
Building Momentum for Patient Engagement in BC Research

A report on interviews conducted for the BC SUPPORT Unit patient engagement plan

Appendix 2 - Interviewees

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Karin	Maiwald	Regional Practice Leader, Research & Knowledge Translation	Interior Health	karin.maiwald@interiorhealth.ca

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Bernie	Pauly	Associate Professor, School of Nursing	University of Victoria	bpaul@uvic.ca
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Appendix 3 – Interview Responses

Note: The order of responses below doesn't correspond with the order of interviewees listed in Appendix 2. The connection between interviewees and their individual responses has been removed to provide a degree of anonymity in most cases.

1. How do you identify yourself? (Check all that apply)	
Role	# of Interviewees
Administrator	11
Researcher	15
Health care provider	7
Health system decision maker	5
Patient	1
Other	Patient Engagement Lead – 1 Facilitation – 1 Health System Change Support – 1 Evaluator – 1
2. Are you primarily involved in working with patients on quality improvement in health care or in the realm of health research? Can you describe an overview of this work?	
QI/health care improvement. 2 specific activities: recruiting and selecting patient advisors.	
QI/health care improvement. My primary role is to chair an action-based PFCC Working Group here at X Hospital that introduces PFCC initiatives. Our team does that through a grassroots movement of ideas and also through moving forward Senior Leadership's priorities with a PFCC lens on them – i.e., ideas can come from the bottom up or top down. E.g. of grassroots – social work & transplant staff had an idea for how to present personal belongings to family of a loved one who had died. E.g. of top down – providing input on a senior leadership idea for improving geriatric care/dementia care. There is also a steering group that meets quarterly and has had a patient rep for some time; working group hasn't had a patient up until now.	
Applied policy research; primary & secondary research for decision-makers. KT & implementation in health services research. Focus on maternity in rural areas (10 years); rural health services: community research with women's experiences of closures/tied to care provider experiences; visit rural communities to ask and catalogue experiences – our work is always grounded in the experiences we heard in the community. Example #2: High acuity rural transports – talked to providers; now need to talk to patients as the patient experience is not yet catalogued. Patient experience must be viewed as "evidence"; rigorous integration into the evidence base. Grant ideas come out of patients' lived experience.	
Work involves a mix of health care QI and research. Involved in Prospective & Outcomes Support Initiative (POSI) which entails collecting patient reported outcomes (PROs) and using these to facilitate improvements in health care delivery. "We need to change how we deliver care." PROs collected via interviews with health care providers (for very sick/vulnerable individuals), iPad	

<p>collection and/or Internet (in development). Use of pre-existing validated survey instruments but patients give input as well. Behind the scenes, data collected are being used for research. Advisory “champions” committee consisting of physicians, nurses, therapists, counsellors and patients that meets monthly to review difficulties. Ground up approach, “committee is run by the allied health professionals.”</p>
<p>Participatory action research in residential care – a marginalized and vulnerable population. Co-defining with patients (5-6 residents) and family/caregivers (5-6) what compassion means and how to improve compassion in the network. Led to development of “Compassion in Action Program.” Involvement was very authentic (compared to another experience where there was one patient on an advisory committee). It was like herding cats in that I knew I had no control, but rather a modicum of influence – and complex but more enriching.</p>
<p>I have a passion for helping people with bi-polar disorder get their hands on the best research. Research focuses on self-management, quality of life, and psycho-social needs. All research is community based and patients are integrally involved all along – e.g., community advisory group; national community consultation group; co-authors; all grant applications involve patients; patients as co-presenters; peer researchers; patients also volunteer at the network (e.g., social media interns). We have strategic partnerships with related agencies at all levels; provincial, national and international and all have patient representation.</p>
<p>Administers the Permission to Contact Program at Island Health; works with front-line clinicians to decide & plan when to implement; interacts with patients & the public – currently debating the merits of systematic ways to respond (e.g., form letters) vs. individualized (e.g., phone calls); works with researchers to contact patients on their behalf – fulfills the role of honest broker/insulating layer/COI guardian; tracks each time someone is contacted using REDCap to ensure individuals aren’t overburdened by study notifications. Commitment to ongoing connections and deeper dialogues to foster greater understanding about research amongst patients and the public (low on the IAP2 spectrum but still considered a leading benefit of the PtoC initiative.</p> <p>Broader PPI activity track: newer, one of 5 tracks. Examples: patients and the public are invited to all events (e.g., 5 Days in May); event for frail elderly was advertised through a patient newsletter and this brought forward a retired nurse who has now agreed to be part of a planning committee. At this 2 X ½ day event, 1st day will be targeted to patients and the public; 2nd day primarily for researchers and clinicians (but open to any interested members of the public) who will be asked to incorporate their summary understanding of what was heard from patients on the 1st day. “There is a strong, genuine patient and public focus to everything we do.”</p>
<p>Policy development and implementation related to PE; facilitates groups engaged in quality improvement and small scale (<=\$4,000/1yr) research to bring on the patient perspective. Helps to “make it happen” – e.g., meet with chairs/co-chairs to decide together how to recruit (e.g., is it important to have someone with lived experience of a particular disease or condition or can the role be filled by someone with a more general perspective?) Go to committee to orient, address concerns, do a mini-orientation, set expectations. Between 2011 to today, 185 patient partners and 60 different engagements.</p>
<p>Participatory action research project related to children’s mental health looking at how to improve the engagement of youth and families in defining their service needs; wanting to better understand the conditions that foster that kind of engagement. Also, how do you engage end-users of service in actually researching, doing analysis, and feeding it back to the providers of</p>

<p>service. Research teams consisted of academic researchers, end users (young people and their parents) and those delivering care. Examined and compared across 4 programs seen as leaders in having youth and parent involvement. Are we doing it well? Identifying best practices and gaps.</p>
<p>Health care quality improvement. New role (spring 2015) – focus on patient advisory council and on leading culture change to be patient and family centered. Pulling together diverse initiatives within the health authority. Working to ensure patient & family involvement at all levels (e.g., councils, steering committees).</p>
<p>Health care quality improvement. Responsible for developing office of patient experience and to link activities within 4 functions to support organization to provide the best patient experience and the best quality within a framework of human experience – i.e., all care providers really connect with why they got into health care in the first place. 4 functions: 1) data and analytics; 2) determining priorities; 3) behavioural changes; 4) support for patient engagement.</p>
<p>A mixture – When I think of research, I think of ethics review. Interior Health now requires an ethics review for all quality improvement work (policy is about 2 months old and not necessarily in force everywhere yet). Job is twofold: Health System Change Support within Community Integrated Health Services (CIHS); and Patients as Partners representative working with Director of Quality, Risk & Accreditation that has responsibility for the Interior Health strategy for patient and family centered care. CIHS work is also connected to the collaborative services committees; support the lead on projects related to the CSCs as well as Ministry initiated projects (e.g., blue sky thinking around new models of care for populations of interest and reducing percentage of acute care usage for those populations).</p>
<p>Quality Improvement – There are generally 8-15 active initiatives in this portfolio. We promote the use of evaluation right from the early planning stages of an improvement project. We ensure it is participatory and has patient representation (among the other stakeholders) so the voice of patients who receive the service in question is heard – e.g., on how survey is crafted; when we have a draft questionnaire, we would pilot it with a group of patient reps to get their input with regard to language, plain language, understanding and length. When we start implementation and data collection we would involve our patient reps at the working group regularly for feedback.</p>
<p>Health Research. Two projects with patient engagement: 1) Preventing cycle of recurrent fractures among patients with osteoporosis. Patient partner [who was] former Chair of the Osteoporosis Canada Patient Network and someone I had worked with before. [He] was a full member of the research team and involved from the early planning stages. 2) Participatory research project engaging the aboriginal community in the Fraser Canyon on a falls prevention project. Community advisory committee steered all aspects of the research project and consisted of elders, community health workers, band chief and council members, a health manager (employee of the band), and health authority managers for fall prevention and Aboriginal health (from both Fraser and Interior Health). (Note: Membership fluctuated over time.) Also engaged patients in focus groups and one-on-one interviews.</p>
<p>Research – Co-founded Rare Disorders Foundation that supports/funds a structured research program that applies the micro-financing concept to health research for children with rare disorders. There is a problem in that there are approximately 7,000 rare diseases and difficulty getting grant funding to study them because there are relatively few patients affected by each rare disease. The foundation provides up to \$3,500 per project; the application process is simple with quick turnaround (15 business days). Applications typically come from clinical specialty</p>

<p>fellows, residents and grad students as well as doctors who treat children with rare diseases. The focus of this research is entirely on improving care for patients. Research <u>is</u> care for this group of patients. Patient families are integrally involved at all levels of the organization – e.g., on the board, with fundraising efforts, allocating funds to parent support groups vs. micro grants, reviewing grant applications. Established in 2008 as a non-profit and 2009 as a charity, the cumulative number of grants has increased from 3 in 2009 to 250 in 2015.</p>
<p>Research – Looking at people’s health seeking experiences and evaluating models of arthritis care. Research focuses on identifying problems and solutions and testing the solutions.</p>
<p>Researcher (for purposes of this interview) – Client-based/community-based research project with street involved youth (aged 15–24 yrs, into street culture and no regular address) investigating risks and resiliency factors in relation to injection drug use. Research through the BC Centre for Disease Control. Hired youth who were considered street involved or at risk of becoming involved as youth co-researchers.</p>
<p>Both – 2 work streams: 1) point of care (patient experience and outcomes) and 2) giving patients a voice in design/re-design (patient engagement). Looking at how we improve our work around patient engagement and experience to ensure we have the patient voice in everything we do. Working to change culture so patient experience and engagement are more integral. Currently working on development of a made-in-BC Cancer Agency patient advisory network. Steering committee consisting of 4 patient partners, clinical and operations leads to develop framework, including structures and standards.</p>
<p>My focus would be in the realm of health research. Incorporation of consumer or community advisory committees as part of research as well as development of collaborative research projects with the community.</p>
<p>Quality Improvement in Health Care – Community Engagement is a department within VCH that supports the engagement of patients and the public to foster quality improvement. Our projects cover the scope of health authority services from public health to acute care. We work to bring the voices of those most impacted by a decision to the decision making process whether that be residents in the Downtown East Side, patients receiving hospital care or a new residential facility.</p>
<p>100% research – Projects with children and families – e.g., developmental, mental health, personalized medicine for patients with Chrono’s disease, chronic pain, etc. – and assessing what are personally meaningful outcomes, often related to quality of life vs. traditional medical outcomes (that which can be measured by physical or biological instruments). In other words, measuring patient-reported outcomes using a qualitative approach.</p>
<p>Research – Planned, developed and completed work disability prevention policy evaluations for British Columbia’s health authorities. Using a stakeholder approach – including employees, managers, occupational health professionals, program staff, union representatives – facilitated group processes to optimize effectiveness.</p>
<p>Research – involved in a variety of projects; e.g., telehealth services research; website to support patients with chronic disease. Patients are involved in pilot testing these models of care, giving feedback on, for example, the telephone interface.</p>
<p>Rick Hansen Institute receives (primarily) non-competitive funding from provincial governments and the federal government to conduct research in spinal cord injury (SCI) under four program areas: cure, care, commercialization and consumers. Each of these 4 areas has an external</p>

advisory committee that develops a roadmap and advises on which programs to develop or support. RHI has a registry of data on the patient journey that can be used to conduct research and analysis on such things as best practice implementation for optimal care. RHI has partnerships across Canada and internationally.

“To advance our vision and mission, our activities are based on four distinct but inter-related program areas: [Cure](#), [Care](#), [Commercialization](#) and [Consumer](#). These programs are intersected by six supporting strategies: translational research, best practices implementation, informatics, network development, consumer engagement and [capacity building through] Best & Brightest. All of RHI's projects and initiatives fall under one or more of these programs and strategies.”
(rickhanseninstitute.org)

Research – This interdisciplinary, public scholarship thesis draws from methodology in health services research and knowledge translation to address two objectives. Objective 1 explores the question: What are the barriers and enablers to informed patient decision-making and evidence-based practice and policy for birth after caesarean in British Columbia? Objective 2 of this study involves engaging in integrated knowledge translation (IKT) with patients, care providers, and decision makers (“knowledge users”). Also known as collaborative research, IKT is a form of public scholarship that engages knowledge users in the research process through mutually beneficial relationships to address critical health problems, create a sense of shared ownership over research findings, and move research findings into policy and practice. The specific IKT goals of this research include: (1) Engage knowledge users in the thesis research process; (2) Develop key messages and knowledge tools for different audiences, based on qualitative study findings and in partnership with knowledge users; and (3) Disseminate knowledge tools to knowledge users.

3. What roles do your patient partners play in the work? Check all that apply

Role	# of Interviewees
Ad hoc advisory committee	16
Ongoing advisory committee	18
Ongoing working group	17
Ongoing steering committee	17
Strategic planning committee	10
Governance body	7
Peer review committee	4
Principal investigator or co-PI on grant app	6
Knowledge user on grant application	12
Participant on priority setting activity	18
Determining/fine-tuning research question	15
Designing research study	10
Conducting the research – e.g., peer interviews	11
Analyzing study results	10

Editing/refining for plain language	19
Knowledge translation – e.g., disseminating	14
Other	<p>Refining initiatives for relevance to the hospital setting – 1</p> <p>Patients providing local knowledge of the politics – 1</p> <p>Collaborators on grant applications – 1</p> <p>Knowledge mobilization: The partners also had a role to play in carrying out the knowledge into practice past the boundaries of the formal study. – 1</p> <p>Volunteers within the network (e.g., social media interns) – 1</p> <p>Presenting results – 1</p> <p>Because of his previous career experience, the patient rep was able to provide linkages with decision-makers and policy makers – 1</p> <p>Advocacy with federal & provincial governments; petitions; awareness building through fund raising events – 1</p> <p>Patients mentor graduate students/trainees – 1</p> <p>The youth co-researchers inspired new research to study them and their process – there is little research on doing this type of co-research – 1</p> <p>To educate other consumers; participant recruitment; navigators: peer follows & helps – 1</p>

4. How do you ensure that patients have credibility (i.e., are considered credible sources of knowledge), legitimacy to represent others from their group, and power to influence decisions?

I struggled with this question; it really resonates with me. As advisors become more involved in groups doing strategic planning, we’re finding the leader doesn’t have 2 days to get the person up to speed. The patient could end up sitting in a vacuum because they didn’t have the necessary background. It’s clear we need people with experience who also have the preparation (i.e., contextual knowledge) and understanding of the specific engagement. Levels of understanding are required. If they’re trained, there’s a greater richness. But it’s a lot and patients are volunteers; it’s not a paid position. And it could be a bureaucratic nightmare if we are not thoughtful about the processes/structures we develop. We legitimize our patient partners by having them registered as Island Health Volunteers which provides them photo ID, a parking pass and explaining/having each sign a confidentiality agreement. We empower patient advisors when we operate in a group that makes decisions by consensus. At our Advisory Council meetings,

<p>every item on the agenda is keyed to the IAP2 spectrum so it's clear what level of engagement being requested of the advisor.</p>
<p>I ensure credibility by working through Patient Voices Network [PVN], which is a credible organization. Automatically, the patient voice is respected because of the patient's relationship with PVN...The patient partner has legitimacy because of her hospital experience and I will tell our working group that by virtue of that experience the patient partner has a legitimate reason to share things with us.</p> <p>However, the patient legitimacy is limited to her personal clinical and relational experience. It would be an illogical leap to assume that the patient partner can make knowledgeable statements about every area of the hospital. I think our group and the patient will be able to recognize the limits of legitimacy, respect the patient partner in those limits, and will also know when the patients' experience does in fact apply everywhere. Power will be given by ensuring the patient has a voice in regards to every decision that has to be made about our initiatives before they come out. Additionally, power is given by evaluating thoroughly the patient's comments and not just tossing the comments aside because the patient isn't a "professional." Decisions are made by consensus and the patient will have a special place at the table but other perspectives must be balanced with that (e.g., that of nursing staff).</p>
<p>Usually get prominent community leaders; unfortunately, it's often the same people who have the potential for a gatekeeping role therefore not all voices are heard. Interested in listening to the disenfranchised which is a challenge. Credibility – take people at face value. Legitimacy ensured through rigors of the academic process.</p>
<p>Would like to get advice on this. We trial and error people. Favour those who are well educated, well spoken and don't use their involvement as a soapbox. In other projects where focus was with aboriginals, there was a bit of training and we engaged with people who have expertise. Re: power – the advisory group has a flat structure and decisions are made by consensus. We encourage the patient to speak up and go out of our way to bring them into the discussion.</p>
<p>RE: Credibility & Legitimacy – how are they not!?! Experience = Knowledge. The onus to ensure these is on the researcher to a certain degree. Mixed methodologies/qualitative helps. Re: Power – Relationships between patients and care providers are inherently hierarchical so we must recognize and acknowledge that. And plan for it by inserting reflective practices in the study designs. I had many opportunities in the compassion in action study to come together as a group and reflect on if we were maintaining the participatory design, and if not, how to change things so we were. This is where allowing for failure became an important learning for everybody.</p>
<p>Re: Credibility/Legitimacy – we emulate our values, one of which is that we recognize that there are different types of expertise – e.g., clinical vs. lived experience. Other values include: equity and inclusivity. Members of the core network (approx. 35 individuals) are tested out to ensure they share these values, considered absolutely essential. Leadership...</p> <p>Re: Power – Everyone has an equal place at the table. It's important to pick the right people in the first place – i.e., people who share that viewpoint.</p>
<p>This is the hardest part of all. Think what's most important is gaining decision-maker's buy-in to ensure patient input will count and be incorporated into the decision; gaining decision-maker commitment. There seems to be a lack of evidence as to what will be gained; the next big gap is evidence to show the value & benefit to take it beyond the trust and transparency argument (i.e., patients and public have a right to be involved). There used to be a lot of discussion around the</p>

<p>question of why research matters; now we need a dialogue about why patient engagement matters.</p>
<p>This is a little bit trickier. Most come from Patient Voices Network or the Vancouver Coastal Citizen Advisory Committee (CEAN) and are pre-screened through them. Legitimacy – recruit from within a program, those with direct experience. Ability to express themselves clearly and articulate well gains them credibility. Power comes [automatically] by virtue of being on the group. Level of power/influence depends on expectations set out at the beginning. Always meet with chairs and patient partners to clarify roles and expectations.</p>
<p>Interesting question because it's attitudinal. Key decision-makers have to be influenced to see it. Legitimacy: helping the patient partner convey the findings in a way that represents the broader population, which requires training/coaching and communicating to see that it's not just about their experience or story – i.e., "their story" vs. "our story". Power: Shouldn't privilege anyone's power, team needs to make that explicit, no one has more power than another, decisions by consensus, honouring variety of interpretations and trying to bring these together but if you can't that can be an important finding.</p> <p>What you carry into the research you do based on a fundamental set of assumptions, a fundamental world view, your core values like equity, diversity, and understanding differences.</p>
<p>We work closely with ImpactBC [former administrator of Patient Voices Network] where they stress that it is not about advocacy ("soap box"), it is about helping to shape service delivery. Patients have credibility by the very fact that they've gone through that orientation. They have the interest and first hand experience as a patient or family member. A guest was recently blown away by the level of education and experience (e.g., masters level education, senior leaders in their careers, highly-educated, well-respected community members, many retired) of individuals on the patient advisory council. Note: we know we have to grow in terms of diversity.</p> <p>Legitimacy – Patients are clear, "I am one voice". There is power in people's stories.</p> <p>Power – We are serious about giving weight to the feedback and input of patients and families so it is not just a tick-box for accreditation. Can't speak to the how yet, but we are looking at terms of reference for the patient advisory council which were written in 2011 and may need updating.</p>
<p>Smiled when I saw that question. It's a real nugget. That's where the culture change comes in. With front line staff, they automatically see the patient as credible and legitimate through the patient story. The training that ImpactBC has done means the patient partner is well trained in how to present their story in a way that doesn't cast blame. They talk about their experience and the impact it had on them. With other committees and councils, we're having a bit more of a challenge. Committee meets for limited amounts of time, there is fear that patients' questions will take a long time and that they'll have a bone to pick, worry about patients as advocates. In this case, have to have leadership commitment and expectation. It is in our service plan but it can always be made more visible. It has to be more than a check box; it has to be meaningful; we need to check back regularly to make sure it's going well. This takes time and it needs to be resourced. The reputation of previous patients we've had has helped to make leaders comfortable with this culture change. We've had fabulous partnerships through ImpactBC – the volunteers selected have been a good match and they're well trained. Starting to hear stories about how patients make us re-think what we thought we knew.</p>
<p>Most patients are recruited through Patient Voices Network. Credibility and legitimacy comes by virtue of their process of screening & orientation; we also interview for a match and, if necessary,</p>

<p>trial the partnership. Meet with patient partners prior to the activity (e.g., focus group) to ensure they are a fit.</p>
<p>By working closely with Patient Voices Network and selecting appropriate patient representatives. By educating clinical staff and project leads on how patients are important partners. Leadership support is key – e.g., it is very helpful when the project lead really understands the value of the patient perspective. The longer the history of working with patient partners, the more comfortable people become, so it depends on how long they’ve had the experience.</p>
<p>[Our patient partner] was credible because he had been Chair of the Osteoporosis Canada Patient Network and I knew he was not afraid to speak his mind and to sit on a research team. I knew he would be able to take an active role. He had legitimacy because of his linkages across the country. Re power: the group/team has to be comfortable that the patient perspective is as valuable as anyone else’s; that the process equally values everyone’s contribution. The facilitator has a role to play to ensure that everyone gets their voice heard; sometimes prompts are needed and people need to be invited to speak. Leadership comes into it to create the right atmosphere and conditions for patients to be considered equals at the table.</p>
<p>Credibility is established through on-going bi-lateral engagement with doctors and scientists. Legitimacy – Patients and families/caregivers are legitimate by virtue of their lived experience. Power – The board of the foundation is parent and/or patient dominated.</p>
<p>In terms of credibility and legitimacy, there is no question because we involve people who have experience and knowledge [about their condition]. In some ways they are more credible and legitimate than the researchers because they’re the experts on their body and they experience and understand how a treatment feels and how it impacts their quality of life. Power depends on the leader of the project – when the leader starts explaining in plain language, others follow; when the leader makes sure the patient has an opportunity to speak, others will follow. Also, patients hold power in that we really value their input.</p>
<p>It was important to screen for certain criteria such as age, experience and ability to do the work (i.e., show up on time, stable enough, and able to express their needs for support.) Recruitment and employment criteria required that YCs [youth co-researchers] had not injected drugs during the previous 6 months, would agree not to work while under the influence of drugs, and would complete assigned work. Because the youth researchers were referred by the healthcare partners – i.e., doctors and counsellors – we had a reference as to their ability to do the work. We created a team with varied experience in the area; balanced gender; diversity in culture. These peer researchers were legitimate by virtue of their lived experience. The power of the [youth co-]researchers came because people wanted to hear from them. They influenced things because they are the end users of the research, so more weight was given to what they had to say. As the process grew and trust was built, there was an increasing trend up the engagement ladder – from involve to collaborate to empower.</p>
<p>Credibility through having robust standards for screening and interviewing and vetting for all volunteers, including advisors. We have used questions and tools from Patient Voices Network. Legitimacy is part of the screening and vetting systems – ensured by virtue of their specific lived experience.</p>

<p>Power also comes back to screening and vetting. Also, it comes from good facilitation. The facilitator should ensure that the patient partner’s voice is heard...that they have opportunities to speak.</p>
<p>They have experience of the health related situations and issues that are the focus of the research.</p>
<p>We use a process whereby potential members/patients self-identify and are then interviewed to ensure their suitability and their intent to do quality improvement and that they don’t have a specific agenda. The person then receives an orientation where they learn the requirements of their role and are given information about the organization; they also complete a confidentiality agreement and learn how to be an effective advisor. When a request comes in for a patient partner, there is a second level of interviewing and people are shortlisted.</p> <p>Power is inherent by virtue of the fact that the project group has requested them; the assumption is that they will have some ability to influence decisions. There is nothing in legislation that mandates health authorities to use citizen engagement, but there is an expectation that it be part of an improvement process, which is a driver. We are pleased that there was an active choice [by leadership] to have a community engagement department. If the team asking for patient advisors is not demonstrating that they intend that the patient or public input will have influence then we would question the reasons for an advisor and support that team to work towards a meaningful engagement experience for them and the advisor. We provide tools for both advisors and staff to support them in the process of engagement.</p>
<p>By working with groups of parents who are already structured, we are able to engage with identified leaders. We don’t question legitimacy; we don’t question their knowledge/credibility; it is accepted that their option is important to consider. Our research is about getting closer to the specific needs of the individual; therefore, by definition, the patient’s opinion is important; i.e., it is “the truth”.</p> <p>Power depends on the study. If it is clinical research and technical, there is less opportunity for the patient voice. But when we go to find the impact of an intervention and whether it is an improvement, decisions are 100% related to perceptions of the family; therefore, there is good recognition of their voice. At the group level with consultation and advisory groups, we consider the contributions of patients and family to be extremely important. We need their insights on how a problem affects their life.</p>
<p>Credibility – participants had to have had relevant experience. Legitimacy – union representatives represented the worker with health-related problems and I trust that when I go to an organization that has representatives that it’s agreed they can speak for them (in this case, the workers with ill-health). I don’t think we can blindly accept that, however, and that we need to keep an open eye on that and reflect on the data – are they really representing the group?</p> <p>Power – used a nominal group technique to ensure that not only the strong and loud voices were heard. In focus groups, we made input anonymous – gave people time to write on an index card 5 ideas, then put up all the ideas and prioritized them anonymously.</p>
<p>Credibility – We put out a call (through Patient Voices Network sometimes). When PVN does this, they respond with a list of patients who are interested along with some details about the patients. From this list and brief description, I may select some, all or none of the patients. Commonly, they’ll provide some information about their background and experience and talk about what they can bring. Sometimes, it’s more formal; we are explicit about our needs, like a</p>

<p>small job description. Individuals are also vetted by the Heart & Stroke Foundation, have heart disease and lived experience.</p> <p>Legitimacy – by virtue of the fact that they actually are patients/caregivers. We target to get at least 3 patients involved and the perspective from both men and women/urban and rural. These criteria might not be found in only 2 or 3 people, so while there may be only 3 people on the committee, we will at times approach other patients for feedback. In one project, there were 7 additional patients engaged.</p> <p>Power – Facilitation is important. Make sure that at meeting/teleconferences, we call them out (i.e., invite them to speak). The facilitator may deliberately direct specific questions to the patients if they tend to be a bit quiet. It’s important to pause and make sure they have an opportunity to speak. Patients are the target audience, so they have the greatest value to inform the user interface.</p>
<p>Credibility/legitimacy – The consumers themselves defined meaningful engagement as engagement of the whole community, stressing that all consumers are different and that no one consumer can represent all consumers. There has been a movement to ensuring that many voices are heard by reaching out to partners who have connections to larger communities and using those connections to conduct surveys and get feedback.</p> <p>The RHI Board of Directors includes individuals with a spinal cord injury. Input from these members was critical in shaping the Institute’s vision and mission statements as well as identifying the three secondary complications that our work focuses on (i.e., pressure ulcers, pain and bladder infections). We are very cautious about tokenism – having someone just because it looks good. Our consumers have had a dramatic impact – e.g., they have been a critical factor in determining the research agenda and identifying that the organization needed to divide our focus between “cure” (e.g., research focussed on how to help people walk again, which is a long-term goal) and “care” (e.g.. management of secondary complications like pain, infection, etc., which are shorter-term/quality of everyday life goals).</p>
<p>The 2 patients advisors who are on the working group are people from the north that I got to know through an earlier interview stage of the project. I got a chance to know and hear their story and to get a clear sense of how their patient experience relates to the overall population sample. Both have university degrees which gave me faith that they have the ability to engage in research. Both are well connected to other patients. I would prefer to work with more vulnerable individuals but it is unfeasible because of funding limitations to provide the support that would be required. Power is conferred by virtue of the fact that both are very articulate and can speak clearly and authoritatively.</p>
<p>5. What mechanisms do you employ for finding patients to engage with?</p>
<p>PVN plus our own networking.</p>
<p>PVN.</p>
<p>Formal community engagement (i.e., the formal route); hang out at coffee shops (rural community context), attend Moms and Tots groups, posters in offices, we have a community participation link on our website (would be interested in linking this to the SUPPORT Unit). We never directly contact individuals, info is passed out and they phone us.</p>

<p>Direct approach through oncologists who recommend patients as “appropriate” (as defined in #4 above). We have advertised using a poster in the Cancer Agency but that led to the soap box people coming forward.</p>
<p>PVN; direct link to residential care sites/network of people who can introduce me. There are residential councils and family councils (mandated) but not well attended.</p>
<p>We used to be very pro-active but now people come to us. We get an average of one email per week from patients who want to become involved. Also, one of our co-leaders has a tremendous network and sends us people.</p>
<p>Permission to Contact program; patient newsletter (sent out via email); Patient Voices Network; Health authority Patient Advisory Council; people come to our events and self-identify; social media (Twitter); coming soon: website (which has been challenging to do at a health authority).</p>
<p>PVN, CEAN, internal recruitment (e.g., a physician will approach people who are offered a chance to be engaged).</p>
<p>Team members were individuals who had received services in the past, recruited through the 4 agencies. Ethics required that researchers seeking patient partners for the research team wrote scripts which were given to the agencies who then reached out to people who had previously given permission to be contacted. Study participants were individuals currently receiving services.</p>
<p>Recruit through Patient Voices Network. Occasionally, through direct referral from a sitting member of the Patient Advisory Council.</p>
<p>ImpactBC/PVN; staff person (patient engagement lead) recruits also.</p>
<p>Patient Voices Network and, when we can’t find anyone that way, by direct recruitment through clinicians’ recommendations.</p>
<p>Patient Voices Network or by direct outreach to clinicians.</p>
<p>Clinicians tend to use their connections. A lot of research has been in my own hospital. It also works to reach out to the groups that represent people with a specific disease or condition (but you have to be conscious of the advocacy piece). Occasionally, there may be opportunities to ask patients for permission to contact for further involvement through the Fraser Health consent to contact program.</p>
<p>There are parent groups in most major cities across Canada and there is a Canada-wide website where people can sign up for membership.</p>
<p>Through personal contacts, relationships and networking, at coffee shops and over the phone – warm calls, not cold calls.</p>
<p>Went to youth agencies providing the services and counsellors; ads at youth centres. Health care partners such as counsellors or doctors and ministry contacts referred youth. No direct approach.</p>
<p>Still in development. In past, have relied on Patient Voices Network. We also have our own volunteer coordinators with databases in every BCCA centre. Also, informally through our own networks. Volunteers have been pretty easy to find and are generous with their time.</p>
<p>Depends on the process itself. Sometimes we go directly to patients who’ve had the experience through the relevant health records. We then send a letter of request. We also have a Community</p>

<p>Engagement Advisory Network (CEAN) consisting of approximately 140 members of the public. We recruit to this group through engagement processes, the internet and community events.</p>
<p>Normally, for each intervention, we contact someone who has contact with that patient group – e.g., the gym teacher or the head of the pain clinic. Also, outreach to families – we organize a meeting and explain what we do or go through a network of people who experience a certain disease or condition.</p>
<p>Email – contacted union reps; put up posters; used snowball sampling where at each interview you get more referrals; group presentation at Toronto conference.</p>
<p>Patient Voices Network. Ongoing connections with the Heart & Stroke Foundation. Students doing research studies on the cardiac ward sometimes approach patients on the ward – e.g., patients from research study are asked if they'd be willing to participate in an advisory role as a next step in research.</p>
<p>The institution is visible within the community (events, collaborative projects, joint projects, proactive network and relationship-building, newsletters, social media and participates actively in the SCI-purpose built Blusson Spinal Cord Centre community (research, educational seminars, Lunch n'learns, etc.). Also, word of mouth is used. If we find a fit, we will approach individuals. Website.</p>
<p>Informal social media – e.g., one interviewee would post something on their Facebook page and then others would contact me; informal social networks such mom and baby groups, breastfeeding support groups; posters and contacts at community centres and public health agencies.</p>
<p>6. Do you provide any kind of training for patient partners in their roles?</p>
<p>Very limited but we planning for a more robust process. We currently offer advisors a brief orientation to Island Health and a patient advisory handbook. As we develop our new structure we will include a more structured Onboarding that will include providing access to the HA's learning management system where there will be modules relevant to new patient partners. Ideally, it should be not be labour intensive and all in one place. We are currently developing a patient experience website.</p>
<p>They are trained by PVN and then I meet with the patient personally to orient them to their role (i.e., give them previous minutes, share expectations I have of the patient, and give an overview of the culture of the group).</p>
<p>Good question! We don't do anything formal. Set ground rules (e.g., no acronyms). Training needs to be "just in time" (e.g., discussion about coding qualitative data at that point in the process).</p>
<p>We provide 1 or 2 one-on-one meetings to get the background around program and goals; documents provided.</p>
<p>Informal orientation provided; other is tailored to questions as they come up (e.g., what is qualitative research? What is participatory action research? Content guided by the research problem.</p>
<p>Yes, but we could be doing better. Training tends to be ad hoc, one-on-one training according to the work we need to do. We should have someone involved in patient professional development.</p>

Ad hoc, depends on the initiative; one-on-one, contextual (Other mechanisms mentioned in interview)
Meeting with them; currently developing training module for people on hiring committees; possibly small training module for patients participating on a small-scale, staff-led research team (<=\$4,000/1yr).
Yes, developed comprehensive training materials, 16 hours, to train lay researchers how to facilitate focus groups, etc.
Patient Voices Network orientation plus there is an expectation that whoever asked for the patient partner will provide orientation. No other internal, formal training provided.
Same as #1.
Spend a lot of time (sometimes up to 1/2 day) preparing patients for their role, answering their questions specifically when involved in Patient Journey Mapping or Focus Groups.
See responses #12.
[Our patient partner] had a gradual introduction by virtue of being part of the planning team one year before the research actually began when we had a planning grant to bring together the stakeholders and work on the research question. He learned along with us. Training is something we've been talking about and is in our 5-year strategic plan.
It is more "mentorship" – i.e., personal connection and then ad hoc based on their questions. We don't want to 'train' them in our ways, we want them to figure out how they will engage a role and then teach us about it. That is the way we continue to innovate in grassroots engagement.
The advisory board takes on the role, mentoring their peers on partnering with researchers. There is a binder that was created that includes tips on working in teams, barriers, etc..
A lot! Training on how to do focus groups, interviewing and note taking, coding qualitative data, about the issues and research in general. Training modules were developed in conjunction with BC Centre for Disease Control, Harm Reduction Program. See: http://www.scivee.tv/node/36246
Yes – we already have training for volunteer roles at BCCA. In the process of developing training and standards around advisory roles.
Yes, but type of training depends on roles – E.g., if they are doing interviewing, then we do interview training and development.
The department is set up to do this. There is an orientation and we have developed tools – e.g., an advisory committee workbook. Training is also done face to face with a professional development focus or through interactions with senior leadership.
No – we're explicit about why we need them (i.e., to get their feedback).
Not directly.
When they come through Patient Voices Network or Heart & Stoke Foundation, they've already had some training. When we find our own, we'll be explicit in terms of what we want and need. Volunteers seem to be more educated and to have had more professional careers, therefore they haven't required too much training.

<p>This is something we need to do. Although we engage, we are just in the process of developing a strategy to put a structure around engagement.</p>
<p>Generally, this consists of me answering questions regarding roles and responsibilities and having one-on-one sessions to answer questions related to each stage of the project.</p>
<p>7. Have you ever received any training in how to effectively engage with patients or do you provide such training for others in your organization?</p>
<p>IAP2 certification.</p>
<p>I receive training through seminars I've taken in my work here...Also, indirectly in my master's degree in conflict analysis and management (i.e., concepts in team building, conflict resolution, collaboration). Much of my training of hospital staff focuses on developing conflict management skills (i.e., getting along with difficult staff, patients, and family).</p>
<p>No but have been doing this for over a decade.</p>
<p>No.</p>
<p>As a PhD student, spent 5 years interacting with patients and families. Have done a lot of reading on how others have done research with vulnerable and marginalized populations; have put those things into practice.</p>
<p>I provide training to people if they ask me.</p>
<p>IAP2; BCPSQC webinars (e.g., Patients for Patient Safety); Canadian Foundation for Healthcare Improvement webinars; learn from hearing examples of what others have done; belong to a MSFHR KT community of practice.</p>
<p>Institute for Patient & Family Centered Care (IPFCC) seminar. I do provide minor training: a couple of meetings with leaders or groups; in the process of developing something more formal but in its early stages.</p>
<p>Doctoral work in participatory action research; reading and doing.</p>
<p>No, but am appreciating the community of practice that has been recently set up. On the organizational level – on the radar but don't offer anything right now on how to engage.</p>
<p>No, but have attended conferences & workshops, lots of reading, & as a clinician establishing therapeutic relations with patients. We have nothing formal; informal coaching, in the moment, helping to surface concerns and then how to deal with that.</p>
<p>Transferable skills from career working with volunteers and as a recreational therapist in residential care; worked closely with residents and families; IAP2 training; various workshops. Don't offer training to others in the HA.</p>
<p>a) One-day seminar on patient and family engagement (March 11th 2015) (Richard Delaney & Associates) b) Patients as Partners Facilitation Workshop March 12th and 13th also by Richard Delaney & Associates.</p>
<p>I learn by doing, watching others and reading. We are developing a workshop on participatory action research for 2016/17 Fraser Health research workshop series. For the aboriginal falls prevention project, we hired a community engagement coordinator (from the communities) who</p>

attended research training workshops about survey methodology, focus group methodology, and quantitative methods.
I have learned from my dealings with patients and families. I provide training through interacting with teams at the various events we run.
Hands-on mentoring from thesis supervisor and patient mentors when doing my Ph.D. as well as other role models. Post-doctoral fellowship working with patients as partners in research projects – they mentored me and told me when I was out of line!
I did a lot of research on my own on community-based research. Since then, I have never done any work without consulting with users or stakeholders. Learned a lot through my experience working directly with the community – e.g., knowing the right way to support and help them grow in their roles involved knowing how to set boundaries around simple things like coming in late.
Yes, by virtue of my role, post-graduate work and conferences. We need to do more with staff and we will be doing more. It is part of our plan going forward.
No.
Yes – affiliated with IAP2 on multiple levels. Actively involved and interact continuously at conferences. We developed a workbook on how to do patient engagement which we deliver approximately 3 times per year and offer to internal teams with 8 or more staff.
Nothing formal but have 30+ years' experience. Patient & family engagement has always been a constant objective in every study because it's a necessary component for success of the study.
Yes – received CIHR funding to complete the Work Disability Prevention Training Program (Diploma), University of Sherbrook, Montreal/University of Toronto. This course included units on engaging effectively with patients/workers with health-related problems. Education at Maastricht University in the Netherlands included research methods for engaging with patients/clients.
It's all been informal. Through trial and error, have improved processes over time. We have informal discussions with staff and students and talk about the need to hear the voices and to get back to patients to close the loop.
No.
1) Mentorship while working as a research assistant for Jude Kornelsen at the Centre for Rural Health Research. Jude shared her process, the literature, and enabled me to watch how she engages and builds relationships. 2) Public health education – working with vulnerable patients and using community-based participatory action research principles grounded in working with populations that are already marginalized. Found there is transferability between some critical theory courses during graduate training – e.g., feminist methodology course.
8. Would you be interested in this kind of training?
Yes, I'm always looking for learning opportunities.
Would love that!
For sure, but only so much time in the day. Would probably delegate to someone with more time.

Absolutely! Suggested format: face-to-face workshops (e.g., 4 workshops in a 12 month period). Some modules online is OK.
Depends how generic it is. Our training is quite focused on bi-polar.
Yes!
Yes, I think so.
Would be more interested in facilitating or consulting with teams who want to do participatory action research. Open to guest speaking.
Yes! Great!
Yes.
Yes.
Yes, for sure.
It really depends on structure due to time issues. Trouble getting physicians to come to a workshop unless scheduled evenings & weekends. Make it accessible: e.g., on-line/WebEx, chat, with perhaps one face-to-face.
Sure!
For sure! It is so important to create a generation of researchers who have experience in partnering with patients as part of their methodology. Everyone should know how to do it.
Yes.
Great!
Yes.
Would be interested in seeing it.
It depends if it has a patient-centered approach. No interest in courses designed to recruit for randomized controlled trials.
Yes, for sure!
Yes, definitely, for staff and trainees as well.
Yes.
Yes. Would like to know how to engage patients from Day 1 as a research team member and how to make the relationship work to its potential.
9. How do you support your patient partners – e.g., in terms of preparing them for their roles, reimbursing them for time and travel, following up with them about their experience or the results of their engagement?
Reimburse for travel & lunch, not honorariums as these are volunteer positions. (We're not great about following up to get feedback on the patient experience of the engagement, but PVN has a close the loop survey).

<p>Pre-meeting meetings with the patient partner (i.e., over the phone or in my office), we cover her parking expenses, and follow-up meetings through email, phone, or in my office. [Note: this person is only dealing with one patient partner.]</p>
<p>Feel strongly that patients should be compensated if true, sustained, collaborative engagement. Budget line in grants for honoraria (although there can be enormous administrative hurdles – e.g., trying to give cheques to homeless people who don't have a chequing account!) If off the sides of our desks, compensation through tokens of appreciation. Reimbursement for travel.</p>
<p>No financial support including no meals, mileage, parking etc. Meetings occur by videolink of 6 centres and it can be very intimidating so we follow up and get feedback centre by centre at a smaller meeting. We share updates through reports, meeting minutes & a newsletter.</p>
<p>We locate our meetings at places easy to get to. We ensure their care requirements are met by asking ahead of time what would be needed and making sure it was available (i.e., nursing care, food, and flexibility in attendance). We give them time to say what they want/need to say and provide quiet. Food and reimbursement for travel (budget part of grant writing). No honoraria – wasn't aware that was something to consider... (I'm learning a lot through this conversation!)</p>
<p>We ask our patient partners about what supports they need/what barriers may get in the way of their involvement/what's holding [them] back: e.g., babysitting money, mood states. We look out for career, training and networking opportunities. In terms of preparing them for their role, sometimes I've assumed too much; you can't assume level of knowledge; you need to touch base and constantly re-visit with them.</p>
<p>This is tricky because health authority is very conservative. We've been told that bringing patients on-site represents a liability risk so may require a full onboarding processes. For that reason, I try to conduct interactions over the phone or by email. Closing the loop: absolutely! Endeavor to produce a report for all participants.</p>
<p>We don't reimburse for time (consistent with PVN and CEAN policies). We encourage project leads to budget for transit and parking. Mileage can be a problem/barrier; can get expensive if travelling a long distance. Some don't ask or some don't care about reimbursement. Typically don't provide food (some grumbling about that from patients).</p>
<p>Training to prepare youth and family for their roles. Reimburse all travel costs, provide daycare or money for babysitting, paid an honorarium (e.g., \$500 to attend weekend training). Honoraria tricky because it could affect social entitlements, may not have SIN, etc.. Workaround by giving Visa credit cards or grocery cards. Closing the loop – everyone invited to a KT dissemination event.</p>
<p>Cover travel & parking. Do not reimburse for time (this is made clear in the PVN orientation – you're paid with smiles). Refreshments? Meals, no; no catering policy at the health authority so typically very little of that. Re: Follow-up/evaluation – looking to develop mechanisms.</p>
<p>We support patients involved in the work we do 1) through PVN and 2) "I'm your contact; I'm your support."</p> <p>There is no official policy re: reimbursement; however, we do reimburse for travel (although sometimes it's tricky because there may not be a budget); we sometimes avoid overnight travel by arranging a video conference; we do not reimburse for time (e.g., no honoraria) in line with the Patients as Partners policy.</p>

<p>PVN does follow-up surveys but this is an area that is our weakest link. Patients sometimes have unrealistic expectations regarding how long it will take to follow up and report out on what happened as a result of their involvement and we need to educate them.</p>
<p>When we have patients participate in focus groups to talk about the service they've received, we make sure to provide a safe space. We also ensure the process is done in an ethical manner and considers cultural awareness. We respect privacy and confidentiality and usually capture input anonymously. We use the ARECCI framework and tools to work through the ethical issues. We pay for travel and provide a meal most often. We always share a summary of the results.</p>
<p>There is generally limited funding. We provide food and reimburse for travel (mileage and parking). No reimbursement for time. Sometimes we give gifts. End-of-project celebration event (60-70 people) with lunch and a bingo game (fun, interactive method) to share learnings of the project.</p>
<p>We reimburse receipted expenses. Reimbursement can be an issue because you can have the perfect study with a rare family and then find out they can't pay the bus fare to get to your meeting. After every grant competition, we review what went well and what could have gone better.</p>
<p>Universally, patients who partner with researchers want the respect they deserve. We support patient partners by keeping them in the loop and avoiding tokenism. In terms of rewards and recognition, we ask them what they deem as appropriate – e.g., their names on papers, funds to go to a talk or conferences, sometimes it's just having us (the leaders) showing up when they're speaking at an event. It depends and may change over time. It depends on the individual – e.g., people on disability will have different needs.</p>
<p>We provided training so they could perform their roles as youth co-researchers (conducting focus groups, note taking, coding qualitative data, etc.). Followed up regularly to see how things were going. Check-ins after every focus group they conducted. (Note: Because the youth co-researchers were themselves former street-involved youth, they were vulnerable to risks such as negative emotions or relapse when interviewing other currently street-involved youth, which is why the debrief was so important.) Team building through group outings for fun – bowling, picnics. Helping with basic needs – e.g., connecting them with agencies for counselling and housing needs.</p> <p>Paid the youth co-researchers \$15/hour. A monetary reward really means something when involving patients as partners in community-based research. It's powerful!</p>
<p>Reimburse for travel, not time. It is a sustainability issue. The jury's out on this, but budgets are tight. We follow up and are in regular touch; it is iterative.</p>
<p>Use of honorariums and ensure we provide resources to support them such as food, bus tickets, etc.. Also, meet in spaces that are safe and comfortable for them as well as addressing issues related to power relations and ensuring negotiation and understanding of roles and responsibilities in the research. This is very time intensive and requires high level of engagement and trust with partners to ensure adequate preparation and debriefing especially in presentation of the findings of the research.</p>
<p>We ensure citizen/patient partners never have to pay out of pocket. We don't reimburse people for their time. When people leave a committee, we do an exit interview. We have a public health</p>

<p>student on board doing a project to evaluate the experience of advisors and the leads of projects in which advisors have been involved.</p>
<p>We meet with families in natural settings like the gym and make efforts to make them comfortable. In recognition of their key role, we budget for things like providing food and providing gift cards. If meetings occur at the hospital, we pay for parking.</p>
<p>We met in small groups to build trust. Reimbursed workers for time when they were interviewed (regular wage). Re: follow-up and sharing results – when speaking at conferences, we engaged the workers and were sure to bring out what they had to say. Organized a student day for Canadian Association Work and Health and invited injured worker representatives to come.</p>
<p>We always try to make sure there’s no cost. Most interactions are through telephone with free teleconferencing because a lot of our projects are telehealth related and patient partners reside in outlying areas. We ensure that they are invited to speak at meetings. Reimbursing for time has not come up, but I think it should be all or none – i.e., we all get paid or no one gets paid. I’ve been involved in some work where only the physicians get paid. When you pay some and not others, it feels unfair. It sends a message, perhaps unintended, about whose input is valued and whose is not.</p>
<p>Honorarium structure for consumers on advisory boards. Professional development opportunities – e.g., funding to attend national and international conferences so consumers can learn and return to share what they’ve learned with the larger organization. In response to consumer feedback, we are developing some funded positions for consumers within research projects (e.g., paid position). We are conscious of the accommodations required – e.g., some people’s care routines are very extensive so we might not start a meeting until 11:00 am or we might provide a call-in option.</p>
<p>Process evaluation: knowing how important it is to constantly check in to see if the person is comfortable, feels heard, and if there’s anything that can be done to make things better. Reimburse participants for expenses such as local travel, refreshments and child care. Would like to be able to make it possible for patients to participate in knowledge dissemination – e.g., travel to speak at a conference – but don’t know where I go to get funding for travel, etc.</p>
<p>10. Can you provide me with the names of any other individuals who are doing this kind of work who I can also talk to?</p>
<p>Note: Responses to this question have been noted and will be followed up on as time permits.</p>
<p>11. Are you aware of any opportunities to learn about patient-centered care or patient-oriented research?</p>
<p>A couple of courses in US – one that provides patient experience certification.</p>
<p>Yes, there are many...often too expensive to attend. 😊</p>
<p><i>Research is Ceremony</i> (Australia).</p>
<p><i>Grey Matters</i> (Nancy Marlett), <i>Am I Doing This Right?</i></p>
<p>PCORI.</p>

Patients as Partners/Patient Voices Network; CFHI On-call series; BCPSQC webinars; PCORI.
IPFCC Seminar 2X/yr (coming up Nov 2-4, [2015] Florida).
National Youth in Care Network, Federation of Community & Social Services (FCSS).
Planetree (Conference Boston in October), Book: <i>Putting Patients First Field Guide</i> , Community of Practice – resource list (books, manuals, print, website, IPFCC (Conference New York in June 2016).
IPFCC, NHS (UK), Global Advisory Board (KT organization), Experience Innovation Network (KT organization), Cleveland Clinic.
This is a gap because my head is usually buried in the most immediate work.
Patients as Partners/Patient Voices Network.
North American Primary Care Research Group (NAPCRG) – family physicians who do research; working group on participatory action research.
This is a new field.
PCORI. Students currently working on a patient engagement research literature scoping review.
Best advice is to do it! Brainstorm with people you're working with – i.e., the stakeholders.
Newsletters.
Upcoming ISOQOL Patient Reported Outcomes Conference in Vancouver.
Read Dutch scientific literature and follow academic news on patient engagement. As well forwarded CIHR-related course information.
I tend to ask myself, which of my colleagues knows about this? Informal opportunities come up – e.g., sitting around a table, reading & discussing things.
12. Any other comments?
This is an area that is growing so rapidly in health care – what is today tends to have expanded well beyond tomorrow. We have created a BC PFCC Community of Practice – we have had two meetings and the excitement and momentum is incredible!
Didn't know anything about SPOR or the SUPPORT Unit.
Would like to reiterate that, currently, the hierarchy of evidence is such that patient experience is at the bottom. We need to value the patient experience more highly as evidence. Feeling a bit in the wilderness so would love to connect! Interested in connecting with others re: engaging marginalized and vulnerable populations: e.g., women, First Nations. Mechanisms for KT: 1) academic papers; 2) 4-page policy briefs/key findings; 3) community appropriate ways of presenting data – e.g., community asked that findings come back to them in the form of a play. Re: patients as co-PIs and knowledge users: the patients I work with are focused on food, shelter and clothing, not on how to complete a complex CV!
Ideas for future conversations: 1) Emphasize the importance of methodology – what kind of research designs are we using to get the patient voice? Would love to have a conversation about what other people think about appropriate methodology. 2) Re: Hoops & Jumps – e.g., consent

<p>process – is there an opportunity to have a conversation about how we get consent? Right now, patients have to fill out an 8 page document for each of two research ethics boards.</p>
<p>What does it take to be identified as a “patient”? That is a question I asked myself when I looked at the options for how I identify myself.</p>
<p>Some of the questions in this interview have helped me to learn (e.g., ones about evaluation and training). A recent survey conducted in the health authority asked whether people were ready to engage patient partners: responses split between “yes” and “not yet” (not no). Fears that patients and family will change the dynamic of meetings, business and the work and that they may have unrealistic expectations (e.g., every hiring panel should have a patient at it – but there are 500 hiring panels each year!)</p>
<p>We have seen a real change with patient involvement at our health authority. I used to have to always ask, where is the patient? Now I don’t have to be a strong advocate for patient involvement. Community Integrated Health Services has been the leader and it is now spreading to the rest of the health authority on the ground and we’re working towards a health-authority-wide policy.</p>
<p>Often, the idea for research comes from the observations of the mother because mothers (or other primary caregivers) observe things others don’t. Studies can bring those observations to bear and give hope that there’s a path to having their voices heard...and also open an unlooked for path to research that can make a real difference.</p>
<p>It’s not just about the researchers and what they get – compensation for their work, published articles, etc.. It’s really about what the patient partner (in this case, the youth co-investigators) get – which is self-empowerment. It is really important to realize that the process of inclusion is just as important as the answers you get or the results of the research you are doing.</p>
<p>I was at Patients as Partners BC Dialogue Conference this year in May and SPOR presented there; first I had heard of the work in this area so it was a good opportunity.</p>
<p>Pediatrics always pays attention to families and recognizes that the psycho-social environment can play a role in health. We don’t separate the disease from the whole person. In this way, pediatrics could provide models of care.</p>
<p>I know that in the Netherlands (and other Western European countries) a lot of work is done on patient engagement and regarding ‘full spectrum, from consultation to empowerment’ and ‘interacting ingredients’. I support that applying and keeping a wide international lens could further inform and may advance the work we do in Canada.</p>
<p>Our assessment is that our group is at the “more” engaging side, but there are lots of researchers who do not engage with patients.</p>
<p>We have found the use of patient reported outcome measures (PROMs), measuring both changes over time as well as factors that are actually important to patients as defined by patients, to be a powerful tool.</p>
<p>I would love to have opportunities to learn from patients as researchers – how are patients engaged in helping to plan services and to apply research? I would like to attend events where patients have set it up and are at the core, not token add-ons.</p>