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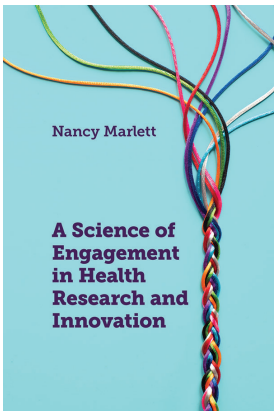

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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ISBN 978-1-77385-733-6

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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