


# The Role of Patient Advisory Councils in Health Research: Lessons From Two Provincial Councils in Canada

Journal of Patient Experience  
2020, Vol. 7(6) 898-905  
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DOI: 10.1177/2374373520909598  
journals.sagepub.com/home/jpx  


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## Abstract

This article describes two patient advisory councils (PACs) in Canada in order to contribute to the limited evidence base on how they might facilitate patient engagement in health research. Specifically, members of PACs from Newfoundland and Labrador and Alberta describe their councils' governance structure, primary functions, creation and composition, and recount specific research-related activities with which they have been involved. Key challenges of these councils and facilitators of their use are also presented. Finally, members from both councils recount lessons learned and offer suggestions for others interested in advisory councils as a mechanism for patient engagement in any health research project. Members believe patient engagement can result in better quality research and encourage decision makers and researchers to utilize patients' valuable input to inform health system changes and drive priorities at a policy level.

## Keywords

patient advisory councils, patient engagement, patient perspectives/narratives, quality improvement

## Introduction

The value of engaging with patients to improve health-care design and delivery is well-documented (1–3). Indeed, health-care organizations regularly consult with patient and family advisory councils (PFACs) about a variety of quality improvement and patient-centered care efforts (1,3). Reports suggest 38% to 55% of acute care hospitals in the United States have PFACs (4,5). In Canada, PFACs are convened at the family practice level (6) and at the regional and provincial health authority levels (3,7). Councils can be *general*, focused on organizational issues and drawing members from across the institution, or *population-specific*, focused on particular communities such as children and youth; still others are *condition-specific* (eg, focused on cancer or diabetes) (3).

Within health-care settings, PFACs advise on patient-centered care practices and contribute to quality improvement initiatives such as signage redesign in hospitals (1,3). Other role of PFACs is to facilitate patient engagement in health *research*, but little is known about whether or how this

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occurs (1), despite its endorsement by leading journals and funders (8,9). Patient engagement exists along a continuum from lower levels of ability to influence research decisions to higher levels that include decision-making authority (10,11). The International Association for Public Participation (IAP2) identifies 5 levels of engagement ranging from lesser to greater levels of engagement: inform, consult, involve, collaborate, and empower (10).

Engagement can impact all stages of the research process and help to identify measures and outcomes that matter to patients, increase study recruitment rates, facilitate patient and physician co-learning about health research, and increase the uptake of study results (11–13). In short, patient engagement can result in better quality research (1). In this paper, we focus on the use of patient advisory councils (PACs) as a mechanism for patient engagement in research. While these councils have long been established in health-care settings, their use in health research is less well described.

## Setting the Stage for Our PACs in Health Research

Following international initiatives (8,14), the Canadian Institutes of Health Research (CIHR) announced Canada's Strategy for Patient-Oriented Research (SPOR) in 2011. Its vision is that "patients are active partners in health research that will lead to improved health outcomes and an enhanced health care system (CIHR 2014) (15)." Strategy for Patient-Oriented Research included the creation of Support for People and Patient-Oriented Research and Trials (SUPPORT) Units across the country whose mandate is to facilitate patient-engaged research on local priorities. Most of these SUPPORT Units have created PACs.

A growing body of literature describes frameworks of patient engagement (16–18), key attributes, best practices, and guiding principles (15,19,20). However, there is virtually no literature describing what PAC members actually do, nor on how PACs are used to further patient engagement in health research.

In this paper, we describe 2 PACs from Western and Eastern Canada, explaining their governance structure, primary functions, creation and composition, and specific activities undertaken by members (eg, review research funding applications and serve as project co-investigators).

It is important to highlight that PAC members from each provincial SUPPORT Unit are authors of this paper and provided their perspectives in tabular format. In the tables, members describe the activities with which they have been involved and report key challenges, facilitators, and lessons learned. All council members from both Units contributed to the lead patient authors' drafts and gave final approval for the article. Additionally, Alberta used data from the annual PAC evaluation conducted in March 2019 to supplement the perspectives in Tables 1 and 2 with consensus from all members. The tables in this paper represent a truly collaborative

effort of over 40 advisory council members from 2 provinces in Canada.

## Description of Provincial Councils

### *Patient Advisory Council, Newfoundland and Labrador SPOR Support Unit (NL SUPPORT)*

The PAC was established in 2015, comprised of 13 members from across NL. The original call for members was placed in regional community newspapers, allowing reach in remote communities. This is particularly important in NL, where over 40% of the population lives in rural settings outside the capital city of St. John's.

Council members provide a broad patient perspective that informs the priorities and strategic direction of the Unit. In NL, the PAC is situated within a governance structure that includes several large programs of health research. Thus, council members not only are active members of NL SUPPORT but also sit on Steering Committees and Scientific Advisory Committees of the larger research programs. They suggest agenda items, lead discussion on these items, and vote on key decisions; as such, they participate fully in committee meetings. Members are also coinvestigators on research projects. The range of activities undertaken by the PAC as a whole and by individual members is presented in Table 1.

Due to increasing demands on the PAC, a second advert was run in February 2016. While membership increased, it remained largely retired and well educated. Patient advisory council members suggested that the Unit undertake a targeted recruitment campaign utilizing social media in 2017 for younger representatives. This led to a more representative advisory council of 21 members including individuals from minority groups (e.g., disabled individuals). For members of the public who are unable to commit to the workload of council members, the Unit maintains a wider advisory "Friends Pool" with whom correspondence is over e-mail. This group is comprised of 15 individuals currently, and they are consulted about specific tasks as needed (eg, to review study instruments).

Members who attend PAC meetings and/or contribute to other Unit-related activities such as committees and working groups are offered an honorarium each year. NL SUPPORT was the first SUPPORT unit across Canada to implement patient appreciation guidelines, developed fully in collaboration with PAC members in order to demonstrate the value of their contributions.

The current council meets twice a year in the capital city of St. John's, supplemented with teleconferences and e-mail correspondence. Terms of reference were developed with the original council in 2015 and these are reviewed annually. There has been a low level of turnover in PAC members. A wide range of perspectives is self-identified on the current PAC including lived or caregiver experience with disorders

**Table I.** Council Member Perspectives on the NL Support Unit PACs' Role, Member Activities, Challenges, and Facilitators.

From a Patient Perspective, What Is the Role of the PAC?	With What Specific Activities Have Members of the PAC Been Involved?	What Are the Challenges Faced by the PAC?	What Works Well Within the NL Support PAC?
Offer advice on the priorities for health and medical research in the province, including different perspectives based on factors such as geographical location, gender, sexual orientation, age, culture, ethnicity, and lived experience	Conduct health research as coinvestigators on local, regional, and national projects. This includes coauthoring research study manuscripts	The lack of long-term funding creates uncertainty about sustainability, which negatively impacts the work and continuity of patient engagement activities	Always being mindful of the need to adequately represent the diversity of patient voices in the province and targeting recruitment of new PAC members to include the differing demographics of patients (eg, targeted recruiting for youth)
Ensure that the opinions and perspectives of as many patients as possible are represented and provided as needed	Provide feedback on promotional materials for Support unit activities, local research programs, and individual projects as the need arises in a timely manner	The difficulty of ensuring high attendance at all meetings (especially face-to-face meetings). This is related to the challenge of ensuring a constant presence of patient engagement at the provincial, regional, and national level	Communication between the PAC and NL Support unit, including printed material, verbal, and electronic forms of communication. This also includes co-constructing a clear terms of reference, updated annually
Act as a sounding board for individual researchers/teams, helping them identify research priorities from a patient perspective, offer suggestions on patient recruitment, formulating of research questions, choice of study design, and dissemination strategies	Act as a reviewer for patient-oriented grants and student fellowship proposals	The establishment of a transparent process for how ethical issues that might arise between researchers and patient partners will be addressed and managed. This is made all the more challenging given health research ethics boards are also challenged by how to review patient partnerships in health research	Support for competency and capacity building. Patient partners are offered numerous opportunities for training through multiple methods (eg, monthly webinar series, attendance at local and national conferences, in site tours of research facilities, and attendance at local public engagement events, such as an annual science day/health fairs)
Members of the PAC sit on the Steering Committee, the body that ultimately approves recommendations for POR grants. PAC members have an equal vote at this table	Co-deliver provincial and national presentations regarding patient engagement in health research, including such topics as ethical issues in patient engagement, how to build effective researcher–patient partnerships, and the role of patients in the design of health research	Recruiting for, establishing, and maintaining a council that represents the varying demographics and cultural diversity of the province, particularly Labrador. This also includes the challenge of seeking out and retaining patient partners with a variety of skill sets, including, but not limited to, those relevant to the conduct of health research	Mutual support, encouragement, and respect between PAC members (safe space)
Offer advice and assist with implementation of capacity building for partners in health-care research. Partners include provincial health authorities, the provincial Department of Health, and data custodian bodies, including the provincial Health Research Ethics Authority	Offer PAC members the opportunity to take part in a variety of health-care research projects and related activities, such as an annual Science Day/Health Fair for the general public, panels at local conferences or webinars. Members can choose in which or in how many of these events they are interested	Providing fair, accurate, and accepted terms regarding appreciation for PAC members/volunteers and ensuring all members' wishes regarding appreciation are respected	Timely response from the local Support Unit when advice or guidance is needed and/or requested

(continued)

**Table 1.** (continued)

From a Patient Perspective, What Is the Role of the PAC?	With What Specific Activities Have Members of the PAC Been Involved?	What Are the Challenges Faced by the PAC?	What Works Well Within the NL Support PAC?
Offer advice on a broad range of health-care initiatives that originate in research projects but ultimately end in public and health-care professional awareness campaigns (eg, promotion of a healthy lifestyle and best medical care practices such as reducing the use of antibiotics or improving health-care for seniors)	Build capacity within the PAC, through participation in networking events, summits, guest presentations, etc	Gaining the support and acceptance of the public, health researchers, health policy makers, and health-care professionals regarding the value and importance of PACs, patient-oriented research, and patient engagement. Patient engagement is a culture change that takes time and this can be disheartening to all	NL Support staff providing effective and efficient administrative support. This includes well organized and productive PAC meetings. With the administrative support of the Unit, members of the PAC lead meetings and help set the agenda, meeting summary, and action plans

Abbreviations: PAC, patient advisory council; POR, patient-oriented research.

**Table 2.** Alberta Support Unit Council Member Perspectives on the PAC’s Role, Member Activities, Challenges, and Facilitators.

From a Patient Perspective, What Is the Role of the PAC?	With What Specific Activities Has the PAC Been Involved?	What Are the Challenges Faced in Being Part of the PAC?	What Works Well Within the AB Support PAC?
To bring together a diverse group of patients/family members who bring lived experience (perspective), passion and a willingness to contribute to the wellbeing of others	<p>Give the opportunity to develop patient voice (confidence) through a variety of regular meetings.</p> <p>Develop competencies for members involved in committee work.</p> <p>Report back to PAC on related respective community activities (e.g., research projects; information from patient organizations). This helps with cohesiveness and connectedness for the PAC.</p> <p>Develop the Patient Registry where both patients and researchers can connect and potentially collaborate on future research projects</p>	<p>The deterioration of health conditions can mean a lack of consistency of meeting attendance.</p> <p>The distance to travel to attend meetings face to face (which are always preferred by patients).</p> <p>PACs experiential nature mean sit requires time for the patient to understand the role and that their contribution has importance.</p> <p>A work in-progress where patients are learning as they become more involved</p>	<p>A variety of members with diverse backgrounds and experience.</p> <p>Patients who attend regular meeting and or committee/ project work have no problem speaking up.</p> <p>A willingness (even eagerness) to participate in projects.</p> <p>Professional staff and other stakeholders who contribute to the PAC are very skilled at supporting patients and adding structure and depth to conversations or related issues</p>
From a researcher perspective, what is the role of the PAC?	With what specific activities has the PAC been involved?	What are the challenges faced in being part of the PAC?	What works well within the AB Support PAC?
<p>To codevelop ideas, think of a problem from all sides, identify challenges and creative solutions.</p> <p>To ensure research, policy, and practice align with patient needs and to promote POR.</p> <p>To be leaders and be an example of meaningful and active patient engagement</p>	<p>Give patients the time to speak while being pragmatic about length of meeting.</p> <p>Ensure patient engagement is meaningful to the individual.</p> <p>Participate in a research project at all stages, design, data collection and interpretation, and dissemination of results</p>	<p>While patients can and should be engaged at every stage of research, not every activity interests every member.</p> <p>The changing in membership results in different levels of understanding and familiarity with projects discussed.</p> <p>The challenge to coordinate appropriate and timely training.</p> <p>Development and maintenance of meaningful activities with all members.</p> <p>Connection building with other groups whose members are part of their own networks</p>	<p>Hearing valuable and different perspectives.</p> <p>Generating new ideas and seeing the diversity of work being conducted.</p> <p>Sharing examples of successful research projects involving patients and researchers who are members of PAC.</p> <p>Respect and consideration of all perspectives.</p> <p>Members have the opportunity to share their concerns and suggestions for improvement.</p> <p>Encouraging attendance at conferences</p>

Abbreviations: PAC, patient advisory council; POR, patient-oriented research.

**Table 3.** Lessons Learned and Recommendations for Others on the Use of PACs in Health Research.

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When planning a PAC for health research, recognize that PACs take time, structure, clear leadership and resources to develop. Advertise broadly, start early, and target adverts as necessary to ensure diversity and varied perspectives within the PAC. Ongoing assessment of members' voices and lived experience is critical if a PAC is to be reflective of the multiplicity of patient voices it is meant to represent

Identify the role and scope of the PAC early in the formation of the group to ensure a focused course of action and role in the health care and research community. Roles of members and the scope of their activities must be discussed with administrators and transparently identified in a formal terms of reference that is codeveloped with members

Allow flexibility to alter the role and scope as the PAC progresses. In many respects, PACs are a work in progress as the health-care landscape is constantly changing and PACs must be able to adapt to that reality

Provide many and varied opportunities for PAC members to participate in training/awareness activities to ensure competency and effectiveness in PAC activities. Encourage PAC members to not only take part but also to help design and implement these activities

Practice patience. Researchers need to be patient with patient partners as they learn about the research process, while patient partners will often not anticipate how long research can take. Patients may find wait times on progress reports are often delayed due to the research process (funding applications, ethics, and organizational issues), while other delays can unfortunately relate to the lack of acceptance or understanding of the patient's role and value in the research. Ultimately, regular communication between researchers and patient partners is vital to keep them informed throughout the life span of a research project

Clarify PAC appreciation policies (eg, honorariums, stipends) and ensure all PAC members can contribute to these policies as they are adopted

Require PAC members to take a lead role in the PAC meetings by acting as Chair and helping to set the agenda, with assistance from the Support Unit. Follow-up meeting summaries, with specific action items, improve the PAC's effectiveness

Require confidentiality in all activities of the PAC (eg proposal reviews, personal health information, and personal views on health-care priorities) to provide a *safe space* to share perspectives and information

Be ready to invest time and support to ensure PAC members can actively contribute to Unit activities, but also health research projects. To this end, it is sometimes helpful for researchers or organizers of patient-oriented activities and patient partners to have pre-event discussions (eg, before a webinar in which a patient partner will be presenting or before setting meeting agendas)

Be respectful of patient partners' busy and competing schedules, as well as personal limitations such as physical abilities, financial resources, and family commitments. Offer as much flexibility as possible in order to allow them to engage at whatever level and in whatever way best works for them. Maintaining enthusiasm and engagement of members can be challenging, but flexibility in engagement opportunities can help mitigate this

Promote success. Share widely the work PACs do. We have found it can serve as an example and provide a template to national, regional, and local research projects of how to effectively use a PAC to promote patient engagement in health research. Promotion of PAC successes might also increase the acceptance of patient engagement/partnership and contribute to PAC members' sense of accomplishment and value

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Abbreviation: PAC, patient advisory council.

such as cancer, arthritis, diabetes, heart disease, among others. Men are underrepresented ( $n = 4$ ); most members have high levels of education.

### ***Patient Advisory Council, Patient Engagement Platform, Alberta SPOR SUPPORT Unit***

The idea of a PAC was conceptualized in late 2014 to have equal numbers of patients and researchers or organization members. The council was established by the Patient Engagement Platform (Platform), Alberta SPOR SUPPORT Unit in 2015. During the first year, 12 members were recruited by word-of-mouth from across AB (rural, remote, and urban) and from different research institutions and patient organizations. By 2016, members from other organizations and geographic regions were recruited; the council is currently comprised of 26 members (9 males). Members identify as having lived experiences with health conditions, whether as a patient themselves, caregiver, friend, or family member, or as a health researcher.

Council members provide strategic advice to guide Platform activities. Their role is to (a) provide input and

feedback on Platform activities and deliverables, (b) assist with development of Platform activities and services, (c) inform exchanges with stakeholders (people with an interest in patient engagement in health research in AB), (d) identify relevant stakeholders to consult and engage with, and (e) be ambassadors for patient engagement within respective communities/networks. Table 2 outlines specific activities reported by patient and researcher council members in AB.

Terms of reference, reviewed annually, were codeveloped in alignment with the primary aim and role of the council. Members are invited to commit to a 3-year term. The council meets in-person quarterly with the option for teleconference and communicates via e-mail between meetings. Members are reimbursed for travel, accommodation, and registration fees associated with the events they attend. Appreciation (e.g. honorarium) is offered to members invited to copresent at events or contribute to activities such as committee work; some members accept these fees and others do not.

There has been a low turnover rate of members; 3 members left close to the end of their term. Although there are various research projects underway, committee work, or document reviews, opportunities do not always appeal to all

members. Sometimes, particular individuals are sought out for opportunities for which they are best suited after an open call to the council. Many members do wish to continue past their membership term. The Unit is currently determining how to negotiate extensions so there is some overlap of existing members who have knowledge and experience to share with new members.

## Discussion

### *Similarities and Differences Between the PACs*

While the Scientific Lead and Patient Engagement Lead in NL are health researchers and faculty members who regularly attend PAC meetings, NL SUPPORT's PAC is formally comprised of entirely patient partners. This differs from AB, where researchers and individuals from relevant organizations are council members. Both models are seen in the literature (eg, 1, 13). AB's model formally provides space for co-learning and interaction between patients and researchers and links to local organizations and the larger AB patient engagement platform and SUPPORT Unit. The Patient Engagement Lead in AB is the cochair of the council, and staff members from the AB Platform coordinate, attend, and support the function and operations of the council.

NL's model provides a fully patient-comprised council. While NL SUPPORT Unit staff help coordinate and support the meetings and activities of the PAC, council members rotate as meeting chair. There is no patient engagement "platform" in NL; rather, the PAC is situated within the larger governance structure of provincial research programs (eg, *Choosing Wisely NL*). This structure is the mechanism by which other stakeholders such as researchers, clinicians, and policy makers regularly interact with the PAC.

Councils also differ in ongoing recruitment methods for members. In AB, initially, recruitment was driven by word-of-mouth, while NL used newspaper advertising in local papers and then targeted adverts for specific demographics. AB is working toward an electronic communication platform that allows interaction between patients and researchers and serves as a tool to recruit new council members. Ultimately, a mix of recruitment strategies is observed and necessary for the ongoing recruitment of patients (21).

Members from both PACs described a wide range of involvement, spanning all stages of the health research process (Tables 1 and 2). Both PACs codeveloped terms of reference and appreciation policies and advise on the strategic direction of their respective Support Units. These PACs serve as examples of meaningful and active patient engagement in health research.

Both councils describe similar challenges, including recruiting a diversity of voices, ensuring full attendance at in-person meetings, providing meaningful engagement, and training opportunities for council members, as well as the resources needed for council creation and maintenance (Tables 1 and 2). Some strategies that work to mitigate

challenges include effective communication with SUPPORT Unit staff, notions of coproduction, transparency, respect for each other's views and lived experiences, and ongoing support for competency building (Tables 1 and 2).

## Conclusions and Lessons Learned

We described 2 Canadian PACs to contribute to the evidence base on how these structures facilitate patient engagement in health research. Members depicted their contribution to numerous health research activities that spanned the health research process from priority setting to knowledge translation (11,12). In both provinces, their impact on research is visible in the sheer volume of research activities with which members are involved. To date, however, there is no systematic process for the evaluation of PAC members' research activities. While SUPPORT units in Canada are evaluated annually by external evaluation companies, a specific focus on the evaluation of the impact of PAC members' research activities would be a valuable area for future research.

Table 3 outlines lessons learned and recommendations as suggested by members of both councils. Respect for diverse viewpoints, varied and ongoing opportunities for engagement and training, clearly defined roles and activities, but also a flexible approach that respects members' personal lives and interests are all key ingredients for a successful PAC. Ways to revitalize membership on both councils strategically and meaningfully requires further exploration. Our work corresponds well with emerging frameworks and best practices for patient engagement (17,18,20). By describing our experiences with PACs, we aspire to encourage their use as a facilitator of patient engagement that will help others to better integrate and utilize patients' valuable input to inform health system changes and drive policy priorities.

## Authors' Note

Ethics review was not required for this feature article; all patient advisory council members provided consent to be listed in the acknowledgements section.

## Acknowledgments

The authors would like to thank the other council members of NL SUPPORT and AbSPORU for their contributions to the Tables and final approval of the article. Specifically, at NL SUPPORT Unit, the authors thank Tina Belbin, Patti Bryant, Cris Carter, Joan Cranston, Everard (Bud) Davidge, Susan Goold, Jamie Green, Brian Johnston, David Lane, Rosemary Lester, Mandy Penney, Dorothy Senior, Mary Sparkes, Kimberley Street, Kristen Pittman, Rachel Valenti, and Emily Wadden. From AbSPORU, they thank council members: Bailey Sousa, Israel Amirav, Jane Ross, Jean Smith, Jessica Havens, John Scharrer, Katharina Kovacs Burns, Katie Birnie, Kinza Rizvi, Lauren Hebert, Melita Avdagovska, Olga Petrovskaya, Terry Kirkland, and Yesmine Elloumi. They are also grateful to NL SUPPORT staff for ongoing support to the PAC including Dale Humphries, Chelsey McPhee, Kathleen Mather, Kate Hogan, and Jessica Hickey.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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**Amanda Hall**, She completed Doctoral and Post-doctoral work in the development, evaluation and implementation of exercise programs for chronic conditions in Australia, Ireland, Canada and the UK. She currently leads two research programs at the Faculty of Medicine at Memorial University in Musculoskeletal Health and Implementation Research.

**Laurie Twells**, is an Associate Professor in the Faculty of Medicine and School of Pharmacy at Memorial University. Her main areas of research include the prevention, management and treatment of

adult obesity with a focus on conducting research that is relevant and meaningful to patients.

**Catherine Street**, trained as a clinical pharmacist in the UK. She has been employed at Memorial University since 2008. She is now the Director of the Translational and Personalized Medicine Initiative (TPMI), which includes the NL SUPPORT Unit and two research programs, each of which engages patients as partners.

**Allan Stordy** is the President and CEO of Arete HR Inc, based in Calgary, Alberta. He is a community partner of the AbSPORU and a supporter of patient oriented research endeavours.

**Kakali Majumdar**, BotanyKakali works as a Senior Research Advisor at the Schulich School of Engineering at the University of Calgary. She is a passionate advocate for incorporating patient voice to optimize the healthcare system.

**Lorraine Breault**, is a professor emeritus in Psychiatry at the Faculty of Medicine and Dentistry (FOMD) of the University of Alberta. She has held the administrative positions of Associate Dean; Community Engagement and Social Responsiveness (CESR) and Associate Dean; Equity. Dr. Breault holds a Ph.D. in Counseling Psychology and has worked within the FOMD since 1990

**Kirsten Fiest**, is an epidemiologist at the University of Calgary and Assistant Professor and Director of Research & Innovation in the Department of Critical Care Medicine. Her research program

focuses on improving the science of patient and family centered care and engagement in critical care medicine research.

**Jananee Rasiah**, PhD Candidate, MN, RN Jananee is the Director, Patient Engagement Platform, Alberta SPOR SUPPORT Unit (AbSPORU); Faculty member, Faculty of Health Disciplines, Athabasca University; and PhD Candidate, Faculty of Nursing, University of Alberta. Her research interests are in the areas of patient engagement, patient-oriented research, and frailty and aging. Jananee works closely with Dr. Maria Santana, Lead of the Patient Engagement Platform, AbSPORU to advance the science and practice of patient engagement in patient-oriented research.

**Maria J. Santana**, PhD is a health services researcher and Assistant Professor in the departments of Pediatrics and Community Health Sciences at the University of Calgary. She is the provincial lead, Alberta Strategy for Patient-oriented Research, Patient Engagement. Her research focuses in developing novel methods to integrate the voice of patients and family caregivers in health care and health service research to improve health and health care.

**Holly Etchegary**, BA, MASP, PhD is the Scientific Patient Engagement lead at the NL SUPPORT Unit and an Assistant Professor of Medicine at Memorial University. Her research program focuses on the psychosocial impact of inherited risk and public and professional engagement with developments in genomics. She brings a patient oriented approach to many research projects.