



A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

Nancy Marlett

ISBN 978-1-77385-733-6

THIS BOOK IS AN OPEN ACCESS E-BOOK. It is an electronic version of a book that can be purchased in physical form through any bookseller or on-line retailer, or from our distributors. Please support this open access publication by requesting that your university purchase a print copy of this book, or by purchasing a copy yourself. If you have any questions, please contact us at ucpress@ucalgary.ca

Cover Art: The artwork on the cover of this book is not open access and falls under traditional copyright provisions; it cannot be reproduced in any way without written permission of the artists and their agents. The cover can be displayed as a complete cover image for the purposes of publicizing this work, but the artwork cannot be extracted from the context of the cover of this specific work without breaching the artist's copyright.

COPYRIGHT NOTICE: This open-access work is published under a Creative Commons licence. This means that you are free to copy, distribute, display or perform the work as long as you clearly attribute the work to its authors and publisher, that you do not use this work for any commercial gain in any form, and that you in no way alter, transform, or build on the work outside of its use in normal academic scholarship without our express permission. If you want to reuse or distribute the work, you must inform its new audience of the licence terms of this work. For more information, see details of the Creative Commons licence at: <http://creativecommons.org/licenses/by-nc-nd/4.0/>

UNDER THE CREATIVE COMMONS LICENCE YOU MAY:

- read and store this document free of charge;
- distribute it for personal use free of charge;
- print sections of the work for personal use;
- read or perform parts of the work in a context where no financial transactions take place.

UNDER THE CREATIVE COMMONS LICENCE YOU MAY NOT:

- gain financially from the work in any way;
- sell the work or seek monies in relation to the distribution of the work;
- use the work in any commercial activity of any kind;
- profit a third party indirectly via use or distribution of the work;
- distribute in or through a commercial body (with the exception of academic usage within educational institutions such as schools and universities);
- reproduce, distribute, or store the cover image outside of its function as a cover of this work;
- alter or build on the work outside of normal academic scholarship.



Acknowledgement: We acknowledge the wording around open access used by Australian publisher, **re.press**, and thank them for giving us permission to adapt their wording to our policy <http://www.re-press.org>

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.

REFERENCES

- Allemang, B., Sitter, K., & Dimitropoulos, G. (2021). Pragmatism as a paradigm for patient-oriented research. *Health Expectations*, 25(1), 38–47. <https://doi.org/10.1111/hex.13384>
- Health E-Learning and Media. (n.d.). What is pragmatism? *Understanding Pragmatic Research*. Retrieved June 27, 2024, from <https://www.nottingham.ac.uk/helmopen/rlos/research-evidence-based-practice/designing-research/types-of-study/understanding-pragmatic-research/section03.html>.
- 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.

Nancy Marlett is associate professor emerita at the University of Calgary. She is the author, with Claudia Emes, of *Grey Matters: A Guide to Collaborative Research with Seniors*, which launched the Open Access publishing program at the University of Calgary Press.



UNIVERSITY OF CALGARY
LCR Publishing

press.ucalgary.ca