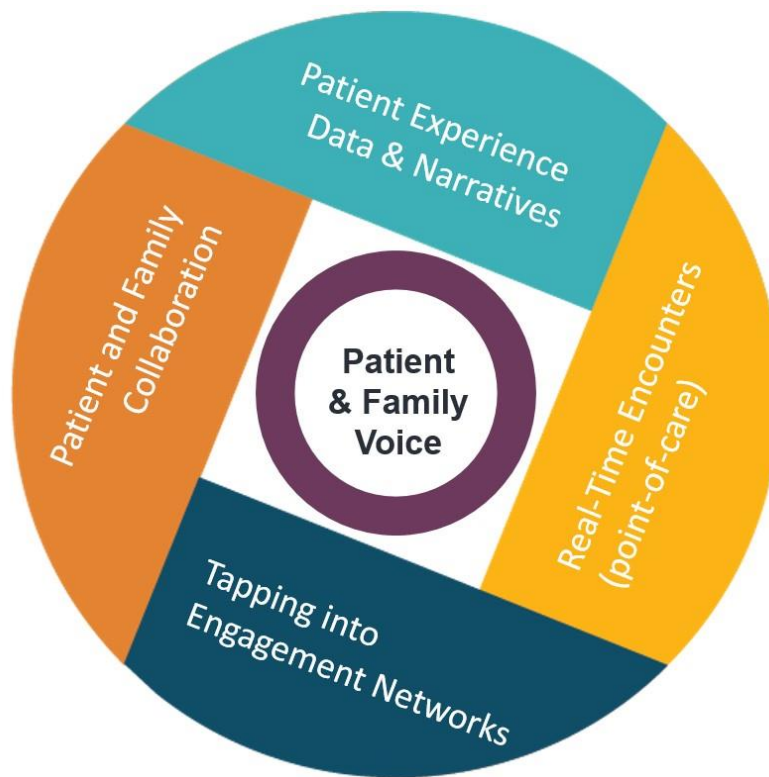


The Voice of Patients and Families



Guide to Patient Engagement 2021

Engagement and Patient Experience

patient.engagement@ahs.ca

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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?”

Introduction

What is patient engagement? The philosophy and behaviours of patient engagement are founded on the belief that patients¹ and their families are integral members of the health-care team, and actively participate in all aspects of care, including as partners in planning, implementation and evaluation of existing and future care and services.

Patient engagement begins with the principles of patient and family centred care (PFCC). AHS has adopted these four principles of PFCC, from the [Institute for Patient and Family Centered Care](#). (see appendix 1)

- Respect and Dignity
- Information Sharing
- Participation
- Collaboration

The Alberta Health Services [Patient First Commitments](#) listed below were endorsed by the Executive Leadership Team, and reflect shared learnings by [Patient First](#) and the other [Foundational Strategies](#) following their initial launches and early implementation.

1. Making sure patients and families have stronger voices and are fully informed and involved in decisions about their healthcare.
2. Partnering with patients, families and communities when developing, delivering and improving healthcare services.
3. Enabling our people, whatever their titles, roles or locations, to act on what matters to patients and families.

The 3rd commitment highlights the interconnected work and shared aims with Our People Strategy, which provides another foundational ‘vehicle’ to help us get to our intended destination of patient experience excellence. This engagement guide is a practical tool to enable our leaders, staff, physicians and other workforce to action these commitments through various methods of engagement.

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.

Another key driver for patient engagement is accreditation. Accreditation Canada includes Client-Centred Services as a key quality dimension and has embedded the need for health care teams to: 1) partner with patients and families in their care, and 2) to include input from clients and families in the design, delivery and evaluation of health services. Patient engagement strategies have consistently been noted during accreditation surveys as demonstration of inclusion of input from patients and families (see Accreditation information [on Insite](#)).

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.”

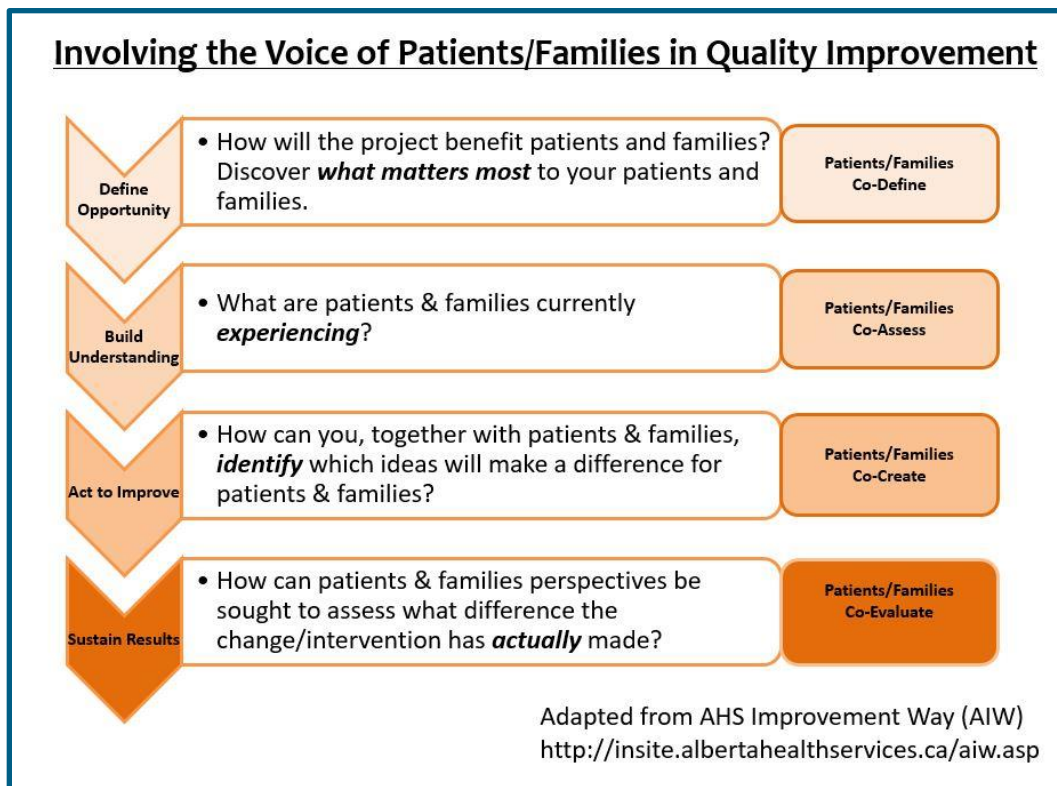
Canadian Foundation for Healthcare Improvement.

The focus of this document is on the ways and means to engage with patients and families to improve patient experience, safety, quality, and healthcare outcomes. This can be intimidating and at first glance can appear complex, but with thoughtful consideration and planning it becomes easier. This guide will help you to think about the many ways you can include the voice of patients and families and where to start.

Begin your endeavour or initiative with an inquiring mind, an openness to new and innovative ideas, and with the intention to learn from patients and families about what they think will be of benefit to them and the system. The best way to find out is to ask, listen to, and involve patients and families.

Quality Improvement and Patient Experience

The AHS Improvement Way (AIW) Model offers a 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 designed in collaboration 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.



Spectrum of Engagement

The [International Association of Public Participation](#) (IAP2) offers a useful tool that illustrates the spectrum of engagement that we can undertake with patients and families. To fully understand the remainder of this guide, if you are not already familiar with the spectrum, it is recommended that you take some time to review Appendix 2. This is the Alberta Health Services adaptation of the spectrum, and describes five levels of engagement, corresponding promises to patients and families, and some examples of techniques under each level. Please note: depending on how the various techniques are used, they can sometimes fit under multiple levels of engagement.

Introduction to the Wheel

The visual of this “wheel” (full printable version on the following page) illustrates four groups of 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 available, and type of input needed. The “Wheel” has been broken down into four sections:



Patient Experience Data & Narratives

This section includes using existing patient experience data, gathering new data, patient stories, focus groups, and interviews. These methods help us better understand how patients and families are experiencing our healthcare system. Each method has the potential to highlight important aspects of care to help improve the patient experience.



Real-Time Encounters

This section includes patient and family feedback that can be used to identify urgent issues (e.g., safety concerns), make real-time improvements, and identify trends over time. Data can be gathered, analyzed, and utilized for quality improvement in practical and often easy ways. Examples of real time encounters include everyday team-patient interactions, leader rounding, and patient advisor rounding.



Tapping into Engagement Networks

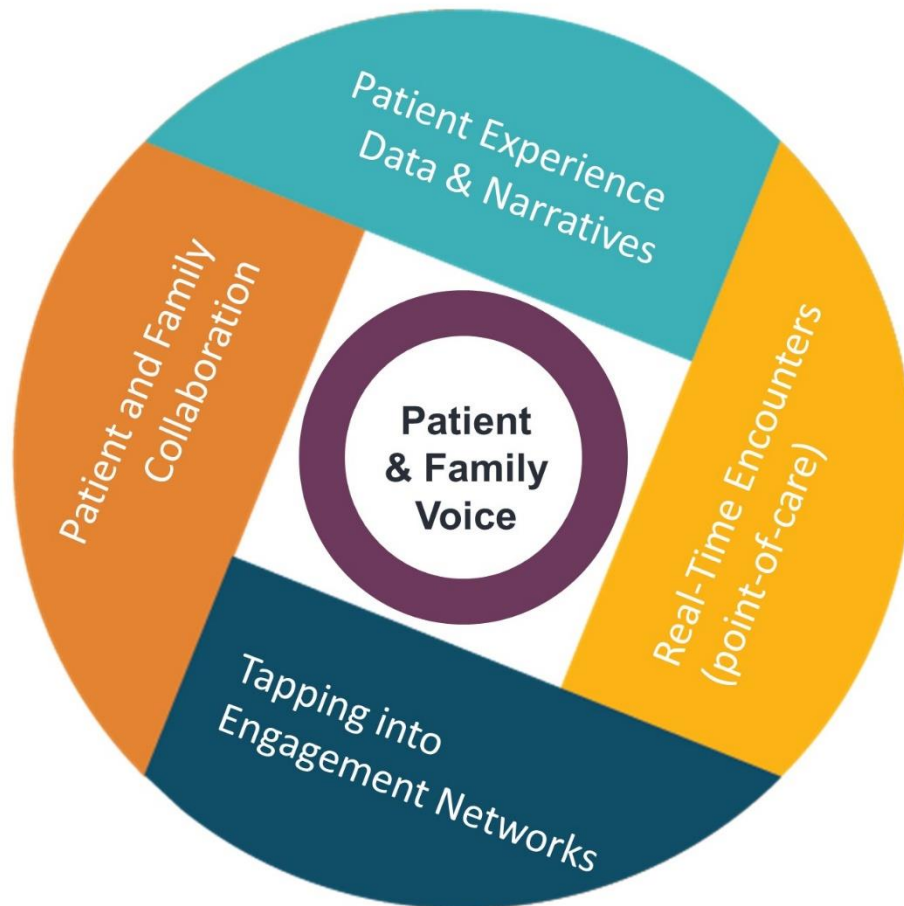
This section is for tapping into existing patient / family advisors and networks to ask questions and consult. This method of engagement is typically short-term. Patient and family advisors are registered in the AHS volunteer registry (managed by Volunteer Resources). There are advisory groups and networks in geographic locations (local, zone, and provincial, e.g., Provincial Patient and Family Advisory Group) and care areas (e.g., Rehabilitation Advisor Group). AHS Community Engagement also has opportunities to connect with citizens / the public (e.g., Health Advisory Councils).



Patient and Family Collaboration

This section includes ways to seek out and partner with patient and family advisors or those with lived experience for a specific project or committee. Generally, this method of engagement is longer term, is more complex and requires more people resources. This can include finding, recruiting, on-boarding, supporting, and sustaining advisors on an advisory group or to join a quality improvement team or project.

The Wheel: Including the Voice of Patients & Families



Patient Experience Data & Narratives

- Surveys
- Patient Relations concerns and commendations, and other sources of feedback (e.g., letter from a patient)
- Digital stories and patient narratives
- Interviews and focus groups with patients and families
- Patient Journey Mapping



Real-Time Encounters (point-of-care)

- Local health care team + patient interactions / observations (identify patients / families to involve in quality improvement)
- Leader Rounding
- Patient Advisor Rounding



Tapping into Engagement Networks

- Consultations with registered volunteers / advisors
- Community Engagement – Together 4 Health, Community Citizen Health Advisory Councils and Provincial Advisory Councils



Patient and Family Collaboration

- Involve people with lived experience on projects / committees
- Patient and Family Advisor members on committees, e.g.:
 - Quality councils and committees (local, zone, provincial)
 - Quality assurance committees
 - Patient and family advisory councils

N.B. Patient is defined as Person, Client, Resident and represents all who access services across the healthcare continuum.

For additional support contact
patient.engagement@ahs.ca

Steps to Successful Patient and Family Engagement

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

1. Where do I start? What's the purpose of the project?
<ul style="list-style-type: none"><input type="checkbox"/> What specifically are you trying to improve?<input type="checkbox"/> Why do you want patient/family input?<input type="checkbox"/> Why will patients be able to help?<input type="checkbox"/> Who will have insights?<input type="checkbox"/> What will you do with the information?<input type="checkbox"/> What decisions will be impacted? How will decisions be impacted?
2. What will be your level of patient participation / engagement?
<ul style="list-style-type: none"><input type="checkbox"/> Is there a belief that patients are experts on their experience and that they have information we need to hear?<input type="checkbox"/> Is there a commitment to value their input? And to act on it?<input type="checkbox"/> Which level of participation is most appropriate / feasible for your project? Consult the IAP2 spectrum (appendix 2) to think through and make decisions about the levels of engagement you will carry out (e.g., consult, involve, collaborate).<input type="checkbox"/> What is your promise / commitment to the patients and families you involve in the project? (e.g., we promise to listen, consider all feedback in our planning and report back on the decisions made, implementation etc.)
3. How do I choose methods to support patient engagement?
<p>Which methods will you choose to gain the voice and involvement of patients / families that will provide the insights you are hoping to realize?</p> <p>What to consider:</p> <ul style="list-style-type: none"><input type="checkbox"/> Remember your purpose and promise.<input type="checkbox"/> Do you have leadership support?<input type="checkbox"/> Is there current data available (e.g., patient concerns, experience surveys)?<input type="checkbox"/> How will engaging patients, families, and communities be of benefit to them?<input type="checkbox"/> Logistics – how will you present the opportunity to patients/families? Recruit?<input type="checkbox"/> What barriers might exist for those you want to engage with?<input type="checkbox"/> Cost, resources, risk, time and timing – ideally patient and family perspectives should be sought throughout the project and involving them as early as possible minimizes the risk of tokenism.
4. Are my methods working? Are we achieving our aims for the project?
<p>*See evaluation section on Page 10</p>

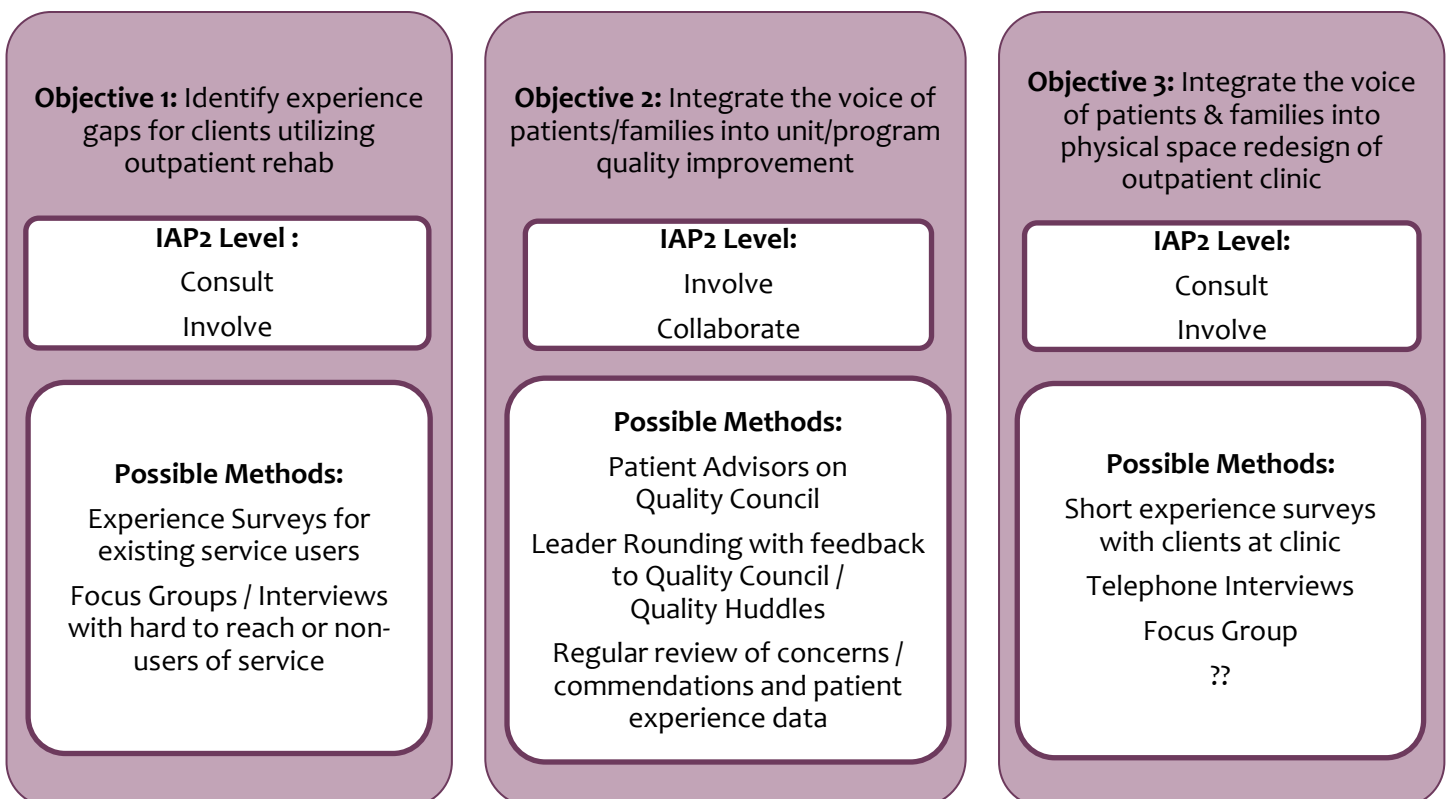
A Practical Example for Matching Method (tactic) with Purpose

When considering various methods of engagement, the process is not always linear. You can tackle things in several ways. You can start by considering what level of engagement you are aiming for (on the IAP2 spectrum – Appendix 2) and pick engagement techniques that correspond with that level. Alternatively, you can start with the various methods you have planned and ensure the level of engagement is appropriate.

Site Quality Council – Rehab Clinic

A Site Quality Council for a Rehab Clinic is involved in a few different projects. In their recent Quality Council meetings, they looked at all the ways they are including (or planning to include) patients and families, and how those fit with different levels of engagement on the IAP2 spectrum.

For their first objective, the team was well under-way in the project design before they considered the possible levels of engagement. They decided in retrospect that they were using methods that got to *consult* and *involve* levels and that this was where they wanted to be. When they looked at their second objective, they picked some methods based on the IAP2 level of *involve* and *collaborate*, which guided their plan to recruit a Patient and Family Advisor for their Quality Council, to implement Leader Rounding, and to consider patient concerns data more carefully. For their third objective, they plan to do some survey work, phone interviews and focus groups. In reviewing this, they realized that these are all *consult* activities, and that if they want to include activities at the *involve* level, they will have to add another method.



Some more tips and ideas

- **It's OK to Keep It Simple.** What about:
 - including a client or family member in a walkabout?
 - including patient and family stories where possible?
 - just asking a few questions to one or ten clients at the point of care?
 - picking one month of the year to look at HCAHPS data for your site/unit?
 - doing leader rounding for one hour, once a month?
 - sending an email to an established patient network to gain their feedback on resources you are developing?
 - consulting an established patient / family advisory group to seek their input

- **There are benefits and pitfalls to all engagement methods**

There is no one right engagement method for a project. It can be easy to fall into the trap of focusing only on one engagement level, for example, the *collaborate* level (which is almost invariably a more resource intensive level). You may assume that this is the better approach because of the depth of engagement, however, by using the *consult* and *involve* levels you may succeed in gaining a wider breadth of patient and family voices.

Ideally, try to use several methods at different touchpoints through the life of a project (e.g., defining and assessing the issue, determining solutions, making recommendations, implementing, and evaluating changes). The methods you choose depends on your project, purpose, promise, resources, time, and energy.

- **Start early... but it's not too late if you haven't already**

"The best time to plant a tree was 20 years ago. The second-best time is now." – Chinese Proverb

Ideally, planning from the start to involve patients and ensure their voice informs a project is the best way to go. But better late than never—find ways and means to engage with patients and families even when your project is well on its way. Be creative, as there are usually ways to go forward with strategies for engagement.

- **Diversity of patient experiences – being inclusive and representative**

Ensure that you have a diversity of voices and patient experiences in your project. Consider carefully who is going to be affected by your project. Include patients and families that represent the patient population related to the project and who have had actual experiences. Categories to include are age, gender, ethnicity, at-risk socioeconomic status, geographical location, disabilities. Consider if there are any barriers inherent in your engagement activities that may make it difficult for certain groups to have their voices heard. You may need to consult other teams (within or external to AHS) to assist in engagement activities with diverse patient populations. A valuable resource is the [Framework for Diversity in Patient Engagement \(CFHI\)](#).

Evaluation

Purpose / Goal

- Were we successful in including the voice of patients and families? How so?
- If not, why not?

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 their voice affected decisions?
- What was of value to the patients / families that I engaged?

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

- What methods did I use to include the voice of patients and families?
- What worked well? What didn't?
- Was the level of engagement effective to meet our goals?
- What would I do differently next time?
- Did the project benefit from including the voice and patients? How so?
- If your project involved patient / family advisors; check out further evaluation ideas in the [A Guidebook for Engaging Patient and Family Advisors](#)

Additional Resources

Resource	Highlights	Link
Patient Engagement HEARD & VALUED (Fraser Health)	<ul style="list-style-type: none"> • Workbook • Highlights issues for marginalized populations • Highlights methods for various levels of engagement 	https://www.cfhi-fcass.ca/docs/default-source/itr/pe-hub/awesome_handbook-fraserhealth.pdf
Engagement Guiding Principles	<ul style="list-style-type: none"> • Provides five guiding principles for engagement 	https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/cfhi-engagement-guiding-principles-e.pdf
Framework for Diversity in Patient Engagement	<ul style="list-style-type: none"> • tool that can be completed together with staff, patients, family and caregivers to help guide and support diverse and inclusive engagement initiatives 	https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/dle-worksheet-e.pdf
Patient and Family Engagement on Insite	<ul style="list-style-type: none"> • Link to The Wheel • Additional resources for each of the methods referenced 	https://insite.albertahealthservices.ca/ghi/Page17294.aspx

If you require assistance in including the voice of patients and families in your projects and work, please contact the Engagement and Patient Experience Team at patient.engagement@ahs.ca

Patient & Family Centred Care Principles

Respect & Dignity



We listen to and honour patient and family perspectives, beliefs, values cultural backgrounds and choices.

Information Sharing



We communicate & share complete unbiased information in ways that are affirming, timely, accurate and useful for making decisions.

Participation



We encourage and support patients to participate in care and decision-making at the level they choose.

Collaboration



We collaborate with patients & families in policy & program development, implementation, evaluation, education, research, and delivery of care.

IAP2's Spectrum of Engagement – Increasing Levels of Patient & Family Participation

	Inform	Consult	Involve	Collaborate	Empower
Goal	To provide patients and families with balanced and objective information to assist in understanding the problem, alternatives, opportunities and/or solutions.	To obtain feedback, analysis, ideas, wisdom, alternatives and/or decisions from patients and families.	To work with patients and families throughout the process to ensure their experiences, concerns, ideas and aspirations are invited, understood and considered.	To partner with patients and families in each aspect of the decision - including the development of alternatives and the identification of the preferred solutions.	To place final decision-making in the hands of the patients and families.
Promise to the Patient	<i>"We will keep you informed."</i>	<i>"We will listen and acknowledge your concerns, experiences, ideas, and aspirations and let you know how your these influenced decision making."</i>	<i>"We will work with you to ensure that your concerns, experiences, ideas and aspirations are reflected in the decisions we make."</i>	<i>"We will partner with you to identify solutions and make decisions together."</i>	<i>"We will implement the solutions you identify."</i>
Ways to Engage	<ul style="list-style-type: none"> ▪ Brochures ▪ Website ▪ Fact Sheets ▪ Digital Stories 	<ul style="list-style-type: none"> ▪ Surveys & Data ▪ Focus Groups ▪ Structured Interviews ▪ Journey Mapping ▪ Leader Rounding ▪ Together 4 Health ▪ Point of Care encounters 	<ul style="list-style-type: none"> ▪ Workshops ▪ Focus Groups ▪ World Cafes ▪ Design days 	<ul style="list-style-type: none"> ▪ Patient & Family Advisors ▪ People with lived experience included in projects, working groups, councils and committees. ▪ Citizen/patient advisory committees 	<ul style="list-style-type: none"> ▪ Delegated decision making to patients and families ▪ Creating Digital Stories

Adapted from: International Association for Public Participation (2006). *IAP2's Public participation spectrum* (pp. 4). In *Planning for effective public participation: Student manual*. Thornton, CO: International Association for Public Participation.