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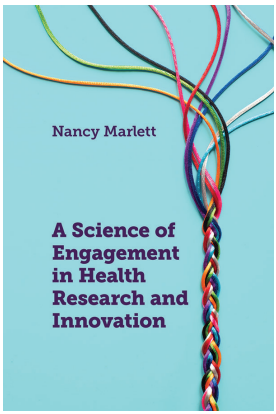

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

Nancy Marlett

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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.

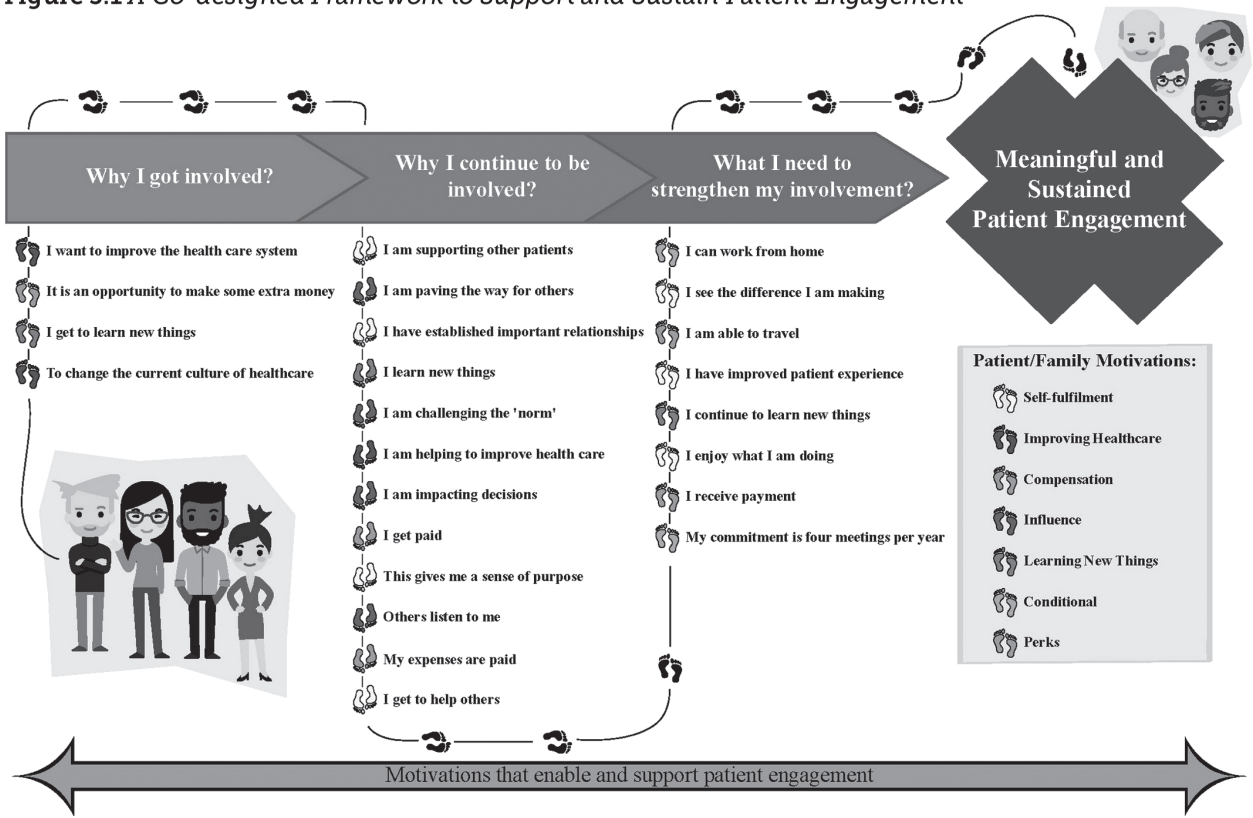
The results of this study, as presented above, mark the first-time that the motivations of patients to become involved in volunteering or becoming peer researchers has been done using established value frameworks from organizational management. The many facets of the study and the large numbers of patients 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.

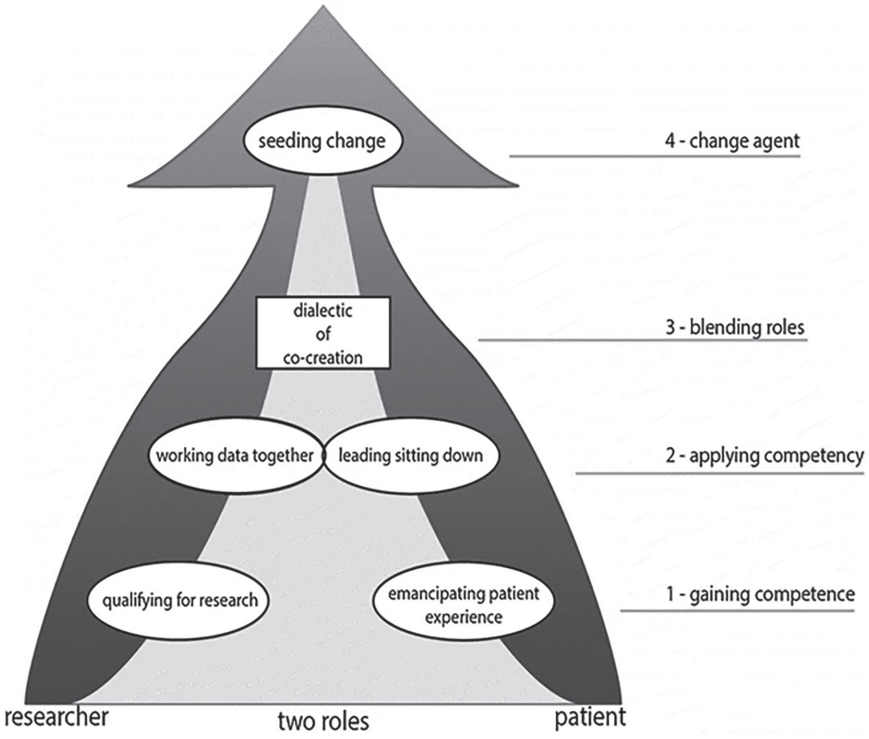
A Dialectic Merging of Patient and Researcher Roles

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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