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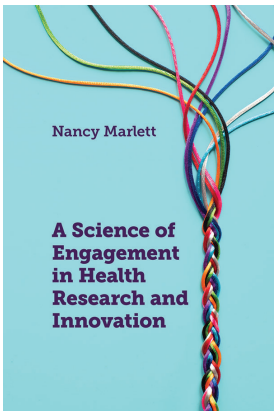

A SCIENCE OF ENGAGEMENT IN HEALTH RESEARCH AND INNOVATION

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

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

Highlights

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

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

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

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

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

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

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

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

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

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

Pillar 1: Biomedical Research

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

Pillar 2: Clinical Research

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

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

Pillar 3: Health Services Research

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

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

Pillar 4: Population Health Research

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

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

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

Health Research Options

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

Quantitative Research

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

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

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

Qualitative Research

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

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

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

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

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

Interpretive Research

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

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

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

Pragmatic Research

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

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

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

Critical Theory

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

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

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

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

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

Levels of Participation as Part of Citizen Science

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

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

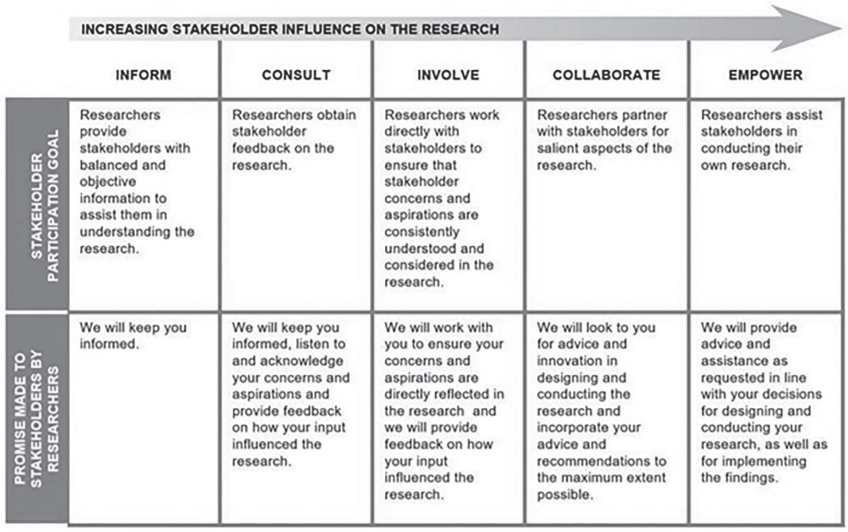
5. **Collegial**: Here the citizen scientist is considered a colleague with the ability to design and conduct their own research with support as needed. They may also create their own products or make policy decisions based on research data. This is the peer research model, where citizen scientists either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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

A Social Contract in Peer Research

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

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

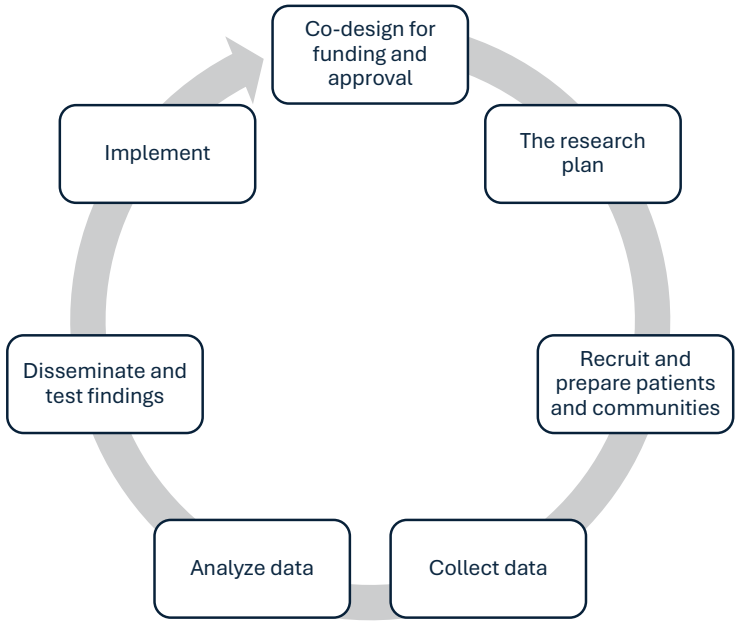
Table 3.2 *A Generic Negotiation Tool for Identifying Roles and Expectations in Research*

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

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

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

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



Co-design for Grant Writing and Approval

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

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

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

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

Summary

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

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

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

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

Questions for Discussion

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

Resources

A Resource Manual for Social Contracting Peer Research with Patients

1. Academic Concerns About Peer Research

Peer Research as Part of Academic and Health Research

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

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

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

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

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

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

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

2. The Players and the Process of Peer Research

Table 3.4 *Patient Roles in Conducting Research*

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

Table 3.4 (*continued*)

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

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

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

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

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

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

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

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

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

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

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

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

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

Grant writing combines distinct steps:

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

Ethics Approval

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Table 3.5 (*continued*)

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

Recruiting and Preparing Patients and Communities for Co-research

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

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

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

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

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

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

Table 3.6 *Planning and Evaluating Engagement in Recruitment*

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

Table 3.6 (*continued*)

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

Conducting Peer Research By, With, and For Patients

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

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

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

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

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

Table 3.8 *Planning and Evaluating Engagement in Conducting Research*

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

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

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

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

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

Disseminate Findings

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Table 3.10 *Partnership in Dissemination*

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

Table 3.10 (*continued*)

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

Implement and Innovate

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

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

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

Table 3.11 *Roles and Expectations in Implementation*

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

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

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

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

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

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

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

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