The Voice of Patients and Families

What Kind of Patient Engagement is Right for You?

A Getting Started Guide – May 2017

Engagement & Patient Experience (EPE) wishes to thank the North Zone Patient Voice Working Team for granting permission to adapt their starter guide on “The Voice of Patients and Families: What kind of patient engagement is right for you?”
Index

Introduction……………………………………………………………………………………………………..Page 3
Purpose of Document……………………………………………………………………………………….Page 3
Quality Improvement and the Patient Experience…………………………………………………………Page 4
Introduction to the Wheel……………………………………………………………………………………Page 5
Steps to Successful Patient and Family Engagement……………………………………………………Page 6
Levels of Patient Engagement………………………………………………………………………………Page 7
General Examples of Engagement…………………………………………………………………………Page 8
Practical Examples for Matching Method with Purpose………………………………………………..Page 9
Its okay to keep it simple……………………………………………………………………………………Page 9
Benefits & Disadvantages for Various Methods………………………………………………………...Page 10
Evaluation………………………………………………………………………………………………………..Page 10
Tying it all Together with Resources (Templates & Tools)………………………………………………Page 11
Introduction

What is patient engagement? The philosophy and behaviours of patient engagement is founded on the belief that patients and their families are integral members of the healthcare team, and actively participate in all aspects of care, including as partners in planning, implementation and evaluation of existing and future care and services.

Involving patients and families in their own care and in co-designing care for patient populations aligns with two foundational Alberta Health Services (AHS) strategies: 1) Patient First Strategy – building a culture of patient-and family centred care, and the 2) People Strategy – enabling staff, physicians, and volunteers to provide high quality patient and family centred care and services.

Nationally, Accreditation Canada includes Client-Centred Services (PFCC) as a key quality dimension and has embedded the need for health care teams to partner with patients and families in their care and to include input from clients and families in the design, delivery and evaluation of health services.

AHS has adopted the four principles of patient and family centred care from the Institute for Patient and Family Centered Care. They are:

1. **Dignity and respect**: Listening to and honoring the individual (patient) and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

2. **Information sharing**: Communicating and sharing complete and unbiased information with clients 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.

3. **Partnership and participation**: Encouraging and supporting patients and families to participate in care and decision making to the extent that they wish.

4. **Collaboration**: Collaborating with patients and families in policy and program development, implementation and evaluation, facility design, professional education, and delivery of care.

---

1 The terms patient and client are used in this document – but other terms such as resident centred care, or person centred care are commonly used in different settings. Please determine for your program what term is suitable and comfortable for you.
Purpose of Document

“Involving patients and families in understanding and designing improvements to care processes leads to different insights and better results than providers working on their own.”

Canadian Foundation for Healthcare Improvement

The focus of this document is on the ways and means to engage with patients and families to improve the patient experience. This can be intimidating - it is not always easy or quick. This starter guide will help you to think about the many ways you can gain the voice of patients and families and where to start. Initial questions may be what is essential to your endeavour or initiative and who do you need to hear from? An inquiring mind, openness to new and innovative ideas, and bottom line, asking patients and families what they think will be of benefit to them are key. And the best way to find out is to ask, listen and involve patients and families.

Quality Improvement and the Patient Experience

The AHS Improvement Way (AIW) Model offers a practical framework for quality improvement projects. We have had a tendency to rely on “expert” clinicians’ best practice and now we know that when that is combined with “best” patient and family experience practices it results in better patient outcomes. We know that better solutions are those co-designed with patients and families. There are several touch points during the phases of a project to include the voice of patients and families and a host of methods for obtaining their input.

Involving the Voice of Patients/Families in Quality Improvement

- Define Opportunity
  - How will the project help patients and families? Discover what matters most to your patients and families.
  - Patients/Families Co-Define

- Build Understanding
  - What are patients & families currently experiencing?
  - Patients/Families Co-Assess

- Act to Improve
  - How can you, together with patients & families, identify which ideas will make a difference for patients & families?
  - Patients/Families Co-Create

- Sustain Results
  - How can patients & families perspectives be sought to assess what difference the change/intervention has actually made?
  - Patients/Families Co-Evaluate

AHS Improvement Way (AIW)
http://insite.albertahealthservices.ca/aiw.asp
Introduction to the Wheel

The visual of this “wheel” illustrates the numerous methods for gaining the voice of patients and families. Each method has its purpose, limitations and advantages contingent upon the scope of the project, patient population, resources and type of input needed. The “Wheel” has been broken down into three categories: collecting feedback, real time encounters, and collaborating at the planning table.

Collecting Feedback (BLUE)
Collecting feedback includes mining existing patient feedback such as survey and patient relations data, and using comment cards, focus groups, narratives and stories to gain a deeper understanding of the patient experience and identify opportunities for improvement.

Real Time Encounters (Turquoise)
Real time encounters such as leadership rounds and patient shadowing are ways to connect personally with patients, families and staff at the point of care to learn firsthand what is working well, what could be improved and acting upon their immediate feedback.

Collaborating at the Planning Table (GREEN)
Collaborating at the planning table involves partnering with patient and family advisors to make decisions and co-create solutions in committees, quality teams and councils.
**Steps to Successful Patient and Family Engagement**

Answering basic questions can get you on your way to successful engagement:

### 1. Where do I start? Start with a purpose and a promise!

- Why do you want patient/family input?
- What will you do with the information? What decisions will be impacted?
- What is the promise back to those whom you engage? (i.e. we promise to listen, and consider all of your feedback in our planning) SEE IAP2 on Page 5

### 2. Do I have any data already?

- Patient concerns & commendations (available on TABLEAU)
- Other data on TABLEAU – i.e. HCAHPS, HCIES, patient safety data
- Unit quality data
- Local patient satisfaction surveys
- Other ______________________________________________________________

### 3. How do I choose a method?

*Firstly: Using the IAP2 spectrum (on page 5) – think about the level at which you want to engage!*

What to consider:
- Remember your purpose and promise
- Is there a belief that patients are experts on their experience and they have information we need to hear? Will their input be valued?
- What is the benefit to the patients, families & communities you engage?
- Logistics – how will you present the opportunity to patients/families? Recruit? What barriers might exist for those you want to engage with?
- Cost, resources, risk, time and timing – ideally patient and family perspectives should be sought throughout the project and involving them as early as possible (consider risk of tokenism)
- Do you have leadership support?

### 4. Are my methods working?

*See evaluation section on Page 10!*
One of our AHS values is engagement, **but what does it mean to engage patients & families?** Consider where on this spectrum you would like to engage patients & families in your project or service.

### Levels of Patient Engagement

**IAP2’s Spectrum of Engagement – Increasing Levels of Patient Involvement**

*Adapted from:*


<table>
<thead>
<tr>
<th>Inform</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Empower</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal</strong></td>
<td>To provide the patient with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or decisions.</td>
<td>To obtain patient feedback on analysis, alternatives and/or decisions.</td>
<td>To work directly with the patient throughout the process to ensure that patient concerns and aspirations are consistently understood and considered.</td>
<td>To partner with the patient in each aspect of the decision - including the development of alternatives and the identification of the preferred solutions.</td>
</tr>
<tr>
<td><strong>Promise to the Patient</strong></td>
<td>“We will keep you informed.”</td>
<td>“We will keep you informed, listen and acknowledge your concerns and aspirations and provide feedback on how patient feedback influenced decisions.”</td>
<td>“We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how patient input influenced the decision.”</td>
<td>“We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into decisions to the maximum extent possible.”</td>
</tr>
<tr>
<td><strong>How Can This Be Done?</strong></td>
<td>Pamphlets • Brochures • Websites</td>
<td>Focus groups • Surveys • Comment box</td>
<td>Workshops • World Cafes</td>
<td>Citizen/patient Advisory Committees • Participatory Decision Making</td>
</tr>
</tbody>
</table>

General Examples of Engagement

INFORM – METHODS

- Brochures, websites, news releases, fact sheets, an information line, open houses, information kiosks, list serves, e-mail.

*Note: Inform generally implies a one-way conversation – and does not include obtaining input from patients/families.

CONSULT – METHODS

- Surveys [e.g. AHS – In-Patients Hospital Consumer Assessment of Healthcare Providers and Systems (HCAPHS)]. Data available at the unit level.
- Other Surveys – kiosks, paper, telephone, online, portable devices, in-person etc.
- Patient Concerns and Commendations (e.g. AHS – Patient Relations Data).
- Focus groups to gather information about opinions, ideas, preferences and experiences.
- Rounding on Patients – Leadership or staff rounding.
- Suggestions/feedback box, comment cards for input on specific questions or topics.
- World Cafés, town hall meetings, open space meetings, public forums, and open houses to solicit input from a large number of people.
- Structured interviews to gather more in-depth information.
- Feedback “registers” – people advise via reviewing materials.
- Patient diaries.

INOLVE – METHODS

- Workshops – convening a group of patients (and planners) to work on an issue, encourage discussion and generate joint problem-solving.
- Open space meetings and appreciative inquiry. World Cafés can also be used to involve patients and families in decision making, co-design, etc.
- Observation of existing services in action to provide a patient perspective on potential areas for improvement – patient experience mapping, shadowing, journey mapping.
- In-depth interviews – patients/staff may interview current patients about their experiences, discuss ideas.
- Focused conversations to explore issues on specific issues.

COLLABORATE – METHODS

- Advisory committees - patients participate in decision making and co-design for the length of time and depth of participation required throughout the whole planning process.
- Patient journey mapping – patients and providers come together to map the healthcare journey then analyse the resulting map to look for ways to improve programs and systems.
- Consensus-building activities/forums.

EMPOWER

- Citizen juries, voting by ballot, stakeholder decision-making.
Practical Examples for Matching Method (tactic) with Purpose

**Objective 1:** Identify experience gaps for clients utilizing outpatient rehab

**IAP2 Level:**
- Consult
- Involve

**Possible Methods:**
- Experience Surveys for existing service users
- Focus Groups/Interviews with hard to reach or non-users of service

**Objective 2:** Integrate the voice of patients/families into unit/program quality improvement

**IAP2 Level:**
- Involve
- Collaborate

**Possible Methods:**
- Patient Advisors on Quality Council
- Leader Rounding with feedback to Quality Council/Quality Huddles
- With patients & families - regular review of concerns/commendations and patient experience data

**Objective 3:** Integrate the voice of patients & families into physical space redesign of outpatient clinic

**IAP2 Level:**
- Consult
- Involve

**Possible Methods:**
- Short experience surveys with clients at clinic
- Telephone Interviews
- Focus Group

---

**It’s OK to Keep It Simple**

- What about including a client or family member in a walkabout?
- What about including stories where possible?
- What about just asking 1 client? 10 clients?
- What about putting up a suggestion box?
- What about setting aside one month of the year to look at HCAHPS data for your site/unit?
Benefits & Disadvantages for Various Methods at Each Level of Patient Engagement

You will likely use many engagement methods throughout your project & what method you choose depends on your purpose, promise, resources, time and energy. Here are two resources that will help explain various benefits and disadvantages:

<table>
<thead>
<tr>
<th>Resource</th>
<th>Highlights</th>
<th>Link</th>
</tr>
</thead>
</table>

Evaluation

Promise - Make sure to communicate and follow up with your clients & families. Consider:

- Are my clients & families waiting to hear back from me?
- How will I provide them with some feedback? How will I let them know how the engagement process affected decisions?

Strategies and Process - Evaluate your engagement strategies – consider process, decisions made and the outcomes of the engagement. Consider:

- What was the process of engagement – what worked well? Did we engage you effectively?
- What was the value to those that I engaged?
- What would I do differently next time?
- How is my program different because I took the time to engage? How so?
Tying it all Together with Resources (Templates & Tools)

<table>
<thead>
<tr>
<th>Resource</th>
<th>Highlights</th>
<th>Link</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AIW A3 TEMPLATE</strong></td>
<td>• Includes ideas and things to think about, to ensure that the voice of patients &amp; families is part of any quality initiative</td>
<td>[PDF](AIW-Patient Engagement Workshop)</td>
</tr>
<tr>
<td>Engaging patients &amp; families as <strong>ADVISORS</strong></td>
<td>• Guidebooks • Decision trees • Resources for recruitment and onboarding • Resources to evaluate patient advisors</td>
<td>Patient Engagement Website <a href="http://insite.albertahealthservices.ca/5255.asp">http://insite.albertahealthservices.ca/5255.asp</a></td>
</tr>
<tr>
<td>Patients &amp; families who want to <strong>VOLUNTEER</strong></td>
<td>• Information on external website</td>
<td><a href="http://www.albertahealthservices.ca/info/patientengagement.aspx">http://www.albertahealthservices.ca/info/patientengagement.aspx</a></td>
</tr>
</tbody>
</table>

If you require assistance in determining which method(s) to use, contact the Engagement and Patient Experience Team at [patient.engagement@ahs.ca](mailto:patient.engagement@ahs.ca)