



bright spot

Organization: ImpactBC

Project Name/Title: *Patient Voices Network*

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Alliance (select one)

Consumer Engagement in System Redesign

About the Organization(s)

The Patient Voices Network (PVN) is a community of patients, families, caregivers and others in British Columbia (BC), Canada, who are using their experiences to influence change in the provincial health care system. There are over 1300 Network members committed to working towards better health care at the individual and the system level.

The Network is led by ImpactBC in collaboration with the BC Ministry of Health's Patients as Partners initiative. ImpactBC is a non-profit organization supporting health care improvement in our province, using evidence-based methods with a strong emphasis on the patient voice. Patients as Partners is a policy and philosophy of the BC Ministry of Health, first outlined in their 2007 Primary Health Care Charter. Its work is guided by a provincial committee and carried out through organizations and agencies in the community.

The guiding principle of Patients as Partners is that patients should always be partners in health care: collaborating with health care professionals to improve their own health as individuals, and having a voice in how health care is delivered in BC. In support of this, the PVN works with a broad range of partners including the Ministry of Health, BC health authorities, the BC Medical Association, the General Practice Services Committee, and many other non-governmental and community organizations.

Describe the problem or issue you were trying to solve.

It is well established that patient engagement offers real benefits – studies show that engaged patients have better health outcomes, while providers report an improved experience and the system itself saves money.

While the benefits were well understood and the commitment was present through Patients as Partners, there was no mechanism in place to link BC patients with the individual, program/service, and system levels of engagement defined in the Patients as Partners framework. In response, the Patient Voices Network was formed in 2009 to recruit, support, and match patients with engagement opportunities throughout the province, and support a learning health system where the patient voice exists at the heart of quality improvement.

Describe and explain your bright spot – the successful program, results, or processes.

In just under two years, the Patient Voices Network has grown into a thriving community of patients who work openly and collaboratively with health care partners towards a better system. There are 1300 patients in the Network, 366 of whom are “activated.” Activated patients participate in an orientation session and ongoing skill-building in areas like public participation, communication skills, and quality improvement. Since 2009 they have been matched with over 700 unique placements working with a diverse range of partners throughout the province.

This includes advisory committees, focus groups, improvement teams, conferences and many other collaborative opportunities with partners such as the Ministry of Health, BC health authorities, the BC Medical Association, the General Practice Services Committee, and dozens of other non-governmental and community organizations.

What were the greatest challenges? How did you overcome these?

Initially there were reservations from both patients and providers about the role of the patient. There was education necessary on both sides to emphasize the role of patient partner – a collaborative role – rather than an adversarial role often associated with a patient advocate. With the tremendous commitment of the Ministry of Health in bringing the Patients as Partners philosophy to life, there was soon a long list of success stories showing the value of the patient perspective, and the Patient Voices Network became recognized as a trusted resource for patients and providers alike.

As one of our health care partners told us, “When it was first suggested to include patients at an advisory committee, 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.” - Provider

Another major challenge, common to many non-profit organizations, is a lack of resources. As our patient registry grows, more staff time is required and operational expenses build. In the spirit of continuous improvement, we also work continually to engage less frequently heard voices and find meaningful ways to involve diverse communities, another difficult task to achieve with limited staff and financial resources. This is an ongoing challenge.

Describe the outcomes, value, results, impact of this project.

In just under two years, the PVN has grown to over 1300 members, 366 activated patients, and over 700 placements. From a trickle of placements in our early days, we are now managing multiple partners and several engagement requests per week.

After each patient placement, PVN staff follow up with both the partner and provider to assess whether the placement was a meaningful experience and determine feedback and learnings. Feedback is typically very positive from both parties: satisfaction ratings from providers are 100% and ratings are upwards of 80% for patients. Health care partners return to the PVN because they have confidence in the partner-patient match and the level of feedback our patients bring to their projects. Patients are proud to be part of the PVN as they have access to so many opportunities, with support, skill-building, and networking provided at every step in their journey.

In the words of some of our partners:

“Having witnessed 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.” - Provider

“Health care providers and government may be so focused on their own part of the system that they lose sight of the big picture. Through the Patient Voices Network, patients provide feedback and the policy makers are listening!” –PVN patient partner

As the only dedicated patient partner registry in Canada, we are also attracting national and international attention, having shared our experience with organizations like the Health Council of Canada, the Saskatchewan Quality Council, and the IHI (Institute for Healthcare Improvement) in the US.

“Ah-a” moment or lesson learned.

One of the most inspiring parts of our journey is seeing how touched and transformed patients become once they have had a meaningful experience as a patient partner. They are delighted to be part of the decision-making, and they contribute countless hours on a voluntary basis. Many people tell us that their experiences through the PVN have transformed their attitudes towards “the system” and given them hope. All of us – patients, providers, and staff – are inspired by how many people in BC are committed to a better system for everyone.

“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.” - PVN Patient Partner

How did patients, staff, or other affected parties react to the new program?

While there was some distrust and “nay-saying” at the beginning, we rarely see this today thanks to quality of patient engagement we’ve witnessed and strong champions at the Ministry of Health, the BCMA and BC health authorities.

The PVN provides extensive support and orientation to patients, emphasizing the partnership role and ensuring the patient placement is a good match on both sides. We continually emphasize that PVN is not an advocacy organization, but an opportunity for patients to partner in solving problems together with health care professionals.

Simply put, our track record of positive, meaningful, and valuable patient engagement experiences speaks for itself after two years of successes.

What advice do you have for others facing similar problems?

Patience. Changing attitudes is a slow process and patient involvement in decision-making is a major shift in our traditional thinking about health care. However, once providers have the opportunity to experience meaningful patient engagement, perhaps on a committee or conference, they quickly see the value and become advocates.

A second piece of advice is to make sure that patients understand the IAP2 Spectrum of Engagement from “inform to empower” and where each placement falls on the spectrum. This should be shared with the health care partners as well, to ensure a common understanding of roles, responsibilities, and intended outcomes.

What else do we need to know?

PVN places a strong emphasis on quality improvement and continually evolves to meet new challenges, needs, and demographics. In our third year, we will have a strong focus on skill-building and networking for PVN members in order to build their interest, abilities, and confidence. Some priorities for 2013 include outreach to Aboriginal communities, a face-to-face forum where PVN members across the province can meet and share stories, monthly teleconferences where PVN members talk about their experiences, informal “coffee chat” meetings at the community level, an interactive discussion forum, a monthly newsletter, and use of social media.

What is a bright spot? You do a lot of work-- a lot of great work, but a bright spot stands out because it made something happen. A bright spot isn't just the meeting or event or training session you held. It's when after that meeting or event, something changed. People DID something. Something got better. It isn't the just report you released; it's what that report sparked-- the change. It doesn't have to be a big change-- just a spark. It's the spark you know to throw fuel on, to see how bright it will become.

I understand that by submitting this Bright Spot, it may be used on AF4Q's website(s) or in materials, and that if selected, could be showcased at the National Meeting in May 2012.

Thanks for submitting your bright spot to Aligning Forces! Your bright spot will be assessed to be featured at the 2012 National AF4Q meeting in New Orleans, Louisiana. If selected, you may be invited to present on a panel, or asked to be in a video. Selected bright spots will be heavily featured by RWJF and AF4Q on their websites and in promotional materials.

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