



# Patient Voices Network

ADMINISTERED BY  
BC PATIENT SAFETY & QUALITY COUNCIL



**ANNUAL 2020  
REPORT 2021**



## **At a Glance**

**Message from Our Oversight & Advisory Committee Chairs**

**Message from the BC Patient Safety & Quality Council**

**About Us**

**PVN By the Numbers**

Highlights from 2020/2021

**Engagement in Action Across BC**

Interior: Collaborative Heart Attack Management Program, BC Emergency Health Services & Interior Health

Fraser: Patient Engagement in Quality Improvement at Burnaby Hospital

Coastal: Virtual Psychiatry Consultations, Providence Health Care

Island: Comox Valley Primary Care Network

North: A Guide to Compassionate Phone Conversations During COVID-19, Northern Health

Provincial: Digital Health Policy Advisory Groups, Ministry of Health

Provincial: Advance Care Planning for Dementia, BC Centre for Palliative Care

**Featured Projects**

Patient Partner Connections

Patient Partner Ambassadors

“What Matters To You?”

Advancing Diversity, Equity & Inclusion

Indigenous Inclusion Group & All Nations Gathering

**Capacity Building for Patient Partners**

Sponsored Learning Opportunities

New Resource: Working Together Virtually

New Training: Zooming Together

**PVN Process Improvements**

New PVN Orientation

New PVN Website

**Looking Ahead**

Strategic Planning

Thank you



## Message from Our Oversight & Advisory Committee Co-Chairs

When we held the Patient Voices Network's 10-year anniversary celebration at the Quality Forum in February 2020, none of us could have anticipated that we would soon find ourselves in the middle of a global pandemic. Like so many of you, our focus had to change quickly: we had to adapt to working from home, physically distance ourselves from those we love and change how we support improvement in our health care system. All of these changes came with unique challenges and despite them, or perhaps because of them, your continued engagement and contributions remained strong.

With a shift in focus came a chance to pause and ask PVN patient partners about their priorities during these unique times. What we heard is that they wanted to:

- Virtually connect with other members of the network
- Receive support to continue current engagement activities virtually
- Continue to participate in learning opportunities
- Ensure PVN processes consider diversity, equity and cultural safety
- Take more of a shared leadership role within the network

The BC Patient Safety & Quality Council, which administers PVN, then asked patient partners to co-create recommendations and ideas to act on those priorities. With your feedback, we launched our PVN Connections Café and a new PVN website, and updated many of our engagement processes and resources to ensure they are inclusive and promote cultural safety. We also supported 153 network members to attend education and conference opportunities to continue their health care system, patient engagement and quality improvement learning journeys.

Throughout this report you will find many examples of incredible work from PVN patient and health care partners. We hope you enjoy reading their stories and, on behalf of the PVN Oversight & Advisory Committee, we would like to offer our tremendous gratitude to our network members.



**Pamela Jessen**

Patient Partner

Co-Chair

PVN Oversight & Advisory Committee



**Tammy Hoefler**

Director, Patient & Public Engagement

BC Patient Safety & Quality Council

Co-Chair

PVN Oversight & Advisory Committee



## Message from the BC Patient Safety & Quality Council

The past year showed how responsive and collaborative our health care system can be when faced with a challenge as complex and unfamiliar as COVID-19. We're thankful to the patient and health care partners who quickly adapted to virtual engagements and new ways of working together – the many accomplishments and projects profiled in this report are wonderful examples of your perseverance and dedication.

But the year also exposed major challenges and gaps in the system. The impact of infection control measures on family presence and visitation access in acute and long-term care was very difficult for many, and highlighted the critical role that families and caregivers play in the care of patients and residents. The *In Plain Sight* report shared devastating examples of Indigenous-specific racism, and a *Health Equity Collaborative* report identified significant barriers to health equity for sexual and gender diverse communities.

These issues expose the fragility and inequity of recent progress to engage patients, families and caregivers as partners in care and improvement. They also underscore why it is imperative to ensure that every person in British Columbia can receive high-quality care which is culturally safe and person-centred. We can and must do better.

The BC Patient Safety & Quality Council is committed to advancing patient engagement, and our administration of the Patient Voices Network is a key component of this work. We are committed to taking action against Indigenous-specific racism in the health care system, and to improving diversity, equity and inclusion within our organization and through our initiatives such as PVN.

We are deeply appreciative of all the patient and health care partners who helped make our health care system better over the past 12 months and we look forward to seeing your impact in the year ahead.



**Christina Krause**  
Chief Executive Officer



**Devin Harris**  
Chair



**BC PATIENT SAFETY  
& QUALITY COUNCIL**  
Working Together. Accelerating Improvement.



## About Us

The Patient Voices Network (PVN) is a community of patients, families and caregivers that has been working with health care partners to improve BC's health care system since 2010. Supported through funding from the BC Ministry of Health and administered by the BC Patient Safety & Quality Council, PVN works to include patient voices in problem-solving and decision-making in health care across the province.

Our mission is to advance authentic patient engagement by building our partners' capacities and capabilities so that person- and family-centred care becomes the foundation on which all health care decisions are made. PVN's operations and activities are guided, co-designed and supported by an Oversight & Advisory Committee consisting of patient partners from across BC and an equal number of representatives from health care organizations and the Ministry of Health. Learn more about our work at [PatientVoicesBC.ca](https://PatientVoicesBC.ca).

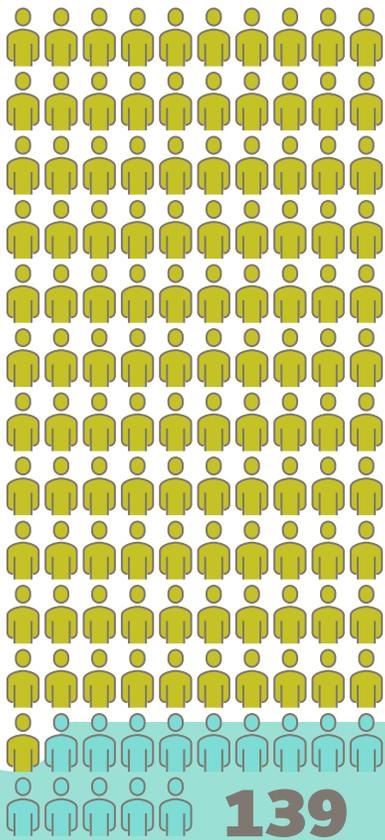


## Highlights from 2020-2021

### PVN Patient Partners

**1251**

Total Patient Partners overall



**139**

Total New Patient Partners  
in 2020/21



**215**

New Engagement Opportunities  
(started in 2020/21)

NOTE: Of these 215, 19 were withdrawn,  
9 are on hold and 9 could not be filled

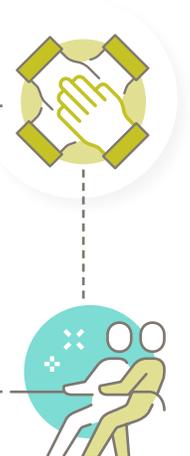
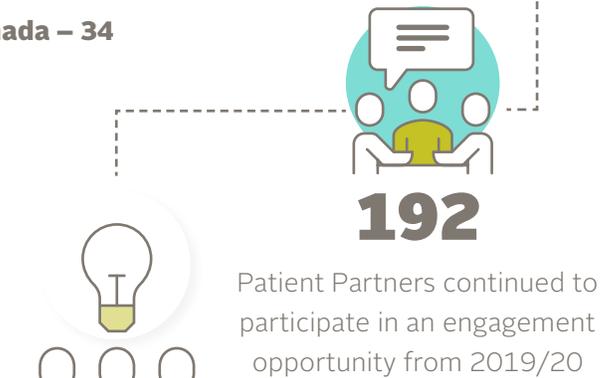
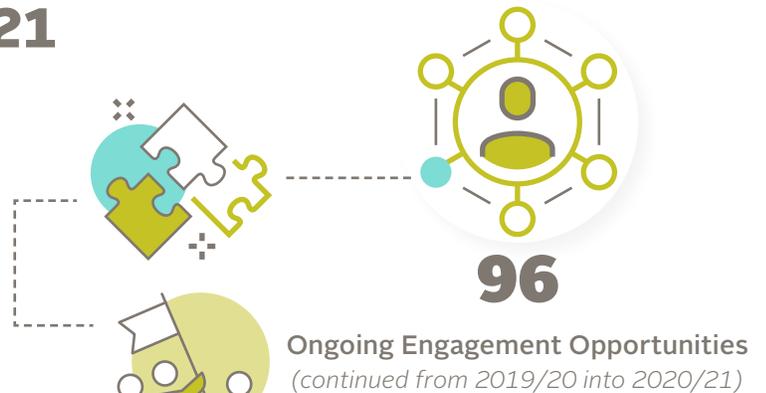
### Diversity

- LGBTQIA2S+ – 56
- Person with disabilities – 85
- Indigenous (First Nations, Inuk/Inuit or Métis) – 112
- Person of colour – 90
- Newcomer to Canada – 34
- Other – 48

### New Patient Partners Diversity

- LGBTQIA2S+ – 17
- Person with disabilities – 31
- Indigenous (First Nations, Inuk/Inuit or Métis) – 16
- Person of colour – 24
- Newcomer to Canada – 7
- Other – 12

NOTE: This information is indicated at the time of sign-up.  
As these questions are optional, this data may not accurately  
capture the diversity within PVN. Some individuals identify with  
more than one group.



## Highlights from 2020-2021

### IAP2 – level of engagement

NOTE: IAP2 levels are a spectrum, not a hierarchy.  
One level is not better than another.



**11**  
Inform



**50**  
Consult



**59**  
Involve

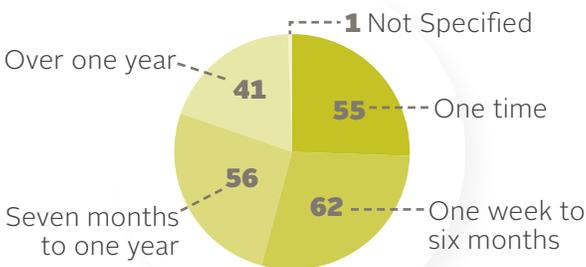


**95**  
Collaborate



**0**  
Empower

### Commitment



### Region



**135**

health care teams submitted an engagement opportunity

**737**

patient partner roles in new engagement opportunities

**378**

patient partners participated in an engagement

**1,075**

RSVPs submitted for new engagement opportunities

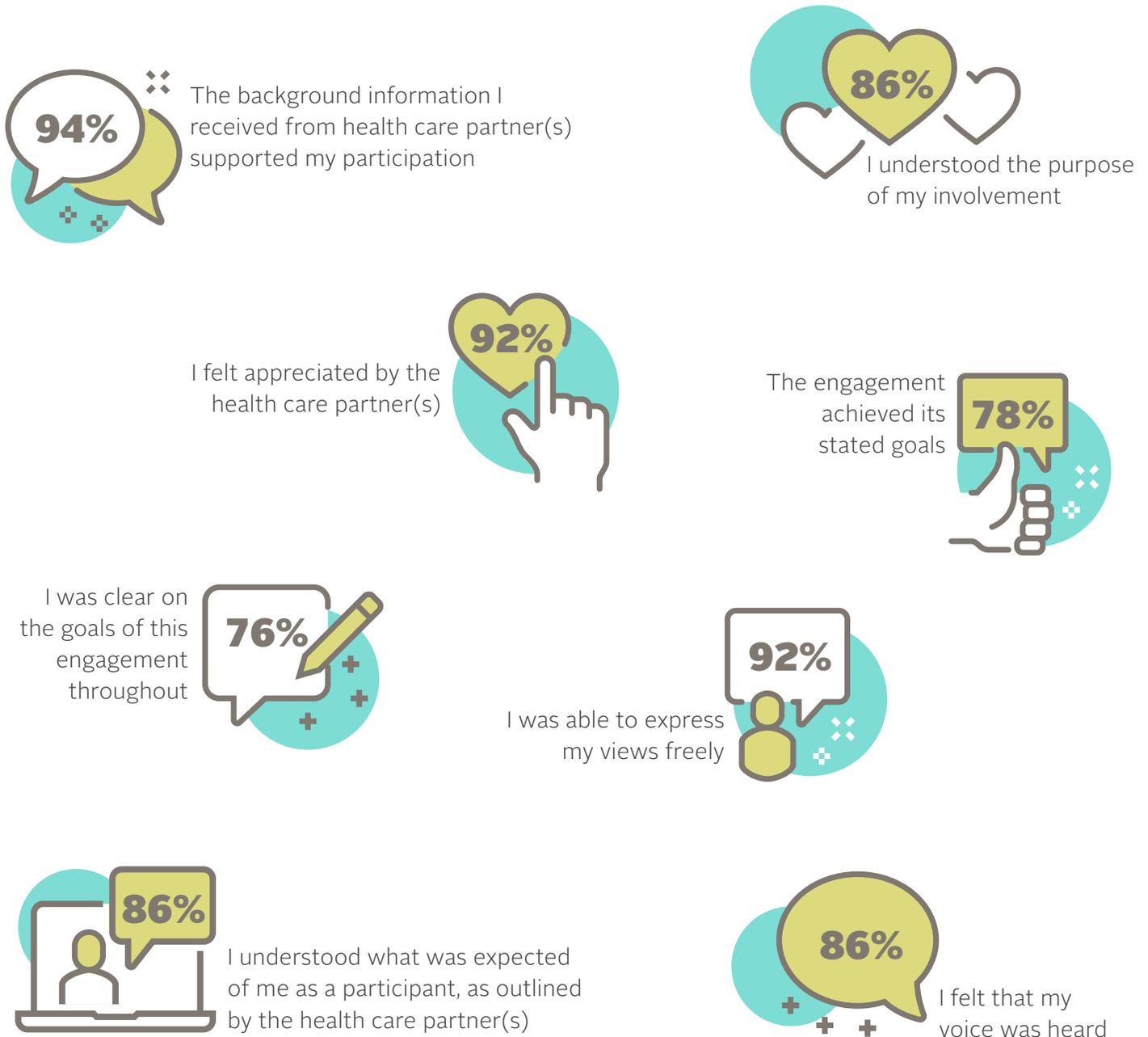
**39%**

of patient partners RSVP'd to at least one opportunity in 2020/21

## Highlights from 2020-2021

### End-of-Engagement Surveys

When an engagement is over, patient partners are asked to complete a short survey. Of the 50 patient partners who responded to end-of-engagement surveys in 2020/21:





## Engagement in Action Across BC

### Collaborative Heart Attack Management Program BC Emergency Health Services & Interior Health

Timely access to care is always important, and especially so when every passing second adds to a patient's risk of a negative outcome – as in the case of a heart attack.

Sumandeeep Dhesi, a cardiologist at Interior Health's Royal Inland Hospital, recognized that precious time was lost by waiting until patients arrived at a hospital to administer life-saving medication (called thrombolysis). Inspired by a model used in Alberta and motivated by newly updated Canadian Cardiovascular Guidelines, Sumandeeep and Interior Health cardiologists partnered with BC Emergency Health Services to pilot a program that would train advanced care paramedics to administer therapeutic clot-busting medication in the field. The Collaborative Heart Attack Management Program (CHAMP) was on a mission to save time and lives.



#### Including The Patient Voice

In the spring of 2019, the multidisciplinary CHAMP team invited PVN patient partner Don Grant to join its quality improvement work. Don, a longtime patient partner with personal experience of coronary artery disease, was keen to get involved.

“I live a reasonable distance from the hospital, so without a drug and program like this...well, it's really a game changer. Plus, I have always been drawn to lights and sirens,” he shared with a laugh. “It's important to me that the voices of the people who will benefit are well heard.”

Don's participation was not intended to influence the actual treatment protocol – that came from evidence and national guidelines. Rather, he helped ensure that efforts to implement the protocol prioritized patients' needs, experiences and outcomes.

Anders Ganstal, a Regional Medical Director with BC Emergency Health Services, collaborated with Sumandeeep on the CHAMP program and acknowledges the fundamental value of patient partner participation.

“With any sort of project implementation, it is really important to ask the people that are using the program, and those who will be receiving the program, for their thoughts on how to best



make the program work. If we are far removed from those people, then we are going to design a system that doesn't include them and might miss a lot of important things," he said.

### Connection Before Content

Relationship building is key to success and Anders did this well. He spent time getting to know Don and ensured he was prepared by explaining the project and proposed partnership outside of formal project meetings where other agenda items can compete with the time and space needed for thorough conversation.

"I remember distinctly, I was walking in a park down in the village along the lake, and Dr. Ganstal called and told me about this program. I have been through a lot of these patient engagement projects, but seldom have I felt so included. Just spending 15-20 minutes telling me about the program to begin with I thought was pretty impressive," shared Don.

### Asking Questions Others Might Not

One of the first ways that Don participated in the project was by attending a training session for advanced care paramedics in Kamloops. He recalled asking a question that he was not sure would be of interest or help to the paramedics in the room, but then noticed others perking up to hear the answer.

"I did sense there was a bit of new understanding among the rest of the people in the audience," he said. Indeed, patient partners often ask questions that others on a project team might not have considered or might not feel comfortable asking.

### No Pandemic Pivots Required

Although the pandemic halted a lot last spring, the occurrence of heart attacks was not one of them. After launching in September 2019, the CHAMP pilot program continued through 2020 without substantial interference from COVID-19. In fact, patients who received the treatment in the field arrived at the hospital more stable than they might have been otherwise, which helped reduce the demand on critical care staff.

### Outcomes & Impacts

As of Spring 2021, CHAMP had treated 21 patients in the Interior Health region. Impressively, the program demonstrated a 57% reduction in treatment time. Prior to the program, the median treatment time from symptom onset to thrombolysis was 94 minutes - now it's down to 25 minutes. The project team is pleased and the patients who have been treated in the field are ecstatic!

When interviewed by BC Emergency Health Services about the program, patients shared their gratitude as well as their interest in supporting its sustainability and expansion:

***"I don't think I would have made it without this treatment,"***

***"The paramedics were amazing,"***

***"If I see any of them now, I would like to hug and kiss them,"***

***"Anybody in my situation should be able to get this."***





The CHAMP team, BC Emergency Health Services and Interior Health are now working to spread the successful program across the region – and eventually to the rest of British Columbia.

### Final Thoughts & Reflections

When asked what advice he might give to others embarking on a patient engagement partnership, Don compared patient engagement to the butterfly effect.

“Everything we do has some effect on something. [After collaborating], we all walk away with a different, improved, or maybe worsened view on a project. But everyone brings something, everyone can change something. We all have a unique perspective. Don’t treat [patient engagement] like a token [gesture]. ‘Tick the box – yes we’ve got a patient involved!’ Be open to criticism. Be open to a ‘dumb question’ – it theoretically could become a really important question.”

Anders recommends being open-minded and ready to receive criticism.

“See patient engagement as an important tool to streamline your project and provide the best possible care. Back in the day, we used to see doctors saying, ‘I am the doctor, and this is what is best for you. I have the white coat, so listen to me, because I know what’s right for you!’ I am hopeful those days are almost completely gone. Putting the patient first, having the patient voice in decision-making in the health care system, is really important to know what’s really best for the patient.”

***“Be open to criticism. Be open to a ‘dumb question’ – it theoretically could become a really important question.”***

– PVN patient partner Don Grant





## Engagement in Action Across BC

### Patient Engagement in Quality Improvement at Burnaby Hospital Fraser Health

In recent years, as the value of patient engagement has become more widely acknowledged, many organizations and hospitals have created designated staff positions to support and expand the practice in their facilities. At Burnaby Hospital, Ryan MacKay acts as the site's Coordinator for Quality & Patient Experience by supporting efforts around quality improvement, virtual care and the integration of patient voices into all quality and operations work.

“We're trying to ensure there is a Patient Advisor in every operations meeting and involved in every new innovation project as a way to advance the culture of person- and family-centred care here,” he explained.

In addition to patient partners sitting on hospital operations management committees, Ryan works with PVN to find patient partners to join accreditation improvement efforts and Quality Walkabouts (senior leaders visiting wards to talk to staff about potential patient safety issues), review patient education materials, participate in hospital redevelopment committees and join various quality improvement project teams.

“Having Ryan as a contact at Burnaby Hospital to help with the process, documents and share his experience has been key. It has been very helpful to have a local contact to help organize this,” shared Melissa Allan, an emergency physician at the hospital.

### Patient Lens on Quality Improvement

Melissa is helping to scale up and spread local quality improvement efforts. She chairs the Medical Staff Associations' Quality Improvement (QI) Subcommittee and runs a monthly “Burnaby Hospital QI Café” where staff present new ideas or updates on current quality improvement initiatives and receive feedback from colleagues and patients. PVN patient partner Ron Hall participates in both endeavours and several others.

“It was essential for us to have someone who can give a patient and community perspective involved too. Ron helps us to understand things from a non-medical view. Ron has participated as a full member on the subcommittee over the last year, reviewing and providing feedback on 16 Burnaby Hospital quality improvement projects,” shared Melissa.

And according to Ron, the subcommittee has “Been excellent about having a patient partner on board, receptive to suggestions, questions and comments. There is a true desire to have us involved and help them make projects more patient- and family-centred.”



## Focus On Patient Experience

A recent Burnaby Hospital QI Café session focused on how staff can optimally involve patient partners in projects. Ryan and Ron shared advice and strategies on how to ask and learn from patient experiences, with Ron drawing on knowledge and experiences from his former work in the public education system to acknowledge that even small changes in big systems can be challenging. He said that aligning proposed changes with true patient needs can help change efforts gain traction and stick.

“It’s a common question I like to hear – ‘Who have you talked to in terms of patients and families and what is their response to what’s going on?’”

Ron also stressed the importance of having a caring and responsive system, and he urges quality improvement teams to think about how their project or proposed change will allow staff to continue providing compassionate person- and family-centred care. He acknowledges this can be hard to do in high-stress environments and situations.

“Last year is a great example of staff needing to be caring and responsive even though they are overwhelmed,” said Ron, noting how every care interaction, negative or positive, can affect a patient’s experience, feelings and overall health. “If the first person a patient contacts is at an info desk, and they are kind and friendly, then they’re going to be better set up for the rest of their stay.”

Encouraging quality improvement teams to prioritize staff’s ability to connect with patients compassionately is one way Ron hopes to advance person- and family-centred care, and Ryan is seeing the impact of those efforts.

“Ron has transformed the tone of our quality endeavours. His participation has enriched our perspectives and put us on a better footing,” shared Ryan.

## Reflections & Lessons Learned

When asked about advice for others embarking on patient engagement partnerships, Melissa stressed the importance of meeting prior to “the meeting” to review mutual expectations and the level of engagement.

Melissa shared:

***“Meet before to review documents and get to know each other. Create opportunities to discuss expectations. Create space in meetings and discussions for patient partners to share their perspective. Understand that there are many perspectives and views are not homogenous amongst us or patients.”***





Ron shared similar advice, noting that it can take some time for a patient partner to understand the health care language, acronyms and metrics used in meetings.

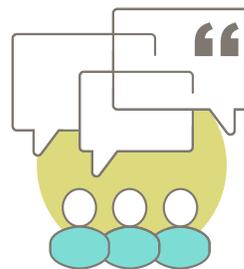
“Including the acronyms that will be used in a meeting in the agenda has been helpful. I also appreciate it when the chair gives me a heads-up ahead of time to say, ‘Ron, we’d really like your feedback on these specific parts.’ Then I can pay close attention to those sections – not all 50 parts of the meeting.”

Ryan encourages health care teams to be receptive to the new ways of thinking that patient partners bring to the table, noting that there are often unexpected benefits or outcomes of working together.

“You just never know what you’re going to get, or what a patient partner might offer. Be ready and open to learn whatever there is to learn,” he said.

Reflecting on the sum of his patient partner experiences to date, Ron notes the positive two-way learning he has witnessed.

“It’s been a highlight to understand the health care system from inside, not just the outside. And such a positive to see that my perspective from the outside is now sitting on the inside. I am certainly learning a lot and hope other people have learned from me and my different viewpoint, too.”



***You just never know what you’re going to get, or what a patient partner might offer.***

Ryan MacKay, Health Care Partner



## Engagement in Action Across BC

### Virtual Psychiatry Consultations Providence Health Care

The Shared Care team at Providence Health Care has been connecting with patient partners since the beginning of the Patient Voices Network – 11 years and counting! Since its first engagement in 2010, which resulted in winning a national award for the Rapid Access to Consultative Expertise (RACE) project, the team has harnessed the power of patient voices in dozens of quality improvement projects.

“It has been really fantastic over the last 11 years, working with PVN to create and shape patient-centred solutions,” said Margot Wilson, Providence Health Care’s Corporate Director of Shared Care & Virtual Health.

This past year, patient partners have been involved in several projects, including establishing a Post-COVID Clinic for patients experiencing “long-haul COVID” and a radiology initiative to improve coordination of patient care in diagnostic imaging. Another initiative, which gained a lot of momentum due to the pandemic, was a virtual psychiatry consultations project.



### Improving Access Through Virtual Care

Physician leaders at St. Paul’s Hospital in Vancouver recognized that without timely access to psychiatric care, patients were ending up in the emergency room. Research suggests that 11% of Vancouver City Centre residents have a mood or anxiety disorder,<sup>1</sup> 83% of patients with a mental disorder are treated by a family physician only,<sup>2</sup> and 54% of primary care providers are not satisfied with the mental health care they could provide.<sup>3</sup>

The development of a virtual psychiatry program was appealing, particularly in the early days of the pandemic, as there was no required travel for patients or physicians and no need for clinical office space. Instead, they could connect from wherever they were, using a computer, tablet or phone.

The team assembled a proposal which was funded by Shared Care – a partnership of Doctors of BC and the BC government – as part of the Adult Mental Health and Substance Use Spread Network.

1 BC Ministry of Health, Health Sector Information, Analysis and Reporting Division. Local Health Area Profiles. July 2019.

2 Gilbody S, Sheldon T, House A. Screening and case-finding instruments for depression: a meta-analysis. Can Med Assoc J. 2008;178(8), 997-1003.

3 Clatney L, MacDonald H, Shah S. Mental health care in the primary care setting: family physicians’ perspectives. Can Fam Physician. 2008; 54(6), 884-9.



## Working Together: Learning from Lived & Living Experience

The project team connected and learned from patients in two ways. Early in the project, they reached out to Coast Mental Health, a local non-profit serving people living with mental health challenges, to gather feedback from patients via a survey and conversation at an organized meal event. This engagement provided baseline data on patient needs and experiences which informed the project.

Then, they connected with the Patient Voices Network to find two patient partners to join the project team.

“It was really helpful having the connection into the Patient Voices Network, to identify the volunteers in the first place. That helped to avoid a conflict of interest that might have arisen if participating physicians were reaching out to their own patients,” shared Claire Doherty, a Project Leader with Providence Virtual Health and Shared Care. “It has also been really helpful to have the structure that PVN provides, because it can be easy to get caught up in the work and forget to loop back and let patient partners know where the project is at. Having those check-ins from our Engagement Leader, Jami, has been really helpful.”

One patient partner, Pat\*, was keen to get involved due to the urgency and importance of the problem – access to care from a psychiatrist – which they understood well from their own experiences.

\*This story includes quotes from a patient partner who wishes to remain anonymous and is referred to here with the pseudonym Pat

“It was an incredibly important solution to a big problem that exists within mental health,” said Pat.

“At first I thought they just wanted quick feedback. But no, it was about structuring a lot of project components and how it would all unfold from start to finish,” they continued. “That’s what I loved about it. I was positively surprised because that’s not the case on all projects and committees. Claire reached out to us for all kinds of things and really wanted our input. She really gets what it means to have a patient-centred approach.”

Over a series of Zoom meetings and emails from June 2020 to February 2021, the patient partners, drawing on their lived experiences, provided feedback on project components. This included the training provided to psychiatrists who participate in the program, the software selected for virtual visits, the wording for patient consent documents and referral forms, the scheduling processes and setting targets for the evaluation framework.

## Influencing Changes

When reflecting on specific examples of patient partner feedback, and how it influenced the project, Claire shared how patient partners pointed out and remedied stigmatizing phrasing.

“At first the referral form said the program was for patients with anxiety, depression, bipolar disorder or stable schizophrenia. One of the patient partners pointed out that by singling out schizophrenia and the need for stability, it implied that people with schizophrenia are normally unstable,” recalled Claire.



Pat remembered this, too.

“The phrase ‘stable schizophrenia’ just really brought my hair up. Like, why are the others just anxiety, depression, bipolar - with no mention of severity? That just made me furious. I suggested a change in three meetings until they finally got it,” they shared. “I remember a doctor saying, ‘I never think in those terms, I’ve never thought about it from that point of view.’ And I was able to say, ‘Well yes, you don’t have a diagnosis that is always portrayed negatively,’” said Pat.

As Claire explained, “What we really meant was that this service wasn’t appropriate for someone who had active psychosis who hadn’t already received treatment for it. And psychosis is something that can appear with bipolar disorder as well. So, we changed the wording to be clearer.”

The referral form now features more accurate and appropriate phrasing. Regarding the changes to the form, and the conversations about stigma that they required, Pat reflects that, “It was encouraging, and why I keep going with these committees, and why I participate [with PVN].”

### **Project Outcomes**

The program launched on October 30, 2020. As of spring 2021, there are three psychiatrists involved, 13 referring family physicians and over 40 patients referred for care. Psychiatrists are connected with patients through a short-term series of virtual appointments, then provide recommendations back to the family physician who can resume appropriate longitudinal

care. Surveys to assess physician and patient satisfaction with the service are currently under review – but anecdotal feedback received to date has been positive.

Although Pat’s participation in the project has formally ended, they continue to be an informal champion for the work and are contributing to the spread of the concept by connecting Claire with other organizations that are interested in similar approaches.

### **Advice for Working Together**

When asked if they had any advice for health care teams working with patient partners, Pat notes that confidentiality works in two directions, and that it is important to have early and explicit conversations about how and if content shared in the group can be shared externally. Doing so can contribute to the sense of safety felt by patient partners, which in turn can influence what and how they are willing to contribute.

“Health care partners usually just bring their professional selves, but patient partners show up and bring their personal selves. We need to think through safety measures. For example, I have a condition that I don’t want disclosed widely, and sometimes I want my participation to be anonymous. Like, I don’t want my name recorded on project documents,” they explained.

Claire also notes the importance of aligning patient partner time and effort on parts of a project where they have the most influence and impact.

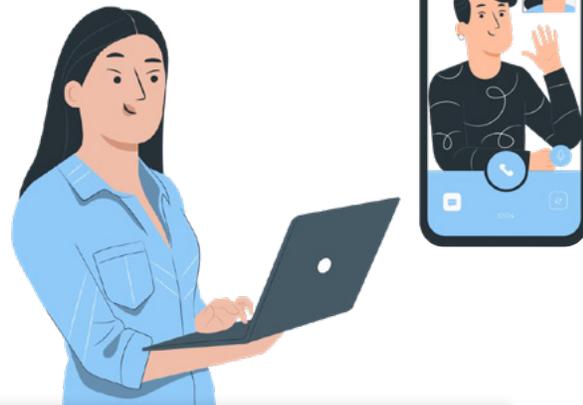
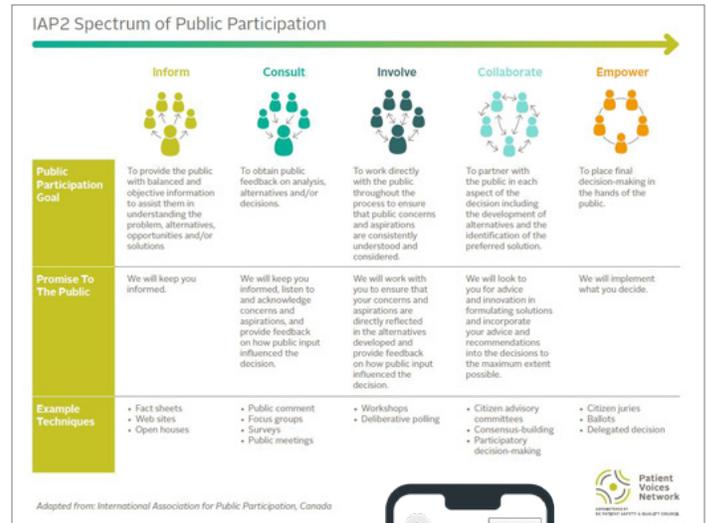


“Have a really clear plan about what the opportunities for engagement are. I really like the IAP2 spectrum and how it forces people to think about what the actual opportunities for engagement are, so there are clear expectations on both sides,” she said.

As for advice for patient partners, “Speak up!” is Pat’s big message.

“You’re there for so many people who are not invited to be there, or not able to be there. You might find you’re outnumbered but speak up! That’s how we make a difference.”

Claire agreed, saying that, “Having Pat’s voice at the table was so helpful, and I really appreciated how they were not afraid to stand up and say things like, ‘It sounds like this project has been developed based on the physician needs – how are we considering patient needs here?’ Ultimately patients are the ones who are intended to benefit from the service – we needed to hear what their needs were too.”



### **An Extra Hope for Patient Engagement**

Pat hopes the health care system and individual practitioners pay close attention to biases they have and the stigma that persists towards people with serious and chronic mental illness. They hope that more people with severe mental illness start to participate as patient partners in quality improvement and redesign work in all areas of care, not just in projects focused on mental illness. Pat points out that people with mental illness experience other types of illness and injury too, and that their perspectives are valuable everywhere.



## Engagement in Action Across BC

### Comox Valley Primary Care Network Island Health

In September 2020, the Ministry of Health announced the creation of a Primary Care Network (PCN) in the Comox Valley as part of the government's Primary and Community Care Strategy focused on team-based care.

#### What is a Primary Care Network?

It is a “geographic space where all community-based primary health care providers are networked together. PCN members work together to collaboratively provide comprehensive, patient-centred, team-based and culturally safe health care to meet the needs of their individual patients as well as the community.”<sup>4</sup>

#### What is team-based care?

It is when “multiple health care providers from different professional backgrounds work together and with patients/clients, families, caregivers and communities to deliver comprehensive health services across care settings.”<sup>5</sup>

The Comox Valley PCN is a partnership between Métis, Inuit and First Nations communities, Island Health, Comox Valley Division of Family Practice and the broader Comox Valley community.

Creating a new model of care for a community is no small feat! This multi-year initiative began in April 2018 when Comox Valley was one of the first five communities in BC identified to develop a PCN. Despite the pandemic striking in early 2020, the momentum continued with the establishment of working groups, stakeholder engagements and recruitment of more staff. In early 2021, the operating model was implemented. To date, the Comox Valley PCN involves 10 medical clinics, 45+ participating family physicians and over 76 individuals supporting the implementation of the PCN across various groups.

#### Patient Partner Involvement

“Patients are at the centre of care in a Primary Care Network – it's a core principle. So, we recognized early on that the patient voice was very important to this work,” said Maureen Clarke, a Leader, Health System Improvement at the BC Patient Safety & Quality Council and the Change Lead for the Comox Valley PCN.

4 Health Match BC. What is a Primary Care Network? [Internet]. 2021 [cited 2021 June 15]. Available from: [https://pcnjobsbc.ca/?gclid=Cj0KCQjw\\_dWGBhDAARlsAMcYuJzK6pOI5OpxGpVN5iNOKP7S1ddwhU-BcPI-mXK\\_i\\_zHzbAUQWDedC8aApk-EALw\\_wcB](https://pcnjobsbc.ca/?gclid=Cj0KCQjw_dWGBhDAARlsAMcYuJzK6pOI5OpxGpVN5iNOKP7S1ddwhU-BcPI-mXK_i_zHzbAUQWDedC8aApk-EALw_wcB)

5 Ministry of Health. Team-Based Care Policy Draft. 2020 July.



Patient partner Edna Leask has been involved from the start, sitting on the network's steering committee as well as its Indigenous Health Working Group.

"I wanted to see change in health care and delivery for Indigenous Peoples. I really think it's important for Indigenous patients to have their own doctor, and to have that attachment and relationship with them. That connection and relationship is so important – it gives people some control over their health care. By developing a relationship, you get to know the person, the person gets to know you, and you have more say into your health and wellness," she said.

Edna is one of four patient partners who are involved in the Comox Valley PCN. Two sit on the steering committee as full voting members and are involved in developing the network's governance structure. Plus, there is one on each of its five working groups: Indigenous Health, Virtual Care, Measurement & Evaluation, Community Wellness Collaborative-Vulnerable Populations, and Team-Based Care. They also review patient-facing communications materials and join feedback loops to continually monitor and evaluate new changes.



This image was developed in partnership with patient partners

## Cultural Safety and Connections with Local First Nations

The Comox Valley PCN is committed to embedding cultural safety in its work as a team and within its approach by connecting with local First Nations to better understand and incorporate Indigenous perspectives on health and wellness, and referring to the *PCN Guidebook for Indigenous Engagement & Cultural Safety*. It has also developed a *Culturally Informed Team-Based Care Learning Journey* – a professional development standard for those providing care within a PCN that includes a localized Indigenous knowledge learning series and a cultural safety community of practice.

"I think it is really important for people in health care professions, if they have questions, to go seek out answers," Edna said. "Sit down with someone. The elders that are on the primary care committee, any one of us, would be willing to sit down with them and talk about this very important and delicate subject. It really speaks to the health and well-being of everyone involved in primary care – the practitioners and professionals – everyone has to take care of themselves and that's another way of taking care of yourself, by getting answers and talking about it, and being open and compassionate."

In addition to contributing to the *Learning Journey*, Edna and the other patient partners have provided insights into the language and imagery used in communications to ensure they are culturally sensitive and will be well-received by Indigenous communities.



“Patient partners have also been the voice in developing two new positions that we’ve recruited for, specifically the Indigenous Wellness Liaison role and the Indigenous Wellness Advocate role,” shared Maureen. “Having Edna, an Indigenous Elder, as a steering committee member and active member on many committees and groups has contributed significantly to our own learning and knowledge of Indigenous Peoples and Indigenous perspectives on health. This has supported us in building deep relationships with our Indigenous partners,” she said.

### COVID Challenges

Despite the progress they have made over the last year, Maureen commented on the challenge that COVID-19 presented with respect to community development.

“Many of our patient partners experience some sort of health risk already, so face-to-face interactions, even socially distanced, were a concern. Not having casual, one-to-one, face-to-face meetings has been a challenge. I think we have all experienced some feelings of loss around that. It really impacted our ability to bring the patient partner team together as it grew. Zoom isn’t the same as popping a box of donuts down on the table and having coffee with everyone, which is what we really wanted to do,” Maureen said.

“But it did bring the patient voice closer to the surface of our meetings, because COVID was all about patients! So, in some ways I saw patient partners speaking up more about their concerns and the need for system change that maybe would not have surfaced as readily without COVID.”



Cultural Safety Connection Respect Compassion Value  
Collaboration Trust Fun Purpose Patients Improvement



## Reflections, Advice & Lessons Learned

“Start early!” is Maureen’s advice to health care teams regarding patient engagement. “At the very beginning stages. The first person you need to find for your project or program is a patient partner. Then have them bring their friends.”

The idea of bringing friends was an aha moment for the PCN team, noting that patient partners were keen to take ideas and materials back to their own circles of friends and family for feedback.

“Each patient partner is an individual within their own network and tapping into those was a more extensive way to access the public for feedback. It’s been successful and enjoyable for everyone,” Maureen said.

Edna encourages patient partners to speak up and share opinions. “Put yourself out there. Say what you’re thinking because you’re not going to help anyone by holding it back. All that’ll do is bug you. I really believe that. I’ve been an advocate my whole life. It’s really important for justice and balance and harmony and compassion and kindness to be included and considered in the policies and laws that govern us.”

Reflecting on the sum of her involvement to date, Edna shared that the highlights have been the relationships and people she has worked with who are so dedicated and determined to see changes.

“I appreciate that. It has been very interesting, and I’m glad that I got involved to contribute. I’ve enjoyed meeting and working and conversing with them and understanding that we all have human frailties – we all want health and wellness for everybody. We all basically want the same thing.”



## Engagement in Action Across BC

### A Guide to Compassionate Phone Conversations During COVID-19 Northern Health

When the pandemic hit, many people felt helpless. They wanted to do more than bang on pots and pans at 7:00 PM to show solidarity to point-of-care workers and support their communities, but were unsure what to do. In the North, three people with a shared passion for and commitment to person- and family-centred care got together to brainstorm how they could contribute.

Cathy Almost, an Engagement Leader at the BC Patient Safety & Quality Council, Tina Strudsholm, Lead, Person and Community Engagement with Northern Health and the BC SUPPORT Unit Northern Centre, and Lee Cameron, a Physician Quality Improvement Coach at Northern Health, started connecting on Zoom to explore possibilities.

“It was early in the pandemic, and there were really tight restrictions on visitation. That was the context, and the challenge we were facing – how to maintain that connection with family that is required,” shared Tina.

Early on, Cathy spotted a resource being shared on Twitter that was developed in the UK and intended to guide health care providers when calling a family about losing a loved one during COVID-19.

The trio was intrigued by the resource and contacted the authors to learn if patients and families had been involved in its development – they had not. So, with the authors’ permission, the team decided to adapt the resource to make it more relevant for their region, by incorporating feedback from people on both sides of the phone call: physicians and families in the North.

**A GUIDE TO COMPASSIONATE PHONE CONVERSATIONS DURING COVID-19**

**SERIOUS ILLNESS CONVERSATION GUIDE**  
Fred is a 72 year old gentleman who is hospitalized with COVID-19. He has underlying COPD and heart disease. His sister is his decision maker and his closest relative. Fred is not doing well and you are phoning to update his sister.

**1 SET UP THE CONVERSATION**  
"I'd like to talk about what may be ahead for you with this illness and do some planning about what is important to you so that I can make sure we provide Fred with the best possible care. Is this okay?"

**2 ASSESS UNDERSTANDING AND PREFERENCES**

**3 SHARE INFORMATION AND PROGNOSIS\***  
Frame as a "wish...worry" or "hope...worry" statement. Allow silence and explore emotion

**INTRODUCE**  
Hello my name is Grace, I am a Physician, and I have been caring for Fred.  
SPEAK SLOWLY  
I'm calling to give you an update on your brother, Fred.

**COMPASSIONATE APPROACH**  
OPEN WITH A QUESTION  
Is there someone there with you?  
► If yes - good  
► If no - do you have someone you can call after this discussion? You might want a pen to write some things down.  
RECOGNIZE CAREGIVER CONTEXT  
Are you okay to talk right now? If not, when is a better time to call?  
WELCOME SUPPORT PERSON  
During COVID-19  
► Many people feel so much guilt that they can't be at the bedside "and fulfil traditional protocols."  
► It has to be this way right now to protect the health of family members and the community.  
► If it could be any other way, we would want you to be with Fred.

**ASK**  
ESTABLISH WHAT THEY KNOW  
What is your understanding of how people with COPD, like Fred, are affected by COVID-19?  
What information about what's ahead would you like from me?  
Can you tell me what you know about Fred's condition?

**TELL**  
SHARE INFO IN SMALL CHUNKS  
I want to share with you, my understanding of where things are with Fred's health.  
✓ Pauses  
✓ Simple language  
✗ Euphemisms  
Eg. comfortable vs dying  
✗ Jargon  
Eg. palliative care  
HONESTY WITH UNCERTAINTY  
Given Fred's conditions, here are some things we think can help keep him comfortable, such as giving him oxygen to help with his breathing.  
ACKNOWLEDGE POSSIBILITY OF DEATH  
We hope Fred improves with these treatments, but I'm worried that he could die.  
Fred is very sick [provide details]. I wish this was not the case, but I'm worried that he is now so unwell that he could die in the next hours to days.  
IN THE EVENT THAT FRED DIES  
Skip the "Explore" step and move to the "Allow Silence" step.  
I'm sorry to tell you this over the phone, but sadly Fred passed away a few minutes ago. I'm sorry that for your own safety you can't be here right now.

**northern health**  
the northern way of caring

Download **A Guide to Compassionate Phone Conversations**



“It doesn’t need to be complicated. Simple tools can be useful and make great impact. That can be the challenge sometimes, thinking about a big concept like [person- and family-centred care], it’s helpful to keep it simple and get some momentum from some practical tools,” shared Tina.



### Including Patient Voices

Four PVN patient partners from the North were also actively looking for a way to contribute to the COVID-19 response and were keen to jump aboard. In a one-time Zoom meeting, the group discussed the resource in a roundtable format where patient partners offered feedback one at a time.

“I’m always very interested in the language that is used in vulnerable situations and supporting the people working in those situations,” shared patient partner Duane Jackson. “I thought the infographic looked very busy and could be overwhelming to anyone using it as a guide. I think the idea was to make the language a little more accessible and to tone down the appearance a bit.”

A major theme of the feedback was to slow the conversation down and to pause and create more space for compassion. Related to that was the importance of establishing connection at the start of a conversation and asking, not assuming, if it was a good time to talk.

“They suggested more attention be given to ensuring the family member was comfortable and had supports available before getting straight to the (clinical) business of delivering the news. I think those are really effective principles of person- and family-centred care that they brought forward,” reflected Tina.

Two of the patient partners who volunteered are Indigenous and were able to offer additional insights into how restricted visitation rules impacted cultural practices and made it hard to fulfill traditional obligations, which could add to the grief and guilt families might be experiencing.

“They also gave us a relational lens, which is very important in an Indigenous world, to how would it feel to have someone phone you to tell you how your loved one is doing, or not doing, or has passed. Getting that feedback was super invaluable,” shared Cathy.

And, according to Tina, “They told us that it’s not just about family being separated, but in many Indigenous communities in the North you have cultural obligations to step up during certain life events and COVID-19 was making it hard to fulfill those roles. It was an excellent contribution and is reflected in the revisions we made.”

### Including Physician Voices

With patient feedback incorporated, Lee took the updated resource to a group of five physicians in the northwest who had previously demonstrated a strong interest in person- and family-centred care. They all found it useful, particularly so by one palliative care doctor.



“Even though this was rapid and simple, since they knew that this resource had been vetted by patient partners, it promoted uptake and understanding. A few of the physicians expressed, ‘I hadn’t thought about that.’ [Getting patient feedback first] made it more poignant,” said Lee. “As a Quality Improvement Coach, I hear physicians say that they support the theory and concept of person- and family-centred care, but they ask, ‘What does this look like in a practical, roll-up-your-sleeves kind of way and show us the tools. How can we actually apply this?’ This resource was a great example.”

### **A New Resource for the North, and Provincial Spread**

The group made several revisions to improve readability and avoid euphemisms. They also added content, including the best practice framework of [ASK TELL ASK](#), starting with questions to gauge comfort and ensure support for the family member, and acknowledging the challenge of fulfilling various cultural protocols.

The revised resource was implemented by Northern Health’s palliative care department, shared on its [physicians’ website](#) and recently featured in its Leadership Digest.

Cathy also shared the resource with leadership at the BC Patient Safety & Quality Council and inquired about the possibility of provincial spread. She received quick and enthusiastic responses from Devin Harris, the Council’s Chair, who agreed to spread the resource within Interior Health, where he is the organization’s

Executive Medical Director of Quality, Patient Safety and Research. David Sweet, an emergency physician at Vancouver Coastal Health and the Council’s Clinical Lead for Sepsis, asked to share it through the BC Sepsis Network, COVID-19 therapeutics and critical care networks as well as local departments.

“That’s the goal! Having an effect on the health care system by creating something helpful that patients have contributed to,” said Cathy.

To the patient partners involved, it was satisfying to know that their comments were being heard, and the resource they contributed to was put into practice.

“The best part of any of the engagement is feeling that you have made a difference in the health care of an individual and to feel that you have supported those that have chosen this field,” shared Duane.

### **Lessons Learned**

When asked about lessons learned that might be relevant for other teams, Tina suggests keeping it simple.

“Meaningful engagement can happen quickly. This was really just one meeting. If there is a real commitment to incorporate feedback as much as possible, you can realize some big results with small effort. It doesn’t need to be an overwhelming process. This was nice, because some engagements get pretty long and drawn out, so it was fun to be part of something that was focused,” she shared.



Lee reminds folks not to reinvent the wheel because “Quality improvement is all about sharing resources, what worked, what didn’t work, and considering appropriateness to the local context.”

Cathy agrees and encourages efforts to spread learnings.

“One of my peeves with the system is that it doesn’t talk to itself, or repeat best practices, or try to teach each other and communicate. So that’s probably what I’m most proud of...how we responded to the pandemic by involving the patient voice and put this together not only for our own organizations, but we succeeded in spreading it province wide which is pretty amazing, in a pandemic, when there is so much else going on,” she shared.

They also note that collaboration is key – across disciplines, departments, organizations and roles.

“We came together with a spirit of ‘OK, we don’t work at the point of care, but what can we do right now right here in this space, that is going to make a difference?’ It’s the spirit of how you show

up. The word collaboration is used a lot, but I think that made all the difference. It was small, nimble. We came from a power-sharing place, and that’s how we showed up,” reflected Lee.

Finally, Duane reminds folks that there is value and power in all perspectives.

“The view from one side of the table is much different than from the other side. Your opinion has value in that it sees things differently and experiences the situation socially, emotionally and cognitively in its own way.”





## Engagement in Action Across BC

### Digital Health Policy Advisory Groups Ministry of Health

2020 was a year of learning to do things in new ways: grocery shopping in a mask, socializing six feet apart, working from home and seeing your doctor through a computer screen. For many British Columbians, 2020 was the first time they encountered virtual care by connecting with a care provider through telephone, video, email or text.

While relatively new in BC, it's common practice in other parts of the world and one that has been on the Ministry of Health's radar due to its potential to significantly improve access to care.

"Our Virtual Care Strategic Framework was actually delivered in October 2019, long before any of us thought a pandemic was coming. When COVID-19 struck, it gave new legs to virtual care," explained Natasha Thambirajah, the Ministry of Health's Director of Digital Health Policy.

#### Involving Patients

Over the summer of 2020, Natasha and her team members Nicole Rennie, Sihan Zhang and Lydia Tang gathered two patient advisory groups as the final step of a province-wide consultation of new policies to support the ministry's Digital Health Strategy.

Natasha explained:

***"Including patient voices to have patient-centred, patient-empowered models of care is a priority for our Assistant Deputy Minister."***

A Provincial Patient Advisory Group, comprised of 23 PVN patient partners across the province, and an Indigenous Virtual Care Advisory Group, comprised of seven Indigenous patient partners, were asked to provide feedback on three policies: Appropriate Use of Virtual Care, Patient Guide to Virtual Care, and Culturally Safe Virtual Care.

Patient partner Barbara Bienkowska had been advocating for virtually enabled care in mental health and addictions for years before the pandemic hit, recognizing the significant difference it could make in creating access to timely care and follow up.

"Navigating an under resourced and overwhelmed mental health system as a parent of an adult daughter with a life-threatening mental illness, has been an almost daily heartbreaking experience for many, many years. I wanted to join this working group to learn about the benefits and challenges of virtual care generally, and to do what I could to ensure that the unique needs of our most vulnerable population were not overlooked," she said.



Elder Gwen Campbell McArthur participated in the Indigenous Virtual Care Advisory Group and contributed her cultural and intellectual knowledge from a patient perspective as a Métis woman, mother, former health care provider, Indigenous researcher, scholar and author.

“We just couldn’t go on expecting to have virtual care and health care that was of a good quality, that was respectful and culturally safe for Indigenous people in BC, without having some kind of guidelines and terms of reference in place,” said Gwen on her motivations for taking part.

### **Zooming Together Line by Line**

In a series of biweekly, 90-minute meetings between September 2020 and February 2021, the groups met via Zoom to review draft policies and provide feedback.

Meeting virtually increased the geographic reach of the consultation, as ministry engagements are most often hosted in Victoria or the Lower Mainland. Using Zoom breakout rooms and staff facilitators also enabled the team to convene a much larger group than may have been possible in a face-to-face consultation.

“We didn’t just present a summary,” explained Lydia. “We would present the whole policy and walk through each paragraph. We went line by line. Patients had the opportunity to edit the wording, not just general content. Line by line might seem, on the face of it, like an awfully tedious way to do things, but every line actually does matter in policy.”

The approach, while intense, was appreciated by the patient partners. Gwen reflected on the skill with which the facilitators listened and captured comments.

“As we were talking, Natasha was going ahead and changing everything but would say, ‘Woah woah woah, go back’ even though it was time consuming. She did it until we got the language right - until it reflected what was really important,” said Gwen.

Barbara also commended the team on its organization, scheduling and facilitating.

“What was even more meaningful was how they genuinely seemed to respect and value our participation, even when some of us fumbled our words while trying to articulate our thoughts, went off topic, or repeated something that had already been said. It takes a lot of patience and skill to genuinely hear people and be able to extract the nuggets at the same time,” she said.

### **Culturally Safe Space to Discuss Cultural Safety**

Appreciating the potential sensitivity of topics and experiences regarding cultural safety, the team created an Indigenous-only group of patient partners for the review.

“Having that space was good because it allowed Indigenous patient partners to speak more comfortably about their experiences and to speak to each other. It provided more space for them to talk openly,” shared Lydia.



The Indigenous Virtual Care Advisory Group made significant contributions to improving the Cultural Safety Virtual Care Policy, embedding an Indigenous patient perspective throughout, from the way it was written to the ideas and concepts within it.

“It’s now much more accessible, easy-to-read and easier to understand. Policy principles and language were strengthened. Indigenous knowledge on the United Nations Declaration on the Rights of Indigenous Peoples, ceremonies and the diversity of Indigenous Peoples greatly helped in enhancing these concepts in the policy,” explained Nicole.

When reflecting on the work and how she hoped the policy would translate into the patient experience, Gwen shared that she would “Think about what words patients and families would want to hear, that would engage them and have them open to doing something on the computer screen that is so disconnected from the relational, in-person care that we are used to as Indigenous Peoples. Words that we as patients can understand at a time when we were perhaps at our lowest ever, or when we had our highest fear. Or words that we had heard from our Elders, from our parents, that we had taught to our children.



“It was important to make sure that people receiving care were treated in a respectful way, that they were getting the reciprocal kinds of give and take that you get in an in-person conversation. And that’s really tough in a video conference,” continued Gwen. “You know, people talk a lot. [Health care providers] will give you this whole description and spend the first 10 minutes describing everything and only leaving five minutes for the patient - and that’s not how it is for a lot of Indigenous people. We tell a story, and we need to tell our health care in that story format. It’s a very traditional way of doing that. And I wondered, how is that going to be reflected in this policy? But Natasha captured that really well,” she said.

Natasha added that “It was an extraordinary experience. I’ve been doing policy for 15 years. I’ve never seen a group of people pore so closely over word choice and discuss diplomatically with each other the meaning of the words and whether it’s convening the right intent with such an extraordinary degree of thoughtfulness.”

### Words Of Wisdom

When asked if she has advice for other patient partners interested in policy engagement work, “Just do it!” was Gwen’s answer.

“Let the word ‘policy’ be friendly to you. It is always changing, and it always needs fresh patient voices. My experience so far is that people are listening. And listening to silence too. There are messages you can get across in so many ways. But to be afraid of [policy/engagement] is to your detriment.”



On a similar note, Barbara says to patient partners, “Don’t feel intimidated to voice your questions or perspectives. You are an asset and your voice matters, even if your words come out a bit muddled.”

She also pointed out the highly involved nature of policy work and the time and effort needed to do it well. In her view, the value of a meeting is related to the collective work of the individuals in the time between meetings. As such, she encourages patient partners to be prepared by reading all circulated materials and making a record of questions, concerns and ideas that surface. She also reminds folks to be familiar with and periodically revisit the terms of reference and be mindful of confidentiality requirements around meeting content and documents.

### **The Result: Person-Centred Policy**

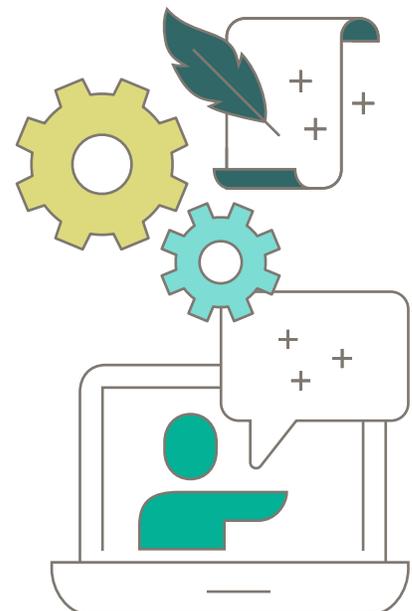
The feedback received from the patient partners was carefully reviewed by the digital health policy team and incorporated into the documents. The result is policies that are more inclusive, person- and family-centred, and reflective of provincial and Indigenous patient perspectives on empowerment and virtual care.

“Seeing [Minister of Health] Adrian Dix standing up there at a press [conference] saying, ‘We have consulted with Indigenous communities, and we have new virtual care for First Nations and Indigenous communities coming’ - that gave me a sense of accomplishment,” said Gwen.

“Knowing that my voice was heard. Knowing that the voice he was hearing/reading, were words from the committee that I was involved in. Some of them even mine. Even if no one else knows they were mine - I do.”

And according to Barbara, “The important takeaway from all of this is that we were given pretty free rein to give voice to anything that we felt could lend value to the work and improve the quality and value of the policies and guidebook. The value came from the collective thoughtfulness, commitment, skill sets and life and health experience of a group of caring people.”

The final policies are now under review and slated for public release in 2021. With new provincial policies in place, the Ministry of Health and health care providers across the province will continue to work to improve the delivery and accessibility of virtual health care. They hope to continue its use in the post-pandemic era, where a combination of in-person and virtual care might best suit the needs of British Columbians.





## Engagement in Action Across BC

### **My Wishes, My Care. Advance Care Planning for People Living with Dementia and Family/Friend Caregivers** BC Centre for Palliative Care

The BC Centre for Palliative Care (BCCPC) defines advance care planning as a process of thinking about and sharing your values, beliefs and wishes for future health and personal care with the people you trust. It helps individuals get the care that is right for them, even if they are unable to speak for themselves.<sup>6</sup>

Advance care planning can ease the burden of making decisions around care options during times of serious illness or injury. As dementia affects decision-making capacity in later stages of illness, there is a window of opportunity for individuals living with dementia to engage in advance care planning conversations and share with family, friends, and health-care providers what matters most to them for their future care. Despite widespread acknowledgement of the importance of advance care planning for people living with dementia, these crucial conversations don't happen as often as they should.

#### The Project

To address this challenge, the BCCPC initiated a two-year project in collaboration with key organizations, experts and researchers to encourage people at risk for dementia, or in the early stages of the disease, to engage in advance care planning conversations with their family/friends and caregivers. The project team built on the success of BCCPC's evidence-based advance care planning model and tapped into the reach of community-based organizations to promote awareness.

“With the help of an advisory committee, expert task group and PVN patient partners, we developed a set of tools, resources and training materials to support community organizations to deliver advance care planning programs tailored for the specific needs of people living with early stages of dementia and family/friend caregivers,” explained Kathy Sheng, the project's manager.

#### *Financial contribution from*



Public Health  
Agency of Canada

Agence de la santé  
publique du Canada

This initiative is supported by funding from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada. Cette initiative bénéficie du soutien de l'Agence de la santé publique du Canada. Les opinions qui y sont exprimées ne représentent pas nécessairement les positions de l'Agence de la santé publique du Canada.

<sup>6</sup> BC Centre for Palliative Care. Advance care planning [Internet]. 2021 [cited June 15 2021]. Available from: <https://bc-cpc.ca/all-resources/individuals/acp/>



The project team adapted two existing, community-led advance care planning programs for people living with early stages of dementia and their family/friends caregivers. “My Wishes, My Care...” is a guided group conversation event to help participants explore their values, beliefs and wishes for future health care and personal care. The second program is a two-part information session to teach participants about the steps of advance care planning, including resources to help them get started.

### **Patient Partner Involvement**

Kathy and the team knew that the project's success hinged on including people who understood the realities of living with or supporting someone with dementia.

“Involving people with lived experience throughout the process helped to ensure that the programs and resources designed for them would reflect their values, beliefs, perspectives and needs,” she explained. To do so, they enlisted the help of nine PVN patient partners from across BC.

Patient partner Doreen F was interested in the project because of her family's own experience with dementia.

“We were completely unprepared when my mother-in-law was diagnosed, and many feelings such as denial, guilt, sadness and loss made it all the more difficult to put an effective plan in place. We would have benefited from advance care planning, and so I was pleased to see

information sessions being offered. I wanted to be part of helping others who may one day face this challenge,” she shared.

From April to August 2020, patient partners contributed to the project in several ways, including sharing personal insights and perspectives on the barriers and facilitators they encountered when engaging in advance care planning conversations. That invaluable information helped to inform the program's curriculum content, instructional design, learning environment and communication strategies. Some of the insights shared by patient partners which were later incorporated into the design of the programs include:

- Emphasizing advance care planning conversations rather than completing forms
- Using storytelling to share information
- Providing easy-to-use ways to start advance care planning conversations
- Providing a concrete, step-by-step approach to advance care planning

“Patient partners also provided feedback on the design, usability and content of our public-facing materials,” said Kathy. “Their feedback helped to address the readability of marketing posters and public-facing handouts, interpretation of advance care planning-related icons designed for visual learners, usability of online evaluation surveys and relatability of resource content.”



## The Pilot & Early Outcomes

“To launch and evaluate the tailored advance care planning programs in the community, we used a stepped approach: first a focused pilot, then a wider implementation. At both stages, we partnered with community-based organizations to deliver the two programs in their communities. BCCPC provided each organization with training, a comprehensive toolkit of resources, and ongoing coaching to support them with program delivery and sustainability,” shared Kathy.

Following a successful pilot phase with four community-based organizations in the spring of 2021, the programs were refined and rolled out in partnership with 10 organizations in BC. Plans are underway for a knowledge translation phase in late 2021 to share the finalized advance care planning programs and lessons learned throughout BC and other jurisdictions. To date, over 40 staff and volunteers from community-based organizations have been trained as advance care planning program facilitators.

The input from the community organizations, facilitators, and public participants was an important element to the success of the programs.

### *Evaluation of the pilot phase showed:*

**95%**

of participant respondents agreed that the guided group conversation event helped them think and talk about their values, beliefs and wishes for future health care and personal care.



**91%**

of participant respondents agreed that the two-part information session helped them understand the steps of advance care planning including how to choose a substitute decision maker and how to prepare an advance care plan.



### *Four weeks after attending the advance care planning programs:*

**89%**

of respondents reported that they thought more about their values, beliefs and wishes for future care.



**77%**

of respondents talked with family and friends about their values, beliefs and wishes for future care.





## Engagement Tips

Doreen commented on the excellent communication and clear expectations for patient partner participation that contributed to the engagement’s success.

“I’ve been involved in quite a number of opportunities as a PVN volunteer and I found this engagement to be very positive,” she said. “I appreciated all the information provided and that it was made easy for someone with limited computer software to access,” she added, noting the importance of taking technology into account when making engagement opportunities accessible for patient partners.

The project tried to minimize technological barriers associated with online platforms such as Zoom.

“Instead of online focus groups, patient partners were engaged in a one-on-one manner via phone

or email, and were sent information, questions, and materials at least two weeks in advance so they could prepare their responses,” Kathy added. She also reflected that conducting the engagement activities remotely also helped to connect with patient partners who would otherwise not have been able to participate in person.

Advice for others? Kathy says, “To the greatest extent possible and through multiple levels of public engagement, involve patient partners and those with lived experience in decisions and initiatives that impact them.”

On that note - there will be more engagement opportunities to come for the project. If you are a person living with dementia or a family/ friend caregiver of a person living with dementia, and you wish to get involved, please email [kathysheng@bc-cpc.ca](mailto:kathysheng@bc-cpc.ca). For more information about the project, visit [bc-cpc.ca](http://bc-cpc.ca).

Funded by Public Health Agency of Canada, the project was developed in partnership with Alzheimer Society of BC; Family Caregivers of BC; United Way of the Lower Mainland – Healthy Aging; the lead of Diversity Access Team in a national study on advance care planning; Hospice Palliative Care Ontario and independent researcher and expert Pat Porterfield.

Workshop posters before (left) and after (right) patient partner feedback



## Featured Projects

### Patient Partner Connections

Results from a survey sent to PVN patient partners at the start of the pandemic indicated a desire to build a stronger sense of community within the network – both during and after the pandemic, with long-term, sustainable opportunities for connection. In response, we established the PVN Connections Working Group in June 2020 with three patient partners and two staff members from the BC Patient Safety & Quality Council. The group is working to identify how connections can be developed locally, regionally and provincially, and it has explored several ideas, including think tank meetings, using social media for conversation starters, regional update meetings and PVN Connections Café.

PVN Connections Café launched in December 2020 to increase social connections between patient partners who have completed the PVN orientation. It has an average of 24 monthly participants who are paired up to connect. When they meet and what they talk about is up to them! Check out our [Frequently Asked Questions](#) document and [sign up here](#) if you are interested in connecting with other PVN patient partners.

In March 2021, the working group submitted its recommendations to PVN’s Oversight & Advisory Committee. Stay tuned for other activities that stem from its efforts!



This word cloud was developed by working group members to reflect their values and how they wanted to work together.



## Featured Projects

### Patient Partner Ambassadors

Our Patient Partner Ambassador Working Group was developed in June 2020 to gather feedback on how to empower patient partners across the province to support one another and the Network. It has developed a process and resources for a PVN Mentorship Program which will pair experienced patient partners with new ones in order to provide support and guidance as well as build their confidence to volunteer in the network. As a result of the hard work of our patient partners throughout the past year, this program will be piloted from May to July 2021 to determine the possibility of a full launch in the future - stay tuned!





## Featured Projects

# WHAT MATTERS TO YOU?



### “What Matters to You?”

“What Matters to You?” is an initiative that encourages meaningful conversations between patients, caregivers and families and their health care providers. It is a simple question that can have a big impact on the quality of care. When providers have a conversation about what really matters to the people they care for, it helps ensure that health care is aligned with patient preferences, builds trusting relationships between patients, families and their health care providers, and advances person- and family-centred care.

International “What Matters to You?” Day was held on June 9, 2020. In our [special edition newsletter](#), we featured Lianne Berst and her family’s story of receiving devastating news about a loved one’s cancer diagnosis and the power of asking, “What matters to you?”

In September 2020, we were invited to speak at BC Renal’s Province-Wide Rounds about “What Matters to You?” and the importance of asking, listening and doing what matters in kidney care. The rounds were attended by over 90 patient and health care partners who shared what matters to them about their health care and the context of “What Matters to You?” conversations. Additional speakers included a patient partner who spoke about their “What Matters to You?” experience as well as a health care partner from the Interior Health Renal Program who shared how they applied the principles of “What Matters to You?” in their practice.

Last year we also sought to embed the principles of “What Matters to You?” into all PVN engagements by adding a question to our RSVP forms\*. All opportunities are now required to have “What support do you need to make this a safe, positive and meaningful space and experience for you?” as part of the form in order to identify what is important to patient partners.

*\*An RSVP form is the online form filled out by patient partners to indicate their interest in an engagement opportunity*



The last year created many challenges for individuals and organizations and reinforced that person- and family-centred care, based on a strong foundation of trust and connection, is extremely important within the health care system.

We also created new “What Matters to You?” resources in response to some of the ways care delivery changed throughout the pandemic. Given the shift to virtual care, a working group of five patient partners and two BC Patient Safety & Quality Council staff co-designed new “What Matters to You?” resources for virtual care appointments for both patients and health care providers. They help to identify what is important to patients receiving care and how trusting relationships can continue to be maintained virtually, and they include a checklist for patients as they prepare for a virtual care appointment. Patient partners involved in the working group helped shape the content and ensured that the language used in the resources was accessible and easily understood.

We also created a resource, Unmasking Communication During a Pandemic, to help care providers overcome some of the communication challenges experienced by wearing personal protective equipment.

## What Matters to You?

### Unmasking Communication During a Pandemic

**Non-Verbal Communication**

- Be mindful and present
- Maintain eye contact
- Use gestures and facial expressions
- Smile with your eyes
- Pay attention to the person's body language
- Be aware of power imbalance

**Written and Digital Solutions**

- Use team member identification boards
- Inquire and accommodate for sensory needs
- Use visual aids and technology
- Provide high-quality wi-fi
- Have technology available for loan

**Verbal communication**

- Introduce yourself
- Make it a human encounter by acknowledging the situation and restrictions
- Keep people informed
- Perform an audio check
- Ask for feedback
- Provide translation services
- Ask “What Matters to You?”
- Speak slowly, loudly or more deeply
- Validate and legitimize feelings

Disclaimer: For accurate, up-to-date COVID-19 information and best practices related to infection control measures, please refer to guidance from your local Public Health Agency and/or the Centre for Disease Control.

For more information, please refer to What Matters to You? Unmasking Communication during a Pandemic pamphlet.

BCPSQC.ca | info@bcpsqc.ca | 604.668.8210

BC PATIENT SAFETY & QUALITY COUNCIL

**Download WMTY?  
Unmasking Communication During a Pandemic**

## “What Matters to You?” with Virtual Care Appointments

### A Resource for Patients

As virtual care is new to most of us, this checklist has been developed with patients to enable you to prepare for and make the most of your virtual care appointments. Prior to booking a virtual care appointment, your health care providers office will instruct you on whether your symptoms can be addressed virtually. If you do not have a family physician or need to access services after hours, there may be other secure virtual services available (e.g., First Nations Virtual Doctor of the Day, or provincial/national telehealth services).

**Prior to the appointment**

I have...

- tested my equipment, permissions, audio/video settings and downloaded necessary software/applications (your care provider's office may be able to provide support with technology related to your appointment)
- checked my computer, smartphone or tablet to ensure it is fully charged or plugged into a power source and connected to the internet (preferably high speed)
- earphones or headphones available (for better audio quality and privacy)
- a comfortable chair in a well-lit area without distractions and noise
- asked a family member, caregiver or translator to be present, if necessary
- my health card or health insurance details available
- my list of medications ready
- my medical history available
- a list of symptoms (when they started and severity) and any associated health data e.g., temperature, blood pressure, blood sugar etc. readily available. There may be apps or other technology that can send health information straight to your health care provider
- a list of other health care providers available (i.e. pharmacists and other medical professionals)
- prepared to answer the question: “What Matters To You?”
- a list of any other questions or concerns

**Download WMTY?  
with Virtual Care Appointments**



## Featured Projects

As noted in PVN's Strategic Plan, we are always looking for ways to advance cultural safety and humility as well as diversity, equity and inclusion within the network and in PVN operations. This year, two working groups were convened to advance this work: the Diversity, Equity and Inclusion Working Group and the Indigenous Inclusion Working Group.

### Advancing Diversity Equity & Inclusion

The Diversity, Equity and Inclusion Working Group was formed to explore how to reduce barriers to joining PVN, and how a welcoming environment (one that supports emotional safety and builds trust) can be promoted across the network.

This new group had its first virtual meeting in September 2020, and began finalizing its terms of reference to develop its purpose, scope of work and core values. The Northern, Island and Lower Mainland regions are represented by members of the working group.

The group has identified and adapted definitions of diversity, equity and inclusion that will guide this work and it is moving towards building relationships with other PVN working groups, community groups and societies, thereby creating the space for shared learning. The group also brought forward [a language guide from the BC Centre for Disease Control](#) for consideration and use by PVN and the BC Patient Safety & Quality Council. It will also continue to explore the emerging needs and priorities of diverse voices within PVN and determine an engagement strategy for reaching out to these members.



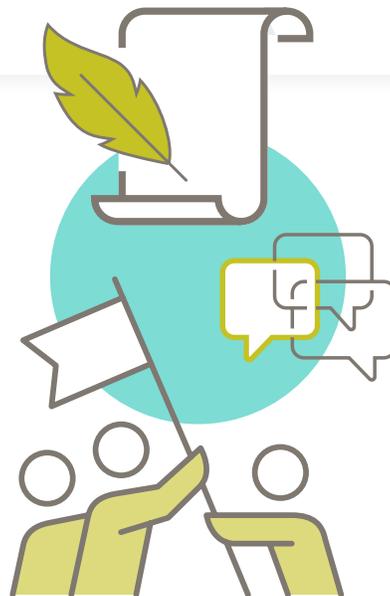
## Key Definitions & PVN working group notes

**Diversity** is about the individual. It is about the variety of unique dimensions, qualities and characteristics we all possess.<sup>7</sup> *The focus is on the individual versus their 'label.'*

**Inclusion** is about the collective. It is about creating a culture that strives for equity and embraces, respects, accepts and values difference.<sup>7</sup> *Inclusion is an active, intentional and continuous process - a mindful effort to ensure everyone feels valued, respected and supported in how they contribute to the work, with the goal to reach our full potential.*

**Diversity and inclusion** is about capturing the uniqueness of the individual; creating an environment that values and respects individuals for their talents, skills and abilities to the benefit of the collective.<sup>7</sup> *Diversity and inclusion refers to an outcome: who is in the network.*

**Equity** is about a fair distribution of services and benefits according to population need. *Equity is demonstrated when every person has an opportunity to achieve their health and wellness [patient engagement] goals regardless of social, economic or geographic location.<sup>8</sup> Equity refers to a process. It is about putting diversity and inclusion into practice by providing whatever is needed to make sure everyone can participate fully in PVN.*



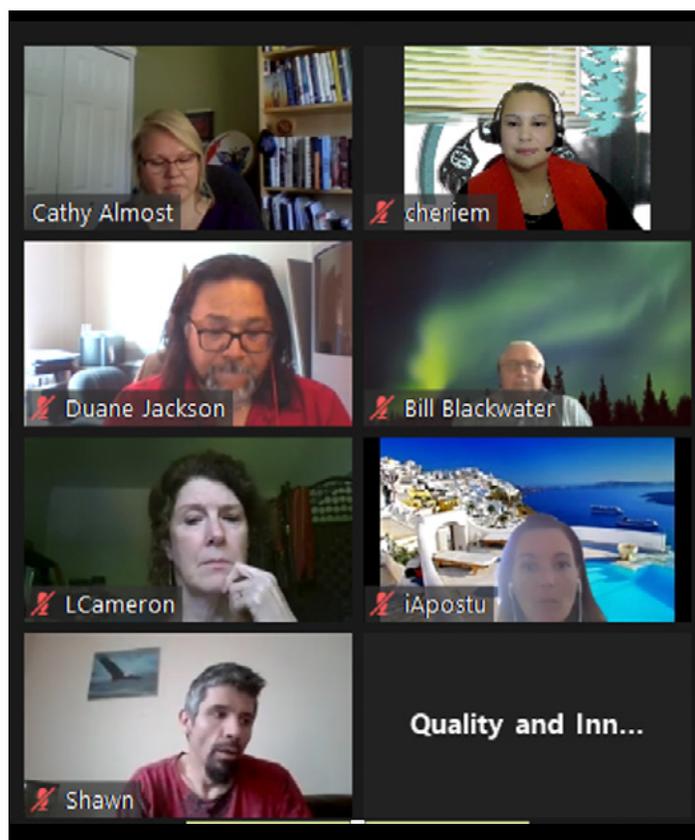
<sup>7</sup> Canadian Centre for Diversity and Inclusion. Diversity defined [Internet]. 2021 [cited 2021 June 15]. Available from: <https://ccdi.ca/our-story/diversity-defined/>

<sup>8</sup> BC Patient Safety & Quality Council. BC Health Quality Matrix. Vancouver: January 2020. p.7. Available from: <https://bcpsqc.ca/resources/quality-improvement/>



## Indigenous Inclusion Group & All Nations Meeting

In the Spring of 2020, Mark Matthew, the Manager for Quality Initiatives and Partner Relations at the First Nations Health Authority and Cathy Almost, an Engagement Leader with the BC Patient Safety & Quality Council, launched a working group of Indigenous patient partners to review our processes and provide recommendations to encourage accessibility and promote cultural safety in our forms, functions and materials. Participants were included from each health region across the province and met monthly via Zoom.



Through these meetings, connections and relationships were forged between Indigenous PVN patient partners in different regions of the province. They are often the only Indigenous patient partner involved in an engagement opportunity, so they were surprised to discover that more than 100 Indigenous patient partners have joined PVN over the past 11 years. The group voiced a desire for a larger virtual gathering, and plans were put in place to pilot the idea with a meeting among those located in the north.

Indigenous patient partners from the northern communities of Tsimshian, Haisla, Nisga'a, Gitksan, Wet'suwet'en, Granisle, Lheidli T'enneh, Fort Nelson, Nak'azdli and Fort St. John First Nation, as well as Métis patient partners, were invited to connect on June 17, 2020, via Zoom. The All-Nations meeting was co-designed and co-led by Cherie Mercer, Nisga'a, with the goal of bringing everyone together to build relationships.

On the day, six PVN patient partners attended. Gitksan Hereditary Chief Bill Blackwater gave the opening prayer, grounding and closing. Everyone had the opportunity to introduce themselves, which was the most important part of the relationship building. A few people spoke in their language as part of their introduction and shared their personal connections with family who had attended residential school. Patient partners mentioned engagement work they had done with BC Cancer, Northern Health, the Health Standards Organization, the Institute for Patient and Family-Centered Care and the BC Patient Safety & Quality Council.



Those who participated agreed that it was a wonderful experience, and they enjoyed the opportunity to share and celebrate their accomplishments of patient engagement through PVN.



***“PVN is returning the service of people being able to serve other people.”***

– Duane Jackson, Gitanmaax

***“It was great to get together with like-minded people”***

– Bill Blackwater, Gitxsan

***“So encouraging to gather with so many likeminded people! We know the system is broken and want to help fix it.”***

– Cherie Mercer, Nisga’a

Gathering with participants for the All-Nations meeting was good medicine and patient partners mentioned that they no longer feel alone in the network and are aware of other Indigenous Peoples making a difference in the health care system. Gatherings like these are good for capturing a sense of belonging, meaningful accomplishments and comraderie. There was interest in hosting gatherings of this nature again and the planning is underway for 2021.

Special Mahsi Cho (thank you) to Bill Blackwater Jr., Gitxsan Hereditary Chief, for opening and closing the meeting and to Cherie Mercer for co-designing and co-leading the gathering.



## PVN Remembers



**Gitxsan Hereditary Chief  
Sim'oogit Ma'os, Bill Blackwater Jr.**

*With great respect and admiration, we acknowledge the life and legacy of Gitxsan Hereditary Chief Sim'oogit Ma'os, Bill Blackwater Jr., from Kispiox, who passed away in July 2021. As a Patient Voices Network patient partner, Bill encouraged all health care providers, particularly physicians, to learn about the land and culture of the local people, to provide continuity of care and to always listen deeply.*

*Bill was integral in developing relationships between Indigenous patient partners and the health care system. He was involved in several events that focused on cultural safety and was known to empower others to share their experiences.*

*We extend deep condolences to the Blackwater family. Bill has unquestionably left his mark on patient engagement and helped us build bridges between Indigenous perspectives and the health care system.*



# Capacity Building for Patient Partners

## Sponsored Learning Opportunities

The BC Patient Safety & Quality Council supported 158 patient partners to attend workshops, events, conferences and other learning opportunities last year.

This includes sponsoring 40 patient partners to attend Quality Forum 2021, three of whom supported our information booth during breaks as an extension of their role on our Ambassador Working Group. Two of the 40 patient partners also presented at sessions during the conference. Everyone was invited to a patient partner breakfast, where they had a chance to socialize and meet other patient partners and members of the Council's Patient and Public Engagement Team, as well as a debrief session after the event where they shared the benefits and challenges of attending an online conference and provided suggestions for improvement.

As well, a group of 43 patient partners had the opportunity to complete the San'yas Indigenous Cultural Safety Training, an online program designed to strengthen the skills of those who work with Indigenous Peoples and enhance self-awareness through learning modules examining culture, impacts of colonization and historical events.

And 50 patient partners were sponsored by the Council to complete the Institute for Healthcare Improvement's Open School Basic Certificate in Quality & Safety. This program improves knowledge and skills in quality improvement practices in health care and provides strategies for problem-solving and planning.

## Sponsored Learning Opportunities for Patient Partners



**40 patient partners**  
Quality Forum 2021

**43 patient partners**  
San'yas Indigenous  
Cultural Safety Training



**11 patient partners**  
2020 IHI National  
Forum Conference

**50 patient partners**  
IHI Open School  
Certificate



**8 patient partners**  
Beryl (Elevation)  
Conference

**2 patient partners**  
BCPSQC Quality  
Learning Series

**6 patient partners**  
Canadian Centre for Diversity  
and Inclusion Conference





# Capacity Building for Patient Partners

## New PVN Resource: Working Together – Virtually

Recognizing that patient engagement through the pandemic would be largely done online, we created a one-pager called Working Together Virtually to support patient and health care partnerships. The goal was to help with the transition from face-to-face to online meetings and identify strategies that could help teams quickly move to a completely virtual approach. Particular attention was paid to acknowledging that in-person engagements do not transfer directly to a virtual platform. It is important to redesign engagements to align with a virtual approach. The resource was distributed to health care and patient partners across the province.



### Working Together Virtually

As we continue to share engagement opportunities, your health and safety is our top priority. Health care organizations are actively updating their COVID-19 guidelines and adapting to comply with public health standards. We recognize that there may be uncertainty in how you work together and whether it's safe to meet in-person. We hope these recommendations can assist you in having those conversations.

#### Can we meet in person?

We recommend that you meet virtually, not in person. Public health guidelines maintain that COVID-19 remains a concern and warrants appropriate physical distancing. Until there is a change in policy, we recommend participating virtually.

#### What if my group wants to meet in person?

There is no expectation for you to participate in person. As you continue to build relationships, we hope that you feel comfortable reaching out virtually to discuss options. However, we recognize that not every engagement opportunity can be transitioned easily to a virtual approach, so it's important that you talk about what makes sense.

#### What about accessibility?

Closed Captioning, sign language and translation should always be a consideration. Check with your organization, and the virtual system you are using to see if accommodations can be made.

#### Where do I start?

You can start by answering the following questions to help think about a virtual approach:

**Preparation** – Does everyone have access to technology and the supports to be successful?

**Timing** – How long do you meet in person? Would that timing be adaptable to a virtual setting? How does it support health and wellness of your partners?

**Content Fit** – A standard health care meeting with complex materials, may not apply to a virtual setting. If this topic is more complex, try adding a 1:1 discussion prior to a group meeting to reduce confusion and use group time efficiently.

**Measuring Value** – What's your intended outcome? Why are you trying to do this? The same rules apply for effective meetings, whether in person or virtually.

Your Engagement Leader is available to support you in partnering virtually. You can reach us at [pvn@bcpsqc.ca](mailto:pvn@bcpsqc.ca) or 1 877 282 1919. For accurate, up to date COVID-19 information, please refer to the BC Centre for Disease Control.

PVN is a community of patients, families and caregivers working together with health care partners to improve BC's health care system.

Download *Working Together Virtually*





# Capacity Building for Patient Partners

## New Training: Zooming Together

Early in the year, as physicians worked through the challenges of using videoconference technologies for patient care, they began to express concerns that not all their patients would have the comfort and support necessary to access virtual care. Along with Northern Health, the BC Patient Safety and Quality Council quickly formed a small collaborative to support patients with Zoom technology.

**DTO** Doctors Technology Office  
A BCPSQC initiative

### Seeing Your Doctor with ZOOM

- 1 Book Your Virtual Appointment**  
You can book your virtual appointment exactly the same way as an in-person visit. Your clinic will explain to you how virtual visits work. Ask questions to ensure you understand the process, give your consent and provide contact information to receive the instruction with next steps.
- 2 Receive The Invitation**  
Your clinic will email you an invitation confirming the date and time of your appointment. It will contain a ZOOM meeting link and instructions on how to start your visit. Do not share this link with anyone. Check your spam/junk folder if you haven't received the email. Contact your clinic if you need help.
- 3 Prepare for Your Virtual Visit**  
Before the first visit, select a well-lit private location with reliable internet or a wired connection. Test your video and audio (consider using headphones for sound quality & privacy). Have the clinic phone #, your ID and your pharmacy address handy. Consider having a friend, family member, or friend available to help troubleshoot or assist with self-exam.
- 4 Click The Link To Start**  
Open your invitation and click the meeting link. Enable your camera if asked. Choose to **Use Computer Audio** or **Phone Call** if audio or internet connection is poor on your computer. Consider writing down the meeting ID, phone number and password for reference if you choose to call in via phone.
- 5 Wait in The Waiting Room**  
You will be admitted into the waiting room until your doctor is ready to see you. Similar to a physical waiting room, your doctor may be delayed while seeing other patients. Please be patient and use this time to test your settings by clicking **Test Computer Audio**.
- 6 Start Your Visit**  
Your doctor will admit you to the meeting room when they are ready to start the virtual visit. Be sure to turn on your camera and unmute your microphone. Once you connect with your care provider, outline your primary health concern.

**Your doctor will end the video visit when your appointment is completed**

**How to Access ZOOM:**

- Already have a ZOOM Account?**  
Simply click the meeting link in the invitation sent by your clinic. Ensure that the name you use for your ZOOM account is recognizable to your physician. Either change it in your ZOOM settings or inform the clinic.
- No ZOOM? Download App**  
Install ZOOM Cloud Meetings.  
On your computer, go to <https://zoom.us/support/download>.  
On mobile device, go to Apple Store (Mac) or Google Play Store (Android).
- No ZOOM? Run via the Internet**  
Copy and paste the meeting link into your web browser. Select 'Join from your browser' at the bottom of the screen and enter your name to start the virtual visit. For optimal results, use Chrome.

Check [Frequently Asked Questions](#) | Contact [ZOOM Help Centre](#)

May 06 2020

**Download Seeing Your Doctor with Zoom**

The team included representation from the Northern Health/Specialist Service Committee's Physician Quality Improvement team, the Practice Support Program, Patient Voices Network, as well as expertise from Doctors of BC and the Doctors Technology Office. With the goal of building capacity and comfort with virtual visits, we worked together to invite patient partners to attend an interactive Zoom learning session where they could practice different functionalities, learn about what to expect in a virtual visit and ask questions.

In total, 57 patient partners and health care partners from across the province took part in the Zoom training calls. Beginners and those self-identifying as needing additional support received a phone call from BCPSQC staff to help them get set up prior to the interactive training.

Feedback from the training was overwhelmingly positive and with support, and 100% of participants were able to access sound and video and participate in interactive Zoom activities. The session was recorded and is [available for view on our website.](#)



## PVN Process Improvements

We continue to take steps to improve our processes so that we can provide better support for our patient and health care partners. This year, we brought together a working group of patient partners to update and improve the onboarding and orientation process for new patient partners. We also redeveloped our website with the goal of making it more accessible and easier to navigate.

### PVN Orientation

In April 2020, the PVN Orientation Working Group was formed with five patient partners from across the province. The focus was to improve the onboarding and orientation process, provide resources for new patient partners and explore the possibility of developing a health care partner orientation.

The working group reviewed evaluation data from the past five years and interviewed 20 patient partners. As a result of this work, the orientation presentation was updated to be more interactive, include our commitment to diversity and cultural safety, and include how we are measuring and spreading the impact of patient engagement. This was coupled with stronger technology support for participants using Zoom for the first time. Examples of two updated resources are the [Patient Partner FAQs](#) and the [Zoom instructions](#) sent to patient partners before attending their orientation.

The new orientation is receiving positive feedback from participants, and in the spirit of continuous quality improvement, will undergo another review in the spring of 2022.





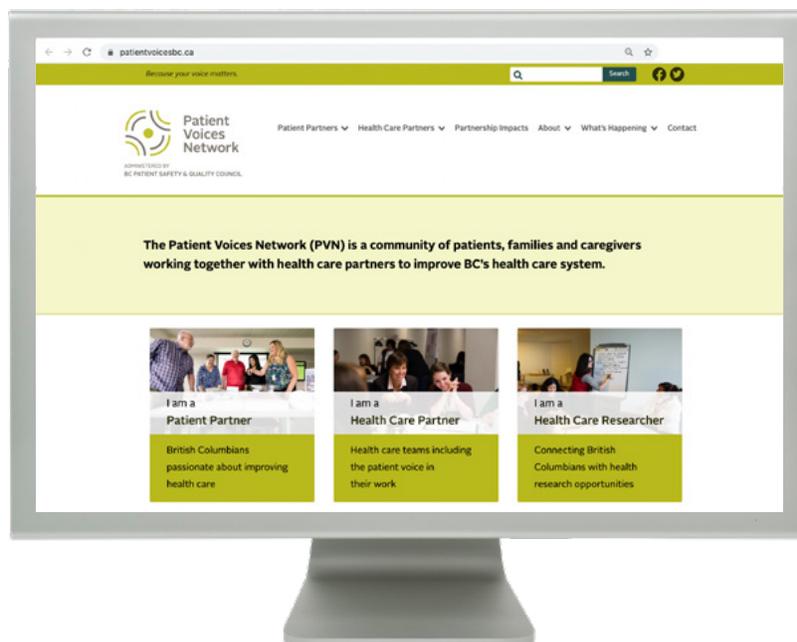
## PVN Process Improvements

### PVN Website

As we continue to grow and patient engagement in BC evolves, we identified the need for a new website that is easier to navigate and more accessible. PVN patient and health care partners helped guide the development of the new website to ensure it supports building partnerships to improve health care in BC. We conducted surveys and created a working group with patient and health care partners to learn about what members liked and did not like about our old website, which helped focus our efforts on providing a website with easy navigation.

Our new website is a modern, efficient design built for desktops and mobile devices that allows users to get what they need, quickly. Web accessibility (making content more accessible to people with disabilities) was a big focus and we were pleased to achieve Web Content Accessibility Guidelines 2.0 Level AA conformance.

The website contains a wealth of information that people can easily navigate when seeking to learn more about us and how they can get involved in regional or provincial health care improvement work. It features prominent sign-up instructions and testimonials from current patient and health care partners – all with the objective of growing and diversifying our membership to ensure all British Columbians can have their voice heard. It also includes a new feature where we share about how PVN partnerships are working together to improve health care. We continue to refine and review the website, and make changes based on what works for our partners.





## Looking Ahead

### Strategic Planning

As our 2017-20 strategic plan ran its final course this past year, a team of patient partners, health care partners and BC Patient Safety & Quality Council staff met regularly through the summer and fall to design an engagement strategy that would inform a refreshed strategic direction for PVN. Unfortunately, this work was paused due to COVID-19, but we are well-primed and eager to move it forward next year. We look forward to connecting with our partners very soon to learn more about their priorities, pressing needs and key areas for focus in patient engagement!

### Thank you

As we wrap the eleventh year of PVN, we would like to acknowledge and thank all the patient and health care partners who have participated to date. We are immensely grateful for your time, wisdom, energy and experiences. This platform of partnership would not be possible without patient and health care partners working together to improve British Columbia's health care system.

This past year has required a lot of pivoting to meet the demands of the COVID-19 pandemic. We look forward to next year with hybrid engagements where we can continue working together virtually but also see more of each other in person. To stay updated on PVN's activities, subscribe to our [newsletter](#), visit our [website](#) and follow us on [social media](#).





## Patient Voices Network

ADMINISTERED BY  
BC PATIENT SAFETY & QUALITY COUNCIL

The BC Patient Safety & Quality Council's work leads to better health care for British Columbians. Using evidence-informed strategies, we advance person- and family-centred care, shift culture and improve clinical practice to support high-quality care for every person in our province.

604.668.8240 / 1.877.282.1919

[pvn@bcpsqc.ca](mailto:pvn@bcpsqc.ca)

[PatientVoicesBC.ca](http://PatientVoicesBC.ca) |   @PatientVoicesBC

    @BCPSQC