

# Patients as Partners: 2019 Community Conversations

March 4, 2019 | Vancouver, B.C.



## Summary Report

*Patients, Family Caregivers, Community Representatives, Practitioners and Health Care Staff Coming Together for Meaningful Engagement*

## Background

This report provides a summary of key themes that emerged from the Patients as Partners Community Conversations event that was held in Vancouver, B.C. on March 4, 2019. Thank you to everyone who presented and provided their ideas – your voices have been heard.

Through the [Patients as Partners Initiative](#), the Ministry of Health funds, organizes and hosts an annual forum where 100-150 patients, families, caregivers, health care providers, health authority staff, community partners and non-profit organizations from across the province discuss topics that we jointly want to address. Previous topics included providing input into Ministry of Health strategic priorities and on how they believe health care organizations should be engaging patients and their families for health care improvement. Specifically, we have heard ideas for the Patients as Partners Strategic Plan; access to primary care; access to health care in rural and remote areas of the province; access to health care for urban Indigenous people; recommendations on how to improve person- and family-centred health care; self-management services offered to patients, families and caregivers in the community; and supports for health care providers funded by the Patients and Partners Initiative.

This year, the Community Conversations was a one-day event that brought together patients, families, caregivers, health-care providers, Ministry of Health representatives, health authority staff, community organizations, and health sector partners to provide information to participants based on input from last year's session, and provide an opportunity for meaningful engagement on the following topics that were selected from the themes recommended from participants at the last year's Regional Tables:

- **Empowering Patients and Building Trust in the Digital Age;**
- **The Need for Community Engagement;**
- **Person- and Family-Centred Health Care; and**
- **Engaging Chinese Communities in Healthcare Transformation.**

### Fast Facts

There were 111 participants:

- 5 health care providers and 50 health sector staff;
- 22 patient partners and 8 family caregivers; and
- 26 community representatives from a variety of community organizations around the province.
- Patient partners/family caregivers came from areas representing all seven health authorities.



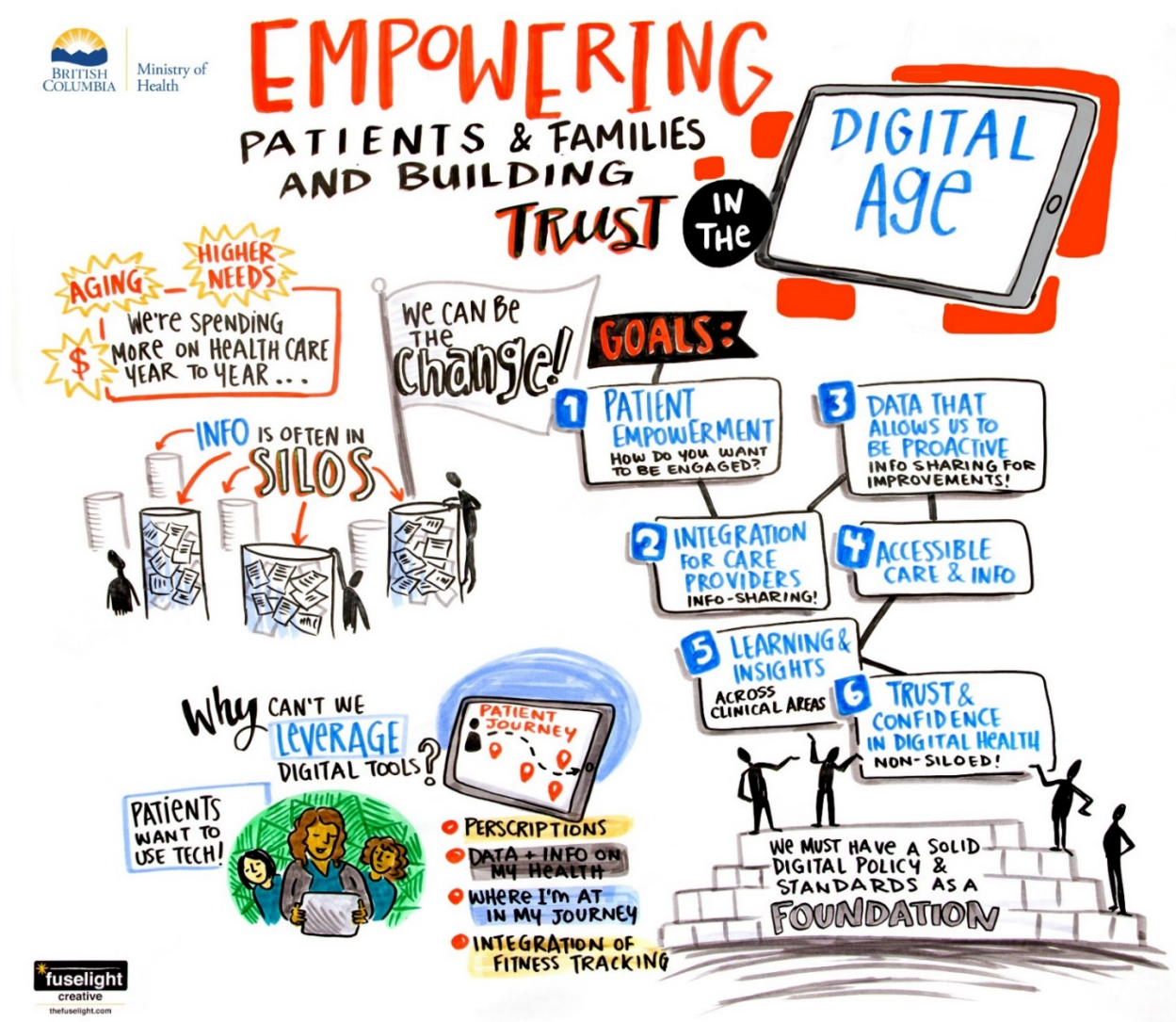
## Opening Welcome

Opening welcomes were provided by the Ministry of Health's Patients as Partners Initiative and an by an Aboriginal Elder. The story of the Elder, reminding us that we need to have an engaged community to be healthy, set the stage for a day of listening and engaging with each other.

## Session 1:

### Empowering Patients and Building Trust in the Digital Age

Ministry of Health staff in the Information Technology Branch provided information on the *Digital Health Strategy and Patient Empowerment* to all participants. A summary of the presentation is provided in the graphic image below. Participants then chose to provide their perspectives in one of two engagement sessions 1) *Information Sharing: Building Patient Trust in the Digital Age* and 2) *Patient Empowerment and Patient Portals*.



## Patient Empowerment and Patient Portals



The overview of the development of a provincial Digital Health Strategy described the imperative for digital transformation in the B.C. health sector. Ministry of Health facilitators explained how digital innovation and digital interactions within the health system can enable an integrated system of care and promote sustainability, improve care delivery, improve accessibility, and enhance patient and provider experiences.

Session facilitators led an activity to seek input from participants in their roles as caregivers, patients, community representatives, clinicians and healthcare administrators that will be used to inform Pillar 1 of the Digital Health Strategy: a priority around patient empowerment. Participants provided responses to the following questions:

### 1. What does patient empowerment mean to you?

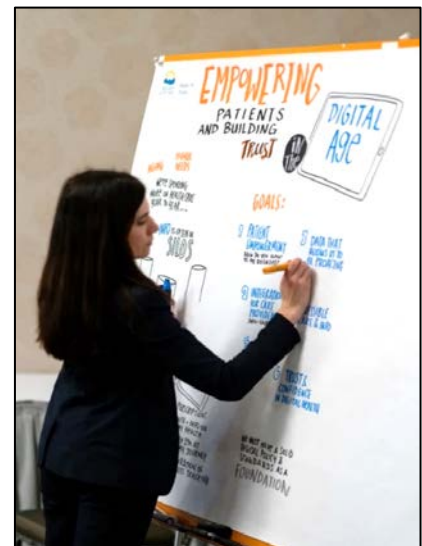
Participants said that patient empowerment was about patient control of their records and having adequate information and support to participate in their health care.

### 2. How do we build trust in the digital age?

Building trust in the digital age involves continuous, meaningful engagement, strong privacy and security controls, and equitable access to digital tools where connectivity might be sparse.

### 3. What does the patient portal experience look like for an engaged patient?

Based on the patient personas provided, participants believed that future patient portals will need to enable family members, support workers and caregivers to access patient records as delegates or proxies. Additionally, patient portals should support patients in understanding their health information with educational information, interpretations, support for other languages, culturally sensitive material and by exploring other formats for delivering information (audio, video, visual).



### 4. How do you use patient portals today and what would you like to see offered in future patient portals?

Patient portals could improve the relationship with their direct care team and assist patients in connecting to support groups, community programs, and a broader network of providers. In iClicker survey questions, participants expressed significant interest in using patient portals as an empowerment tool, especially to: view laboratory test results, discharge and specialist reports, book appointments, and communicate with their care providers.

## Information Sharing: Building Patient Trust in the Digital Age

Ministry of Health facilitators provided an overview of the information privacy policies and laws that govern personal health information in B.C., challenges of the current state, and the objectives of the future state. Namely, the future state would have a simpler and more useful set of information privacy rules for the health sector. The facilitators explained how technical innovation, including the Ministry of Health's Digital Health Strategy, presents an opportunity to modernize the rules that govern personal health information (PHI). The overall aim would be to enable digital health and protect patient privacy while meeting the overarching goal of supporting direct patient care, health system planning, and research.

Participants then discussed some information-sharing situations relevant in digital health. Participants provided responses to the following questions:

**1a. What is your comfort level with a patient's personal health information being shared digitally for health care purposes?**

Nearly all participants said they are comfortable with PHI being shared digitally. Specifically, 58% said they were very comfortable and 39% said they were somewhat comfortable.

**1b. Do you use a commercial device for tracking your own health/fitness (e.g., fitbit or AppleWatch)?**

57% said they use a health or fitness tracking device.

**2. How important do you feel it is for patients to be able to share their health record with people of their choosing (e.g., family, home support staff)?**

73% of participants were very supportive and 12% were somewhat supportive of having patients choose who they share their PHI with.

**3. How likely are you to support patients being able to add their information (e.g., home blood pressure readings) to their health record for their care providers to see?**

60% of participants were very supportive and 18% were somewhat supportive of being able to upload PHI to their own health records. However, some participants said that it could be burdensome for providers and the information's accuracy could be questionable.

**4a. Do you consider some patient health information to be more sensitive?**

While 88% of participants agreed that some PHI is more sensitive than others, there was less consensus on whether PHI should be treated differently.

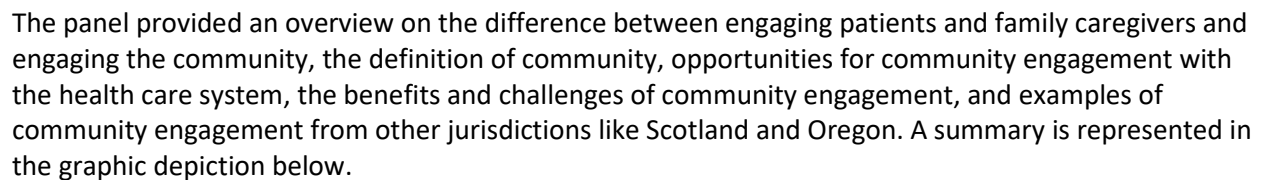
**4b. How likely are you to support sensitive patient health information being treated differently (e.g., restricted access to such information, limits on when it can be shared)?**

42% of participants were very supportive, 30% were somewhat supportive and 15% were not supportive.

**4c. Would you support the ability for patients to decide who can access their information or easily see who has accessed their health information and when?**

When asked to decide between supporting controlling access (e.g., masking records or blocking providers) versus providing transparency (e.g., allowing patients to see audit logs), participants were split: 42% supported patient control over transparency and 55% supported transparency over patient control.

The focus of the session was on the importance of engaging community, as well as individual patients and family caregivers, in developing an effective health care system and successful strategies for reforming primary and community care. The session was divided into: 1) a panel presentation and a dialogue with panelists; and 2) a table engagement activity on community engagement. The Ministry of Health invited the BC Health Coalition and individuals representing community-based social service organizations and population-based groups (e.g. indigenous, rural, newcomer communities) to share their ideas and perspectives and present in the panel presentation.



Participants then had the opportunity to engage with people at their table to identify the challenges and benefits of community engagement and strategies that would facilitate a greater role for community organizations. Overall, participants wanted to have an increase in representation of community organizations. Common themes that were identified during table discussions are summarized below.

### **Lack of trust**

Many participants identified lack of trust as a barrier, particularly among participant who may have had past negative history with some community organizations. Racial/cultural discrimination was highlighted as a particularly common theme.

Potential strategies identified for addressing lack of trust included educating communities on the benefits of participation and creating meaningful relationships to help build trust. The expected benefits of addressing lack of trust included stronger relationships and healthier and more untied communities.

### **Lack of health literacy or cultural literacy**

Many participants highlighted there is often not enough health or cultural literacy in community organizations. Further, cultural health practices are often not addressed or utilized at community events.

Suggestions for improving health or cultural literacy included communicating in plain language, providing more access to personal health information, and facilitating translation of health information (e.g. by Primary Care Networks). Overall, the expected benefit of increasing health and cultural literacy included allowing individuals to understand more of what is being discussed at community events and increasing demand for access to personal health information.

### **Barriers to access**

Participants noted that geographical location can be a challenge for individuals who live far from the community organization and that there is often a lack of funding and reimbursement for community members to participate.

Potential strategies for reducing barriers to access included increasing funding for partnerships, which in turn could lead to an increase in individual participation. Representation might increase through the use of Primary Care Networks, which would themselves benefit from the increased representation of different perspectives and opinions. Identified benefits of improving access included an increase in community engagement.

### **Communication challenges**

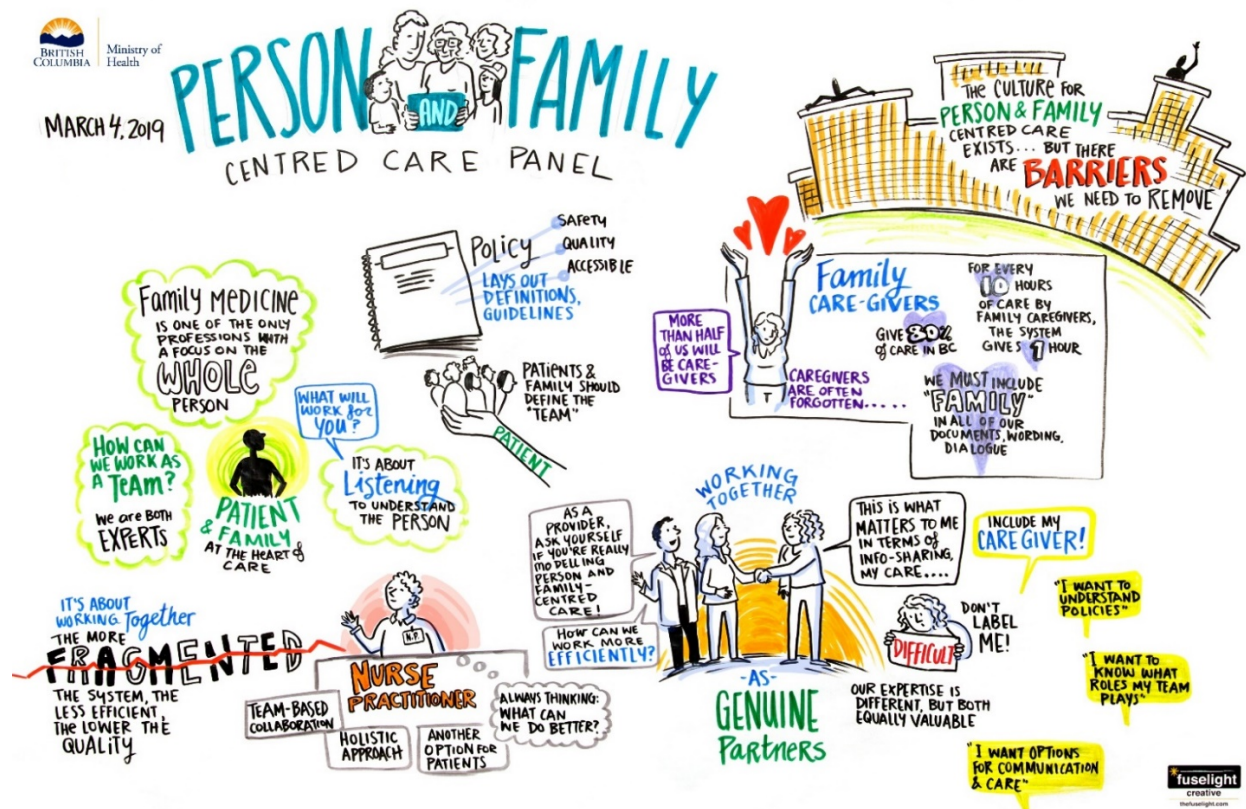
Several participants identified that there is not enough information promoting community organizations to the public and health care providers. Language barriers were also identified as a common challenge in community organizations.

Suggestions for addressing communications challenges included having a communication plan and ensuring proper planning, organization and coordination of community organizations. Participants also noted the benefits of using a range of media including the use of social media, focus groups and various other platforms. Identified benefits included that plain language communications and the use of translators allows everyone to understand and would make team-based care more efficient.

## Session 3: Person- and Family-Centred Health Care Panel

The objective of this session was to provide a variety of perspectives (family physician, nurse practitioner, patient partner, and family caregiver) on person- and family-centred health care and to receive input on the draft Person-and Family-Centred Health Care Policy.

The session was designed in two parts: 1) panel presentations from the Ministry of Health, a partner organization, a patient partner and other external organizations followed by a question and answer period and 2) a paired conversation among participants on a questionnaire about the draft policy. In the panel presentation, participants heard an overview of the patient-doctor relationship, team-based care and collaboration and partnerships and how these relate to team-based care; the role of nurse practitioners; and the role of family caregivers. A summary is represented in the graphic depiction below.



Themes and ideas that arose during participant conversations are summarized below.

**Person- and Family-Centred Health Care is about:**

- putting patients and families at the heart of care;
- listening and understanding the person to find what will work for them and what can be done better;
- a group of health care providers that work together in a coordinated and integrated manner with patients and populations to achieve health care goals;
- working together as genuine partners;
- building trusted relationships that lead to shared and better decision making; and
- team-based care and continuity of care that lead to more efficient care and healthier persons and families.

**Some of the potential benefits of person- and family-centred care discussed were:**

- accessible, acceptable, safe, efficient, and quality care;
- improved clinical outcomes and adherence to medications;
- improved patient and provider satisfaction; and
- increased health status and quality of care.

**Suggestions for working towards Person- and Family-Centred Care included:**

- adopting holistic or other methods of care;
- getting feedback from patients on how to make health care improvements;
- including family in all the documents, wording and dialogue (family caregivers give 80% of the care in B.C. yet tend to be forgotten); and
- giving patients options for communication and care.



## Session 4: Case Studies

### Engaging Chinese Communities in Health Care Transformation

This session thematically explored the question of how the health system could optimally engage multicultural communities in health care transformation through discussions of a case study of working with Chinese communities followed by a question and answer period. A panel discussed a case study that showed how multicultural patient engagement is supporting health care transformation in Richmond through partnerships between the: interCultural Online Health Network (iCON), Vancouver Coastal Health (VCH) Richmond's Primary Care Network and Palliative Care Initiatives.

Topics that were explored included: the need for coordinated, clear and accessible information; self-management and family caregiver support as part of a team-based approach to focus on wellness and patient empowerment; lessons learned from iCON's engagement with Chinese communities; and an introduction to the work of VCH's Richmond Primary Care Network and the Palliative Care Initiative in engaging multicultural communities in the development of services, including how the partnership with iCON can support and accelerate this work in the future.

A summary is represented in the graphic depiction below.



## Theme 1: Barriers to meaningful participation by multicultural groups

It was recognized that cultural minorities face additional barriers accessing and navigating health care services and information. Several barriers to accessing primary care services were identified, including:

- **Language:** Limited proficiency in English coupled with limited access to interpretation services.
- **Social isolation:** Some new immigrants lack a family or network to support them and experience social isolation. This sense of isolation is exacerbated by language barriers.
- **System navigation:** Limited awareness of existing health services and resources and knowledge of how to access them may be compounded by a lack of confidence to seek out and obtain services.
- **Cultural considerations:** Culturally-specific health-seeking and health-management behaviour may be a barrier to engagement if these factors are not known or considered by providers and program administrators, particularly for sensitive topics such as palliative care, which can carry stigma in some cultural groups.

## Theme 2: How can we better support/engage multicultural populations?

Healthcare providers, administrators and authorities can help reduce these barriers through thoughtful engagement and culturally-tailored education. Panelists discussed how it is important to approach cross-cultural interactions with humility where healthcare providers keep an open mind, and continually practice self-reflection in their efforts to cultivate collaborative, meaningful, and authentic relationships with communities. The panelists offered the following strategies to optimize multicultural engagement:

- **Partner with ethnic media to reach target population:** Media outreach can be a highly effective channel to reach different pockets of the community, promote dialogue, and serve as an education portal for the general population and seniors.
- **Introduce the concept of team-based care to multicultural communities and explore community readiness:** Primary Care Networks and integrated care across B.C. could be an excellent opportunity to develop and improve multicultural engagement in healthcare. Because cultural beliefs may influence patient and family conceptions of healthcare, it will be important to introduce multicultural communities to team-based care and empower them to effectively navigate new systems of care.
- **Work with community champions and respected leaders or peers in community networks:** Gather community perspectives through advisory groups, consultation sessions, or other means of seeking input and feedback to ensure cultural appropriateness of resources and implementation support. Partner with communities to create a vision, develop strategies, and undertake joint implementation.
- **Facilitate connections between patients, families, and health and social organizations:** Through partnerships with local health authorities and health and social organizations, provide platforms to connect patients and families with local resources and services.

While these best practices in community engagement are drawn from iCON's experiences with multicultural populations, it is important to continuously learn about cultural nuances, discern the differences between communities, and adapt these engagement principles accordingly in specific cultural contexts.

Throughout the session, participants used iClickers to answer the following questions, highlighting a keen interest in multicultural community engagement and the importance of continuing these conversations:

- 1. I am involved in an organization, program, or activity that needs to address issues related to multicultural populations.**  
89% of the participants said yes.
- 2. In your opinion, how important is multicultural patient and family engagement in your work?**  
65% of the participants thought it was extremely important.
- 3. I have a clear vision of how patients/families from multicultural communities can be engaged in health system change.**  
47% of the participants somewhat agreed with this.

During a question and answer session, participants expressed the importance of partnering with and listening to Indigenous peoples' needs, perspectives, and wisdom in health care transformation, as well as the need for sufficient Indigenous representation around the table to ensure they are equal partners to bring about change. Participants additionally identified the importance of learning about the communities we are engaging: their history, culture, and origins.



## Input on Themes for Next Year's Event

At the end of the day, the participants had an opportunity to network and, in line with the tradition at previous Patients as Partners' events, provide recommendation for themes for the next year's event.

Two recommended themes were:

- How to reach/support very poor and/or disabled populations.
- The role of the volunteer within hospitals and patient care facilities and patient-centred care.

A further suggestion for improvement was:

- More patient and family voices on the panels.



In the evaluation survey, 100% of participants said they strongly agreed or agreed that they were satisfied with what they learned at 2019 Community Conversations.

*"Interesting speakers and topics. I am so pleased to have been invited to this event, to share and exchange thoughts and ideas and to network with so many amazing and inspiring individuals. I particularly enjoyed the discussion around the need for Community Engagement."*