Building Momentum for Patient Engagement in BC Research

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

May 2016
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Acknowledgements

We would like to extend our sincere thanks to all of the participants who gave their time to be interviewed and to provide feedback on initial drafts of this document. Their input has proven to be invaluable in shaping the patient engagement plan being developed by the BC SUPPORT Unit. (See *Building Momentum – Appendices 2 and 3* for a list of participants and interview notes.)

Executive Summary

Background

The BC SUPPORT Unit (Support for People and Patient-Oriented Research Unit/the Unit) is a multi-partner organization preparing to support, streamline and increase patient-oriented research throughout British Columbia. We define patient-oriented research as research that engages patients as partners and focuses on patient-identified priorities with the goals of improving patient experiences, health outcomes and the health system.

The Unit is developing a patient engagement plan to guide its work in this area. To begin to understand the current state of patient engagement in BC and help plan for the future, interviews were conducted in the fall of 2015 with 27 health researchers and other professionals who have engaged patients in patient-oriented research or other initiatives to improve the health of the population and the health care system.

Interview participants were recruited through referrals from the BC SUPPORT Unit Interim Operations Team and Interim Governing Council, and also through the Unit’s newsletter. The interviews were conducted by phone and consisted of 12 standardized questions. Interview notes were taken, and a draft was sent to each interviewee for verification before being included in the report. The interview questions covered topics such as what roles patient partners have played in quality improvement or health research and how they have been recruited; how health care and health research professionals have ensured patient partners play a meaningful role; whether they have trained patients, whether they have received training in how to engage patients, and whether they would like to receive training; how they have supported patient partners otherwise in terms of compensation or project preparation and follow-up; and whether they were aware of opportunities to learn about patient-oriented research.

Summary of Findings

The interviews reinforced that there are many positive things happening in the realm of patient engagement in British Columbia. Patients appear to be engaged in a wide variety of ways from consultation through more active involvement as decision makers on governing councils and boards; examples were collected and will be an important resource for the SUPPORT Unit as we finalize our plan.

Despite the active involvement of patients in health care and health research, interview responses suggest there is quite a bit of variation in terms of the amount and formality of training that patient partners receive; an opportunity exists to standardize training for various levels of involvement and to develop a provincial approach and mechanism for such training. There also seem to be a lack of opportunities for patient engagement training for researchers, health care partners, and other stakeholders – but a high degree of interest in such training.
Responses about how patient partners are supported raised one issue in particular: whether or not patient partners should be financially compensated for their time and expertise. The inconsistencies among approaches lead to questions of fairness and equity. However, there are also questions of financial sustainability and how these might be balanced.

Twelve of the interviewees spoke about patients being credible when they were well-educated and articulate or when they were properly oriented by Patient Voices Network to understand that they should not act as advocates or “get on a soap box”. This raised the issue of how to engage patients from populations that require more support. As far as representation, it appears that in many cases one or two patients are asked to represent populations, even though this is less than ideal and may lead to tokenism.

A wide variety of recruitment mechanisms were provided, suggesting that if patient engagement in research is to increase in BC, it will be important to explore the ethics of approaching patients directly to be involved in health research other than as a study subject. An opportunity also arises for a provincial mechanism to connect patients and research teams.

In summary, the interviews highlighted:

- A need for increased patient-oriented research training opportunities for all stakeholders: patients, researchers, clinicians, and health system decision-makers.
- A need for a provincial mechanism to connect patients and research teams for research projects, but also for dialogue on emerging issues related to patient engagement.
- The question of how to support patients from vulnerable and marginalized populations to become credible members of research teams, and how to ensure that there is adequate representation from a population of interest.
- The question of how to ensure that all parties understand the patient role and the degree to which they have power to influence decisions.
- A need to discuss the ethical considerations of engaging patients in health research, including how to ensure fairness and equity when supporting patients to engage.

Next Steps

Next steps in the development of the plan are to circulate this report to a wider audience, ensure close connections with individuals and organizations beyond the Unit that are involved in patient engagement, conduct further research, and create opportunities to discuss issues that need to be resolved to complete the plan.

When finalized, the BC SUPPORT Unit patient engagement plan will address training in patient engagement for all stakeholders, connecting patients with researchers and other stakeholders, advancing the science of patient engagement in research, appropriate policies and procedures, and raising awareness about the importance of patient engagement in research.
Introduction

The BC SUPPORT Unit (Support for People and Patient-Oriented Research Unit/the Unit) is a multi-partner organization preparing to support, streamline and increase patient-oriented research throughout British Columbia. We define patient-oriented research as research that engages patients as partners and focuses on patient-identified priorities with the goals of improving patient experiences, health outcomes and the health system. The Unit will have two main roles: providing services to researchers, patients, health care providers and health system decision makers, and facilitating initiatives identified as provincial priorities.

The Unit is one of several SUPPORT Units being established across the country as part of Canada’s Strategy for Patient-Oriented Research (SPOR) led by the Canadian Institutes of Health Research (CIHR). It is also part of the BC Academic Health Science Network (BC AHSN) established in February 2016, with the network’s interim board providing governance and oversight.

The Unit’s patient engagement work will consist of several elements: training in patient engagement for all stakeholders; providing a website to recruit patients and connect them with research teams; developing policies and guidelines related to patient engagement; and advancing the science of patient engagement. To guide this work, the Unit is developing a patient engagement plan that will be provided to CIHR by September 2016 for review as part of the Unit’s overall implementation and operations plan.

To inform this planning, the Unit’s interim patient & stakeholder engagement lead, Colleen McGavin, conducted interviews in the fall of 2015 with 27 health researchers and other professionals in BC who have engaged patients in patient-oriented research or other initiatives to improve the health of the population and the health care system. The interview project had three main aims: to begin to create an asset map of people and resources dedicated to patient engagement, to get a sense of the “state of the science” of patient engagement in BC, and to start to build a community of practice.

This report presents the findings of those interviews. It proceeds with definitions, followed by methods, results, a discussion, and conclusions and next steps. Following the report, Appendix 1 explains the spectrum of participation in patient engagement as defined by the International Association of Public Participation (IAP2). The companion document, Building Momentum – Appendices 2 and 3, lists the interview participants and their responses (without connecting participants to individual responses).

Definitions

For the purposes of this project, the following definitions are used:

**Patient** – Individuals with personal experience of a health issue and informal caregivers, including family and friends. Note: It is recognized that some groups and individuals prefer terms such as *people with lived experience, clients, consumers or community members*, and these alternatives appear throughout the responses provided by the interview participants.

**Patient engagement** – Working with patients along a spectrum ranging from consultation, to involvement, to collaboration and empowerment (see Appendix 1 for an explanation of the International Association of Public Participation (IAP2) *Spectrum of Participation*).
**Patient-oriented research** – Research that engages patients as partners, focuses on patient-identified priorities, and is conducted by multidisciplinary teams in partnership with stakeholders.

**Methods**

Snowball sampling was used to find interview participants, starting with people identified by the BC SUPPORT Unit Interim Operations Team and Interim Governing Council. An announcement of the project inviting participation was also included in the Unit’s newsletter posted online and distributed by email. The target group was people who engage patients in either health care quality improvement or health research.

For researchers, it was specified that the project sought to involve those who engage patients as other than study subjects. People who engage patients in health care quality improvement were included because there is a relatively well-established history of patient engagement in that realm as opposed to in the realm of health research and it was assumed there would be commonalities in terms of how both groups recruit, train and support patient partners. Participants included patient experience and patient engagement leads in health authorities, academic and clinical researchers, knowledge translation experts, and representatives of not-for-profits. People who would identify primarily as patients were not interviewed for this project but will be engaged in other aspects of the patient engagement plan.

The interviews were conducted by phone and consisted of 12 standardized questions. Each interview lasted approximately one hour. Notes were taken and a draft was sent to each interviewee for verification before being included in this report. Permission was sought to share the notes and to include identifying information such as names, title and organization, and all participants agreed. Interviewees were sent a draft of this report and given an opportunity to provide feedback before its publication.

Results are summarized in the question-by-question reporting below – including quotes that typify themes that emerged – and discussed broadly in the final section of the report. Because this was an initial set of interviews designed for broad understanding of the patient engagement in research environment in BC, answers were not analyzed according to stakeholder type, region of the province, years of experience and so on. Analysis of such factors may be important in the development of specific parts of the Unit’s patient engagement plan.

**Results**

1. How do you identify yourself?

   Participants were given a list of categories (see chart below) and asked how they would identify themselves. The categories were loosely based on stakeholder categories referenced in the BC SUPPORT Unit business plan. “Patient” was included as a category even though the interviews did not specifically seek patients to interview; the argument is often made that “we are all patients at one time or another.” Participants were welcome to choose more than one option and 16 people identified with more than one role. Four people did not identify with any of the professional categories listed; responses under “Other” included: patient engagement lead; facilitation; health system change support; and evaluator. Two people chose patient as well as one other role.
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 this work?

Participants were asked whether their work with patients is primarily related to quality improvement or health research, because there seems to be some overlap in discussions about patient engagement, and it may be important to understand the similarities and differences as well as what the BC SUPPORT Unit can learn from the former as it develops research-focused services and support.

Quality improvement work typically focuses on making positive change in three dimensions: patient experience, health outcomes, and the sustainability of the health care system overall.\(^1\) It uses various formal approaches such as Plan-Do-Study-Act (PDSA) and lean.\(^2\)

Research is “investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts, or practical application of such new or revised theories or laws”.\(^3\) Formal research is governed by accepted practices, methodologies and rules covering such areas as ethics approval, which may not apply to quality improvement work.

There was some overlap with four individuals describing a mixture of quality improvement and research activities. A wide range of projects that engage patients were described. See Building Momentum – Appendices 2 and 3 for a full description.

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3. What roles do your patient partners play in the work?

Interviewees were given a list of roles common to research, as shown in the chart below, and asked to check off which roles patients played in their projects. Results in the chart are sorted by frequency. An option to identify other roles was given. Other roles identified include:

- Refining initiatives for relevance to the hospital setting
- Providing local knowledge of the politics or linkages with decision- and policy-makers
- Advocacy with federal & provincial governments; petitions; awareness building through fundraising events
- Mentoring graduate students/trainees

<table>
<thead>
<tr>
<th>Role</th>
<th>Frequency</th>
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<tbody>
<tr>
<td>Peer review committee</td>
<td>20</td>
</tr>
<tr>
<td>Principle investigator or co-PI on grant app</td>
<td>18</td>
</tr>
<tr>
<td>Governance body</td>
<td>16</td>
</tr>
<tr>
<td>Analyzing study results</td>
<td>14</td>
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<tr>
<td>Strategic planning committee</td>
<td>12</td>
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<tr>
<td>Designing research study</td>
<td>10</td>
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<tr>
<td>Conducting the research - e.g. peer interviews</td>
<td>8</td>
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<tr>
<td>Knowledge user on grant applications</td>
<td>8</td>
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<tr>
<td>Knowledge translation - e.g. dissemination</td>
<td>6</td>
</tr>
<tr>
<td>Determining/fine-tuning research question</td>
<td>6</td>
</tr>
<tr>
<td>Ad hoc advisory committee</td>
<td>4</td>
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<tr>
<td>Ongoing working group</td>
<td>4</td>
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<tr>
<td>Ongoing steering committee</td>
<td>4</td>
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<tr>
<td>Participant on priority setting activity</td>
<td>4</td>
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<tr>
<td>Ongoing advisory committee</td>
<td>2</td>
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<tr>
<td>Editing/refining for plain language</td>
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<table>
<thead>
<tr>
<th>Research Role</th>
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<tr>
<td>Quality Improvement</td>
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<td>0 2 4 6 8 10 12 14 16 18 20</td>
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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?

This question draws on the work of Antoine Boivin et al. in a study entitled What Are the Key Ingredients for Effective Public Involvement in Health Care Improvement and Policy Decisions? A Randomized Trial Process Evaluation.³ Three main theoretical constructs were proposed to explain the public’s influence on collective health care decisions: (1) public members’ credibility and ability to contribute knowledge that is considered valid and relevant to inform collective health care decisions, (2) their legitimacy to speak on behalf of people affected directly or indirectly by health care services and policies, and (3) their power and ability to influence collective health care choices.

Credibility

Credibility and legitimacy were conflated by 18 of the interviewees, and generally described in terms of the patient’s ability to participate constructively, often by virtue of having been properly selected, vetted and trained.

Commonly, interviewees stressed that credibility is automatically accorded to the patient by virtue of their lived experience.

But there was another dimension that emerged with 12 of the interviewees: credibility was ascribed by virtue of having personal qualities such as being articulate, well-educated and not an advocate.

“It’s clear we need people with experience who also have the preparation (i.e., contextual knowledge) and understanding of the specific engagement.”

“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.”

“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’re more credible and legitimate than the researchers because they’re the experts on their body ad they experience and understand how a treatment feels and how it impacts their quality of life.”

“How are they not [credible]!? Experience = Knowledge.”

“We trial and error people [and] favour those who are well educated, well-spoken and don’t use their involvement as a soapbox.”

Legitimacy

As defined in the question and explained during the interview process, legitimacy relates to the idea of how representative someone is: does the patient have connections to other patients so they can speak for a broader perspective? Eight interviewees spoke to the fact that one or two patients cannot always adequately represent everyone who has experience with a certain situation, disease or condition.

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“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 patient’s experience does in fact apply everywhere.”

“Legitimacy [is about] helping the patient partner convey the findings in a way that represents the broader population which required training/coaching and communicating to see that it’s not just about their experience or story – i.e., “their story” vs. “our story…”

“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.”

Power

Often, the power given to patients was dependent upon the attitudes of those leading the project as well as by how decisions are made, for example, by consensus. Organizational leadership and buy-in were also seen as critical.

Power was found to be more formalized – through terms of reference and governance structures – within not-for-profits such as the Rick Hansen Institute and the Rare Disease Foundation where patients sit on the boards.

“We empower patient advisors when we operate in a group that makes decisions by consensus.”

“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.”

“Power...comes from good facilitation. The facilitator should ensure that the patient partner’s voice is heard...that they have opportunities to speak.”

“You shouldn’t privilege anyone’s power, the 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. 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.”

“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 question of why research matters; now we need a dialogue about why patient engagement matters.”

“The RHI Board of Directors includes individuals with a spinal cord injury.”

“The board of the [Rare Disease Foundation] is parent and/or patient dominated.”
5. What mechanisms do you employ for finding patients to engage with?

This was an open-ended question intended to inform development of the patient engagement plan. Mechanisms cited included:

- Organizational contacts (e.g. Patient Voices Network, direct approach by clinicians and care providers, health authority patient advisory councils)
- Websites and social media
- Networking (e.g. community events, presentations at conferences)
- Personal contacts (e.g. word of mouth, snowball sampling)

6. Do you provide any kind of training for patient partners in their roles?

Three interviewees described training materials (e.g. workbooks and manuals) that have been developed and are being used. In the other cases, the answer to this question was that training was done informally, on a just-in-time basis, often one-on-one. Patient Voices Network was mentioned three times under this question and seven times under Question #4 at least in part because of the orientation and training they offer to volunteer patient partners who work in health care quality improvement. Some researchers provide relatively extensive training, especially for specific tasks such as how to conduct a focus group or code qualitative data.

"I meet with the patient personally to orient them to their role..."

"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.)"

"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."

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?

Three researchers reported being trained in methodologies such as participatory action research and community based research, but more often than not, formal training in patient engagement was rare. However several interviewees identified the transferability of knowledge and skills from other disciplines and realms of their life. They also talked about how experience is a teacher. In addition, several sources were identified, including International Association of Public Participation (IAP2), and webinars by the BC Patient Safety & Quality Council and the Canadian Foundation for Healthcare Improvement (CFHI).

"...indirectly in my master’s degree in conflict analysis and management...”

"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 and have put those things into practice.”

"No but I’ve been doing this for over a decade.”

8. Would you be interested in this kind of training?

Overwhelmingly, the majority of those interviewed are interested in training opportunities. One person said no. In four cases, there were reservations.
“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.”

“For sure, but only so much time in the day. Would probably delegate to someone with more time.”

“Depends on how generic it is…”

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?

Perhaps due to the wording of the question, there was a lot of focus on reimbursement and financial compensation. In general, those who engage patients in health care quality improvement reimburse patients for out-of-pocket expenses such as mileage and parking but not for their time. Often, refreshments are provided at meetings but not always. Budgets are often described as being tight and measures such as meeting by teleconference rather than in person are sometimes taken to reduce costs.

It is more common for patients involved in research to be compensated for their time through honoraria or other means such as gift cards, or by having the opportunity to travel to attend or present at a conference. The Rick Hansen Institute is developing some paid positions for consumers within research projects.

Other ways to support patient partners included:

- locating meetings at places that are easy to get to
- attending to care requirements (e.g. nursing care, food and flexibility in attendance)
- affording patients enough time to say what they need to say
- providing a safe environment

“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).”

“We ask our patient partners about what supports they need/what barriers may get in the way of their involvement, what’s holding you back? For example, babysitting money, mood states. We look for career, training and networking opportunities.”

“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.”

10. Can you provide me with the names of any other individuals who are doing this kind of work? Answers to this question have been noted and will be followed up on as time permits.
11. Are you aware of any opportunities to learn about patient-centred care or patient-oriented research?

Participants were asked to identify opportunities to learn about patient-centred care or patient-oriented research. A number of resources were recommended for follow-up, including:

- Patient Centered Outcomes Research Institute (PCORI)
- Patients as Partners | Patient Voices Network
- Canadian Foundation for Healthcare Improvement (CFHI)
- BC Patient Safety & Quality Council
- Institute for Patient & Family Centered Care (IPFCC)
- National Youth in Care Network, Federation of Community & Social Services (FCSS)
- Global Advisory Board (knowledge translation organization)
- Experience Innovation Network (knowledge translation organization)
- North American Primary Care Research Group (NAPCRG)
- International Society for Quality of Life Research (ISOQOL)

12. Any other comments:

Participants were offered an opportunity to provide additional comments in this open-ended question. Answers were quite varied but some thoughts were repeated and so bear mentioning. A number spoke about their excitement over the momentum that is building in this field. Others talked about valuing the patient experience more highly as evidence. People expressed a desire to connect and to have future conversations about things such as defining appropriate methodologies for patient-oriented research and how to engage marginalized and vulnerable populations. Participants commented that they had learned a lot about SPOR and patient engagement by doing the interview itself. Comments can be found in Building Momentum – Appendices 2 and 3.

“This is an area that is growing so rapidly in health care ... the excitement and momentum is incredible!”

“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).”

“Some of the questions in this interview have helped me to learn (e.g. ones about evaluation and training).”

Discussion

A discussion of the interview questions and responses follows.

Question 1 attempted to categorize interviewees by their roles. While some people identified as “health system decision makers,” there was some confusion as to what this term refers to. The BC SUPPORT Unit defines this group as those who have authority for policy and funding decisions within the health system; interviewees interpreted it more generally as those with decision-making authority within their jobs. The responses highlighted the need for role clarity as stakeholders are engaged in patient-oriented research in general (i.e., “What hat am I
wearing at this table? Who can I speak for? How much influence do I have?”) and also suggests a need to engage with more senior decision makers as the patient engagement plan develops, for awareness and buy-in.

Question 2, which asked people to provide an overview of their work in patient engagement, provided a valuable collection of case studies and an important resource for further follow-up. Full descriptions can be found in Building Momentum – Appendices 2 and 3.

In Question 3, interviewees were given a checklist and asked to indicate which roles their patient partners play. This checklist was keyed to the International Association of Public Participation (IAP2) spectrum (see Appendix 1) in an attempt to document the frequency of engagement at the various levels. Due to time constraints, the interviewer made little effort to probe as to whether there was a common understanding of the role titles or how frequently a given role occurs. As such, all that we can conclude from the answers provided is that patients appear to be engaged in a wide variety of ways all along the spectrum – for example at the consultation level as ad hoc advisors; at the involve level as members of on-going advisory and working groups; and at the collaborate and empower levels through roles on governing councils and boards. While this is good news, it will be important to explore what is necessary to prepare patients to engage at these very different and specific levels, and what kinds of training are needed for the different skills that are required.

The answers to Question 4 concerning credibility, legitimacy and power highlighted a need for further discussion about the different interpretations of the word “credibility,” as well as how to ensure legitimacy and power. With regards to credibility, in the Boivin study, they concluded that: “Their [patients’] credibility was supported by their personal experience as patients and caregivers, the provision of a structured preparation meeting, and access to population-based data from their community.”

The findings echoed the first two of those conditions; however, another dimension of credibility emerged that was not consistent with Boivin’s findings. Several interviewees spoke about how people are credible when they are relatively well-educated and articulate individuals who are trained not to “advocate” or “get on a soap box.” It seems that such individuals are viewed as being credible because they are easy to work with and to support in terms of time and money. The problem is, the highest priorities for research often concern populations which, more typically, require more time and financial resources; for example, people with mental health and substance use issues, youth, seniors and First Nations. And yet, if one applies the description used by many who were interviewed, those individuals would be deemed to be not credible. This leads to the question of what needs to happen to support people from marginalized and vulnerable populations to become involved.

The question about legitimacy surfaced a picture that is consistent to Boivin et al; that is, that legitimacy is “fostered by the recruitment of a balanced group of participants and by the public members’ opportunities to draw from one another’s experience.” In many cases, however, it appears that one or two patients are asked to represent groups, even though this is less than ideal and may lead to tokenism. Some groups have recognized this problem and interviewees spoke to how they are attempting to address it; for example, by reaching out to organizations with links to many patients so that more sampling can be done through such methods as surveys and focus groups.

According to Boivin et al., power is fostered through “the combination of small-group deliberations, wider public consultation, and a moderation style focused on effective group process [to] level out the power differences between professionals and the public.” Of all these enablers, a moderation style focused on effective group

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5 Boivin et al., p. 322.
6 Boivin et al., p. 322.
7 Ibid.
processes was most often talked about. It appears that patients are afforded power by those who are leading a given project. In most instances, this appears to be working, at least from the perspective of the researcher or quality improvement person; however, it gives rise to the question of whether power structures may need to be formalized in order to ensure that patients are not patronized. It would be necessary to ask patients how they feel about their experiences during these engagements to know.

Question 5 yielded a wide range of ideas for where to recruit patient partners and these are documented in the reporting section. Although there are many good ideas and practical mechanisms, with the increasing involvement of patient engagement in research, an opportunity arises for a provincial mechanism to connect patients and research teams.

Also important to explore is the ethics of recruitment – specifically, the ethics of approaching patients directly to be involved in health research other than as a study subject. The key to understanding this issue may be in the qualifying term “active.” While the Canadian Institutes of Health Research (CIHR) has not yet published a policy on this subject, other organizations, for example INVOLVE in England, have. At INVOLVE, the thinking is that when patients are meaningfully and actively involved in roles other than as study subjects, the same rules (i.e., informed consent) need not apply.\(^8\) The BC SUPPORT Unit will need to take this issue into consideration as it develops policies and guidelines.

The answers to Question 6, on training, suggest that there is quite a bit of variation in terms of the amount and formality of training that patient partners receive. Anecdotes from patient partners who were consulted separate from this project suggest that training is essential for a successful engagement experience; further study will be important to find out what the patient experience has been and what patients themselves feel they need in terms of training, which will inform our patient engagement plan as well.

Questions 7 and 8 reveal that there is a lack of opportunities for patient engagement training for researchers, health care partners, and other stakeholders while, at the same time, a high degree of interest in such training. This supports the need to develop formal education and training in methodologies for researchers and others such as clinicians and policy decision-makers to authentically include patients in research.

Question 9 concerning how patient partners are supported raised one issue in particular: whether or not patient partners should be financially compensated for their time and expertise. The inconsistencies among various groups leads to questions of fairness and equity. However, there are also questions of financial sustainability and how these might be balanced. Other organizations are beginning to address this question, and the BC SUPPORT Unit can learn from their experiences. In addition, as of January 2016 the Unit is participating in a national initiative of the CIHR SUPPORT Unit patient engagement working group to develop recommendations on this subject that, if implemented, would lead to guidelines that would apply to SUPPORT Units across Canada.

Questions 10 and 11 yielded numerous resources for learning more about patient-centered care or patient-oriented research, which have been catalogued for future reference. These include the names of other individuals who could be interviewed and quite a few organizations, articles and events from which more could be learned. Finally, Question 12 provided an opportunity for interviewees to underscore their views or to add related thoughts.

Conclusions and Next Steps

The interviews reinforced that there are many positive things happening in the realm of patient engagement in British Columbia. Ideas were gleaned for how to successfully recruit, train and support patients. Contacts were made and there now exists the beginnings of a community of practice within the province. The interviews surfaced a number of resources and pointed to some themes that may require further thought as the practice of patient engagement matures and spreads. All of this is informing the patient engagement plan under development for the BC SUPPORT Unit.

The themes that surfaced include:

- A confirmed need for increased patient-oriented research training opportunities for all stakeholders: patients, researchers, clinicians, and health system decision-makers.
- A need for a provincial mechanism to connect patients and research teams for research projects, but also for dialogue on emerging issues related to patient engagement, and ongoing improvement.
- The question of how to support patients from vulnerable and marginalized populations to become credible members of research teams.
- The question of how to ensure that there is adequate representation from a population of interest and thus to avoid tokenism.
- The question of how to ensure that all parties understand the patient role and the degree to which they have power to influence decisions.
- A need to identify the next generation of ethical considerations when patients are engaged in health research.
- The question of how to ensure fairness and equity when supporting patients to engage in health research while balancing considerations of financial sustainability.

Next steps in the development of a patient engagement plan for the BC SUPPORT Unit are:

- Circulate this report to a wider audience through the BC SUPPORT Unit communications channels.
- Ensure close connections, and partnering, where appropriate, with CIHR nationally, SUPPORT Units across the country, and Patient Voices Network in BC, on elements of the BC patient engagement plan.
- Conduct further research, environmental scanning as required for the plan (e.g., patient experience of health research).
- Create opportunities to discuss issues related to effective patient engagement that need to be resolved for the development of the plan (e.g., forums, working groups, consultations).
- Finalize the plan in the context of the BC SUPPORT Unit goals. The plan will address:
  - Providing training in patient engagement for all stakeholders.
  - Developing and maintaining a provincial website to connect patients with researchers and other stakeholders.
  - Ensuring meaningful and active engagement in governance, priority-setting, the conduct of research, and knowledge translation.
- Furthering the science of patient engagement research.
- Developing policies and guidelines related to patient engagement in research.
- Raising awareness and generating buy-in of the need for patient engagement.
Appendix 1 – International Association of Public Participation (IAP2) Spectrum of Participation

**Range of activity level** – Participants become more active and more empowered as you move from left to right. All levels – from consult to empower – are valid.

**Inform** – You will be kept informed. The inform level is not what we’re talking about.

**Consult** – We will listen to you and acknowledge your concerns and aspirations. Invitation to provide input or feedback on solutions others will develop or have developed. E.g., patients are invited to give feedback on an intervention that is being developed by a research team.

**Involve** – We will work with you throughout the process to ensure that your concerns and aspirations are directly reflected in the alternatives developed. E.g., 1) patients are involved in the development of a grant application and help to determine the research methodologies and end points for the study; 2) patients conduct focus groups and interviews as part of a qualitative study.

**Collaborate** – We will partner with you in each aspect of decision-making, including the development of alternatives and the identification of the preferred solution. Everyone is respected for the particular expertise they bring to the table. Patients bring their lived experience – something the researcher may not typically have. E.g., patients sit on a steering committee for a major study.

**Empower** – We will implement what you decide – e.g., parents sit on the board of a non-profit foundation. The foundation approves funding for research. Parents have an equal vote in who gets funded.

Adapted from: Planning for Effective Public Participation, International Association for Public Participation (IAP2) (2006)