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Executive Summary

The B.C. Ministry of Health has a significant history of support for self-management, and patient, family and caregiver programs. The value of Patients as Partners, first introduced in the 2007 Primary Health Care Charter, has been reinforced in both ministry strategic planning documents and policy directions over the past two years.

The Ministry of Health, through the Patients as Partners Program has been funding, organizing and hosting an annual forum (also known as the Provincial Dialogue) for patients, health-care providers and community partners for a number of years. The Provincial Dialogue, a two-day annual event, was hosted in Vancouver in May 2015 and brought together the Ministry of Health, patient and family partners, health-care providers, and non-profit organizations from across the province. They learned about progress in Patients as Partners, patient- and family-centered care and self-management support. This report provides an overview of the process, content and outcomes of the dialogue, including ideas for Patients as Partners to consider in moving forward.

Presentations from a variety of partners highlighted innovative examples of patient and family centered care in B.C., as well as successful self-management support programs. Additional presentations included e-health and patient oriented research.

Thoughtful deliberation identified many ideas to move self-management and patient- and family-centered care forward. The areas of education, e-health, communication and access to information were more closely examined for emerging opportunities.

Some of the overarching themes for future direction included the need for consistent, standardized information including strategic materials about Patient as Partners, patient- and family-centered care, and self-management support. This may be achieved through the development of a centralized, accessible data location. Most significantly, participants overwhelmingly supported the continued inclusion of the patient voice at all levels of health care system decision-making.
Introduction

“My favourite part of the event was interacting with so many people who have a passion to improve the quality of health care for the citizens of this province.”

The Ministry of Health, through Patients as Partners, has been funding, organizing and hosting an annual forum (the Provincial Dialogue) for patients, health-care providers and community partners for a number of years.

The Ministry of Health Patients as Partners Provincial Dialogue hosted in Vancouver on May 14-15, 2015, brought together 166 diverse B.C. stakeholders. Ministry of Health staff, patient and family partners, health-care providers and non-profit organizations learned about progress in Patients as Partners, patient- and family-centered care and self-management support. Thoughtful deliberation focused on how to advance patient- and family-centered care through Patients as Partners, and included in-depth discussions of self-management support in alignment with the ministry’s change agenda described in its policy documents.¹

The alignment of self-management with a patient- and family-centred approach occurs at both strategic and operational levels. Since 2002, the B.C. Ministry of Health has supported a variety of patient self-management programs, and training for health-care providers to engage in self-management support in clinical practice. The ministry also has a history of patient, family and caregiver involvement through Patients as Partners, first outlined in the 2007 Primary Health Care Charter.² Patients as Partners work is guided by a provincial committee, with membership composed of representatives from the health authorities, health-care organizations, health-care providers, not-for-profit agencies, and patients, families and caregivers in the community. Leadership for the committee is provided jointly by both the Ministry of Health and health authorities through the Primary Health Care access branch.

Shortly after the 2014 release of the Ministry of Health document, Setting Priorities for the B.C. Health System³, the inaugural Patients as Partners Provincial Dialogue was hosted. The dialogue focused on building a definition for patient- and family-centered care, and identifying ways to increase awareness throughout the province. The information gathered was provided to the Province and other partners to inform this work.

In February 2015, the ministry released a number of policy papers building on previous work that defined a broad strategy and future direction for the B.C. health-care system. These policy papers identified important health-care priorities to help reshape the system to better meet the needs of patients and families. One of the documents, The British Columbia Patient-Centered Care Framework describes patients, families and caregivers as partners in care, and outlines several key components that patient-centered care incorporates, including self-management.⁴ The definition, goals and other components of the framework are in alignment and consistent with the work of Patients as Partners. In addition, the policy paper Primary and Community Care in B.C. highlights the importance of Patients as Partners.⁵

¹ Setting Priorities for the B.C. Health System, Ministry of Health, February 2014.
The patient-centered care framework is intended to build on current work in the B.C. health-care system and accelerate the adoption of patient- and family-centered care. This report provides an overview of the process, content and outcomes of the dialogue, including ideas for Patients as Partners to consider in moving forward with self-management and patient- and family-centered care. Both Patients as Partners, and patient- and family-centered care consider self-management support as a key component of the work. Finally, measurements collected throughout the dialogue reflect on its success and provide ideas for the dialogue next year.
Dialogue Overview

“I enjoyed learning about the many family and patient engagement activities and initiatives happening throughout the province, and contributing to their improvement.”

The 2015 dialogue provided an opportunity for participants to gain a deeper understanding of patient- and family-centered care and self-management support.

A working group was drawn from the Provincial Patients as Partners Committee and included the Ministry of Health, Self-Management BC, interCultural Online Network, Vancouver Coastal Health, Interior Health, Fraser Health, ImpactBC and patient partners from the Patient Voices Network. The group created an Improvement Charter that defined the following goals for the dialogue:

- Create a common understanding of the definitions and purpose of self-management support.
- Increase awareness of specific self-management support programs in British Columbia.
- Increase awareness of family and caregivers in self-management support and resources provided by Family Caregivers Network.
- Increase awareness about potential of e-health and e-patient and discuss innovations.
- Increase understanding of the impact of patient oriented research.
- Generate stakeholder input about gaps in care and innovations for self-management support.
- Identify possible future directions of patient- and family-centered care.

There was a total of 166 participants from B.C., representing government, health authorities and other healthcare partners, physicians, allied health professionals, patient partners, university and research organizations, and non-profit organizations. The participant breakdown is shown below:

![Attendees, by demographic chart]

- Gov't & Health Care Provider: 40%
- Patient Partner: 29%
- Not-for-profit: 16%
- University/Research: 8%
- Gov't & Health Care Provider: 40%
- Not-for-profit: 16%
- University/Research: 8%
- Patient Partner: 29%
The day and a half event built on the momentum from the patient- and family-centered care discussions in the 2014 Patients as Partners Dialogue, and provided an opportunity for participants to share their experiences from the past year with the core principles of patient- and family-centered care: dignity and respect; information sharing; participation; and collaboration. The program was supported by presentations from organizations represented on the Patients as Partners Provincial Committee including health authorities, patient partners, Ministry of Health, university partners and not-for-profit organizations.

Several innovative examples of patient- and family-centered care in B.C. were profiled, as well as an overview of self-management support followed by presentations of current self-management support programs in the province. Additional presentations included e-health and patient oriented research. These presentations set the stage for small group discussion on the status of self-management to identify opportunities for quality improvement. Building on the first day, topics (focused on how to advance patient and family centered care and self-management support with more specific action plans) were identified for deeper discussion on the second day.

A poster session displayed during the dialogue provided the opportunity for organizations to share their accomplishments in patient- and family-centered care or self-management support. In addition, the e-health Strategy Office from the University of British Columbia provided an e-health station where participants could explore how to safely select and use online applications to monitor their health.

The event was interspersed with interactive elements including opportunities to explore ideas at individual tables; reflect and share personal experiences with the four core principles of patient and family centered care on the “experience wall”; share feelings and attitudes on a communal “word wall”; and, provide instant feedback throughout the event using iClicker voting technology.

The dialogue was an opportunity for British Columbians to learn more about patient- and family-centered care and self-management support, how to access and support the spread of the ideas and services, as well as provide collaborative ideas about spreading these philosophies.
Experiences with Patient- and Family-Centered Care

The British Columbia Patient-Centered Care Framework identifies four core principles of patient-centered care: dignity and respect; information sharing; participation; and collaboration. The dialogue began with individual reflection on personal experiences with patient- and family-centered care over the past year, in relation to these core principles. Participants wrote their experiences on sticky notes, shared them in discussion at their tables, and posted them on an Experience Wall. The following are examples of experiences shared:

**Dignity and Respect**
“Mom was listened to by her home care worker. She mentioned it would be nice to be read to (she is blind) the next week this home care worker took 15 min and read to her.” – Family caregiver

**Information Sharing**
“I participated in an engagement with the College of Family Physicians and was truly amazed at the ability of physicians to listen intently to me when I had something to share. I have participated in a number of very powerful dialogues. Your [those in the room] leadership is going to change what happens in the health-care system. I know this because I’ve been profoundly affected because they [the patient partners] don’t seem to realize the impact they can have.” – Patient partner

**Participation**
“I work with children and youth and look at ways to listen to their voice; allowing them to engage and advocate for themselves. At a recent event For Youth by Youth, a group of youth showcased a video that they produced and acted in on how to prepare for becoming a patient at Children’s Hospital. They were participating and collaborating on advocating for themselves and for each other.” – Health-care partner

**Collaboration**
“I recently participated in an engagement where we developed practice guidelines to help staff assist mental health patients when goals don’t align with expectations of system. The work was a great example of collaboration, for me.” – Patient partner
Innovations in Patient- and Family-Centered Care

“I loved the balance of presentations and information sharing mixed with opportunities for engagement and dialogue.”

Within the past year, acute care settings have focused more intently on including patient- and family-centred care in their day-to-day operations. The dialogue was an opportunity to showcase how three acute care organizations are applying the principles of patient- and family-centred care.

Kelowna General Hospital
- **Butterfly** images– taping a butterfly image to a patient’s door provides a subtle way to alert hospital staff that a patient has died, is about to die or that a serious incident has occurred and the patient and family require sensitive engagement from hospital staff entering the room.
- **WOW** posters – a reminder to patients and staff that anyone entering a patient’s room should introduce themselves with Who they are, their Occupation, and Why they are at their bedside.
- **It’s OK to Ask** posters – let patients know they can ask clinicians and staff about areas of their treatment (e.g.- What is my health issue? What do I need to do? Why do I need to do this?).

Ridge Meadows Hospital
- **Family and visitor policy** encourages families and visitors to spend time with their loved ones while in hospital instead of only at specified hours.
- **Staff wear white scrub tops** to promote recognition of staff by patients and families.
- **White boards in all patient rooms** where care teams, patients and families use two-way communication.

Providence Health Care
- **Family Presence Policy** – “family” is defined by patients and are not viewed as visitors. Visitation hours are based on patient’s preference.
- **Human resources** engages patient and family partners on hiring panels and includes intentional questions about patient- and family-centered care.
- **Code Help** - a patient and family activated safety system staffed by clinical resource nurses who respond 24/7 to calls directly from patients and families regarding medical changes and the plan of care.
Self-Management Support in B.C.

Since 2002, the Ministry of Health has a strong history of supporting self-management programs. This support has been primarily directed to the delivery of evidence-based self-management programs for persons with chronic health conditions and training in self-management support strategies for health professionals.\(^6\)

The context for discussion about self-management support included a review of the definitions of self-management and self-management support in B.C., key principles, and evidence-based information. The Triple Aim to improve patient and provider experience, and improve population health at an affordable cost was discussed in the context of self-management support. It further reinforces the need for a patient- and family-centered care approach in health care.\(^7\)

**Definition of Self-Management and Self-Management Support**

Self-management relates to the tasks that a person must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management and emotional management.\(^8\)

Self-management support is defined as the systematic provision of education and supportive interventions by health-care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and problem-solving support.

Self-management refers to the behaviors that individuals engage in outside the health-care context while self-management support refers to how individuals are supported in their self-management goals and activities by health care professionals. Both self-management and self-management support embody patient- and family-centered care.

**Core Principles of Patient-Centered Care\(^9\)**

The core principles of patient-centered care can also be applied to self-management support. This includes:

- **Dignity and Respect** - active listening, and honouring choices and decisions by incorporating family values, beliefs and cultural norms.

- **Information Sharing** - communicating accurate and complete information, and validating what patients have heard and understood.

- **Participation** - encouraging/supporting patients and families in making decisions to their own comfort level.

- **Collaboration** - providing meaningful opportunities for patients and families to engage with care providers in quality improvement, policy and program development, evaluation, system redesign, professional education and delivery of care.

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\(^6\) [Self-management Support: A Health Care Intervention](https://www.ihi.org/engage/initiatives/tripleaim/pages/default.aspx)

\(^7\) Institute of Healthcare Improvement. [www.ihi.org/engage/initiatives/tripleaim/pages/default.aspx](https://www.ihi.org/engage/initiatives/tripleaim/pages/default.aspx)


Self-Management Programs

Presentations of self-management programs in B.C. that were funded through Patients as Partners during the year provided background for a broad exploration on the current state of self-management support. Each program highlighted the successful patient impacts. These programs included:

**BounceBack: Reclaim Your Health (Canadian Mental Health Association)**
- Provides easily accessible mental health supports for patients.
- As part of a stepped-care model, Bounce Back provides people with the least restrictive, resource intensive, expensive, and intrusive intervention. Research-based effective self-help is based on principles of cognitive behavioral therapy.
- The scope has expanded to include patients with mild to moderate depression, anxiety or worry.
- Patients have shown statistically significant improvement on all measures for depression, anxiety, quality of life enjoyment and self-rating of physical health after participating in the program.

**Chronic Disease Self-Management Program (University of Victoria)**
- Persons with chronic health conditions are recruited and trained to deliver self-management programs to other persons with chronic health conditions.
- Participants increase their knowledge and skills for better managing their own chronic conditions.
- A pivotal objective is to change people’s behavior.
- Patient impacts include better disease control, better health, improved quality of life, improved patient satisfaction and decreased health-care use.

**interCultural Online Health Network (iCON - University of British Columbia e-health)**
- Provides self-management programs for Chinese and South Asian communities in British Columbia.
- Brings health practitioners and community members together to share and learn about chronic disease prevention and management.
- The approach is culturally tailored and provides language appropriate health information through community outreach (in-person events, webcasts, online and print resources, TV, radio, video).
- Patient impacts include: 60% of participants made health lifestyle changes and 43% took action in the management of their own health.

**Brief Action Planning (Centre for Collaboration, Motivation, and Innovation)**
- A self-management support technique based on the principles and practice of Motivational Interviewing.
- Motivational interviewing aims to strengthen a person’s own motivation and commitment to change.
- People trained in Brief Action Planning and Motivational Interviewing reported that it helps them partner effectively with patients and frame the use of other tools.

**Family Caregivers Network Society**
- Self-management supports are provided to family caregivers to support them in the caring role and reduce negative impacts of caregiving on their health.
- The society provides education, caregiver support (individual support and coaching, information referral and navigation, support groups and a virtual resource centre), and collaboration and engagement in the health sector.
Following the presentations, discussion at each table focused on the successes and gaps in services related to self-management support. Thoughtful deliberations led to identification of many ideas to move self-management forward.
Emerging Opportunities for Patient and Public Engagement

The areas of e-health and patient-oriented research were introduced as emerging opportunities for public engagement and influence, with the potential to affect the future of patient- and family-centered care and self-management support in the province.

Increasingly, e-health is becoming a fundamental component of self-management. It also raises some interesting questions that may not arise with traditional access to health information including privacy concerns, information security, and health and electronic literacy.

Patient-oriented research has the potential to provide patient involvement in direct research funding and focus. In the context of self-management support, identifying and researching current self-management supports and areas that need greater focus or that have been neglected, are opportunities for increased patient involvement.
Moving Forward with Action

“I most enjoyed the “Deep Dive” work. This provided the opportunity to communicate with others for possible Patients as Partners next steps.”

The second day focused on exploring in greater depth four priority areas, as determined by the audience’s suggestions, (education, e-health, communication and access to information) and developing ideas for moving self-management support, and patient- and family-centered care forward in these areas.

Developing Action Plans
Facilitators for each of the four topics guided groups of participants through the following questions:

- What do we want to achieve in this priority area in the next year? And why?
- How can we work together to make these changes happen?
- Who else needs to be involved?
- What are the next steps you suggest Patients as Partners takes?
- How will we know a change is an improvement?
- What are the next steps you, personally, will take? And, who will you tell?

The intent of the exercise was to propose tangible actions, or first steps, that Patients as Partners may consider for improving self-management support, and patient- and family-centered care across the province. Suggested themes from the discussions are summarized below.

1. **Education about self-management and patient- and family-centred care**
   - Create a co-ordinated, central location for information about self-management support programs.
   - Increase patient engagement in development of resources and delivery of information.
   - Develop a communication strategy for disseminating information.
   - Create communication materials (e.g., script or booklet) related to self-management support and patient- and family-centered care.

2. **E-health support of self-management and patient- and family-centered care**
   - Develop a centralized location for e-health that includes:
     - A directory of e-health resources.
     - Education about e-health.
     - A list of credible sources.
   - Educate patients and health-care providers about what is available and how to access it.

3. **Communication about self-management support and patient- and family-centered care**
   - Develop a centralized location for patients and caregivers to access information about self-management support, patient- and family-centered care, and Patients as Partners.
   - Create and use consistent messaging.
   - Educate patients and the public about what resources are available and where they can be found.
   - Be aware of how different stakeholders access information (e.g., differences in culture, geography, age).
4. **Access to Information about self-management support and patient- and family-centered care**
   - Collect and analyze data on how and where people are accessing information.
   - Develop a communication strategy including key messaging, information kit and education campaign.
   - Develop a strategy for hard-to-reach populations to improve access.
   - Involve patients in developing the processes.
   - Promote what resources are available, where they are available and how to access them.
   - Create central hub(s) of information (by region/health authority).

The similar themes across all topic areas include:

1. Develop a centralized, accessible database for information relating to patient- and family-centered care, and self-management support.

2. Develop strategic materials for use by all partners to provide consistent information about Patient as Partners, patient- and family-centered care, and self-management support.

3. Continue to promote the inclusion of the patient voice in health-care system change decisions in all levels of the health-care system.
Measurement of Goals

Participants had two avenues to provide feedback on the dialogue: iClicker polling technology used throughout the event; and an experience survey available in hard copy and emailed to all participants after the event.

The iClicker technology provided instantaneous measurement of the content and materials delivered at the dialogue via remote clickers provided for each participant. Overall, the data collected by the iClicker system confirmed that the dialogue met the aims and goals set out by the planning committee. Results for the goals are reported below:

**Goal: Increased understanding of self-management support**
- 92% of participants understand the difference between self-management and self-management support.
- By the end of the event, 94% of respondents had a clearer vision of how patients/families/caregivers and health-care professionals can be engaged in advancing self-management support, compared to only 63% of respondents at the beginning of the dialogue.
- 83% of participants understand how patient- and family-centered care and self-management fit together.
- Compared to before the event, 85% of respondents were more inclined to work with Patients as Partners to advance self-management support and in British Columbia.

**Goal: Increased understanding of self-management support programs in B.C.**
- 85% or more participants have a clearer understanding of how each of the five self-management support programs presented use self-management support to improve patient outcomes.

**Goal: Increase awareness of family and caregivers in self-management support**
- 91% of participants have an increased awareness of the Family Caregivers Network Society, and resources provided to families and caregivers.

**Goal: Increase understanding of the impact of patient oriented research**
- Close to 80% of participants have a clear understanding of what patient-oriented research means.

**Goal: Increase awareness about potential of e-health and e-patient**
- 91% of participants have a clear understanding of e-Health and e-Patient.
- 81% of participants have a clear understanding of how self-management can be spread through e-Health.

**Goal: Opportunity to participate in discussion related to gaps in care**
- 96% of respondents had an opportunity to express their opinions or perspectives.

**Goal: Identify possible future directions of patient- and family-centered care**
- 100% of participants had an opportunity to participate in small group discussions related to gaps in care, and in larger group dialogue (world café format) identifying priorities for action. The themes/suggestions from these discussions were documented.
Participants were also provided a paper based and email survey to give additional feedback on the dialogue. Seventy-six participants (46%) completed the survey. Overall, 96% of respondents rated the 2015 dialogue as good or excellent and 93% would recommend the event to a colleague.

Respondents said that they most enjoyed networking, the dynamic and diverse group of presenters, the respect for time, and the balance between presentations and opportunity for discussion. The facilitator was also mentioned as being personable and inclusive.

Areas for improvement included both content and logistical elements. Suggestions ranged from providing presenter names and presentations prior to the event, reducing the number of topics/presentations, and allocating more time for discussion or networking. Other suggestions included lengthening the event to two full days, and increasing both the diversity of the activities and participants.
Conclusion

The Patients as Partners 2015 Provincial Dialogue was well attended, with representation from health authorities, government, physicians, allied-health professionals, patient partners, not-for-profit organizations, and university and research organizations. The event provided many opportunities for participants to engage in thoughtful dialogue on how to advance self-management and self-management support in British Columbia, as part of patient- and family-centered care.

Participants engaged in a series of conversations that progressed to action-oriented recommendations in four key areas: education; access to information; communication; and e-health. The dialogue contributed to an increased understanding of self-management and self-management support, and an understanding of how patient- and family-centered care and self-management fit together. The information collected in this dialogue will help inform Patients as Partners in setting future strategic direction, for moving forward patient- and family-centered care, as well as self-management support.

To all the participants of the dialogue, thank you for attending and being candid with your experiences and imagination.