

Patients as Partners

2014 Provincial Dialogue Event Summary

March 31, 2014



Table of Contents

Executive Summary	2
Introduction	3
Method	4
Patients as Partners: What have we learned and how can we improve?	6
Opinions on Progress	6
Increasing Diverse Voices	7
Measuring Impact	8
Patient-Centred Care: Creating meaningful positive impact on health system quality improvement efforts.....	9
Conclusion.....	12
Appendix A: Provincial Dialogue Committee Membership	13
Committee Members	13
Appendix B: Provincial Dialogue iClicker Questions Results	14
Day 1	14
Day 2.....	16

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Executive Summary

On March 13-14, 2014, 126 people from 30 communities across the province, met in Vancouver to reflect on recent Patients as Partners successes and to help shape a deeper understanding of what patient-centred care could become as it takes an integral role in supporting the B.C.'s health system priorities.

This report describes the collective wisdom, which emerged from the two-day event. It provides insights into what has been achieved, and how the evolution of patient involvement in health system change can be improved. Important ideas about ways to strengthen the patient-centred care definition as it becomes embedded in provincial policy were also described.

Participants describe seeing an increase in opportunities for patients, caregivers and families to participate in health system change efforts and that they feel respected and valued. Improvement opportunities include increasing the spread of engagement opportunities to the acute system and beyond, building strategies to increase participation from diverse populations, and embedding a robust measurement system to evaluate the benefits of patient, family and caregiver engagement.

Event participants supported the presented draft definition of patient-centred care and encouraged the B.C. Ministry of Health to consider using language in the definition that accentuates the active participation of patients, their families and the communities in which they reside. Participants also requested that the definition use plain language that translates well within the many cultures served by the health system.



Introduction

In February 2014, the B.C. Ministry of Health released a document outlining strategic goals for the B.C. health system. The goals include supporting the health and well-being of B.C. citizens, delivering a system of responsive and effective health care services for patients across B.C., and ensuring value for money. A key priority woven through these goals is the importance of patient-centred care. It is positioned to help shift the culture of health care towards being patient and wellness-focused and away from being disease and provider-centric.

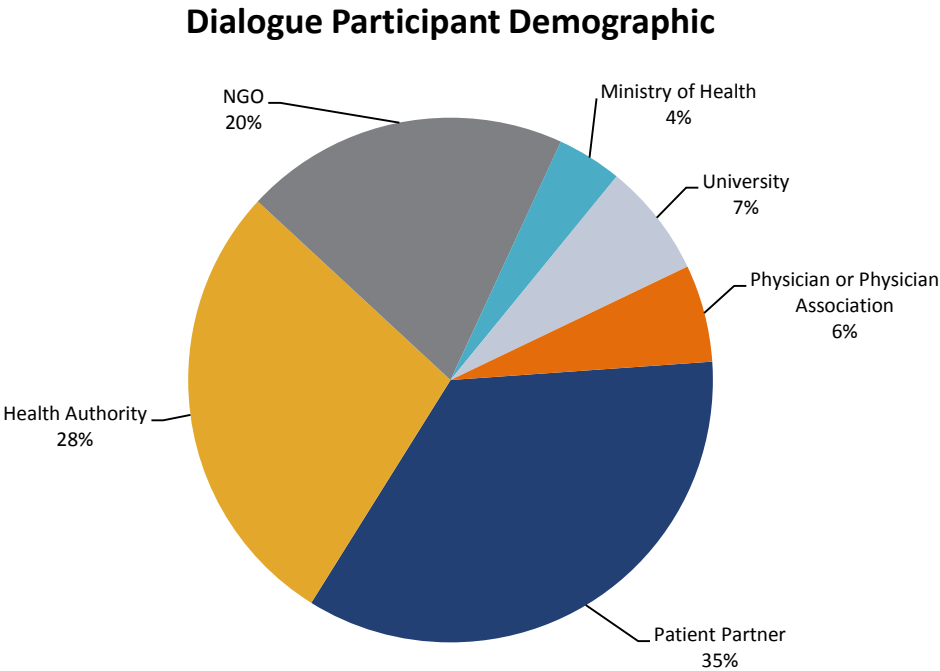
British Columbia has a robust history of civic engagement, including patient and family involvement in health system change efforts, most recently accentuated by a successful provincial policy focused on promoting patient and family involvement in all aspects of their personal care planning, health system planning and provincial policy development. Under Patients as Partners, the B.C. government promotes increased patient, family, and caregiver involvement by ensuring the Ministry of Health funded strategies include patient perspectives in their health system change improvement work. One highly visible enabling strategy of this work is the development of a program called Patients as Partners|Patient Voices Network, a network that supports skill building and placement opportunities for patients wishing to participate in health system change processes.

On March 13-14, 2014, 126 people from 30 communities across the province, met in Vancouver to reflect on recent Patients as Partners successes and to help shape a deeper understanding of what patient-centred care could become as it takes an integral role in supporting B.C.'s health system priorities. This report describes the collective wisdom that emerged from the two-day event. It provides insights into what has been achieved, how the evolution of patient involvement in changes to the health system can be improved and important ideas about ways to strengthen the patient-centred care definition as it becomes embedded in provincial policy.



Method

Event participants were selected through an existing network of the Ministry of Health, health authorities, joint collaborative committees, associations, universities and programs that support patient, family and public involvement in health policy development. In total, 126 people from 30 communities throughout B.C. attended the two-day event. See below for the diagram of participant demographics of the groups represented at the event by percentage.



The event agenda was collaboratively designed by a planning committee that included patient, government, university and health authority representation (see Appendix B to review the agenda and committee member names). An integral element of the agenda included developing the content for the second day by reflecting on what emerged through the first day of dialogue. Consistent with the planning process, patients were involved in this process.

Event dialogue and summary notes form the basis for this report. This report provides a description of what transpired as participants came together to discuss a variety of questions.

The event summary is organized into two sections:

1. What have we achieved and learned across the province through the Patients as Partners agenda?
2. How can the Ministry of Health's focus on patient-centred care evolve to have a meaningful positive impact on health system quality improvement efforts?



Patients as Partners:

What have we learned and how can we improve?

Participant dialogue and notes highlight three key themes. These include: opinions on progress, increasing diverse voices and measuring impact.

Opinions on Progress

Event participants described a belief that patients have greater ability to engage with health system planners, yet there are opportunities for this to further increase. Patient participants described being valued and feeling respected when they were involved in health system planning initiatives. Some saw their perspectives integrated into the direction the work had taken.

While there are increased opportunities for patients, caregivers and families to participate in health system planning, participants also identified that these efforts are not evenly distributed across the health system landscape.

Significant attention has been placed on area of primary and community care and transitions across service streams. As efforts to involve patient and family voices in health system changes continues, participants supported increasing their inclusion in acute, preventive and other service redesign processes.

“ Coming from a rural area, we often feel forgotten or like our issues are not considered... But I felt like I was able to bring that perspective, and that it was heard and honoured. This truly energized me and helped me to remain hopeful about the work I’m doing and the future of health care in our province. ”

Jo-Ann Tisserand,

integrated primary and community care facilitator, Interior Health

Increasing Diverse Voices

An impressive number of patients and families have participated in health system change processes since the establishment of Patients as Partners, including: University of Victoria's chronic disease self-management programs; University of British Columbia's Intercultural Online Health Network; Canadian Mental Health Association's (BC Division) Bounce Back program; and the Patients as Partners | Patient Voices Network.

Event participants described the importance of continued learning opportunities, strengthening the ways that culturally diverse and geographically located populations can participate and inform system improvement processes, and increasing the number of tools that are used to facilitate engagement.

With regard to increased learning opportunities, two areas were identified. First, participants valued increasing clinician and administrator awareness and support for patient, family, and caregiver involvement in the health system and helping them understand how to integrate their voice, choice and representation in their work. Secondly, participants appreciated the degree of patient and family orientation and support prior, during and after their placement in an engagement opportunity.

Throughout the event, participants requested that a more concerted effort towards engaging diverse and underrepresented populations be pursued. Recognizing that not all individuals can or choose to participate in traditional committee activities, participants described the importance of creating opportunities for locating flexible ways to reflect diverse perspectives.


Many participants described examples of patient and family involvement on committees, and through events that focused on patient journey mapping – an engagement technique that assists patients and families to describe their experiences of accessing health care services.

While this is a good start and not an exhaustive list of the ways that patients and families have been engaged with the health system, there is value in exploring how additional engagement tools could be used to create meaningful involvement opportunities for groups of people who have less ability to participate through traditional committee structures.

Measuring Impact

Consistent with event presentations, participants accentuated the importance of measurement. This included emphasis on process – how patients and families were engaged and the outcomes – and what difference their involvement made to the project with which they were involved. Participants also valued aligning these evaluation opportunities with existing measurement efforts currently underway across the province. One example that was highlighted was the Ministry of Health’s patient centered measurements such as Patient Reported Experience and Outcome Measures.

Given that patients, families and caregivers are engaged at the patient care planning, program improvement and provincial policy levels, attention to aligning evaluation efforts in order to provide a robust picture of patient and family involvement was seen as important.



“ I was excited to be able to lend my voice and experiences to the proceedings not just from a professional point of view, but mostly from a personal, human perspective... The report that comes out of the Dialogue will be a collage, a composite of all the voices and ideas. ”

Helen Novak Lauscher,

assistant director of research, UBC faculty of medicine,
eHealth Strategy Office

Patient-Centred Care: Creating meaningful positive impact on health system quality improvement efforts

The event began with an introduction to patient-centred care. The starting definition was generated through a literature review. Participants were informed that patient-centred care is used to describe numerous related concepts but has no universally accepted definition.

Patient-centered care is about engaging the hearts and minds of those you work with and those you care for. It is about reconnecting staff with their passion for serving others. It is about examining all aspects of the patient experience and considering them from the perspective of patients versus the convenience of providers. Ultimately, it is about a collective commitment to a set of beliefs about the way patients will be cared for, how family will be treated, how leadership will support staff, and how staff will nurture each other and themselves.

Additional core concepts were shared with participants:

- **Dignity and Respect:** Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing:** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.
- **Participation:** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration:** Patients, families, health care practitioners and leaders collaborate in policy and program development, implementation and evaluation; in health care facility design; in professional education; and in the delivery of care.

Participants also learned that the Change Foundation in Ontario (www.changefoundation.ca) conducted a series of focus groups to get a better understanding of the patient experience. The following elements of patient-centered care emerged:

- ▶ Comprehensive care
- ▶ Co-ordination of care
- ▶ Time
- ▶ Continuity and stability
- ▶ Functioning e-health
- ▶ Respect
- ▶ Fairness
- ▶ Convenience
- ▶ Timeliness
- ▶ Empathy and understanding
- ▶ Clear and reliable communication

Additionally, participants learned of the Institute for Family Centred Care's seven important factors in achieving patient centred care at the organizational level.

These include:

1. An engaged senior leadership.
2. A clear strategic vision.
3. Patients and families involved at many levels of the organization.
4. A supportive work environment.
5. Systematic measurement and feedback.
6. A quality built environment.
7. Supportive information technologies.

Drawing from this information, participants engaged in dialogue about how this information resonated with them and were encouraged to share ideas that could strengthen the patient-centred approach in British Columbia.

Participants described the concept of patient-centred care primarily as a philosophy. When adopted, patient-centred care would form a basis for how a person acts and communicates. The audience suggested, to achieve patient centred care, a number of specific goals and strategies could be established. Overall, the majority of the presented information on patient centred care was supported by participants.

Event participants understand that the presented values and concepts define a patient-centred care approach, yet they struggle with the words "patient" and "centred." Some participants believe the term "patient" holds negative history or paints a picture of someone who is docile. They saw the power of patient-centeredness to be focused more on an empowered or an active person who participates with others to decide on their own care plan, or to shape quality improvements to the health system.

Terms generated during the event include "patient and family-centred", "partner-centred" and "citizen-centred." It was argued "citizen" as a term captured ideas of taking ownership of a system and being an active steward. While no term seemed to resonate with most participants, they encouraged

the evolving definition of patient-centred care to be flexible enough to accommodate the active role of patients, their families and communities.

“ I was inspired by the ideas and recommendations that came from all the participants.

It was great to work with a diverse group of people who all shared the common goal of improving health care in B.C. ”

Pamela Jessen,
patient volunteer,
Patients as Partners | Patient Voices Network

Participants also described an opportunity to expand the definition of patient-centred care approach to accentuate the importance of clear, consistent, culturally competent language that mirrors the populations that the health system serves. They described the importance of accentuating that all partners have something to learn from each other and that this learning experience will help strengthen respectful relationships. Lastly, participants consistently requested that they be informed in a reasonable amount of time as to how their information was used in decision-making processes.

Conclusion

The Patients as Partners event provided an opportunity for patients, administrators, clinicians and government representatives to learn from each other and help to foster a new phase in patient and family engagement in B.C.'s health system change efforts.

Participants measured their perspectives during the event through quantitative survey software (see Appendix D for a list of questions and responses). Results demonstrate a high degree of confidence that participants believe in the direction that patients as partners and patient-centred care are headed.

In addition, more participants believed that they had a stronger understanding of how patients, families and caregivers can be engaged in health system change efforts. Most notably, 81 per cent of participants stated that, as a result of attending the event, they were more inclined to work with Patients as Partners to advance the patient and public voice within the health system.

Consistent with best practices, participants were invited to a dialogue before any final policy was cemented. Participants provided feedback on how patient and family engagement has evolved in recent years, and provided suggestions on how to frame a collective understanding of patient-centred care. They are looking forward to learning how their feedback will be used in the development of a patient-centred care framework and additional opportunities to inform its development.



Appendix A: Provincial Dialogue Committee Membership

Committee Members

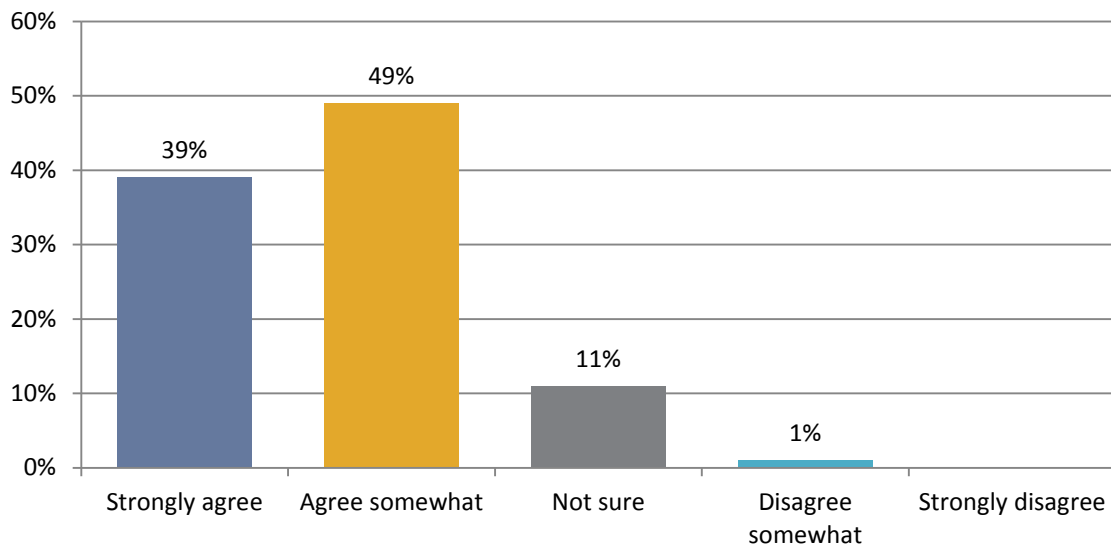
Patients as Partners Provincial Dialogue Planning Committee	
Caryl Harper, Ministry of Health (co-chair)	Marischal De Armond, De Armond Management
Diane Miller, ImpactBC (co-chair)	Paula Young, Fraser Health
Brian Evoy, isBrite Consulting	Regan Lal, ImpactBC
Cheryl Rivard, Vancouver Coastal Health	Susan Lanyon, patient partner, PasP PVN
Devon MacFarlane, Island Health	Sherry Bar, Ministry of Health
Helen Novak Lauscher, UBC iCON	Tanya Cromwell, ImpactBC
Kendall Ho, UBC iCON	

Patients as Partners Provincial Dialogue Working Group	
Brian Evoy, isBrite Consulting	Kendall Ho, UBC iCON
Caryl Harper, Ministry of Health	Marischal De Armond, De Armond Management
Diane Miller, ImpactBC	Regan Lal, ImpactBC
Helen Novak Lauscher, UBC iCON	Sherry Bar, Ministry of Health
Harriet Rogan, patient partner, PasP PVN	

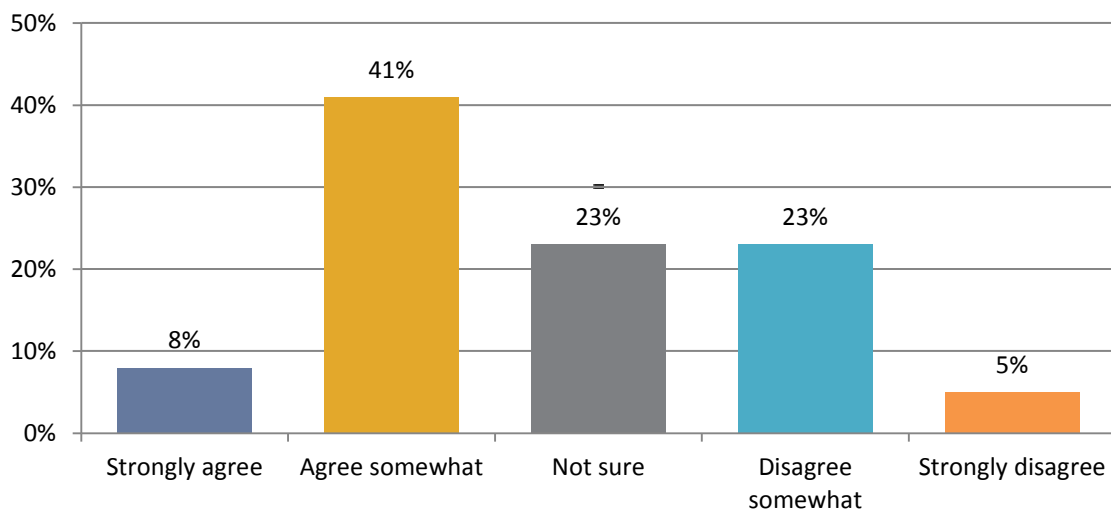
Appendix B: Provincial Dialogue | iClicker Questions Results

Day 1

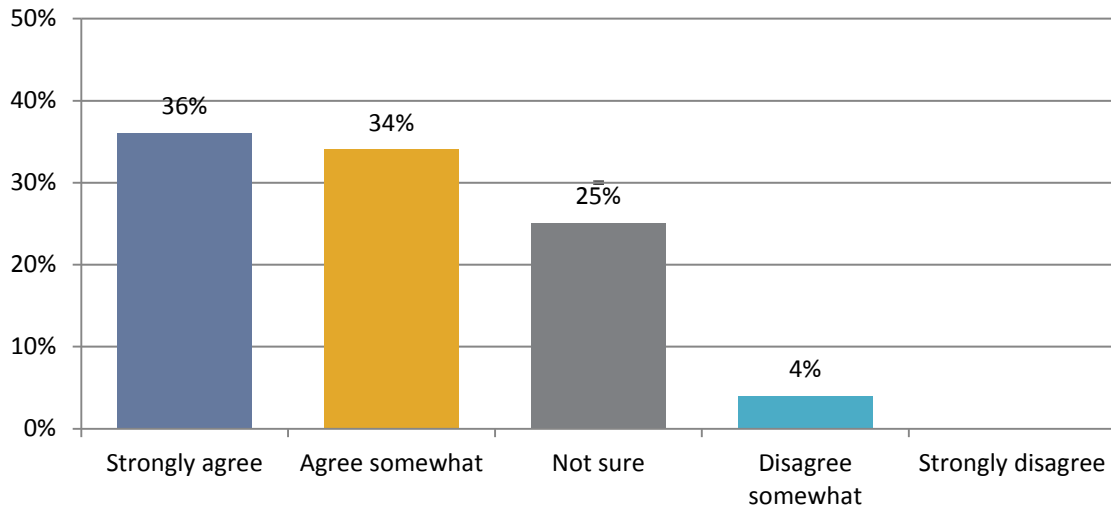
Q1: I have a clear personal vision of how patients/families/ caregivers can be engaged in health system change. (n= 108)



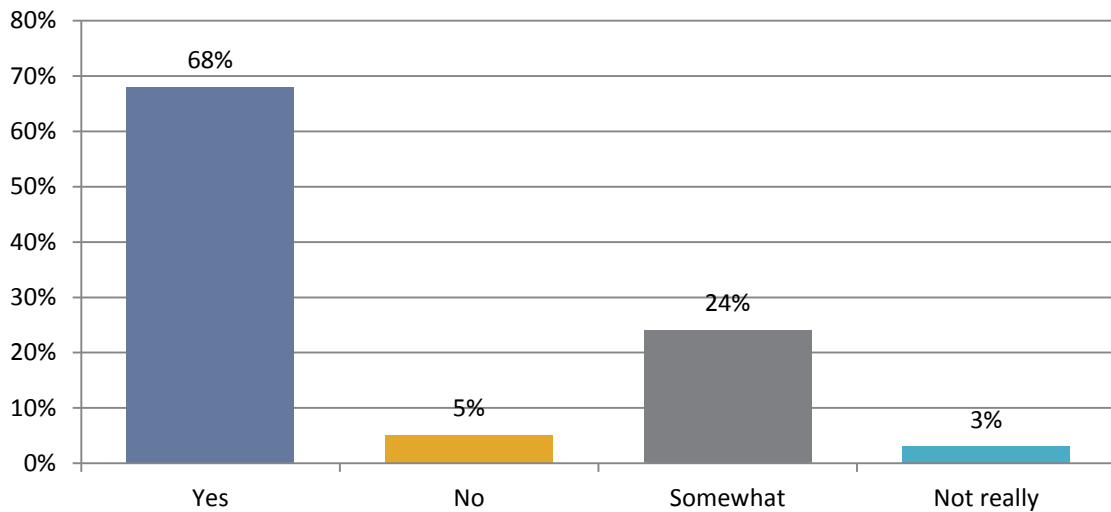
Q2: I have a clear understanding of the vision of the province of how patients/families/caregivers can be engaged in health system change. (n= 103)



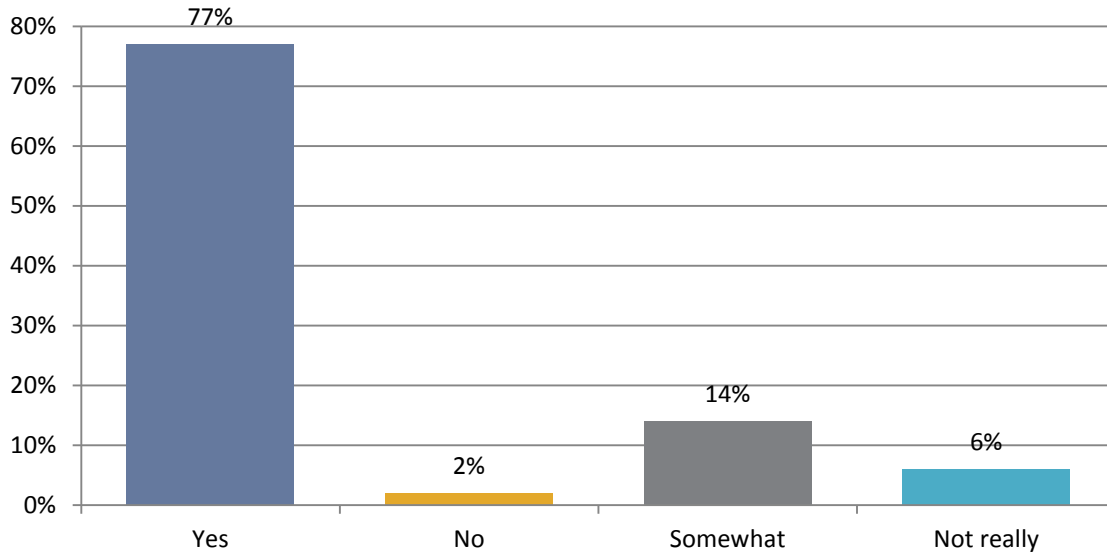
Q3: I am confident that the ideas I am going to share today will inform and contribute to future actions by the Ministry Patient-Centred Care strategic direction. (n= 96)



Q4: I gained insight into at least one point of view very different from my own today that has made me change my thinking in some way. (n=88)

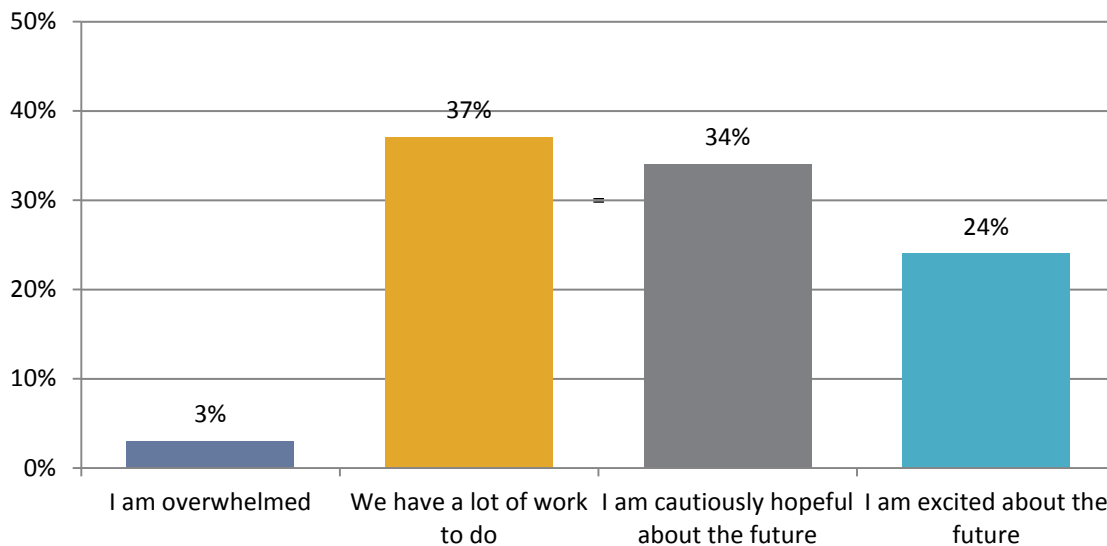


Q5: I have gained insights from attending this event and I will use it to further our common patient-centred agenda. (n=87)

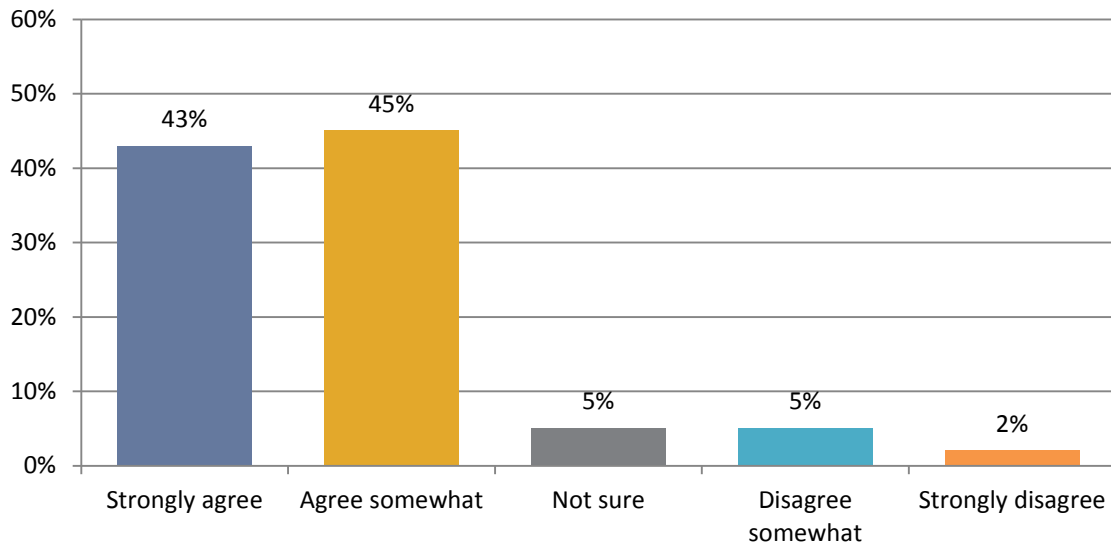


Day 2

Q6: Which of the following BEST describes your current thoughts about patient engagement in health system change. (n= 90)



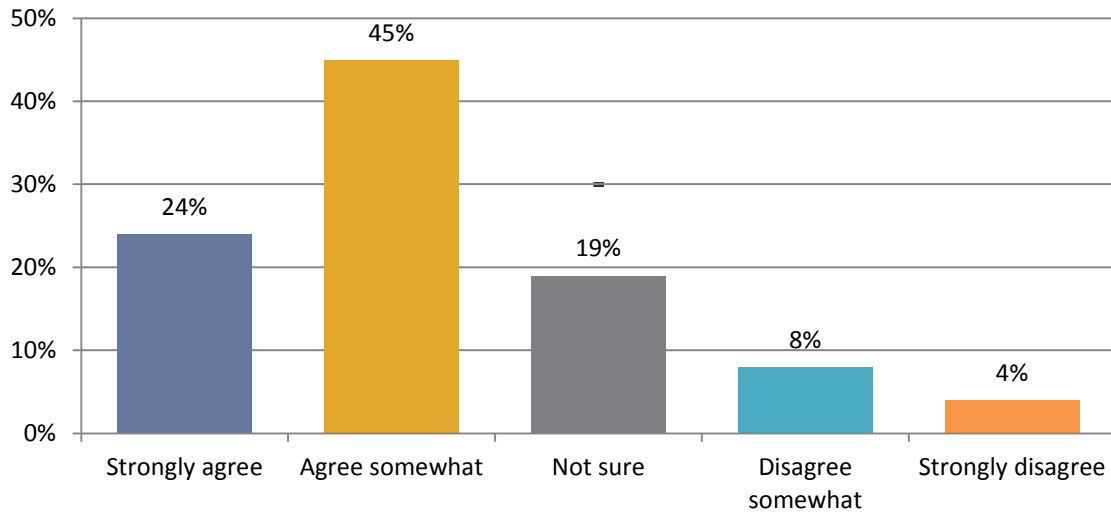
Q7: I have a clear personal vision of how patients/families/ caregivers can be engaged in health system change. (n= 86)



COMPARISON (Question 1 vs. 7):
I have a clear personal vision of how patients/families/caregivers can be engaged in health system change.

	Day 1 (Q1)	Day 2 (Q7)
A. Strongly agree	(39%)	(43%)
B. Agree somewhat	(49%)	(45%)
C. Not sure	(11%)	(5%)
D. Disagree somewhat	(1%)	(5%)
E. Strongly disagree		(2%)

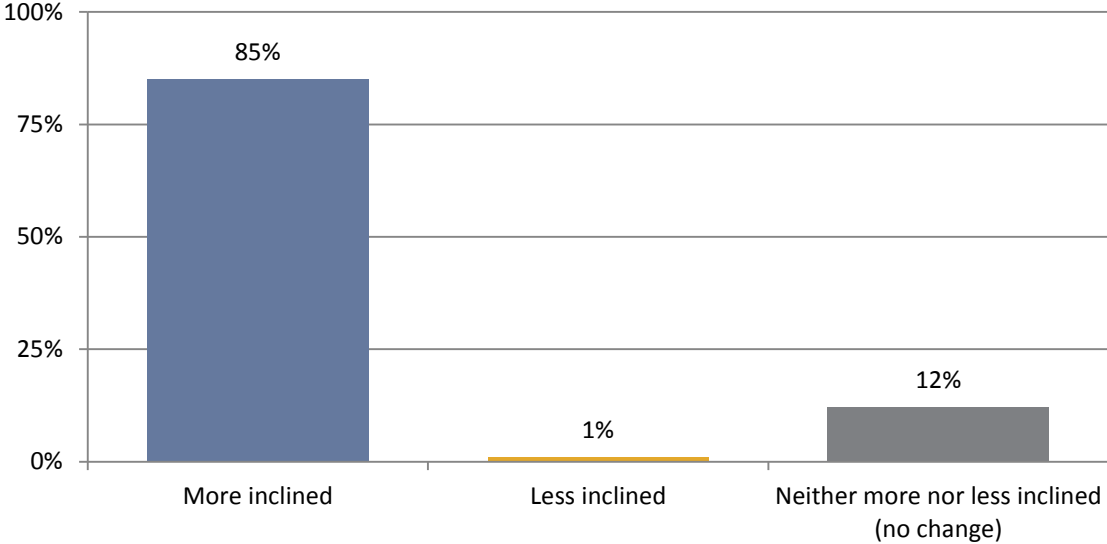
Q8: I have a clearer understanding of the vision of the province of how patients/families/caregivers can be engaged in health system change. (n= 84)



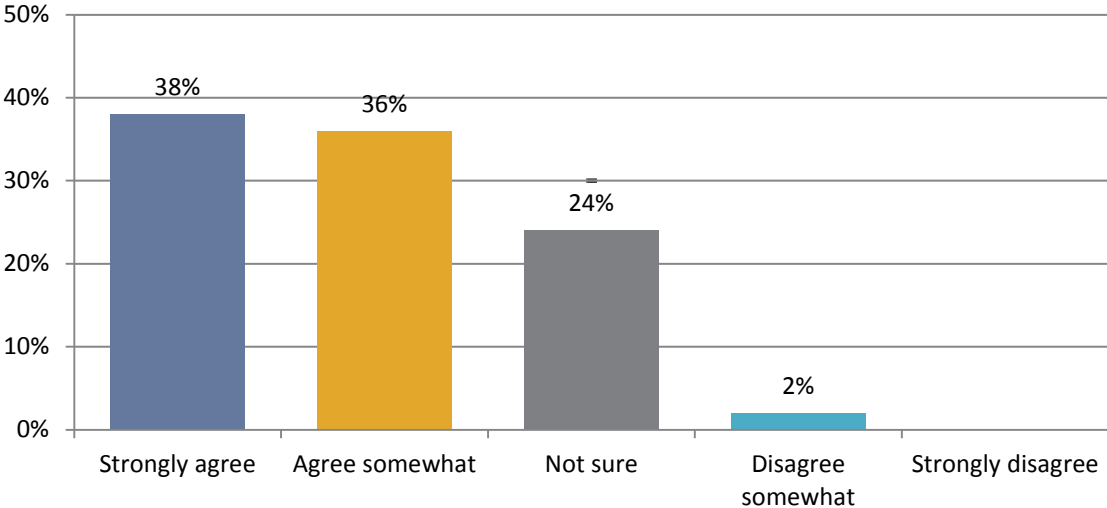
COMPARISON (Question 2 vs.8):
 I have a clear understanding of the vision of the province of how patients/families/caregivers can be engaged in health system change.

	Day 1 (Q2)	Day 2 (Q8)
A. Strongly agree	(8%)	(24%)
B. Agree somewhat	(41%)	(45%)
C. Not sure	(23%)	(19%)
D. Disagree somewhat	(23%)	(8%)
E. Strongly disagree	(5%)	(4%)

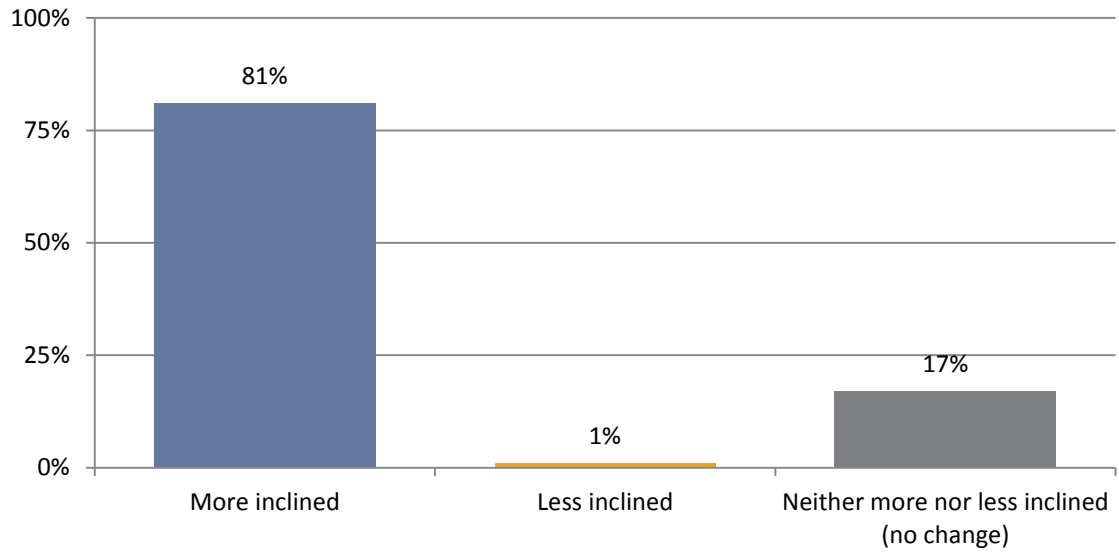
Q9: Compared to before this event, how inclined are you towards advancing the patient/public voice? (n=88)



Q10: The ideas I shared over the last two days will inform and contribute to future actions of the Patients as Partners Patient-Centred Care initiative. (n= 90)



Q11: Compared to before this event, how inclined are you to work with Patients as Partners to advance the patient/public voice? (n=89)





BRITISH
COLUMBIA

