



**2021-2022**

# Annual Report

**PATIENT VOICES NETWORK**

Administered by:

**BC Patient Safety & Quality Council**



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

# **About the Patient Voices Network**

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 services across the province.

PVN's mission is to advance authentic patient engagement by building our partners' capacities so that person- and family-centered 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 at [PatientVoicesBC.ca](https://PatientVoicesBC.ca).**

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## Message from the Oversight & Advisory Committee



**Vikram Bubber**

Co-Chair  
*PVN Oversight &  
Advisory Committee*

Patient Partner



**Tammy Hoefler**

Director,  
Patient & Public  
Engagement  
*BC Patient Safety &  
Quality Council*

Co-Chair  
*PVN Oversight &  
Advisory Committee*

British Columbia has faced a unique set of challenges over the last several years, resulting in significant change and disruption to our health care system. We know what a toll this has taken on patients, families and caregivers throughout BC, and we thank you for your continued commitment to making our health care system better. While the challenges we've faced affected how we work together, it did not affect our shared passion and resolve to strengthen health care in BC. In fact, we share a renewed focus on ensuring patient voices are at the forefront of all our conversations and plans.

We heard the importance of continuing to work towards the priorities our PVN members identified at the beginning of the pandemic. That led to us connecting you with other network members, developing resources to support online engagements and advance cultural safety and humility, and welcoming new co- and vice- chairs to our Oversight & Advisory Committee to continue putting patient voices first.

This focus was complemented by support and initiatives from the BC Patient Safety & Quality Council, which administers PVN, to build knowledge, skills and capability needed by patient and health care partners to participate in network activities and transform our health care system. This included supporting 78 PVN patient partners to attend workshops, conferences and courses to continue their health care system, patient engagement and quality improvement learning journeys.

If the challenges we've faced have taught us anything it's that a strong health care system is one that reflects the voices of the people it serves. 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 offer our tremendous gratitude to our network members.



Tammy Hoefler



Vikram Bubber



**Christina Krause**

Chief Executive Officer  
BC Patient Safety &  
Quality Council

## Message from the BC Patient Safety & Quality Council

As our health care system navigated a second year of COVID-19 challenges, we saw patient and health care partners continue to adapt to evolving circumstances such as changing public health orders, new variants and visitor restrictions. The many projects and accomplishments detailed in this report demonstrate your flexibility and perseverance – and for that, we’re so thankful.

Added to the pandemic were the consequences of climate change many of you experienced firsthand, including heat domes, forest fires, flooding and atmospheric rivers. Our health care system exists within a much larger context, and one which will no doubt require new solutions co-created by those who provide and receive health care services. How we deliver health care and its impact on climate change and planetary health is more important now than ever before.

Those solutions – and many more in the years ahead – will rely on patient partners’ lived and living experiences sparking improvement in the quality of care in BC, as well as health care partners ensuring their work reflects the needs and experiences of the people it impacts.

Administering PVN is a key component of the Council’s commitment to advancing patient engagement. We are regularly awed by your passion for making health care better for everyone, and we thank you for your commitment and action to improve health in BC.



**Devin Harris**

Chair  
BC Patient Safety &  
Quality Council

Christina Krause

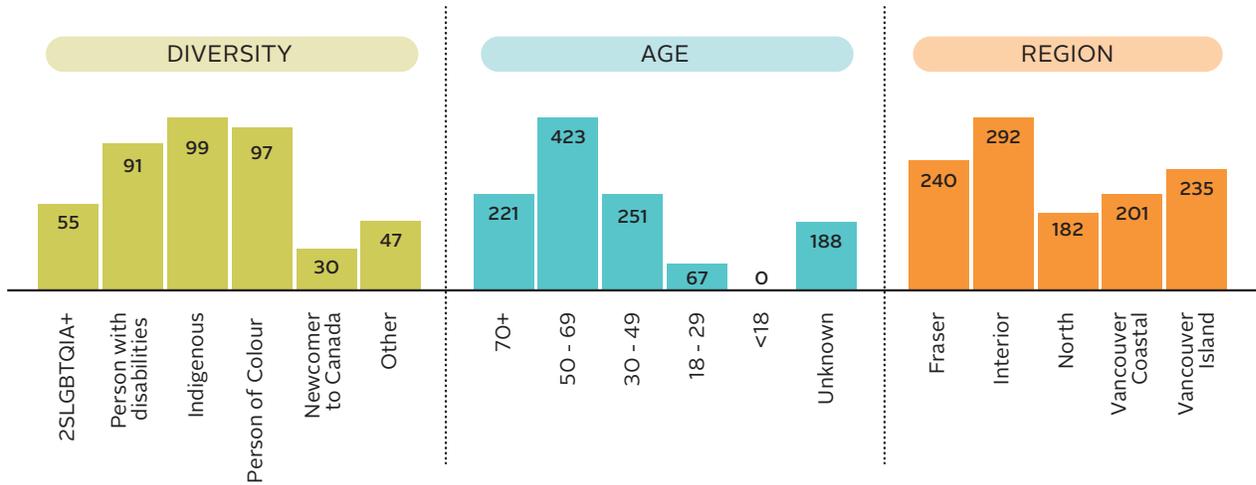
Devin Harris

# PVN by the Numbers: Highlights from 2021-2022

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.

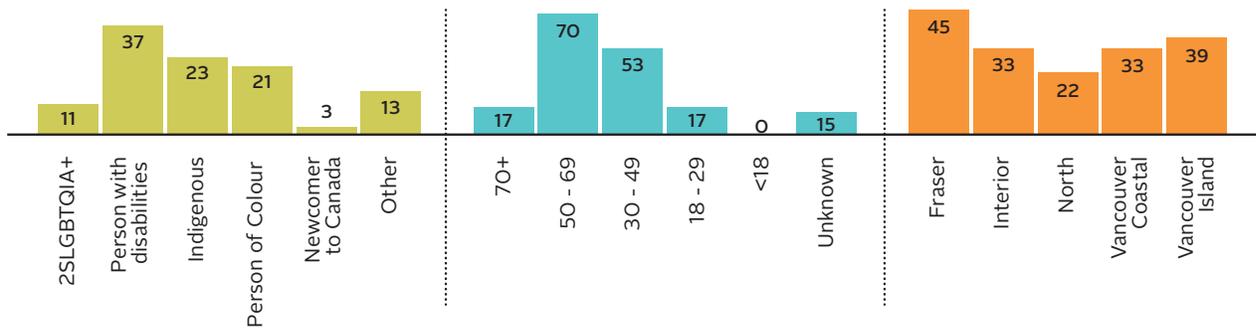
## Who is in the Network?

As of March 31, 2022, there were 1150 patient partners in PVN.



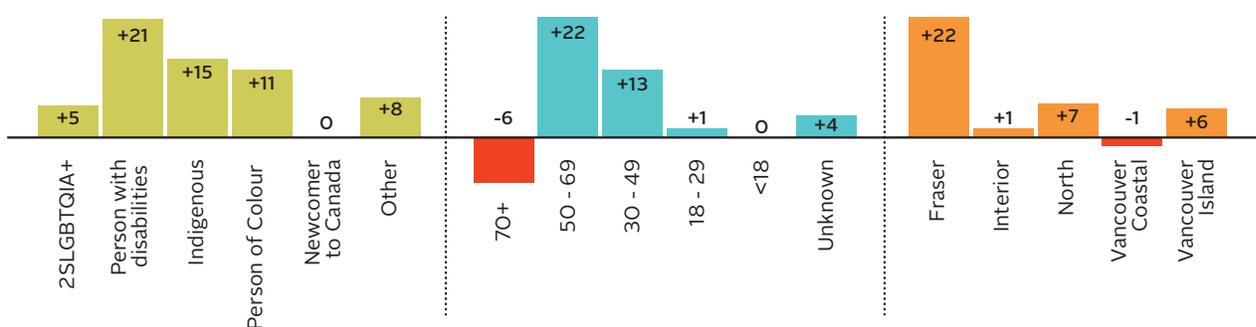
## Who joined this year?

We welcomed 172 new patient partners in 2021/22!



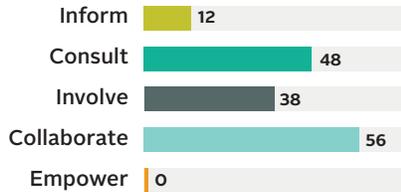
## Change from last year:

We looked at the new people who joined PVN compared to the previous year.



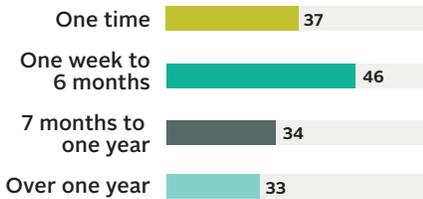
## What were we up to? We supported 154 new engagement opportunities this year!

### By IAP2 Level of Engagement:



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

### By Commitment Length:



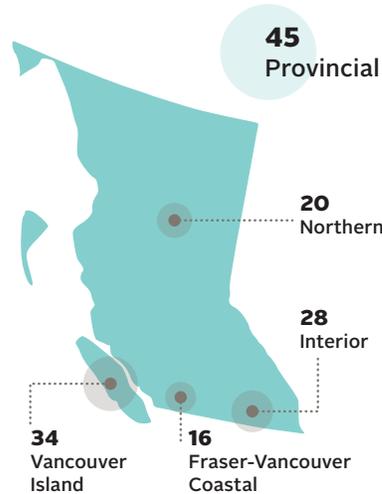
### 918 applications

to participate in engagement opportunities were received from patient partners

### 44% of patient partners

in the Network applied to participate in at least one opportunity

### By Region:



### Who participated?

**137 different health care teams** submitted an Engagement Opportunity.

**694 patient partner roles** were recruited for and filled by 383 individuals. Of them:

- 38 were Indigenous
- 3 were First Nations
- 3 were Métis
- 2 were Elders or Knowledge Keepers
- 13 were 2SLGBTQIA+
- 35 were Persons with Disabilities
- 8 were Newcomers to Canada
- 25 were Persons of Colour
- 19 identified as Other

### Ongoing Engagement Opportunities:

On top of all of that, there were:

**158 engagement opportunities** that continued on from last year 2020/2021

**317 patient partners** continuing to participate in engagements started last year

## How did they go? 76 Patient Partners completed end of engagement surveys in 2021/2022. Here's some highlights:



**88% agreed**

"The background information I received from health care partner(s) supported my participation."



**87% agreed**

"I understood what was expected of me as a participant, as outlined by the health care partner(s)."



**91% agreed**

"I was able to express my views freely."



**89% agreed**

"I felt that my voice was heard."



**92% agreed**

"I felt appreciated by the health care partner(s)"



**81% agreed**

"I was clear on the goals of this engagement throughout"



**85% agreed**

"I understood the purpose of my involvement"



**78% agreed**

"The engagement achieved its stated goals."

# Engagement in Action Across BC

Patients, families, caregivers and health care teams are working together to improve the quality of care within BC's health care system. We are honored to highlight some of those impacts through the following stories of dedication, learning and partnership facilitated through PVN.

## ● ENGAGEMENT IN ACTION ACROSS BC

### Interior Fraser Northern Coastal Island Provincial

# Putting People at the Centre of Website Design

## Interior Health

**In late 2020, Interior Health began the task of re-building its public website – which receives over six million page views per year – from the ground up.**

The goal was to create a site with a modern look and leverage the latest technology to make it easy to use. More importantly, it had to be a person-centred website, where all elements – from the images to the content and organization – were all focused on what the public expected to see.

## Patients Included

To achieve this goal, the project team reached out to the Patient Voices Network (PVN) to create meaningful opportunities for patient partners to be involved in the work.

By mid-January 2021, 10 patient partners from across the Interior Health region were chosen to become the project's Public Advisory Group. This group represented much of the diversity of experience, demographics and perspectives that are seen in this vast region, covering 215 square kilometers. An additional two members of the public were also chosen to sit on the project's steering

committee. This further ensured the decision-making process would remain accountable to the patient and public perspective.

In the early phases of the website project, patient partners participated in workshops, surveys and individual phone calls to provide input on what they wanted to see in a new health care website.

## Suggestions to Action

Interior Health stakeholder engagement lead, Megan Kavanagh, had nothing but positive things to say about the quality and range of input provided by these volunteers:

“Bill Shuttleworth, a PVN patient partner, felt strongly that it should be easy for people to book lab tests online – that feature was added to the front page of the website,” said Megan. “Olivia Levesque, another PVN patient partner, helped us tap into the expectations of young people for a modern website that leverages current technology and information searching patterns.”

As the website began to take shape, patient partners provided feedback on individual sections. They reviewed them and provided feedback on how closely these pieces reflected the person-centred focus and where changes could be considered.

“Jared Basil, a patient partner, reminded us that when it comes to creating a website that is welcoming to Indigenous people, words matter and imagery does too,” said Megan. “His guidance shaped the photo selection and content of the pages throughout the site.”

Shortly before the website was released to the public, patient partners took part in usability testing where they completed surveys and participated in 1:1 demonstrations and interviews to test out the website and provide final feedback.

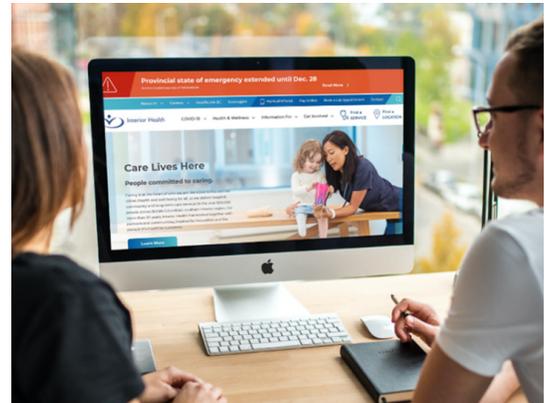
## A New Website Revealed!

Thanks to the energy and involvement of these patient and public members, the new Interior Health website was introduced publicly on November 16, 2021. Since then, page views to the new website have almost doubled. And the website bounce rate – visitors who only view one page and then leave the site – dropped by 28%, indicating that significantly more users are finding the information they are looking for.

“Public involvement made for a stronger process, project and outcome,” said Aisha Sinclair, Director of Brand and Marketing at Interior Health and website project lead. “Our public members helped to validate assumptions and key decisions in digital design, content and understanding of Interior Health services and access to them, as well as the overall user experience.”

Learn more about the [Interior Health website](#) and read interviews with public participants [Maria Klement](#), [Kari Wutzke](#) and [Jared Basil](#) on how their unique perspectives were incorporated into the website.

“With so much information to organize and convey, it’s easy to get lost in the details,” says Megan. “Our public partners were a constant reminder to us of specific people we needed to consider. They made us accountable in a very tangible way.” ●



## ● ENGAGEMENT IN ACTION ACROSS BC

### Interior Fraser Northern Coastal Island Provincial

# Psychological Safety in the Surgical Suite

## Fraser Health

### Psychological Safety. It's a notion that most would agree is important, but a bit elusive.

The formal definition is “the degree to which people view the environment as conducive to interpersonally risky behaviours like speaking up or asking for help.”<sup>1</sup> In health care environments, when it is lacking, staff and patients are less likely to suggest new ideas, offer feedback, or seek assistance for fear of reprisal or embarrassment.<sup>2</sup>

Lawrence Yang is a Family Doctor in Surrey practicing in a community clinic and as a locum at Surrey Memorial Hospital. In recent years, psychological safety is a topic he has become quite passionate about.

“When I first learned about the idea of psychological safety, in both the Physician Quality Improvement program and the Council’s Clinician Quality Academy, I thought ‘Yes! We need this – like 50 years ago! We all need to be talking about it.

We need to know how to facilitate it. We need to know how to create and hold safe spaces for people!’ That kicked off this journey of exploring how I could bring psychological safety into my practice,” he shared.

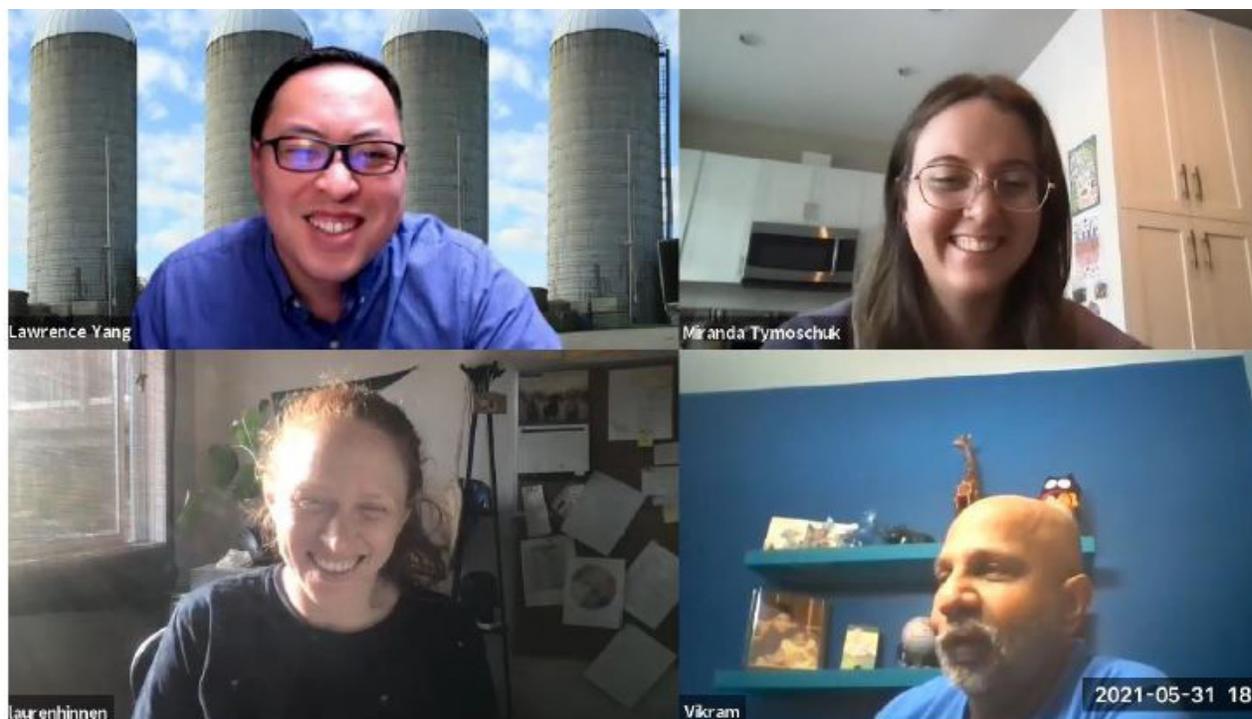
His enthusiasm for the subject led to his participation on the Doctors of BC Psychological Health & Safety working group, as a representative for Fraser Health. It was there that brainstorming began on how to introduce the concept to hospital-based surgical teams, in hopes of increasing staff comfort to speak up when they feel something is wrong.

From his view, there are many contextual factors impeding psychological safety in the health care workplace, including decades of pre-existing over-work in physician cultures, a culture of martyrdom, a culture of harsh inner critics from perfectionists entering training in the health professions, as well as the added stress of the pandemic.

Most conversations and research on psychological safety focus on the well-being of health care staff, the functioning of teams and care coordination, reduction of errors and improved cost effectiveness. While important, of course, Lawrence was also curious about how and why the psychological safety of care providers, matters to patients.

<sup>1</sup> Amy C. Edmondson, Monica Higgins, Sara Singer & Jennie Weiner (2016) Understanding Psychological Safety in Health Care and Education Organizations: A Comparative Perspective, *Research in Human Development*, 13:1, 65-83, DOI: 10.1080/15427609.2016.1141280

<sup>2</sup> Doctors of BC. Policy Statement. Promoting Psychological Safety for Physicians (2017). Available from: [https://www.doctorsofbc.ca/sites/default/files/2017-06-promotingpsychologicalsafetyforphysicians\\_id\\_113100.pdf](https://www.doctorsofbc.ca/sites/default/files/2017-06-promotingpsychologicalsafetyforphysicians_id_113100.pdf)



## Patient Engagement – A ‘Creative’ Conversation

“It is so easy for health care professionals to be provider-centric in their improvement work and lose sight of the real end goal: patient health outcomes and experience. By bringing a patient partner in, you can stay focused and have much more satisfaction at the end of a project,” said Lawrence. “Both the PQI [Physician Quality Improvement] and Clinician Quality Academy programs had really stressed the importance of patient engagement. So, I reached out to the Patient Voices Network and the Engagement Leader, Jami Brown, connected me with three patient partners: Vikram Bubber, Lauren Hinnen and Miranda Tymoschuk.”

This was Lauren’s very first patient engagement opportunity, and she was happy to have an opportunity to share her perspectives on the system, and some pieces of her own journey of care.

“Over the past 10 years I have learned to live with a chronic illness where I’ve had hospital stays, medical procedures and countless tests. Without the health care system I wouldn’t be here today, so I wanted to use my firsthand knowledge to create positive changes for patients and health care staff. This was my first project with PVN and starting with just telling my story seemed like an easy way to start getting involved,” she said.

In this project, the patient voices didn’t just inform the project, they were the project. Initially, Lawrence had hoped to invite the patient partners into the Operating Room to speak directly with surgical teams. However, with COVID-related visitor restrictions in hospitals at the time, the group instead decided to create a dialogue-based video. Appreciating that people are overloaded with email and various reading materials, they hoped that leveraging creative media might help them to reach more hospital staff.

In May of 2021, the three patient partners met with Lawrence in a 2-hour recorded Zoom session to share their perspectives on what psychological safety is and why it is important to them as patients, and how it benefits members of their health care teams. An abridged [5-minute video](#), and a [full version](#), are now available on YouTube.

## Patient Insights

Of the many ideas shared, some of the most poignant included:

- *If our health care teams had more psychological safety, the patient experience and sense of security during our treatment/care would likely improve.*
- *If our health care teams had more psychological safety, then patients would have a greater likelihood of trusting their health professionals.*
- *Health care staff seem to be overwhelmed with work from the patient perspective. Staff rarely seem “present” when with patients, it feels like they are always trying to complete the next task - and because of this, they miss important information.*
- *Our health care teams give the impression that they do not talk to each other, patient stories are not passed on between siloed teams - communication must improve between teams and with patients and patient families.*

Another idea the group chatted about was that the psychological well-being of staff can impact that of the patients. “One of the patient partners talked about doctors and nurses needing training on how to respond

to patients’ suffering and emotions. How they need to be more present and have more tolerance for emotional challenges. That made a lot of sense to me. You know, all of my colleagues are good people who want to do a good job, but I’ve seen in the hospital, when people are busy and whatnot, sometimes the intensity of a patient’s emotions scare them away, and then they abandon the patient, instead of just being there. And it’s actually quite healing, to just ‘be there’. To walk away and isolate a patient in those moments, because of our own discomfort is probably counter productive to their healing,” reflected Lawrence.

## Advice for Health Care Teams on Patient Engagement

“When you’re meeting with patient partners, be ready to listen and learn and stay curious. Don’t jump to conclusions. Know that patient partners have valuable input that could make or break your project. They might be able to tell you ‘It’s way off! It’s not going to work!’ and that can help you too! Seeing where to redirect your resources, etc. They can really help you to level up your project to greater effectiveness,” offers Lawrence.

## Advice for Patient Partners

“Come as you are. Don’t be afraid to ask questions of the health care partner. Sometimes I worry about the sense of power differential in engagements – that patients might not feel psychologically safe or able to speak freely. So, I would encourage them to be bold, and to recognize the value of their lived experience,” said Lawrence.



Without the health care system I wouldn't be here today, so I wanted to use my firsthand knowledge to create positive changes for patients and health care staff.

LAUREN HINNEN



When you're meeting with patient partners, be ready to listen and learn and stay curious. Don't jump to conclusions. Know that patient partners have valuable input that could make or break your project.

LAWRENCE YANG

## Next Steps: Sharing, Spreading & Learning From the Video Resource

The team is now looking for online training curriculums and opportunities to share and make use of the videos. The YouTube links can be shared with any audience embarking on a learning journey around psychological safety in the health care workplace. One program that picked it up as a learning resource is a new initiative launched by Doctors of BC and Fraser Health to provide leadership coaching and psychological safety training to physician and administrator dyads in Fraser Health.

Lawrence is hopeful that as the video is viewed by more people, it will shape many learning journeys. "When they see how eloquently these patient partners speak about their needs in health care, I think they will remember it. It is not an easily forgettable experience, watching these patient voices speak about how important it is, that their health care providers feel safe in their teams," he said. "I really enjoyed connecting with these patient partners and I learned a lot from them. I was inspired by their level of knowledge and awareness of the system, how compassionate they were towards care providers, and how understanding they were of our challenges as health care professionals."

Lauren reiterates the compassion that she and many patients hold for their providers. "I hope those watching the video see how grateful we all are for the health care system, and how much it needs to get better for the patients, and for the staff," she shares. ●

## ● ENGAGEMENT IN ACTION ACROSS BC

### Interior Fraser Northern Coastal Island Provincial

# Falls Prevention: With Patients. For Patients.

## Northern Health

**Falls are a leading cause of injury-related hospitalizations and often the reason why older adults lose their independence.**

Without prevention efforts, it is estimated that one third of people over the age of 65 will fall once or more each year<sup>3</sup>. Fortunately, falls are not inevitable. Coordinated prevention efforts and systems of care can reduce falls and subsequent negative impacts to quality of life. In 2021, Northern Health's Rehabilitation Services Program set out to ramp up its prevention efforts.

### Part 1: Policy & Standard Updates

Their first step was to update the Northern Health falls prevention strategy for community settings to include the latest evidence and best practices, as well as to ensure a person- and family-centred approach. In his role as Executive Lead, Rehabilitation Programs, Tysen Leblond set about assembling a project team, enlisting help from clinicians and staff from the population health and

policy offices, but quickly realized that an important perspective was missing. "Patients bring a unique perspective that was missing from our group, and we wanted to ensure our practice standard would be valuable to our clients," he shared.

Tysen reached out to PVN, and two patient partners were recruited to provide feedback on the draft. One of them was Vern Mitchell, a self-described 'young at heart senior' whose interest in this initiative was piqued due to personal experiences with falls.

"I have seen my Mom advance through stages of MS which in the early years saw her falling a lot. My late Father had dementia and many balance and falling issues as he progressed. I myself was born with rickets (very rare in the late 50s but it got me) which has left me with lifelong balance issues with stairs and inclined surfaces."

Those lived experiences and the insights into risk, assessments and care they produce are exactly what the team was looking for. Tysen and his team took care to orient the patient partners to the project through an initial 1-hour orientation session to review the development of policies and clinical practice standards and background information on the falls prevention strategy at Northern Health. The patient partners went away and independently reviewed the materials, then reconvened for a draft discussion meeting where they shared their feedback and discussed ideas for improvement.

<sup>3</sup> <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/disease-and-injury-care-and-prevention/fall-prevention>



“They were involved in reviewing the policy in its entirety including all attached links, the client-focused resources and language used in clinical assessments within the policy,” explained Tysen.

“Through that process, I was able to share my experiences from family and my volunteer work in a care home setting,” shared Vern.

## Part 2: Education & Awareness

Following the updates to the Clinical Practice Standards, a second project was initiated in the fall of 2021 to develop an educational and awareness package about falls prevention for health care providers working in community settings. Two additional PVN patient partners joined the working group to share their perspectives and experiences

with risk assessments, interventions and follow-up care. The working group met weekly via Zoom for a month. The hope was that incorporating patient experiences into the training materials would encourage person-focused learning, as opposed to a task-only orientation. “The patient partners also helped us to develop staff education case scenarios, anonymizing details of course,” added Tysen.

## Outcome & Impacts

The policy is now live and used by staff across Northern Health, and staff education on its application is ongoing.

“The patient partners’ suggestions helped to ensure that the core principles of (a) person- and family- centred care approach shaped the clinical practice standard. They really helped us hone in on the importance of collaborative practice, including exploring ways to work closely with the patients/ family, physicians and other clinical staff throughout the entire process: assessments and care planning in falls prevention,” shared Tysen. “The introduction of a shared (patient and provider) falls prevention assessment is the first of its kind in Northern Health, to my knowledge,” he added.

“The engagement resulted in a stated commitment from clinical practice standard developers to employ more consistent wording throughout the document that tasks be done in partnership with clients and families. We hope this will encourage client activation and maximize opportunities for shared decision making with regards to falls prevention,” said Tysen.

## Challenges & Benefits

When asked about any challenges encountered along the way, Tysen shared that it was, at times, tough for the team to find time to work on this project amid the chaos of the pandemic. However, taking the time to thoughtfully include patient partners was meaningful and motivating. “It was great to hear positive feedback from our patient partners and knowing we are on the right track,” shared Tysen.

## Advice for Others

Tysen hopes that more policy staff and patient partners will embrace the idea of patient engagement. “I would encourage health care partners to include patient partners in policy development, as they offer a perspective that most staff just cannot replicate,” he said. “And I really encourage patient partners to get involved in policy work too. Their differing perspectives and experiences provide so much value to this process. There is no need to be a content expert – your lived experience is your expertise,” he shared.

In addition to contributing to an issue of personal importance, Vern shared that he also found meaning in “hearing from others in the group who also had a history of family members dealing with falling issues”. From that lens, his advice to fellow patient partners is to “pick a subject you can relate to”. ●



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TYSEN LEBLOND

● ENGAGEMENT IN ACTION ACROSS BC

Interior Fraser Northern Coastal Island Provincial

## **Skunkworks: Hacking Pain**

### Providence Health Care

**“We need to think differently!”**

**“We need to step outside the box!”**

**“We need creative solutions!”**

These are common declarations in response to persistent and widespread problems. What’s less common is a high-impact example of such innovation in action.

Enter: Skunkworks. It’s an approach to problem-solving that assembles multidisciplinary teams and empowers them with mentorship and tools to tackle big challenges and prototype solutions.

In November 2021, Providence Research and the St. Paul’s Foundation teamed up to plan and host [Skunkworks: Hacking Pain](#), a two-day event where researchers, clinicians, academic partners, patients/residents, students and the broader community put their heads together to address pain with innovative ideas.

“The event helped to underscore a particular Providence tradition of putting people in the greatest need at the center of our research priorities,” shared Josephine Jung, Manager, Special Projects and Strategy.

The Skunkworks event focused on pain, given its widespread prevalence and significant impact on quality of life. It is currently estimated that over seven million, or one in four Canadians, live with chronic pain.<sup>4</sup>

### Skunk-what?

Skunkworks. The term originated in the 1940s as an alias for an American engineering lab that worked on top-secret and innovative programs at Lockheed Aircraft Corporation. Today, the word “skunkworks” describes a project developed by a loosely structured group of people who identify issues and pilot creative solutions.<sup>5</sup>

Josephine’s team hoped the event would help to develop and facilitate a culture of innovation at Providence Health Care. They saw Skunkworks as a creative way to address a complex local problem with global relevance. They also hoped it would break down silos and help to bridge the gap between diverse individuals and disciplines.

### How did it work?

Prior to the event, registered participants were invited to submit “problem ideas” regarding either the physiological or psychological aspects of pain, including the dynamics of pain, causes and alleviation of pain and/or treatments to prevent or mitigate pain. On day one of the event, approximately 75 participants gathered at the Holiday Inn in Vancouver.

<sup>4</sup> <https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2020.html>

<sup>5</sup> <https://www.providenceresearch.ca/skunkworks>

The group included patients, doctors, nurses, pharmacists, occupational therapists, physical therapists, designers, engineers, data analysts, computer scientists, project managers, administrators and students from many disciplines. The “problems” were presented, and teams were formed as people gravitated toward the problems that best suited their interests, technical skills or personal experiences.

From there, teams worked through the design process under the guidance of facilitators from the Alberta Health Services Design Lab and other mentors in the room. By the end of two action-packed and energetic days, the teams presented their prototyped solutions to a panel of judges and prizes to advance winning ideas were awarded.

## Patient Partners’ Perspectives

Two PVN patient partners were recruited to help ensure the event was designed and conducted with patients, families and caregivers at its core.

“It was important to have patient partners involved and participating – to hear their lived experiences, to go through the process of working with interdisciplinary professionals and having that interaction and bidirectional learning happening,” shared Josephine.

Patient partner Kristie Nicol was keen to get involved due to her own experience with chronic pain but also her passion for innovation and creation.

“While I don’t expect my pain to ever be at zero, I know there is opportunity and possibility for change, and that comes from looking at things differently – not going with the status quo. What really appealed to me about this event was bringing



together people who were open and willing to think differently. I think that is what the world – and health care – needs. We’ve been doing a lot of the same things over and over again, so let’s change it up!”

As a steering committee member, Kristie attended planning meetings to iron out details and tighten up the project’s framing.

“Along the way, Josephine would bounce ideas off of me, and I reviewed and edited public-facing documentation to make sure the patient voice – the user, the audience – was always at the center,” she shared.

At the event, Kristie contributed as a judge and a mentor, drawing from her knowledge as a patient with chronic pain and her technical communications background to coach teams through their design efforts.

“I walked around, sat with different groups, they asked me questions, I provided some feedback, advice and comments,” she recollected.

Kristie knew that solutions would only stick if they were based on a solid understanding of, and empathy for, the experiences and emotional needs of patients. As a mentor, it was important for her that participants really understood the needs and realities of the end-users they were designing for.



“I think I was able to provide more insight into what it is like to live with chronic pain and the many challenges and barriers we face. People came to Skunkworks with ideas and skills, and with enthusiasm and openness, which is so important, but they really needed to understand the audience first. I was able to come to the tables and say, ‘Great idea, but how is this going to work for someone with cognitive challenges because of pain?’ Digging into some ideas and making them a little more realistic for people,” she shared.

The most meaningful and challenging part of the event for Kristie was helping teams consider that trust is often a barrier for people with chronic pain. Past experiences with the health system may affect their willingness to engage in a new way.

“I wanted people to understand that we [people with chronic pain] are often revictimized when we go to appointments: not being treated with respect, our problems are dismissed, sometimes we are lied to, some people have struggled with employment conditions, or with their

family and friends when turning there for support. Trust is lacking for a lot of people. For me, it was meaningful that I could highlight the fact that you have to start with trust – whether in a relationship or interaction with a doctor or with an app or website. How do you build trust? And what does trust look like for someone who has been repeatedly traumatized in different aspects of their life? How do you reach them? How do you provide hope and respect their experiences?”

Kristie shared that the approach, tact and diplomacy needed to dive into those conversations wasn’t always easy.

“It was a bit tough to say, ‘No, you’re starting in the wrong spot,’ and telling people to step back and think about the user. You know, asking teams, ‘Who is your audience? Who are you working for? What is in it for that patient, person, family member or caregiver? How do we build trust for them?’ When you’re dealing with people who have chronic pain, you need to be objective but also emotional.

Behavioural change is challenging, but if people don't feel comfortable in an interaction or situation, they are not going to change," she explained. "So, finding ways to politely bring some assumptions down to reality was a bit tricky," she added.

While challenging, it seemed as though her message was well received and took root.

"You could see the groups, the people I interacted with, knowing how their conversations started on Friday morning, how by Saturday, words had softened, and how they really got the problems and people they were designing for."

## Putting Prototyped Solutions Into Action

At the end of the event, the Research Impact Award, which came along with a \$15,000 prize to advance the idea, went to the team that developed the ADAPT (Accelerate Distance Access to Pain Treatment) app to help people living with pain in rural and remote communities to access treatment and services more easily. From January to April 2022, the team worked with students from the [Centre of Digital Media](#) to produce a functional prototype, now called "PEPITA", that delivers a personalized experience to the user by curating a list of chronic pain management resources that meet the users' specific needs. Providence Health Care Ventures and Providence Research will be reviewing the next steps.

The Service Innovation Award went to a team that developed LOOP: a web-based clinical concept to support youth aged 18-24 who have aged out of pediatric care and need support navigating treatment and care services. Miranda Tymoschuk, another

PVN patient partner, was a member of this winning team! Since the event, discussions with [Foundry](#) have been underway to explore partnership opportunities.

## Advice for Health Care Teams

When asked if they had advice for health care teams embarking on patient engagement work, Josephine suggested to "be really clear on what your goals are, and what you seek from them, to make sure their time is well used." Kristie echoed the importance of clear goals and expectations and added "to make sure it's working along the way. Make sure there is a meaningful relationship there. Think about how to build trust!"

"I really enjoyed working with Josephine and the team. It was a really fun opportunity to see the whole project go from start to finish! I hope there can be more opportunities like this," said Kristie.

## Next Steps: Skunkworks Round 2!

The team hosted its second Skunkworks event on Sept 22-23, 2022, seeking innovative solutions related to wound prevention and care. ●

### Interested to learn more and possibly attending?

Visit [providenceresearch.ca/skunkworks](https://providenceresearch.ca/skunkworks) or email [skunkworks@providencehealth.bc.ca](mailto:skunkworks@providencehealth.bc.ca).

### Check out this 4-minute video of the event!

[discoveryforward.ca/innovators-join-forces-to-tackle-chronic-pain/](https://discoveryforward.ca/innovators-join-forces-to-tackle-chronic-pain/)

● ENGAGEMENT IN ACTION ACROSS BC

Interior Fraser Northern Coastal Island Provincial

# Improving Emergency Psychiatric Care at Cowichan District Hospital

## Island Health & Physician Quality Improvement

### **It is no secret that people with mental illness experience stigma in society.**

While not a secret, what is less broadly understood are the ways in which structural and interpersonal stigma around mental illness have contributed to a system of care that leaves much to be desired.

Unfortunately, for many people experiencing a psychiatric emergency, the only place available to receive care and treatment – the hospital emergency room – is often a place they experience some of the harshest effects of stigma and discrimination.

The Canadian Psychiatric Associations' position paper on stigma shares results from a Canadian survey where “stigma and discrimination toward people with mental illness in the emergency department” followed by “addressing structural inequities within the health care system” were ranked as the highest priority areas for action.<sup>6</sup>

It's a topic that Rachel Grimminck, a Vancouver-Island based psychiatrist, is passionate about. “My background is in Emergency Psychiatry. Over the years, I have witnessed a lot of really traumatic and dehumanizing care in seclusion. I've frequently heard patients say, 'I had more rights in jail than in this emergency department' – there are some really big gaps in the way the system provides care. It is something pretty close to my heart,” she shared.

When she relocated to the island from Alberta in 2021, she was pleased to connect with a newly established committee at Cowichan District Hospital where Emergency Department and Mental Health & Substance Use staff were working to identify gaps in adherence to BC's Provincial Seclusion guidelines.

As a participant in Island Health's Physician Quality Improvement program, it was an easy decision to connect her project to the momentum and efforts underway to improve quality of care for people with mental illness in the Emergency Department for people with mental illness. Specifically, the project set out to reduce the time patients in the Cowichan District Hospital spend in locked seclusion (under the Mental Health Act) when experiencing a psychiatric emergency and improve their overall experiences of care.

<sup>6</sup> Stigma and Discrimination. The Canadian Journal of Psychiatry, Vol 56 No 10. Available from: <https://www.cpa-apc.org/wp-content/uploads/Stigma-2011-51-web-FIN-EN.pdf>

## Patient Voices

Understanding patient perspectives and experiences is a crucial component of any quality improvement endeavor. In addition to the instrumental value of patient participation for quality improvement, hearing and learning directly from people with lived experience of mental illness and recovery has been identified as a powerful means to challenge and reduce stigma and discrimination among medical learners and providers.<sup>7</sup> Rachel understood both concepts well and was quick to include patient partners in the project. Not only would a better understanding of patient experiences in seclusion help to engage stakeholders and highlight the depth and extent of problems, but the team recognized that the best suggestions for improvement are made by the people who will benefit from them.

“It is distressing as health care providers to witness this, but it would be far more

distressing to actually experience being in seclusion, so it was really critical to include patient voices in this project,” she said.

Three patient partners, with personal experience of being in seclusion in a BC emergency department, were recruited through PVN, and invited for a 1:1 interview at the start of the project.

For patient partner Pat\*, this was an incredibly unique, and important conversation to take part in. “I haven’t seen opportunities like this before, on a subject that is very controversial. You see lots of touchy feeling things, but not a lot of people want to touch issues like seclusion rooms and the mental health act and rights of patients when they are admitted involuntarily. I applaud this project for even coming into being.”

Pat also knew they were the right type of person for the gig.

**Mental Health Act:** BC’s Mental Health Act enables physicians to admit and treat people with serious mental health issues who are a risk to themselves and/or others. People who are certified under the Mental Health Act can be treated involuntarily for a mental disorder.<sup>8</sup> [Learn More.](#)

**Seclusion:** Seclusion is a method of restraint during which a patient perceived to be in psychiatric crisis is contained in a room that is either locked or “from which free exit is denied” (Mayers et al., 2010, p. 61). An individual who has been contained and prevented from leaving a space in the course of a psychiatric intervention is considered to be experiencing seclusion whether or not the intervention is carried out in a formal secure room or other alternatively labeled environment, including a patient’s hospital bedroom.<sup>9</sup>

\* Name has been changed for this story

<sup>7</sup> CPA Paper

<sup>8</sup> BC Mental Health and Substance Use Services. The Mental Health Act [Internet]. 2022 [cited 2022 June 16]. Available from: <http://www.bcmhsus.ca/about/governing-legislation-bodies/the-mental-health-act#:~:text=British%20Columbia's%20Mental%20Health%20Act,involuntarily%20for%20a%20mental%20disorder>.

<sup>9</sup> Provincial Quality, Health and Safety Standards and Guidelines for Secure Rooms in Designated Mental Health Facilities under the B.C. Mental Health Act. Available from: <https://www2.gov.bc.ca/assets/gov/health/managing-your-health/mental-health-substance-use/secure-rooms-standards-guidelines.pdf>

“I have personal experiences related to the topic, and I also have experience from other health care committees as a patient partner. I know how important it is to get varied perspectives, and I thought my input would offer them something new. I had insights to share on my experience of being in seclusion rooms, and lots of suggestions and recommendations on what nurses and doctors could do differently to make it all understandable from the patient perspective,” they added.

## Trauma-Informed Approach

### The Health Care Partner perspective

Recognizing the difficult nature of the topic, the team took great care to create a trauma-informed approach to the interviews. In addition to a formal ethics and privacy review through the health authority, the interviewers clearly explained what the interviews were for and how the information would be used. They also discussed matters of confidentiality and privacy, asked for permission to record the interviews for transcription purposes only and explained they could stop at any time and that cameras could be turned off. They took frequent breaks, checked in with the patient partners, and at the very start, made sure that they had a support plan in place should the conversation be difficult for them.

“We talked about their experiences of being in seclusion. We asked questions about whether their basic needs were met, were their rights under the Mental Health Act explained, what kind of care, or absence of care they received, their suggestions for improvement, what care providers could do differently, and what system changes would better support their wellness,” explained Rachel.

“It’s a balance,” she added. “It is tough to talk about, but also at the same time, hopefully it helps to talk about it. Knowing that it is influencing, in a small way, how care is delivered. Knowing how it is helping people. That can be a part of post-traumatic growth and resilience too – making sense of a difficult life experience.”

“This is an area that because of stigma, people don’t want to talk about it, it is a difficult topic. For many patients, it has been traumatizing. So, the courage of these patient partners to do so was really incredible. It’s not easy to talk about. But their voices absolutely need to be heard,” she added.

### The Patient Partner perspective

Pat appreciated that the interview took place via Zoom, and that it was conducted by Rachel.

“It wasn’t a work study student or someone just gathering information and distilling it down for the doctor – but she herself led and conducted the interview. That was amazing. Often doctors don’t take the time to get involved in that way, but she did. She is an emergency room psychiatrist – the absolute most appropriate person to do such a study. I thought it was remarkable”.

For Pat, there was some initial safety in that they had never received care at Cowichan District Hospital, or from Dr. Grimminck, nor would they be likely to based on their geographic location. But upon further reflection, they offered another perspective as well.

“If she ever did take care of me in a challenging situation in the future, it would actually be comforting to know that she knows a little bit more about me. I think that is often missing



in care. People are just seen as ‘a patient’, not a whole person with a life behind them. People in psychosis, or people who go into seclusion rooms are just seen as, you know, people not able to take care of themselves who don’t know what’s going on around them. So, it could be beneficial for my future psychiatrist to get to know me and my life story now to see that this is who I am, and if I’m sick, well, then I’m a different person.”

## Change Ideas & Early Outcomes

Although the project continues, some change ideas and improvements have already been introduced thanks to the diligent efforts of the committee and project team.

“It is an exceptional, energetic and innovative group of people working on this,” shared Rachel. “They started this work despite the pandemic and staffing problems. It’s a pretty remarkable group of people”.

While the project team wasn’t in a position to tackle issues like the availability of beds and bigger system level issues that reflect the challenges of systemic stigma and underfunding, they have been taking strides to empower nurses

and physicians to approach this patient population through a different lens.

They’ve made some improvements to ensure people’s basic needs are met, such as meal trays and access to phones, clear communication and privacy.

“We’ve also had conversations with staff about asking patients what works for them, what would be supportive for them in those moments, and engaging with them rather than avoiding them,” explained Rachel.

Staff education and process changes have been introduced, as well as including a nursing checklist around adherence to the provincial seclusion guidelines, and a physician checklist for considering alternatives to seclusion and/or time-limited seclusion with an active treatment plan.

The team recently presented some findings and recommendations, including the patient partners’ perspectives, to the local Island Health Quality Council. “There were quotes in the presentation from the patient partners, and some of the suggestions for improvements were based on patient partner feedback – highlighting how we can make this care more patient-centred,” Rachel confirmed.

Rachel has also invited Pat back to do some coaching and mentoring with medical learners at the hospital – another area Pat has experience in and passion for.

## Acknowledging Challenges and Meaning

For both Rachel and Pat, physician and patient, the biggest challenge in this project didn't stem from the project itself, but from the ever apparent, increasingly visible, scope and size of systemic stigma in mental health care.

“It was challenging to realize how sadly little is researched and written about this topic, and how little and how slowly things are changing,” offered Pat.

On the flipside, that's also what made this such a meaningful engagement. “The most important part for me, was that someone was tackling this taboo topic. I am hoping that this project will open a floodgate of other projects that will look at the trauma inflicted by both seclusion rooms and the mental health act, and will hopefully, you know, bring a little bit more opportunity for people like myself to be involved at a decision-making level,” Pat shared.

For Rachel, the patient engagement aspect of the project was one of the most exciting and rewarding parts. “It is sad that patient engagement is still so novel – that this isn't just a core part of what we do. That we are still so often designing systems without the people using them. I think this is critical no matter what the project is. The value is exceptional for bringing in that human side. Particularly in Emergency Departments, where staff can be disconnected from the person in front

of them. It is hard work. It's even worse now in the pandemic, people are burned out and exhausted. But bringing that human element back in – through engagement projects like this – it can help to reconnect staff with why they went into health care.”

“I'm grateful that BC has [the BC Patient Safety & Quality Council] and PVN. I think it's fantastic that there is this formal process and am grateful to Charmaine [Council Engagement Leader] and the support of PVN to walk us through this,” she added.

## Advice for Patient Partners

Pat offers the caution that engagement work can, at times, be emotional. “It can bring up past experiences. It can bring up ‘why me?’ questions, and frustration over why the system isn't responding in a different way”.

They also encourage others, particularly those with mental health and trauma experiences, to get involved. “I don't see a lot of people like me involved as patient partners. Maybe they are not well enough to participate in structured meetings, or interviews or surveys. But we need more people speaking up. So, if there is an opportunity to participate, please do. The more pressure we put on the system, the more opportunity there is for change – change that is so needed,” they said.

Rachel echoes Pat's call for patient participation.

“If you feel you're in a place where you can do this, your voice really matters. It's hugely important. The more people who are willing to speak up about the significant gaps in mental health care – then that will slowly but surely impact the system”. ●

## ● ENGAGEMENT IN ACTION ACROSS BC

### Interior Fraser Northern Coastal Island Provincial

# Measurement for Successful Patient Engagement

## Patients as Partners

**If you've ever dabbled in or googled 'patient engagement evaluation' you've likely come across the name Clayon Hamilton.**

Clayon, who currently works as the Regional Practice Lead in Research & Knowledge Translation for Long-Term Care in Fraser Health, has been working over the last number of years to advance the practice of measurement and evaluation in patient engagement.

As a post-doctoral fellow at UBC in 2015-2020, Clayon and his collaborators produced a framework<sup>10</sup> and tools for planning, implementing, and evaluating the engagement of patients and family caregivers within health research. The Patient Engagement in Research Scale (PEIRS)<sup>11</sup> is now a well utilized tool in health research for evaluating the quality of patient-researcher partnerships.

But what about patient engagement outside of the research arena? Despite the growing momentum and practice of patient engagement in quality improvement, system redesign and other health system projects, there remains no widely agreed upon way to determine how well, or if, these efforts are working.

## Defining success in patient engagement in health systems decision-making

In 2018, Clayon's efforts expanded from the health research sector to health systems more broadly, to explore how, and how well, patients and family caregivers were being engaged in health system decision-making. He was awarded a CIHR-MSFHR Health Systems Impact Fellowship at the BC Ministry of Health to help evaluate the engagement component of the MOH's Patients as Partners Initiative. "It was a good fit for my background," explained Clayon, "I wanted to expand my expertise and apply my knowledge base more broadly, not just to patient engagement in research but in engagement in the health system."

[Patients as Partners \(PasP\)](#) is a government initiative working to promote person- and family-centred care in BC through the work of several funded partner organizations.

<sup>10</sup> Hamilton C, Hoens A, Backman C, et al. (2018) An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expect.* 21:396-406

<sup>11</sup> Hamilton CB, Hoens AM, McQuitty S, McKinnon AM, English K, Backman CL, et al. (2018) Development and pre-testing of the Patient Engagement in Research Scale (PEIRS) to assess the quality of engagement from a patient perspective. *PLoS ONE* 13(11): e0206588. <https://doi.org/10.1371/journal.pone.0206588>

“Originally, we wanted to evaluate what kind of impact patients and family caregivers had on the PasP initiative, but we realized we would need to do that in phases. We started by asking how we would define success of patient and family caregiver engagement in health system decision-making. We needed a framework to do that, and nothing existed at the time. There wasn’t a strong evidence-base to draw on,” explained Clayon. “We quickly realized this would be more work than anticipated!”

The team decided to start with a scoping review of the literature to identify key elements that could define success in patient engagement.

The study protocol<sup>12</sup> was published in 2019 and the study findings were published in 2021.<sup>13</sup>

## The Team – Patients & Family Caregivers Included

Along with staff from MOH PasP Initiative, the team included Clayon’s post doc supervisor from UBC, Dr. Linda Li, Beth Snow, Program Head – Evaluation at the Centre for Health Evaluation & Outcome Sciences (CHEOS), research assistants from SFU and UBC, staff from the BC Patient Safety and Quality Council’s Patient & Public Engagement team, a family caregiver representative from Family Caregivers of BC and a patient partner recruited through Pain BC.

They spent their first meeting together setting expectations and determining how they would best work together as a team, giving everyone an opportunity to speak to how they would be able to participate in the project. From there they met and worked together frequently to write and publish their plan for the scoping review.

Clayon recalls that the family caregiver and patient partner on the team influenced the design of the protocol quite significantly by voicing their perspectives on the [IAP2 spectrum of engagement](#). “Initially, the team had assumed that engagements at the level of consult weren’t meaningful enough to be considered a “good” level of engagement,” he explained. But the patient and family caregiver partners challenged that in fact those opportunities were important, and often a very worthwhile use of everyone’s time. As a result, they updated the study’s protocol to include projects at the consult level.

In the second year of the project, two additional patient partners from PVN were welcomed to the team: Vikram Bubber and Allison Kooijman.

Vikram was keen to contribute to a project that would help articulate successful patient engagement and describe its outcomes, to help build the business case for patient engagement. “Decision-makers need to be able to see if what is being done – is working, or not working. We might automatically think that patient engagement is important, but they are always looking at costs, and whether there is any benefit.”

<sup>12</sup> Hamilton C, Snow ME, Clark N, et al. (2019) Quality of patient, family, caregiver, and public engagement in decision-making in healthcare systems: a scoping review protocol. *BMJ Open*, 9(11).

<sup>13</sup> Hamilton C, Dehnadi M, Snow ME, Clark N, Lui M, McLean J, Kooijman A, Bubber V, Hoefer T, Patients as Partners Team, Li LC. (2021) Themes for evaluating the quality of patient and family caregiver engagement in decision-making in healthcare systems: a scoping review. *BMJ Open*.

Allison enjoyed the research aspect of the project. “I think it’s important for patients to be involved in the development of knowledge in this area – which is what we did in this work with Clayon. I was keen on the mechanism by which we could think about and measure successful patient engagement,” she shared.

Clayon explained that Allison and Vikram joined the project after the literature review was underway – “at a point in the project where they could inform the data analysis and help to interpret the data. We really needed to ensure that we were capturing patient partner and family caregiver perspectives, because this is a framework geared towards defining the success of their engagement in health system decision-making,” said Clayon.

Allison agreed. “A lot of this work was technical, but there was a huge interpretive piece, which is where we were able to contribute – reframing information and bringing a patient lens to it all,” she added.

In addition to data analysis and contributing to the development of the framework, Allison and Vikram participated in writing an article they submitted for publication, and Allison co-presented about the project at Quality Forum 2021.

“

We started by asking how we would define success of patient and family caregiver engagement in health system decision-making. We needed a framework to do that, and nothing existed at the time.

CLAYON HAMILTON

“

Decision-makers need to be able to see if what is being done – is working, or not working. We might automatically think that patient engagement is important, but they are always looking at costs, and whether there is any benefit.

VIKRAM BUBBER



## The Framework: 18 Key Themes for Successful Engagement

The result of their work was the development of a preliminary framework “[Engagement of patient and family caregivers \(PFCs\) in health care system decision-making](#)”.<sup>14</sup> The 18 key themes help to describe the components of what ‘successful engagement’ should include and fall under three broad categories: structure, process and outcomes. The framework lays the groundwork for future evaluation work: developing logic models and mechanisms to evaluate patient and family caregiver engagement initiatives.

“It was actually Allison who brought forward Stakeholder Experience as an important engagement outcome to include in the framework. We hadn’t considered that, and then we realized we should ensure that all of the quadruple aim should be included as outcomes,” said Clayton.

“We don’t know what it would have looked like without the patient partners, but I feel like with them involved, we are shaping something that makes sense, from various perspectives, most importantly from their perspectives – defining the themes of what quality engagement looks like.”

### Engagement of patients and family caregivers (PFCs) in healthcare system decision-making

#### Themes for evaluation

Structure	Process	Outcome
<p><b>Engagement Plan</b> Clear plans guided engagement of PFCs</p> <p><b>Level of Engagement</b> PFCs had appropriate levels of influence over decision-making</p> <p><b>Time and Timing of Engagement</b> Appropriate time was given to engage and engagement exercises occurred at appropriate times</p> <p><b>Format and Composition</b> Format of the decision-making group and composition of PFCs in the group were appropriate</p> <p><b>Support</b> Adequate training and resources were offered and used to support PFCs’ roles</p> <p><b>Environment</b> Spaces of power (physical/virtual and sociocultural conditions) enabled input from PFCs</p>	<p><b>Objectives</b> Engagement events reflected priorities of PFCs</p> <p><b>Engagement Approach</b> The approach and underlying loci of power enabled engagement</p> <p><b>Communication</b> Information flow allowed PFCs’ perspectives to be heard and used</p> <p><b>Engagement Activities</b> The type and extent of PFCs’ contributions to various activities were appropriate</p>	<p><b>Decision-Making Process</b> Decision-making process was strengthened</p> <p><b>Stakeholder Relationship</b> Relationships among PFCs and other parties were enhanced</p> <p><b>Capacity Development</b> PFCs had enhanced competencies and opportunities</p> <p><b>Stakeholder Experience</b> The engagement experience was positive</p> <p><b>Shape Policy, Service, and Program</b> PFCs’ perspectives helped to shape policy, service, or program</p> <p><b>Health Status</b> Patients affected by decisions had improved health status</p> <p><b>Healthcare Quality</b> Patients affected by decisions had improved healthcare quality</p> <p><b>Cost-Effectiveness</b> Cost containment or savings improved for health services responsive to populations’ needs</p>

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<sup>14</sup>Hamilton C, Dehnadi M, Snow ME, Clark N, Lui M, McLean J, Kooijman A, Bubber V, Hoefler T, Patients as Partners Team, Li LC. (2021) Themes for evaluating the quality of patient and family caregiver engagement in decision-making in healthcare systems: a scoping review. BMJ Open.

## A Solid Working Relationship

Both Vikram and Allison commented on how approachable and inclusive Clayon was in their work together.

“We could talk freely. If I didn’t understand something that had been sent to me, I could just contact him to clarify,” recalled Vikram. “He was willing to continually engage with us and took time to make sure we understood some of the bigger overall concepts, which he understands so well from his background in research”.

Allison appreciated the many opportunities to provide input. “I really felt like he cared about what I had to say,” reflected Allison. “It was a very well done, robust consultation. It didn’t feel tokenistic at all,” she shared.

## Advice For Others

Clayon reminds health care partners that an approach that might work well for one patient partner, may not for another. “It’s important to take the time to understand the situation of each patient partner. Usually, the reason that patient partners get involved is that they have some sort of health issue, so be sure to create a space that is equitable by considering specific individual needs. For example, a 1-to-1 conversation might work better for someone, than having them attend a meeting to provide feedback,” he offers.

He also suggests that patient partners and health care partners on teams spend time early in their work together to discuss and define expectations for working together, but also to be flexible when changes arise during the process.

Vikram’s advice for patient partners is to participate to the full extent the engagement allows and persevere even when participation seems challenging. “Don’t be afraid to speak up about what is on your mind. That can be hard and discouraging when there are roadblocks ahead of you, but there is always a way to work around them,” he shared.

Allison encourages both health care partners and patient partners to recognize the critical importance of trusting relationships. “It’s so important for care providers, teams and patient partners to create space to have meaningful trusting relationships. We have talked about tokenistic engagement for years – and it still happens. I think that is in part because of how little time we all have. But the most meaningful engagement initiatives are the ones that are based on strong relationships.”

## Next Steps

What’s next? The team hopes to build on the 18 themes and create a provincial framework for patient and family engagement in health system decision-making. Eventually they’d like to do more research on the topic too.

When asked to reflect on the best part of the work to date, Clayon shared the following:

“Being able to start something that never existed, and working as a team, getting everyone’s input, hearing different perspectives and being able to create something new that will work for the different partners and intended users. That is a great part of it – building something to meet and fit the needs”. ●

● ENGAGEMENT IN ACTION ACROSS BC

Interior Fraser Northern Coastal Island Provincial

# **Engaging Patients, Caregivers and Families in Developing BC's Stroke Quality Standard**

BC Patient Safety  
& Quality Council

The [BC Health Quality Matrix](#) is an excellent resource that presents a definition and common language for understanding quality through seven dimensions: respect, safety, accessibility, appropriateness, effectiveness, equity and efficiency.

But what does quality care mean for a specific health condition or journey? Certainly “best practice recommendations” and “clinical guidelines” highlight the current scientific evidence, principles for care and necessary infrastructure to treat specific conditions.

But where does truly person-centred quality come in? What should it look and feel like for the individual patient? How do organizations put those broad concepts of quality into practice and track their performance?

And with so many moving parts, how does our health system know where time and attention are needed to continuously improve?

Enter: quality standards.

A quality standard is a set of concise statements and associated indicators that outline where improvement work can have the biggest impact on patients' health and wellness. They focus on areas of the patient journey where the need for improving quality is the greatest.

In 2020, the BC Patient Safety & Quality Council (the Council) initiated work to lead the development of [quality standards for BC](#), the first of which [focused on stroke care](#). In partnership with Stroke Services BC, health authority stroke leaders, BC Emergency Health Services, the First Nations Health Authority, UBC Research and patient partners, the Council worked to combine evidence guidelines, best practices and the perspectives of point-of-care providers, patients and families.

“We wanted to improve the likelihood that those experiencing stroke in BC receive care that is evidence-informed and culturally safe, regardless of where they are,” explained the Council's strategic Initiatives Leader, Ed Elkins, who led the project.

“Developing a common set of goals, along with clear, evidence-based measures to monitor progress towards them, should help to reduce unwarranted variation in the services and support offered across the province.”

Unwarranted variation is key when it comes to quality standards. It refers to differences in care received that cannot be explained by the condition or the preference of the patient – it can only be explained by differences in health system performance.<sup>15</sup> By reducing unwarranted variation, quality standards can help ensure that care provided is consistent regardless of where in the province it takes place.

## Patient Engagement – A Trio of Tactics

Appreciating that a person-centred standard was a key goal and that no two patients or journeys are the same, the team recognized that a one-time-one-size-fits-all engagement strategy wouldn't be appropriate. Instead, they used three different engagement strategies to include diverse patient perspectives at various points of the project.

The first approach was to ensure patient partners with a personal connection to stroke care were members of the project's development committee. PVN patient partners Lesley and Art Erasmus as well as Bob Strain first joined in October 2020, participating at the [IAP2 level of "collaborate."](#)

"Personally, surviving a stroke and working on the [development] committee, have been of special interest and meaning for me," shared patient partner Bob Strain.

"I was one of three patient partners and each of us focused on the patient perspective. Ed went out of his way to assure everyone on the committee that the standard we were developing reflected this focus."

As committee members, the patient partners were invited to speak about their own experiences, contribute to discussions and decisions, and review key documents and drafts. Bob was very impressed with the extent to which they were included.

"On every discussion, I was able to present my views, both positive and negative, about points under consideration. I was able to submit feedback both before and after every Zoom session. I know I was being listened to, judging from comments from other participants. I had a chance to receive more information about the project and its process than practically any other committee I've been on!"

The second approach, true to the Council's values of collaboration and transparency, was to take the draft standard out for a four-week public review process between April and May 2021. In total, 542 people shared their perspectives via an online survey. Their feedback helped to ensure the standard would be applicable across all regions of the province.

And its third approach took a critical look at who was, and was not, "at the table" during the public review. The team recognized that very few Indigenous Peoples had participated. With equity and cultural safety and humility being critical parts of the standard, it was imperative to find a different way to connect with and learn from those voices.

Ed reached out to Cathy Almost, one of the Council's Engagement Leaders, to plan a culturally safe engagement approach. Three Indigenous patient partners from PVN agreed to participate in a review of the standard.

<sup>15</sup> Hamilton C, Dehnadi M, Snow ME, Clark N, Lui M, McLean J, Kooijman A, Bubber V, Hoefler T, Patients as Partners Team, Li LC. (2021) Themes for evaluating the quality of patient and family caregiver engagement in decision-making in healthcare systems: a scoping review. *BMJ Open*.

Ed and Cathy took care to send materials and clear instructions ahead of time, focusing on the sections related to patient experience and cultural safety. They provided both digital and hard copies of the draft standard and then met for a 2-hour Zoom meeting to discuss each statement in the standard.

## Taking the Time to Do It Right

Good engagement isn't always easy, and it certainly isn't always quick. But taking the time to thoughtfully listen and learn from patient partners can have rich payoffs for all involved.

“The most rewarding part of this engagement was being supported by a well-prepared leader who insisted that the patient voice be loud and clear. Organization was superb, with lots of preliminary work, and then follow-up checks being made on every salient point, even at the end of the work,” said Bob.

## Engagement Outcomes & Impact

The patient partners on the development committee were heavily involved in advising the wording of the standard and really pushed for the use of non-abbreviated, plain language, so that the standard would be understandable to all. Coupled with the feedback received through the public review and Indigenous patient partner advisory group, several changes to the standard were made:

- Additional content on systemic barriers to health for Indigenous Peoples in BC, specifically calling out racism, stereotyping, discrimination and geographical barriers.
- Updated the wording around “traditional medicine” to instead be more inclusive: “Natural healing and traditional and/or complementary medicine.”
- Brought in a knowledge translation expert to review the document for readability and ensure abbreviations were appropriately defined.
- Added a reminder for clinicians to check that their patients understand information and instructions.
- Added guidance that education materials should be available in a variety of languages.
- Designed the final documents to be aphasia friendly.

“Working alongside patient partners on this project helped all involved to stay grounded in what this work is intending to do: improve the care of those experiencing stroke. They ensured that the Stroke Quality Standard centres around the person experiencing stroke,” said Ed.

## Initiative Outcomes & Impact

The Council and its many collaborators were pleased to launch the Stroke Quality Standard and Patient Family and Caregiver Guide on Sep 7. Going forward, implementation, measurement and evaluation will be led by Stroke Services BC and the Council will turn its attention to developing the next quality standard, focusing on maternity care.

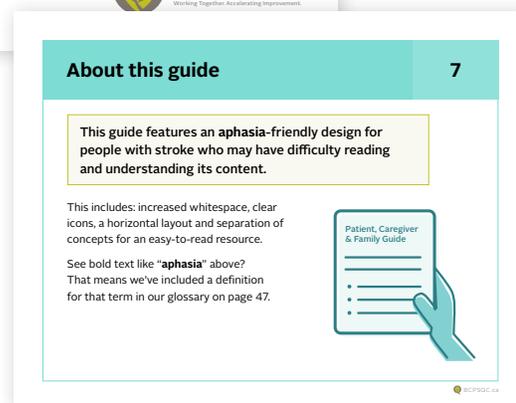
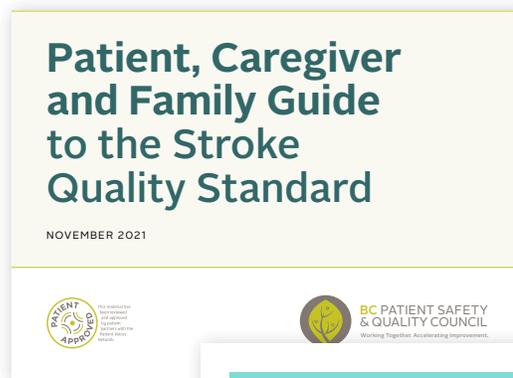
## Reflections, Advice & Lessons Learned

When asked about advice for patient partners or others interested getting involved in a similar partnership, Ed said, “Look for a project that speaks to you, that you're passionate about. Your experience and perspective can help change the way the system works for the better.”

As for advice for health care teams, Ed offers that, “Patient partners can be some of the greatest team members in your work. They have passion and interest in making the system better. Involve them authentically and be open to growing from their knowledge and experience.”

Bob’s reflections on the success of this engagement offers pearls for health care teams embarking on engagement work: the importance of thoughtful planning, kind and inclusive facilitation, documenting process and communicating progress and impact with patient partners.

“Successful patient engagement is about the opportunity to present my views and react to those of others on the committee, and still being able to enjoy what is happening during the intense moments. Engagement means knowing the project is meeting its goals after a lot of input. Engagement means that the upshot of all our work will mean patients in our system, and not just those who have had stroke, will be aware of the thoroughness of our deliberations, and the impact which will come from developing a well-thought-out document,” said Bob. ●



● ENGAGEMENT IN ACTION ACROSS BC

Interior Fraser Northern Coastal Island Provincial

## **COVID-19: PVN Patient Partners Respond**

**After two full years of co-existing with COVID-19, it may no longer seem like a ‘novel’ virus.**

With each new wave, new challenges wash ashore, and the societal and health system impacts of COVID-19 continue to evolve. Like health care staff, PVN patient partners rose to the challenge and contributed to COVID-19 response efforts in a myriad of ways over the last year. Here are a few examples:

### **Priority Setting – Understanding the Problems at Play**

Island Health’s COVID-focused Patient Partner Group started in the spring of 2020 and has continued for the last two years to ensure the voice of patients regularly informs the new and emerging priorities and work plans that arise as Island Health responds to COVID-19.

The meetings are hosted by the VP of Pandemic Planning and include close to 20 patient partners. The group meets regularly via Zoom to provide feedback and advice on issues such as the Island Health visitor policy, Site Ambassador training requirements, vaccine rollout and more.

### **Communication & Knowledge Translation**

Recognizing the ongoing need to develop and share critical COVID-19 information with the public, the BC Centre for Disease Control (BCCDC) approached the Council in early 2021 and together assembled the Knowledge Translation User Review group: 37 PVN patient partners who have been ‘on call’ to review and provide feedback on public-facing COVID-19 materials as they are drafted. To date, the group has provided valuable opinions and feedback as public consumers for many initiatives.

The first was the [BCCDC School Microsite](#), a section on the BCCDC website housing information and resources about health and safety measures in kindergarten to grade 12 schools and what happens if there are COVID-19 cases. BC was one of the only provinces able to keep schools open for in-person learning last year, and the groups’ contributions to clear information on the site helped students, parents, teachers and administrators to all play their parts to ensure it. This microsite was later seen as a gold standard when developing sites for post-secondary institutions. The review group, as well as some Indigenous patient partners through PVN, were also asked to identify questions they had regarding the safety, registration and regulation of vaccines, and provide feedback on draft messages regarding COVID-19 vaccination for children 5-11.

“The group has been invaluable in providing real-time, thoughtful and realistic feedback on the knowledge translation products created across the province for COVID-19. The rapid response group ensures that we are sharing messaging that makes sense to the audiences we are trying to reach, and that we are ensuring an equitable approach to our work,” said Katie Fenn, Director, Quality, Safety & Accreditation, BCCDC.

## Immunization Campaign Promotion

To support the immunization campaign, eight PVN patient partners responded to Northern Health’s call for ‘vaccine testimonials’ and lent their names, photos and personal motivations for vaccination to be used in communication efforts across the north to encourage fellow citizens to get vaccinated.

## Technology

The province has embraced a variety of technology mediums to reach and exchange information with the public about COVID-19.

In the spring of 2021, for example, the Ministry of Health reached out to PVN when the public needed vaccine information and a way to book immunization appointments, in addition to information about symptoms, testing and isolation. Through the COVID-19 Immunization Digital Supports Review engagement, the Ministry of Health shared prototypes of the Immunization Digital Platform with a group of 13 PVN patient partners who provided feedback on ease-of-use in a series of online 1-1 meetings.



**Northern Health** @No... · 2021-08-02 ...  
PG resident **Linda Weeks** shares why she got her vaccine:

I chose to get vaccinated because I care for my family and community, and I would like to see us all get through this together.

To find a COVID-19 vaccination clinic near you, visit: [northernhealth.ca/health-topics/...](https://northernhealth.ca/health-topics/...)



**Northern Health** @Northern\_Health

Getting both doses of the **vaccine** was a no-brainer for Becky Grimsrud. [#healthynorth](#) [#northernhealth](#) [stories.northernhealth.ca/stories/fort-s-...](https://stories.northernhealth.ca/stories/fort-s-...)



**Northern Health** @No... · 2021-08-04 ...

When it comes to the COVID-19 **vaccine**, everyone has their own reasons why they got the shot. Fort Nelson community member Krista Vandersteen shares why she decided to get her **vaccine**. Read on: [stories.northernhealth.ca/stories/my-why-...](https://stories.northernhealth.ca/stories/my-why-...) [#healthynorth](#) [#northernhealth](#)



## Chronic Symptoms following COVID-19

The last year also brought increased awareness to the reality that, for some people, COVID-19 infection results in persistent and disabling symptoms and ongoing care needs. Sometimes referred to as “long COVID-19” or “post-acute COVID-19 syndrome”, there are a growing number of people affected by a broad cluster of respiratory, cardiac and mental health symptoms who need care and support.

Back in 2020, PHSA launched the Post-COVID-19 Interdisciplinary Clinical Care Network (PC-ICCN), a partnership with regional health authorities, patients and research organizations, to support clinical care, education and research to help people with persistent symptoms of COVID-19.

One project stemming from the PC-ICCN, with funding and collaboration from Shared Care (a partnership of Doctors of BC and the Ministry of Health), and financial and project management support from Providence Health Care, was the launch of the Post-COVID-19 Collaborative Care initiative: a group of family and specialist physicians from the Lower Mainland working together to identify the needs and gaps in communication, referral and follow-up care processes for adults who have had COVID-19. Two PVN patient partners joined the team to share their lived experience with COVID-19, identify gaps and propose action plans.

In the spring of 2021, the Post-COVID-19 Collaborative Care initiative team invited 18 patient partners to a focus group to share their lived experience with COVID-19

### Symptoms of post COVID

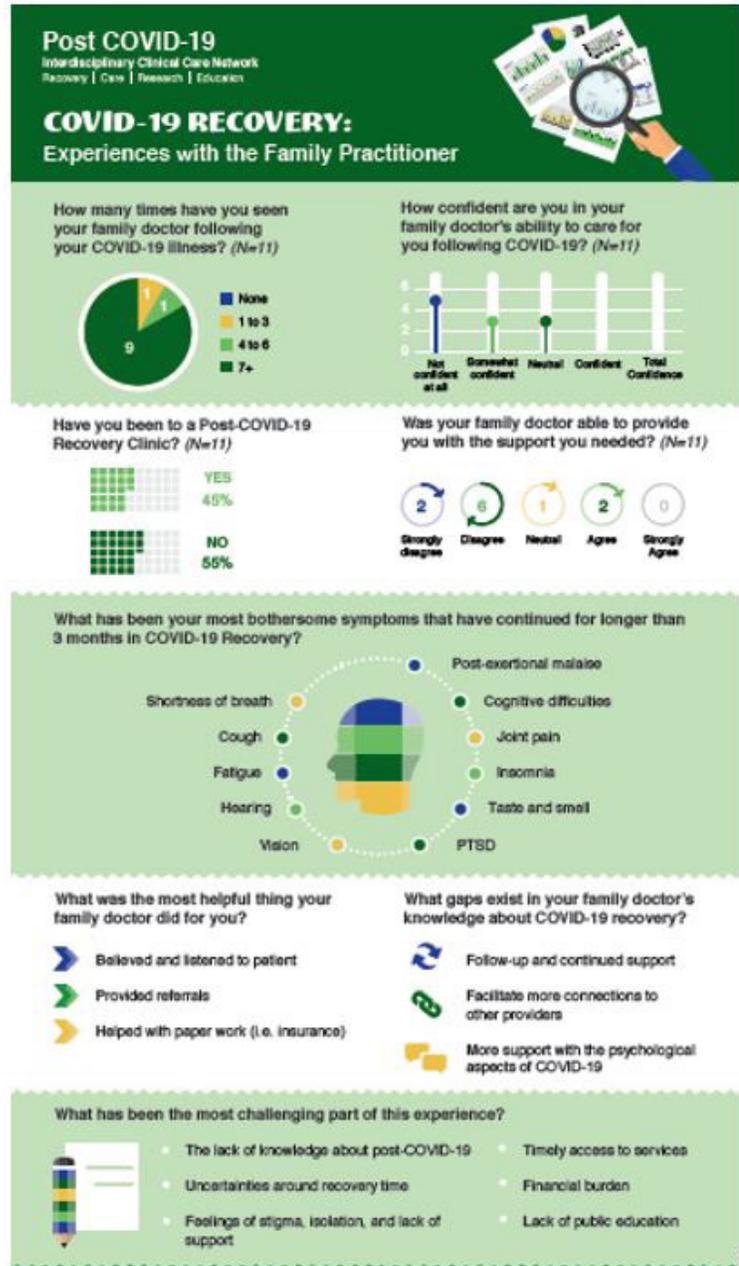


lasting more than three months, to inform the development of an educational program: BC ECHO for Post-COVID-19 Recovery. This educational program was designed for family doctors and other health care providers to support their patients who are struggling with their COVID-19 recovery. The patient partners’ feedback (see infographic below) helped the group clarify their understanding of what patients need from family physicians, and care provider knowledge gaps regarding post-COVID-19 syndrome. For example, two of the commonly mentioned symptoms were memory problems and PTSD. As a result, one of the education sessions focused on the mental health perspective of COVID-19.

The curriculum and learning objectives were approved for accreditation through UBC Continuing Professional Development (CPD), and the free virtual learning community is now up and running with monthly 1-hour education sessions scheduled through July 2022.

“Patient engagement has been central to the network since inception. This allows us to learn from and with patients, to understand the needs and identify opportunities for improvement,” shared Michelle Malbeuf, Clinical Operations Lead with the PC-ICCN.

In early 2022, to ensure that services continue to meet the needs of patients, families and caregivers, PC-ICCN worked with PVN to establish the post-COVID-19 Patient & Family Advisory Team comprised of 27 (and counting!) patient partners. In the coming months/years, patient partners on the team will be invited to participate in various ways including education content reviews, the PHSA Post-COVID-19 website redesign, research proposals, clinical care processes, recovery clinic planning, and more. ●



# How we support people to be successful

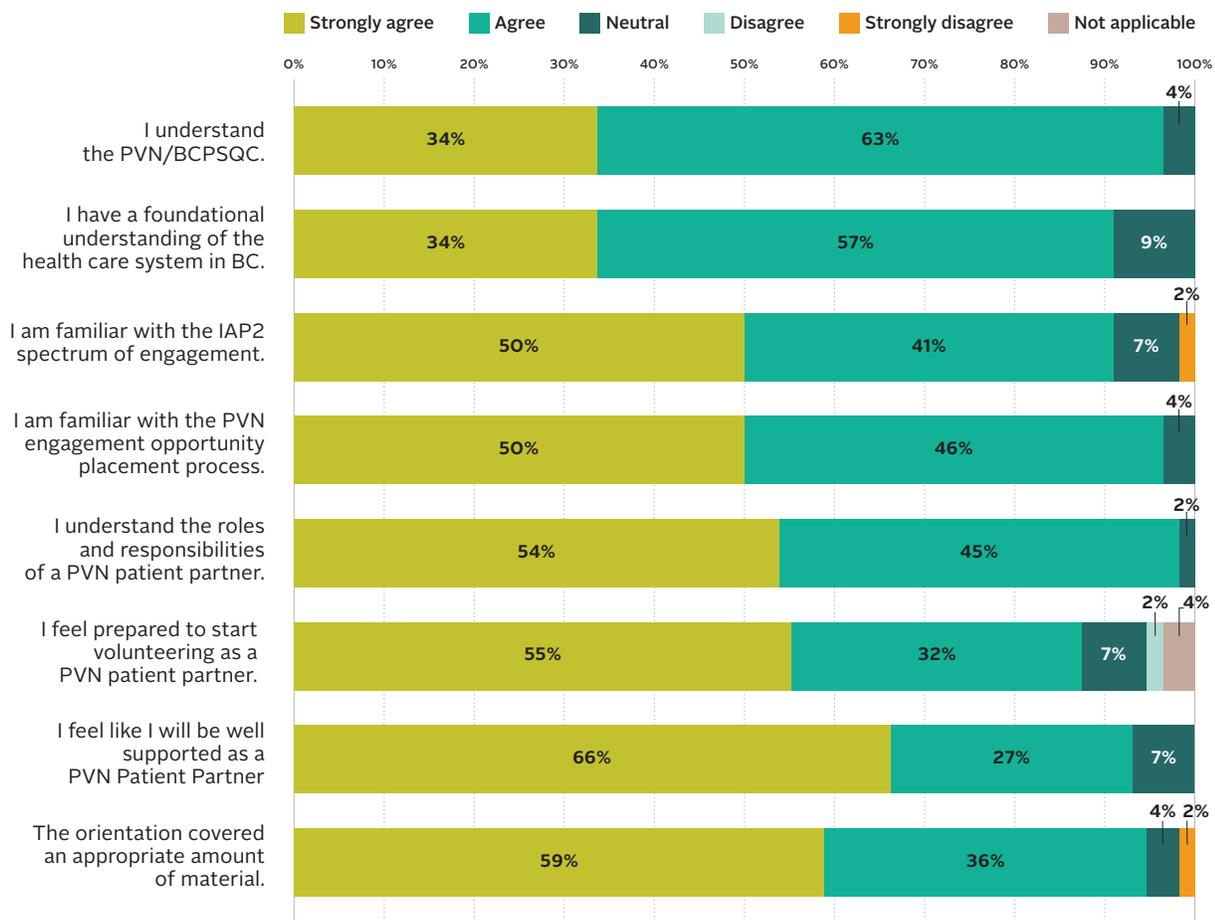
This year was exciting and full of impactful engagements and opportunities to learn and build relationships. We're pleased to share some of the work we undertook to develop capacity and advance partnerships through the Network.

## ● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

# PVN Orientation

This year we hosted 54 orientation sessions that were attended by 146 new patient partners. We offer the option of attending an online group session, or a 1:1 session with an Engagement Leader. These sessions are intended to introduce participants to the form and function of PVN, meet the Council team who supports PVN, review the IAP2 spectrum of engagement and discuss the role(s) of patient partners in health system improvement.

Here's what patient partners shared with us in their evaluations of the sessions:



Year after year, our evaluations of these sessions have been very strong, but we are always seeking to improve them. Feedback received this year that we will explore in upcoming offerings includes:

- Additional information on the outcomes and impacts of patient engagement
- A more thorough overview and introduction to the PVN website
- Increased time for conversation, discussion and questions.

● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

## **Patient Partner Connections**

In addition to serving as a platform for partnerships between health care teams and patient partners, for many folks, PVN also serves as a means to connect with like-minded patient partners.

To better support local, regional and provincial connections we have offered the following:

### **Regional Update Meetings**

We hosted five regional update meetings in the fall of 2021 (one in each of the health authority regions of the province) that were attended by 98 patient partners. These meetings were offered to share updates on PVN and the Council, answer related questions and increase the sense of community among patient partners.

Of those who returned surveys:

- 97% strongly agreed or agreed that as a result of their attendance, they were more aware of things that are happening related to PVN, the Council and/or across their region.
- 88% strongly agreed or agreed it increased their sense of community with the network.

### **Connections Café**

This initiative uses Spark Collaboration to match participating patient partners via email once a month. Together, they can arrange a meeting time/place for a social connection: a coffee, Zoom or phone call. PVN Connections Café celebrated its first Anniversary on December 24, 2021, and to date has 30 participants. Check out the [Frequently Asked Questions](#) document and [sign up online](#) if you are interested.

### **PVN Mentorship Program - Pilot**

Over the summer of 2021, we ran a small pilot of a PVN Mentorship Program, with four mentor/mentee dyads participating over 12 weeks. Mentors, experienced PVN patient partners, provided support and guidance to new patient partners through a series of semi-structured coaching sessions with learning goals defined by mentees.

Feedback received was very positive with mentees indicating increased confidence, knowledge and skills for engaging as a patient partner, as well as increased social connection. Mentees applied for more engagement opportunities on average than other new patient partners, and all indicated that they would recommend this program to others and would consider being mentors in the future. A second pilot is being explored for 2022/23. ●

● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

## **Diversity, Equity & Inclusion in Patient Engagement**

We continued our learning and action journey around Diversity, Equity & Inclusion (DEI) this year, under the leadership of our DEI working group; a four-person committee comprised of three patient partners and Strategic Initiatives Leader, Cassy Mitchell. With the goal of increasing the profile of DEI among the people who support and engage through PVN, this year we've taken the following steps to learn, share and foster conversations:

### **Community Connections**

The working group developed a strategy for outreach and connection with community-based organizations. Last year we connected with BC Mental Health & Substance Use Services; MOSAIC, a settlement non-profit organization serving immigrant, refugee, migrant and mainstream communities throughout the province; and the Two-Spirit Dry Lab (BC Centre for Disease Control and Simon Fraser University) to discuss health equity and sexual gender diversity.

### **New and Renewed Resources**

We've shared and translated our learnings through [blog posts](#), made updates to the PVN sign-up form with more inclusive language, contributed to the [Health Care Partner Commitments document](#), and released a brand new resource, [Diversity, Equity & Inclusion: Elevating the Voices of All in British Columbia](#).

### **Discussing DEI with the PVN Oversight & Advisory Committee**

To establish a foundational understanding of key concepts related to DEI and support the continued learning journeys of PVN Oversight & Advisory (O&A) Committee members around DEI, we invited MT Consulting Group to run a Foundations in Diversity, Equity & Inclusions workshop with the group in March of 2022. The workshop was supplemented by an online resource reading list. The PVN O&A endorsed a statement on DEI for the Network, adapted from Island Health's Research & Capacity Building Department, and will continue discussions on how to support the participation of diverse voices.

### **DEI Social Meet Up**

In February we hosted a DEI social meet up in an effort to create a sense of belonging within PVN for patient partners with diverse or intersecting identities. Hosted via Zoom by the working group and attended by 16 patient partners, the meetup was a nice way to foster and strengthen relationships.

● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

## **Indigenous Inclusion & Culturally Safe Engagement**

Eliminating anti-Indigenous (First Nations, Inuit and Métis) racism and promoting cultural safety and humility is a high priority across our health system. Indigenous perspectives must be included in health care decision-making to support the continued decolonizing of services and ensure equitable access to high-quality care. Meaningful engagement with Indigenous patient partners is foundational to obtaining this perspective, and this year, the Council and PVN patient partners made some important strides to improve Indigenous inclusion in patient engagement.

### **For the Greater Good**

We kicked off the year with a Zoom event called For The Greater Good on April 15, 2021, co-designed and co-facilitated by patient partner Sheila Dick, Secwepemc and Engagement Leader, Cathy Almost, NWT Métis. It was attended by 29 Indigenous patient partners and a few health care partners who shared experiences of bringing an Indigenous voice to health system tables and committees. The gathering was greatly appreciated by those who attended, and successful in building relationships, empowering each other, and creating a sense of community among Indigenous patient partners.

### **Culturally Safe Engagement Circle: What Matters to Indigenous Patient Partners?**

On June 17, 2021, the Council hosted another virtual event, called Culturally Safe Engagement Circle: What Matters to Indigenous Patient Partners? It was co-designed and co-facilitated by First Nations patient partner, the late Gitxsan Hereditary Chief Sim'oogit Ma'os, Bill Blackwater Jr., Tammy Hoefler, Director of Patient & Public Engagement and Cathy Almost, Engagement Leader. The 13 Indigenous patient partners in attendance discussed what mattered to them when participating in culturally safe patient engagement opportunities. Health care partners were invited to attend as witnesses to the patient partners' stories by being compassionate and silent observers, giving attention to others without judgement and providing a space for partners to speak their truth.

Following the event, the discussion notes were themed, and eight key principles emerged:

- Awareness & Understanding
- Learning & Education
- Build Relationships
- Prepare
- Kindness & Empathy
- Respect
- Value
- Listen

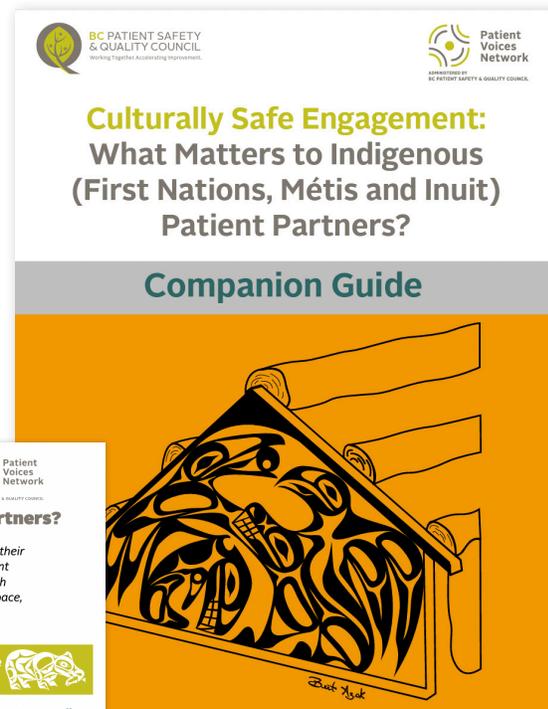
## New Resources

The principles were developed into key messages, recommendations and actions. Bert Azak, a Nisga'a graphic designer, contributed his artwork, based on the Seven Sacred teachings and designed two resources: an [at-a-glance document](#) which summarizes the principles, and a [companion guide](#) which provides further details about the conversation that took place during this event, gives more detailed actions, live links to further readings, lists those involved and tells the story of how the principles were created.

These resources represent a moment in time when 13 patient partners from across the province gave their opinions about culturally safe patient engagement. Our circle included First Nations, Métis and Inuit participants and we recognize they have distinct voices. We wanted to avoid a pan-Indian approach and note that these are 13 individual perspectives.

## Words Matter – Updates to PVN Forms

In the fall of 2021, we looked to where in the PVN structure and process we could do better to promote safety for Indigenous patient partners. Building off suggestions put forward by a number of patient partners, we updated the PVN sign-up form with more inclusive language and added preambles to a number of sections to explain why the information was being asked.



### Culturally Safe Engagement:

#### What Matters to Indigenous (First Nations, Métis and Inuit) Patient Partners?

*This document was created from the voices of Indigenous patient partners in June 2021 and is written using their words. Partners were asked what mattered to them when participating in Indigenous culturally safe patient engagement opportunities. Eight key principles, starting with Awareness & Understanding and ending with Listen, emerged along with a series of recommended actions. As you consider your role in creating a safer space, please be curious and open to learning as you engage Indigenous voices.*

1. Awareness & Understanding	2. Learning & Education	3. Build Relationships	4. Prepare
<p><b>Acknowledge the history of racism in Canada and the impact of systemic racism. Have a level of cultural awareness and sensitivity.</b></p> <p>Start off well. Provide a meaningful land acknowledgement.</p> <p>Get to know people from the territory you work and live on. Be a lifelong learner.</p> <p>Avoid translation exhaustion so that you have some cultural competence.</p>	<p><b>Humility is key to being influenced by indigenous culture and open to learning.</b></p> <p>Complete cultural safety and humility training before working with us.</p> <p>Research local cultural practices and protocols.</p> <p>Required reading:</p> <ul style="list-style-type: none"> <li>• In Plain Sight Recommendations</li> <li>• Truth and Reconciliation Recommendations</li> <li>• Jordan's Principle</li> <li>• Joyce's Principle</li> </ul>	<p><b>Get to know us in order to balance the power dynamic, enable collaboration and build trust. Consider ways to learn about our culture and connect with us.</b></p> <p>Include time for relationship building throughout the project.</p> <p>Be aware of sensitivities in building relationships due to generational trauma. We suggest you consider the need to create an action plan for trauma-informed practice.</p>	<p><b>Provide documents well in advance of the meeting and allow opportunity for questions to be asked.</b></p> <p>Be aware of cultural seasonal practices and events and prepare to be flexible.</p> <p>Send relevant documents ahead of time. Make pre-meetings and debriefs standard practice.</p> <p>Ask us if email communication is acceptable or if printed materials are preferred.</p>



## Culturally Safe Patient Engagement Webinar

To close the year, in the spring of 2022, equipped with these new resources, Engagement Leader, Cathy Almost and patient partner, Tina Miller, Nisga'a, presented a webinar, [Culturally Safe Patient Engagement – What Matters to Indigenous Patient Partners](#) – as the third part of the Patient Engagement Learning Series. Over 240 people from across BC and beyond tuned in to learn about culturally safe and appropriate ways for health care partners to work with Indigenous patient partners in engagement opportunities.

## Indigenous Patient Partners – Featured Engagement Opportunities

In addition to these Council-led initiatives, Indigenous PVN patient partners participated in a number of other health system initiatives to re-develop policies, standards and structures poised to improve care experiences and health system interactions for Indigenous people in BC, and across Canada.

One opportunity was to inform the new Cultural Safety and Humility Standards for the [College of Physicians and Surgeons](#) and [BC College of Nurses and Midwives](#) which came into effect on February 25, 2022. The facilitator and college representatives shared that the patient partners who participated in this work profoundly impacted and changed the direction of the standards based on their words and suggestions.

Another group of patient partners collaborated with the First Nations Health Authority and PHSA on the Cultural Safety in Patient-Centred Measurement Methodologies project, to identify ways Indigenous people would prefer to share their experiences with the health system and ensure that survey tools and methodologies are culturally safe and enable Indigenous people to tell their health care stories.

In support of the work led by the In Plain Sight Task Force to create a more culturally safe patient complaints system in BC, three PVN patient partners shared their stories, experiences and suggestions for a better complaint process through a patient journey mapping exercise with Council staff

in the Fall of 2021. The themes identified were shared at the Provincial Dialogue Day: Improving Patient Complaint Processes for Indigenous Peoples on January 27, 2022, hosted by the Council in partnership with the Ministry of Health on behalf of the In Plain Sight Task Team Complaints Working Group. The stories and experiences shared helped attendees better understand the improvements needed for Indigenous patients and families navigating the complaint process.

The event was attended by over 100 people, both executives and front-line staff, from 20 organizations including the Ministry of Health, regional health authorities, regulatory colleges, the Coroner's office, Human Rights Tribunal, Office of the Ombudsperson, Friendship Centers, as well as 12 Indigenous patient partners through PVN. Together, they participated in collaborative rounds of dialogue to identify and explore the necessary components of a safe, accessible and meaningful complaints process.



**The Indigenous patient partners not only provided important feedback into our discussion, their insistence on having their experience be the guiding force to change through a relational lens, rather than a 'complaint' frame was an important foundation for our further conversations. It was an aha moment that shifted our conversations for the better, and was critical to really getting to the real forces that are impeding progress.**

PROVINCIAL DIALOGUE DAY  
PARTICIPANT



**The Indigenous patient partners brought truth and honesty to our discussions. They challenged us to do better. Sharing their experiences to really highlight how the current system doesn't work, but also offering great suggestions and solutions to look forward to.**

PROVINCIAL DIALOGUE DAY  
PARTICIPANT

The contributions of the patient partners grounded the health care partners and brought their lived experiences forward. Person-centred care was supported by having patients at the tables during these important discussions. They challenged the status quo and brought forth real life suggestions on how to improve the system.

On the national stage, three Indigenous PVN patient partners have been participating as members on the Cultural Safety and Humility Technical Committee, led by the Health Standards Organization and First Nations Health Authority, on the development of a first-of-its-kind [B.C. First Nations, Métis and Inuit Cultural Safety and Humility Standard](#). The standard aims to counter racism, discrimination and the stigma towards Indigenous peoples, working to make health care systems safer, more accessible and respectful. Over the summer of 2021, the standard went out for public review prior to its publication, and PVN patient partners also contributed to that review through a facilitated focus group. ●

● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

## Capacity Building for Patient Partners

We're committed to building the capacity of patient partners to participate in health system improvement efforts. This year we sponsored and supported:

- **25 patient partners** to attend the Institute for Healthcare Improvement Open School. This online certificate program provides essential training and tools on quality improvement methods, measuring change and patient safety. [Read more!](#)
- **34 patient partners** to complete San'yas Anti-Racism Indigenous Cultural Safety Training. This online training program introduces key aspects of cultural safety and addressing anti-Indigenous racism. [Read more!](#)
- **12 patient partners** to attend the Beryl Institute Patient Experience Conference in 2021 and 2022. These two virtual conferences featured dozens of sessions from presenters around the world, bringing together the voices of people committed to elevating the human experience in health care.
- **6 patient partners** to attend the Canadian Centre for Diversity and Inclusion UnConference. This two-day virtual event engaged participants from coast to coast in networking, storytelling, discussions and ideas to increase cultural competence and safety. [Read more!](#) ●



“I now have a better understanding of the complexities of health care systems and an appreciation of how difficult it can be to make changes to procedures and programs. Input from all stakeholders is important, including patients, families and caregivers.”

THELMA BOILEAU,  
PVN PATIENT PARTNER

“This learning and unlearning opportunity is so valuable. I highly recommend this course and thanks everyone who has and will contribute to providing this important education.”

PVN PATIENT PARTNER

“Self-awareness was highlighted in the conference as a key component to cultural competence. That may seem incredibly simplistic, but for many it's incredibly challenging, myself included. No one wants to look in the mirror and assess their values, beliefs, behaviors, attitudes, motivations, etc. and how they may affect our interactions in the world. Self-reflection is uncomfortable but necessary if we want to become culturally competent and inclusive towards those who might have a different worldview.”

BEV POMEROY,  
PVN PATIENT PARTNER

● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

## Capacity Building for Health Care Partners

We create, curate and share resources and learning opportunities to support the continued capability development of health care partners in engagement planning and facilitation. This year we launched a number of new resources, as well as a four-part, Zoom-based Patient Engagement Learning Series. Check them out!

### Downloadable Resources

- [Leading Great Meetings: Improving Health Care Together.](#)  
A one-pager tip sheet on leading great meetings and setting the stage for a positive patient and health care partner experience.
- [Selecting Patient Partners.](#)  
A one-page, four-step process, for finding patient partners.
- [Committee Principles & Guidelines for Health Care Partners.](#) A 16-page resource designed to introduce different committee types, tips for including patient partners, and address FAQs.
- [Patient Partner Appreciation & Recognition Guide.](#) This two-page resource outlines ways that health care partners can show appreciation for the time and commitment given by patient partners involved in their work.

### Patient Engagement Learning Series

Co-developed and presented by patient partners and health care partners, these webinars offered a one-stop shop for education and resources on skills needed for authentic patient engagement in health care, within the context of BC. Recordings and materials are [available online!](#)

- A Foundation of Patient Engagement – Improving Health Care Through Partnerships.
- Culturally Safe Patient Engagement – What Matters to Indigenous Patient Partners.
- Diversity, Equity and Inclusion in Patient Engagement.
- Measuring the Success and Impact of Patient Engagement – Evaluation and Closing the Loop. ●

● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

# “What Matters to You?”

International “What Matters to You?” (WMTY) Day started in Norway in 2014, with the simple goal of encouraging meaningful conversations between patients, caregivers, families and their health care providers. It is a simple question that can have a big impact on care and has now gained momentum as an international movement.

In addition to celebrating WMTY Day on June 9 with a Twitter chat and special edition newsletter, we’ve been working to encourage providers to have these conversations each and every day to support building trust, empathy and understanding with their patients. We’ve expanded the suite of [online resources](#) this year with the addition of the “[Share Your Story](#)” and “[Background Resource for Health Care Partners](#)” resources.

New this year was the launch of the Council’s “What Matters to You?” Ambassador program: inviting representatives from health care organizations across BC to champion the “What Matters to You?” initiative in their workplaces. Our hope is that through this collaboration, we will build participation in the “What Matters to You?” movement while promoting person- and family-centred approaches to care. Recognizing the time and resource constraints in the current health care climate, we’ve pitched a variety of ways for Ambassadors to participate as



they are able to: circulating materials, collecting WMTY case studies and stories, joining a working group to plan for the June 9, 2022 events, and participating in WMTY evaluation activities. To date we have 14 Ambassadors participating from seven different organizations – thank you! ●

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● HOW WE SUPPORT PEOPLE TO BE SUCCESSFUL

## **An Evolution of Evaluation for PVN**

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In the summer of 2021, we kicked off a deep dive into what and how we monitor and evaluate in PVN. We know it is important for everyone involved in patient engagement efforts to reflect on and make note of what is working well, what could be improved, and what is happening as a result of patient and public participation in the health system.

With input and participation from patient partners, health care partners, the PVN Oversight & Advisory Committee and an evaluation expert, we started by creating a logic model for PVN to clearly see the inputs, activities and outcomes of our collective work together.

From there, we agreed on the questions we really wanted to answer about PVN, and through a detailed evaluation framework, mapped out how we would go about answering them. The last step was to create a few new measurement tactics, retire some old ones and refresh a few oldies but goodies!

In March 2022 we put the new PVN evaluation strategy into play, and we will keep refining the strategy to ensure we continue to learn, improve and support patient and health care partners in their quality improvement and engagement efforts. If you'd like to learn more about the evaluation strategy, feel free to connect with us – we're happy to share! ●

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# Thank you!

The successes, accomplishments and learnings in this report are the results of the efforts of patient and health care partners who believe that sustainable and meaningful solutions are found when we work together.

**Thank you for your ongoing commitment to patient engagement in BC!**



# 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.

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