural support https://projecttraumasupport.com/	**Analysis**
"Pain is nothing more than a sensation of extreme discomfort, meant to alert you to the need for attention. It is not meant to make you hide or withdraw. Its purpose is to focus your attention."	Crisis is recognized as a temporary position in the plot, leading one to infer that a transition is necessary.
The group provides a forum where openness and honesty are admired and encouraged, under an umbrella of assured confidentiality and anonymity.	Acceptance: The group is the external locus of control that admires the patient for their openness and honesty, encouraging the patient to increase their self-regard
"I feel like taking care of myself is worth it."	Competence: patients sees themselves with positive self-regard and realize that taking care of themselves is an active choice.
"We are in a position to walk in the dark suffering that others are feeling and to bring in the light and love we cannot see for ourselves. We cannot and should not be cutting the cords of the collective just to protect ourselves—we are better than that." https://projecttraumasupport.com/peters-thoughts-on-light-love-pain-and-suffering/	Competence: Contributing to others with a similar journey as a necessity. Locus of control is internal, in that it's an individual decision to contribute to others' well-being.
Summary: Patients come to the group in crisis with low self-regard and an internal locus of control. The group allows them to contribute to the healing of others, therefore lessening their locus of control so that it becomes more neutral and less extreme. Coming to a personal place of acceptance is important to group members, and increased opportunities to contribute to society outside of the group could be innovative for patients and allow them to reach a place of competence. Through growth within, the group patients are able to improve their self-regard and transition from crisis to competence. Some control is given up when they join the group, as they follow the group's rules and experience the group's reactions to their story, showing that acceptance is necessary before competence. Contribution is an important patient role and signals that they are in a position to walk in the dark suffering that others are feeling.	

Findings

Using standpoint theory to understand how patients feel about themselves and the amount of control they perceive to have on their circumstances is useful when creating a social innovation, as it shares what patients need in order to feel good about themselves again. Someone in the competence quadrant is confident and feels in control of their life. Their SoC is strong, thus they are equipped to handle the usual stressors they experience in their everyday life. People with a moral injury may have been in the competence quadrant prior to the morally injurious incident, but the incident proved to be too great a stressor for their GRRs to work effectively. They then rapidly transitioned to the crisis and change quadrant—their self-regard was negative and highly internalized. Within members of the military, who were the focus of my treatment and diagnosis and peer and natural support system examples, individuals seemed to be in the crisis and change quadrant when the intervention was introduced to their lives. However, at the Whole Health Medicine Institute and in my review of the grey literature, healthcare providers seemed to predominantly be in the learned helplessness quadrant, as they had negative self regard of their professional performance but felt that this was out of their control. Control instead lay with the medical system itself. Because moral injury in healthcare providers is only emerging as a field of study, this is significant because it shows that interventions that work for members of the military may not be as effective as for healthcare providers: healthcare providers attribute the cause of their negative self-regard to external forces and, therefore, have different needs to eventually transition back to competency.

CONCEPT PROPOSAL

A finding of my analyses was that people with a moral injury seemed to lack a sense of coherence: there was no meaningfulness, manageability, or comprehensibility attributed to the morally injurious event. Combining this observation with the observation that healthcare providers with a moral injury typically exist in the learned helplessness quadrant points to PRRs needing to be created to meet the needs of healthcare providers with a moral injury to allow them to create a sense of meaningfulness, comprehensibility, and manageability about the stressor that is the moral injury. Specifically, the stressor/cause of moral injury seems to be the individual being unable to overcome the stressor created by the morally injurious event, rather than the event itself. This premise leads to two conclusions: firstly, to prevent moral injury, healthcare providers' generalized resistance resources (GRRs) need to be sufficiently developed to respond to potentially morally injurious events, and secondly, those with moral

injury would benefit from an intervention that specifically develops their sense of coherence so that they can develop their own resistance resources.

Using design thinking, I have shown above the process by which I came to create my innovation for healthcare providers with moral injury. The COVID-19 pandemic has illuminated to many the unique stressors that come with being a healthcare professional. Healthcare professionals face time constraints, long shifts, patient quotas, and pressure to increase billable services, resulting in less time being spent with patients and the knowledge that they are structurally unable to do their job in a manner that they see as morally permissible. Stories shared by physicians include being unable to treat patients without insurance, sending patients into debt because of unnecessary testing, and patients dying because they were unable to find the cause of their illness or treat their injury (Bailey, 2020; Kay, 2018). The intention of the innovation is to strengthen personal agency and improve self-regard of healthcare providers: to assist participants into the competence quadrant. Standpoint theory informs the innovation by using data gained from the above analyses to insert patient voices into the innovation. The accumulated analyses above point to healthcare providers with moral injury predominantly being in the learned helplessness quadrant, as opposed to members of the military who are firmly entrenched in the crisis and change quadrant. Standpoint theory shows us that if we increase healthcare providers' agency prior to their self-regard, they will be pushed into the crisis and change quadrants. This quadrant is characterized by the individual feeling traumatized and guilty; it was where the individual was immediately after the morally injurious event. Instead, healthcare providers' self-regard should be improved first, followed by encouraging a more internal locus of control. From learned helplessness they transition to a place of acceptance prior to using contribution to regain their feeling of competency.

The innovation is a PRR that takes shape in a website where users can anonymously post their stories of moral injury caused while working in the healthcare sector. Stories are not limited to be shared in written essay form—participants will be encouraged to use any medium they find meaningful. Because so many healthcare professionals, notably home care workers, are immigrants, sharing stories in English may not give the participant the ability to express themselves fully. Reddit was considered as a sharing platform, but the ability of users to upvote and downvote stories could open up the potential for shame or comparison to others with more popular stories. For example, a story about passing COVID-19 on to residents in a long-term care home may receive more sympathy from others due to the fact that it was unavoidable and unintentional, than a story about a doctor forgetting surgical sponges in a patient who eventually passes away from sepsis. The idea of the website is not to cure the

patient, but to assist them in beginning their healing journey in a space where they don't have to be afraid of judgment. These are individuals who may genuinely feel that they are not worthy of feeling joy or being treated with kindness or experiencing any kind of recovery. By creating space for participants in my peer support project to share their stories in a way they define as meaningful, participants have agency to share what they determine as important to share, as opposed to within the treatment system where the professional demands that the patient is completely open with the professional. Sharing stories moves the participants away from the crisis quadrant by lessening their internalization of shame over their actions. Opening up to a community can introduce new narratives being shared by others (i.e., for the individual who passes COVID-19 on to a resident at their place of work, repeatedly hearing that they are not morally at fault could combat the self-perception of them being a terrible person). The intention of creating a tangible product is so that participants can see that they have something physical to contribute to others, helping them transition from acceptance of their actions to a sense of competency.

Barriers to participation could be participants believing that they don't deserve to recover from moral injury as a hallmark of injury is a negative self-regard. Having participants at various stages of recovery—acknowledging that recovery is not an end point but a lifelong journey—could encourage those whose moral injury has left them entrenched in the crisis and change quadrants to try something new with the motivation that they could improve the healthcare system for others. This doesn't require them to believe that they are worth helping, and I think this could overcome that particular self-created barrier.

Stakeholders that could be involved in discussing my moral injury website are: healthcare professionals who self-identify as having a moral injury; healthcare administrators; former healthcare professionals; writers, artists, singers, and others who have experience sharing stories in alternative ways to verbally in a conversation; civil servants from the Ministry of Health who both impact and are impacted by the innovation; and members of the military who could share their experiences of regaining their sense of coherence and competency after suffering a moral injury.

McCarron et al. (2020) hypothesize that there are seven motivations for patient engagement in healthcare. The seven motivations are self fulfillment, improving healthcare, compensation, influence, learning new things, perks, and conditional (McCarron et al., 2020). I found it helpful to place these motivations onto the standpoint theory diagram in the way that I understood individuals in the four quadrants to be primarily motivated. For those in the crisis and change quadrant, they are motivated to get out of the crisis; they need emotional compensation and conditionally participate on that basis. Those in

learned helplessness are characterized by their lack of motivation and need to improve their self regard to transform in accepting themselves and their situation, thus they had the least number of motivations out of all the quadrants. I determined that their motivation was conditional on the basis that there was some perceived benefit to the individual as this seemed the strongest motivation in terms of a mental cost-benefit analysis by the individual.

In order to promote this innovation, I would aim to contact the human resource departments of private healthcare companies such as Sienna Senior Living, who managed Altamont Care Community prior to it being taken over by the Ontario government due to mismanagement during the COVID-19 pandemic; hospitals with busy intensive care units and emergency departments; medical associations; and nursing unions to spread word of the website to their employees/ members. This innovation exists within the peer and natural support system, but for it to be effective there needs to be sufficient 'buy-in' for there to be a community.

REFLECTION

I am thankful to have had this course as my last CORE course needed for my BCR, as I think it captures all of the components that make the CRDS program so necessary in a time of radical social change. Faith was placed in us as students to take theory and quickly learn to use insights gained from theory application to create a product that has data to back up its legitimacy as an effective innovation to solve a social problem. Based on conversations and class discussion, it seems that students embraced the opportunity, and the skills learned went beyond those necessary to continue in the field of design thinking and social innovation. Having patients assist in teaching the course was a highlight for me in that the course 'walked the walk' that the CRDS program has been instilling in its students that individuals are experts of their own experiences. To me, it helped confirm the belief that the role of a critical studies academic is to use the institutional power gained by their position to amplify marginalized voices.

As we see, post the Me Too movement and during the current Black Lives Matter protests, information is becoming more open and accessible and allows for the empowerment of groups that feel unheard and unseen. Design thinking capitalizes upon this to allow for users of services to have a voice in the services that they use. When systems are not designed to meet the needs of groups or result in some groups receiving beneficial treatment over others, the system is inherently undemocratic and is not fulfilling its purposes. Design thinking and subsequent social innovations shape systems so that they work for the people rather than shape the people so they can work for the system. This type of knowledge is lacking from traditional university courses, and the exclusion

of applicable knowledge seems to me to further ingrain academia as an ivory tower, with little understanding of the real world. When students graduate with real skills, they are better equipped to succeed in their roles and make lasting change to the systems that they will begin to shape

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Epilogue: What Works and How

I originally set out to write a follow up book to *Grey Matters* (Marlett & Emes, 2010, https://press.ucalgary.ca/books/9781552382516/), about what had been learned about citizen and patient engagement in health research to support a science of engagement (SoE) for health researchers interested in expanding their research options. Along the way I realized that creating the SoE protocol opened the door to new possibilities for health research.

This Is What We Found

- Patient-led research will be an essential component in technology-informed futures where patients will become key stakeholders in co-design, evaluation, and implementation.
- The testing and categorizing of methods as part of SoE led to new theories, created specifically to understand health experience and health systems from patient perspectives.
- New theories created new frameworks for peer research methods that build the capacity of patients to analyze and interpret narrative data from a patient perspective.
- The SoE creates new roles and partnerships in health research where patients become full partners in open innovation and science to democratize science for all.
- In this era when socio-political ideologies of health are being noticed and questioned, emancipatory research that fosters identity empowerment is warranted.

So much is happening, both frightening changes not only for our planet but in democracies that are reversing our time-honoured beliefs in communal values and support. Forces for change are ramping up fast, especially with health technologies that could create reduction in illnesses and extended productive lives where they could enjoy new roles for patients. These changes come with an

urgent need to figure out how to introduce the skills needed to be part of health technology innovation and then technology and data literacy. The need for local research to handle wicked problems provides opportunities for community science and expansion of community-based participatory health research. These issues can be supported by new roles for citizens as peer researchers and educators. There are already examples of these new roles emerging in online chronic care networks and online healthcare options.

A Pragmatic Science Framework for the Science of Engagement

A science of engagement is only effective if there is a concerted effort to recognize the signs of change and research that identifies why the change is happening and what we can do to prepare for it. Action research, as part of PAR, grounded theory, and PaCER/peer research are platforms for research that studies what is happening now to explain how to adapt to change and solutions that will lead to new patient roles as collaborators in change. Only patients can ask the right questions, explore solutions, and ensure that everyone has the ability and resources to take advantage of change.

The following is a definition of pragmatism as a decision tool in SoE methodologies, adapted from the University of Nottingham's Health E-Learning and Media platform (https://www.nottingham.ac.uk/helmopen/rlos/research-evidence-based-practice/designing-research/types-of-study/understanding-pragmatic-research/section03.html):

> *In inductive peer research as part of SoE, pragmatic decisions about recruitment, research methods, analysis, interpretation, and theory incorporate operational decisions based on 'what will work best, and why' in order to find action-based solutions to main concerns of patient populations.*

I am both excited by potential changes in health for everyone involved and the potential for new roles for patients. I am also concerned that we are not ready for challenges ahead for health professionals and researchers.

Because SoE focuses on practical solutions to problems from the perspective of those who will use innovative products and services, it aligns with innovation and market driven research design thinking that bring additional business, engineering, and motivation perspectives. This common practical orientation made the peer research bridge between academic research and innovation possible. A pragmatic peer research is not a threat to medical science but a practical companion that brings focus to everyday concerns related to research topics that lead to promising and innovative results.

JEDI and Pragmatism in the Science of Engagement

OCAP (ownership, control, access, and possession) have taken up the challenges faced by equity-seeking groups to own and use their data for the betterment of their groups. The journey to a science of engagement in health research was informed by those most impacted by systemic discrimination. The early pioneers with disabilities fought to control their lives as citizens with rights to make decisions about their healthcare. Populations who were marginalized because of race, culture, gender, and poverty were next to fight systemic discrimination in healthcare. PaCER continues to learn from equity-seeking groups and has also moved into mainstream hospital, acute, primary, community, and population health when it became apparent that the lessons learned about EDI were emancipatory.

The Bridge Between Academic Research and Innovation Is Built on Pragmatic Principles

The last chapter's peer research bridge between academic research and innovation is symbolic of the challenges of pragmatic clinical trials to identify what works in real life situations from the perspective of patients, care providers and communities. Allemang (2022, https://doi.org/10.1111/hex.13384) explores the need to use the most appropriate research frameworks and methods to solve real-life problems. It is hoped that this science of engagement provides strategies, theory, and methods to justify new directions to embed the practical gaze of patients and communities in academic research.

Finally, being part of peer research is a practical life skill. Those who participate in peer research learn about themselves as observers, decision makers, analyzers, and change agents. They are motivated by being part of a group who want to make a difference. They do this by learning together to understand concerns and to explore ways to address them in ways that help the patient flourish for themselves and others.

Thank you for being part of this journey and good luck discovering new ways to implement a science of engagement in health research and innovation. I look forward to meeting you in manifold groups and hearing about your experiences.

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Marlett, N., & Emes, C. (2010). *Grey matters: A guide to collaborative research with seniors*. University of Calgary Press. https://press.ucalgary.ca/books/9781552382516/

A richly described compilation of accessible resources for those interested in centering 'patient' voices in health research and innovation . . . This book has something for everyone seeking a world in which power and privilege can be more equally shared.

—Bonnie Lashewicz and Meaghan Edwards, University of Calgary

A Science of Engagement in Health Research and Innovation presents a thorough exploration of advances in patient engagement in medical research with a focus on two key questions: Why is research done by patients and communities essential as aging and siloed systems struggle to respond to the growing impact of health-related technologies that will dramatically change our health and health care? How would future relationships, policies and practices be different if patients and community members were trained to conduct pragmatic research as part of health research and innovation teams?

New technologies and health inequities offer new challenges and the potential to democratize health science as our understanding of health care transforms. *A Science of Engagement in Health Research and Innovation* explores foundations of the science, methods and theories of engagement, and possibilities that suggest current best practices. It introduces methods of peer- and citizen-led research that challenge practitioners to build next steps in collaborative health research.

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