

A Guidebook for Engaging Patient and Family Advisors

September 2020

The Engagement and Patient Experience Team has developed a step-by-step process to assist you in partnering with patient and family advisors.

Two different delivery options are available, depending on your preferred learning style:

- an algorithm format, which includes a checklist and decision tree, or
- the Guidebook, which is a narrative format.

The Engagement and Patient Experience Team is available to support you through your work with patient and family advisors and welcomes all your feedback.

Contact us at patient.engagement@ahs.ca



This work is dedicated to the volunteer patient and family advisors, staff and physicians who are working together in AHS to help improve the quality and safety of health services and the patient experience for all Albertans and beyond.

The Guidebook for Engaging Patient and Family Advisors reflects current knowledge for developing these important partnerships. The Guidebook is a living document and will be updated regularly. Original version January 2016.

If you have any comments or suggestions, please send them to patient.engagement@ahs.ca

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Introduction

AHS has as one of its guiding principles that Patients and Families must be central to all we do in AHS. Including the voice of patients and families in our work improves the safety and quality of care and the patient, staff and physician experience. There are multiple ways to gather the patient voice from looking at data (HCAPs, Concerns, Clinical data), feedback forms, interviews, focus groups and actual involvement of patient and family advisors in the projects from inception (see voices wheel).

With the [Patient First Strategy](#), AHS is strengthening its culture and practices to fully embrace Patient-and Family Centred Care (PFCC) at AHS. Patient- and family-centred care sees patients and families as integral members of the health-care team, and encourages their active participation in all aspects of care, including as partners in planning, implementation and evaluation of existing and future care and services.

Patient engagement through partnering with patient and family advisors is one approach to improving the culture of Patient and Family Centred Care in AHS. Evaluating the experience of this partnering is important for continuous quality improvement.

Successful engagement or partnering with patient and family advisors requires rigorous planning, skilful execution and typically involves a series of steps. 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 makers reports back to the participants about how their involvement shaped the decision. (from Ministry of Health BC, Patient, Family, Caregiver and Public Engagement Framework 2018.)

The Guidebook for Engaging Patient and Family Advisors provides a framework for developing successful partnerships with patient and family advisors. In this document, engaging with advisors includes the work of informal groups, working groups, and more formal committee structures.

The *Readiness Checklist for Partnering with Patient and Family Advisors* (Appendix A) and the *Decision Tool* (Appendix B) are also available on the Patient Engagement webpage to help guide the process.

Who are Patient and Family Advisors?

“We know when patient and families collaborate with staff and health leaders, good things happen.”

Engaging Patients and Families to Improve Healthcare,

Canadian Foundation for
Healthcare Improvement

Patient and family advisors are individuals who volunteer their time and experience to improve the quality, safety and experience of healthcare services. Each patient and family advisor brings their lived experience of being a patient, or a patient’s family member to help us understand what matters most to patients and families, and how we can effectively design programs that meet the needs of those we serve.

The Guidebook provides a sequential five-step process and the tasks necessary in each step to help you partner successfully with patient and family advisors (See Figure 1 and Appendix C). This five-step process was developed from evidence based best practices as well as from the lived experience of the AHS Engagement and Patient Experience Department, Volunteer Resources and patient and family advisors working with AHS.

The five steps are:

1. Make the decision
2. Get ready
3. Recruit, register and orientate
4. Support and mentor
5. Monitor progress and results

Resources for each step are included in the Appendices and are also available on the Engagement and Patient Experience [webpage](#).

Five Step Process to Engage Patient and Family Advisors

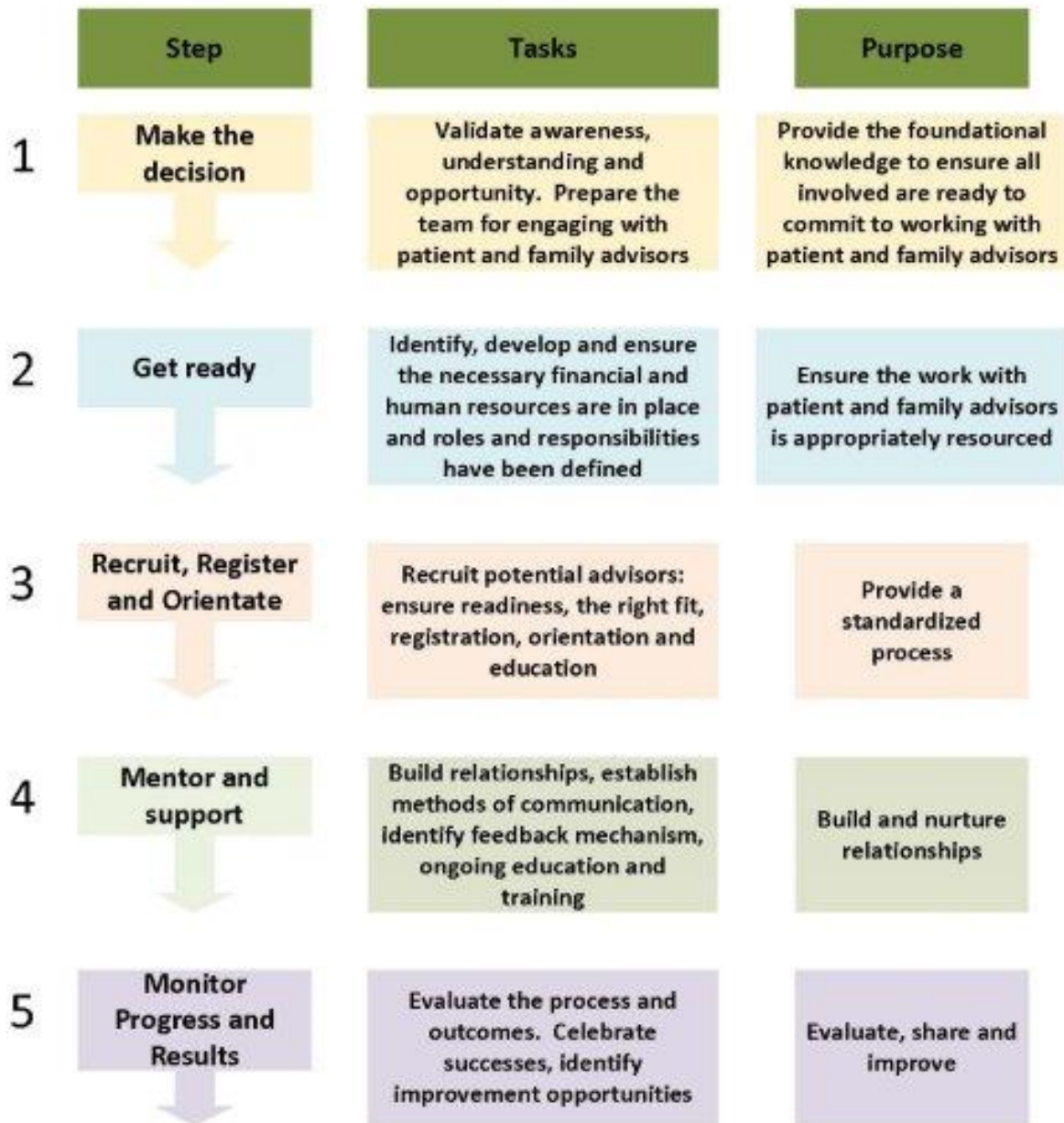


Figure 1: Five-Step Process for Engaging Patient and Family Advisors (developed by Carol Eigenseher, Consultant, Engagement and Patient Experience, 2015)

If you require additional support, please contact the Patient Engagement and Experience Department at patient.engagement@ahs.ca.

Step One – Make the Decision

This step is about doing the critical preparatory work to ensure successful Patient Engagement. It includes building an understanding of the concepts of Patient and Family Centred Care (PFCC), Patient Engagement and Patient Experience along with determining the goal and objectives of including the patient voice, determining the level of engagement the work will be at (IAP2 Spectrum) and determining readiness of the team from leadership down.

Task 1: What is Patient Engagement?

Understanding the concepts of Patient Engagement, Patient and Family Centred Care and Patient Experience is helpful to build confidence and knowledge about working with Patient and Family Advisors. Patient and Family Centred Care (or person/people centred care) is the philosophy of care, Patient Engagement is an approach to Patient and Family Centred Care and Patient Experience is an outcome.

Patient engagement is the act of involving the patient and their family in decision-making, design, planning, delivery and evaluation of health services. When patients are actively engaged, they can become informed decision makers in their own care and help improve the healthcare system. When healthcare providers listen to and work with patients and family members, programs, service delivery and policy can be improved by their first-hand knowledge, insight and experience. ¹

Patients and families are uniquely placed to understand Alberta Health Services (AHS) from their lived experiences with healthcare services.

In AHS we use the International Association of Public Participations Spectrum of Engagement as a guiding framework on how to look at levels of engagement and the promise back to participants.

Task 2: Understand the Value of Working with Patient and Family Advisors

Health-care organizations around the world have adopted patient engagement and patient- and family- centred care practices as approaches to improve the quality and safety of health services.

Foundational reports like the *2004 Canadian Adverse Events Study* by Baker and Norton, the 1999 Institute of Medicine report, *To Err is Human*, and the follow-up report in 2001, *Crossing the Quality Chasm*, reveal there is a gap in the quality and safety of the care we want to provide and the care that is being provided. Including the patient and family voice in health care and quality improvement is recognized as an important way to help bridge that gap.

Numerous ministries and organizations across Canada have developed excellent frameworks, guides and resources around Patient Engagement. Some of these organizations are the Canadian Foundation for Health Care Improvement, Health Quality Council of Ontario, , Change Foundation of Canada,, Government of BC Ministry of Health , and the Patient Voices Network of BC just to name a few at end of document).

“Patient Engagement creates an opportunity where the focus is on the ‘we’ and not on patients, the system or providers so the expertise and experience of all stakeholders could be heard and acted on.”

Calgary participant

¹ Baker GR, Judd M, Fancott C, Maika C. Creating ‘engagement-capable environments’ in Health care, 2016 [cited 2019 Mar 2] Available from : <https://www.theberylinstitute.org/page/DefiningPatientExp>.

In AHS we now have over ten years of on the ground experience of working to embed the culture and practices of PFCC and partnering with patient and family advisors. There have been many learnings over the years and recognition that our vast geographical area and accountability for so many facets of the health service delivery means that partnering with advisors must be adaptable and flexible.

The benefits for the patient and family advisor in working with AHS are the same regardless of where you are in the system:

- A chance to improve the quality and safety of health services
- The opportunity to make a contribution
- The opportunity to be a part of meaningful change
- Increased ability to understand and share information with other patients and families about the health system and policies of health care
- The opportunity to network with staff, providers and leaders and other advisors
- Expand knowledge and skills about patient- and family-centered care and the health system

“The only true measures of quality are the outcomes that matter to patients”
Porter & Lee, 2013

The benefits to AHS in working with patient and family advisors:

- Improve the quality and safety of health care
- Gain a broader, different or fresh perspective
- Help to address the “most important” issues and objectives
- Validate good practices and what matters most to patients
- Create innovative solutions
- Help to achieve more complete results
- Increase empathy for understanding patients and families

Task 3: Determine Your Goals and Objectives for Including the Patient Voice

Projects that impact patients and families need to have a patient and family perspective. The tool *Making the Decision to Engage* can help clarify your goals, objectives and readiness for engagement (Appendix D). It is important for successful engagement that you determine why you want to include the patient and family voice in your work.

There are multiple ways for obtaining the voice of patients and families. Working with patient and family advisors is one of many options (See Figure Two).

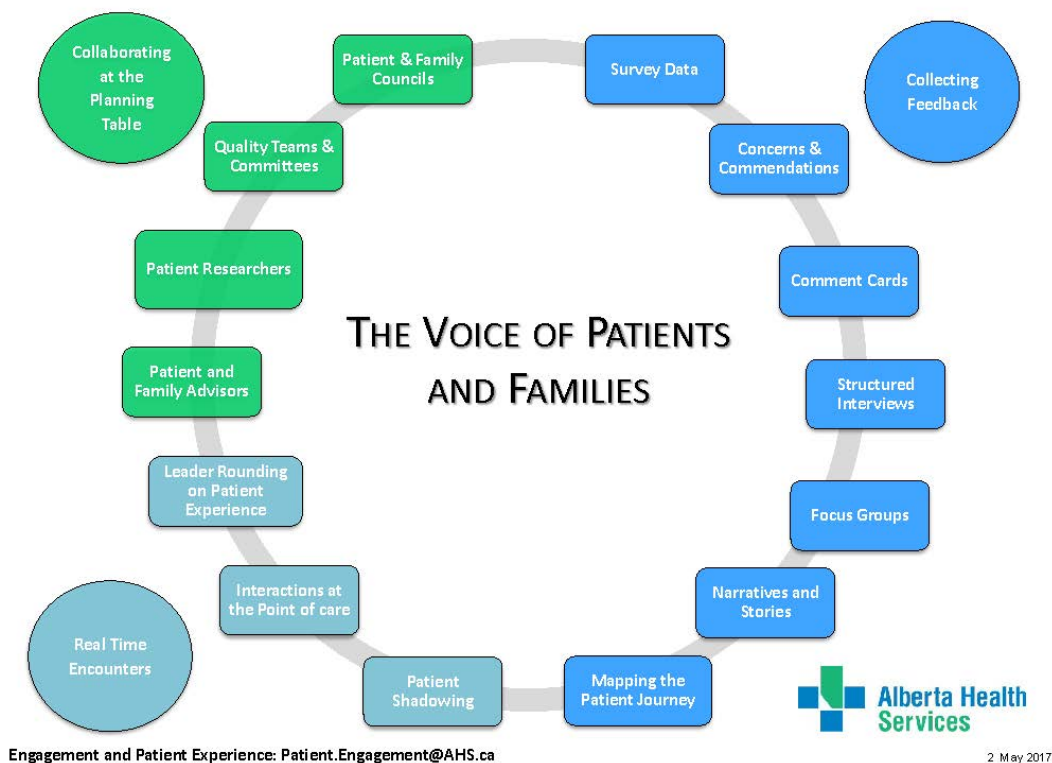


Figure 2: How do you include the voice of patients and families?

When choosing how to include the patient and family perspective, consider what method of participation would be appropriate for your purpose, patient population, resources, type of input you need and capacity to act on the patient and family voice.

As well, to truly get the patient and family voice, it is often preferable to include different methods of engagement throughout the course of the project.

If you require assistance in determining the best method(s) for the purpose and scope of your work, contact the Engagement and Patient Experience Team at patient.engagement@ahs.ca

Task 4: Determine the Level of Engagement

The International Association of Public Participation Spectrum (IAP2) helps to determine what level of engagement is most appropriate for your work.

The spectrum describes five levels of engagement with increasing intensity and participation: Inform, Consult, Involve, Collaborate and Empower (See Figure Three).

Points to note about the IAP2 Spectrum of Engagement are the participation goal (how the patient/family voice will influence the decision), the promise back to the patient/family (how their input affected the decision), and multiple methods for engaging at each level.

	Inform	Consult	Involve	Collaborate	Empower
Goal	To provide the patient with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain patient feedback on analysis, alternatives and/or decisions.	To work directly with the patient throughout the process to ensure that patient concerns and aspirations are consistently understood and considered.	To partner with the patient 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 patient.
Promise to the Patient	<i>"We will keep you informed."</i>	<i>"We will keep you informed, listen and acknowledge your concerns and aspirations and provide feedback on how patient feedback influenced decisions."</i>	<i>"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."</i>	<i>"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."</i>	<i>"We will implement what you decide."</i>
How Can This Be Done?	<ul style="list-style-type: none"> • Pamphlets • Brochures • Websites 	<ul style="list-style-type: none"> • Focus groups • Surveys • Comment box 	<ul style="list-style-type: none"> • Workshops • World Cafes 	<ul style="list-style-type: none"> • Citizen/patient Advisory Committees • Participatory Decision Making 	<ul style="list-style-type: none"> • Citizen/patient Advisory committees • Delegated Decision Making

Figure 3: IAP2 Spectrum of Engagement

When choosing a level of engagement, consider what level of participation would be appropriate for your purpose, patient population, resources, type of input you need and capacity to act on the patient and family voice. In a long term or complex project, you may work at a number of engagement levels depending on where you are in the project. **It is important to note that no one level is more important than another but usually when partnering with PFAs you are most often working at the collaborate level.**

The table below outlines some suggested methods for gathering the feedback from your stakeholders.

List of engagement methods for the Consult, Involve and Collaborate levels of engagement	
Consult	<ul style="list-style-type: none"> • Surveys (e.g., AHS – In-Patients Hospital Consumer Assessment of Healthcare Providers and Systems (HCAPHS) data available at the unit level) • Patient Concerns and Commendations (e.g. AHS – Patient Relations Data) • Focus groups to gather information about opinions, ideas, preferences and experiences • Interviews with Patients to gather information about opinions, ideas, preferences and experiences
Involve	<ul style="list-style-type: none"> • Workshops – convening a group of patients (and planners) to work on an issue, encourage discussion and generate joint problem-solving • Patient observation of existing services in action to provide a patient perspective on potential areas for improvement • Patients may interview current patients about their experiences

List of engagement methods for the Consult, Involve and Collaborate levels of engagement	
Collaborate	<ul style="list-style-type: none"> • 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 health-care journey as a way to understand the patient experience and then analyse the resulting map to look for ways to improve programs and systems

Task 5: Ensure there is Leadership Support

Having senior leadership support for your project and for partnering with patient and family advisors is crucial to sustaining this practice and building it into the culture of your area.

The senior leader is able to align the work with strategic priorities and other initiatives and ensure the required resources are in place to support patient and family engagement. The senior leader is in a key position to act on the patient and family advisor input.

The committee chair or project lead plays a key role in creating the partnership culture and ensuring the patient and family voice is heard and included in the work. It is important for both leaders to **actively and visibly** support including patient and family advisors.

Task 6: Are You Ready for Partnering with Patients and Families?

Working in partnership with patient and family advisors is new to many. It is important to recognize and acknowledge that it may be new and challenging for both sides.

Staff and advisor partnerships should provide added value for all stakeholders.

Voicing fears and concerns, learning from the experiences of others and addressing barriers will help improve individual and committee readiness to commit to partnering with patient and family advisors. It may be helpful to invite patient and family advisors to your group to share their experiences.

Some of the common fears we have heard and suggested responses/tactics to help ease the fear are:

“The most important factor for ensuring the success of efforts to work with patient and family advisors is the belief that partnering with patients and families is absolutely essential to improving quality and safety.”

Essential Allies Institute for Patient and Family Centred Care

Fears	Responses
Who will the patient and family advisor be?	Each committee is unique and requires a mutually beneficial relationship with patient and family advisors. The committee recruits and selects their own patient and family advisors.
How will we manage patient and family advisor expectations?	By openly sharing with patient and family advisors that while every idea for change may not be possible to achieve, the aim is to be open to different perspectives and to steadily take steps toward improvement
We don't understand the role of the patient and family advisor	The role of the patient and family advisor is to provide the patient and/or family perspective on the topic of discussion.

Fears	Responses
What if the patient and family advisor tries to take over or hears confidential information?	Clear roles and responsibilities are set for patient and family advisors. All advisors receive education and sign AHS confidentiality agreements in their orientation.
They don't understand our business	Patient and family advisors understand more than we think; they know and they understand based on their experience
We don't want to show our weaknesses "We don't want to air our dirty laundry"	Patient and family advisors already know our dirty laundry. They hear it behind closed curtains and experience it in their own or family members' care.
What if there is a problem?	The staff liaison, staff from Volunteer Resources and staff from Engagement and Patient Experience are available as a resource to the advisor and group/committee members if concerns arise about the readiness, accountability, skills or "fit" of a patient and family advisor.
We're not ready "Let's wait until we get our ducks in a row"	The timing will never be perfect. Best practice is to engage as early as possible.
Fear of tokenism. Advisors don't want to just provide a checkmark/ rubber stamp for decisions that have already been made	Be clear on the reason you are involving patient and family advisors. For engagement to be meaningful: <ul style="list-style-type: none"> • Invite honest feedback and input • Incorporate this input in decision making and advise why feedback cannot be incorporated
Individuals or group has difficulty working through fears and concerns	Contact Engagement and Patient Experience Department at patient.engagement@ahs.ca

The following checklist will help to determine that you have completed all the necessary tasks and that you are ready to proceed to Step Two.

Step One: " Decision to Engage" Checklist		
Task	Description	Yes
Task 1	Team members understand what patient engagement and other concepts such as PFCC and Patient Experience are	
Task 2	Team members understand the value of working with patient and family advisors	
Task 3	Your team is clear on your goals and objectives for including the patient voice in this project or work	
Task 4	Your team is comfortable with determining the appropriate level of engagement for your project/work	
Task 5	There is leadership support (senior leadership/committee chair/project lead)	
Task 6	Fears and concerns have been addressed and your team is ready to commit to partnering with patient and family advisors.	

Step Two – Get Ready

This step provides guidance on infrastructure and administrative considerations to think about when partnering with patient and family advisors.

Task 1: Identify Roles and Responsibilities

The specific roles and responsibilities for all group members, including the patient and family advisor(s), should be defined in the Terms of Reference for the group/committee.

Key responsibilities for the staff liaison, patient and family advisors, group/committee chair and group/committee members are as follows:

Staff Liaison

The staff liaison plays a key role in supporting the patient and family advisor (recruiting, training and mentoring) and connecting the members of the group together.

The staff liaison is a group member who is:

- Patient, persistent, flexible, and curious
- An excellent listener
- Willing to learn and educate
- Positive, proactive and perceptive
- Able to reflect on their own assumptions about people and processes
- Able to hear another person's perspective
- Open and responsive to changing situations and new information
- Able to assess the support needs of both advisor(s) and the team in general
- Able to provide sufficient administrative and communications support to the advisor
- Able to acknowledge and respond positively to each person's unique contributions
- Formally connected to the main decision maker(s) of the initiative

Their role:

- Co-ordinates the recruitment and selection of patient and family advisors
- Gets to know the patient and family advisor
- Ensures the patient and family advisor receives an orientation to the committee
- Coordinates any additional education or training needed
- Oversees advisor activities, provides mentoring and coaching, facilitates participation
- Provides support to the patient and family advisor (e.g. briefing, during meetings, debriefing)
- Fosters collaborative relationships between the patient and family advisor and other members
- Assists members in understanding the role and importance of patient and family advisors
- Problem solving
- Tracks and communicates advisor accomplishments

Patient and Family Advisor

Patient and family advisors are individuals who volunteer their time and experience to improve the quality, safety and experience of healthcare services. They bring their lived experience as a patient or family member in our health system to help inform quality improvement.

Their role is to:

- Provide their perspective as a patient/family member on the topic of discussion
- Be an equal member at the table
- Be open to hearing the perspective of others
- Prepare for and attend meetings as previously agreed
- Informs the contact person if they are not able to attend
- Be aware of personal limitations and boundaries and seeks support if needed
- Provide information about availability and preferred ways to communicate (e.g. phone, email)
- Submit expenses to the appropriate person within the agreed upon time frame
- Communicate his/her expectations about the outcomes and benefits of engagement
- Communicate concerns or issues in a timely manner to the staff liaison
- Take advantage of training and educational opportunities
- Maintain confidentiality in all communications

“This is different than advocacy. This is a collaborative endeavor where they share their insights, perspectives and experience and listen to the insights, perspectives and experiences of those who work in the system and it is together we will get profound change.”

Beverley Johnson
President and CEO,
Institute for Patient and Family Centred Care

Note: Through sharing lived experience of AHS services, Patient and Family Advisors advocate for the value and benefit of co-designing health care services with patients and families to advance patient and family centered care and elevate patient and family experiences.

It is important to note that there are some nuances between Advisory and Advocacy work:

- **Advocacy** work seeks to ***influence outcomes***, whereas,
- **Advisory** work seeks to ***inform process***.

While this may seem like a distinction without a real difference, a close examination of the underlying concepts proves otherwise.

When an individual seeks to *influence* an outcome, they assume the power to produce certain effects on a decision maker that align with that outcome. An advocate will take action to achieve that desired outcome.

When an individual seeks to *inform* a decision-making process, that person imparts a certain viewpoint for a decision maker’s consideration but does not assume the power to effect decisions based on that viewpoint. An advisor will take action to ensure information is readily available before decisions are made.

Patient and Family Advisors will often see themselves in both roles simultaneously; this may shift depending on the work/project and level of engagement. Striking a balance of using personal experience to inform and ensuring patients and families are at the centre of the work differentiates the volunteer Advisor role from other volunteer positions.

Committee Chair(s)

- Ensures resources are in place to support patient and family advisors and staff liaisons
- Assists with the recruitment and selection of patient and family advisors
- Provides final approval for the selection of patient and family advisors
- Includes the patient and family advisor perspective in the decision-making/solution

Committee Members

- Assist with the recruitment and selection of patient and family advisors
- Welcome patient and family advisors
- Create a culture where the advisor is comfortable to ask questions and provide input
- Listen to understand the patient and family perspective

The resource tools "[Roles and Responsibilities of Advisors, Staff and Leaders](#)" and "[Staff Liaisons are Essential](#)" may provide additional support (Appendix D).

In addition, the Strategic Clinical Networks have developed a resource titled "[Engaging for Excellence: A Staff Liaison's Guide to Best Practice](#)".

Task 2: Develop the budget, cost centre and approval process

It is important to recognize that partnering with patient and family advisors takes the resource of time from the staff who will be partnering with the advisors. The amount of time involved can be substantial if setting up and supporting an Advisory Council. Other costs include the staff liaison's time and other administrative costs. The staff liaison's time is considerable, especially at the beginning of the process. The staff liaison's time needs to be recognized, approved and planned for.

Patient and family advisors are volunteers and the costs for their participation are usually minimal. Patient and family advisors are eligible to receive compensation for their expenses in accordance with [AHS policies](#).

The staff liaison, in collaboration with the committee chair or project lead, will develop and communicate the compensation process to the advisor inclusive of the following information:

Eligible expenses:

- Travel to attend out-of-town meetings and educational requirements (e.g.: mileage, flights, bus fare, taxis, parking, and accommodations)
- Meals: if the meeting is during regular meal-times

The process for submitting claims should include:

- Where to get the Payment Requisition Form and how to fill it out
- Cost centre to use
- When should expenses be submitted and to whom
- Approximate timeframe for reimbursement
- Contact person for unpaid claims

It is important to ensure patient and family advisors know what expenses are eligible and the reimbursement process before starting work on the project/committee. The goal is to make this process simple and easy for the patient and family advisor.

An [Expense Guide for Patient and Family Advisors](#) is available.

Task 3: Setting up a collaborative partnership

All group/committee members have a role to play in the development of a partnership culture.

Key elements of collaborative relationships include:

- Mutual respect for skills and knowledge
- Honest and clear communication
- Understanding and empathy
- Mutually agreed upon goals
- Shared planning and decision making
- Open and two-way sharing of information
- Accessibility and responsiveness
- Joint evaluation of progress
- Absence of labeling and blaming
- Opportunities to get to know one another
- Navigating differing opinions, feelings, perspectives and conflict
- Clear roles and expectations for all committee members

“In interviews conducted with patient advisors, providers, and leaders who participated in the development of the AHS All Aboard for Patient Engagement Toolkit, each stakeholder group strongly expressed the need to build and support effective relationships with patient and family advisors.

All Aboard for Patient Engagement,
Engagement & Patient Experience Department
Alberta Health Services

Resource Tool: *“Collaborative Relationships Build a Strong Foundation”* (Appendix D)

The following checklist will help to determine that you have completed all the necessary tasks and that you are ready to proceed to Step Three.

Step Two: “Get Ready” Checklist		
		Yes
Task 1	The budget, cost centre and approval process for expenses are in place	
Task 2	The roles and responsibilities are clear and well defined including the Staff Liaison and advisor roles.	
Task 3	Your team is ready to engage in a collaborative partnership	

Step Three – Recruit, Register and Orientate

The purpose of this step is twofold: provide a standardized process for the recruitment, orientation and education of patient and family advisors and to make sure there is a good fit between the patient and family advisor and the group/committee.

Recruitment involves determining what Patient and Family Voices are important to be part of your work. The patient and family voices required drive how and who you recruit. Some groups of individuals may not be comfortable with the role of the being a Patient and Family Advisor and you will need to look at other methods for capturing that voice. For example, looking to get the voice of new immigrants or individuals with a lived experience with opioids may involve other patient engagement techniques than the PFA role.

In addition the formalized process involved to become a Patient and Family Advisor may appear as a barrier to some individuals. It is important to consider whether you have the resource to support your advisors to fill out the forms , support them through the process if required. If, for your current situation, the formal onboarding process is a barrier, consider other ways of including the patient and family voice. The resource *The Voice of Patient and Families* may be a help to you. <https://insite.albertahealthservices.ca/qhi/Page17294.aspx>

If you are recruiting for a large number of advisors such as when you are forming a Patient and Family Advisory Council you need to consider recruiting for diversity within the purpose and intent of the council. For instance, a provincial patient and family advisory council will be firstly looking for individuals who have experience of the current Health system and then looking for diversity of geography, age, gender, culture, education etc.

An advisory group focussing on a specific Clinical diagnosis or service may first recruit for experience in that particular area and then at the other facets of diversity.

There are a number of resources on the AHS website on [Diversity and Inclusion](#) and also other provincial organizations such as [Health Quality Council of Ontario](#) have develop guides for considering and recruiting for diversity.

A good fit is defined as “a mutually beneficial opportunity for the patient and family advisor and the group/committee based on relevant experience, interests, and personality styles.”

The staff liaison has the lead for co-ordinating Step Three.

There are five tasks in Step Three:

1. Identify potential patient and family advisors
2. Interview and select the patient and family advisor(s)
3. Involve Volunteer Resources
4. Registration
5. Orientation and education.

Task 1: Identify potential patient and family advisors

The staff liaison has the lead role for co-ordinating the identification of potential patient and family advisors. However, the chair and all group members can be involved in the process of identifying potential advisors. The patient and family advisors that will be needed for a committee or project should be based on the work that was done in Step 1 where the goal, purpose and reason for working with Patient and Family Advisors was identified. That work would have identified the depth of the Patient and Family voice required for the work.

For example, patient and family advisors may represent those individuals who this work serves or you may go for a broader perspective of patient and family voices for working on improvement projects., As much as possible, patient and family advisors should represent the breadth of relevant patient and family interests and perspectives, geography and demographics required for your work.

Hard to Reach Patients and Families

There are a number of patient and family voices that can be hard to reach.

Children and young people	People with learning disabilities
Older people (those over 75)	People in custody (prison population)
Refugees and asylum seekers	people within theLGBTQ2+ community
People for whom English is a second language	persons without a home
People with disabilities	People living with a chronic illness
People with hearing impairments	Those with culturally diverse backgrounds
People with mobility needs	Socially, economically or geographically isolated communities
People with sight impairments	People with low levels of literacy
People who use mental health services	Mothers with young children
Indigenous people	People who use drugs
Victim of domestic abuse	People who work

When needing to recruit patient and family voices that are hard to reach consider:

- Adjusting the advisor role to enable a meaningful dialogue (e.g. meet informally with the patient and family member and bring the information back to the committee)
- Personally invite patient and family members during a routine encounter
- Working with a local community or social agency to help identify a potential advisor
- Enlisting the help of colleagues and co-workers who are working with this population.

Skills and Characteristics of Patient and Family Advisors

The skills and attributes you look for in potential patient and family advisors will vary depending on the purpose, goals and objectives of your project/committee. In addition, the literature and our experience tells us to look for Patient and Family Advisors who can:

- Share insights and information about their experience
- See beyond their personal experiences
- Demonstrate a passion for improving health services for others
- Represent a broad cross-section of people being served
- Show concern for more than one issue
- Listen well
- Respect the perspective of others
- Interact well with many different types of people

- Speak comfortably in a group
 - Work in partnership with others
 - Show a positive outlook and have a sense of humor
 - Have a broad base of health-care/life experience
-
- Are ready to contribute
 - Additional unique skills specific to your committee.

Recruitment Methods

Quite often, group members know a patient or family member who might be an effective patient and family advisor.

Volunteer Resources and the Engagement and Patient Experience Department may also be able to help with recruitment and can be reached at:

- Patient Advisor Coordinator (Patient Engagement Collaborative) VolunteerResources.Engagement@ahs.ca
- Patient Engagement: patient.engagement@ahs.ca

Other recruitment methods include:

- Ask physicians and other providers to identify potential patient and family advisors
- Ask other patients and families, who are already involved, if they have a friend or family member who might be interested in participating
- Contact patient or family networks, support groups, or advocacy organizations
- Post notices on bulletin boards, educational, recreational, and social service programs, clinics serving patients families, public libraries
- Include information about opportunities for patients and families to participate as advisors in patient satisfaction surveys
- Post information on the AHS Internet site
- Connect with people in the community who are knowledgeable about patients and families and are a link to other patient and family groups
- Review emails and letters to identify patients and family members who have provided constructive feedback
- Work with other health care professionals, e.g., social workers, to identify potential advisors
- Consider the potential for advertising or using social media Resource tool : Finding *Potential Patient & Family Advisors* (Appendix D) Resources need to be reviewed

Sample letters for recruiting patient and family advisors and for asking staff, physicians and patients and families to help recruit potential advisors are included in Appendix E.

Once a potential patient and family advisor has been identified, a personal invitation is the most effective method of recruitment.

Application/Expression of Interest Form

Completing an application form helps the potential patient and family advisor decide if he/she is interested in pursuing next steps and a written application can be included as part of the patient advisor's file with Volunteer Resources.

An Application/Expression of Interest Form for patient and family advisors is included in Appendix F.

Making the Decision to be a Patient and Family Advisor

Many patients and family members wonder if this role is right for them. The following resources are included in Appendix D, to assist patients and family members make their decision.

- Are you thinking about becoming a Patient or Family Advisor?
- Determine if the Advisory Role is a Good Fit for You
- What does it take to be a Patient & Family Advisor?

Patient and Family Advisor Readiness

Patient and family advisors are people who want to help improve the quality and safety of health services. Each advisor is unique and has a personal reason for wanting to be involved.

Sometimes it is because they or a loved one had great care and they want to give back. Other times, being an advisor is a way to make sense out of a personal tragedy. Occasionally, people interested in becoming a patient and family advisor have experienced harm from the services we provide and they want to help make sure this does not happen to someone else.

Being an advisor can be a healing experience, but if the patient and family advisor is not ready, it can also be stressful and add to the harm. Each circumstance is different, but as a general rule, a person is ready to be an advisor when they can talk comfortably about their experience.

The following characteristics are important readiness indicators for people applying to be a patient and family advisors:

- I believe AHS Leadership has a firm and visible commitment to working with patients and families
- I believe that quality and safety improvement is important and meaningful
- I believe I can bring a perspective to safer health care that no one else can provide
- I understand the difference between being an advisor and an advocate and want to be an advisor
- I am comfortable talking about my positive and negative care experiences constructively
- I will bring a positive attitude to discussions about improving health services
- I am willing to keep an open mind and be willing to cope with disagreement, while at the same time holding firm to the conviction that being part of a group/committee will bring about positive change

If you require assistance in determining advisor readiness, contact Engagement and Patient Experience Team at patient.engagement@ahs.ca.

Task 2: Involve Volunteer Resources

Patient and family advisors are volunteers. In AHS, a volunteer is defined as an individual who provides their time freely on an ongoing basis to be involved with AHS activities.

Volunteer Resources has departments throughout the organization that are staffed with volunteer management professionals committed to ensuring community members are involved in AHS through approved volunteer programs and roles.

Volunteer Resources works with all AHS team members to involve volunteers through defined standards of practice in recruitment, screening, placement, orientation and training, supporting and supervising volunteers, evaluation, recognition and records management.

[AHS Policy, 1128](#) – Volunteers outlines AHS’ commitment to volunteer involvement in the healthcare system.

Patient and family advisors need to register with Volunteer Resources. The registration process ensures that the required security screening and orientation to AHS are completed. The volunteer registration process includes:

- A Police Information Check
- An AHS confidentiality and user agreement, and optional photo consent form
- Additional requirements may include a health screening and site-specific orientation
- An AHS security ID badge
- Access to the advisor’s volunteer record for receiving information, maintaining their contact information and recording their volunteer hours.

For more information, visit the [Volunteer Resources Guidebook](#)

As you begin Task Two, contact the Volunteer Resources team in your area to discuss where you are at with the recruitment process and the support available.

For additional information, visit the [Volunteer Resources webpage](#) or email VolunteerResources.Engagement@ahs.ca

Task 3: Interview and select patient and family advisors

The interview is an opportunity to explore if the engagement opportunity is mutually beneficial for the potential patient and family advisor and for the group/committee. A poor fit can be disappointing for the advisor and the committee and can cause the partnership to fail.

Planning for the Interview

Potential patient and family advisors are volunteers. They may be employed and have personal commitments. Please consider the following factors when setting up the recruitment interview:

- Where will the interview take place – face-to-face, virtual (app or the phone)?
- Is the time and location convenient for both parties?
- Is the time allotted appropriate, e.g. are there too many questions for the allotted time?
- Does the allotted time allow for full discussion?

- Who will conduct the interview? What is their role on the group/committee? How many other AHS staff or patient advisors will take part in the interview?
- If there is more than one candidate, is the selection process clear to all participants?
- How will information about the interview be shared with the potential advisor (e.g. interview questions, interview process and next steps)?

The Interview

The interview itself is similar in some ways to a job interview, but less formal. Important information to discuss during the interview includes:

- The role and responsibilities of a patient and family advisor
- The term on the group/committee is usually defined in the Terms of Reference. If the term is not defined, a two- to three-year commitment is recommended. A two-to-three year term gives the patient and family advisor an opportunity to become familiar with the work and also recognizes this is a volunteer commitment. It is also important to acknowledge that depending on life circumstances, the patient and family advisor might need to resign early
- The time commitment to prepare, attend, and debrief after meetings
- What costs will be covered and the process for reimbursement
- What kind of training /orientation will be provided
- How to find out if the patient/family is interested in pursuing this opportunity
- How to let the patient/family member know if the committee is interested in pursuing this engagement opportunity

Note: At this time, it is very important to let the applicant know this is an **advisory role** and not an advocacy role and to make sure the advisory nature of the role is aligned with the applicant's expectations. A misunderstanding between the actual role and the patient and family advisor's expectations can result in a poor fit.

Important Information to obtain in the interview:

- Why does the individual want to become an advisor
- What is their Health Care experience
- What other skill sets do they have that might support their involvement
- If the reason for their involvement is due to a medical error – real or perceived – where are they in their healing journey? Do not want to cause secondary harm.
- As you converse –what is your sense of the individual – is there a potential fit with the committee or project team

It is also important to encourage the potential patient and family advisor to ask questions. This information discussed during the interview will help the applicant decide if they are interested in the engagement opportunity.

Some suggested interview questions are attached as Appendix G

Resource tool: *"Interviewing Potential Patient & Family Advisor"* (Appendix D).

References

References can provide valuable information about an applicant and augment information shared during the interview. A reference template for patient and family advisors is provided in Appendix H.

Offer/Welcome letter

Once a patient and family advisor has been selected and has verbally accepted the role, a letter of offer or welcome letter completes the selection process. A sample offer letter is provided in Appendix I.

Unsuccessful Applicants

If an applicant is not considered a good fit, it is important to close the recruitment process and to thank the applicant for their interest. This should be done informally over the phone and also followed up with a formal regret letter. A sample regret letter is provided in Appendix J

Task 4: Registration and Documentation

Once the applicant has accepted the role of patient and family advisor, the staff liaison needs to ensure the registration process with Volunteer Resources is underway.

Volunteer Resources completes the required documentation.

Task 5: Orientation and Education

Patient and family advisors should receive a general orientation to AHS as well as an orientation specific to the group/committee they will be working on.

General Orientation

There are numerous resources posted on the AHS external website to help with the general orientation, including webinars and slides on Patient and Family Advisor Roles and Responsibilities, Staff Liaison Roles and Responsibilities and Patient Engagement. [These resources](#) provide most of what is required for the general orientation.

In addition, on this page is access to learning modules on Patient and Family Centred Care, Patient Engagement and Quality is Everyone's Business. These are modules that are also part of the education requirements for all staff.

The general orientation should include information on:

- AHS Values and Mission
- AHS Strategic Direction
- Patient- and family-centred care
- International Association of Public Participation (IAP2)
- The role of advisors (Who, What and How) and benefits and challenges
- Responsibilities of the Engagement & Patient Experience team and Volunteer Resources
- Policy, governance and legislation applicable to volunteers
- Administrative and health and safety FAQs
- Common words and acronyms, useful links (e.g. IPFCC, IAP2, Beryl Institute)
- How to access their volunteer record and update their volunteer hours

Committee/Project Orientation

The staff liaison provides and/or coordinates the group/committee orientation and sets the tone for relationship building.

The following topics should be included in this orientation:

- A copy of the Terms of Reference
- A glossary of commonly used terms and acronyms
- Administrative information, such as a list of people on the committee, their roles and their contact information
- A schedule of meeting times
- Information on past committee work, if applicable
- Information on current committee work, if applicable
- A description of roles and responsibilities for the staff liaison
- A contact number for the staff liaison
- A description of the roles and responsibilities of the patient advisor
- Who the decision maker is and the relationship of the committee to the decision maker

Specialty Orientation

The staff liaison will arrange for any additional specialty orientation needed.

Other Educational Opportunities

Other educational opportunity are also very beneficial (e.g., President Speakers Series) and can be discussed with the patient and family advisor as opportunities arise.

AHS Network Access and Email Address

Patient advisors are eligible to receive limited AHS network access and email address. The process for obtaining Network access is described in Appendix K.

Step Three: "Recruitment and Onboarding" Checklist		
		Yes
Task 1	Potential Patient and Family Advisor(s) have been identified	
Task 2	The staff liaison has contacted Volunteer Resources	
Task 3	Patient and family advisor(s) have been interviewed and selected	
Task 4	Patient and family advisor(s) have registered with Volunteer Resources and documentation is complet3	
Task 5	Patient and family advisor(s) have been orientated to AHS and to the Committee/proj	

When all of the tasks in Step Three are complete, the patient and family advisor is ready to begin work on the Group/Committee

Step Four – Mentor and Support

Successful engagement requires both a commitment to developing and supporting a strong partnership between all stakeholders and having the time to prepare and plan for meetings and working sessions. Just as patients and staff have different perspectives, patients and families come from diverse backgrounds, both within the health-care setting and in their personal lives. Effective relationships promote learning from each other's experiences and foster collaboration in working towards the common goal of improving the quality and safety of health care.

The staff liaison has the lead role for mentoring and supporting the patient and family advisor on the group/committee. For relationship building, it is preferable to have one consistent person in this role. The staff liaison is in a unique position to get to know the patient and family advisor and to make a personal connection. We hear often that this relationship enriches both lives.

Being a patient and family advisor is a new role for most people. Some advisors will need more support than others. With ongoing mentoring and support, individuals can grow and develop in the advisor role.

There are five considerations in Step 4:

1. Establish and maintain relationship
2. Meeting prep
3. Meeting facilitation with Patient and Family Advisors
4. Post meeting debriefs
5. Special considerations

Step 4 takes time and commitment especially at the start of the committee/ project and start of the relationship building.

Consideration 1: Establish a Relationship

This will take some time but it starts with the interview and then orientation. It is important to understand why a patient and family advisor wants to give back. What are their passions and drivers? With this knowledge and the advisor permission you can get them involved in projects meaningful to them. (Less chance of tokenism happening).

If you are not their staff liaison for all the work the advisor is doing make sure you make time every couple of months to touch base and see how they are doing. These connection points should be more often at the beginning of an Advisors partnering with AHS but should never be discontinued until the advisor steps away from the role. If you are their staff liaison on the project these connections will happen at regular meeting times – either the briefings or in the meeting itself.

- Invest in the relationship: ensuring that advisors are well prepared demonstrates respect and commitment to the value that advisors bring to the partnership

Consideration 2: Plan for Meeting Logistics

Pre-planning for meetings is an important opportunity to connect with the patient and family advisor. When you are sharing information remember the advisor might not have access to all of the same technology and equipment as AHS staff.

It is important to ensure your advisor:

- is able to access the meeting space – be it virtual or in person.
- for virtual meetings set up a time to test their connection and whether the meeting platforms are working for them.
- for in person meetings make sure they have a name tag and that someone is available to provide access into building, floors and rooms.
- should have access to all the same information as other people on the project or committee.

Patient and family advisors are volunteers and may have other commitments. To facilitate planning for meetings:

- Ask the advisor for the best way to communicate with them (e.g. phone, what time)
- Ask the advisor for the best way to send them meeting packages (e.g. email, fax, postal services)
- Respect the advisor's privacy. If the advisor is using a personal email, ask the advisor if they are comfortable to share their email address with others via invites and emails to the group. AHS does not share employee home addresses, and, unless permission is provided, it is important to follow the same practice for advisors.
- Find a meeting time and location that is convenient for advisors and staff, if possible
- Send the agenda and minutes in advance, providing ample time for review
- Recognize that there is a lot of new information for advisors. They will have many questions to gain a better understanding of the issues and to feel prepared
- Ensure the patient and family advisor has a list of all committee members with a brief description of each person's role
- Provide the staff liaison's contact number
- The staff liaison or alternate should plan on being with the advisor in person or virtually as a support and resource.

Briefing the Patient and Family Advisor

A key part of the partnership is making sure patient and family advisors have the necessary knowledge, skills, and resources for participating effectively. Ensuring advisors are fully prepared helps build confidence and enables them to engage to their full capacity.

Important elements of the briefing include:

- Set dedicated time to meet with advisor(s) prior to each meeting (phone or in person)
- Allocate adequate time to avoid being rushed. More time will be required with new advisors
- During the briefing:
 - Review and understand all agenda items
 - Provide additional context: historical perspectives, sensitivities, etc.
 - Familiarize the advisor with policies, technical terms, and acronyms
 - Ask questions in a safe setting

- Invest in the relationship: ensuring that advisors are well prepared demonstrates respect and commitment to the value that advisors bring to the partnership
- Get to know the patient and family advisor

Consideration 3: The Meetings

The First Meeting

It is the role of the chair to introduce patient and family advisor to the group/committee. To make sure the introduction contains the information that is important to the patient and family advisor, it is recommended that the chair/project lead connect with the patient and family advisor ahead of time to determine how they would like to be introduced.

The patient and family advisor’s introduction should be what the patient and family advisor wants it to be. Sometimes a patient and family advisor biography does include personal information, which can help to build trust and the partnership relationship but this is only recommended if sharing is going to be reciprocal.

Suggested topics for the patient advisor bio include:

- Relevant patient/family experience with group/committee work
- Their health experience
- Credentials (e.g. professional designation) and work highlights
- Past and current patient advisory work
- Other notable projects or achievements.

“Patient advisor are invited guests into our world. They bring with them a suitcase full of experience and expertise and the heart and courage to share that suitcase with us. It is our duty and our privilege to make sure they feel warmly welcomed and appreciated.”

Consultant, Engagement and Patient Experience Department, AHS

Many patient and family advisors are motivated to volunteer because of a personal experience. If the advisor wants to tell their story and the chair thinks this would be helpful to the group, dedicated committee time should be scheduled and the patient advisor should be coached in story telling techniques. The staff liaison or patient and family advisor can contact patient engagement for information and coaching on storytelling at patient.engagement@ahs.ca

Committee Introductions

After the Chair has introduced the patient and family advisor, round table introductions using NOD (name, position, and role on the group/committee) should occur.

Table-top name cards may be helpful for patient and family advisors as a reminder of who the team members are and their respective roles.

All Meetings

Important considerations for all meetings are:

- Be sensitive to the advisor’s comfort level in participating. Don’t force participation, especially in the beginning. Invite advisors to participate at the level they choose
- Ensure that advisors feel safe and comfortable enough to share their thoughts and experiences

- Emphasize the value of hearing from everyone in order to understand the full range of experiences and to gain a clearer picture of the issue (people like to participate when they feel they have something valuable to contribute)
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as fully contributing members
- Acknowledge negative experiences and move the discussion forward by asking, “What can we learn from this? How can we prevent or improve this?”
- Avoid jargon, technical terms and acronyms. Take the time to explain them whenever they are used.

Consideration 4: Debriefing

Debriefing is an important opportunity to learn how the meeting went from the patient and family advisor’s perspective. It is also an important opportunity to discuss how the advisor feels about their role and to see if they have any suggestions for improvement or concerns.

The need to debrief and also to have pre-meetings will decrease over time as the advisor fits into their role

Important considerations in the debriefing are:

- Set dedicated time: allow ample time to avoid feeling rushed
- Debrief immediately following the meeting
- Check with the advisor(s) on their comfort level, understanding, participation
- Check if the briefing was helpful. Are additional support/resources needed?
- Discuss any concerns/issues and, if necessary, develop a plan to remediate

Consideration 5: Special Circumstances

Anticipate Absences

Patient and family advisors may not be able to attend all meetings. They may have health concerns and/or other demands on their time and energy. If an advisor is unable to attend a meeting:

- Follow up via the advisor’s preferred communication method
- Let them know that their participation is valued and their presence was missed
- Send the minutes of the meeting and provide opportunities for feedback
- Create alternate ways of participation (e.g. conference calls, written review of materials, etc.)
- Send future agendas and welcome them back when they are able to return

Advisor Burnout

Advisors are motivated by a deep desire to improve the quality and safety of AHS services and, like staff, they can experience burn out. Advisors who are participating because of a deep, personal experience are at greater risk of burnout.

Care must be taken to protect and support advisors who are balancing the demands of their own personal and work life along with the demands of the advisor role.

Factors to consider:

- Do you have enough advisors or are you relying on a few to do the work of many? It is strongly recommended to have more than one advisor on the committee

- Has the time commitment increased from the original ask?
- Is the time commitment manageable or has it become stressful?
- Is there pressure on the advisor to commit to a project?
- Is the advisor able to take a break without fear of letting down the team?
- Are there opportunities for networking or educational opportunities?
- Are peer mentors available?
- Do advisors know and understand that it is OK to say “no”?
- Are timelines/deadlines for advisors realistic?

It is important to frequently check with patient and family advisors and reduce stress whenever possible. If you require any assistance, contact Volunteer Resources at PE.Volunteers@ahs.ca or the Engagement and Patient Experience Team at patient.engagement@ahs.ca

Managing Conflict

Group/committee members participate in decisions that have the power to change lives. This can create situations in which people’s emotions are aroused or past emotions are triggered.

It is important to be sensitive to conflict situations and to work through and resolve the issues as soon as possible. Patient and family advisors may require additional support in the conflict resolution process.

Ongoing Training

The committee/ organization has a responsibility to provide patient and family advisors with the resources, training, and support needed to effectively sustain their work. Look for opportunities for advisors to grow and develop in their roles by encouraging educational and networking opportunities and mentoring from more seasoned advisors where possible.

When It Isn’t a “Good Fit”

The Five Step Process (Appendix C) is intended to ensure the engagement opportunity is a good fit for Both the patient and family advisor and the committee.

Sometimes, despite everyone’s best efforts, it isn’t a good fit. There can be many reasons for this. Three of the most common reasons are:

1. **The advisory nature of the role.** People who are passionate about the care they or a loved one received often want to be a catalyst for change at the front line. The advisor role is **advisory, not advocacy**, in nature. If the advisor did not understand the difference in these roles, it can create difficulties.
2. **The level of the committee.** There is also potential for a misfit if the advisor wants to be involved in change at the front line and is on a high level committee where the focus is on strategic planning.
3. **The slow pace of change.** Patient and family advisors who want to see immediate action can be frustrated with the slow pace of change that occurs in a large organization such as AHS.

There can also be personal reasons the partnership is not a good fit. The advisor’s personal circumstances change or they did not understand the impact this work would have on their personal lives.

It is important to frequently check in with the advisor to see how things are going. Give the advisor an opportunity to talk about their impressions and satisfaction with the role. The debriefing is a good opportunity to do this but it is also important for the staff liaison to have an open-door policy to discuss concerns. Sometimes, talking with the advisor can help to resolve problems and/or feelings of dissatisfaction. If this isn't possible, talk with the advisor about the role to see if it is really something they want to continue doing.

If the chair, staff liaison, or group/committee members are concerned that the engagement opportunity is not a good fit for the advisor or the committee, and it is not possible to resolve these concerns, there is support available. Engagement and Patient Experience staff or Provincial Volunteer Resource staff can provide guidance to reach a resolution or help find a more suitable placement for the advisor. In addition, support and guidance is available through the Human Resources if required.

Step 4: "Mentor and Support" Checklist		
		Yes
Task 1	Establish and maintain a relationship	
Task 2	Meeting Prep	
Task 3	Meeting Facilitation with PFAs	
Task 4	Debriefing	
Task5	Special Circumstances	

Step Five – Monitor Progress and Outcomes

Evaluation is an essential component of any activity and is especially important for patient engagement. Although ongoing assessment will occur informally as a routine part of giving and receiving feedback, to fully evaluate the effectiveness and value of working with patient and family advisors and as a way to capture learnings, a formal evaluation should also occur. The staff liaison has the lead for monitoring progress and outcomes and for reporting results to the committee chair.

The evaluation of engagement activities should include the process used and the outcomes from the perspective of both the advisor and the committee members. Evaluating the process ensures the integrity of the engagement approach, while evaluating the outcome measures the impact of the advisor on the work being done.

There are two tasks in Step Five:

1. Review process and outcome criteria
2. Develop An evaluation plan

Task 1: Review Process and Outcome Criteria

Common process and outcome evaluation criteria for patient engagement include:

Process and Outcome Evaluation Criteria		
Process Criteria	• Representativeness	• Inclusivity
	• Perceived openness of process	• Transparency
	• Structured decision making	• Task definition
	• Comfort	• Convenience
	• Satisfaction	• Fairness
	• Number of patient advisors	• Communication
	• Cost within budget	• Staff time within budget
	• Advisor time within estimate	
Outcome Criteria	• Advisor influence on the decision/solution	• Impact on general thinking

Task 2: Develop an Evaluation Plan

A survey is often used to conduct the formal evaluation. It is best practice to include the patient and family advisor and committee members when developing the evaluation plan.

Sample process and outcome questions that can be used to develop an evaluation survey for the patient and family advisor and committee members are included in Appendix L.

The following is a Sample Evaluation Survey:

Evaluation Questions for the Advisor

1. How effective is the support and guidance you receive for your participation on the group/committee (e.g. briefing, meeting, debriefing)?
2. How at ease do you feel being included on the group/committee?
3. How well do you feel that the group/committee considers the patient/family perspective?
4. What has helped your participation on the group/committee the most?
5. What are the greatest challenges/obstacles to being a patient and family advisor?
6. What do you most appreciate about your participation on the group/committee?
7. What personal benefits have you gained from your participation on the group/committee?
8. Overall, how satisfied are you with your experience as a patient and family advisor on the group/committee?

Evaluation Questions for Committee Members:

1. How effective is the support and guidance you receive to enable the patient and family advisor to participate and contribute in the meetings?
2. How at ease do you feel including a patient and family advisor on the group/committee?
3. How well do you feel that the group/committee considers the patient perspective?
4. What has helped you the most to include a patient and family advisor on the group/committee?
5. What are the greatest challenges to including a patient and family advisor on the group/committee?
6. What do you most appreciate about the patient and family advisor’s participation on the group/committee?
7. What personal benefits have you gained from the patient and family advisor’s participation on the group/committee?
8. Overall, how satisfied are you with your experience having a patient and family advisor on the group/committee?

Resource tool: *Evaluating Engagement Initiatives* (Appendix D)

Step 5: “Evaluation” Checklist		
		Yes
Task 1	Advisor evaluation Plan is in place	
Task 2	Team member evaluation plan is in place	

Summary

Including patient and family advisors on AHS committees is one way to include the voice of patients and families in the design, delivery and evaluation of health services. The readiness checklist (Appendix A), the decision tool (Appendix B) and the Five-Step Process (Appendix C) outlined in the Guidebook are intended to help you decide if this is the right level and method of engagement for your project/committee. If you have any questions or need assistance, please contact the Engagement and Patient Experience Department at patient.engagement@ahs.ca.

Conclusion

Our core values of compassion, accountability, respect, excellence and safety are at the root of all we do. Including the voice of patients and families in the work of AHS reflects these values and is a critical part of a patient- and family-centred care approach to quality and safety

“Health care is a journey that patients, families and providers are on together. We share a common goal - to give and receive the best care possible. Combining our passion, energy, and expertise on committees is an exciting opportunity to help make healthcare better for us all.”

Patient Advisor, AHS

This does not mean this work will be easy. You are exploring new territory and forging new relationships. Expect challenges but be inspired to know all Albertans will benefit from your success.

The generosity of patient and family advisors in helping us to improve the quality and safety of the services we provide cannot be measured or put into words yet all we can say is a heartfelt, **Thank You!**

We would also like to say a special thank you to AHS Patient and Family Advisor Kari Bulger for volunteering her expertise and experience in helping to develop the first edition of the Guidebook. Kari’s insight and experience as a patient advisor are reflected throughout the Guidebook and will benefit all who use it.

Engaging with Patient and Family Advisors reflects current knowledge on this important partnership and is intended to help guide your own partnerships. The Guidebook is a living document and will be updated regularly. If you have any comments or suggestions, please send them to patient.engagement@ahs.ca

Glossary of Terms

Patient: An adult or child who receives or has requested health care or services from Alberta Health Services and its health care providers or individuals authorized to act on behalf of Alberta Health Services. The term patient includes residents, clients and out-patients that are commonly used in continuing care, community care and allied health. (AHS)

Family: Means one or more individuals identified by the patient as an important support and who the patient wishes to be included in any encounters with the health care system including but not limited to family members, legal guardians, friends or informal caregivers. (AHS)

Patient- and Family-Centred Care: An approach to planning, delivering and evaluating health care that is grounded in establishing mutually beneficial partnerships. Patient- and family-centred care means working in partnership with patients and families by encouraging active participation of patients and families in all aspects of care, as integral members of their health-care team, and as partners in planning and improving of existing and new health services. Patient- and family-centred care applies to patients of all ages and to all areas of health care.

Patient Experience: The sum of all interactions, shaped by an organization's culture that influences patient perceptions across the continuum of care. (Beryl Institute)

Patient Engagement: The involvement of patients, their families or representatives, in working actively with health professionals at various levels across the healthcare system (direct care, organizational design and governance, and policy making) to improve health and health services.

Patient and Family Advisor: Patients and family members who volunteer their expertise and experiences as AHS patients and families to help improve the quality and safety of the health services we provide.

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6. Institute of Medicine (IOM). 2000. [To Err Is Human: Building a Safer Health System](#). L. T. Kohn, J. M. Corrigan, and M. S. Donaldson, eds. Washington, D.C: National Academy Press.
7. Institute for Patient and Family Centred Care. <http://www.ipfcc.org/>
8. Pomey, Marie-Pascale; Hihat, Hassiba; Khalifa, May; Lebel, Paule; Néron, André; and Dumez, Vincent (2015) "Patient partnership in quality improvement of healthcare services: Patients' inputs and challenges faced," *Patient Experience Journal*: Vol. 2: Iss. 1, Article 6. Available at: <http://pxjournal.org/journal/vol2/iss1/6>

Resources

1. A Guide to Patient Engagement by Patient Voices Network (BC): available at <https://patientvoicesbc.ca/resources/>
2. Demystifying Authentic Patient Engagement-Practical tips for success By Patient Voices Network : Available at <https://patientvoicesbc.ca/resources/>
3. British Columbia Ministry of Health , Patient, Family, Caregiver and Public Engagement Framework 2018 available at <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>

Appendix A: Readiness to Engage

Readiness Checklist for Partnering with Patient and Family Advisors

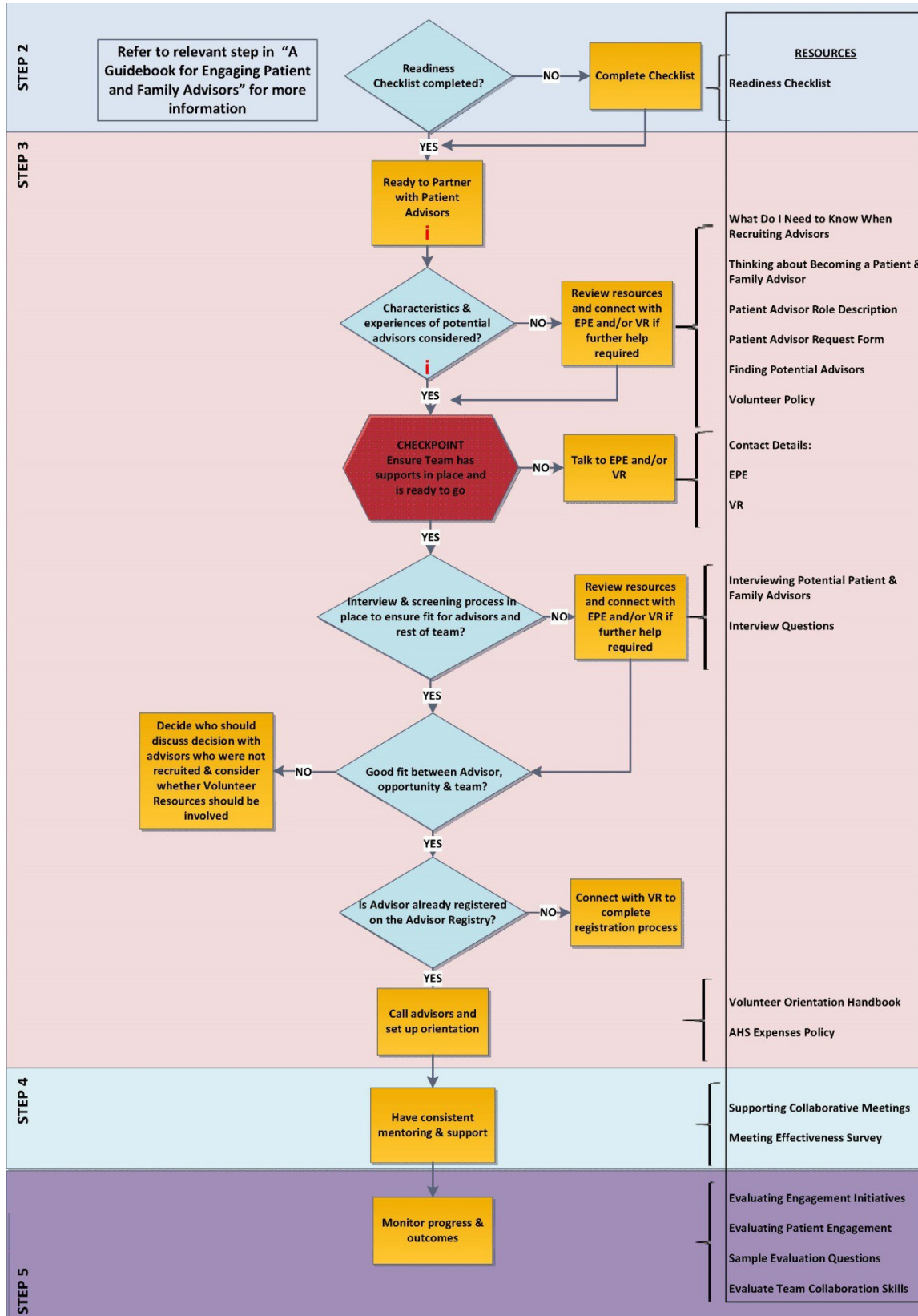
Better outcome and results are accomplished in partnering with Patient and Family Advisors if the work described below is completed prior to bringing the advisors on board. If you would like more information about any of the considerations, please refer to the indicated section of the "A Guidebook for Engaging Patient and Family Advisors".

Additional education, resources and tools are available through the Engagement and Patient Experience Department to assist with this work.

	Readiness Considerations	Y/N	Guidebook Step	Resources to Assist
Purpose	There is a clear purpose and scope to the work you are undertaking and your leader is supportive of this work.		1	<ul style="list-style-type: none"> AIW Roadmap to Engagement Guidebook
Patient Voice (input)	You are familiar with all the various methods to obtaining the Patient Voice and determined that a Patient and Family Advisor would be one method for the purpose and scope of this work amongst others.		1	<ul style="list-style-type: none"> Methods of Engagement & Crucial Considerations IAP2 Spectrum of Engagement
Goals and objectives	<p>You are clear about the reason for partnering with Patient and Family Advisors.</p> <p>What is it you want to achieve by engaging with Patient and Family advisors?</p> <p>What will your advisors achieve with this work?</p> <p>You have identified what Patient and Family Advisors will contribute to this work and your commitment back to them</p>		1	<ul style="list-style-type: none"> Value of Engaging Pts and Families Avoid Engagement Pitfalls Making the Decision to Engage
Leadership Support	<p>Your Leader is supportive of involving Patient and Family Advisors.</p> <p>They understand their role in making this work successful.</p>		1	
Staff Readiness	Your team is open, ready and willing to listen and respond to the Patient and Family Voice.		1	<ul style="list-style-type: none"> Are You Ready to Engage?
Staff Liaison	A staff liaison has been identified and their roles and accountabilities determined		2	<ul style="list-style-type: none"> Staff Liaisons are Essential What Do Staff Liaisons Do? Set Yourself Up for Success! Learning from Other Staff Liaisons
Orientate & Support	You have identified the respective roles of your team members and how you will work together		2	<ul style="list-style-type: none"> Roles and Responsibilities for Patients, Families, Staff and Leaders Advisor Role Description Collaborative Relationships Tool
Logistics and Budget	The budget, administrative and logistical aspects of this opportunity have been considered (e.g. parking, travel costs and refreshments)		2	<ul style="list-style-type: none"> AHS Expense Policy Volunteer Policy
	Any additional gaps or concerns you need answered before moving forward?			<ul style="list-style-type: none"> Contact the Engagement & Patient Experience Team

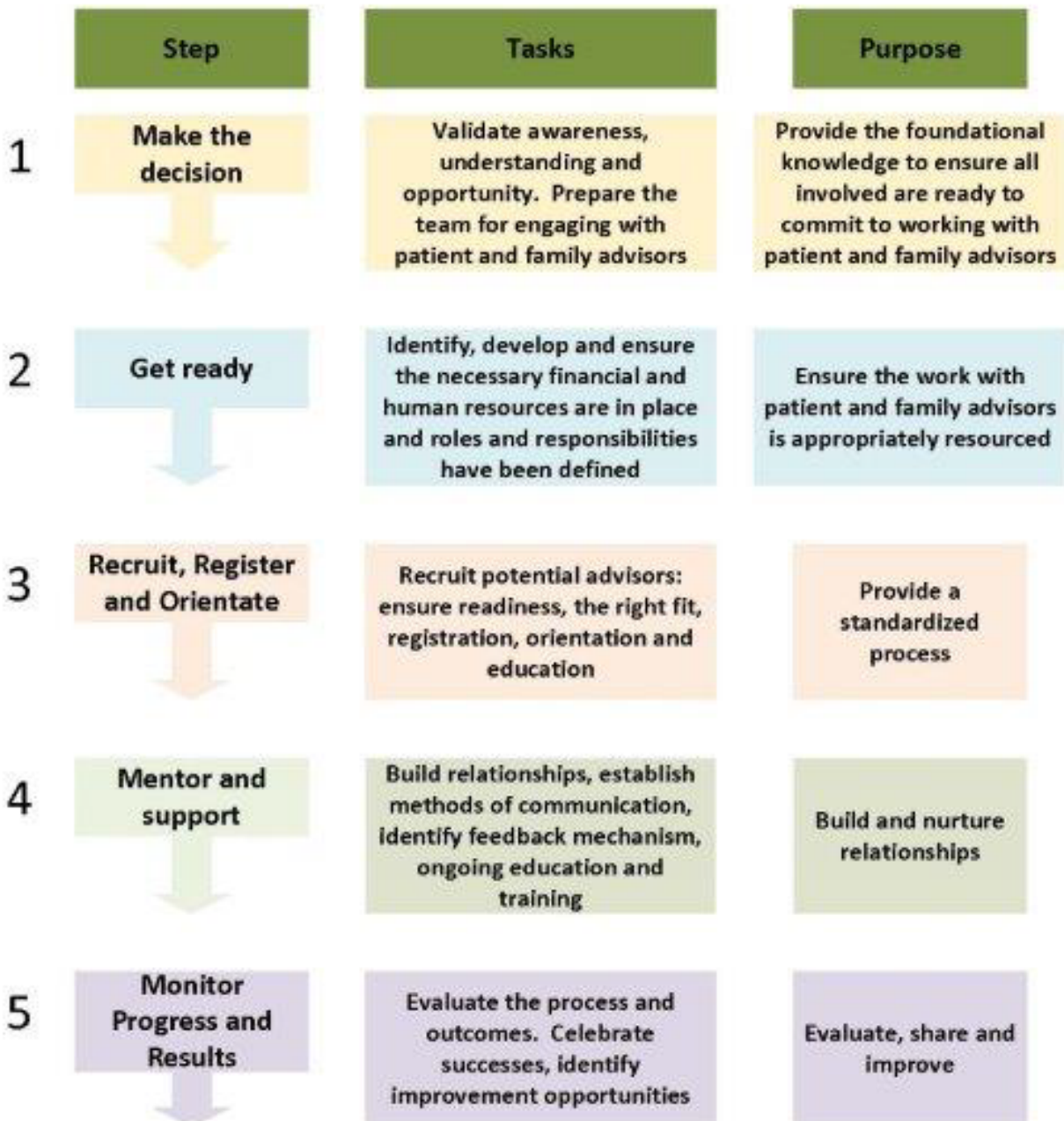
If you answer no to any of the considerations, it is strongly recommended that you connect with Engagement and Patient Experience to discuss how to proceed in order to be successful in partnering with patient advisors. Otherwise use the Decision Tree to guide you through the recruitment process.

Appendix B: Decision Tree



Appendix C: 5 Step Process

5 Step Process to Engage Patient and Family Advisors



Appendix D: Tools for Engagement



Making the Decision to Engage

Use the following questions can support your team to clarify your **goals, objectives** and overall **readiness** for successful engagement! You can have more than one reason for wanting to engage patients & families in a decision-making process.

Be aware that the more complex and multi-faceted the decisions are, the more ambitious and resource intensive your engagement plan will need to be.

Before you begin, as a team discuss these questions:

- What is your reason for wanting to engage?
- Are we clear on what issues or concerns we are trying to address on this project?
- Has the project involved patients & families in the past, if so what has been the implications of this?
- What support do we have from our leadership to ensure this is successful for the duration of the initiative?
- What other stakeholders will need to be engaged in this project?
- Does your team see the value and benefit to partnering with patient & family advisors in your work?

Ensure that your Engagement Goal Benefits Patients & Families!

Is the scope and intended goal of your project:

- To improve service design and/or the process of receiving care?
- To ensure appropriate treatment and care?
- To improve health outcome?
- To reduce risk factors and prevent ill health?
- To improve safety?
- To improve patient experience?
- To set priorities for action?
- To strengthen accountability?
- To ensure access to treatment?
- To improve transitions between services?

*If you **cannot** say "yes" to any of these broad goals, please reconsider your current plan for engaging patients and families.*

Contact us for support and guidance on how to best use this information at Patient.Engagement@albertahealthservices.ca

Adapted From: Engagement Framework and Toolkit. (2011) Capital Health. <http://www.cdha.nshealth.ca/system/files/sites/317/documents/engagement-framework-and-toolkit.pdf>.
Capital Health. Engagement Framework and Toolkit. Version 1.1 (March 16, 2011).

Institute of Patient and Family Centred Care. Partnering with Patients and Families to Accelerate Improvement Readiness Assessment. Nova Scotia.

Tool 2: Roles and Responsibilities



Roles and Responsibilities of Patient & Family Advisors, Staff, and Leaders

There are three major roles when engaging with patients & families: **the patient and/or family advisor, staff liaison, and leader.** Each role is critical to the success of the engagement process and outcomes. Although the responsibilities of each role will vary depending on the method of engagement, the following are some of the key responsibilities for each role:

Patient Advisor

- Believe the patient & family perspective is important.
- Do your best to understand and lead the issue from the patient & family perspective.
- Provide the patient and/or family perspective during the engagement activity.
- Attend meetings, as previously agreed, or let the contact person know if you are not able to attend.
- Provide information about your preferred way to communicate (e.g. phone, email, fax, or mail).
- Communicate your availability beyond agreed upon times.
- Submit claims for expenses according to current AHS processes.
- Communicate your expectations about outcomes and benefits of engagement.
- Take advantage of learning opportunities.

Leader

- Believe the patient & family perspective is important.
- Encourage and support staff and physicians to include patients and families on design and quality improvement projects.
- Include the voice of patients & families in decision-making at all levels of Alberta Health Services.

Staff Liaison

- Believe the patient & family perspective is important.
- Participate in scoping the role & engagement activity with both the advisor and leader and defining a beginning and end to the work.
- Get to know the advisor
- Ensure the patient or family advisor receives an orientation to the work.
- Act as a primary contact person for the advisor during the engagement activity (e.g. preparation, debriefing)
- Foster a collaborative relationship between the patient/family advisor and other participants.
- Assist other staff in understanding the importance of patient engagement.
- Track contributions of the patient & family advisor.
- Evaluate the success and challenges of the engagement opportunity.

Contact us for support and guidance on how to best use this information. Patient.Engagement@albertahealthservices.ca

Adapted from: Institute for Patient and Family Centered Care. Staff Liaison To Patient And Family Advisory Councils and Other Collaborative Endeavours retrieved from http://www.ipfcc.org/advance/Staff_Liaison.pdf

Staff Liaisons are Essential for Successful Engagement

The staff liaison role is essential for successful patient & family engagement. Dedicate one or more staff liaisons to support your patient & family advisors to sustain long term, face-to-face engagement activities.

Who is a Staff Liaison?

A Staff Liaison is a consistent dedicated person who takes responsibility for building relationships with your advisors. They are the primary point of contact for the Advisor and act as a bridge, supporting advisors to fully integrate and partner with the team. They are also responsible for facilitating and navigating recruitment and orientation of the Advisor along with supporting ongoing communication and administrative needs.

The Staff Liaison is...

- patient, persistent, flexible, and curious
- an excellent listener
- willing to learn and educate
- positive, proactive and perceptive
- able to reflect on their own assumptions about people and processes
- able to hear another person's perspective
- open and responsive to changing situations and new information
- able to assess the support needs of both advisor(s) and the team in general.
- able to acknowledge and respond positively to each person's unique contributions
- believes that patient and family participation is essential to the design, delivery and evaluation of optimal care and services
- formally connected to the main decision maker(s) of the initiative.
- able to provide sufficient administrative and communications support to the Advisor.

Adapted from: Calgary Health Region. (2007) *Involving Patient Experience Advisors on Region Committees and Teams*.

What do Staff Liaisons do?

- ...**Support ongoing advisor orientation** in collaboration with Volunteer Resources and the team; identify key opportunities for learning and ensure that advisors are supported throughout the process
- ...**Foster connections between all participants** by breaking the ice to create opportunities for stories to be shared. You provide emotional support and ensure that advisor perspectives are sought out and heard.
- ...**Ensure potential barriers to the full participation of advisors are identified and addressed** (i.e. meeting accessibility, hearing or visual impairments, childcare, travel arrangements etc.).
 - ...**Prepare and debrief with advisors** after engagement activities regularly to answer questions, acknowledge contributions and further develop your relationship with the advisor.
- ...**Help navigate challenges** by connecting leaders, staff and advisors to appropriate individuals when they have questions or concerns and support the resolution of challenging situations.
- ...**Lead (or support) tracking the contributions of advisors** depending on the chosen evaluation strategy. You track successes and challenges from the perspective of both leaders, staff and advisors.
 - ...**Tell the story of engagement to stakeholders** by identifying activities where patient & family advisor input made a difference and find ways to communicate engagement stories out broadly.

Contact us for support and guidance on how to best use this information at Patient.Engagement@albertahealthservices.ca

Adapted from Jeppson, E.S. & Thomas, J. (1997). Families as Advisors: A training guide for collaboration. Bethesda, MD: Institute for Family Centrec

Collaborative Relationships Build A Strong Foundation

Successful engagement requires a commitment to developing and supporting a strong partnership between *all* stakeholders. **Mutual respect, trust, honesty, equity, dialogue and negotiation are essential elements for successful collaboration.** Relationships look different depending on the level of engagement (see *IAP2 Spectrum*) and method of engagement (see the *Voice of Patients & Families* wheel). Patient & family advisors participating in engagement activities that take place face-to-face and over the long term will require more support.

What Does a Collaborative Relationship Look Like?

- Mutual respect for skills & knowledge
- Honest, timely & clear communication
- Understanding & empathy
- Mutually agreed upon goals
- Shared planning & decision making
- Open two-way sharing of information
- Accessibility & responsiveness
- Joint evaluation of progress & successes
- Absence of labeling and blaming

Focus on Collaboration

Patient engagement is an opportunity to create a *third space* where the focus is on the **'we'** and not on *patients, the system or providers*. Through engagement the expertise and experience of *all* stakeholders can be heard and acted on!

Respecting Expertise

Making engagement a priority supports patient & family advisors by acknowledging the importance of their stories and perspectives while also recognizing that they are the **"experts on their own experience"** not the health care professionals or administrators.

Contact us for support and guidance on how to best use this information
Patient.Engagement@albertahealthservices.ca



Adapted from Calgary Health Region. Involving Patient Experience Advisors on Region Committees and Teams. 2007
Jeppson, E.S. & Thomas, J. Families as Advisors: A training guide for collaboration. Bethesda, MD: Institute for Family-Centred Care.1997.

Finding Potential Patient & Family Advisors

There are many ways to find potential patient & family advisors. The way you recruit advisors will vary depending on the level and method of the engagement activity. Generally, the more formal the engagement, the more formal the recruitment method (e.g. recruitment for a long-term provincial advisory council would be more formal than recruitment for a short-term focus group or working committee).

Where to find Patient & Families to Serve in Advisory Roles

- Contact **AHS Volunteer Resources** to see if there are any existing advisors with health care experiences needed to inform the work you will be doing.
- The best advisors are the people who have **experienced care in the specific program** area you are interested in improving. You may already have ideas and relationships!
- Ask **physicians** and other **providers** to identify patients and families.*
- Ask **other patients & families** who are already involved if they have a friend who might be interested in participating.
- Contact patient or family **networks, support groups, or advocacy organizations**.*
- Post **notices** in appropriate language on bulletin boards in reception areas in clinics and on hospital units.
- Include information about opportunities for patients and families to participate as advisors in patient **surveys**.
- Use **“key informants”** – people in the community who are knowledgeable about patients and families’ needs and are a link to other patient and family groups.*
- Ask community and service **leaders**.*

* Suitable for recruiting hard to reach groups

Recruiting for Diversity

The demographics and healthcare experiences of your patient & family advisors need to align with the services that you are providing. This may involve recruiting from diverse or hard-to-reach groups. Advisors should come from a broad range of backgrounds and represent diverse genders, expertise, socio-economic levels and cultural demographics.

Examples of diverse groups include (but not limited to):

- Those who do not speak English as a first language
- Children / Youth
- Seniors (65 Years +)
- Gay, lesbian, bisexual and transgender
- People living with chronic illnesses
- People with disabilities
- Those living in geographically isolated communities
- People with sensory impairments
- Newcomers to Canada
- Those living with culturally diverse backgrounds
- People with mobility issues
- People with low levels of literacy
- People with mental illness and/or addictions

Bellows, M., Oberman, H., & Zimmerman, M (2012). Meaningful recruitment of patient and family advisors. *Canadian Foundation for Healthcare Improvement*, Retrieved from http://www.cfhi-fcass.ca/sf-docs/default-source/collaborations/PEP_Brief_Recruitment_EN.pdf?sfvrsn=0

Adapted From:

Tool 6: Are You Thinking of Becoming a Patient/Family Advisor

Are You Thinking about Becoming a Patient or Family Advisor?

Patient & family advisors play a unique role in helping Alberta Health Services (AHS) to improve the quality and safety of health services. There are many advisor roles in AHS. The most common are members of advisory committees, boards or councils, document reviewers, participants/speakers at conferences and focus groups.

Why should I Consider Being a Patient or Family Advisor?

- A chance to improve the quality and safety of health care services for you & your family
- The opportunity to be a part of meaningful change and make a contribution
- Increase your ability to understand and share information with other patients & families about the health system & policies of health care
- The opportunity to network with staff, providers and leaders and other advisors.
- Expand your knowledge & skills about patient and family centred care and your health care system

Why Does AHS want you to be a Patient or Family Advisor?

- To improve the quality and safety of health care
- Increase the knowledge and skills of leaders and staff about the importance of the experience of patients & families
- Increase our ability to do our jobs better when planning services
- Give a fresh perspective on problems and create innovative solutions

What can Patient and Family Advisors Do?

- Participate on long term committees or short term working groups
- Attend focus groups or offer their patient experience story
- Speak at conferences and health care events
- Give feedback about facilities and communications planning
- Be members of councils and review teams
- Help educate others by talking about their health care experiences as they relate to improving patient and family centred care
- Become a patient and community engagement researcher

Examples of ways AHS currently partners with patients and families:

- Cancer care patient councils
- Ethics Committees
- Emergency room advisors
- Site based Citizens' Advisory teams
- Steering Committees
- Supportive family volunteer programs
- Child and Youth Advisory Councils
- Strategic Clinical Networks

Adapted from:
Thomas, J. & Jeppson, E.S. (1997), *Words of Advice: A guidebook for families serving as advisors*. Bethesda, MD: Institute for Family Centered Care.



Tool 7: Determine if Advisory Role is a Good Fit For You.

Determine if the Advisory Role is a Good Fit for You!

Ask these questions to help you determine whether the potential advisory role will be *meaningful for you* and *what you would be committing to*.

About The Project

- Why include patient & family advisors on this project?
- What are the goals of this project?
- How will my input and feedback be communicated to others and utilized by the decision-maker(s)?
- How will information about the project be shared with me (eg: by email, fax or telephone)?
- How long will I be engaged in this project?
- How many other patients and/or family members will be involved?
- How much time will I be committing to this project monthly?
- Will I be reimbursed for my travel, parking, child care costs? What other costs might I incur and will I be reimbursed for them?
- Where will the meetings be? What time will meetings be at?

About The Role

- What skills, background, experiences, or perspectives would you like the advisor to have? What are your goals in engaging me specifically?
- What will my role be? What will my responsibilities be?

About Support for the Position

- Who will be my key contact person at AHS for this engagement project?
- Who will I go to with questions and for support?
- Who else is involved in the project?
- How will you prepare other project members for the inclusion of patient & family presence and voice?
- How often and when will we re-examine my commitment to adjust my participation according to my needs and also yours? *If you decide to take on an advisory role, be sure to re-examine your commitment from time to time and adjust your participation to meet your personal and family needs.*
- What is your policy for patient & family advisors when they need to take a leave from advising due to personal circumstances or illness?
- Will I need to register with **Volunteer Resources**? If so, what does that involve and who is my contact?

If you are interested in becoming an advisor, check out The Patient Experience web pages at <http://www.albertahealthservices.ca/patientengagement.asp> or call Patient Engagement at 1-877-735-1102 or email at Patient.Engagement@albertahealthservices.ca

Tool 8: What does it Take to be a Patient and Family Advisor



Patient.Engagement@albertahealthservices.ca

What Does it Take to be a Patient & Family Advisor?

When considering whether or not to become an advisor, it may help you to think about the following *attitudes* and *strengths* that you bring to the role:

Ask Yourself...

Personal Strengths

- Do I believe* that the patient & family perspective is as important as providers? Yes No
- Do I believe* that I bring a valuable perspective to the relationship with providers? Yes No

Supporting Others

- Am I willing* to share my experience as a patient or family member? Yes No
- Am I nonjudgmental and accepting* of others? Yes No
- Am I coping* well with my own feelings and emotional issues? Yes No
- Can I recognize* the needs and feelings of others? Yes No

Working with Others

- Am I willing* to get involved with other people for a common goal? Yes No
- Can I handle* confidential information without sharing it with others? Yes No
- Can I listen* as well as contribute? Yes No
- Can I work* without expecting praise and recognition? Yes No
- Can I challenge* my assumptions? Yes No

Working Collaboratively

- Do I treat* each provider as an individual and avoid letting past negative experiences or negative attitudes affect me? Yes No
- Am I able* to deal with conflict and disappointment constructively? Yes No
- When I have* experience to share do speak up? Yes No
- Do I have* realistic expectations for myself and others? Yes No

A Few Other Considerations...

- I understand the project and I am interested in it.
- I understand and am comfortable with what is expected of me
- I am able to make the expected time commitment
- The time and location work for me
- I have a process in place to send and receive necessary information
- I believe my input will make a difference
- I am comfortable that I will get the support I need to be successful
- I am comfortable with how I will be reimbursed for my out of pocket costs
- My involvement will make a difference to me, my family and the people I know
- My participation will have an impact on the way services are planned & delivered for AHS patients & families
- This is worth my time

The most successful advisors are able to say **yes** to most of these questions!

Tool 9: Interviewing Potential Patient and Family Advisors



Interviewing Potential Patient & Family Advisors

The interview process is a two-way street in which both you and your potential advisors will investigate whether or not the opportunity is a 'good fit'. Making sure your prospective patient & family advisor knows what they are committing to is a dual responsibility.

Things to Consider when Setting up Recruitment Interviews for Patient & Family Advisors

- Is the time and location convenient for everyone?
- Where will the interview take place? Face-to-face (recommended), over the phone or by videoconference?
- Will the time allotted allow for full discussion and questions?
- Who will conduct the interview? What is their role in the engagement project?
- Will other patient and family advisors be part of the interview committee?
- How will the interview be recorded; e.g., taped or note taking?
- Is the selection process clear to all participants?
- How will the outcomes of the interview be shared with the potential advisor?
- How will information about the interview be provided to the potential advisor; questions and process?
- Is the purpose of the interview clear; to determine the "fit" of the advisor only, or is it a competitive selection process? Are there other advisor positions to be considered as well?
- Who will respond to those not selected for an advisor role?



Consider using the Following Format for the Interview

- Create a welcoming environment
- Get to know each other and develop rapport
- Provide an overview and aim of the project
- Explain why advisors are important
- Discuss what skills and qualities are needed
- Ask a few pre-set questions.
- Define roles, expectations, and time commitment
- Discuss the expectations of the advisor
- Provide opportunity for the advisor to ask lots of questions

Contact us for support and guidance on how to best use this information Patient.Engagement@albertahealthservices.ca

Adapted from: Parent Leadership Program. Thomas, J.; Jeppson, E.S. (1994). Essential Allies: Families as Advisors. Bethesda, MD: Institute for Family Centered Care
Stollery Family Centred Care Network. (June 2012).

<http://www.albertahealthservices.ca/5510.asp> email: StolleryFCC@albertahealthservices.ca

Tool 10: Sample Evaluation Questions

Sample Evaluation Questions

You may wish to evaluate the *process* of engagement (how the activity unfolded) the *outcomes of the engagement strategy* (what you achieved) or both!

Types of things to evaluate in the engagement process:

- Representativeness
- Early involvement
- Clearly defined task(s)
- Transparency of decision making process
- Clear articulation of roles and responsibilities
- Patient/family and staff satisfaction with process
- Timeliness, participation rate and costs

Types of things to evaluate in the outcomes of engagement:

- Influence / contribution of patients and families on decision
- Patient & family experience of being heard and understood
- Effect on staff attitude towards patient engagement
- Patient and staff satisfaction with overall engagement experience
- Engagement goal and promise met

For Patients & Families

<p style="text-align: center;"><u>Engagement Process Questions</u></p> <ul style="list-style-type: none"> • How detailed, complete and easy to understand was the background information provided to you? • Do you feel you had enough of the right information to take part in the discussion? • Overall, how is your experience as an advisor? • How could your experience as an advisor be improved? • What would you do differently next time? • Any additional comments? 	<p style="text-align: center;"><u>Engagement Outcome Questions</u></p> <ul style="list-style-type: none"> • Overall, how satisfied are you that your opinions were heard and understood? • Overall, how confident are you that your opinions will influence the final decision/outcome? • How satisfied are you with the decision/outcome? • How satisfied are you with the communication of the decision or outcome? • Any additional comments?
--	--

For Provider & Leaders

<p style="text-align: center;"><u>Engagement Process Questions</u></p> <ul style="list-style-type: none"> • How many patient/family advisors participated in the engagement activity? • Were the right patients and families, including hard to reach populations, at the table? • Did you use any incentives to encourage participation? If so, what incentives did you use? • Was staff time within estimates? • Were engagement costs within budget? 	<p style="text-align: center;"><u>Engagement Outcome Questions</u></p> <ul style="list-style-type: none"> • Did the patient engagement activity or the participation of the patient/family advisor contribute to the project? If so, explain how. If not, explain why. • Was the decision and rationale communicated to the advisors? • Was input from the advisor included in the decision-making process? • Was the organizational goal and promise back to patients and families achieved? • What would you do differently next time?
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Adapted from: Capital Health. Engagement Framework and Toolkit. *Capital Health*. [On Line] 2011. [Cited: July 23, 2011.] <http://www.cdha.nshealth.ca/system/files/sites/317/documents/engagement-framework-and-toolkit.pdf>.

Appendix E: Sample Letters for Advisor Recruitment

Sample Letter To Recruit Potential Patient And Family Advisors

Dear Patient and/or Family Member,

As a patient/family member you have a unique perspective and can help us to improve the quality and safety of the services we provide. We are currently looking for a patient or family member to participate on the (insert name) Committee as a patient advisor. (provide brief description of committee).

Patient Advisors are valued volunteers who contribute not only their time but also their insights and experiences to help bring a higher quality of safety and patient care to healthcare for all Albertans. The time commitment would be about (insert time commitment) a month.

If you are interested in learning more or expressing interest, please contact (name and contact info) to get more information and to receive an application form.

Sincerely,

Sample Letter To Assist Physicians And Staff Recruit Potential Patient And Family Advisors

Dear Physician/Staff

Involving patients as partners on the (insert name) Committee is integral to creating responsive programs and services sensitive to patient and family needs. Improved decision making, increased quality and safety, and an enhanced patient experience are benefits associated with including the patient voice on AHS committees.

The main goals of the (insert name) Committee are to (insert goals)

We are asking you to identify and speak with patients and their families that you have encountered who may be interested in being involved as a patient advisor on the (insert name) Committee. We are seeking individuals who are able to see beyond their personal experience and share insights. If you have a patient/family that you believe would be interested, we have prepared a letter for you to give them that includes a contact number for further information.

Thank you in advance for all of your help. We look forward to hearing from you and working with your patients and families.

Sincerely,

Appendix F: Patient Advisor Application/Expression of Interest

Thank you for your interest in being a patient advisor for Alberta Health Services. Your interest in this role is much appreciated. The recruitment process for including patient advisors on AHS committees has been designed to help make sure that the engagement opportunity is a good fit for you and that you are a good fit for the committee. This application form is an important part of this process.

Who are Effective Patient Advisors?

Effective patient advisors are volunteers who:

- are interested in helping to improve the quality and safety of health services for *all* Albertans.
- Understand the difference between being a patient advisor and a patient advocate and want to work as an advisor. (A patient advisor is someone who seeks to inform a process, while an advocate seeks to ensure an outcome)
- Can work effectively in partnership with healthcare providers.

Please start by telling us a little about yourself:

First Name: _____	Last Name: _____
Address: _____	City/Town: _____
Postal Code: _____	Home Phone Number: _____
Work Phone Number: _____	Cell Phone Number: _____
Email: _____	

Your Communication Preference with us: Telephone In Person: Email Online

Other _____

Tell us about the area of healthcare you are interested in:

Tell us about you (attach extra sheet if you wish):

Tell us about your preferred availability:

Are you able to provide your time regularly during weekdays, and during daytime hours? Yes No

If so, about how many days per month (on average) would you be available? _____

Are you interested in participating in other engagement opportunities? Yes No

Are you an existing Alberta Health Services Volunteer/Employee? Yes No

If yes, please tell us at what facility: _____

Authorization and Acknowledgement

I declare that the information provided in this application is true and complete. I understand that any false information provided may be cause for denial of an advisory placement, or dismissal after placement and my status may be immediately revoked by Alberta Health Services at its own discretion. This information will be used to process my eligibility for a suitable Advisory position.

Signature	Date (yyyy-mm-dd)
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The personal information collected by this application form is collected under the authority of section 33 (c) of the Freedom of Information and Protection of Privacy Act and will be used and disclosed by Alberta Health Services (AHS) for verifying the statements in this application and for determining appropriate placement as a volunteer. If you have any questions about AHS' privacy policies and practices, please contact Information and Privacy at 1-877-476-9874. You may also write to Information and Privacy at 10301 Southport Lane SW, Calgary, Alberta T2W 1S7 or e-mail us at privacy@albertahealthservices.ca.

All new volunteers are subject to a Criminal Records Check with a Vulnerable Sector Search satisfactory to Alberta Health Services. This information is collected by the authority of the [Protection For Person In Care Act \(Section 10. \(4\)\)](#).

Thank you for your interest in collaborating with Alberta Health Services!

OFFICE USE ONLY Referred by: _____

Received in Volunteer Resources: _____

Appendix G: Sample Interview Questions

Interview Questions to ask the Potential Advisor
• How did you hear about the committee and why did you apply?
• Briefly tell us about yourself and involvement/experiences with Alberta Health Services (or specific site/program)?
• Tell us about your experience working with committees or councils (can be through your work, community, school). What have you found most rewarding about the work, and most challenging?
• What unique skill set or perspective do you bring to the committee?
• Based on your experience, what areas/issues do you feel should be addressed by the committee?
• How do you see yourself participating on the committee?
• Committee members are required to see beyond their own personal experience in order to listen to other perspectives and come to a solution that works for everyone. Can you provide an example of how you may be able to do this?
• What sort of time commitment would work for you? Are you able to commit to work in between meetings?
• What form of communication in between meetings are you most comfortable with?
• You will be required to register with Volunteer Resources which includes a criminal record check as part of that process. Is that okay with you?
• Are you familiar with the nature of an advisory role?
• What are your questions?

Interview Questions Potential Advisors might want to Ask Committee Members
• What does a patient advisor do and what role does the patient advisor have on the committee?
• How many patient and family members will be involved?
• Do I need any special training to be a patient advisor? If so, how will I get that training and if there are any costs, who will pay?
• What skills/background/experience/perspective would you like the patient/family member to have?
• How will you prepare other committee/project members for the inclusion of the patient advisor presence and voice?
• Who are the key players?
• How will information about the project be shared; email, fax
• What is the time commitment?
• How will patient advisor input be utilized?
• Where are committee meetings held? If I do not live in that location, how will I join the meeting?
• Is there reimbursement for expenses? If so, what expenses are covered?
• Will I need to register with Volunteer Resources? If so, what does that involve?

Appendix H: Reference Check Template

Reference Check Template			
Name:		Relationship to the Applicant:	
Daytime Phone Number:		Evening Phone Number:	
[Applicant Name] has applied for a volunteer position with Alberta Health Services and has given us your name as a reference. We would like to obtain further information regarding their suitability for a volunteer position. Are you willing to provide a reference? If yes:			
1. In what capacity and how long have you known them?			
2. Can you comment on how they have demonstrated commitment/leadership in the past?			
3. They may be interacting with patients, staff and other volunteers. Could you tell me about their work relationships? Were they able to easily adapt to the environment?			
4. Can you provide an example of how this applicant works as part of a team?			
5. Can you give me an example of one of their strengths?			
6. Which of their qualities or traits would you feel would be an asset to volunteering with Alberta Health Services?			
7. Please comment on such things as are they a good listener, punctual, responsible, dependable, patient, tactful, friendly, and willing to learn.			
8. Are there any areas of concern which you feel we should be aware of?			
9. Would you recommend them for a volunteer position?			
Any additional comments you would like to add?			

Appendix I: Sample Offer/Welcome Letter

Dear (insert name)

I am pleased to invite you to join the (insert name) Committee as a patient advisor. We are excited about this opportunity to include patient and family expertise on the committee and look forward to working with you.

As this is a volunteer role, if you have not already done so, please register with Volunteer Resources. The Volunteer Resources Coordinator can be reached by email at (insert email address) or by phone at (insert phone number). The registration process includes:

- *registering on the online Volunteer Resources system*
- *completing a Volunteer Police Information Check*
- *signing the AHS Confidentiality and User Agreement*
- *reviewing the patient advisor orientation package.*

The next meeting of the committee is on (insert date, time, location). At this meeting we will make introductions. (insert name) (insert title) will be your key contact for the committee and (insert name) will call you within the next few days to talk about how you would like to be introduced, the best way to send you the meeting package and to arrange a briefing session before the meeting. Once again, we thank you for your time, energy and the expertise and experience you will bring to the committee.

Thank you for helping AHS improve the quality and safety of the health services we provide.

Sincerely,

*(insert name), Chair
(insert name) Committee*

Appendix J: Letter of Regret to Unsuccessful Candidates

Dear (insert name)

Thank you for your interest in being a patient advisor for the (insert name) Committee. We very much appreciate your time and your commitment to improving health services for Albertans.

We regret that we are unable to offer you a position at this time.

If you are interested in finding volunteer opportunities in your community we recommend contacting Volunteer Alberta www.volunteeralberta.ab.ca

If you are interested in applying for other volunteer opportunities within Alberta Health Services you can find a listing of the Volunteer Resources contacts and locations here: <http://www.albertahealthservices.ca/4295.asp>

Thank you for your interest, we wish you the best in your future volunteer endeavours.

Sincerely,

Appendix K: AHS Network and e-mail Access

To obtain a Network Access and Email address for the patient and family advisor an Identity and Access Management Request or IAM needs to be submitted. This is the same process that happens when a new staff member starts and requires network access. Volunteer Resources and the staff liaison will need to manage the process to acquire the advisor's Network Access and Email address. The IAM process is as follows:

- Volunteer Resources will submit the IAM for the Advisor, with the respective Volunteer Resources Manager approving the request. Volunteer Resources will also take responsibility for cancelling the network access when an Advisor leaves their role
- IT will send the patient advisor's Username and a temporary password to Volunteer Resources, who will send the patient advisor's username and temporary password to the designated staff liaison
- The staff liaison will give the Username and temporary password to the Advisor
- The patient advisor can then login to their account through the external AHS website and change their password
- Because the staff liaison is generally in a better position to be able to interact with IT on behalf of the Advisor, in case of technical difficulty, the staff liaison is the first point of contact to access IT (may also have the Advisor on the line and be there to guide the conversation and answer questions to IT as needed)
- It is recommended to have the staff liaison available the first time the patient advisor logs on and when they register for a course.

The network access is setup to expire one year after the initial date; Volunteer Resources will be responsible for renewing this access but if access needs change, or the Advisor leaves their role the staff liaison should inform Volunteer Resources to cancel the access.

Appendix L: Process and Outcome Questions

Process Questions – Advisor

- How detailed, complete, and easy to understand was the background information provided to you?
- Do you feel that you had enough of the right information to take part in the discussion at the meeting?
- Do you feel that you had the support needed to effectively participate and contribute as an advisor?
- Did you feel that you adequately represented the patient population being served?
- Overall, was the time commitment reasonable and as expected?
- Overall, how would you rate the meetings?
- Using a scale of strongly agree, mostly agree, neither agree or disagree, mostly disagree not applicable, please indicate your level of satisfaction with your experience as a patient advisor on the (insert name) Committee:
 - My involvement as a Patient Advisor has been meaningful
 - I have the support and guidance I need
 - Generally the meeting times and locations are convenient
 - I feel able to freely express my views, opinions, and advice
 - Staff make an effort to make me feel that I am a valuable member of the committee
 - I participate as an equal with all committee members
 - In my opinion, my involvement as a patient advisor has been meaningful for the hospital and staff.
 - Being a patient advisor gives me a sense of accomplishment
 - Overall, I am satisfied in my role as a patient advisor
 - I feel my voice as a patient advisor is heard and respected
 - There is a positive climate of teamwork among staff and clinicians on the team and me, as a patient advisor
 - Having a patient advisor is an effective way to engage patients and their families
- How at ease did you feel joining the committee?
- What has helped your participation on the committee the most?
- I would be more satisfied with my advisory experience if.....
- What additional training or support would be useful to you as a patient advisor?
- What were the greatest challenges/obstacles to being a patient advisor on the committee?

Outcome Questions – Advisor

- What do you most appreciate about your contribution to the committee?
- Overall, how satisfied are you that your opinions were heard and understood?
- Overall, how confident are you that your opinions will influence the final decision/outcome?
- What are the greatest impacts on patients that will result from your participation on the committee?
- How satisfied are you with the decision/outcome? Please comment?
- How satisfied are you with the communication of the decision/outcome?
- Using a scale of strongly agree, mostly agree, neither agree or disagree, mostly disagree not applicable, please indicate your level of satisfaction with your experience as a patient advisor on the committee to the following statements:
 - The committee actively listens to and applies lessons learned from the patient advisor's experiences and suggestions.
 - I would recommend becoming a patient advisor to a friend.
 - The work of the patient advisor improves patient care

- Overall, the work of the patient advisor helps make AHS a better health care organization.
- What personal benefits (gains) have you derived from your participation on the committee?

Process Questions – Committee Members/Staff

- Using a scale of strongly agree, mostly agree, neither agree or disagree, mostly disagree not applicable, please indicate your level of satisfaction with your experience working with a patient advisor on the (insert name) Committee:
 - Working with a patient advisor has been meaningful
 - The patient advisor was well prepared and able to participate effectively
 - The patient advisor was an equal member of the Committee
 - Committee members actively listened to and applied lessons learned from the patient advisor
- Did the patient advisor represent the patient population being served?
- Was the cost within budget?
- Was staff time within estimates?
- What are the greatest challenges/obstacles related to having a Patient Advisor on the Committee

Outcome Questions – Committee Members/Staff

- Did the participation of the patient advisor contribute to the work of the committee? If so, explain how. If not, explain why.
- Was input from the patient advisor communicated to the decision-maker and included in the decision making process?
- What are the greatest impacts on patients that will result from the patient advisors contribution on the committee
- As per IAP2, was the engagement goal and promise back to the patient, achieved?

Appendix M: Five Step Checklist

Engaging with Patient & Family Advisors Five Step Process Checklist

Step 1: Decision to Engage		Yes
Task 1	Team members understand what patient engagement is	
Task 2	Team members understand the value of working with advisors	
Task 3	Your team is clear on your goals and objectives for including the patient voice	
Task 4	Your team is prepared to engage at the “collaborate level”	
Task 5	There is leadership support (Senior Leadership / Committee Chair / project lead)	
Task 6	Fears and concerns have been addressed and your team is ready to commit to partnering with advisors	
Step 2: Get Ready		
Task 1	The staff liaison has been identified	
Task 2	The roles and responsibilities are clear and well defined	
Task 3	The budget, cost centre and approval process for expenses are in place	
Task 4	Your team is ready to engage in a collaborative partnership	
Step 3: Recruit, Onboard and Orientate		
Task 1	The staff liaison has contacted Volunteer Resources	
Task 2	Potential Advisor(s) have been identified	
Task 3	Patient & Family Advisor(s) have been interviewed and selected	
Task 4	Advisor(s) have registered with Volunteer Resources and documentation is complete	
Task5	Advisor(s) have been orientated to AHS and the Committee/project	
Step 4: Mentor and Support		
Task 1	Meeting logistics	
Task 2	Briefing times are scheduled	
Task 3	Support during meetings is planned for	
Task 4	Debriefing times are scheduled	
Task5	A plan to mitigate any special considerations is in place	
Step 5: Evaluation		
Task 1	Advisor evaluation Plan is in place	
Task 2	Team member evaluation plan is in place	