



MINISTRY OF HEALTH
PATIENT, FAMILY, CAREGIVER AND PUBLIC
ENGAGEMENT FRAMEWORK 2018



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PATIENT, FAMILY, CAREGIVER AND PUBLIC ENGAGEMENT FRAMEWORK 2018

Executive Summary

The Ministry of Health's Patients as Partners Initiative brings together patients, families, caregivers, health care providers, not-for-profits, health authorities, non-governmental organizations, and universities to work together to include patients' voices, choices and representation in health care improvement.

Health care improvement can be obtained by supporting the Triple Aim. The term "Triple Aim," developed by the Institute for Healthcare Improvement, refers to the simultaneous pursuit of improving patients' care experiences, improving the health of populations, and reducing the per capita cost of health care.¹

To achieve the Triple Aim goals, the Patients as Partners Initiative has developed a Patient, Family, Caregiver and Public Engagement Framework for those working in the health sector. Leveraging activities that engage patients and the public can help enhance patients' experiences improve population health and lower the cost of health care.

This framework updates and replaces the original *Integrated Primary and Community Care Patient and Public Engagement Framework* published in 2011.² Our current framework acknowledges that engagement can occur in direct care where the health-care provider is working with a patient or group of patients. It can also occur in other settings throughout the health-care system where a health-care worker or engagement practitioner can be working with small or large groups of people. Additionally, engagement can be used to shape organizational design, governance, and policy making.

In B.C., as in other jurisdictions, the understanding of how patients are engaged has evolved in the four years since the last publication. This updated framework has been developed by conducting a comparative analysis of other jurisdictions, incorporating best practices and consulting with health-care workers, engagement experts and patients. The framework is a stand-alone document but is related to a series of resources, tools and references.

Engagement is critical for a variety of reasons. Patients working with care providers and community resources to take command of their and their families' health will particularly aid the prevention and management of chronic diseases, which are among the major cost drivers in Canadian health care. Partnering with patients through community resources, such as designing hospitals that work for patients and their families will also lower costs while improving health. And finally, harnessing patients' contributions will help design and redesign a health-care system that better responds to patients' needs in the most cost-effective way.

¹The Institute for Healthcare Improvement. The IHI Triple Aim. Available at: <http://www.ihl.org/engage/initiatives/tripleaim/pages/default.aspx>

² British Columbia Ministry of Health. Integrated Primary and Community Care Patient and Public Engagement Framework. 2011. Available at: <http://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/primary-health-care/patients-as-partners-public-engagement-2011.pdf>

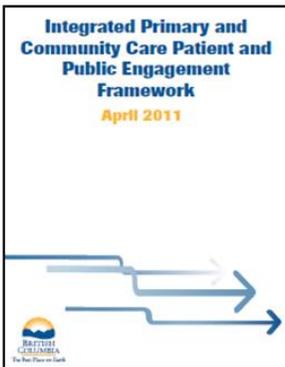
ENGAGEMENT

Thought leaders in health care – the Institute of Medicine, the Institute for Patient and Family Care, the Institute for Healthcare Improvement, the Picker Institute, and others – are all advocating for greater patient and family engagement, based on solid evidence of the value of engagement.

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What is this document?



This document is about co-creating a person- and family-centred approach to health, well-being and care through engagement with patients, families, caregivers, health care providers, employees, managers, leaders and health sector organizations. It builds on the 2011 Patient and Public Engagement Framework that was developed by the Ministry of Health. Since development of the framework in 2011, the Ministry of Health's Patients as Partners Initiative has expanded across the health-care system and contributed to a variety of activities to advance engagement. These engagement activities include promoting shared decision making, funding self-management programs and supporting education and mechanisms for public engagements. Since 2010, the Ministry of Health has provided engagement training for more than 800 health-care workers and has involved more than 40,000 patients in a variety of

engagement activities. In order to continually improve, the approach and tools used to plan and support effective implementation for patient, family, caregiver and public engagement have been reviewed and updated. This new Engagement Framework will help guide patient, family, caregiver, and public engagement in British Columbia.

Based upon the strength of interviews with patients, online surveys and focus groups with health engagement professionals, the 2011 framework has been updated in three important areas:

- A customized spectrum of engagement for the health-care sector is aligned with the current International Association for Public Participation (IAP2) spectrum.
- The appendix of planning and reporting tools is being replaced with a comprehensive planning template (not contained in this document) that incorporates current best practices in patient, family, caregiver and public engagement.
- A patient guide is being added as a supplemental document to help patients better prepare for engagement by providing them with more complete and user-friendly information on patient, family and caregiver engagement.

The framework follows world-wide best practices in engagement. This framework has been developed from a British Columbia health care perspective to ensure the voices of patients, their families, caregivers, communities, the public and other health-care stakeholders can be incorporated into decisions that affect their lives. The final framework was developed by consulting with patients, families, caregivers, health authority representatives, community partners, engagement experts and Ministry of Health staff.

Who should read this document?

This document is useful for anyone involved in improving and transforming health-care services in British Columbia, including patients, families, caregivers, community organizations and partners, universities, non-governmental organizations, and the public. It is particularly aimed at:

- Patients, families and caregivers
- Leaders and decision makers in the health-care sector
- Managers in the health-care sector
- Practitioners in the health-care sector

Why should you read this document?

A person-centred health-care system puts patients at the forefront of decision making about their care. Patients, families, caregivers, communities and the public are partners (stakeholders) in health care when they are supported and encouraged to:

- participate in their own health care
- participate in decision making about that care
- participate at the level they choose
- participate in quality improvement and health-care design and redesign in ongoing and sustainable ways³

What is Patient, Family, Caregiver and Public Engagement?

What is the definition of engagement?

Definitions of patient engagement and conceptions of how it improves the health-care system vary widely. Angela Coulter's well-known definition focuses on the relationship between patients and health-care providers as they work together to "promote and support active patient and public involvement in health and health care and to strengthen their influence on health-care decisions at both the individual and collective levels."⁴ A model for public engagement developed by James Conway at the Institute of Healthcare Improvement is organized around the settings in which patient engagement occurs: during the care experience, within the microsystem of the clinic or ward, within the health-care organization, and within the larger community".^{5 67}

At a broad level, engagement is a process that brings people together, either in person or virtually, to support decision making. When people and organizations that are impacted by a decision participate in the process of making that decision, it is said they are "engaged" with one another. Engagement is also used to consider an opportunity, to aid the healing process, to build mutual understanding, to collect information and build consensus. Engagement would not be used if all parts of the decision had already been made or if the situation was urgent. Engagement, therefore, is a process where the decider or decision-making authority invites those impacted into the decision-making process.

"Patients are partners in care when they are supported and encouraged to participate: in their own care; in decision making about that care; at the level they choose; and in the redesign and quality improvement in ongoing and sustainable ways."

B.C. Ministry of Health – Integrated Primary and Community Care Policy Paper²

"Public engagement – processes by which individuals, groups and organizations have an opportunity to participate in decision making that affects lives."

Public Health Agency of Canada

³ British Columbia Ministry of Health. 2015. The British Columbia Patient-Centred Care Framework. Available at: http://www.health.gov.bc.ca/library/publications/year/2015_a/pt-centred-care-framework.pdf

⁴ Coulter A. *Engaging patients in healthcare*. New York (NY): McGraw-Hill Education; 2011. p. 10.

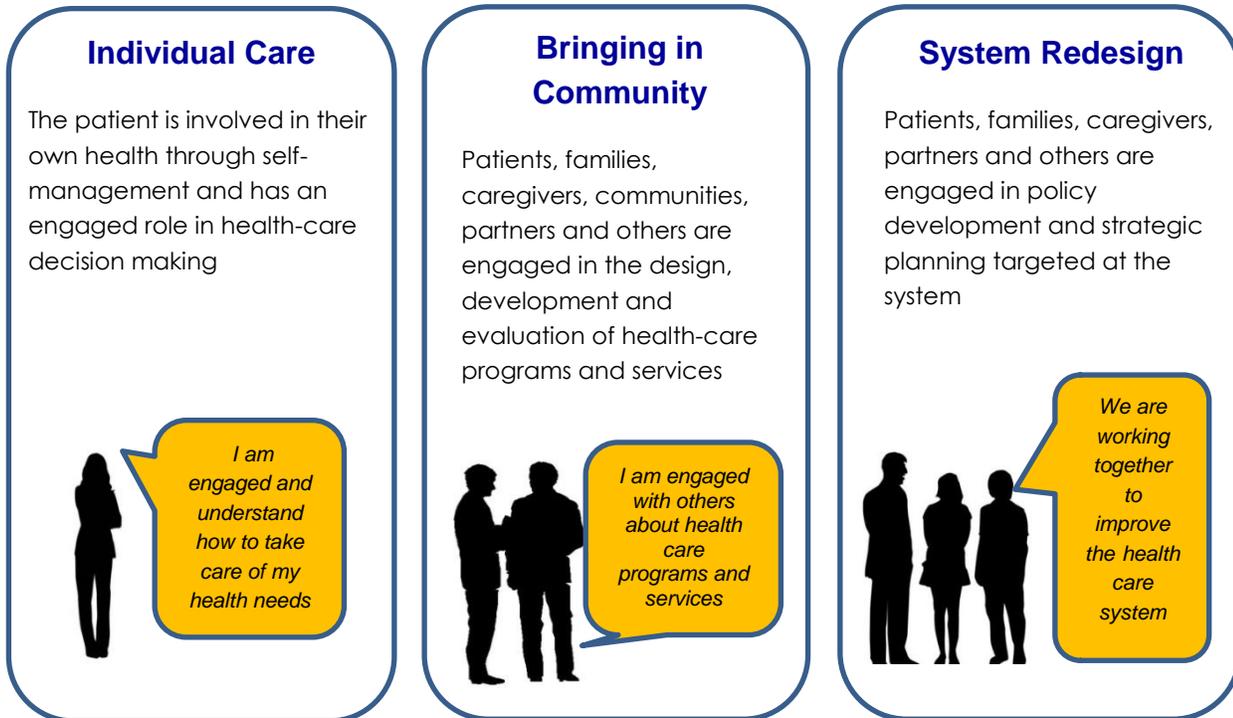
⁵ Institute of Medicine. Engaging patients to improve science and value in a learning health system. Chapter 4 in: Institute of Medicine. Patients charting the course: citizen engagement in the learning health system: workshop summary. Washington (DC): National Academies Press; 2011. p. 103–10.

⁶ NHA England Patients and Information Directorate. 2013. Transforming participation in health and care. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>

⁷ Center for Advancing Health. 2010. A new definition of patient engagement: what is engagement and why is it important? Available at: www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf

What are the three domains of Engagement?

In health care, the focus for engagement is on patients, families and caregivers in the community, and on the broader public. Our framework acknowledges that engagement can occur in direct care where the health-care provider is working with a patient. Additionally, engagement can be used in the community with regional health authorities or community organizations for things like hospital expansions, or designing, developing or improving programs and services. And finally, changes can be made to the health-care system where policy or strategic planning can impact the entire province. The practice of patient, families, caregivers and public engagement occurs at three domains, as described in the Patients as Partners Charters:



Individual care engagement

Individual care engagement is about how the values, goals, culture and choices of patients, families and caregivers should influence their care. It is about the relationships with providers, staff, friends, family and community that support people to be active in managing, promoting and sustaining their health. Individual engagement, as opposed to engagement at the community or system domains, is powered from within a person with their decision to be engaged. It is about their interests, actions and drive to understand and manage their health. Engagement at the individual or direct care domain is about taking actions and having relationships with helpers.

Asking a patient to be active in their own health is *not* about asking them to do it alone or manage without a health-care team around them. It is *not* about asking people to pick up more responsibility so the health-care system can retreat. It is about working together to change the culture of health care from one where providers do “to” and “for” people to one where providers do things “with” people. The person who is most expert in the patient is the patient themselves along with their families and caregivers. Health care is better when they are engaged and active in the choices being made.

Community engagement

Numerous positive service and program improvements have resulted from the involvement of patients and families in health-care decision making in the community. Some examples include the following:

1. Patients and families who have lived experience with surgical services at a regional health authority were involved with developing tools for the surgical patient education website on topics such as how to improve health before surgery and how to prepare to meet your surgeon.
2. Patients, families and caregivers are engaged with health-care practitioners and self-management service providers in their community to learn how to manage their chronic diseases. This may include peer support groups, health literacy, coaching and education.
3. Patients, families and caregivers are engaged with hospital administrators, employees and clinicians to re-design hospital services and evaluation methods that are relevant to that particular community.

System engagement

System engagement occurs when patients, families and caregivers are invited to participate in activities that are part of policy development or planning with policy makers, leaders and others and will affect the entire health-care system. An example of system engagement are the engagement sessions on the proposed new system of primary and community care for all British Columbians held in Kelowna, Vancouver and Surrey in January 2017. The Ministry of Health held these sessions in partnership with Vancouver Coastal, Fraser Health and Interior Health authorities and was supported by the General Practices Services Committee. Patients and families provided input on the new approach to accessing primary and community care (establishing and implementing Patient Medical Homes and Primary Care Homes). Feedback was given on the language describing the systems, what good care looks like, team-based care and evaluation of experience with the health system.

A diverse group of 47 people were in attendance, including men, women, younger, older, multicultural populations, indigenous populations, caregivers, those with chronic complex health and mobility issues from rural and urban centers. The sessions also included representatives from the Ministry of Health, Doctors of BC, General Practices Services Committee, Divisions of Family Practice, clinicians, the Practice Support Program and the health authorities. Patients provided valuable feedback and some of their suggestions have been included in the policy development work.

What is the Goal of Patient, Family, Caregiver and Public Engagement?

The goal of patient, family, caregiver and public engagement should reflect the Triple Aim. The term “Triple Aim,” developed by the Institute for Healthcare Improvement, refers to the simultaneous pursuit of improving patients’ care experiences, improving the health of populations, and reducing the per capita cost of health care. The Triple Aim “describes an approach to optimize health-system performance,” and provides a foundation for engagement goals within the B.C. Ministry of Health:

- Improved partner and health provider experience
- Improved population health
- A cost we can afford



Rooted in the context of the Triple Aim, Patients as Partners advances person- and family-centred care.⁸ This is the belief that health care improvement requires collaboration between patients and health-care providers at the individual, community and system level. The vision is a health-system that actively reflects the needs and interests of the people it serves – the patients.

The Ministry of Health’s Patients as Partners Initiative brings health-care providers, not-for-profits, non-governmental organizations, and universities to work together to include the **patients’ voices, choices and their representation** in health care improvement.

Patients as Partners is guided by the principle of “**nothing about me without me**,” based on the belief that patients are partners in their own health care — in discussions about system change or when interacting with health-care providers.

⁸ Ministry of Health. The British Columbia Patient-Centred Care Framework. Available at: http://www.health.gov.bc.ca/library/publications/year/2015_a/pt-centred-care-framework.pdf

Why conduct Patient, Family, Caregiver and Public Engagement?

Engagement is critical for a variety of reasons. Patients taking command of their health will particularly aid the management of chronic diseases, which are among the major cost drivers in Canadian health care. Partnering with patients through community projects, such as designing hospitals that work for patients and their families will also lower costs while improving health. And finally, harnessing patients' contributions will help design and redesign a health-care system that better responds to patients' needs in the most cost-effective way.

Engagement is an effective way to advance the Triple Aim of improved health outcomes, improved patients' experiences and reduced costs. Beyond the Triple Aim, however, there are a number of additional rationales for engagement.

These include:

- Supporting better, long-lasting decision making
- Fostering transparency in decision making
- Managing risk effectively
- Building broader awareness, motivation and participation in health-care planning
- Harnessing the vast amount of expertise patients have for helping others



Patient, family, caregiver, and public engagement is not a passing fad. It is being embedded in how the Ministry of Health makes decisions moving forward. Implementation of engagement initiatives needs to be flexible and relevant for the health population or community with which it is engaging. It is about working together to transform the health-care system to one where the Ministry of Health and health-care providers are not always the sole decision makers, but in many situations are facilitators and collaborators in health-care delivery, promotion, planning and design.

Fundamentally, patient, family, caregiver, and public engagement is about identifying ways to achieve all or part of the Triple Aim at any health

system level: individual, program and service design, or at the community/system level. Moreover, it is recognized that those who are impacted by health-care decisions should have an opportunity to contribute to the decision-making process.

Patient, family, caregiver and public engagement also recognizes that citizens are demanding greater accountability and transparency from government at all levels. Increasingly, citizens are seeking to understand how decisions are made and how their input can play a role in shaping the final decision. This is especially true in health care, as the patient is both the consumer and contributor to the health-care system. A publicly funded health-care system needs to include patient, family, caregiver and public engagement to ensure its long-term sustainability.

How this is achieved with different populations and in different regions needs to be flexible and rooted in a person-centred approach. This means that engagement must be grounded in best practices, and consistent values, principles and approach; however, it also needs to be designed and implemented in a way that reflects the needs of unique decision makers, stakeholders and participants in the process. "Getting public participation right is essential....Getting it wrong simply frustrates all participants."⁹



What are the Principles of Engagement?

While there are different approaches for the individual, community, and system levels of engagement, there are six key overarching principles that guide all levels:

1. A deep commitment to respect, dignity, and listening to understand;
2. A recognition that the Triple Aim cannot be achieved without engaged patients at all levels;
3. Person-centredness takes place across all levels and works to ensure that the motto "nothing about me, without me," is respected and realized;
4. Engagements need to work for patients;
5. Trust-based relationships are critical to achieving individual, community and system goals; and
6. Engagements use co-design techniques that actively involve all stakeholders (employees, patients, families, caregivers, managers, providers, leaders, citizens, and health-sector organizations) in the design process to help ensure the results meet their needs and are usable.

⁹ Office of the Auditor General of British Columbia. Public Participation: Principles and Best Practices for British Columbia. 2008. Available at: <https://www.bcauditor.com/sites/default/files/publications/2008/report11/report/public-participation-principles-and-best-practices-british-columbia.pdf>

What are the considerations of Patient, Family, Caregiver and Public Engagement?

Are you ready for the change?

The change initiated and supported by patient, family, caregiver and public engagement is a significant one; it is a paradigm shift, one that may challenge health-care providers' and administrators' training and professional socialization. The sharing of power can leave people feeling uncertain and tempted to revert to previous ways of thinking and behaving. Providing information and educating patients, families, caregivers and the public are certainly elements of engagement — thinking back to the principles of transparency and the free-flow of communication — but they must be coupled with meaningful opportunities to participate in care, in planning and in evaluation.



Successful engagement requires rigorous planning, skillful execution and typically involves a series of steps. Often the focus is on the method of engagement and the “engagement event” – the focus group, the workshop, the information meeting. The critical steps are the preparatory ones – defining the decision to be made, determining the objective of the level of engagement and any inherent promise within, identifying relevant internal and external stakeholders, connecting with the stakeholders and designing a process appropriate for the purpose. A final step is one where the decision maker (or delegate) reports back to the participants about how their involvement shaped the decision.

What are the success factors of Patient, Family, Caregiver and Public engagement?

Like any major organizational change, advancing patient, family, caregiver and public engagement is dependent on a series of critical success factors. Some critical success factors include:

Identify Change Champions – Engagement requires champions at all levels of the organization – from front line staff that are passionate about person-centred care, to planners who recognize the value of patient/public involvement, to managers who understand the powerful potential of working collaboratively. Leaders have a key role to play in expressing commitment to engagement, shifting their own views of engagement as a “nice to do” to “must do” and communicating and supporting this expectation to the organization’s staff and physicians.

Identify Resource Requirements – Like any significant change, engagement requires resources: dedicated staff, time, money, a framework that outlines the organization’s commitment and training that guides engagement efforts.

Make Effective Organizational Change – Effective engagement holds tremendous potential to transform people, relationships and organizations. However, implementing the principles and practices of engagement requires bold leadership to move away from the status quo. It means moving from ‘doing to’ or ‘doing for’ and moving to ‘doing with’ by embracing innovative learning approaches, adopting new improvement methods, and bringing more rigor to planning and decision making. It means working in partnership and acknowledging the rightful participation of patients and the public in their own care, in design and evaluation of programs and services, and in the broader system and community. Putting patient, family, caregiver and public engagement into practice requires making, and fulfilling, a promise to patients, their families and the public.

Secure Shared Understanding – With any interaction we have with patients, families, caregivers and the public, there needs to be shared understanding of the definitions and purpose of the engagement. As well, we need to be clear about why we are involving people by clarifying objectives; explaining links to organizational priorities;



explaining what can change and what is not negotiable; being clear in advance on how patients', families' and caregivers' views will feed into the decision making and influence what action we intend to take once the engagement concludes. Finally, we need to see the practice of engagement in the context of our improvement efforts and apply the same careful approach to planning, doing, studying and acting – enabling us to contribute to the goals and objectives of the

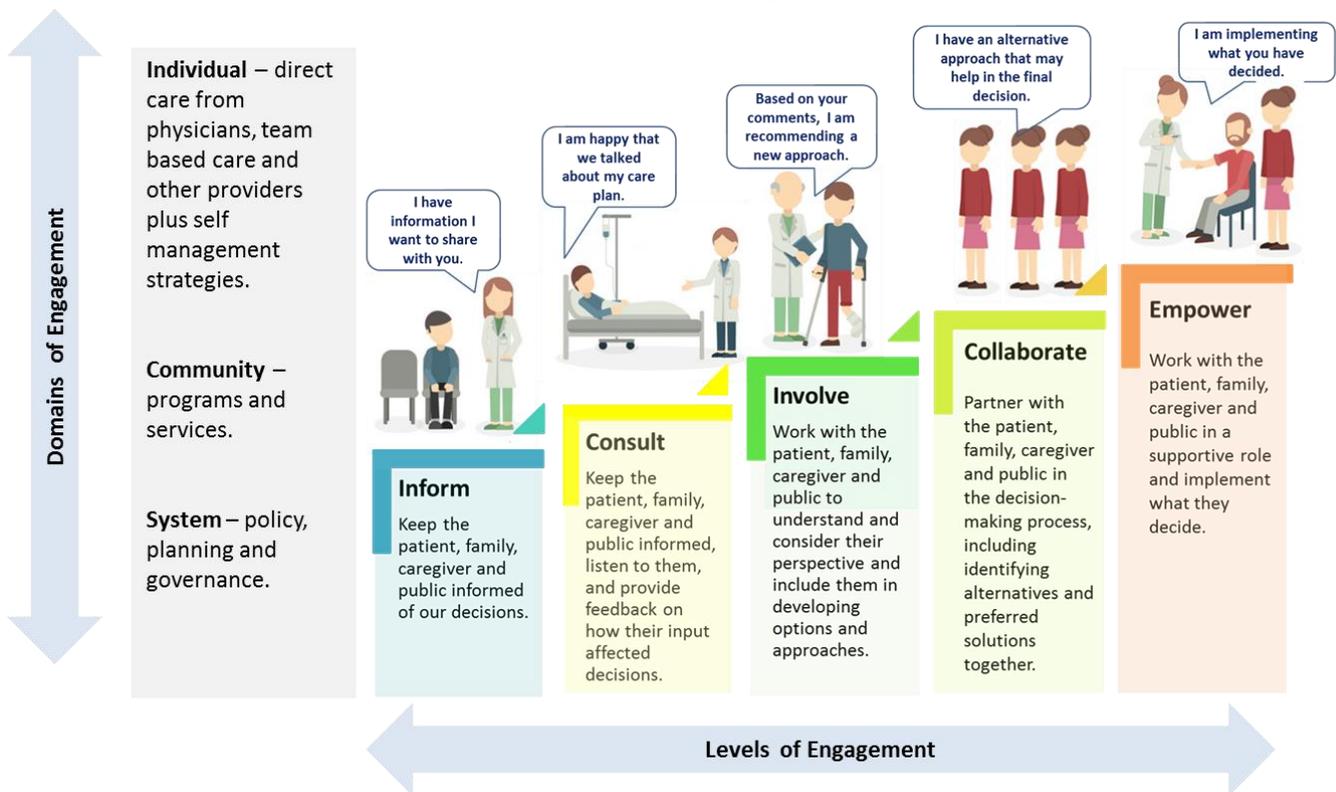
engagement while supporting the strategic priorities of the organization. Reporting on results from engagement activities helps health-care workers and leaders learn and spread the practice.

What is the Spectrum for Patient, Family, Caregiver and Public Engagement?

Engagement can be viewed as a series of activities in a spectrum, ranging from one-way sharing of information (Inform) without input from patients or the public, to shared or delegated decision making (empower) with gradations of engagement between.¹⁰ As you move along the continuum below, engagement level can be characterized by how much information flows between patient and provider, how empowered the patient is with care decisions and how involved the patient, family, caregiver or public is involved in health organization decisions and in policy making.

The Ministry of Health's Patients as Partners spectrum includes a range of different levels of engagement. The level that is chosen will define and drive engagement planning and process as the levels reflect different objectives and demand different commitments. Moving across the spectrum requires a greater promise to the people being engaged and results in an increasing level of impact. The levels on the spectrum build upon one another – for example, all engagement requires a minimum interaction between two individuals, such as a health-care worker and a patient and is depicted below as informing.

A Multi-Dimensional Health Sector Engagement Framework for Patients, Families, Caregivers and the Public



This spectrum is adapted from the International Association for Public Participation (IAP2), a well-known model and the continuum outlined in the report from the B.C. Office of the Auditor General, "Public Participation: Principles and Best Practices for British Columbia."

¹⁰ Carman KL, Dardess P, Maurer M, et.al. Patient and family engagement: A framework for understanding the elements and developing interventions and policies. 2013. Health Affairs 32:2 pp 223-229.

What are the definitions of each level of the Spectrum?

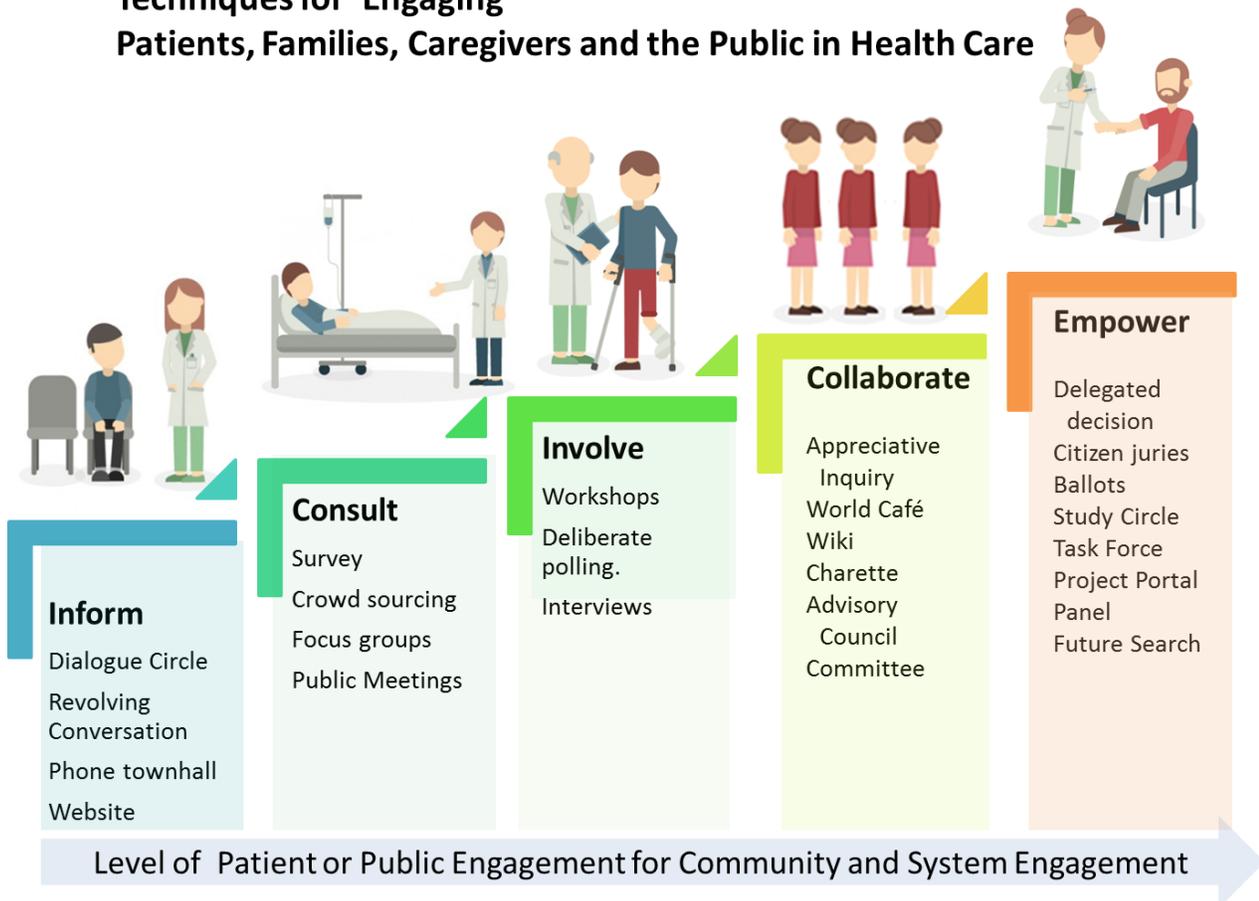
Ministry of Health Role	Definition of each level of engagement on the spectrum	Decision Making Authority
	<p>Inform – The promise to you is that the health-care partner will provide you with clear and objective information. When working with patients as partners, the objective is to provide information to increase understanding. This is one-way communications.</p>	No decision for the patient or public
<p>The Ministry of Health will usually conduct patient, family, caregiver and public engagement using these levels on the Spectrum</p>	<p>Consult – The promise to you is that the health-care partners will listen and acknowledge your ideas and concerns, and provide feedback on how your input affected the decision. When working with patients as partners, the objective is to obtain feedback on things like draft plans or recommendations. This is two-way communications.</p>	Shared decision making ¹¹
	<p>Involve – The promise to you is that the health-care partner will work with you to ensure that your ideas and concerns are reflected in the recommendations, and provide feedback on how your input affected the decision. When working with patients as partners, the objective is to involve the patients in planning or in the design phase to ensure their ideas and concerns are considered and reflected in alternatives and recommendations. This is two-way communications.</p>	
	<p>Collaborate – The promise to you is that the health-care partner will work together with you on developing the solutions and include your recommendations into the decision as much as possible. When working with patients as partners, the objective is to engage patients in decision-making alternatives, recommendations and solutions to the fullest extent possible. This is two-way communications.</p>	
	<p>Empower – The promise to you is the health-care partner will implement what you decide. This is delegating the responsibility of the decision to patients or the public. This is two-way communications.</p>	Delegated decision to patients and public

¹¹ Kon A. The shared decision making continuum. 2010. JAMA 34: 8 pp. 8903-904.

What are the tools and channels for each level of the Spectrum?

Once you have chosen the level of engagement, based on the spectrum, there are a variety of communications tools and channels that you can use in your engagement activities. Those tools and channels are depicted below under each level of the spectrum.

Techniques for Engaging Patients, Families, Caregivers and the Public in Health Care



Who should play a role in Patient, Family, Caregiver and Public Engagement?

Within health-care organizations, everyone has a role to play in engaging patients, families, caregivers and the public.

Leaders and Decisions Makers

- Set expectation of engagement as a required function
- Make the promise to patients and other stakeholders
- Champion engagement
- Support organizations in building capacity for engagement
- Provide resources for engagement
- Ensure timelines and resources are available (when appropriate) for meaningful engagement

Program Managers

- Create opportunities for engagement in program planning and evaluation
- Involve patients, families, caregivers and the public
- Model engagement practice for front-line staff

Front Line Staff

- Demonstrate responsiveness to the preferences of patients, families and caregivers, and believe in the care relationship
- Support the active participation of patients/families in their care and decision making
- Provide information to support patients, families, caregivers in decision making

Engagement Specialists

- Design and implement the engagement process
- Coach colleagues on “how to” conduct engagements
- Act as a neutral “facilitator” or process guardian
- Support patients, families, caregivers and the public in the engagement process

Patients, Families, Caregivers and the Public

- Listen and learn
- Communicate values, preferences and needs
- Provide input and advice on proposals
- Engage in deliberation of ideas, and co-develop alternatives
- Identify issues and solutions

Health-care Providers

- Family physicians, Specialist physicians, nurses, allied health-care providers, nurse practitioners and others can be involved in engagement work at the individual, program/services and system level.
- Create opportunities for engagement in program planning and evaluation
- Involve patients, families, caregivers and the public
- Model engagement practice for other health-care providers

According to the
Institute for
Healthcare
Improvement

“By engaging patients and their families at multiple levels of organizational performance, we can not only improve their own health-care experiences but also gain valuable insights for actions necessary to improve the health of populations and to extract greater value from our limited health-care resources.”

How do I get involved in Patient, Family and Caregiver Engagement?

There are a number of ways that you can get involved with engagement.

1. Learn more about self-management at <http://www.selfmanagementbc.ca/>, http://www.iconproject.org/dnn_icon, <https://www.painbc.ca/>, <http://www.healthlinkbc.ca/>.
2. Volunteer to get involved in health-care system change through the Patient Voices Network at <https://bcpsqc.ca/about-the-council/patient-voices-network/> or the Family Caregivers of British Columbia at <http://www.familycaregiversbc.ca/>.
3. Participate in public engagements in your community where organizations such as health authorities have made public announcements requesting input from patients and the public in decision making.
4. The government of B.C. has launched a consultation and dialogue website where citizens can get involved on a variety of topics that may or may not be related to the health-care sector. GovTogetherBC is the hub for government engagement opportunities that require your participation – to listen, get informed and speak up. It supports the government in its objective to become more transparent and accessible. Here you can browse and submit feedback on current public consultations, stay connected via Twitter, subscribe to our monthly newsletter, and check up on consultation results. Go to <https://engage.gov.bc.ca/govtogetherbc>.

Where can I find other resources, tools and references?

There are other resources that can be used as supplemental documents with this framework. These documents are located at <http://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/patients>.