Online Communities of Cancer Patients and Their Caregivers: Construction and Sharing of Multiple Expertise

Olivier Galibert, Symposium Chair

When it comes to the Internet and health, most research focuses on information seeking. However, patients develop their own expertise on their diseases, treatment, and more. As part of cancer treatment, patients and their relatives receive information from health professionals, and increasingly more from the Internet, where not only knowledge about diseases and therapies is exchanged, but also emotional and social support is given and advice derives from experiences shared. This symposium offers a detailed account of a project that involves multiple research sites allowing a deep understanding of the phenomenon of online communities of patients and caregivers. By focusing on different types of expertise, we shall examine the contributions of patients in three online forums, and how new health knowledge is built and shared. The first paper presents the validation of a controversial “lay expertise” on the use of medical marijuana. The second paper explores the social expertise of using online community for well-being in a large-for-profit forum. The third paper examines the construction and sharing of experiential knowledge, and how this everyday expertise of cancer treatment helps to build a forum with valuable knowledge for its members.

Abstract 1: Controversial Lay Expertise Around Medical Cannabis

Stéphane Djahanchahi, Université de Bourgogne Franche-Comté
Benoit Cordelier, Université du Québec à Montréal

As cannabis is being legalized in several countries for its therapeutic values, the way it can be used as a medicine is discussed by the biomedical system as by connoisseurs who express themselves on online forums. The fact that it is prohibited in France impedes doctors to say positive things about it and thus may influence health behavior as a distrust in authorities grows in many countries. In that situation, the link between scientific expertise and connoisseur expertise is increasingly tenuous. Online resources like testimonies and discussions can influence therapeutic use of cannabis as an alternative or either a complement to the biomedical system. The gathering and ranking of information taking place on specialized forum gives users access to particular knowledges and lead them to a different expertise level. Thereby, forums are a way for researchers to observe careers of users who access expert status, interacting during online discussions, with exchanges of experiences and information. This paper explores Alchimiaweb.com, one of the few French websites about medical marijuana. It provides information about seeds, gardening equipment, cannabis extraction tutorials, and online medical consultations, the process taking place in online forums by lead users of medical use of cannabis. Their expertise starts with growing cannabis, to a form of lay expertise (for instance, the medical properties of cannabis), and sometimes up to a form of medical knowledge that can be recognized outside their community.

Abstract 2: Empowerment of Cancer Patients Through the Development of Social and Emotional Support Expertise

Elodie Crespel, Université de Bourgogne Franche-Comté
Olivier Galibert, Université de Bourgogne Franche-Comté

This paper presents a subtle form of expertise links to empowerment and well-being. The appropriate online support can improve cancer patient health outcomes. Online communities are known to provide added alternative support for patients, but how do the members of those groups know how to help each other? This paper explores emotional and social expertise in
Abstract 3: Building Community via Experiential Knowledge
Aurélie Pourrez, Université de Bourgogne Franche-Comté

Cancer patients and their caregivers have to make appropriate health decisions, but they also need to learn about complementary treatments and other types of knowledge that will allow them to cope with the impact of the disease in all aspects of their lives. Les Impatientes was created by an association for and by women fighting breast cancer. Beyond a popular medical knowledge, which is proposed to facilitate the care path, this website is mostly a virtual place where experts in everyday knowledge exchange. In fact, the forum has over a hundred topics organized by main categories such as first steps with breast cancer, metastases, and recurrences, so on. This regular support can help with many aspects of living with cancer, including care, support for social life and the maintenance of autonomy, administrative procedures, coordination, permanent vigilance, psychological support, communication, domestic activities, so on. Beyond sharing experiences, emotions, and information, there is the question of the place of the patient community in the care path, in holistic care. A qualitative approach allowed us to determine more precisely who are the Impatientes, what factors determine their involvement in the community, and how they transform their experiences into experiential knowledge that will help other members of this community.

Quick Strike: A Mixed-Methods Research Project to Better Understand Children With Complex Health Conditions (CCHCs) and Their Families
Shelley Doucet, Symposium Chair

Advances have been made to improve health care for children with CCHCs; however, little is known about the needs of these children and their families in the Canadian context. In this symposium, we will present our Canadian Institutes of Health Research (CIHR) funded Quick Strike project, which used a mixed-methods research design to explore this population in two Canadian provinces to better understand the needs of CCHC and their families. This included identifying the gaps and barriers to accessing services for this population and applying a computerized algorithm to yield information on CCHC. Our first presentation outlines our research design that incorporated engagement from various stakeholders. The second presentation describes our experiences and learnings when engaging stakeholders in an integrated approach to knowledge translation. Finally, we highlight the development and implementation of NaviCare/SoinsNavi, an integrated service delivery model informed by the Quick Strike findings as well as the involvement of CCHC stakeholders.

Abstract 1: Learning About Children With CCHCs and Their Health-Care Experiences: A Mixed-Methods Study Protocol
Shelley Doucet, University of New Brunswick
Daniel A. Nagel, University of New Brunswick
Pat Charlton, University of Prince Edward Island

Childhood is a time of good health for most children; however, approximately 15–18% of children in North America have a chronic condition that impacts their health and causes limitations in their lives. Little is known about the needs of children with CCHCs and their families when faced with accessing services and navigating the health-care system in Canada. One limitation in research with this population is that experts do not agree on a common definition for CCHC. In this presentation, we outline our Quick Strike project, a mixed-methods and multisite research protocol that consisted of four components: three qualitative and one quantitative. Respectively, these components were (a) developing a concept definition of CCHC, (b) exploring the needs of CCHC and their families, (c) conducting an environmental scan of services for CCHC and their families, and (d) testing a customized algorithm to extract data relevant to CCHC from administrative databases. We describe the methods and procedures for data collection and analysis for each of the components of this project. One of the main sources of data was interviews from 121 stakeholders, which included CCHC and family members, as well as health, social, and education professionals. Our Quick Strike project was designed to engage stakeholders and the public with integrated knowledge translation (iKT) as a core element threaded throughout the research process, with innovative strategies to validate and disseminate findings.

Abstract 2: Lessons Learned Through Creating a Culture of Community Engagement in Our Quick Strike Project
Nicky Hyndman, University of Prince Edward Island
Roger Stoddard, Horizon Health Provincial Advisory
William J. Montelpare, University of Prince Edward Island

Patient-oriented research refers to a continuum of research that engages patients as partners, focuses on patient-identified priorities, and improves patient outcomes. A strategy for patient-oriented research was identified as part of CIHR’s strategic plan and is a framework incorporating (a) collaboration; (b) engagement; (c) innovation and integration; and (d) evidence-based
practice. In this presentation, we describe how we operationalized these principles of patient oriented research in our Quick Strike project. We describe how we worked on building relationships and partnerships in the community with the families of CCHC, professional stakeholders, policy makers, and health researchers to develop and disseminate knowledge from our Quick Strike findings through iKT. A challenge common to most academic research is translating knowledge to a usable form, ideally to improve patients’ health-care experiences, health equity, and health system outcomes. An iKT approach requires collaborative and participatory strategies to be embedded in the research process. In our research project, we identified facilitators to this process but also challenges and barriers. Here we highlight our experiences and lessons learned as we engaged stakeholders in iKT, building on the essential partnerships between researchers, members of the community, government, and clinical environments to support the development of knowledge creation, knowledge translation, and knowledge dissemination. This iKT approach informed the development and implementation of a new service delivery model for CCHC, which is discussed in our third presentation.

**Abstract3: Research Toward an Innovative Model of Service Delivery: Development and Implementation of a Navigation Center for Children With CCHCs**

Shelley Doucet, University of New Brunswick  
Alison Luke, University of New Brunswick  
Rima Azar, Mount Allison University

Our research findings and stakeholder feedback identified a need for integrated service delivery models for children with CCHCs and their families. However, providing comprehensive and integrated services for this population is challenging given the varied needs of CCHC and the absence of exemplar service delivery models for this population. We will describe NaviCare/SoinsNavi, an innovative patient navigation center for CCHC, and how our Quick Strike research project informed the development and implementation of this center. The primary aim of NaviCare/SoinsNavi is to facilitate convenient and integrated care to support the complex needs of children and their families with the guidance of a patient navigator. This navigator, a registered nurse, helps families coordinate access to appropriate services and resources for their children and acts as a resource for the child’s care team. Engagement of a Family Advisory Council, whose members have firsthand experience with CCHC, informs the ongoing implementation and evaluation of the center.

**Abstract1: An Anthropological Perspective on Vaccine Hesitancy**

Eve Dubé, Université Laval

Vaccination is one of the greatest public health achievements in modern history. Prior to the introduction of mass vaccination, diseases such as smallpox, measles, and polio devastated families and communities. Yet, despite the scientific and medical consensus on the benefits of vaccination, a growing proportion of Canadian citizens are skeptical of vaccination. In Canada, less than 5% of parents refuse all vaccines for their children, but up to 35% are hesitant about vaccination. Vaccine-hesitant parents may refuse some vaccines but agree to others; they may delay vaccines or accept them according to the recommended schedule but feel unsure about their decisions. Using findings of qualitative studies that we have conducted among Canadian parents of young children, this paper explores risk perception and its impact on vaccination acceptance, hesitancy, and refusal. I will explore tensions between the public health and the anthropological approaches to citizen resistance to vaccination programs. In contrast to the vision of “rational decision-makers” approach promoted by public health, I will illustrate how citizens assess vaccine risk in different and unique ways that reflect their cultural, emotional, social, and political worlds. In the context of a globalizing mass media, the awareness of certain risks may have changed, but people continue to understand and negotiate risks in localized contexts. This case study will also serve to highlight opportunities and challenges in working as an anthropologist within interdisciplinary team.

**Abstract2: Studying Vaccine Hesitancy With an Online Ethnography: Methodological Issues**

Maryline Vivion, Université Laval

In Quebec, although vaccination is considered to be one of the greatest achievements of public health, studies have shown an
increase in hesitancy toward vaccination. It is often argued that the omnipresence of antivaccination content on the Internet has contributed to the increase of vaccine hesitancy among parents. Some researchers consider that the Internet allows a faster and larger diffusion of rumors, myths, and negative information that could lead to a decrease in vaccine uptake. However, few studies have confirmed this hypothesis. Then the aim of my doctoral project is to explore the role of the Internet on citizens’ and parents’ vaccination attitudes. I carried out an online ethnography in 2015 based on nonparticipant and participant observation on social media groups where discussions on vaccination occurred. The ethnography was conducted with two groups of mothers having the same month of delivery. One group was on Facebook and the other one was on a forum from a parenting website. In order to complete these observations, 19 interviews have been conducted with mothers.

Research on Internet is relatively new and the evolution of technology has forced researchers to adapt their methodological tools rapidly. Some of them seek to develop new methods especially for Internet research, while others claim that we need to adapt existing tools. As all field in anthropology, the researchers need to adapt themselves to each situation. Based on my fieldwork experience, the aim of this presentation is to explore methodological challenges of an online ethnography.

Abstract3: Anthropology and “Social acceptability”: Hospital Professionals’ Opinions Regarding a New Technology

Armelle Lorcy, Université Laval

Applied anthropological studies on social acceptability are becoming more prominent in the public health field. Participants’ interest and involvement in these studies depend on the methodology and objectives of the research. Since May 2015, we have been carrying out a longitudinal study in Quebec hospitals, which focuses on infection prevention and control practices, and the implementation of a new point-of-care diagnostic test. Interviews and observations are conducted in care units and microbiology laboratories with health and laboratory professionals. Participants’ opinions of this new technology are then analyzed. The anthropological approach used in this study acknowledges participants’ points of view and work experiences, which in turn facilitates their involvement in our research. Some participants have criticized hospitals’ “top-down” systems and have expressed their desire to be involved in the collective decision-making process. This study provided participants with an opportunity to voice their opinions on current hospital working conditions, politics, and changes. Although this new technology may contribute to lower hospital cross-infection transmission and better patient care, the anthropological approach has been useful in explaining how it may be perceived as a threat by laboratory personnel and a challenge for nurses.

Engaging Audience Participation in Qualitative Health Research via Embodied Practice

Geoffrey Edwards, Symposium Chair

Embodied practice is used here as a leitmotif to bring together several studies that investigate new possibilities for interactions between researchers and diverse publics in the health arena. This work also draws on methodological frameworks grounded in contemporary philosophies of embodiment, with a particular focus on the writings of Gilles Deleuze, James Gibson, Peter Sloterdijk, and Alfred North Whitehead. Embracing both health research and artistic sensitivities, the research presented seeks to disrupt existing understandings of disability and interaction, and to open the possibility for new spaces of interaction that are both safer and more embodied, both on- and offline.

Abstract1: A Dance-Play Event Highlighting Untapped Physical and Social Interactions Amongst Children With Diverse Abilities

Coralee McLaren, Ryerson University

Geoffrey Edwards, Université Laval

In this paper, we present a current CIHR-funded project that challenges our knowledge of children with diverse movement abilities and their integration at school. Radical embodied cognition and similar theoretical approaches posit an “extended cognitive medium” which parallels modern and recent developments in our understanding of neurological processes. Fluctuating rhythms and the role of synchrony between people challenge traditional mind/body, able/disabled dualisms, and subsequent ideas about how children play and learn together. Building on previous work and a novel Deleuzian-Gibsonian theoretical framework, we describe two phases of a dance-play-event-in-progress that will culminate in a third phase, public showing involving child participants and an audience of interdisciplinary stakeholders. Our interest in dance is to investigate spontaneous rather than scripted choreographies, engendered by the interplay between movement and childhood environments, and to develop artistic–scientific methodologies that disrupt traditional understandings of the body and how it moves. There is a pressing need for this work because publicly funded schools are required to meet the needs of all children; however, the environmental prerequisites for effective social and physical inclusion of disabled children remain unknown. Findings will be used to develop a conceptually derived framework of body-space principles that will guide the design of integrated classrooms. Ultimately, we aim to gain critical insights into relationships between movement and cognitive processes that have implications for the physical, psychological, and social health and development of children with diverse abilities.
Abstract2: Lithospheres: Integrating Body Practices Within On- and Offline Social Networks
Jocelyne Kiss, Université Laval
Geoffrey Edwards, Université Laval

Although modern online social networks have revolutionized parts of our public engagement, they also pose significant challenges to personal safety as well as healthy social practices. Drawing on the Bubbles-Globes-Foam concepts of contemporary philosopher Peter Sloterdijk, combined with his ideas about developing coimmunity, we are seeking to integrate body practices within both online and off-line social networking activities. By focusing on the concept of coimmunity or shared immunity, we hope to restore some level of safety to the sharing of personal information within a collaborative problem-solving framework. We encourage people by giving them feedback when their participation is in concordance with the collaboration. Furthermore, we are seeking to ensure the new environment is inclusive for people with a broad range of disabilities.

We are using focus groups as well as codesign methodology to develop our framework. The framework is based on making available visualizations of breathing and posture in tandem with other embodied aspects of shared experience, combined with engagement in body practices such as martial arts, dance, or yoga. Breathing and posture can be powerful indicators that lead to greater levels of trust in group settings. We use Shin-taido, a Japanese body practice that combines movement and voice, as our initial focus. We are hence rethinking how social interactions take place as well as developing embodied interfaces for enabling these renewed interactions.

Abstract3: Pinnacle: An Interactive Opera Dealing With Acceptance of Differences
Geoffrey Edwards, Université Laval
Jocelyne Kiss, Université Laval
Ernesto Morales, Université Laval

We present a 15-min interactive opera based on a science-fiction scenario concerning people with radical differences and the struggle to find acceptance in the midst of intolerance. The opera consists of a combination of prerecorded virtual elements combined with live vocal production and offers the audience the means to participate with their own voices in the denouement of the opera—the final scene plays out differently depending on the quality of the audience’s participation. It is still a work in progress. The opera’s libretto was constructed with a focus on difference, resonating with themes such as transgender acceptance, disability, and mental illness. The presentation of this short opera allows us to engage with audiences in interesting ways to address issues of embodiment, health, and difference. We will supplement the opera presentation with discussion of some of the methods and theoretical choices that went into the opera production, which gives shape to ongoing preoccupations with health-related issues and how these are brought into the public arena.

Listening: Illuminating Liminal and Uncertain Spaces in Narrative Research
Laurene Shields, Symposium Chair

Death, dying, and the uncertainty of living are realities of life for people and their families living with chronic fatal conditions. In this symposium, we will focus on the methodological design of a longitudinal narrative project with 84 participants, exploring how people with end-stage kidney disease, heart failure, chronic obstructive lung disease, and advanced cancer, and their families, navigate the uncertainties of living and dying. We will share/discuss our approaches to listening for and navigating the uncertain terrain within (1) narrative interviewing, (2) dyadic engagement, and (3) photo elicitation. In addition, we will share knowledge translation approaches aimed toward public involvement. Arts-based knowledge translation is one approach to increasing engagement of patients, their families, care providers, and the public in the research process. Exemplars of arts-based findings will be used throughout this symposium to further illuminate how understanding liminal spaces of living and dying may improve care for people living with serious illnesses.
silences and strong emotion as they surfaced. While participants sometimes shared being grateful for the opportunity to discuss these relatively unspoken experiences, they also reinforced that within society and health care, silence often prevails about impending death. We offer our experiences as a way to contribute to opening spaces from which people can be heard and supported when sharing (or choosing not to share) their uncertainties of living with a life-threatening illness.

Abstract2: Dyadic Approach to Weaving Cross-Threads of Patient and Family Narratives
Marcy Antonio, University of Victoria
Laurenec Shields, University of Victoria
Kara Schick-Makaroff, University of Alberta

Life-threatening disease affects not only the lives of those suffering from illness but also family members who care for them. Few studies explore the experiences of both the person with illness and their family member(s) living with changing trajectories of fatal chronic conditions. In this study, attention is given to both the patients’ and caregivers’ narratives, recognizing that experiences they have shared together living within and through serious illness may (and often do) vary. This study was designed to explore such contrasting stories by conducting separate interviews with patient participants and family members on three occasions. We will present on our dyadic narrative methodology and the unique considerations in relation to ethical practices, recruitment, and interviewing. This will include some of our unanticipated challenges, for example, while our intention was to interview participants separately, it did not always unfold this way. We will share lessons learned in navigating these issues as well as the richness and depth in analyzing patient and family member narratives, voices, and photo images both separately and together. Examples will be provided to demonstrate the range of dyadic pairings (spouse, child, sibling, and friend). M´etissage will be used as an arts-based approach, to illustrate how we are exploring convergent and divergent narratives of patients and family members, and their distinct “third space” constructed in between.

Abstract3: Expanding Analytical Approaches Using Photo Elicitation With Performative Listening
Lacie White, University of Ottawa & University of Victoria
Anne Bruce, University of Victoria

How might we understand the unformed, uncertain, and perhaps unsayable aspects of living with fatal chronic illness? How might people convey the uncertainties of dying or caring for a family member with a fatal chronic condition? Participants in this study were invited to take pictures and speak about how their photos conveyed experiences of uncertainty and illness. The images, audio recordings, and transcripts of these interviews were reviewed within the research team. The process of eliciting and analyzing participant photos and their storied responses will be presented. Riessman’s (2008) narrative visual analysis and McCrae’s (2015) “performative” listening were used to describe our processes for listening with our eyes, ears, and bodies. Narrative visual analysis included the three methods of (1) looking at the production of an image, including participants’ social identities; (2) focusing on the image itself; and (3) looking at how an image is read by diverse researchers, and the stories they bring to the image. Performative listening was used to engage with participants’ narratives about their photos, and as an approach to analysis of the audio recordings and transcripts. Listening is an interiorizing experience; it draws us into the ineffable, gathers together thoughts, feelings, and a felt sense [that] can offer-unique interpretations. We will describe listening-centered strategies of listening for, listening with, and listening into stories shared visually and aurally of living with serious illnesses. Lastly, we will share preliminary findings from the visual analysis and performative listening about living with the uncertainties of fatal chronic conditions.

Patient-Produced Knowledge: Evolution of Participatory Grounded Theory in Patient Engagement Research
Nancy Marlett, Symposium Chair

For the last 4 years, Patient and Community Engagement Research (PaCER), a program within the O’Brien Institute for Public Health, University of Calgary, has been adapting qualitative methods to engage trained patients in collaborative health research. The basic components of this innovative approach to peer-to-peer research had emerged before the initiation of PaCER, rooted in conducting research with and by seniors. In PaCER, the methodology was tested and refined through multiple patient-led studies on a variety of patient experiences from critical care to mental illness. This symposium demonstrates an evolution of the method from experimenting with various analytical strategies and engagement techniques such as focus groups, interviewing, and field observation, to the emergence of a specifically designed engagement framework within the classical grounded theory tradition. We present three PaCER studies to demonstrate methods, procedures, and results illustrative of generating patient-produced knowledge through participatory grounded theory research.

Abstract1: A Case Study of Engagement and Participation: Lessons Learned Doing Grounded Theory in Peer-to-Peer Research
Nancy Marlett, University of Calgary
Svetlana Shklarov, University of Calgary
Susanna Koczkur, University of Calgary

Building new health research on principles of engagement and partnership requires an exploration of specifically designed
methodological tools. Classical grounded theory is open to new relationships in research because of its iterative nature, relevance, and openness to participation. The internship of the PaCER Program has been an incubator of engagement research while training patients in qualitative methods. As part of their yearlong training, five consecutive cohorts (2012–2017) conducted 16 research projects, advancing and testing the methods each successive year.

This case study highlights the lessons learned through merging engagement strategies and classical grounded theory, analyzing research processes through the five cohorts of patient interns. We track the movement to a systematic participatory grounded theory method based on iterative data collection and analysis, adapting the method to meet both engagement expectations and classical grounded theory standards. Some adapted data collection strategies included narrative interviewing, artistic expression, culturally sensitive family interviewing, and large community forums. Adaptations of analytical techniques responded to the need for group analysis across diverse sets of data and utilized a novel way of identifying “units of analysis” that enabled constant comparison in collaboration. This discussion outlines challenges and methodological discoveries made through the evolution of our approaches over time: the challenges of trustworthiness and credibility, negotiating engagement relationships and dual roles, the evolution of codesign and codiscovering theory with peers, some ethical considerations of peer-to-peer research, and the emergence of a working engagement research frame.

**Abstract2: Creating Self-Worth Together: A Participatory Grounded Theory of Wellspring**

Nancy Marlett, University of Calgary  
Svetlana Shklarov, University of Calgary  
Pattie Ghent, University of Calgary  
Colleen Morrison, University of Calgary  
Susan Nguyen, University of Calgary  
Nathan Owen, University of Calgary

This peer-led study explored the processes that enable people with cancer find healing in a new social organization community cancer wellness center. Social wellness in oncology conventionally relies on psychoeducation and support programs conducted by health professionals, with most models focused on traditional provider—patient relationship. In these models, health professionals provide the information, guide, and motivate patients, and provide feedback about success, leaving the patient in a passive role. New support organizations such as the national Wellspring program challenge this pattern by heavily relying on self-help and peer relationships. We chose to study cancer supports at Wellspring Calgary that offers a wide range of natural, peer-to-peer holistic programs. We specifically set out to explore their community programs and resources to identify what works and how.

This grounded theory study was conducted by patient researchers in training, who used their experiences of being both insiders (members of Wellspring) and outsiders. Data sources included modified participant observation, document analysis, and a sequence of focus groups specifically designed to engage participants as coresearchers in all iterative cycles of data collection and analysis. We identified two central categories: a place to go (resources to resist stresses inherent in cancer) and give it a go (building internal resources). The core concept of creating self-worth together emerged from discovering an emergent fit with the sensitizing theoretical concept of salutogenesis. The theory explains how a peer-run program works beyond traditional professional–patient relationships. We include a discussion of research processes involved in a participatory grounded theory.

**Abstract3: “A Feeling of Dread So Deep I Didn’t Feel Anybody Would Understand”: The Experiences of Younger Women Patients with Cardiac Symptoms**

Romita Choudhury, University of Calgary  
Sandra Robertshaw, University of Calgary  
Laura Wheeler, University of Calgary  
Winnie Pearson, University of Calgary

Younger patients, especially women, commonly experience coronary heart disease without typical cardiac chest pain. The risk of serious consequences that these women could face is reasonably well-documented. Patients’ level of health literacy in the risks of developing coronary heart disease, gender definitions of “at risk” candidates of heart disease, and the paucity of heart-health messages directed at women have all been identified as reasons for the invisibility of women’s experiences from the discourse about heart disease.

This qualitative study was conducted as part of an internship in the Patient and Community Engagement Research Program, the University of Calgary. The researchers came from diverse backgrounds, connected by their personal experience of complex chronic illness. Using a blended methodology of participatory grounded theory and narrative analysis, this research was able to capture a polyphonic story of young women’s journey through the diagnosis or absence thereof of heart disease.

Our research goal of better understanding how younger women patients make sense of their heart-related symptoms—with or without pain—further highlighted this gap in communication and intelligibility between such patients and health-care professionals. However, more importantly, our research revealed deeper gaps in women’s autonomy and self-representation within the dominant discourse of heart health. What emerged as key factors in women’s ability to exercise agency through comprehension and self-management are the struggles to articulate the specific nature of their illness, to be credible witnesses of their own fear and suffering, and to find support within their traditional communities for hope and strength.
Patient Engagement in Qualitative Health Research: Challenging the Status Quo

Virginia Vandall-Walker, Symposium Chair

The practice of engaging with patients beyond the role of participants to encompass, as well, idea generation, design, planning, conduct, analysis, and translation of health research, has grown substantially in developed countries over the last 15 years. Through their lived experiences with illnesses or situations, patients (inclusive of family, caregivers, and friends) are able to provide a unique perspective to research, helping to ensure that research outcomes are more applicable to patients.

A number of patient-engagement-in-health-research studies are showcased in this symposium: from priority setting in depression and mapping the arrhythmia patient’s journey, to engaging patients and family members in critical care research and in deliberative fora about medical aid in dying. These diverse examples are presented to challenge the status quo in qualitative health research, to demonstrate the possibilities, and to highlight what can result from engaging patients across the breadth of the research process.

Abstract 1: The Research Interests of Those With Lived Experience of Depression

Ping Mason-Lai, Athabasca University
Lorin Vandall-Walker (person with lived experience)

The Alberta Depression Research Priority Setting Project involved engaging patients/persons, carers, and clinicians/researchers, all with lived experience of depression, as partners on a Steering Committee to create a Top-10 list of depression research questions most relevant and important to those dealing with depression. Meaningful engagement and partnership were critical to the project: The Steering Committee designed and implemented a survey to solicit questions that Albertans thought needed to be focused on by mental health researchers. All survey response questions were sorted and themed. A literature review was conducted to highlight underresearched questions that warranted further investigation. These questions went through a two-step prioritization process modeled after the James Lind Alliance methodology.

Over 900 questions were submitted by Albertans. The majority were well conceived, thoughtful, and intentional. Some themes that emerged were treatment (methods, options, access), biology/physiology (heritability, recovery), and age-specific topics (child/youth behavior, education). Questions were reduced through several prioritization stages until final reduction by the Steering Committee to a Top-25 list. Additional stakeholder perspectives were solicited in an all-day workshop to reach a Top-10 prioritization of depression research questions. The Top-10 priorities are being shared with several organizations: Addictions and Mental Health Strategic Clinical Network, Alberta Health Services, and the Canadian Depression Research Intervention Network.

Patients/persons with lived experience bring thoughtful and important insights to research idea generation. This project provided evidence that engaging patients/persons with lived experience as collaborators and partners in priority setting is an effective method of patient engagement and beneficial for patient-oriented research.

Abstract 2: Cartography and Cardiology: Mapping the Arrhythmia Patient’s Journey

Mary Runte, Patient Lead
Caroline Wong, Cardiac Arrhythmia Network of Canada (CANet)
Sylvain Bédard, University of Montreal

How does a patient make sense of the experience of “being a patient”? How do patients maneuver their way, not just through the medical system, but through the complex social context in which they are situated? A better understanding of the social context of the patient experience can enable partners in health to create efficiencies and to co-design innovations that can fundamentally “humanize” the medical system.

For patients suffering from arrhythmia-related problems, even defining when one “becomes” a patient can be challenging. Is it when the first symptoms occur? When one is first hospitalized? Or only with a medical expert’s official diagnosis? Nor does patient arrhythmia care affect only the patient. How family members and patient caregivers experience and perceive these same events may be very different from the patients themselves. Journey mapping has the potential to reduce disruptions to both the individual and their social networks (i.e., missed days of work, stress leave, missed family responsibilities).

This project is patient-led, recognizing that patient expertise is fundamental to an understanding of the patient experience. We partnered patients with researchers and policy actors, to capture the patient journey “beyond” the traditional system and without the usual medical-centric biases. A qualitative sensemaking method was used to describe the lived experience of patients and caregivers in terms of how they “make sense” of the process that they have experienced and included a post hoc reevaluation of how they got to who they are today, and how these past experiences influence future decisions.

Abstract 3: Engaging Patients and Family Members in Critical Care Research

Peter Oxland, Alberta Health Services Critical Care Strategic Clinical Network
Tom Stelfox, University of Calgary

Alberta Health Services’ Critical Care Strategic Clinical Network (CCSCN) is a community of stakeholders (patients, family members, providers, and decision-makers) from a range of Alberta Critical Care units (19 adult, cardiovascular, and pediatric intensive care units [ICUs] totaling 274 beds) who work together to develop and implement evidence-informed, team delivered, health improvement strategies. Findings from a recent study have helped extend the understanding of patient and family member experiences with critical care including the benefits to be gained from engaging with patients and family members in health research.
The CCSCN’s Scientific Research Team used a novel patient and community engagement qualitative research approach (PaCER) to better understand Alberta patient and family experiences with critical care. The University of Calgary PaCER approach includes the analysis of qualitative data collected through semistructured focus groups and interviews with patients and family members. Findings were combined with survey results from over 1,100 Alberta ICU providers to identify important areas needing improvement. A list of prioritized improvement opportunities to inform the “world of ICU” was generated.

The process of engaging former ICU patients and family members in the research project—from helping with grant submission, leading the qualitative study, acting as project participants (focus groups, interviews), helping with presentations and manuscript writing, and advocating for the results—is helping to inform how to leverage the expertise of former ICU patients and family members and engage them in new critical care research initiatives.

**Abstract #4: What Do We Need to Know About Medical Aid in Dying? Patient Engagement and Deliberative Fora in Quebec**

Francois-Pierre Gauvin, McMaster Health Forum
Antoine Boivin, University of Montreal
André Néron, Patient Team Member

In 2014, Quebec adopted Bill 52 addressing medical aid in dying. In the spring of 2016, two deliberative fora were held, involving the public (including patients and caregivers) and health-care professionals, to explore their information needs on this issue. Additionally, a patient partner engaged as a critical member of the research team, involved in project development, public member recruitment, analysis, and report writing.

Purposive sampling ensured diversity of age, gender, socioeconomic status, expertise, and perceptions about medical aid in dying. Forty-three participants engaged in the 1-day face-to-face forum and 42 in the 3-week online forum (60% being members of the public).

Thematic analysis revealed patterns in the data. All agreed that information initiatives about medical aid in dying were limited and fragmented, resulting in asymmetry of information between and among the public and professionals. Nonetheless, 21 information needs were identified (e.g., interpreting eligibility criteria; supporting patients, caregivers, and professionals throughout the process; the potential risks; maintaining privacy of requests; humanizing the process). Participants identified key information needs at specific stages of medical aid in dying (from formulating a request to documenting and evaluating practices).

The fora provided key insights about the need for a common information base to strengthen the capacity of the public and professionals to engage in relevant conversations about medical aid in dying to support meaningful partnerships at the end of life. With the inclusion of the patient partner on the research team, this project also provided evidence of meaningful patient engagement in health research.