



Patient  
Voices  
Network

# ANNUAL REPORT 2016





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

PVN is supported through the



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

We are pleased to share an account of the Patient Voices Network's (PVN) first year being supported by the BC Patient Safety & Quality Council (the Council). Although PVN has been operating since 2009, our recent shift in structure and support inspired us to recap our changes and growth over the past year.

PVN was created by the Ministry of Health as part of its Patients as Partners strategy. Its early years were spent building awareness of the importance of engaging patients in changes to their health care system, as well as creating mechanisms to help that engagement take place. In December 2015, the Ministry of Health transferred the responsibility for coordinating and leading PVN to the Council, given an alignment with the Council's mandate to "engage and inform the public as active participants in their own care."

Over the past year we have grown our membership, welcoming new patient and health care partners. We've rebranded with a fresh, new look and have made better use of our online resources to connect with PVN members and the public at large.

With our newly strengthened foundation and the continued support of the Council, we look forward to the future: to further growing and diversifying our membership, creating new opportunities for patient and health care partners to collaborate, and making patient engagement the norm in health care. We invite you to learn more about us through this report, connect with us on social media, and join us as a patient or health care partner in creating a better, patient- and family-centred health care system.

## WHO WE ARE

The Patient Voices Network is a community of patients, families and caregivers working together with health care partners to improve BC's health care system. The inclusion of patient voices provides new perspectives and greater understanding for both patient and health care partners, leading to more informed decisions. Our community of patient and health care partners share a common purpose to include the patient voice in problem solving and decision making to improve our health care system.

PVN's mandate is to bring patients, families and caregivers into conversations with health care partners so that they can share their experiences and bring about positive change. Those interested in joining our Network may sign up either as patient partners, who participate in engagement opportunities that seek to include the patient perspective, or as friends, who receive news about PVN and may participate in surveys and learning events. Our patient partners are a diverse group from a variety of backgrounds with a passion to improve health care in BC.

Our health care partners consist of health authorities, health organizations, and non-profit groups who share our vision of including patient voices to improve quality of care. See **Appendix A** on page 20 for a list of health care partners who hosted engagement opportunities over the past year.

Health care partners bring opportunities for engagement to PVN and together we help create meaningful engagement with patient partners.

Supported by the BC Patient Safety & Quality Council, PVN aligns with the Council's mandate to engage British Columbians in their own care and its belief that patient- and family-centred care is essential to improving quality of care. The Council's work centres on:

- providing system-wide leadership on quality, in collaboration with stakeholders;
- engaging patients, caregivers and the public as partners in their health care system;
- building capability for health care system transformation and improvement; and
- supporting improvements in the quality of care.

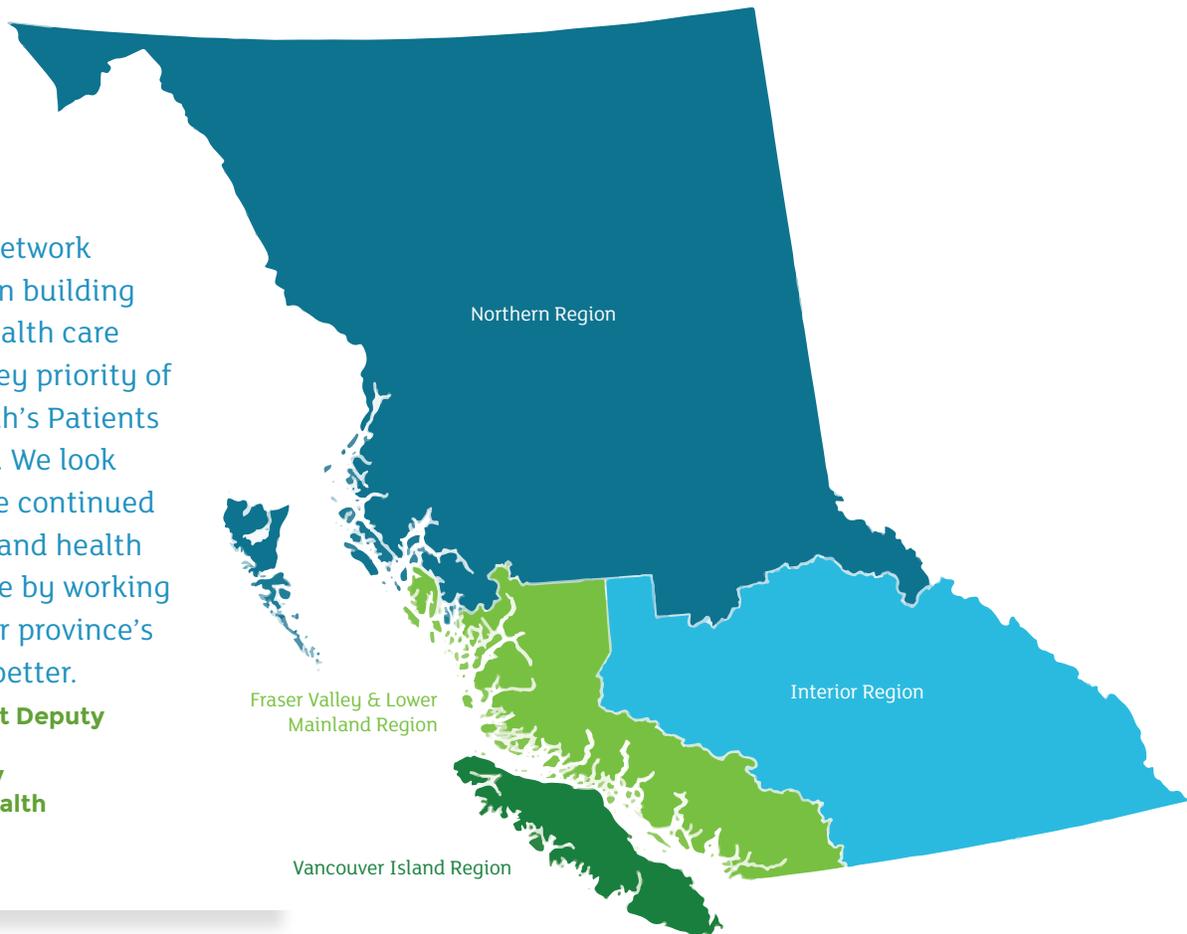
“Patient and family consultation is important as it keeps health care partners accountable and focused on what is important to the patient and family experience. The patients and families bring to the table a different perspective than the health care partners and the insights they share can transform the health care system and the patient and family experience.

**Tannis Knutson, Health Care Partner**

“

The Patient Voices Network plays a critical role in building a patient-centred health care system, which is a key priority of the Ministry of Health’s Patients as Partners strategy. We look forward to seeing the continued impact that patient and health care partners achieve by working together to make our province’s health care system better.

**Doug Hughes, Assistant Deputy Minister, Primary and Community Care Policy Division, Ministry of Health**



Engagement Leaders from the Council recruit, orient and support patient partners, while working with health care partners to develop and promote engagement opportunities. They are located in communities throughout the province to build relationships and provide understanding of the local environment – the image above shows the regions in which they work.

Engagement Leaders have a variety of backgrounds and share extensive experience supporting and leading engagement opportunities. To connect with the Engagement Leader in your community, visit our website: [www.PatientVoicesBC.ca](http://www.PatientVoicesBC.ca).



Patient partners Angela Sterling and Edie Copland participate in an engagement opportunity as judges for the Council’s annual Quality Awards.



## WHO WE ARE

### Oversight & Advisory Committee

PVN is guided by an Oversight & Advisory Committee which includes members from health authorities, health organizations, non-profit groups, the Ministry of Health, and the BC Patient Safety & Quality Council, as well as an equal number of patient partner representatives from across the province. The Committee, which is co-chaired by the Council and a patient partner, meets every two months and its meeting agendas and minutes are posted on our website.

The committee was created to co-design, guide and support the activities of PVN. It provides guidance and recommendations to the Council in leading the Network and ensures the patient voice is included in the planning of PVN's strategic directions and activities.

### PATIENT PARTNER REPRESENTATIVES OF THE OVERSIGHT & ADVISORY COMMITTEE:

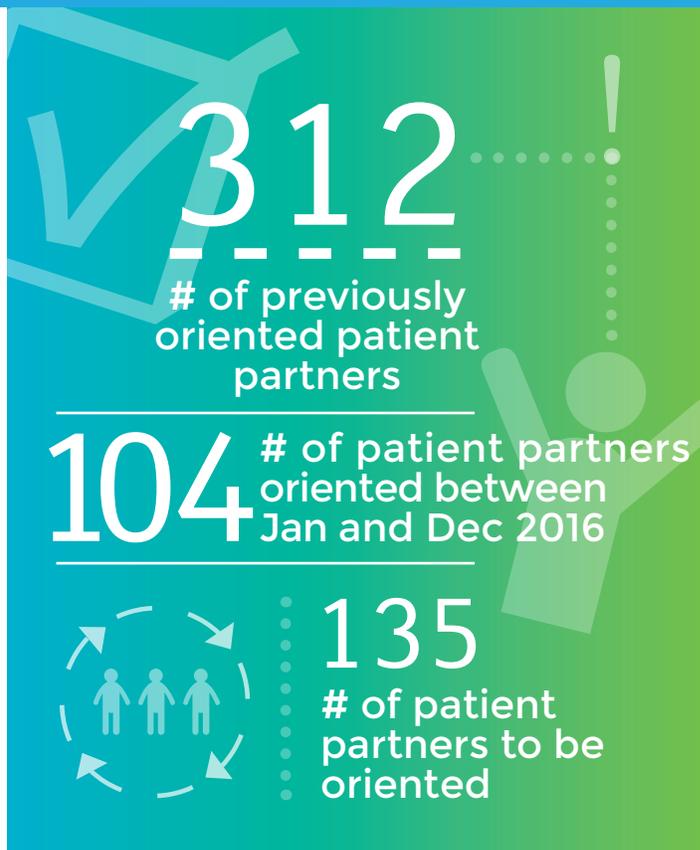
- Betty Murray (Greater Vancouver & Sunshine Coast Region)
- Joyce Sandercock (Greater Vancouver & Sunshine Coast Region)
- Dustine Tucker (Interior Region)
- Leya Stringer (Interior Region)
- Kimberly Strain (Fraser Valley Region)
- Sunaina Sharma (Fraser Valley Region)
- Sandra Smith (Northern Region)
- Stephanie Hendrickson (Northern Region)
- Cherie Mercer (Northern Region)
- Alyson Hagan-Johnson (Vancouver Island Region)
- Jillianne Code (Vancouver Island Region)
- Jim Cawsey (Vancouver Island Region)



At Fraser Health's Patient Experience Summit, patient and health care partners discussed patient engagement projects across the organization.

## HEALTH CARE PARTNER REPRESENTATIVES OF THE OVERSIGHT & ADVISORY COMMITTEE:

- Colleen McGavin (BC SUPPORT Unit)
- Katie Hughes (Canadian Mental Health Association)
- Alana Godin (Doctors of BC)
- Sonia Isaac Mann (First Nations Health Authority)
- Joshua Myers (Fraser Health)
- Karla Warkotsch (Interior Health)
- Deborah Harver (Island Health)
- Shannon Holms (Ministry of Health)
- Sheila Gordon-Payne (Northern Health)
- Kate McNamee (Providence Health Care)
- Kris Gustavson (Provincial Health Services Authority)
- Belinda Boyd (Vancouver Coastal Health)



BC Patient Safety & Quality Council team members joined PVN patient and health care partners to learn more about the Network at a recent coffee networking event.

## SUPPORTING PATIENT & HEALTH CARE PARTNERS

The Patient Voices Network connects patient partners – patients, families and caregivers – with health care partners so that they can work together on improving our health care system. Each connection takes place through a unique engagement opportunity that depends on the needs of a health care partner. Local opportunities enable patient partners to help improve care in their communities, while provincial opportunities address care across British Columbia (a few examples can be found on page 8).

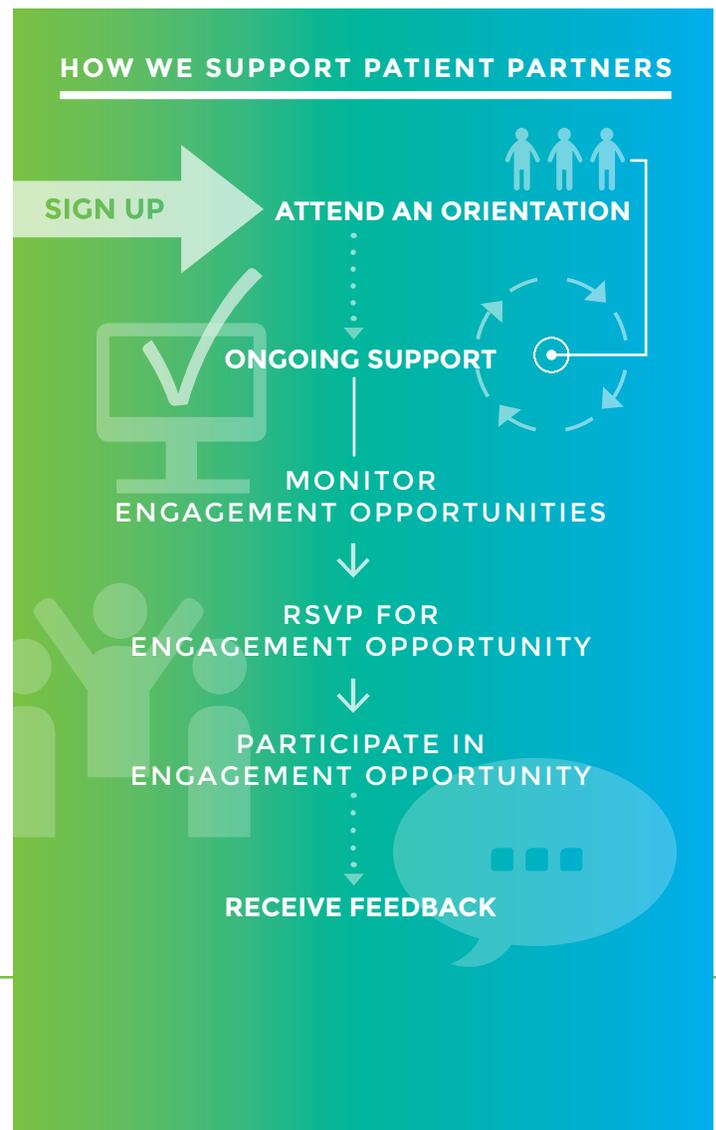
We work closely with health care partners to clarify the objectives of the engagement opportunities, recruit patient partners, and provide ongoing support.

“ The perspectives of patients and their families will change health care because we are ‘experts by experience.’ We are motivated by a strong desire that not one more family should suffer. PVN gives us the opportunity to partner with professionals who see the same problems but can be hampered by being embedded in the very system that created them.

**Johanna Trimble, Patient Partner; Council Member, BC Patient Safety & Quality Council**

### Supporting Patient Partners

PVN supports patient partners from the moment they sign up through to their first engagement opportunity with a simple orientation, access to resources, and initial connection with health care partners to set the foundation for meaningful engagement. Our process ensures patient partners are prepared, confident and ready to share their experiences and perspectives on improving care.



# IAP2 Spectrum of Public Participation



	Inform	Consult	Involve	Collaborate	Empower
<b>Public Participation Goal</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
<b>Example Techniques</b>	<ul style="list-style-type: none"> <li>• Fact sheets</li> <li>• Websites</li> <li>• Open houses</li> </ul>	<ul style="list-style-type: none"> <li>• Public comment</li> <li>• Focus groups</li> <li>• Surveys</li> <li>• Public meetings</li> </ul>	<ul style="list-style-type: none"> <li>• Workshops</li> <li>• Deliberative polling</li> </ul>	<ul style="list-style-type: none"> <li>• Citizen advisory committees</li> <li>• Consensus-building</li> </ul>	<ul style="list-style-type: none"> <li>• Citizen juries</li> <li>• Ballots</li> <li>• Delegated decision</li> </ul>

## Supporting Health Care Partners

Once a health care partner brings an engagement opportunity to PVN, our Engagement Leaders assist with defining the objectives, clarifying the engagement plan, and finding patient partners who best fit the opportunity. Our process ensures everyone begins on the same page, the agenda stays on track and the objectives of the opportunity are achieved.

Each engagement opportunity uses the International Association of Public Participation (IAP2) spectrum of engagement to help communicate how PVN patient partners' input will influence decisions and manage expectations of how they will be asked to participate.

We have created resources to build the skills of our patient and health care partners. For patient partners, resources include how to communicate health care experiences, teleconference etiquette, and how to join webinars; for health care partners, we have a readiness checklist and FAQs regarding our engagement request form and evaluation process. Along the way we collect feedback so that we can continuously improve our own processes; feedback is also passed to patient and health care partners to aid their participation in future engagement opportunities.



Sometimes it is hard for us to change our way of working - from having the patient on the periphery of what we do to having them partner with us as a member of the health care team. Creating opportunities where patients and families are involved through meaningful experiences takes time and thoughtfulness, two things that are sometimes hard to find in busy schedules. Having the PVN resources guide us through the recruitment of a patient partner has been instrumental in supporting us during this important transition.

**Veronica Nickerson, Health Care Partner**



## SUPPORTING PATIENT & HEALTH CARE PARTNERS

PVN supports many types of engagement opportunities to help include the patient voice in efforts to improve the quality of health care. Since December 2015, PVN has supported more than 200 new engagement opportunities across BC. These engagements take many forms, such as advisory committees, focus groups, interviews, workshops, and review teams. A few examples of past engagements are highlighted below.

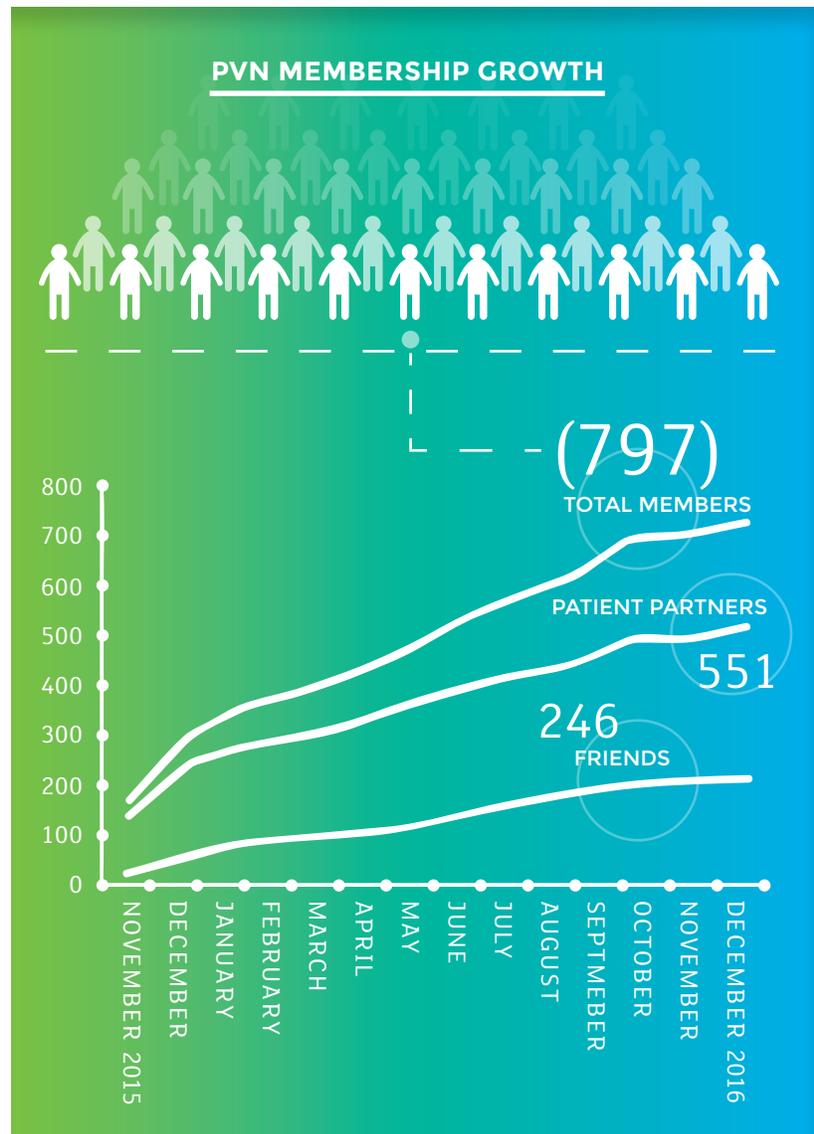
### Hospital Redevelopment Focus Groups:

Providence Health Care wanted to ensure that the new St. Paul's Hospital will meet the needs of patients, families, staff and leaders. Focus groups gathered input from patients and families about what is important to them when receiving care at the hospital.

**Virtual Care Projects:** Multiple engagement opportunities have included patient partners in projects that aim to use technology to connect patients and health care providers. Patient partners often provide input into a project's implementation and accessibility, so that the right care can be provided in the right place at the right time.

**PVN Ambassadors:** PVN patient partners were invited to a wellness fair in Prince Rupert that focused on child and youth mental health. They hosted an information table and interactive activities for youth and parents, while sharing their enthusiasm about the Network, answering questions, and explaining how to become involved.

**Developing Palliative Care Resources:** For roughly 18 months, patient partners worked with Interior Health to develop a new website, resources and guides on palliative care. Patient partners provided insight into the resources' content, graphics and layout; they also ensured that the language used is respectful and compassionate.



## GROWING OUR COMMUNITY

An early area of focus this year was growing the Network through local connections and outreach activities such as health fairs, networking coffees, and wellness events. We grew our network almost 350% over this past year!

We created a fresh new look including branding, colours and a logo that have been used in brochures, business cards, postcards, rack cards and banners, all of which help to spread the word about the Network. Our new look was developed with feedback from the Oversight & Advisory Committee and features vibrant colours and an image which reflects themes of connection and communication.



Patient and health care partners say hello at a recent coffee networking event.

### CASE STUDY: COFFEE NETWORKING EVENTS

#### Let's Grab Coffee!

Networking coffee events are a great way for our Engagement Leaders to get to know our patient and health care partners better, and to learn about their hopes and expectations for the Network.

In September, we co-hosted an event in Victoria with Island Health. Eight patient partners joined us - highlights included a discussion of learning opportunities for patient and health care partners as well as a review of the IAP2 Spectrum of Engagement, which patient partners asked for in order to better understand the levels of engagement and their roles in engagement opportunities. They also talked about the importance of good facilitation to ensure smooth and productive meetings, so that all voices are given a chance to speak and be heard.

“Nothing beats physically networking with like-minded people. It builds an important sense of community and shared purpose,” said our Engagement Leader, Ryan Sidorchuk.

The coffee drinkers also suggested many ideas that we've put into action, including creating more opportunities for patient partners to connect with each other both online and offline, and ensuring engagement opportunities reflect the most appropriate level of engagement.



## CASE STUDY: OKANAGAN COLLEGE

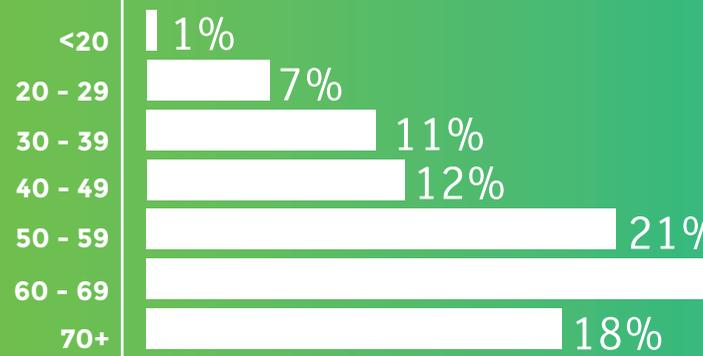
**“So often we get caught up in caring for the client that the family perspective is not heard.”**

In early 2016, Okanagan College contacted us in search of an experienced caregiver who could speak to a health promotion and gerontology class. With experience caring for her husband, and as a nurse in Penticton, PVN Patient Partner Lois Dalrymple was a perfect fit for the engagement opportunity.

“So often we get caught up in caring for the client that the family perspective is not heard,” said Dana Susheski, a health care partner with PVN from the college. “Lois talked a lot about community resources and how their home had been modified to meet the needs of her husband over the years. She even offered students the opportunity to visit and see these modifications.”

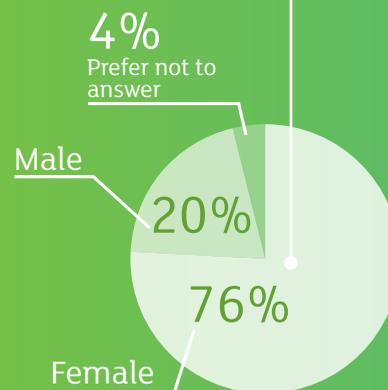
As Dana notes, patient partners offer a lived experience and perspective not found in textbooks or curriculum - some students weren't aware that someone with complex care issues can be cared for at home.

The experience was very rewarding for Lois as well: “The best thing about volunteering with PVN is that I get to help change health care in a very positive way.”



PATIENT PARTNERS BY AGE

PATIENT PARTNERS BY GENDER



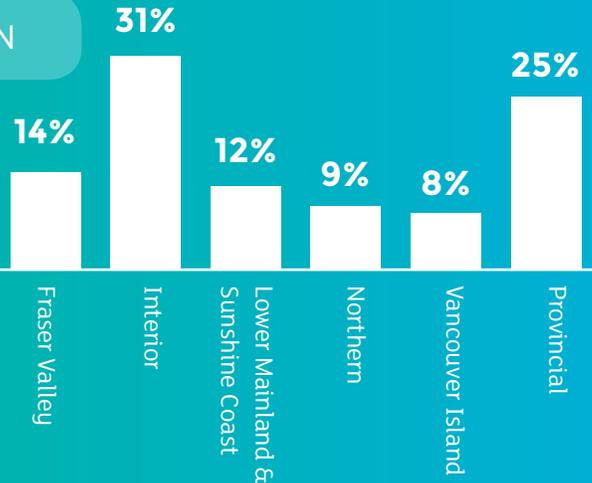
PATIENT PARTNERS BY REGION



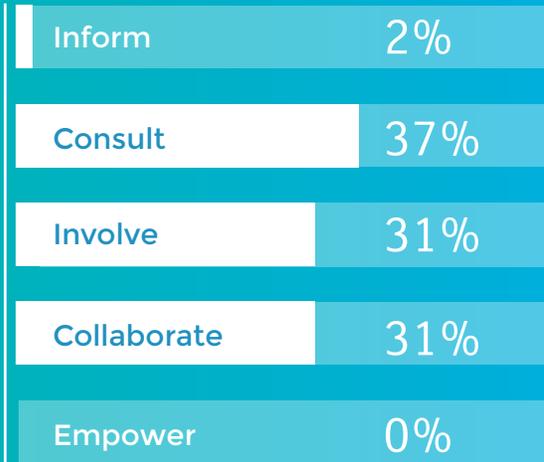
## ENGAGEMENT OPPORTUNITIES BY REGION

%

30%



## ENGAGEMENT OPPORTUNITIES BY LEVEL OF ENGAGEMENT



**204** ENGAGEMENT OPPORTUNITIES

**428** PATIENT PARTNERS ENGAGED IN OPPORTUNITIES

“The best thing about volunteering with PVN is that I get to help change health care in a very positive way.”

Vancouver Island

**18%**



## CONNECTING WITH OUR COMMUNITY

In an effort to grow our membership and make it easier for patient and health care partners, as well as the public, to connect with us and each other, we've improved our online presence, developed a blog, increased our reach through social media, and launched two newsletters.

PVN has increased connectivity with members by creating an "online home." We now post all of our engagement opportunities from across the province online, distribute them in a weekly newsletter and share them on social media, so that everyone can see and access the choices they have to become involved. We've made it easier for patient partners to express interest in opportunities through an online RSVP process.

“ 2016 was a learning curve for us all - the BC The BC Patient Safety & Quality Council has brought PVN to a new level of professionalism and this is very evident when we see the quality of our patient partner opportunities and the efficacy of the new RSVP process.

**Fran Banks, Patient Partner**

“ I enjoy seeing the opportunities across BC [via the weekly newsletter] even though I can't participate in opportunities outside my health authority. I REALLY REALLY like this.

**Anonymous, Patient Partner**

Health care partner Tannis Knutson and patient partners Bill Conolly and Joyce Sandercock share ideas for the redevelopment of Royal Columbian Hospital.



Our blog is a place for Network members to share stories and learn about PVN activities. Some recent blog posts have covered ways to connect Network members together, a recap of personal experiences, and profiles of patient partners. The posts are featured in our biweekly Patient Voice Mail email newsletter, which also features news, learning opportunities and events from PVN, our patient and health care partners, and other organizations whose work might interest our members.

WE LAUNCHED OUR WEBSITE AND SOCIAL MEDIA PROFILES IN OCTOBER 2016.

**IN ONLY 3 MONTHS:**

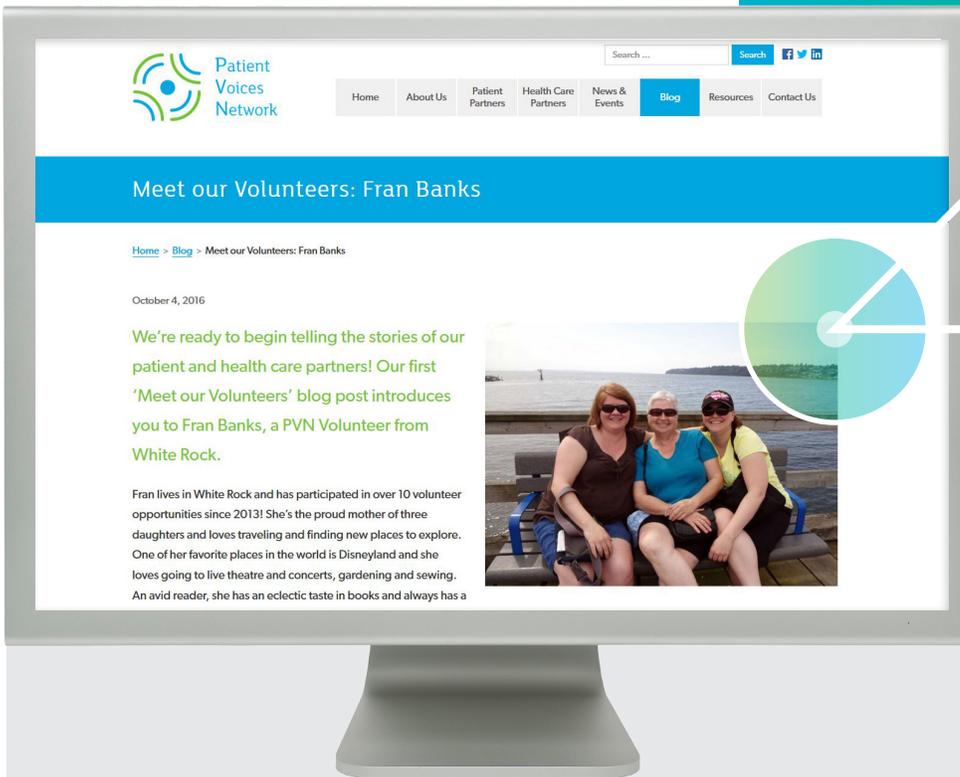
**389** followers on social media

**451** POSTS ON SOCIAL MEDIA

**2,732** UNIQUE WEBSITE VISITORS

**19,322** views on the website

Our first blog post profiled long-time patient partner Fran Banks, who's been volunteering with PVN since 2013.



## CONNECTING WITH OUR COMMUNITY

“ PVN is a valuable resource. I am finding many people share with me experiences and insights into their health care experiences. I can easily connect them with the PVN website where they can view the blog and engagement opportunities and resources. I regularly tweet and share the blog posts to invoke engagement in our community. #bethechange  
**Edwina Nearhood, Patient Partner**

Facebook, Twitter and LinkedIn help us connect and engage with our patient and health care partners – and anyone else interested in our work – on a daily basis. We are able to respond to questions and post our engagement opportunities, news, resources and events. These tools also help us amplify the work of our patient and health care partners; in turn, our posts can easily be shared, helping them to reach an audience far larger than our networks.



Together with a patient partner, we led a workshop at Quality Forum 2016 where participants co-created an agenda to discuss, explore and create opportunities for patient- and family-centred care.



New connections are created during a networking coffee event in Vancouver.



Patient partners Paul Burgener and Colleen Driscoll with our Engagement Leader for the Interior Region, Selena Davis, during Nelson's Connect Day Health Fair.



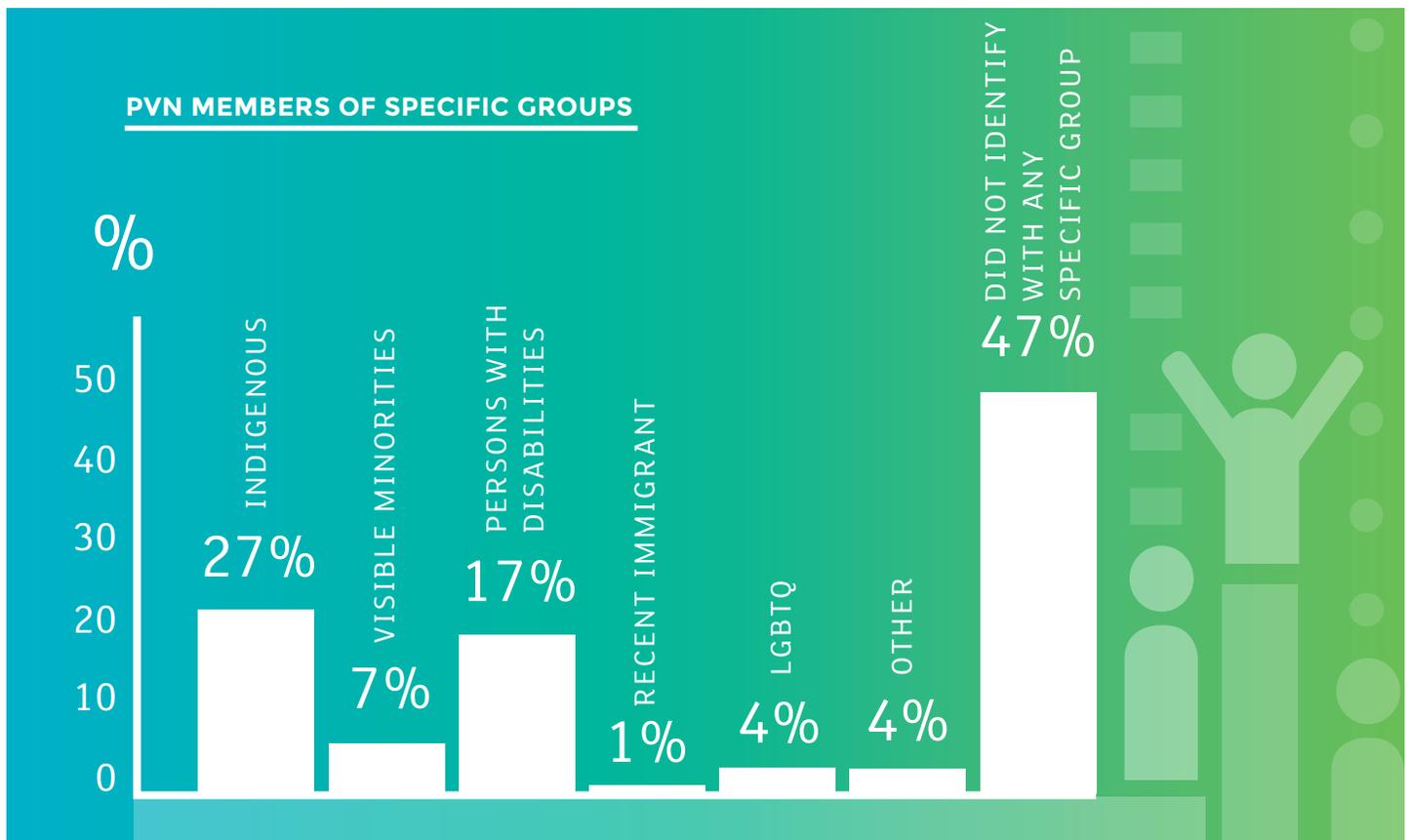
Our patient partner Rob Goffinet poses for a photo with Cathy Almost, our Engagement Leader for the Northern Region, during the Haisla Health Fair.

## REFLECTING BRITISH COLUMBIA'S POPULATION

The Patient Voices Network has recruited patient partners from across the province, representing a variety of backgrounds. The graph shown here and the infographic on pages 10 and 11 provide a snapshot of our members.

We have started collecting demographic information to track how our membership reflects BC's population. The graph below illustrates responses from 225 of over 500 patient partners; we are currently collecting this data from our other patient partners.

Our Oversight & Advisory Committee identified populations which are under-represented within our membership, including people with disabilities, youth and men, as well as populations of varying social and cultural backgrounds. We are now reaching out to recruit patient partners represented in these populations. We want to ensure all British Columbians, no matter their background or location, have an opportunity to improve their health care system.





## REFLECTING BRITISH COLUMBIA'S POPULATION

“ As a youth, volunteering with an incredible organization such as PVN allows me to voice the concerns, hopes, challenges, and successes of our health care system in the eyes of our young people.

**Kyle Warkentin, Patient Partner**

A key priority for PVN is to diversify our membership to better reflect the population in BC. We recognize that our province's communities are culturally diverse, and that characteristics such as age, ethnicity and gender affect our health care experiences and needs.

For example, we are excited to be working with the First Nations Health Authority (FNHA) to include the voice and perspectives of Indigenous people and communities in health system planning. With FNHA, we are exploring the use of their existing pathways for sharing PVN engagement opportunities, including social media channels which will reach over 4,000 Indigenous community members.

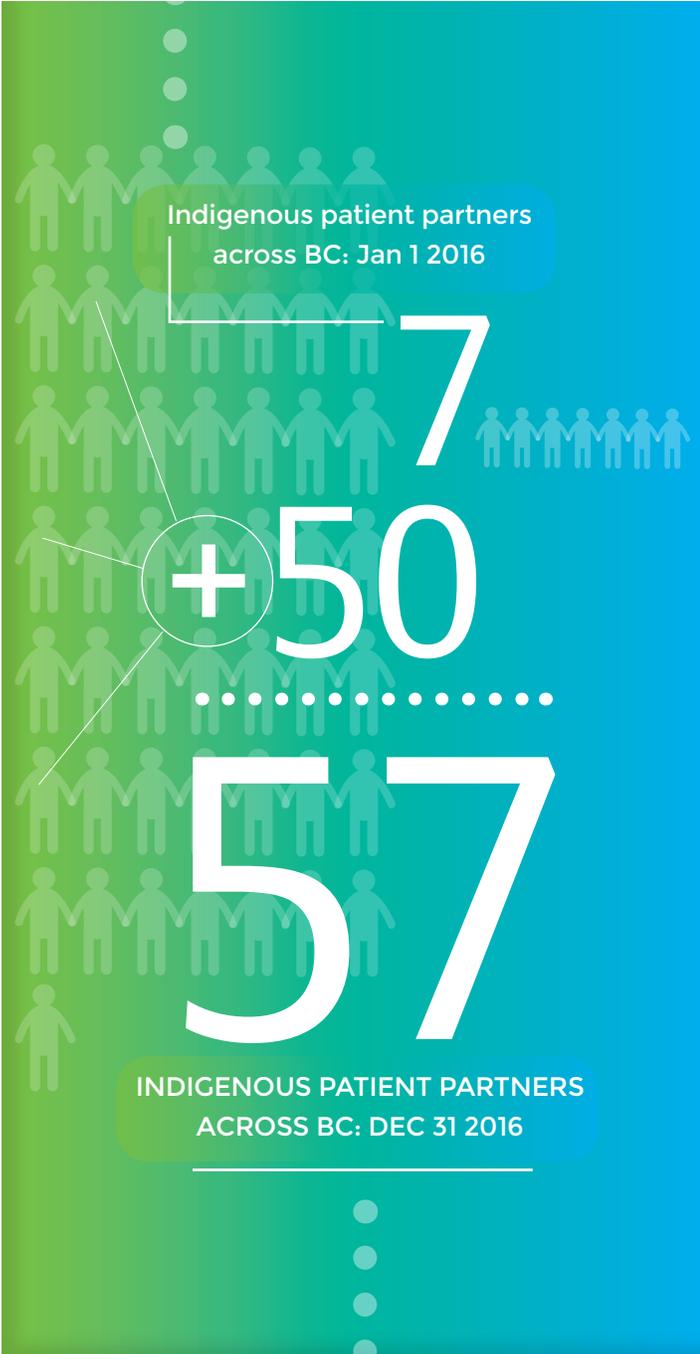
“ A health care team at Royal Inland Hospital is looking to improve the Mental Health and Substance Use (MHSU) patient experience for urgent and non-urgent care in the emergency department. We engaged patient representatives from PVN who have previously accessed MHSU services to help us understand the patient perspective. We had the pleasure of having an Indigenous patient representative; having her perspective was truly invaluable, bringing light to some of the challenges she faces as an Indigenous woman living in a small rural community.

**Naomi Erickson, Health Care Partner**

Further, our Engagement Leaders have reached out in person at Indigenous celebrations, Regional Caucus meetings, the All Native Basketball Tournament, the Provincial Elders' Gathering, Friendship Centres, band health centres, and Métis support organizations.



Our local Engagement Leaders attended the Okanagan Nation Annual General Assembly in July.



Patient partner Basil Morissette and Jacquelyne Foidart, our Engagement Leader for the Interior Region, connected with new patient partners at an Elders Gathering Fair in Kamloops.



New patient partners with our Engagement Leader for the Northern Region, Cathy Almost, during an orientation session in Kitsumkalum.



## LOOKING AHEAD

“ Over its first six years, the Patient Voices Network really increased awareness of the need to include the patient voice and built momentum for engagement. What we’re excited about next year is the opportunity to start making engagement part of regular practice, embedded across the health care system.

**Ben Ridout, Director, Patient & Public Engagement, BC Patient Safety & Quality Council; Co-chair, Oversight & Advisory Committee**

The Patient Voices Network is well-positioned to support the Ministry of Health’s strategic priority to deliver patient-centred care. We have a strong and passionate membership as well as mechanisms to connect patient and health care partners for engagement opportunities.

Looking ahead, we see the opportunity to further engage patient voices to improve the quality of our health care system. The Oversight & Advisory Committee is developing a three-year plan for the Network, in collaboration with our patient and health care partners, to ensure PVN continues to advance patient and public engagement in BC. We look forward to setting and implementing our strategic priorities for the next three years.



Our Engagement Leader for the Vancouver Island Region, Ryan Sidorchuk, listens to patient partners’ suggestions during a networking coffee event in Victoria.



We will launch new evaluation tools in 2017 to ensure we continually improve how we work with and support our patient and health care partners. These evaluations will capture feedback on the outcomes of engagement opportunities, including the role of patient partners, to assist us in measuring the impact of patient engagement on BC's health care system.

We will also continue to develop educational resources and host learning events to support meaningful engagement, as well as to increase diversity and connections within the Network.

If you would like to join us as a patient or health care partner, visit our website: [www.PatientVoicesBC.ca](http://www.PatientVoicesBC.ca).



At Fraser Health's Patient Experience Summit, patient and health care partners discuss patient engagement projects across the organization.



## Appendix A - PVN Health Care Partners

Association of Registered Nurses of BC  
BC Alliance on Telehealth Policy  
and Research  
BC Baby-Friendly Network  
BC Cancer Agency  
BC Care Providers Association  
BC Centre for Palliative Care  
BC Emergency Health Services  
BC Emergency Medicine Network  
BC Health Information Management  
Professionals Society  
BC Medical Quality Initiative  
BC Ministry of Health  
BC Palliative Care Association  
BC Patient Safety & Learning System  
BC Patient Safety & Quality Council  
BC SUPPORT Unit  
Beacon Community Services  
Camosun College  
Cardiac Services BC  
Child and Youth Mental Health Prince Rupert  
College of Chiropractors of BC  
College of Licensed Practical Nurses of BC  
Divisions of Family Practice  
Doctors of BC

Fraser Health  
Genome BC  
Health Leaders/Informatics Network for  
the BC Interior  
Interior Health  
Island Health  
Northern Health  
Northern Partners in Care  
Northwest Community College Faculty  
of Nursing  
Okanagan College  
Perinatal Services BC  
Providence Health Care  
Provincial Health Services Authority  
Simon Fraser University  
Spirit of Wellness Expo  
The Centre for Collaboration, Motivation  
and Innovation  
Trauma Services of BC  
Trinity Western University  
University of British Columbia  
University of Northern BC  
Vancouver Coastal Health  
Vancouver Community College



## Connect with us!

Please connect with us online, with a local Engagement Leader,  
or contact our head office in Vancouver:

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Fax: 604.668.8220

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

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