Integrated Primary and Community Care Patient and Public Engagement Framework

April 2011
## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>03</td>
<td>Patient and Public Engagement Defined</td>
</tr>
<tr>
<td>05</td>
<td>The Impetus for Engagement</td>
</tr>
<tr>
<td>06</td>
<td>The Evidence Supporting Engagement</td>
</tr>
<tr>
<td>08</td>
<td>The Spread of Engagement Practice</td>
</tr>
<tr>
<td>09</td>
<td>The Principles of Engagement</td>
</tr>
<tr>
<td>10</td>
<td>The Spectrum of Engagement</td>
</tr>
<tr>
<td>11</td>
<td>Making Engagement Happen</td>
</tr>
<tr>
<td>14</td>
<td>Who Should Play a Role in Engaging Patients, Families and the Public?</td>
</tr>
<tr>
<td>14</td>
<td>Evaluation of PPE Processes</td>
</tr>
<tr>
<td>15</td>
<td>Making a Paradigm Shift</td>
</tr>
<tr>
<td>16</td>
<td>Appendix 1</td>
</tr>
<tr>
<td>18</td>
<td>Appendix 2</td>
</tr>
<tr>
<td>19</td>
<td>Appendix 3</td>
</tr>
<tr>
<td>20</td>
<td>Appendix 4</td>
</tr>
<tr>
<td>21</td>
<td>References</td>
</tr>
<tr>
<td>22</td>
<td>Acknowledgments</td>
</tr>
</tbody>
</table>
INTEGRATED PRIMARY AND COMMUNITY CARE PATIENT AND PUBLIC ENGAGEMENT FRAMEWORK

Patient and Public Engagement Defined

“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 redesign and quality improvement in ongoing and sustainable ways.”

BC Ministry of Health – Integrated Primary and Community Care Policy Paper

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

Public Health Agency of Canada (PHAC)

In health care, the focus for engagement is on both patients and their families and on the broader public. The practice of patient and public engagement occurs in three domains:

**Individual care**
The patient is activated, involved in their own health through self-management and an engaged role in health care decision-making. The health care system is patient-centred - responsive, respectful, collaborative.

**Program and Service Design**
Patients, families, community organizations, strategic partners are engaged in design, delivery and evaluation of health care programs and services.

**System and Community**
Patients, families, communities, and strategic partners are engaged in policy development or strategic planning. There may be representation from patient, families, communities, and strategic partners in governance.

In the individual care domain, patient engagement enables the patient and their family to be active, involved in their own care decisions and in the day-to-day management of their health and well-being.
The system is responsive to needs, values and preferences, supporting patient choice, fostering collaboration and enabling involvement.

In the **program and service design domain**, patients, families, communities and/or strategic partners are engaged in the design, delivery and evaluation of programs. For example, people living with diabetes may participate in a workshop to assess and improve diabetes self management or the Canadian Mental Health Association’s youth program participants may give feedback on the design of a new program for early psychosis intervention.

In the **system and community domain**, patients, families, communities and/or strategic partners are engaged in strategic planning or policy making activities, including setting priorities, informing resource-allocation decisions and playing a role in governance.

The change initiated and supported by patient 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 us feeling uncertain and tempted to revert to previous ways of thinking and behaving.

It can be helpful to remind ourselves what engagement is not – meaningful engagement is not just a one-way communications process, not just educating patients or the public to understand our point of view, and not a means to get others to agree with a decision that has already been made. Engagement recognizes the agency and autonomy of patients and the public; *it’s about not doing to and not doing for*, and supporting their role in care, program and service design and in the system and community domain. When engaging patients and the public in design and evaluation of policy and programs, engagement must be meaningful and include a diversity of voices – *not one patient speaking for many*. However, feedback from patients and families is only one of many inputs into decision-making. Decision-makers take many things into consideration: financial information, best practices, legal and risk management considerations and other factors – as well as input from patients and the public.

**Engagement is not...**

A **one-way** education or communications exercise

A way to get public to agreement on a pre-determined decision

The only input into decision-making

Doing to

Doing for

One voice representing many

Providing information and educating patients 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.
The Impetus for Engagement

Health-care organizations are increasingly looking for ways to improve health outcomes for the people they serve, make the system more sustainable and improve the experience of patients and providers. While organizations have their own drivers for improvement, there are additional pressures for change.

Patients' deference to medical professionals is receding. Far from passive recipients of care and advice, today's patients are engaged, informed and expect to be treated as equal partners. They're increasingly activated, wanting to play a significant role in their own health and have a say - not only in their own care but in the design, delivery and evaluation of the health-care system.

This individual desire for involvement is mirrored on the macro-scale; as tax-payers and citizens, the public is demanding greater accountability and transparency from public institutions and wanting to be involved in decisions that affect their lives. Around the world, governments and societies are advancing engagement under a variety of names - consultation, civic engagement, public participation and others. Broad participation in processes such as the Citizens’ Assembly on Electoral Reform and the Conversation on Health illustrate a keen interest in civic participation in B.C.

The shift towards a more collaborative model is happening among health-care providers as well. Many now see themselves as agents in a movement for participatory medicine, in which “networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.”

Sometimes, the drivers for engagement are as much stick as carrot, with higher levels of government and/or the courts mandating engagement.

- In B.C., Ministry of Health outlines Key Results Areas (KRAs) for each health region; KRA #3, Integrated Primary and Community Care (IPCC) outlines expectations for engaging patients, their families and the public as partners in all three domains. While the expectation is set out for IPCC, engagement can and is happening across the health-care continuum (e.g., tertiary acute leukemia/bone marrow transplant program).

- Regional health authorities are increasingly working collaboratively with patients and the public when developing new facilities, altering the use of existing buildings or co-developing programs with municipal or other partners. Many municipalities require specific engagement approaches prior to granting development permits or allowing changes to programs and services in the community.

---

“Getting public participation right is essential, including striking the right balance amongst competing priorities of government; being clear to the public about what can and what cannot be accomplished in the short term. Getting it wrong simply frustrates all participants - government and the public - and requires time to rebuild the trust required to engage successfully.”

John Doyle
Auditor General of British Columbia
“Public Participation – Principles and Best Practices for British Columbia”
The Supreme Court of Canada, as well as lower courts and provincial policy, have set out legal obligations for private sector companies and public sector organizations to consult with First Nations in cases where the rights or interests of Aboriginal people could be infringed upon. Engagement of Aboriginal people in health-care delivery, planning and evaluation is guided by the Transformative Change Accord — an agreement established in 2006 between the B.C. government and the BC First Nations Leadership Council. The Tripartite Health Plan clearly lays out expectations of deep engagement – in identifying issues, creating solutions and in developing new models of governance for health services.

Engagement is also being encouraged through the standards of accrediting bodies, who are increasingly measuring individual patient involvement as a key quality measure. Accreditation Canada measures patient experience and engagement through such measures as the number of charts with documented patient/family-identified goals and the provision of written and verbal information to patients and families about their role in safety.

The Evidence Supporting Engagement

For many years, patient and family engagement was promoted because it made intuitive sense. Practitioners, planners and policy makers who used engagement approaches came forth with success stories and anecdotal evidence. As the practice has matured, there have been efforts to quantify the value and develop a rigorous evidence base for patient and public engagement. Research is starting to demonstrate what we know intuitively – that patients having greater control over their care and their health results in better outcomes and that involving the public results in more knowledgeable citizens and better decisions by public bodies.

The value of engagement is now supported by a rich body of evidence, linking the practice to a host of quality, safety and business measures: improved health outcomes for patients, superior patient and provider experience, better financial performance, fewer errors, more diligent decision-making, better risk management and a more knowledgeable, cohesive citizenry.

**Improved health outcomes:** research has demonstrated the link between patient involvement in care and improved health outcomes. Better outcomes are influenced by greater patient involvement in managing chronic conditions and more informed decision-making, as well as through improved patient/provider communication, often resulting in greater adherence to treatment plans. As people become more engaged, they are more knowledgeable about ways to promote their own health, as well as that of their families and communities.

**Improved patient and provider experience:** organizations implementing engagement policies and practices demonstrate significant improvements in patient and provider experience. Improving patient experience has been shown to improve a host of clinical and business measures – from better adherence to treatment plans, to increased capacity in self management of chronic conditions, to greater continuity in the care relationship and retention of employees.
Better financial performance: despite demonstrated benefits, engagement is often seen as an extravagance, an expensive add-on to the core services provided by health-care institutions. Research defies this, demonstrating that engagement results in improved financial performance, making a positive contribution to the bottom line.\textsuperscript{viii} Evidence from the Planetree group shows engagement and patient-centred care resulting in reduced length of stay, lower cost per case, fewer errors, reduced operating costs, fewer malpractice cases and other positive measures.\textsuperscript{x}

Improved patient safety: in patient safety, engagement is linked to fewer medical errors. The practices of engagement (e.g., free flow of communication, patients being encouraged to observe care processes, ask questions and provide input on improvement) have been shown to enable the culture of safety that health-care organizations are seeking.\textsuperscript{x, xi}

Better decisions: there is much evidence demonstrating the value of engagement to decision-making. Research shows that consideration of diverse perspectives actually leads to more creative solutions and sustainable decisions being developed, that listening to different opinions offers hitherto unheard of alternatives to emerge.\textsuperscript{xii} Patient and public engagement offers an antidote to bureaucratic blind-spots, and guards against vested interests (including those of administrators and providers). Listening to the people who experience the health-care system as “users,” “customers” and “owners” can shed new light and offer sometimes startling insights. Engagement with patients and the public can send a proverbial canary into the coal mine – to learn about barriers to implementation before planning is complete.

More effective risk management: Consulting with affected parties prior to decision-making and documenting such demonstrates prudence and provides assurance of reasoned decision-making. Patient and public engagement can mitigate controversy in the case of unpopular decisions; in cases where the final decision hasn’t been made, there’s an opportunity to partner and co-create a more acceptable solution. In cases where unpopular decisions are final, transparent communication and hearing concerns can ease tensions and foster understanding. Hospitals in the U.S. have seen dramatic decreases in litigation and malpractice claims – a result attributed to the practice of engagement being embedded in their organizations.\textsuperscript{xi}

A more knowledgeable citizenry and strengthened community identity: Evaluation reviews of public participation illustrate significant outcomes: improved knowledge and understanding of political processes, greater engagement in civic affairs, strengthened community identity and increased trust in democratic processes.\textsuperscript{xiv} However, a consistent finding was that outcomes were highly context dependent – that is, the process of engagement was a determining factor in achieving positive outcome measures.

Thought leaders in health care – the Institute of Medicine, the Institute for Patient and Family Centred 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.
The Spread of Engagement Practice

Health-care systems, in Canada and internationally, are responding to the mounting evidence for engagement.

Internationally:

- The United Kingdom’s National Health Service has developed robust infrastructure for patient and public engagement; patients and the public are engaged in all aspects of the health system, from the individual domain to system design and implementation to policy and governance.
- New Zealand and Australia have also mandated engagement, developing a variety of mechanisms for advancing the practice (e.g., quotas for patient representation on planning committees).
- In the United States, the Joint Commission on the Accreditation of Healthcare Organizations, national accrediting body for U.S. health-care organizations, measures patient engagement through a series of measures (e.g., patient involvement in medication management, patient-focused education). The Planetree group of hospitals has built their brand around patient-centred care and engagement, with mounting evidence of the benefits and resulting demand for Planetree membership among U.S. hospitals.

In Canada:

- Organizations across the country are adopting engagement frameworks, hiring dedicated positions focused on patient and public engagement, and providing education to staff and physicians. Ontario has legislated engagement of the community by the local health integration networks, recently launching a set of mandatory guidelines.\textsuperscript{xv}
- In B.C., the Ministry of Health has worked with ImpactBC to establish the Patient Voices Network (PVN), a provincial initiative to support patients and their families in promoting healthy living, fostering community activation and in shaping the health-care system. In the health authorities, community engagement resources are being established or are already in place.
- The B.C. Office of the Auditor General (BCOAG) has identified principles, best practices and developed a voluntary framework for public sector institutions, outlined in “Public Participation: Principles and Best Practice for British Columbia.”\textsuperscript{xvi}
- In 2010, Canadian Health Services Research Foundation (CHSRF) allocated 2.6 million dollars to projects engaging patients in design, delivery and evaluation of health services, as well as to researching the outcomes and promising practices emerging from the projects. In 2011, $650,000 will be awarded to this research stream.\textsuperscript{xvi}
  In 2010 “Your Voice Counts” and IPCC partnership initiative with MoH, FH, UBC Faculty of Medicine eHealth Strategy Office and ImpactBC received CHSRF project funding.
The Principles of Engagement

In British Columbia, engagement with patients and the public will be guided by the following nine principles:

1. **Dignity and Respect**: The perspectives and choices of patients, families, communities and partners will be listened to and honoured. The knowledge, values, beliefs and cultural backgrounds of patients and the public will be incorporated into the planning and delivery of services.

2. **Participation**: Engagement occurs in policy and program development, implementation and evaluation, as well as in the delivery of care.

3. **Partnership**: Engagement will be early and continuous. Opportunities will be sought to deepen partnerships through engagement.

4. **Information sharing**: Patients, families and the public will receive timely, accurate and complete information in order to effectively participate in decision-making. Complete and unbiased information will be shared with patients, families and the public in ways that are affirming and useful.

5. **Transparency**: Communication will be clear and transparent. The type of decisions being made and the level of patient engagement will be shared with patients, families and the public.

6. **Commitment**: Appropriate time and resources will be committed to ensure meaningful engagement.

7. **Inclusiveness**: Efforts will be made to include all affected stakeholders in the engagement process and to mitigate barriers to participation. Diversity of opinion will be sought.

8. **Accountability**: Patients, families and members of the public will be informed about how their involvement affected decisions.

9. **Integrity**: Input and concerns will be responded to in a forthright and honest manner. Engagement will have impact on decision-making to the level communicated at the outset.
The Spectrum of Engagement

Engagement is typically conceptualized as a spectrum, ranging from the one-way provision of information (“inform”) to shared or delegated decision-making (“empower”), with gradations of engagement between. There is a range of how much impact patients or the public may have in any process; there may be varying levels of engagement at different stages in a decision-making process or with different groups of stakeholders (e.g., one group of stakeholders may be informed while another may be involved).

Moving along the continuum, the degree of influence exerted by the patient and/or public increases.

The spectrum level that is chosen will define and drive engagement planning and process as the levels reflect different goals and demand different commitments. Moving across the spectrum requires a greater promise to the people being engaged and results in an increasing level of public impact. The levels on the spectrum build upon one another – for example, all engagement requires the provision of information (“informing”).
<table>
<thead>
<tr>
<th>Objective</th>
<th>Inform</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Empower</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide balanced information to increase understanding</td>
<td>Solicit feedback on proposals, alternatives and/or decisions</td>
<td>Work with the patient/public to understand and consider concerns, preferences and values</td>
<td>Partner with the public/patient in each aspect of decision-making, including identifying alternatives and preferred solutions</td>
<td>Delegate responsibility for identifying issues, solutions and actions to the patient/public</td>
<td></td>
</tr>
</tbody>
</table>

| Commitment | To keep the public/patient informed | To keep the public/patient informed, listen to concerns and acknowledge how input affected decisions | To understand public/patient perspectives and include them in developing options and approaches | To seek advice and innovations from the public/patients and include these in decision-making to the fullest extent possible, acknowledging how input affected decisions | To work with the public/patient in a supportive role and to implement what they decide |

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

**Making Engagement Happen - Bringing Patients and the Public into Decision-Making**

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 goal/level of engagement and *the promise inherent in it*, identifying relevant stakeholders and designing a process appropriate for the purpose – and the final ones, where the decision-maker (or delegate) reports back to the participants about how their involvement shaped the decision.
The typical steps in PPE planning are:

1. Define the decision and determine the need for PPE: Prior to engaging stakeholders, the decision must be defined and the decision-making process articulated. Write down the problem to be solved, opportunity to be explored, or decision to be made and use this to guide the PPE planning process. Recognize that the definition of the decision may vary among stakeholders; the organization may view the problem or opportunity one way while patients or the public see it another way.

2. Gain commitment to PPE among decision-makers and key internal stakeholders: Gaining internal commitment to PPE at the outset is critical to the success of the engagement process. Explore the implications of engagement with the relevant decision-makers and if relevant, help staff understand the promise that is being made to patients or the public. This helps to clarify expectations, ensures the legitimacy of the PPE process, enables actionable suggestions to come forward for implementation, and prepares staff for changes that may come from the PPE process.

3. Determine the goal or level of engagement: The goal or level of engagement must fit the needs of the project and the needs of stakeholders. Objectives for engagement must be defined in order to ensure internal and external stakeholders have realistic expectations about the process. Deciding on the level of engagement means making a promise, a promise that must be honoured by the decision-maker and the organization. Review your decision-making process, consulting the spectrum of engagement and asking the following questions:

   a. At each step, what is the role of the patient/public? What is the purpose of engaging them?
   b. How will the input from the process be used?
   c. What promise are we able to make to our stakeholders?

4. Identify stakeholders and determine their standing: Identify which individuals and groups are affected by and interested in the decision to be made. This might include patients in a particular program and their caregivers, non-profit organizations, cultural communities, other levels of government, businesses, or members of the public. Once a list has been generated, ask key stakeholders for input. Remember to bring in groups or individuals that may be opposed to your project or decision; they may have significant insights to offer.

5. Design an engagement process aligned with your goal and appropriate to your stakeholders: The goal determined in step 3 will drive the process and determine the method for engagement. If the goal was to inform, no input would have been gathered. If the goal was to involve, input would have been gathered and would be factored into the development of options or plans. In order to choose the appropriate tools and techniques, refine your PPE plan by:

   a. Reviewing information about your stakeholders
   b. Analyzing barriers to participation
   c. Determining methods of recruitment

For more information on process design, refer to Appendix 3 and 4 and consult your organization’s Engagement staff.
1. Carry out the process: Execution of PPE processes requires a particular set of skills. Maximize the success of your process by involving skilled facilitators, interviewers or other engagement experts.

2. Analyze the results from the engagement process: Results from the PPE process may come in a variety of forms: focus group flip charts, collated interview summaries, graphs depicting alternatives and the preferences of stakeholders. Package results appropriately for decision-makers, staff and external stakeholders.

3. Reflect on input and/or apply to the decision-making process: The results of the PPE process will be dependent on the engagement goal and on the method of engagement. Results should be considered by the decision-maker and key internal stakeholders, keeping in mind the promise made at the outset of the process. If the promise was to consult, the results must be considered as an input into decision-making but may not be acted upon. If the promise was to empower, the results must be taken forward.

4. Make decisions: A secondary value of PPE is that it demands the articulation of the decision-making process. Often, planning and policy development go on without clarity about what problem is being solved, what opportunity pursued or what question answered. In this step, reflect back on the initial decision statement to assess the integrity of the process. In addition, assess what other issues, opportunities or questions came up through the PPE effort.

5. Communicate how engagement influenced the result: Once decisions have been made, the results of the engagement process must be communicated to stakeholders. If feedback was acted upon, this should be shared, making explicit the value of engagement to the decision-making process. If input was not implemented due to constraints on decision-making (e.g., best practices, policy or legislation), these other factors should be shared with stakeholders. Often, some degree of input is implemented, if not every suggestion – in these cases, it is important to be transparent with stakeholders about the value of their engagement AND the other factors that went into the decision.

6. Evaluate the engagement process and outcome: PPE, like other improvement efforts, demands a commitment to continuous evaluation. Ongoing assessment during the project allows PPE practitioners to adapt the process as it is unfolding and make improvements during subsequent PPE projects. Evaluation should examine both process and outcome measures, ensuring that the process was meaningful and that the PPE goal was met.

See appendices 1 through 4 for more detail on PPE planning considerations, stakeholder assessment and process design.
Who Should Play a Role in Engaging Patients, Families and the Public?

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

Leaders and Decision-Makers:
- Set expectation of PPE as required function
- Make the promise to the patients and/or public
- Champion PPE
- Support development of organizational capacity for PPE
- Provide resources for PPE
- Ensure timelines accommodate meaningful PPE

Program Managers:
- Create opportunities for engagement of patients/families and the public in program planning and evaluation
- Make the promise to the patients and/or public
- Model engagement practice for front-line staff

Front Line Staff:
- Demonstrate responsiveness to patient/family values, preferences, beliefs in the care relationship
- Support active participation of the patient/family in care and decision-making
- Provide information to support patient/family decision-making

Engagement Practitioners:
- Design/implement PPE process
- Coach system on “how tos” of PPE
- Act as “neutral facilitator” or process guardian
- Support patients or public in PPE process

Patients/Families and the Public:
- Listen and learn
- Communicate values, preferences, aspirations
- Provide input and advice on proposals
- Engage in deliberation on ideas, co-develops alternatives
- Identify issues and solutions for implementation

Evaluation of PPE Processes

Research demonstrates that participants are typically satisfied with the engagement process itself but unhappy with the outcome - either their input was not acted upon or the sponsoring organization failed to communicate how the PPE process affected the decision. Evaluating both the process and the outcome is important to ensure good practice.
Key aspects of evaluation:

1. The goal of engagement was clear
2. Information provided during the engagement process was timely, balanced and easily understood
3. The appropriate stakeholders were identified
4. Design and implementation of the engagement process enabled meaningful participation
5. Information from stakeholders was accurately captured
6. Commitments made to stakeholders about their level of involvement were met
7. PPE led to better decision-making
8. Stakeholders understood how their input influenced decision-making
9. Opportunities for stakeholder evaluation of the PPE process were provided

Making a Paradigm Shift:
Advancing Engagement in Our Organization and Community

Like any major organizational change, advancing PPE is dependent on several critical success factors. What can be learned from other organizations that have embedded PPE?

Patient and public engagement requires champions at all levels of an organization - from front line staff that are passionate about patient-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 PPE, shifting their own view of engagement as “nice to do” to “must do” and communicating this expectation to the organization’s staff and physicians. The shift can be enabled by Health Human Resources planning, by pre-licensure curriculum change and by PPE-focused Continuing Professional Education.

Like any other significant change, PPE requires resources: dedicated staff, a framework that outlines the organization’s commitment and training that guides engagement efforts. Finally, we need to see engagement practice 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 evidence base for PPE. Reporting on results from engagement activities helps organizations learn, fosters ownership and spreads the practice.

Effective engagement holds tremendous potential to transform people, relationships and organizations. However, implementing the principles and practices of engagement requires a move away from business as usual. It means embracing innovative learning approaches, adopting new improvement methods, and bringing more rigour to planning and decision-making. It means democratizing organizations, 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 PPE into practice requires making, and fulfilling, a promise to patients, their families, and the public.
## APPENDIX 1
### Patient and Public Engagement Planning Worksheet

**PPE Project:**

<table>
<thead>
<tr>
<th>PPE Planning Considerations:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the decision to be made/question to answer?</td>
<td></td>
</tr>
<tr>
<td>Who is the decision-maker?</td>
<td></td>
</tr>
<tr>
<td>What is the decision statement?</td>
<td></td>
</tr>
<tr>
<td>What is not negotiable for legal, technical, clinical, fiscal or other reasons?</td>
<td></td>
</tr>
<tr>
<td>What are we hoping to achieve by engaging patients/families or the public?</td>
<td></td>
</tr>
<tr>
<td>What do we want to avoid?</td>
<td></td>
</tr>
<tr>
<td>What is the commitment of the project leadership to PPE?</td>
<td></td>
</tr>
<tr>
<td>What is staff commitment to PPE?</td>
<td></td>
</tr>
<tr>
<td>If necessary, what might build commitment to the PPE process?</td>
<td></td>
</tr>
<tr>
<td>What is the engagement goal? What is the level of engagement that we are committing to?</td>
<td></td>
</tr>
<tr>
<td>What resources are allocated for the PPE process? (funding, personnel and time)</td>
<td></td>
</tr>
<tr>
<td>What outside influences do we need to take into account?</td>
<td></td>
</tr>
<tr>
<td>What are the likely benefits of this PPE project?</td>
<td></td>
</tr>
</tbody>
</table>
**Data Collection and Documentation:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>What information already exists that can inform the engagement process?</td>
<td></td>
</tr>
<tr>
<td>(e.g. previous consultations, best practice literature, internet resources, staff knowledge, evaluations)?</td>
<td></td>
</tr>
<tr>
<td>How will the information gathered be presented to the decision-maker?</td>
<td></td>
</tr>
<tr>
<td>How will the information gathered, and the decision made, be presented back to the stakeholders?</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 2
Stakeholder Assessment Worksheet

PPE Project:

Decision Statement:
Stakeholders are individuals or groups who:
- May have an interest in the decision
- May be affected by the decision
- May have a significant contribution to make to the decision (knowledge or information, solutions, resources)

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Issues, Concerns, Values, Preferences</th>
<th>Level of Concern</th>
<th>Level of Influence</th>
<th>Level of Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 3
Stakeholder Engagement: Process Design Worksheet

PPE Project:

Decision Statement:

- Once stakeholders have been identified, their concerns understood, and their level of influence and engagement determined, the engagement process must be decided upon.
- The method must be matched to the engagement level/goal: if stakeholders are to be informed, communications materials may be prepared and distributed. If they are to be involved, an advisory group or other mechanism may be established.
- The stakeholders’ barriers to engagement must be identified in order to maximize accessibility of engagement efforts. For example, if a stakeholder group has low literacy, communications materials must be written in plain language. If stakeholders have mobility issues, the venue for engagement must be accessible.
- Recruitment strategies must be aligned with stakeholder needs, preferences and values. If the goal is to recruit youth for a focus group, using social media may be a suitable strategy. If the stakeholders are members of a remote First Nation, the best recruitment method may be to work with the local band office or through their community health representative.
- Engagement methods should be designed to:
  - Align with the engagement goal/level
  - Mitigate barriers to participation experienced by stakeholders
  - Reflect cultural values, preferences and beliefs of stakeholders. In First Nations communities they should also adhere to appropriate cultural protocols.

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Engagement Goal/Level</th>
<th>Barriers to Engagement</th>
<th>Recruitment Strategies</th>
<th>Engagement Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 4
Sample Engagement Methods

The following table illustrates examples of engagement methods appropriate to the different levels of patient and public participation.

<table>
<thead>
<tr>
<th>IAP2 Spectrum of Public Participation</th>
<th>Increasing level of public impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inform</td>
<td>Consult</td>
</tr>
<tr>
<td>News releases</td>
<td>Websites</td>
</tr>
<tr>
<td>Fact sheets</td>
<td>Focus groups</td>
</tr>
<tr>
<td>Websites</td>
<td>Surveys</td>
</tr>
<tr>
<td>Open houses</td>
<td>Public/small groups meetings</td>
</tr>
<tr>
<td>Ads/flyers</td>
<td></td>
</tr>
<tr>
<td>Info hotlines</td>
<td></td>
</tr>
<tr>
<td>Talk shows</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inform</td>
</tr>
<tr>
<td></td>
<td>Consult</td>
</tr>
<tr>
<td></td>
<td>Involve</td>
</tr>
<tr>
<td></td>
<td>Collaborate</td>
</tr>
<tr>
<td></td>
<td>Empower</td>
</tr>
<tr>
<td>Workshops</td>
<td>Advisory committees</td>
</tr>
<tr>
<td>Charrettes</td>
<td>Charrettes</td>
</tr>
<tr>
<td>Roundtables</td>
<td>Partnerships</td>
</tr>
<tr>
<td>Deliberative polling</td>
<td>Consensus building</td>
</tr>
<tr>
<td>Public/small group meetings</td>
<td>Participatory decision making</td>
</tr>
<tr>
<td>Citizen juries</td>
<td>Ballots</td>
</tr>
<tr>
<td></td>
<td>Delegated decisions</td>
</tr>
<tr>
<td></td>
<td>Service contracts</td>
</tr>
</tbody>
</table>


For more information on engagement methods, refer to IAP2’s worksheet on participation tools:
References

i www.participatorymedicine.org

ii http://www.gov.bc.ca/arr/social/down/transformative_change_accord.pdf

iii http://www.gov.bc.ca/arr/social/health/down/tripartite_health_plan_signed.pdf


v Compendium of Bibliographies from the Institute of Patient and Family Centred Care: http://www.ipfcc.org/advance/BI_Compendium_Bibliography_032010.pdf


xi http://psnet.ahrq.gov/primer.aspx?primerID=17


xvi http://www.bcauditor.com/online/pubs/394/394

xvii http://www.bcauditor.com/online/pubs/394/394

xviii www.iap2.org


Further reading

- Institute for Patient and Family Centred Care: http://www.ipfcc.org/
- IHI presentation: http://iom.edu/~media/Files/Activity%20Files/Quality/VSRT/2010-APR-017-Encouraging%20patient%20engagement%20and%20participation.ashx
- Agency for Healthcare Research and Quality report: http://www.google.ca/#sclient=psy&hl=en&q=engaging+patients+and+families+in+the+medical+home&aq=0&aqi=g1g-v1g-c1&qurl=&fp=ef685858c76d519f
- The Picker Institute: http://pickerinstitute.org/
- Invest in Engagement (Picker Institute Europe): http://www.investinengagement.info/
- International Association for Public Participation: http://www.iap2.org/

Please see your organization’s PPE staff for additional resources.
MEMBERS OF THE PATIENT AND PUBLIC ENGAGEMENT WORKING GROUP REPRESENT THE FOLLOWING ORGANIZATIONS:

- B.C. Ministry of Health www.gov.bc.ca/health
- ImpactBC www.impactbc.ca
- Interior Health www.interiorhealth.ca
- Fraser Health www.fraserhealth.ca
- Northern Health www.northernhealth.ca
- Provincial Health Services Authority www.phsa.ca
- Vancouver Coastal Health www.vch.ca
- Vancouver Island Health Authority www.viha.ca