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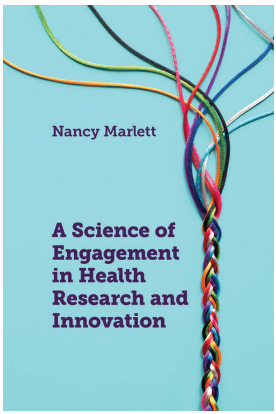

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

Nancy Marlett

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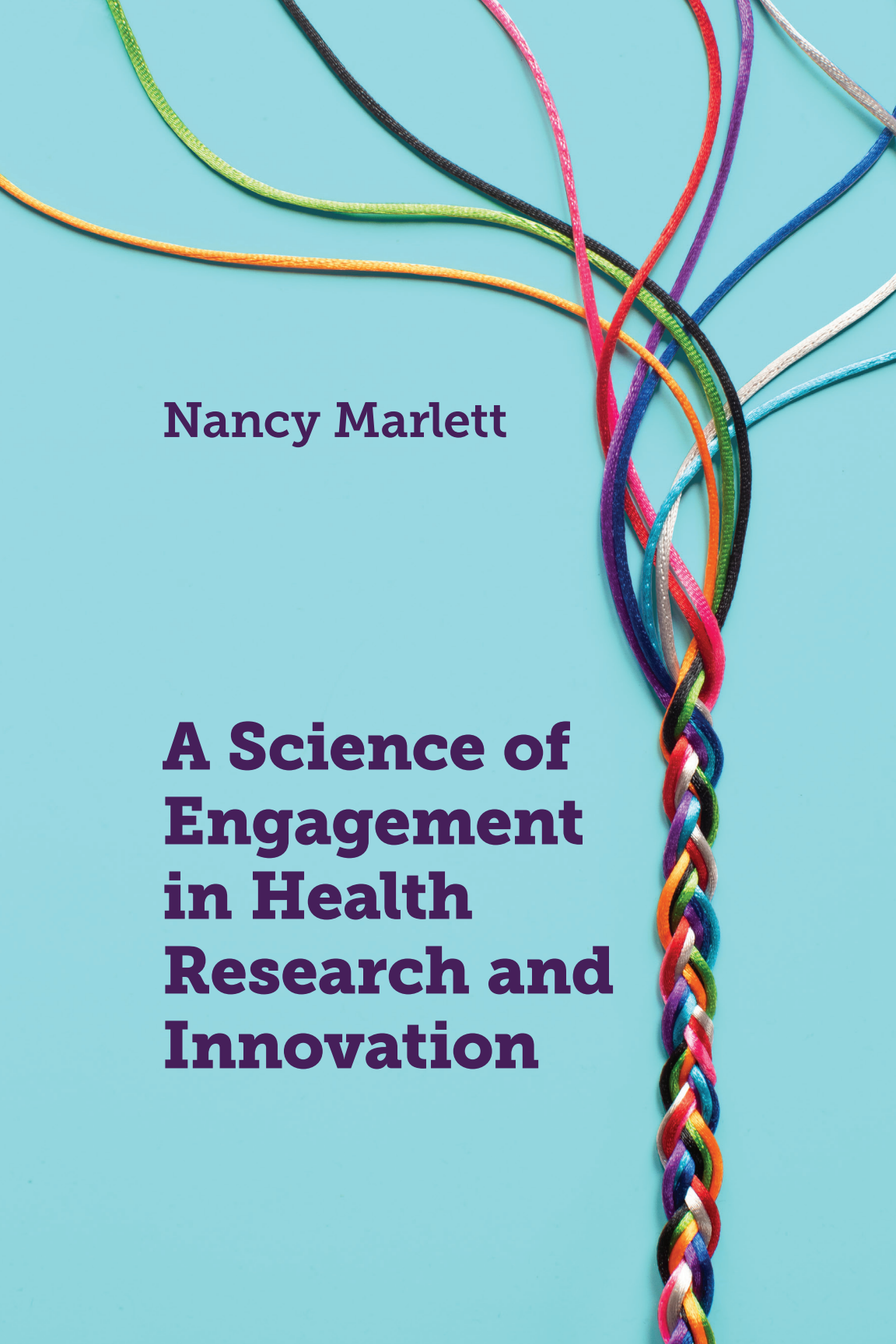

Nancy Marlett

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.