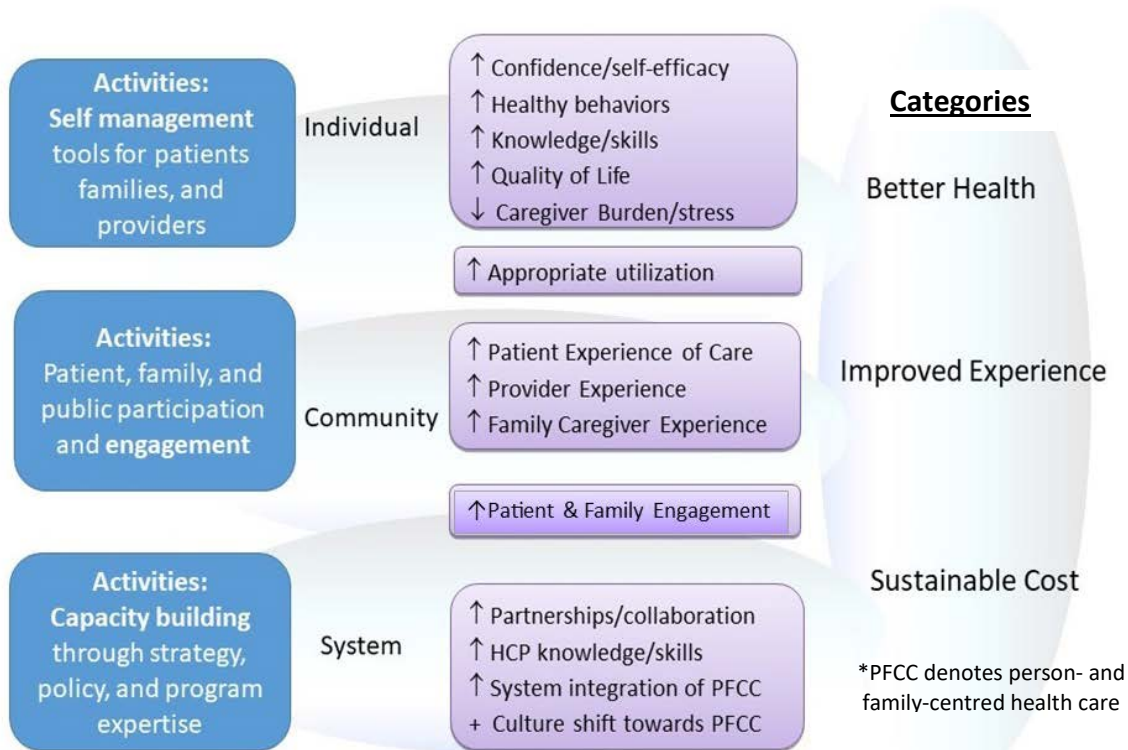


PATIENTS AS PARTNERS: COLLECTIVE IMPACT SUMMARY 2018-19

1 BACKGROUND AND OVERVIEW

The Ministry of Health Patients as Partners Initiative works in collaboration with non-profit organizations, non-governmental organizations and universities to provide leadership, tools and resources that help integrate patients' and families' voices, choices and representation into decision making to positively affect people's health and health system improvements. To that end, Patients as Partners currently supports six organizations ("funded partners") to engage patients and families, develop broader organizational capacity for person- and family-centered health care, and deliver programs that support self-management and engagement.

Beginning in 2016-17, Patients as Partners and the funded partners developed a collective evaluation framework to ensure quality, measure success, and demonstrate collective impact across the areas of work. Anonymous surveys were voluntarily completed following participation in events and services, either in-person or online. Across all six organizations, 1,666 participants completed these surveys. In addition, a total of 32 patients, family caregivers, health-care providers and staff participated in interviews and a focus group sharing their experiences and reflections on participating in Patients as Partners activities. The results are summarized by using in the Patients as Partners Evaluation Framework: Better Health, Improved Experience and Sustainable Cost.



Between April 2018 and March 2019, more than 14,000 patients, families, caregivers, health-care providers, and health administrators were reached through programs, services, and resources. In addition, the partners had nearly 500,000 web hits and over 75,000 newsletter/e-blast recipients. Resources were distributed to nearly 200,000 patients, over 115,000 caregivers, and over 325,000 staff and health-care providers.

2 COLLECTIVE IMPACT OF THE PATIENTS AS PARTNERS INITIATIVE

2.1 BETTER HEALTH

PATIENTS AND FAMILY CAREGIVERS GAINED KNOWLEDGE AND SKILLS FROM PATIENTS AS PARTNERS ACTIVITIES (INCLUDING WORKSHOPS AND COACHING SERVICES) WHICH IMPROVED THEIR HEALTH AND QUALITY OF LIFE.

Both patients and family caregivers increased their knowledge and skills in navigating the health system and learned how to make healthy lifestyle improvements (such as monitoring waist circumference and reading nutritional labels), manage stress and increase resilience. Chronic disease participants learned skills including how to develop and follow action plans, manage disease-specific symptoms, and prepare for medical appointments.

90% of patients and family caregivers (n=591) planned to make a change in their health behaviour/caregiving.

“My health and quality of life have improved through using the three main workshop activities: problem-solving, decision-making, and action planning. I use these activities on a daily/weekly basis.”

- Patient participant



2.2 IMPROVED EXPERIENCE

PATIENTS AND FAMILY CAREGIVERS FELT EMOTIONALLY SUPPORTED BY PATIENTS AS PARTNERS SERVICES.

“[The information and service provided] helped me emotionally put one foot in front of the other. It feels good to be supported and valued.”

- Family caregiver participant

Patients and family caregivers described how they felt emotionally supported and less isolated after their experiences were acknowledged and validated through support lines. This was especially appreciated by people living with chronic pain who had struggled to have their conditions recognized. Family caregivers also expressed how the support from Patients as Partners services encouraged them to take action on self-care to prevent or address burnout.

PATIENTS AS PARTNERS ACTIVITIES INCREASED CONFIDENCE AND SELF-EFFICACY IN PATIENTS AND FAMILY CAREGIVERS.

Patients and family caregivers report that Patients as Partners participation gave them “confidence, knowledge, and strength”. Participants report feeling empowered and better equipped to navigate the health system (“because of what I know, I know how to ask for it”) and “work with the system not against”. They also describe an increased activation and ownership over their own health. Additionally, their participation in Patients as Partners activities encouraged them in their health/caregiving journeys by affirming their experiences and decisions.

“Since I participated in these programs, I take better care of myself and understand I have a part in making myself feel better.”

- Patient participant

PATIENTS AS PARTNERS ACTIVITIES IMPROVED COMMUNICATION BETWEEN PATIENTS, FAMILY CAREGIVERS, AND HEALTH PROVIDERS.

“When I meet with a patient, I’m actively trying to pursue the patient’s health goals. I’m becoming even less paternalistic and more patient-centred... I am more effective in engaging patients in their care.”

- Health-care provider participant

Health providers described how training in collaborative conversation has positively impacted their practice. Health providers are now able to more effectively co-develop health plans with patients and family that are centred on patient priorities and goals, fostering patient resiliency and self-efficacy.

95% of health-care providers and health administrators (n=530) planned to make a change in their practice.

Patients report that they are learning how to be better prepared for medical appointments and how to communicate with health providers. Overall, Patients as Partners activities have led to better and more productive clinical relationships and empowered patients and family caregivers, ultimately improving patient and provider experience of receiving and giving care.

“Learning better communication skills, keeping track of issues, writing them down and bringing them with me to appointments means I can help health care providers use both theirs and my time better. If I’m prepared and take responsibility as a user of the health system, it works better for everyone.”

- Patient participant



93% of patients and family caregivers (n=655) felt more confident about working with health-care providers.

96% of health-care providers and health administrators (n=510) felt more confident about engaging patients and families in their health-care conversations.

2.3 EMPOWERMENT AND BUILDING BLOCKS FOR SUSTAINABILITY

PATIENTS AS PARTNERS ACTIVITIES BUILT CAPACITY FOR PERSON- AND FAMILY-CENTRED COMMUNITIES OF PRACTICE.

Through the Patients as Partners Initiative, health authority staff received train-the-trainer training in Brief Action Planning. Staff that have completed programs to become certified in training go on to train their colleagues in these collaborative communication skills. This has given trained staff opportunities to “*expand what they’re doing and really feel valued in their work*”. Impact of this work is made sustainable as trained staff take on the role of peer champions and equip the organization with capacity to train new hires in these skills.

By building trusting relationships with a wide network of partners, Patients as Partners has created a “*safe space*” to have otherwise “*difficult conversations*” on Indigenous health. Patients as Partners activities have facilitated meaningful knowledge sharing between Elders and diverse groups of health providers and staff. Event participants have subsequently shared their learnings with their colleagues.

Additionally, by bringing together like-minded professionals working towards person- and family-centred health care, Patients as Partners activities have boosted morale among the health services community. Upon reflection on his participation at a dialogue event that brought together health-care providers, staff, patients, and family caregivers, one General Practitioner felt encouraged by being able to connect with other individuals sharing similar values and perspectives.

“The most potent impact was that it reminded me that other people care about... getting together and talking and trying to innovate around how to improve our system as well... In the silo of being a GP... it gives you hope that you can keep going.”

- Health-care provider participant

98% of participants (n=1307) were satisfied with the program they participated in.

PATIENTS AS PARTNERS BUILT VALUABLE SKILLS AND CAPACITY WITHIN ITS ACTIVE VOLUNTEER COMMUNITY.

“Because I had to leave my job due to my medical issues, being able to facilitate these self-management programs have been a life saver for me. It allows me to be part of society beyond the walls of my home in which I spend a lot of time due to illness.”

- Patient leader participant

830 patient peer leaders, health-care providers, students, and community members contributed 26,566 volunteer hours.

Many self-management workshops are facilitated by Patients as Partners-trained patient leaders who were first involved in these workshops as participants. These patient leaders describe being able to improve the lives of other patients as very meaningful because of their lived experiences. Being actively involved as patient leaders instilled in them a sense of confidence and purpose and given them the opportunity to develop public speaking and group facilitation skills. Recognizing the value of accessing these self-management programs, patient leaders have taken on advocacy roles in their communities, sharing what they’ve learned and spreading the word with their health and social networks.

Volunteers (some aspiring health care providers) described the skills learned such as communication, active listening, demonstrating empathy, and supporting patients in meeting their health goals, as pivotal to shaping their understandings of person- and family-centred health care. These volunteers describe these experiences as potent in preparing them for their future practices.

3 SUGGESTIONS FOR IMPROVEMENT

1. **Engage key leaders:** Support from leaders was identified as crucial for sustaining the impact of initiatives. Ongoing effort from the Patients as Partners Initiative is needed to collaborate with key stakeholders to ensure change is sustained.
2. **Build capacity for broader and deeper patient and family caregiver engagement:** While patient/family caregiver engagement efforts both inside and outside of the Patients as Partners Initiatives were acknowledged, participants suggested that more resources and support would broaden and deepen engagement.
3. **Broaden scope of reach:** The Patients as Partners Initiative should reach more staff, patients, and family caregivers by raising awareness of their programs and services through more promotions and expanding initiatives to reach those experiencing barriers to participation, such as patients and family caregivers who may be less willing or able to attend these activities.

98% of patients and family caregivers (n=646) would recommend the program or service they participated in.

On a scale from 0 (extremely unlikely) to 10 (extremely likely), 81% of health-care providers and staff (n=524) rated their likelihood of recommending the program they participated in to their colleagues an 8 or above.

4 LOOKING FORWARD

- The Patients as Partners website at www.PatientsasPartners.ca has been enhanced with a more interactive calendar of free community events for the public that are provided by the funded partners.
- Additional engagement resources are being developed by Patients as Partners. These will provide additional best practice supports to those who are planning engagements or looking for person- and family-centred care resources.
- The Patients as Partners Initiative is also bringing in the community in alignment with the implementation of primary care strategic priorities and community health centre expansion.

FOR MORE INFORMATION

Visit our website: www.PatientsasPartners.ca

Visit our online Activity Calendar for Patients, Families and Caregivers: events.gov.bc.ca/PatientsasPartners

E-mail us at: PatientsasPartners@gov.bc.ca



5 FUNDED PARTNER PROFILES



The Centre for Collaboration, Motivation and Innovation (CCMI) is a not-for-profit organization based in B.C. that creates partnerships to improve health and well-being. They provide training, often train-the-trainer sessions, with follow-up quality improvement support. Training topics include: structured evidence-based self-management support techniques that help patients make concrete action plans to improve their health (e.g. Brief Action Planning and Motivational Interviewing); health literacy, informed decision making, working with diverse populations, and person- and family-centred care. For more information, see centrecmi.ca.



Pain BC is a collaborative non-profit organization comprised of people in pain, clinicians, researchers, and other supporters. Their services include the telephone-based Pain Support Line where volunteers connect people with chronic pain to existing local, provincial, or federal services; the Live Plan Be online self-management and peer support program for people living with chronic pain; pain management education; and fostering local chronic pain action teams and health sector collaboration including on opioid use disorder issues. For more information, see www.painbc.ca.



The University of British Columbia's interCultural Online Health Network (iCON) supports multicultural communities, patients and caregivers across B.C. to optimize chronic disease health literacy and self-management. They provide in-person and technology supported multicultural community education on chronic disease management; multicultural health resource development and dissemination; and knowledge sharing and partnership development with numerous multicultural, community, media and health care providers. For more information, see iconproject.org.



Delaney + Associates is a family business specializing in engagement, facilitation and communications. They provide: International Association of Public Participation (IAP2) certificate training, facilitation of patient and community engagement training, engagement training based on the Ministry's Patient, Family, Caregiver and Public Engagement Framework; and engagement planning and implementation for designated public engagements that support current Ministry priorities. For more information, see www.rmdelaney.com.



Family Caregivers of British Columbia is a provincial not-for-profit society dedicated 100% to supporting unpaid family and friend caregivers. They provide a 'hub' with supports, tools and resources that family caregivers can use to effectively carry out their caregiving role; caregiving educational sessions/information for family caregivers and health professionals; and caregiver engagement and health sector collaboration to focus on the systemic identification, support and inclusion of family caregivers as partners in care. For more information, see www.familycaregiversbc.ca.



University of Victoria Self-Management provides self-management and coaching programs for people experiencing chronic health conditions. These include the evidence-based peer-led Stanford chronic disease management, chronic pain, cancer survivor, diabetes and chronic disease self-management programs to patient/family caregiver participants; health improvement telephone coaching for patients; emails and newsletters to support patients who have received training; and self-management support training for health professionals. For more information, see www.selfmanagementbc.ca.