

# First Annual Report

## April 2011

# PATIENTS AS PARTNERS

## Nothing about me without me!

INTEGRATED PRIMARY AND COMMUNITY CARE



BRITISH  
COLUMBIA

The Best Place on Earth



## Contents

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- 03    **Introduction**
- 04    **Who Delivers Patients as Partners?**
- 05    **How do We Work?**
- 06    **What Guides our work?**
- 07    **Highlights from the past year in the  
three Charter areas**
- 08    **Individual Health Care**
- 10    **System Change**
- 11    **Bringing in the Community**
- 12    **Lessons Learned**
- 13    **Moving forward into 2011**
- 14    **Provincial Committee Goals for  
Next Year**
- 15    **The Partners**
- 16    **Leadership is also provided by the  
Integrated Primary and Community  
Care Steering Committee**

# PATIENTS AS PARTNERS FIRST ANNUAL REPORT: NOTHING ABOUT ME WITHOUT ME!

Patients, families, and caregivers are partners in health care when they are supported and encouraged to:

- ✓ participate in their own health care
- ✓ participate in decision making about that care
- ✓ participate at the level they choose
- ✓ participate in quality improvement and health care redesign in ongoing and sustainable ways





# INTRODUCTION

Patients as Partners (PasP) is both a policy and a philosophy of the British Columbia Ministry of Health which was first outlined in the 2007 Primary Health Care Charter. In 2008, the ministry showed its commitment to moving this forward by creating a leadership position, the director of Patients as Partners, based in the ministry's primary health care branch.

The unofficial motto of this work is “nothing about me without me.” The principle that patients should always be partners in health care stands at the centre of PasP work. Of course, the word “patient” is itself a bit complicated. Sometimes people prefer words like ‘client’ or ‘service user.’ We use this word to include the patient, the caregiver, the family and loved ones who all experience the use of the health care system; and when we use the word ‘caregiver’ we mean family and friends, not medical professionals. Patients, their families, friends and caregivers have a unique perspective on the health care system that is different from that of the provider, health care worker or administrator.

Patient engagement offers real benefits. Studies show that patients who are more engaged in their own health care have better health outcomes, are safer and have an improved experience of care. Providers report an improved experience in care delivery when they work with patients at the centre of care and the system itself saves money when people are healthier and safer. Patient care is improved when a single patient feels more knowledgeable about their health and can communicate with his/her doctor. Including the patient voice helps create an entire health care system that puts patients at the centre.

PasP is currently focusing attention on integrated primary and community care, a plan to establish a community-based health care system in which teams of health care providers work together to support patients, families and caregivers as full partners in health. The result will be a system that more effectively meets the needs of frail seniors, mental health, substance use conditions, patients with chronic diseases and women during pregnancy and childbirth. These services could include more timely access to primary care physicians or home care. This will require cooperation between different health care providers to ensure that patients have access to all the services they need and to be strong partners in their own care.

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<sup>1</sup> Picker Institute “Best Buys” [Invest in Engagement](http://www.investinengagement.info/PublicEngagementBestBuys). March 7, 2010  
<http://www.investinengagement.info/PublicEngagementBestBuys>

<sup>2</sup> Charmel, P & Frampton S. “Building the business case for patient-centered care: patient-centered care has the potential to reduce adverse events, malpractice suites and operating costs while improving market share.” *Healthcare Financial Management* Mar. 2008, Feb25, 2010  
[http://findarticles.com/p/articles/mi\\_m3257/is\\_3\\_62/ai\\_n24942366/?tag=content;col1](http://findarticles.com/p/articles/mi_m3257/is_3_62/ai_n24942366/?tag=content;col1)

# WHO DELIVERS PATIENTS AS PARTNERS?

Patients as Partners is a philosophy promoted by the Ministry of Health, with the work accomplished through organizations and agencies in the community. PasP is guided by a provincial committee comprised of patients, involved organizations and agencies. Examples include the five regional health authorities in B.C. that manage hospitals, provide community services like home care, run residential facilities and multiple other services to support community well-being and health. Academic institutions also promote PasP through their influential research and preparation of professionals. Community-based organizations (also known as non-governmental organizations) are often organized around a particular issue and work to educate and advocate on behalf of patients, their families and their caregivers. The General Practice Services Committee (GPSC) is a collaboration between the BC Medical Association (BCMA) and the Ministry of Health (MoHS) and they work together to improve primary care for British Columbians. The GPSC has endorsed PasP as an underlying theme for their work. The Shared Care Committee, a committee of GPSC and Specialist Services Committee is committed to involving patients in all aspects of their work.

This report is intended to celebrate the early work of the PasP initiative and its partner agencies. PasP is brought to life through their work and the work we do together.

*"It has made me aware of my thinking. It's got me thinking about how I think, act and live my life and that change is possible. It doesn't have to be all or nothing. It can be small steps and that's really given me hope."*

—Patient, Bounce Back Program, Canadian Mental Health Association



## HOW DO WE WORK?

In order to create a health care system that is better for everyone we believe in the principles of Continuous Quality Improvement and collaboration.

When we use Continuous Quality Improvement we set aims and goals so we know what we are working on and why, create measures to make sure that our changes actually lead to improvement and we are never afraid to try something new. This way of working holds us accountable to the goals we set, but gives us the room to be bold and “start before you are ready.” Collaboration can only occur when everyone that has a stake in an issue is at the table. We know, from our own experience and from that of others, that having the patient voice, choice and representation present when talking about possible changes leads to creative ways of thinking and accelerates improvements.

We know that patients, providers and administrators sometimes have a hard time seeing exactly how they can all work together, but waiting until everyone understands completely could mean missed opportunities for learning together. We believe in starting right away and letting the value and importance of the patient voice become clearer and clearer to everyone in the system.

*“The session included participants from all of the stakeholder groups including Patient Advisors. Everybody seemed to be focusing on the same issue from different backgrounds, namely, the application of scarce resources to achieve maximum positive benefit for consistent and excellent health care.”*

–Anonymous, IPCC Initiative Fall Learning Session, Vancouver Coastal Health

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<sup>3</sup> The Picker Institute “Improving Patient Safety: Building Teams, Trust and Technology: Confronting the ‘Chassis Gap’ in American Health Care” New Visions for Health Care, Ideas Worth Sharing. March 08, 2010  
<http://174.120.202.186/~pickerin/wp-content/uploads/2010/06/Pt-safety-building-trust.pdf>

# WHAT GUIDES OUR WORK?

The work itself is guided by three improvement charters. An improvement charter is collaboratively developed by the group and clearly states the aim of the work being done, what we are trying to achieve and why it is important we do the work now. These charters help us all know we are on the same page and what we are working towards. The three charters for PasP cover the three ways our stakeholders see that patients and the health care system benefit from patients as partners.

- Individual Care – This work supports and improves the ability of patients to communicate clearly with their health care providers, to have the skills and knowledge required to manage their own health and to be supported to make healthy lifestyle choices. This work also teaches health care providers to communicate better with their patients by being sensitive to issues of literacy, culture and the need to have an empowered patient at the centre of care.
- System Redesign – There is a great deal of work currently being done to improve the health care system in BC. It is the intent of PasP that patient voices, patient experience, patient diversity and the patient perspective will help inform this redesign.
- Bringing in the Community – As changes are made in the overall health care system, each community will implement and experience them differently. Each community partner is working to improve care in the community they serve. Through the PasP focus the partners are ensuring that communities have a voice in deciding how care is organized and that the services address local needs.

*"I decided to share my Mom's story in the hope that the family voice will be heard and valued by all health care providers and that patient/family/medical team partnerships will become the norm in BC Healthcare, particularly for frail, elderly patients."*

*-Louise Donald, Community Engagement Advisory Network Volunteer,*

Vancouver Coastal Health



# HIGHLIGHTS FROM THE PAST YEAR IN THE THREE CHARTER AREAS

All of the partner organizations, agencies and authorities did amazing work over the last year, advancing the PasP philosophy and work farther and faster than we had dared hope for. Not every one of their initiatives and innovations can be fully represented here. Many do work across the spectrum of the three improvement charters. Many, such as the Ministry of Health and the health authorities, also partner with many of the organizations included here. This section is intended to celebrate the success of our collective work and share the scope of what is being done.

*"It is my hope that the transformation of our health care system will be an innovative, sustainable and patient driven system that makes sense."*

-Susan, Patient Voices Network, Vancouver Island Health Authority

# INDIVIDUAL HEALTH CARE

The Alzheimer Society of B.C. is working to ensure that support is available as soon as possible to those diagnosed with dementia and their families. Information, education and support can help dispel myths and ensure that isolation does not make the situation more difficult. The Society provides education to patients referred through family doctors using the First Link program and through proactive outreach to individuals and their families. The education program Shaping the Journey helps individuals and their families know what to expect and empower them to plan for the care they want.

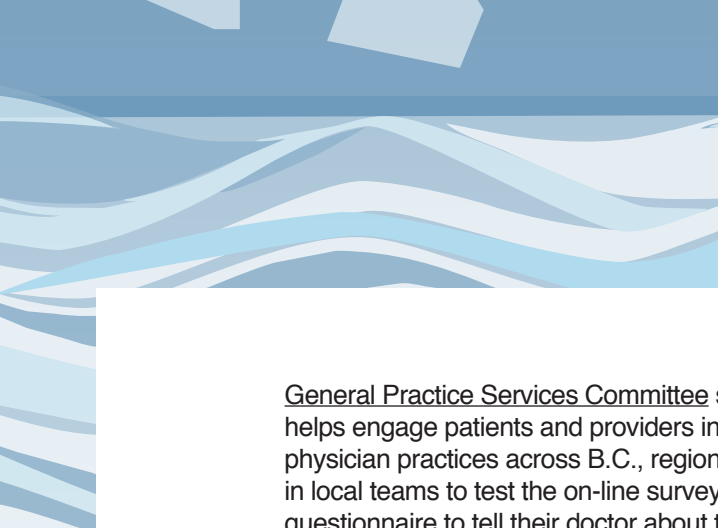
The Canadian Diabetes Association (CDA) sought the input of patients with diabetes to develop a new information and tool kit to give health care providers the best possible information and to empower patients to self-manage. The kits, one for the doctor and one for the patient, were distributed to over 49,000 health care providers. The patient kits were also given to people at risk who attended public diabetes education forums. The CDA collaborates with multiple community partners, ensuring it can reach the most people and help them take control of their lives and health. Over 3,000 people were taught food skills for families with more facilitators being trained so the impact next year can be even greater. The goal of all the programs they offer, from multicultural education to kids' camps, is to increase the confidence of patients to manage their diabetes.

The Canadian Mental Health Association BC Division runs Bounce Back, a program to help patients with mild to moderate depression work both with their doctor and on their own to re-claim their health. Trained community coaches provide telephone support and information to supplement advice and care from a family doctor. This guided self-help assists people in completing a plan to help improve their mood and understand the condition they are experiencing.

Family Caregivers' Network Society represents and supports the over one million individuals in B.C. that care for a friend, family member or loved one. They offer workshops and tele-workshops on self care, stress, navigating the health care system and how the caregiver can work as part of the health care team. By helping caregivers stay healthy themselves they provide a vital resource in ensuring that the patients can have their care delivered by someone they love.

*"Patients become advocates due to negative, sometimes tragic events [that] they or a loved one, have experienced. I am no exception. My adversarial stance has shifted to feeling that I am part of a group of dedicated people within the system working passionately for health care change."*

-Johanna Trimble, Patient, Patient Voices Network



General Practice Services Committee sponsored a test of [www.howsyourhealth.org](http://www.howsyourhealth.org), which helps engage patients and providers in health and office practice improvement. Fifteen physician practices across B.C., regional health authority staff and patient partners worked in local teams to test the on-line survey and tools. Patients completed an anonymous online questionnaire to tell their doctor about their health care needs and their perception of the quality of care they were receiving. As a result of this pilot, some physician practices improved office wait times, some improved their health care information to make it more understandable for patients and, some became more aware of the impact of financial circumstances on health. Doctors and patients are continuing to use [howsyourhealth.org](http://www.howsyourhealth.org) in B.C.

The Intercultural Online Health Network (ICON), a program of the Faculty of Medicine at the University of British Columbia, has been working since 2007 to ensure that culturally appropriate self-management support is available on the Internet for Aboriginal and multicultural patients, families and caregivers in B.C. They provide tools and workshops in multiple languages using the latest in self-management information and health care research, using plain, non-scientific language. Hundreds of community members attend forums, both in person and online, to receive self-management information in their own language as well as using the language specific websites they host. ICON regularly uses feedback from participants to improve their programs and services

Pain BC educates and engages those living with chronic pain and those providing their health care. They also advocate for a greater understanding in general of what it means to live with chronic pain. Those living with chronic pain are central in the work of the organization and to the design of the programs they offer. This year they held their first public education forum in Prince George and used a patient focus group to develop their strategic plan. They advance the goal of patient-centred pain management at all levels of the health care system.

The University of Victoria Centre on Aging, offers a variety of programs aimed at increasing healthy living and reducing the risk of falls in seniors. With a goal of having self management programs accessible to every British Columbian, the Centre also holds a peer-led chronic disease self-management program in communities across the province. Last year, the Centre surpassed its goal of having its self management programs accessible to 75% of British Columbians and its internationally recognized programs are now available to 86% of the population. The Centre also offers training to assist doctors and other health professionals to better at support patients in managing their own health.

Provincial Health Services Authority is supporting Impact BC to build capacity for mapping the patient journey in 14 prototype communities across the province. Using a train-the-trainer approach, participants are taught to work through the steps and process of mapping the patient journey and plan for change based on the findings. The goal of this initiative is to provide the tools necessary to guide and sustain the integration of primary and community care in each of the regional health authorities. Within PHSA, family representatives from the Partners in Care Family Advisory group at BC Children's Hospital are actively participating in planning discussions to ensure that the design of the new hospital facilities being built on the site of BC Children's and BC Women's will be customer focused.

# SYSTEM CHANGE

Interior Health is involving the patient voice to develop a three-year plan to change the delivery of diabetes prevention and management services across its region. A number of communities are undertaking patient journey mapping, which brings together patients and providers to create a “map” of all the steps involved in being a patient with a particular concern. Interior Health is mapping the experience of patients with diabetes to see how care can be improved. Patient experts are also being sought to sit on the working group to turn what they learn into improved care for all patients with diabetes across Interior Health. They are also using patient expert advice to assist them in distribute provincially-developed information and resources for families with children who have diabetes.

The Patient Voices Network (PVN) was created last year to support the PasP work across the province. PVN is a mechanism to recruit, train and support patients and their caregivers to participate in suggesting changes that may benefit the health care system. There is an online, virtual network of interested patients who receive updates and complete surveys to inform improvement work. The activated network consists of trained patient experts who are able to sit on working groups or committees, participate in focus groups and multiple other processes to help ensure the patient voice is guiding change in B.C.

The Practice Support Program, an initiative of GPSC, provides education to family doctors to help them improve patient care. One program is group medical visits, which are like classes for multiple patients who all need the same health care education. At a learning session in Nelson, one patient spoke about his experience with group medical visits from a patient perspective. This perspective helped doctors understand how group medical visits benefit patients.. He was able to answer questions and help the doctors feel more confident about trying this technique for patient care.

Shared Care aims to improve the coordination of patient care to improve health outcomes and help ensure a smooth flow of patients from primary to specialist care. The committee uses focus groups of patients to gain the patient perspective. In addition, projects across BC aim at improving specialist referrals from primary care include patients on their advisory groups. This has proven invaluable, in framing the needs of patients and ensuring that changes made keep the patient at the center of the discussion.

*“Everybody wins.”*

–Karen Archibald, Mission Healthy Community Council

The Vancouver Coastal Health’s (VCH) strategic direction is guided by a people first lens which means that, where possible, patients should be treated as they wish to be treated and patients, families, caregivers and communities should be involved in shaping services. To this end, VCH has a dedicated community engagement department which recruits, orients and supports the citizens that sit on advisory councils or committees as well as holding public consultations to inform how VCH develops, runs and evaluates its programs.



## BRINGING IN THE COMMUNITY

Established by GPSC, Divisions of Family Practice are groups of family doctors working to improve primary care in their communities. The provincial Divisions team works with every Division across the province to understand the value of bringing the patient voice into improvement work. Divisions are encouraged to contact the Patient Voices network to find out which volunteers are trained and supported in their community and who may be interested in participating.

Fraser Health partners with every municipality in its region to form healthier community partnerships and work with communities on the health issues they identify as most important to them. These projects range from supporting citizens and governments to develop informed policies that promote a healthy city to assisting with healthy living or chronic disease awareness forums. Both Fraser Health Authority and its municipal and community partners are committed to hearing and responding to the voice of the community.

*“It is important that more patients get involved in their own health care and the decisions that will affect how health care is delivered in BC.”*

–Pearl, Patient Voices Network, Vancouver Island Health Authority

Northern Health is holding “Let’s talk about Primary Care” forums in communities across its territory to engage its citizens. In the communities where Northern Health is working to re-design and integrate aspects of primary care, patients will sit on the committees to help establish what is best for their area. Sometimes the patient perspective needs to be more specific, which is why Northern Health brought patients and providers together to create a “map” of all the steps involved in accessing mental health

services in Mackenzie. Providers then knew exactly what it is like to navigate the health care system and can make improvements based on the patient perspective.

Vancouver Island Health Authority (VIHA) actively seeks patients and to participate in designing how services are delivered to them. VIHA regularly solicits the opinions of patients and families to ensure health services are meeting the needs of the community. They seek the patient and family voice in quality improvement activities at facilities like the Comox Valley Nursing Centre, the Ladysmith Community Health Centre and the Health Point Care Centre in Victoria.

# LESSONS LEARNED

Collaboration is key Collaboration is at the core of all the work you see in this report. Patients collaborate with providers and organizations collaborate with each other. What we know is that the health care system is incredibly complex. There are so many moving parts and ways of thinking about the system that improvement will require everyone from every perspective to work together and learn from each other. There are many ways we already communicate with patients or the community, but real collaboration is different. It means understanding the issues and building the improvements together and it can only come with a respectful, trusting relationship. PasP is working to re-enforce the culture of collaboration, which seeks the input of all partners.

Change is hard Our work of seeing that the patient voice is included all the time in every way – Nothing about me without me – isn't yet complete. Sometimes people – be they, patients, doctors, administrators or government officials – are just not certain how to begin. Sometimes medicine thinks of patients as passive recipients of care and making them an active partner is a very different way of thinking. Sometimes organizations think that what they do is too complex for a patient to understand and recognizing the value of the patient perspective is a big shift. Sometimes patients choose to be passive recipients of care and may lack the confidence to become engaged. The health care system has always worked to improve, but it often improved itself for its own ease, from its own perspective doing 'for' patients vs 'with' patients. This is changing in leaps and bounds, as you can see from the amazing work being highlighted here, but there is still a distance to travel till we get to "nothing about me without me."

Including patients is essential Care is made better when the patient voice is present and we partner together to make improvements. We know, from studies as well as from the experience of those groups represented in this report, that having a patient in the room when health care is discussed shifts the conversation and generates more innovative ideas. When doctors, for example, think about patient care, they generally think about it mostly from a clinical perspective. We know more perspectives make us more creative, so adding the patient voice and their life experience to that of providers and administrators can't do anything but help. Studies find that patients who work as part of team managing their health care, especially around chronic disease, are healthier than those that do not. A patient can be a fully informed and active partner – for their own care, for their community and for the improvement of the system.

Including system partners is essential Without a partner to share the journey we may never build understanding or influence behaviour toward change. Patient voice to improve IPCC is all about the power of partnerships and relationships. Patients can't receive health care or services without providers. Providers can't deliver care without patients.



## MOVING FORWARD INTO 2011

As PasP and its partners move forward into the next year we will all continue to put into practice the principle of “nothing about me without me” as best we can. Some of us will work with health care providers to build common understanding of how to help patients manage their own care or have a voice in plans to improve the health care system -- to support them to authentically engage with patients. Others will help prepare patients to be proactive in their own health care through self-management techniques or by engaging with their community or with the system itself. Still others will be the ones able to sit in the rooms with patients and providers, listening to and learning from the perspectives of all. It has been an amazing year; we have surprised ourselves with how far we have gone in such a short time. There is no reason to think next year won't be even more inspirational, especially with the patient voice to guide us as a partner in care.

*“We don’t always need to look for traditional medical goals, but instead need to understand the patient goals. Look what’s meaningful for a person. This required a paradigm shift for me as a doctor because that’s not always how we’re trained.”*

-Dr. van Wyk, Patient Self-management Program

# PROVINCIAL COMMITTEE GOALS FOR NEXT YEAR

Over the next year, the provincial committee will focus on four ways to advance these charters. The provincial committee will:

- Create a clear vision for PasP work in redesigning integrated primary and community care in B.C. that is accompanied by expectations, timelines, measures, support and guidance. We will do this through work plans with clear responsibilities and goals.
- Raise awareness about PasP philosophy throughout B.C.. We will do this through developing and sharing an annual report to celebrate our successes and what we've learned and by leading the hosting of an International Patients as Partners Workshop here in B.C.
- Build capacity in organizations and citizens to be engaged in the primary care in B.C. We will do this through supporting the development of the skills among providers and administrators needed for patient engagement and supporting patients to enhance their self-management or advisory skills.
- Create a consistent sustainable measurement strategy and tools. We will do this ensuring that patient experience and patient confidence is at the centre of what we measure and work towards.
- Enhance the options for patients, families and caregivers to be proactive partners in care through the delivery of evidence informed self-management programs and services.

*“When it was first suggested to include patients at the MD advisory committee of the Partners in Care project at Providence, a concern was raised over how their presence would change the dynamics of the room. It was thought that the members of the committee would not open up and that the patients might be a distraction. In fact, their presence did change the dynamic...the meetings became patient focused.”*

– Health care provider, Patient Voices Network interview



# THE PARTNERS

## Patients as Partners Provincial Committee membership:

- B.C. Medical Association
- B.C. Ministry of Health
- B.C. Patient Safety and Quality Council
- Canadian Mental Health Association
- Family Caregivers' Network Society
- Fraser Health
- Impact BC
- Interior Health
- Northern Health
- Patients, families and caregivers
- Provincial Health Services Authority
- University of Victoria Centre on Aging
- Vancouver Coastal Health
- Vancouver Island Health Authority

*"But having witness[ed] the patient's voice in a number of situations, I would not proceed without having them in the room. It has completely changed my way of thinking and doing business."*

—Health care provider, Patient Voices Network interview

# LEADERSHIP IS ALSO PROVIDED BY THE INTEGRATED PRIMARY AND COMMUNITY CARE STEERING COMMITTEE

**Many organizations are contributing to advancing the agenda including:**

- Alzheimer Society of B.C: [www.alzheimerbc.org](http://www.alzheimerbc.org)
- The Arthritis Society – British Columbia/Yukon [www.arthritis.ca](http://www.arthritis.ca)
- B.C. Lung Association: [www.bc.lung.ca](http://www.bc.lung.ca)
- B.C. Medical Association: [www.bcma.org](http://www.bcma.org)
- B.C. Ministry of Health: [www.gov.bc.ca/health](http://www.gov.bc.ca/health)
- B.C. Patient Safety & Quality Council: [www.bcpsqc.ca](http://www.bcpsqc.ca)
- Bounce Back (Canadian Mental Health Association): [www.cmha.bc.ca/bounceback](http://www.cmha.bc.ca/bounceback)
- Canadian Diabetes Association: [www.diabetes.ca](http://www.diabetes.ca)
- Centre on Aging (University of Victoria): [www.coag.uvic.ca](http://www.coag.uvic.ca)
- Divisions of Family Practice: <http://www.divisionsbc.ca/>
- Family Caregivers' Network Society: [www.fcns-caregiving.org](http://www.fcns-caregiving.org)
- Fraser Health: [www.fraserhealth.ca](http://www.fraserhealth.ca)
- General Practice Services Committee: <http://www.gpscbc.ca/>
- Heart and Stroke Foundation: [www.heartandstroke.com](http://www.heartandstroke.com)
- ICON UBC eHealth Strategy: [www.iconproject.org](http://www.iconproject.org)
- ImpactBC: [www.impactbc.ca](http://www.impactbc.ca)
- Interior Health: [www.interiorhealth.ca](http://www.interiorhealth.ca)
- Northern Health: [www.northernhealth.ca](http://www.northernhealth.ca)
- Pain BC: [www.painbc.ca](http://www.painbc.ca)
- Patient Voices Network: [www.patientvoices.ca](http://www.patientvoices.ca)
- Practice Support Program: <http://www.practicesupport.bc.ca/>
- Provincial Health Services Authority [www.phsa.ca](http://www.phsa.ca)
- Shared Care Committee: [www.bcma.org/partners-patients](http://www.bcma.org/partners-patients)
- Vancouver Coastal Health: [www.vch.ca](http://www.vch.ca)
- Vancouver Island Health Authority: [www.viha.ca](http://www.viha.ca)

*"A doctor on a steering committee I am part of said:  
you remind us why we're here."*

–Johanna Trimble, Patient, Patient Voices Network



**NOTES:**



**NOTES:**



