



PATIENT
VOICES
NETWORK
2017/18
ANNUAL
REPORT

A person with long hair is seen from the back, looking at a wall covered in sticky notes. The sticky notes contain various handwritten notes and questions. The background is a light blue color with a grid pattern. The text is overlaid on the image in a white, sans-serif font.

It's been a busy year for the Patient Voices Network and we are excited to share the accomplishments of the network with you. In our second full year of being guided by patient and health care partners and administered by the BC Patient Safety & Quality Council, we have grown our network, strengthened our partnerships and continued to advance authentic patient engagement.

We are proud to say that, since last year, we have grown our numbers of patient partners to 980 and we are working to increase the involvement of populations who were previously underrepresented in PVN. We supported patient partners to attend valuable learning opportunities, such as workshops and the Council's annual Quality Forum conference. We continued to expand our community outreach platforms and have strengthened several important partnerships with other health organizations, such as the BC SUPPORT Unit.

This report celebrates our achievements and looks ahead to new and exciting opportunities to come. We invite you to join the conversation and get involved as a patient or health care partner in your region.

A Look Inside

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Highlights of the Year: PVN by the Numbers

We accomplished so much together last year! PVN connected patient and health care partners who came together, shared information and collaborated on initiatives that created positive changes in our health care system. We supported patient engagement by sponsoring learning opportunities, growing our membership, creating and sharing new resources, and so much more. Here is a look back, by the numbers:

235

New engagement opportunities supported



347

New patient partners joined our network



90%

of patient partners felt their voice was heard

168

Events were promoted on our website





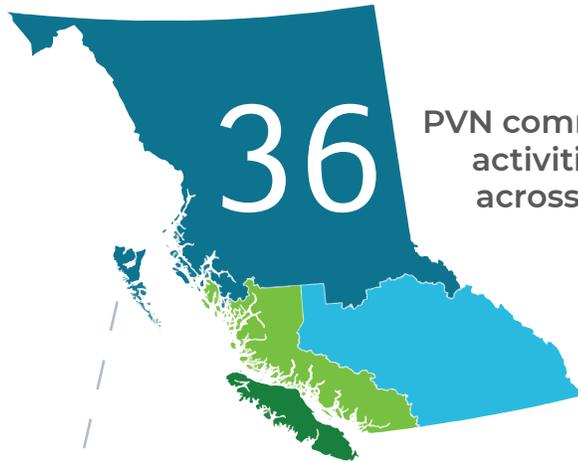
73% of PVN Patient Partners & 93% of PVN Health Care Partners

indicated their engagement was a success.



80

Newsletters sent to our subscribers



36

PVN community outreach activities took place across the province



426

Patient partners engaged in opportunities

62

Engagement opportunities which we shared and promoted for other organizations



48

Patient partners sponsored to attend learning opportunities



10

Patient partners told their stories on our blog

About Us

The **Patient Voices Network** 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.

VISION

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

MISSION

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

VALUES

Our values guide our strategic priorities and day-to-day decisions:

- ✓ **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

The Oversight & Advisory committee works in partnership with the BC Patient Safety & Quality Council to ensure that patient voices are included in the planning of PVN initiatives and operations, and that patient and health care partners co-develop recommendations for all activities.

Patient Representatives

Betty Murray (Greater Vancouver and Sunshine Coast region)
Lin Chen (Greater Vancouver and Sunshine Coast region)
Dustine Tucker (Interior region)
Kimberly Strain (Fraser Valley region)
Kyle Warkentin (Fraser Valley region)
Sunaima Sharma (Fraser Valley region)
Cassy Mitchell (Northern region)
Cherie Mercer (Northern region)
Sherri Mytopher (Northern region)
Alyson Hagan-Johnson (Vancouver Island region)
Jim Cawsey (Vancouver Island region)
Pamela Jessen (Vancouver Island region)

Health Care Representatives

Colleen McGavin (BC SUPPORT Unit)
Elisa Murru (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)

STRATEGIC PRIORITIES

We launched our 2017-2020 strategic plan in August 2017. It was created in consultation with our partners in communities and organizations across British Columbia and co-created with our Oversight & Advisory Committee. Through conversations with our network, as well as with other patient engagement practitioners across the country, we defined three strategic priorities:

1

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

2

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

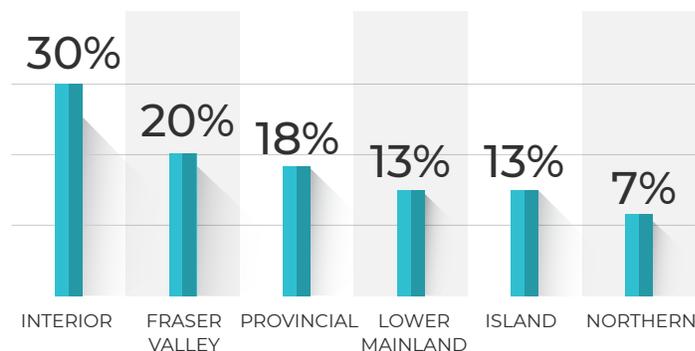
3

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

Supporting Patient Engagement

The Patient & Public Engagement Team at the BC Patient Safety & Quality Council supports PVN by working with diverse partners to provide a wide variety of engagement opportunities across the province. Over the past year, we have been a part of 235 new engagements with 426 patient partners. As shown in Figure 1, patient partner engagement took place throughout British Columbia.

Figure 1: PERCENTAGE OF ENGAGEMENT OPPORTUNITIES BY REGION IN 2017/18 (N=235)



We support a range of ways for patient partners to engage with our health care system. Shown in Figure 2, patient partner involvement in these opportunities can take many forms, including participating in advisory committees, focus groups, co-design workshops, surveys and many other activities. Similarly, as shown in Figure 3 the commitment of engagement can be anything from a one-time 10-minute online survey, to several months or over a year. Lastly, the engagements that we support follow IAP2's Spectrum of Public Participation, with most engagements falling under the levels of "consult, involve and collaborate" (Figure 4). As demonstrated by the variety of formats, levels of engagement and terms of commitment for opportunities, we are able to facilitate opportunities that engage patient partners across British Columbia.

Figure 2: PERCENTAGE OF ENGAGEMENT OPPORTUNITIES BY FORMAT (N=235)

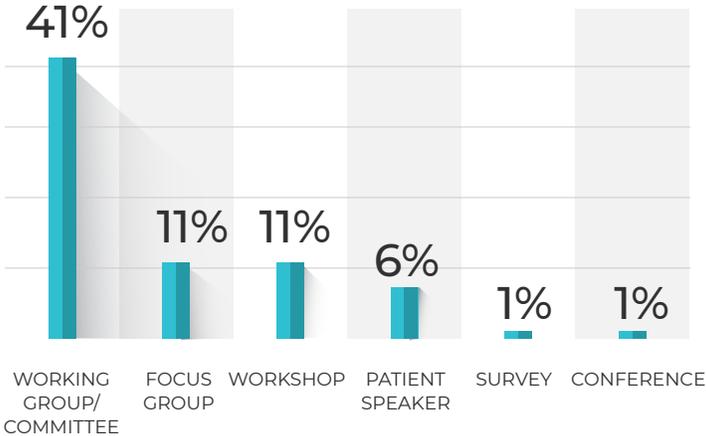
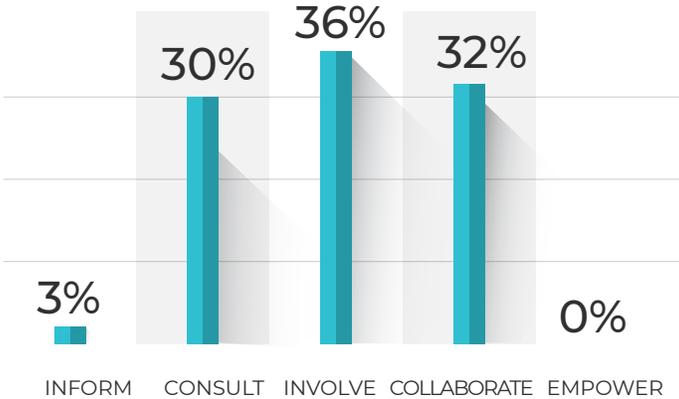


Figure 3: PERCENTAGE OF ENGAGEMENT OPPORTUNITIES BY COMMITMENT LENGTH (N=235)



Figure 4: PERCENTAGE OF ENGAGEMENT OPPORTUNITIES BY AP2'S SPECTRUM OF PUBLIC PARTICIPATION (N=235)



IAP2 Spectrum of Public Participation



Inform



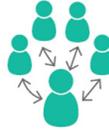
To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.

Consult



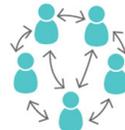
To obtain public feedback on analysis, alternatives and/or decisions.

Involve



To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.

Collaborate



To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.

Empower



To place final decision-making in the hands of the public.

Public Participation Goal

Supporting Patient Engagement

To ensure we are making an impact and providing value, we send out two surveys following each engagement in order to gather feedback from our partners. We are proud to say that 73% of PVN Patient Partners and 93% of PVN Health Care Partners have indicated that the engagement they participated in was a success!

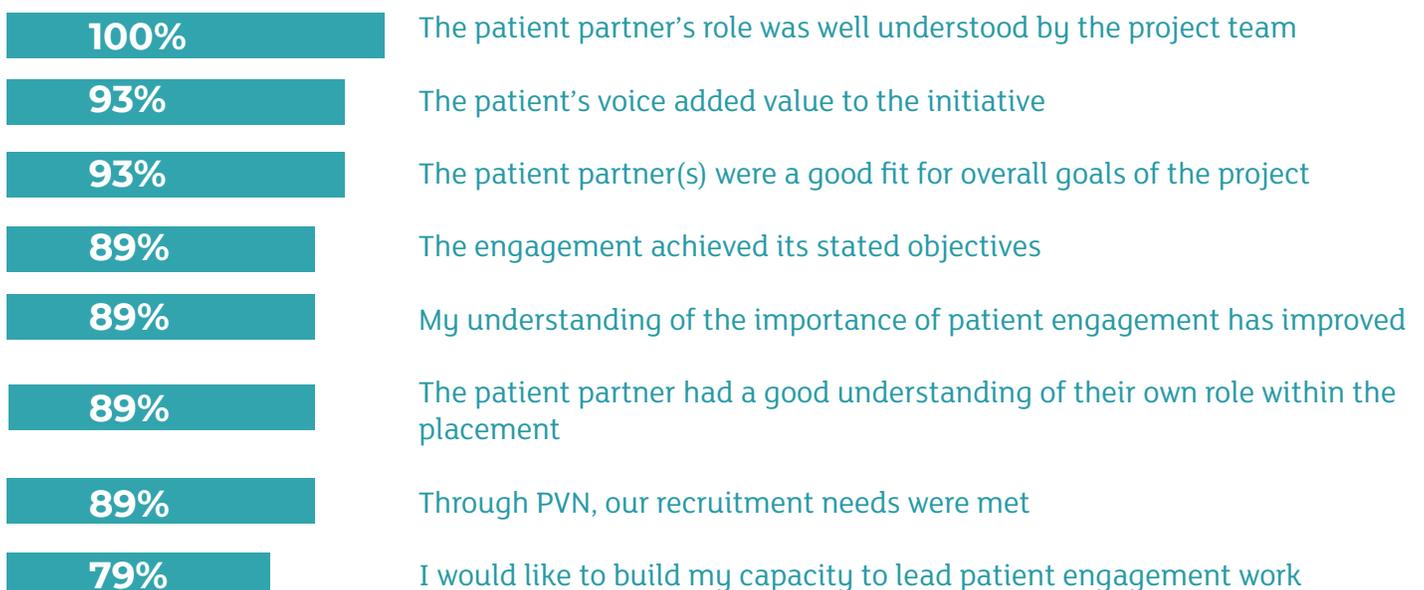
The following data was collected between October 2017 to March 2018. As detailed in Figure 5, the majority of PVN Patient Partners understood their roles (90%) and the purpose of their involvement (84%) in their engagements. Additionally, they felt appreciated by the health care partners (84%) and that their voices were heard (83%). While most patient partners understood how their participation contributed to the overall goals of the engagement (76%) and indicated that their participation influenced the outcome of the engagement (69%), we believe we can better support all of our partners to better understand the impact of patient partners' involvement. To that end, we are working towards enhancing how we support health care partners in closing the loop with participants.

Health care partners expressed that patient partners' voices added value (93%), the engagement achieved its stated objectives (89%) and that their understanding of the importance of patient engagement has improved (89%) (Figure 6). Additionally, health care partners indicated their interest in building their capacity to lead patient engagement work within their organization. In response, over the upcoming months the PVN team will be working towards developing resources that will build our partners' capacity to advance authentic patient engagement.

Figure 5: PVN PATIENT PARTNER FEEDBACK SURVEY RESPONSES - OCTOBER 2017 - MARCH 2018 (N=59)



Figure 6: PVN HEALTH CARE PARTNER FEEDBACK SURVEY RESPONSES - OCTOBER 2017 - MARCH 2018 (N=28)



Supporting Patient Engagement

Case Study: Journey Mapping

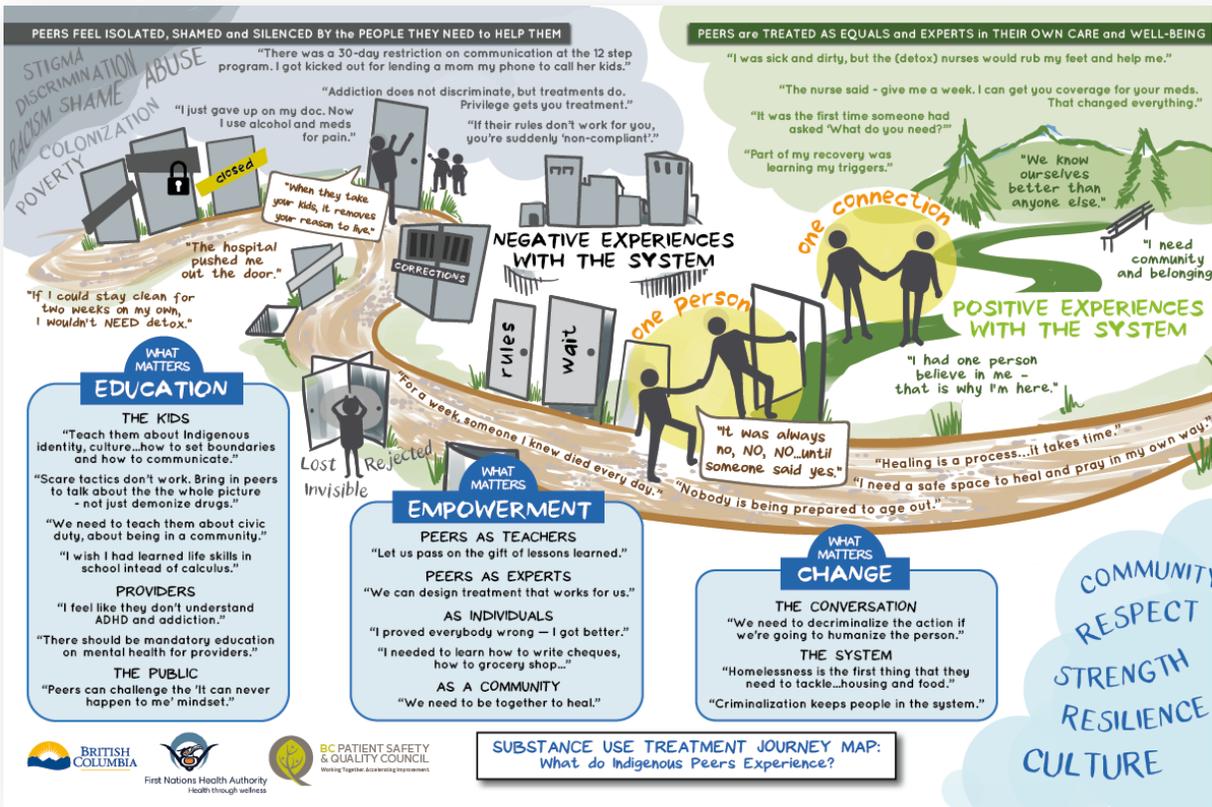
In April 2016, British Columbia's Provincial Health Officer, Dr. Perry Kendall, declared the opioid crisis a public health emergency in BC. In order to better understand how the system can best meet the demands of the crisis, the BC Patient Safety & Quality Council collaborated with the Ministry of Health, the Ministry of Mental Health and Addictions, the First Nations Health Authority and the General Practices Services Committee to host journey mapping sessions.

These sessions, held in the summer and fall of 2017, explored the current state of treatment options and support for people with substance use concerns in primary care settings – from both the health care provider and the patient/peer perspectives.

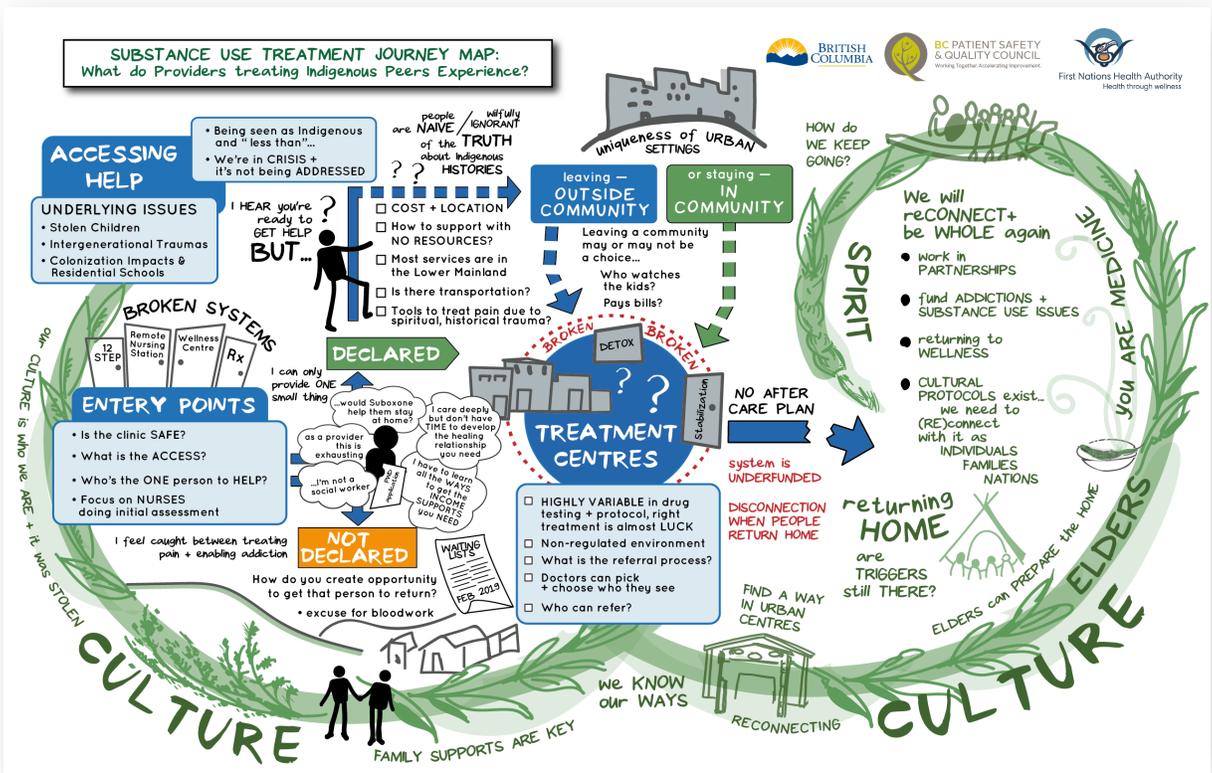
PVN supported a session specifically with Indigenous peers to better understand their perspectives and experience of care when accessing treatment. Given that drug overdose deaths during the opioid crisis have disproportionately affected Indigenous peoples, this was a timely project to ensure that the voices of those most affected were heard. Through these sessions, eight major themes and associated change ideas were identified and a journey map was put together.

The journey mapping sessions represented a unique chance for patient partners to work in partnership with multiple health organizations. This was a valuable opportunity to improve care by offering a shared understanding of how the current system is experienced by both Indigenous peers and health care providers.

Download the maps and a report of the journey mapping sessions at BCPSQC.ca.



SUBSTANCE USE JOURNEY: INDIGENOUS PEER EXPERIENCES



SUBSTANCE USE JOURNEY: PROVIDERS TREATING INDIGENOUS PEERS EXPERIENCES

Increasing Capacity for Patient Engagement

Increasing the capacity of our patient and health care partners through skill-building and education is an important strategic priority for the Patient Voices Network. We support patient partners from the first day that they sign up for the network. We know that each volunteer comes to PVN to use their voice to make a difference, and we seek to provide them with the tools and support they need to share their stories and make sure their experiences are heard.

Over the course of the year, we strived to build the capacity of our patient and health care partners to meaningfully participate in patient engagement by providing orientations, resources, connections with health care partners and learning opportunities. These opportunities help prepare our members for engagement projects and ensure our patient partners are equal members of the team.

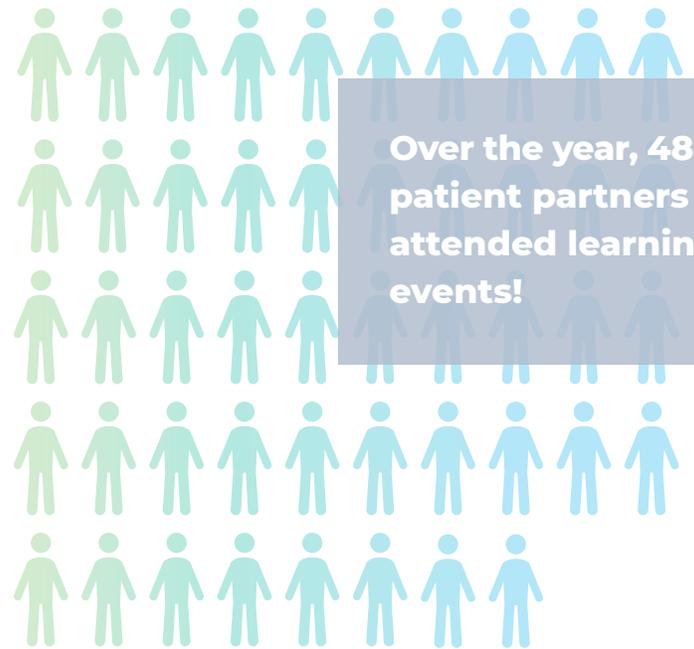
RESOURCES

In 2017, we created a Resource Centre for engagement materials on our website. The Resource Centre houses materials to support patient and health care partners before, during and after engagement opportunities. The resources are a mixture of guides, tips and checklists that we created, as well as materials by other organizations we have curated. We also added a glossary to demystify health care language, tips for effective communications, preparation and planning materials for engagement opportunities, teleconferences tips and much more.

LEARNING OPPORTUNITIES

Learning opportunities equip patient partners with new skills and knowledge to help them effectively work with health care partners. Over the past 12 months, we expanded our support to include even more skill-building workshops, health care conferences and other educational events. We provided orientations for 252 patient partners in 2017/18.

We supported a total of eight patient partners to attend four workshops offered through the Council on a variety of topics related to health system improvement.



In addition, we sponsored 20 patient partners to attend Understanding Experience & Co-Designing Solutions, a full-day workshop on co-design. And in February, PVN brought 20 patient partners to Quality Forum 2018, a two-day conference about improving quality across the continuum of care. For those who were unable to attend in person, we supported over 12 hours of programming that was live streamed from the Forum, widening the event's reach and providing its learning opportunities to as many people as possible.

Case Study: Being an Effective Change Agent Workshop

In October 2017, we supported two patient partners to participate in Being an Effective Change Agent, a BCPSQC workshop focused on building knowledge and skills for leading change in an organization. The workshop taught attendees about applying social movement and community organization principles to their work.

Our patient partners learned new approaches to building alliances, analyzed resistance to inform strategies for change, and discovered new ways digital and social media tools can support change processes. After the workshop, Chad Dickie, one of the selected patient partners, wrote a blog article about his experience.

While Chad noted that the day was fast-paced and how he was initially nervous to be in a room of almost 40 health care professionals, he soon felt comfortable contributing to group discussions, adding the unique perspective that only a patient can contribute and picking up a wealth of new knowledge and skills.

“Though most of the content was geared to organizational change within health care provision, as an end-user of health care, my viewpoint was as valid as that of a person overseeing emergency medical technicians scheduling, clinical management design, or care facility management.”



Case Study: How to Tell a Good Story in Health Care

Here is one example of how our Engagement Leaders support building capacity.

Providing patients, families and caregivers with the right tools to share their experiences can make their stories that much more impactful. Clear, well-delivered storytelling empowers patient partners while encouraging and supporting meaningful patient engagement.

Our Engagement Leader for the Fraser Valley region, Jami Brown, held a learning café in May where she shared some key tips about storytelling with a group of patient and health care partners. This workshop was developed at the request of patient partners who had been asked to share their health care

journeys at conferences, committee meetings and other events.

During this fun, interactive learning opportunity, participants learned practical storytelling skills while also meeting and gaining insights from other PVN members. The workshop sought to build confidence and help patient partners tell their stories in ways that are impactful and influential.

After the workshop, Jami collected feedback on the content so we can continue to improve our offerings and help more patients, families and caregivers share their stories and inform improvements in the BC health care system.





Over the last
12 months, 347
new patient
partners joined
PVN, bringing
our total to 980!

Diversifying Our Membership

NEW CONNECTIONS AND PARTNERSHIPS

Authentic patient engagement requires involving patients with varied experiences and backgrounds in all health care conversations. Another of our strategic priorities is featuring a diverse range of voices that are representative of BC's communities.

Since our inception, we have been collecting demographic information to ensure that our membership is inclusive of all groups across cultures, ages, and gender identities, and represents the population in British Columbia.

In recent years, our Oversight & Advisory Committee identified a number of populations that were underrepresented in PVN, including young adults, Indigenous peoples and men. Over the last year, we increased our efforts to connect with these groups and encouraged all patients, families and caregivers to participate in improving our health care system.

Engagement Leaders strengthened relationships with Indigenous Elders and advisors to improve our outreach strategies to Indigenous communities, and to increase cultural awareness within the health care system. In addition, we visited colleges and high schools to partner with students and increase awareness about our opportunities.

While we have made progress in recruiting patient partners from these underrepresented groups, we understand the importance of increasing the diversity of our patient partners and will stay committed to developing a membership that includes voices of all backgrounds, experiences and ages as we move forward.

This year, we've increased recruitment of youth and working age patient partners. Over 45% of new patient partners were under 50 years of age!



Case Study: Recruiting Young Adults

In order to reflect the diverse population of our province, it's important that health care partners involve a wide range of viewpoints in health care discussions. One underrepresented group that we sought to recruit this year was young adults.

Our Engagement Leader for the Interior region, Carol Stathers, partnered with two nursing students from the University of Victoria at Selkirk College to explore how we could include the voices of young adults in the Interior region in the Kootenay Boundary Collaborative Service Committee initiatives.

The team conducted engagement and research-based work. These efforts resulted in 20 new volunteers, 15 of which have already completed orientation by April 2018! The project will continue to run in 2018/19 under two new nursing students, with Carol offering support and guidance.

The group identified a number of factors that contributed to their success, such as developing in-person relationships with new volunteers, encouraging health care partners to provide flexibility in their projects and using electronic means of communication for participation. New learning from the project will be compiled into a resource for health care partners to help them diversify their audience and recruit young adult patient partners for future engagements!

Figure 7: PVN PATIENT PARTNERS BY GENDER

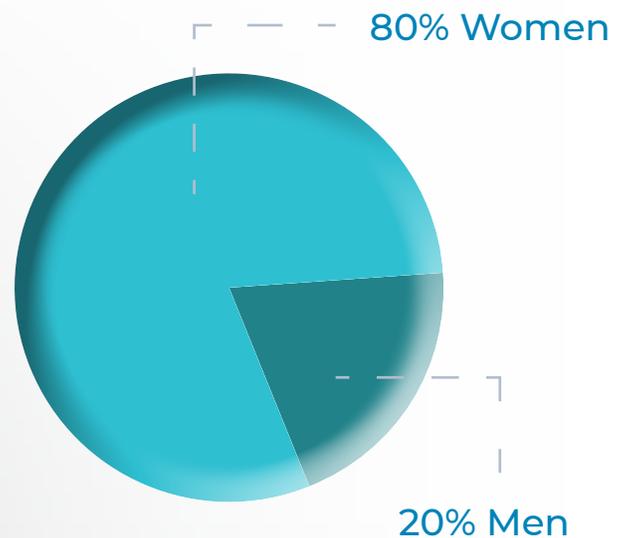


Figure 8: PVN MEMBERS OF SPECIFIC GROUPS



Building Connections in Our Community

Throughout the year, we continued to grow our network through digital communications and community outreach. We are always looking to connect patient partners to each other, and to health care partners. Additionally, we seek to create new partnerships with diverse health care organizations to support their patient engagement efforts and feature a wide variety of engagement opportunities across the health spectrum.

OUTREACH ACTIVITIES

PVN attended and led a wide range of community outreach events, such as conferences, community events, health and resource fairs, wellness events and networking coffees, to build local connections, foster bonds between patient and health care partners, and recruit new members to PVN.

FACEBOOK

Our Facebook group provides a place for patient and health care partners to connect, share experiences and discuss their ideas for improving BC's health care system. It also gives PVN members a constant connection to each other and patient engagement efforts, fostering a larger sense of community. This year, the PVN Facebook group grew to over 170 members (almost 20% of our network)!



Case Study: Partnering with BC SUPPORT Unit

Last year, we furthered our partnership with the BC SUPPORT (Support for People and Patient-Oriented Research and Trials) Unit, a multi-partner organization created to support, streamline and increase patient-oriented research throughout British Columbia. The BC Unit is one of 10 SUPPORT Units established across the country as part of Canada's Strategy for Patient-Oriented Research (SPOR) led by the Canadian Institutes of Health Research.

We are committed to improving health care systems and practices, and patient-oriented research is one method that will help to achieve this goal.

To support this partnership, we launched a special section of our website to showcase SPOR opportunities. The goal was to help clarify patient-oriented research and support patients as partners in research. A special symbol (bottom right) was created to highlight engagement opportunities with the BC SUPPORT Unit and to make these opportunities easier for patient partners to locate and get involved in.

To date, PVN has supported patient partners' participation in over 25 engagement opportunities with the BC SUPPORT Unit!



Looking Ahead

While we are very proud of the accomplishments of the network over the past 12 months, our goal remains to build the capacity of our partners so person- and family-centred care becomes the foundation from which all health care decisions are made. As strong, passionate champions for advancing the patient voice, we will continue to work on supporting authentic patient engagement, increasing the capacity of our patient and health care partners, and evaluating the impact of PVN activities.

We will continue to grow our network, focusing on groups that have historically been underrepresented in our membership. These efforts began in March 2018 with the development and release of new health care partner resources to support recruitment of young adults and improve cultural diversity in patient engagement opportunities. We will also work to support our current members by offering more learning opportunities, skill-building workshops and educational resources.

Our membership has done so much to increase awareness around the importance of authentic patient engagement, and we see many exciting opportunities in our future. We look forward to working together, building new partnerships and continuing to support our partners in improving BC's health care system.

If you would like to get involved as a patient or health care partner, please visit our website at PatientVoicesBC.ca.





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

Mail: 201-750 Pender St W, Vancouver, BC, V6C 2T8

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