# PATIENT VOICES NETWORK ANNUAL REPORT 2018-2019

PVN is guided by patient and health care partners and administered by the:





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

Thank you for your interest in the Patient Voices Network (PVN). This annual report highlights just a few examples of the inspiring engagement work that took place throughout the province in 2018-19.

The efforts of the 1,102-member network have positively impacted health services within British Columbia. Patient partners have increased confidence that their thoughts and ideas on how to improve are welcomed, listened to and acted upon. To illustrate, this year's annual report shares five impact stories which highlight the different ways PVN works toward improving health care in the province.

None of this work could have happened without the dedication of our patient partners and BC Patient Safety & Quality Council (the Council). We would like to acknowledge the work of the Oversight & Advisory Committee (comprised of patient partners, the Council, Ministry of Health and health care partners). Also, we would like to give a special thanks to the members whose term on the committee is ending for their tireless contributions. In turn, we welcome new members to both the committee and the network as we continue to advance patient engagement and discover new impact stories.

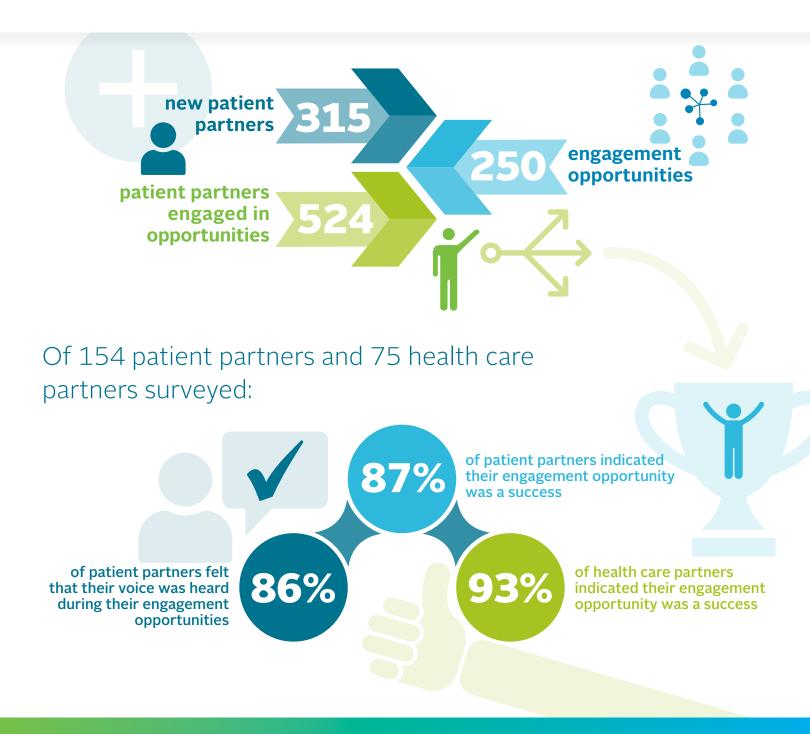
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Jim Cawsey and Tammy Hoefer Co-Chairs, PVN Oversight & Advisory Committee

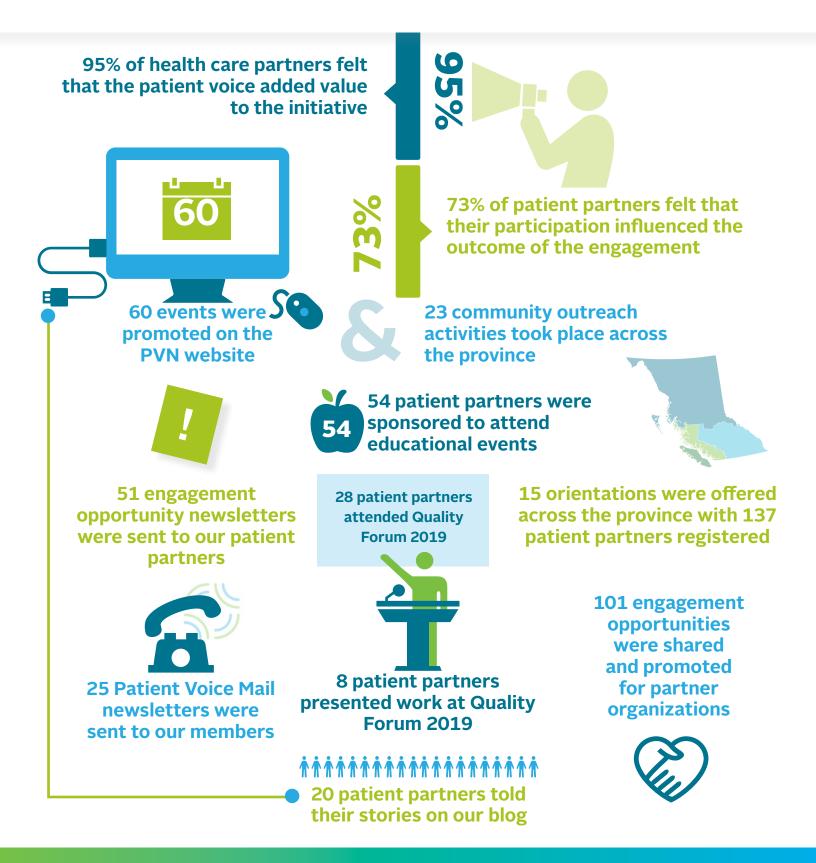


## Highlights of the Year: **PVN by the Numbers**

This year was exciting and full of impactful engagements, growth, community outreach and collaboration. We drove change within our health care system by creating opportunities for patient and health care partners to work together to engage the patient voice. In addition, patient partners attended educational events, blogged about their experiences and contributed to many new resources.



## Highlights of the Year: **PVN by the Numbers**



### About Us

The Patient Voices Network (PVN), which is administered by the BC Patient Safety & Quality Council (the Council), is a community of patients, families and caregivers working with health care partners to improve our health care system. We are dedicated to bringing patient and health care partners together to share knowledge, build bridges and make a difference. To learn more about our work, visit PatientVoicesBC.ca

The Council supports PVN by working with diverse partners to provide a wide variety of engagement opportunities across the province. These engagement opportunities are facilitated by leaders located in each health service area across BC.

### **Our Vision**

Patients, families and health care partners co-designing improved health care through authentic voice and diverse representation.

### **Our Mission**

Advance authentic patient engagement by building the capacity of our partners so that personand family-centred care becomes the foundation from which all health care decisions are made.

### **Our Values**

**PARTNERSHIP** We engage in mutually-beneficial partnerships to co-create and achieve a collective vision. We value opportunities to learn from others and share our knowledge widely.

**AUTHENTICITY** We support partnerships that enable participants to add value and have meaningful impact on decisions.

**TRANSPARENCY** We build trust and respect through a culture of openness, accountability and inclusion.

**RESPONSIVENESS** We are guided by the diverse voices of our partners and adapt to their evolving needs and efforts to improve quality of care.

**INNOVATION** We challenge the status quo and embrace new ways of thinking in order to support improvement.

## Oversight & Advisory Committee

Our Oversight & Advisory Committee works in partnership with the Council to ensure that patient voices are included in the planning of our initiatives and operations, and that patient and health care partners co-develop recommendations to enhance the Network. Members as of March 31, 2019 included:

### Patient Partner Representitives

Sunaina Sharma (Fraser Valley) Kimberly Strain (Fraser Valley) Kyle Warkentin (Fraser Valley) Lin Chen (Greater Vancouver and Sunshine Coast) Kevin Barry (Interior region) Cindy Charleyboy (Interior region) Megan O'Reilly (Interior region) Esther Storvold (Interior region) Sherri Mytopher (Northern region) Jim Cawsey – Co Chair (Vancouver Island) Alyson Hagan-Johnson (Vancouver Island) Pamela Jessen (Vancouver Island)

### Health Care Partner Representatives

Helen Chiu (BC Renal)
Colleen McGavin (BC SUPPORT Unit)
Christina Thomas (Doctors of BC)
Megan Hunt (First Nations Health Authority)
Mandy Lindsay (Fraser Health)
Karla Warkotsch (Interior Health)
Jana Archer (Island Health)
Tanis Hampe (Northern Health)
Marlene Apolczer (Northern Health)
Kate McNamee (Providence Health Care)
Kris Gustavson (Provincial Health Services Authority)
Belinda Boyd (Vancouver Coastal Health)



## Impact Stories Interior Health: Primary and Community Care Transformation Patient Reference Group

#### "It's the way we do our work."

That's how Greg Cutforth, Interior Health's director of primary and community care transformation, describes engaging patients in health care improvement.

This past year, Interior Health's Primary and Community Care Transformation Patient Reference Group continued work they began in 2017. The committee's five patients are highly regarded for their thoughtful opinions on primary and community care transformation initiatives. The patients represent different regions and demographics so they can provide diverse feedback.

Committee lead Karla Warkotsch describes the group as highly engaged, with all members finding ways to provide input. She could not think of an instance where the patient partners' feedback had not been incorporated in the work and highlighted their contribution to a presentation on Primary Care Networks and Specialized Community Services Programs. The work and the system can be complex; the patient partners were asked to look at the presentation through the eyes of a person unfamiliar with its language and purpose and recommend ways to make the presentation more person-centred. This patient reference group is a vital source of feedback in Interior Health and contributes in other ways such as helping to create a new electronic appointment system for home health services.

"I have been pleased to help on the committee because I receive feedback from Karla and the various presenters on how our comments have assisted in making the project explanations easier for the public to understand. It is easy to volunteer when I know it actually helps someone."

– PAUL BURGENER, PRIMARY AND COMMUNITY CARE TRANSFORMATION PATIENT REFERENCE GROUP MEMBER

Sharing and embedding successful engagement approaches is a key step forward in advancing the foundation of person- and family-centred care. Knowing how important it is to share outcomes, Karla makes sure she "closes the loop" whenever possible so that the patient partners know the impact they had. Thank you to Karla and all committee members for their valuable contributions!

## Impact Stories Fraser Health: Delirium Quality Improvement Project

Delirium is a common complication for approximately 30% of geriatric medical inpatients. It leads to drastically longer length of stays, increased morbidity, increased mortality and loss of function.<sup>1</sup>

In 2018, Eagle Ridge Hospital physician Jean Warnebolt approached PVN about involving a patient partner in a quality improvement project aiming to better support hospital patients with delirium and their caregivers.

Patient partner Wendy Alston volunteered to provide input into the project based on her experience supporting her mother with delirium. Her input focused the care team's efforts on things that were meaningful and practical for patients. This included using information boards in patient rooms and identifying measures important to patients such as going home and returning to normal life. As health care workers do not have the same perspective as those on the receiving end of care, patients and families can provide immense value and complement the team. The next steps for this project involve a continued focus on delirium as a complex illness through staff training, the early identification of delirium and the development of an elder-friendly care environment. Engaging patient partners in this work will continue to ensure aspects of care that are important to patients and families are considered. Their dedication surely sets the project up for success!



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## Impact Stories Northern Health: Quality Improvement Training

One of the ways we drive change is by improving skills and knowledge of staff. In October, four patient partners along with Council engagement leaders delivered patient engagement training for Northern Health's Intermediate Quality Improvement training program. Four patient partners were invited to share their stories and the importance of providing family support in their care.

The training aimed to help Northern Health staff learn from patient partners' experiences, consider patient or family involvement in their improvement work and hear the patient voice.

According to the organization's Quality & Innovation Team, "patient partner insights on how to work with the public are invaluable for students who are completing their own quality improvement projects." "The most relevant pieces of today's session were the patient partner session and patient stories. They help to focus on the reason we are doing this work: to make improvements to care and the system in which we provide care to the persons and families in Northern Health. The patient voices were powerful and moving."

NORTHERN HEALTH'S INTERMEDIATE
 QUALITY IMPROVEMENT TRAINING
 PROGRAM PARTICIPANT



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Impact Stories Providence Health Care: Importance of Hand Hygiene for Patients and Residents When Admitted to Health Care Facilities

Preventing health care-acquired infections relies heavily on hand hygiene and typically emphasis is placed on health care workers' hand cleaning. Providence Health Care connected with patients/ residents and family members to learn about the importance of hand hygiene during their care experiences in hospitals or long-term care homes.

Patient partners Margaret MacLennan, Bob Strain, Joan Levy, Wendy Alston and Irene Toy were recruited for their input on patients' hand hygiene practices while in care. The patient partners and staff decided to use focus groups as forums to share stories about patient hand cleaning in health care settings, and their stories were shared with staff during hand hygiene education sessions to emphasize the importance of enabling patients to clean their hands.

In all, 14 stories were shared with staff as well as colleagues across the province during Hand Hygiene Week. Staff stated that patient hand hygiene was not always top of mind in their daily work and appreciated the reminder. Other health authorities used the input and experience to focus on this aspect of patient/resident care. In 2019, Bonnie Lantz, the heath care partner leading this engagement, and patient partner Margaret MacLennan shared this work to Infection Prevention and Control Canada and the International Foundation for Integrated Care Conjoint Conference in Quebec. The work has also been published as a Leading Practice with the Health Standards Organization, an agency with national and international reach. It is exciting to know that the stories from PVN members may have a wider impact than first imagined!



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### Impact Stories Island Health: Patient Advisor-Led Environmental Assessments

In 2017-18, Island Health collaborated with patient partners in a pilot project to conduct patient advisorled site environmental assessments. These are site visits conducted by patient partners and site leadership where the quality of the care environment is assessed from a non-clinical perspective. They provide Island Health with the opportunity to hear how patient partners consider:

- The physical condition of the site,
- Site cleanliness,
- Food quality and the dining experience,
- Safety,
- Privacy, dignity and well-being,
- General perception and appearance, and
- Wayfinding (navigating the physical environment).

As a result of the pilot's success, Island Health collaborated with patient partners to co-design a formal assessment program. This included working directly with patient partners every step of the way to:

- Incorporate lessons learned from the pilot project,
- Finalize guidelines for how assessments would take place and what to look for,
- Develop an application to record and report findings electronically,
- Onboard patient partners from across Vancouver Island (through PVN), and
- Develop the initial schedule of assessments for 2019.

The co-design phase of the program consisted of a day-long orientation session with patient partners and Island Health representatives. The session launched the program, provided an opportunity for patient partners to meet one another, discuss the program and participate in team building exercises. During the session, the program guidelines were also reviewed and the spring schedule for assessments was released.

Between April and June 2019, patient partners visited and assessed nine Island Health locations (12 when including pilot project sites), making hundreds of observations and recommendations. The results of the assessments are being shared with site leadership, support services and quality councils for action planning and continuous improvement activities. The results are also used to provide input to the annual capital planning process for physical improvements and inform future state design/ renovation principles.

Moving forward, an assessment program review is planned for 2020. It will involve all the patient partners and Island Health representatives to discuss what is working well within the program and what could be improved. At minimum, the intent of the program is to ensure visits at all Island Health ownedand-operated sites on an ongoing, rotational basis.

## Strategic Priority Highlights

## **Strategic Priority #1:**

Evaluate the impact of patient engagement activities, share our findings with our partners, and use them to inform our actions

### **PVN Evaluation**

In 2018, the Council conducted a program-wide evaluation of PVN to help document and understand the impact of patient engagement activities and inform future engagements and priorities. Out of 391 patient partners and 199 health care partners, 229 (154 patient partners and 75 health care partners) members responded to the evaluation survey. This evaluation largely focused on PVN members' feedback but also provided a basis for future reports which will go further in evaluating the tangible outcomes of PVN activities.

### Impact

Patient and health care partners were asked for their perception of PVN's impact on (1) patient care, (2) patient outcomes and (3) patient experience. The high rate of "don't know" responses suggest there is an opportunity to continue to work with health care partners to improve the process of closing the loop with patient partners so they are aware of the impact of their efforts. This is discussed further in the next section.

#### **IMPACT ON PATIENT CARE**

DON'T KNOW | MINOR IMPACT | MODERATE IMPACT | MAJOR IMPACT

Patient Partner	15%	19%	33%	33%	
Health Care Partner	<mark>5% 5%</mark>	32%		57%	

#### IMPACT ON PATIENT OUTCOMES

#### DON'T KNOW | MINOR IMPACT | MODERATE IMPACT | MAJOR IMPACT

Patient Partner	26%	16%	28%	30%	
Health Care Partner	8% 7%	41%		45%	

37%

### **STRATEGIC PRIORITY #1**

#### **IMPACT ON PATIENT EXPERIENCE**

DON'T KNOW | MINOR IMPACT | MODERATE IMPACT | MAJOR IMPACT

**Patient Partner** 

•	19%	19%	26%	
artner	<mark>5%4</mark> %	26%		65%

Health Care Partner

### What patient partners said:

"Since I joined PVN, I feel that patient engagement has moved from having a 'minor impact' and being less common to where it is now. It is on its way to having a 'major impact' and has become much more widely accepted. The biggest change I've seen in acceptance is amongst higher-level administrators and decision makers which is such a positive change!"

"Patient engagement is a shift in culture – the process is iterative and slow but progress toward person- and family-centred care and health system design is happening."

### What health care partners said:

"Having patients involved in strategic work provides valuable reminders and insights for developing patient-centred care."

"Having their voice helps us to see where we fall short."

"Patient partners assisted in helping us make decisions about programing based on their perspective. Their experiences have guided us in determining where to put our focus and how to identify gaps or poor service areas."

### **PVN Members' Satisfaction**

#### PATIENT PARTNERS' PERSPECTIVES

Patient partners were asked about their satisfaction with the support from the Council during their involvement in an engagement opportunity. This is a significant aspect of authentic engagement, as it is important for patient partners to feel prepared for their involvement, be comfortable with their role and understand the purpose and scope of the engagement opportunity.

Patient partner responses indicate satisfaction with the support received, with 84% reporting being satisfied or very satisfied with their involvement.

#### UNSATISFIED | NEUTRAL | SATISFIED | VERY SATISFIED



#### "I feel honoured to be part of a worthwhile network to participate in what health care deems as priorities and to be able to influence these priorities based on my own and observed patient experience."

#### HEALTH CARE PARTNERS' PERSPECTIVES

Supporting health care partners throughout engagement opportunities can enhance their collaboration with patient partners, and 93% of health care partners reported being satisfied or very satisfied with our support.

#### UNSATISFIED | NEUTRAL | SATISFIED | VERY SATISFIED



"PVN is excellent at facilitating the patient engagement process. Their engagement leaders are clear in their communication and strong in their support"

### **Closing the Loop**

In response to feedback we received from patient partners indicating they don't know the impact of their work with the health care system, we focused on keeping patient partners updated on the impact of their efforts both during and after engagement opportunities. In summer 2018, we piloted a new Closing the Loop process which consists of three steps to share outcomes and impacts of patient engagements:

- **1.** Acknowledgement of participation: acknowledging the project's completion and thanking all involved for their participation;
- 2. Project outcomes: sharing how/if the aim of the project has been met;
- **3.** Project impact: sharing how the patient partner's contribution and participation influenced the outcome (impact);

We received positive feedback from both patients and health care partners on the new Closing the Loop process. When patient and health care partners reflect on their work, they have an opportunity to share lessons learned and celebrate successes. Patient partners feel recognized when they receive validation for their efforts, and health care partners benefit from closing the loop because it gathers vital information about improvements that can be shared with the public and partners.

To better understand the impact of the process, Engagement Leader Carol Stathers started a partnership with four nursing students from Selkirk College and the College of the Rockies to analyze our Closing the Loop efforts. Look for the results of this partnership in an upcoming newsletter.

## "...Interaction after the engagement event and feedback on how my voice made an impact makes all the difference."

- PATIENT PARTNER



## Strategic Priority Highlights

## **Strategic Priority #2:**

### Increase the capacity of patient and health care partners to support authentic engagement

Authentic engagement uses a collaborative approach that incorporates patients' experiences and perspectives and often requires support to empower both patient and health care partners to communicate and collaborate effectively.

For patient partners, authentic engagement starts during their orientation to PVN; for health care partners, it starts during project planning. Guidance on how to support partnerships and achieve successful outcomes may include individual connections, presentations to teams, online webinars and other educational resources.

In June 2018, we presented our work on "Demystifying Patient Engagement" at the International Patient & Family Centered Care Conference in Baltimore, Maryland. Presenters included engagement leaders Karen Estrin and Cathy Almost as well as patient partner Cherie Mercer, Noxs Sak'al Gyoo. The presentation focused on the key principles of authentic patient engagement, health care team preparation and facilitation strategies which strengthen the overall experience and create more robust project outcomes.

Cherie, from the Nisga'a Nation in New Aiyansh, a small rural community in Northern BC, was a valuable addition to the presentation team. She spoke about being supported by PVN to be an engaged patient and how she helps others engage by encouraging them to get involved to co-create lasting solutions.



The Mercer family, from I-r: Lennox, Paul, Nishaya and Cherie.

"Most First Nations people have high hopes for a healthier, authentic health care system, one that will thrive, regardless of whether the experience was positive or not, a system that is committed to wellness. That is why I agreed to present at the conference and why I remain a part of PVN, as well as to encourage others to help co-create the solutions that last."

- CHERIE MERCER

Throughout the year, we also shared techniques to support authentic engagement in our day-to-day conversations with patient partners, health care partners, groups in each health region and at Council learning events. These sessions provided the opportunity to learn best practices and share experiences of improvement leaders across the province.

#### "My engagement leader introduced me to the concept of authentic patient engagement and how to help our patient partner feel welcomed and valued."

- PATIENT PARTNER

"...Interaction after the engagement event and feedback on how my voice made an impact makes all the difference."

- PATIENT PARTNER

## "In the end, it is the constant 'welcome-ness' that makes the most difference for me when I participate in engagement opportunities. And the fact that my insights are taken seriously and with respect."

- PATIENT PARTNER

## Strategic Priority Highlights

## **Strategic Priority #3:**

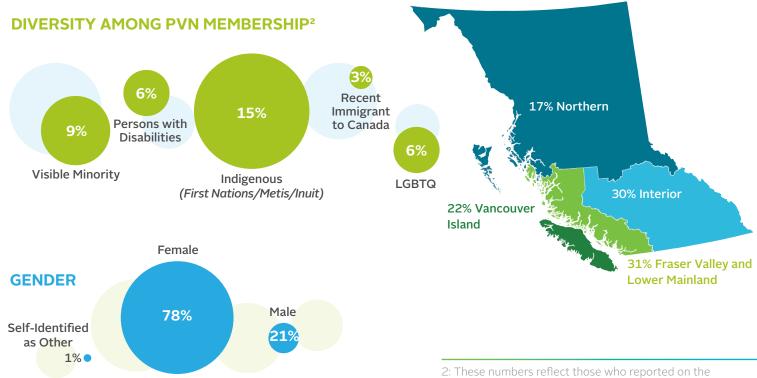
Diversify our membership so that it represents the individuals, communities and groups who access health care services

### Diversity

We grew substantially over the past year. By the end of 2018-19, the number of patient partners reached 1,102 – an increase of 122 people since the end of 2017-18.

Diversifying our membership is a key priority. To support authentic and meaningful engagement, it is important that partners reflect the heterogeneity of BC in terms of geographic location, age, Indigenous peoples and representation from other groups who may have different experiences within our health care system such as visible minorities, persons with disabilities, members of the LGBTQ2S community and recent immigrants to Canada.

The graphs below show the distribution of patient partners throughout the province, as well as how various groups are represented within PVN:



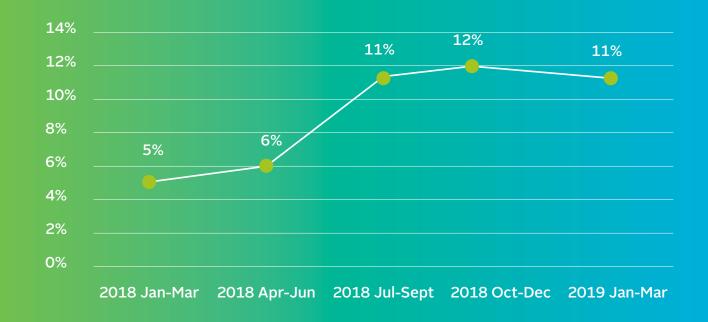
diversity question during the sign-up process

### **The Indigenous Voice**

One of the goals we have worked toward is ensuring the Indigenous voice is included in creating change. This past year, we welcomed 30 new Indigenous patient partners. Our outreach activities included participating in special celebrations and community events such as health fairs, attending feasts and building relationships. We have also been involved in developing a recruitment strategy for Indigenous communities with the First Nations Health Authority as well as Fraser Health's Aboriginal Health and Patient Experience departments.

From 2018-19, a total of 62 Indigenous patient partners joined the network and are working together to ensure the Indigenous voice is included in creating change. The graph below illustrates the percentage of active Indigenous patient partners in comparison to total active patient partners<sup>3</sup> in the network.

#### % INDIGENOUS PATIENT PARTNER ACTIVITY OF TOTAL PATIENT PARTNER ACTIVITY



<sup>3:</sup> Active patient partners are defined as having applied or been confirmed for an engagement opportunity.

### Canadian Foundation for Healthcare Improvement – National Diversity Learning Exchange

The Council staff as well as patient partners Alison Dennis and Vikram Bubber had a wonderful opportunity in March 2019 to inform diversity in patient engagement on a national exchange, representing British Columbia on the steering committee for the first National Diversity Learning Exchange. Coordinated by the Canadian Foundation for Healthcare Improvement, the learning exchange brought together patient and family advisors and patient engagement leaders from across Canada.

The event aimed to share emerging patient engagement practices from across the country, to learn from each other about reaching out to diverse populations and to contribute to developing a framework to guide the work.



# Special Projects Patient Partner Compensation

When PVN was established in 2009, the Ministry of Health consulted with stakeholders, including patient and health care partners, regarding financial compensation for patient engagement. It concluded that patient engagements were voluntary in nature, and it was agreed that patient partners would be reimbursed for outof-pocket expenses but not provided compensation for their time.

Since that time, the scope and level of patient engagement activities have evolved. Patient partners serve as members on standing committees, provide keynote addresses and participate in full-day conferences and learning events. Accordingly, the commitments and expectations of patient partners have also evolved. In addition, as patient engagement has spread throughout the health care system, disparity in compensation practices amongst organizations has been introduced. While most areas have followed the approach of not providing compensation, some, such as mental health, research and Indigenous health, have longstanding practices and cultures of compensating that pre-dates the Ministry of Health's direction. Recognizing these factors, in 2018 the Ministry asked the Council to lead a consultation with PVN members to assess current perspectives on financial compensation.

In order to maximize opportunities for PVN members to participate and provide input, the consultation consisted of a two-phase engagement strategy. All PVN members, including patient partners and health care partners, were invited to participate in Phase 1 of the engagement (electronic surveys) and/or Phase 2 (interviews/focus groups).

Of 1,148 patient partners and 655 health care partners, 32% of patient partners and 25% of health care partners completed the survey. Most patient partner respondents were between 51 and 69 years of age, though all age groups were represented in the survey responses. Most patient partners who responded to the survey had less than two years experience with the network, which is reflective of the network overall and reflects growth in new members in recent years. For health care partners, 31% had worked with PVN for less than two years, and another 31% had a two to four-year history with PVN.

The final report has been submitted to the Ministry of Health.

## Special Projects **"What Matters to You?"**

**"What Matters to You?"** is an international campaign that started in Norway in 2014 with the aim of encouraging more meaningful conversations between patients, caregivers, families and their health care providers. When health care providers have a conversation about what really matters to the people they care for, it helps them build trust, develop empathy and understand their patients.

The movement has now spread to over 15 countries, and the Council was the first organization to bring the campaign to Canada. Over the past year we have been supporting "What Matters to You?" as an ongoing program encouraging health care providers to embed the question "What matters to you?" into care conversations each and every day. A total of 312 partners joined us in participating in and encouraging "What matters to you?" conversations in 2018-19. We asked them to complete an evaluation so we could capture the program's impact.

#### THESE PARTNERS INCLUDED:



ACCORDING TO OUR "SHARE YOUR STORY" SURVEY:

## 89% of our 49 partners

Who completed the survey felt that our support and resources helped them feel comfortable in supporting and promoting the program.

In the evaluation, 89% of 49 health care providers shared that asking, **"What matters to you?"** had a positive impact on their relationships with patients and their families. Health care providers shared with us that asking patients about what matters often sparked self-reflection on what high-quality person- and family-centred care should look like, and what would matter to them if they were a patient themselves.

## Special Projects **"What Matters to You?"**

## "Yes, it reminds me to slow down and reflect on how I can provide the holistic person- and family-centred care I continually strive for."

- HEALTH CARE PROVIDER

Additionally, 76% of health care providers agreed that asking patients what mattered to them helped them to be more receptive to patients' needs and allowed them to treat the whole person versus just their symptoms.

100% of patient partners stated that it was very important to them to be asked "What matters to you?" because it made them feel valued by their health care providers. Patients reported that having the opportunity to express what they needed most also made them feel reassured and safe. This level of care went beyond relationship-building for patients and allowed patients and families to feel that their preferences truly mattered.

"It gives me the opportunity to share with my health care provider what matters to me - my health, health care, making every day a gift and telling them my medical history. It opens up amazing doors and lets people know that someone cares and that their voice can and will be heard."

– PATIENT PARTNER

## Looking Ahead

The past year has set a strong foundation for our ongoing work to advance authentic patient engagement. 2020 marks PVN's 10-year anniversary and throughout the year we will be reflecting on the past decade and celebrating our successes.

In the final year of our 2017-2020 Strategic Plan, we will ramp up our focus on evaluation through partnering with the Ministry of Health to develop a provincial patient engagement framework. We are also planning to redesign our website and central database to better support the needs of our patient and health care partners.

Our team is also enthusiastic about responding to our partners' requests for opportunities to dive deep into authentic engagement learning. In spring and fall 2019, our team will provide new regional workshops designed for peer learning.

While the network's diversity has bloomed, we will continue to strive for membership that represents the population served by health care in BC. We will also focus on new processes to ensure our members are well supported, recognized, connected and engaged as they provide the health care system with their time and patient, family and caregiver experience.

We will also be creating a new strategic plan which will reflect the new state of patient engagement in the province and set direction and goals for the upcoming years. We look forward to driving patient engagement in BC!

> PVN is guided by patient and health care partners and administered by the:



BC PATIENT SAFETY & QUALITY COUNCIL Working Together Accelerating Improvemen



The BC Patient Safety & Quality Council is a driving force for highquality health care in British Columbia. Using evidence-informed strategies, we shift culture, improve clinical practice and advance person- and family-centred care to support the best care possible for every person in our province.

604.668.8240 / 1.877.282.1919 pvn@bcpsqc.ca PatientVoicesBC.ca | ♥ f@PatientVoicesBC ♥ f in Ø @BCPSQC