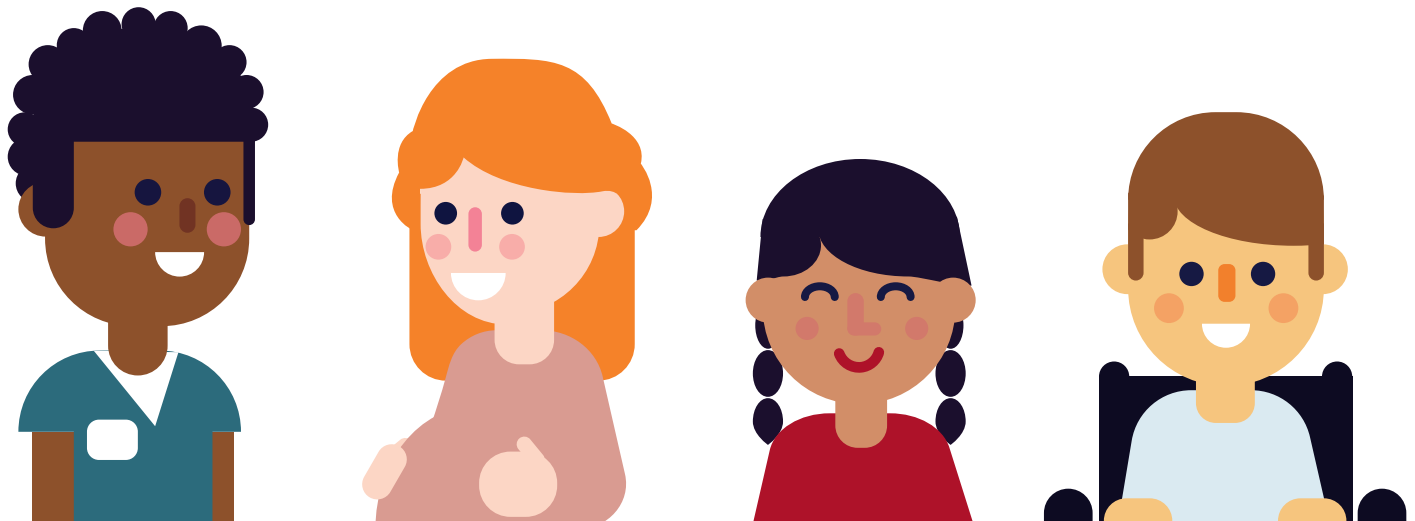


ASK, LISTEN, DO



# WHAT MATTERS TO YOU?

Integrating Advisors into Your Team or Committee: Tips & Tools for Staff



## WHO IS THIS GUIDE FOR?

This resource guide was created for Southern Health-Santé Sud program staff and managers interested in integrating patients, clients or members of the public into committees to serve as volunteer advisors.

The hope is that you will be able to use and adapt the material in this guide to fit the needs of your program/services as you begin working with advisors on your teams and committees.

This Guide is a collection of material gathered from many engagement experts across Manitoba, Canada and beyond. References are available for many of these materials.

**Advisors** are patients, clients or family members who volunteer as active advisory partners with the health system. Whether they have had recent experiences with the system, or are members of the public who care about the “big picture” of health services, they want to make things better. Advisors can see many points of view, and bring their own experience to share. Advisors might volunteer on advisory councils, be part of committees with health care staff, act as research partners, participate on a focus group, or share their views online.

## WHAT MATTERS TO YOU: A PEOPLE-CENTRED CARE STRATEGY FOR SOUTHERN HEALTH-SANTÉ SUD

What Matters to You? is about providing opportunities for patients, families and members of the public to become active participants in all levels of the health system:

From the bedside: regarding their own clinical care and self-management

To the boardroom: regarding higher-level decision-making, offering another voice to the shaping of health programs, policies, evaluation and research.

What Matters to You? is based on 3 main principles:

**ASK:** what matters

**LISTEN:** to what matters

**DO:** what matters

This Resource Guide is a toolkit meant to support staff to integrate patients and community members into committees for making decisions about program design, services, and system planning and policy development.

## WHY DOES ENGAGEMENT MATTER?

Advisors can offer unique information and insight of which health care providers and planners may not otherwise consider or be aware. Giving patients and family a voice in the delivery of care ensures that what matters most to them is part of treatment planning and decision making. Their input can help drive improvement, innovation and responsiveness to create a health care system that will benefit all. Engaging patients, clients & families in designing services and policy has become the gold standard in health systems world-wide. The benefits of engagement for system responsiveness, innovation, safety and sustainability have become so pervasive that engagement is now a requirement for accreditation.



## 5 KEY CONSIDERATIONS BEFORE GETTING STARTED

1. **The Reason:** Why do you want to engage clients & families? What problem needs to be solved or decision needs to be made? What do you hope the patient perspective brings to the table, what will be the role of the advisor and what will you do with their input?

Tools: [\*"Should We Engage?" Assessment\*](#)

2. **The Method:** How are you going to include the patient voice? Are you going to send them a survey, invite them as speakers to share their experiences, integrate them into your working groups or committees? There are many methods- be creative!

Tools: [\*Engagement Techniques, Anticipating Barriers to Participation\*](#)

3. **The Timing:** When do you want to bring advisors on board? As a rule of thumb, inviting advisors to participate as early as possible is ideal, but this will depend on the context of the project and your organization. Sometimes it can make more sense to bring in different groups of advisors using different formats as your work progresses. Advisors, just like staff, will often feel more invested in the project when they've been involved from the start and have had an opportunity to contribute to the shape and direction of the project.

Tools: [\*Preparing Your Team for Advisors\*](#)

4. **The Level:** Make sure you and team have considered what you are comfortable promising to patients and families. One valuable tool is the IAP2 Spectrum of Public Participation. It outlines goals and promises for your team which can be used to communicate expectations to advisors about the engagement opportunity.

Tools: [\*IAP2 Spectrum of Public Participation, Determining the Advisors Role and Scope\*](#)

5. **The Advisor:** Who does your team want to engage with? Do they need to have any specific experiences that they can speak to? Are there any requirements to participate in the opportunity such as living in a certain geographical region, having access to reliable technology, or a willingness and ability to travel to meetings? How will your team let the advisor know the impact of their time and effort?

Tools: [\*Finding the Right Advisor, Advisor Recruitment Tips\*](#)

# 3 STEPS TO MEANINGFUL ENGAGEMENT

## 1. Orientation/Preparation

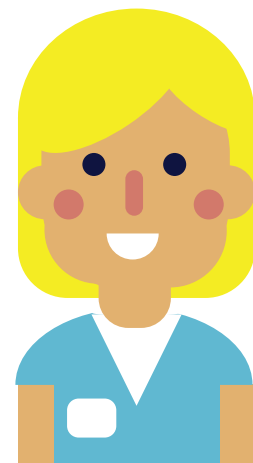
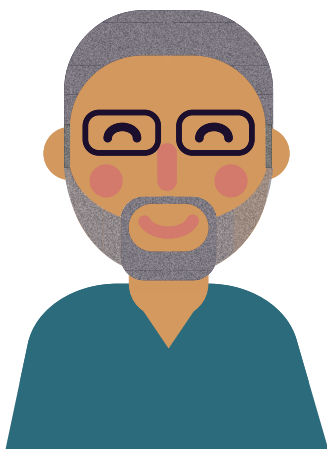
Research has shown that the first few meetings are the key to creating a good experience for both advisors and the rest of the working group. Just like any staff member, your advisors will need to be oriented with both corporate requirements such as Personal Health Information Act (PHIA) training, as well as an orientation to the organization and initiative. It can help to reserve the first meeting as an orientation for the entire group, giving members an opportunity to socialize, connect and understand the group's purpose. Keep in mind that your advisors may feel like 'outsiders'. It is helpful to identify a staff mentor to provide an orientation and debriefing opportunity both before and between meetings to answer questions and provide additional support. If you are recruiting advisors to join a pre-existing committee, you will want to take extra care in acclimatizing them; this could mean slowing down committee work for one meeting to introduce the advisor(s) to the team, and bring the new member up to speed comfortably.

- *Preparing the Advisors for their Role*
- *Setting Up for Success*

## 2. Sustainability

Advisors are volunteers whose ongoing participation will be influenced by their experience and encounters. Respect, trust and transparency are critical. Advisors do not have access to the same information as a staff person, so effective communication is important; reports and summaries can likely be easily emailed so that advisors feel informed about the process and progress throughout. Follow through on promises and integrate feedback whenever possible. When problems or issues arise, ensure that they are addressed in a timely fashion. Most importantly, always ensure that advisors are given adequate opportunity to contribute ideas and opinions so they know their presence has an impact. Discuss how you are going to check in with advisors and your team and set a schedule to do it. After the initial meeting or phone call, it is good practice to follow up with advisors about their experience participating and whether your team could do anything differently to support them moving forward. Reassure them that they can check in in any way and any time that makes sense for them.

- *When Things Don't Go as Planned*



### 3. Closing the Loop

Closing the loop is an essential ingredient to successful engagement efforts. Advisors spend time and energy working on projects and sometimes share incredibly personal and emotionally exhausting experiences. After each engagement opportunity, and ideally throughout it, it is crucial that advisors are informed how their participation affected and/or contributed to the objective or the end result. Some endings to an advisor's engagement are predictable such as the end of planned term of commitment, or the completion of an initiative. Some endings may not be planned, such as a change in an advisor's health or availability. Whatever the reason, you should acknowledge the Advisor for their time and service. Ensure that the entire team is aware and has the opportunity to acknowledge the advisor. Consider an exit interview if you can to help evaluate the effectiveness of the engagement. This can be done by email or over the phone.

- [Exit Survey Questions for Advisors](#)

## IN CONCLUSION...

What Matters to You? is a critical component of the culture we want to promote in Southern Health-Santé Sud. This resource guide is part of a suite of tools and strategies to help cultivate a People-Centred Care culture in the region. Please visit the Health Provider Site and [www.southernhealth.ca](http://www.southernhealth.ca) for more information.

### References

1. Patient Voices Network: A Guide to Patient Engagement [Internet]. Available from <https://patientvoicesbc.ca/resources/a-guide-to-patient-engagement/>
2. Roy McCallum S, Rees J., Alberta Health Services. What is patient & family engagement and why do it? [PowerPoint Presentation]. Canadian Foundation for Healthcare Improvement. [2014 January] Available from [https://www.cfhi-fcass.ca/sf-docs/default-source/on-call/m1presentation2014v1postweb.pdf?sfvrsn=dc27c344\\_0](https://www.cfhi-fcass.ca/sf-docs/default-source/on-call/m1presentation2014v1postweb.pdf?sfvrsn=dc27c344_0)
3. International Association for Public Participation. IAP2 spectrum [Internet]. [cited 2020 Nov 30]. Available from [https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20\(1\).pdf](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf)

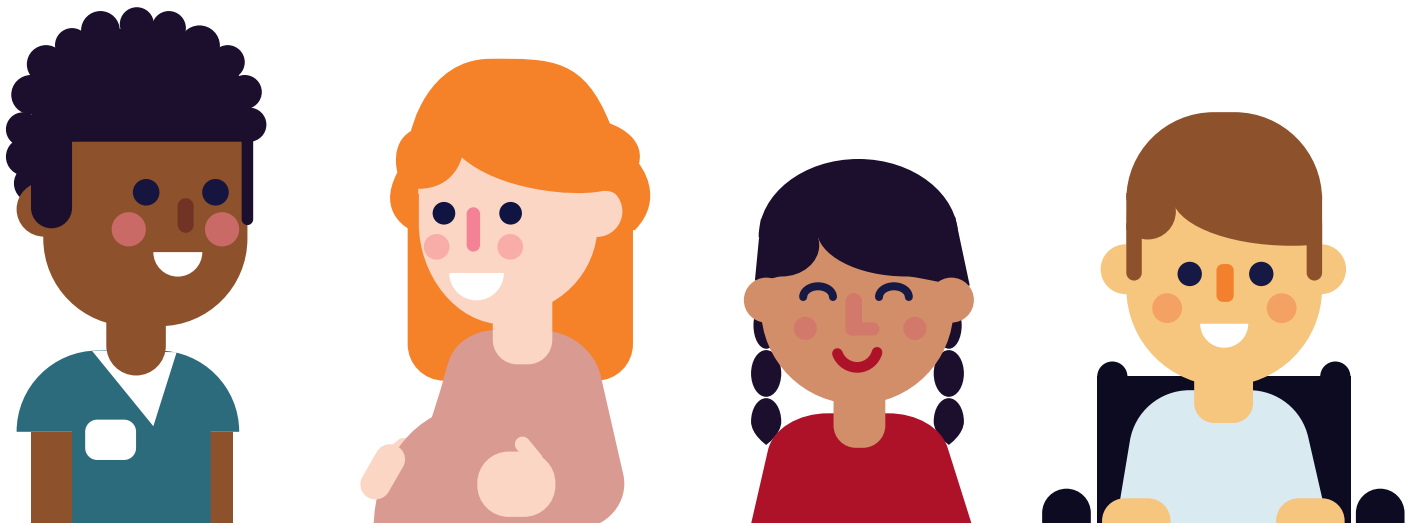


ASK, LISTEN, DO



# WHAT MATTERS TO YOU?

Integrating Advisors Tools for Staff





# “SHOULD WE ENGAGE?” ASSESSMENT

The table below will assist you in assessing your readiness to engage with health care advisors. Read each statement and check the appropriate box. Think about what you require to move your group to “We’re Ready to Proceed”

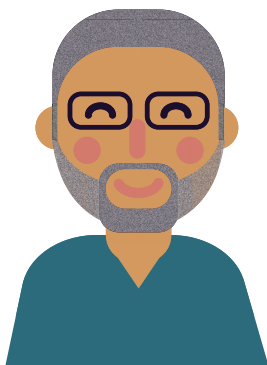
<b>1. SHOULD WE ENGAGE?</b> <i>Can you say YES to the following?</i>	<b>We’re Ready to Proceed</b>	<b>Maybe</b>	<b>More Work To Get There</b>
Is there a decision to be made?			
Will there be tangible outcomes as a result of the process?			
Is the working group and team sponsor truly open to considering diverse perspectives in the process?			
Would advisors be well informed enough to participate?			
Is the process or discussion relevant to patients/public?			
Is asking for them to be involved ethical? (are they participating on their own free will, their participation is legal and fair, participation is beneficial to the advisor and does no harm)			
<b>2. IS THE ORGANIZATION READY TO ENGAGE WITH PATIENTS AND/OR PUBLIC?</b> <i>Can you say YES to the following?</i>			
Have all legal, regulatory or policy requirements for engagement been considered (e.g. privacy, accreditation, standards, etc.)?			
Have the risk and benefits of engaging an advisor been considered?			
Is there genuine potential for patients/public to influence outcomes?			
Is the final decision-maker willing and likely to consider patient/public input?			
Are there adequate resources to support the advisor?			
Have the reputational risks to the organization been assessed. Is there a plan to mitigate them?			
<b>3. ARE PATIENTS/PUBLIC READY TO ENGAGE?</b>			
Have any risks to advisors been assessed. Is there a plan to mitigate them?			
Are there significant impacts on those affected by the decisions made as a result of the engagement initiative?			

Adapted from *Engagement Framework and Toolkit*, Capital Health, Nova Scotia, 2011  
<http://www.nsmhlin.on.ca/~media/sites/nsm/PrimaryNavigation/CommunityEngagement/Pt%20Caregiver%20-%20Day%20Nov13/Capital%20Health%20Toolkit.pdf?la=en>

# ENGAGEMENT TECHNIQUES

The following provide alternative methods to engage patients or public members. The tools are arranged according to the goal of engagement or degree of impact as described by the Spectrum of Patient and Public Engagement.

Goals:	Possible tools:
<p><b>Inform</b> To provide Stakeholders with balanced and objective information to assist them in understanding the problem, alternatives and solutions</p>	<ul style="list-style-type: none"> <li>▪ Websites</li> <li>▪ General information channels ex: 1-800 numbers, email, voicemail</li> <li>▪ Videos</li> <li>▪ Infographics</li> <li>▪ Social media (Facebook, Instagram)</li> <li>▪ Advertising and media coverage – press releases, interviews</li> <li>▪ Print materials – newsletters, letters, posters, brochures, etc.</li> <li>▪ Presentations / Livestreaming</li> <li>▪ Expert panels (at public meetings, conferences)</li> <li>▪ Displays / exhibits (in public venues, community events)</li> <li>▪ Site Visits, Tours</li> <li>▪ Public Meetings</li> </ul>
<p><b>Consult</b> To obtain stakeholder feedback on analysis, alternatives and/or decisions.</p>	<ul style="list-style-type: none"> <li>▪ Polls (online, public)</li> <li>▪ Voting</li> <li>▪ Surveys</li> <li>▪ Interviews (face-to-face, telephone, focus groups)</li> <li>▪ Focus groups</li> <li>▪ Online Forums (through websites, social media)</li> <li>▪ Online commenting (as above)</li> <li>▪ Social Media Listening (aka Monitoring – using analytics to gather information on mentions, discussions)</li> <li>▪ Social Media Discussion / Town Halls.</li> <li>▪ Workshops (like focus groups but more interactive)</li> <li>▪ Door-to-door survey/polling</li> <li>▪ Kitchen table talks</li> <li>▪ Open Houses / Pop-ups</li> <li>▪ Comment boxes</li> </ul>





Goals:	Possible tools:
<p><b>Involve</b> To work directly with stakeholders throughout the process to ensure that their concerns and aspirations are consistently understood.</p>	<ul style="list-style-type: none"> <li>▪ Crowdsourcing Ideas/ Ideation (brainstorming)</li> <li>▪ Community Mapping (services, activities, assets)</li> <li>▪ Digital Storytelling</li> <li>▪ Design Charrette (intensive, collaborative, planning session)</li> <li>▪ Mind Mapping</li> <li>▪ Most Significant Change technique (participatory monitoring and evaluation)</li> <li>▪ Visioning (developing a shared vision)</li> <li>▪ Scenario Testing</li> <li>▪ Citizen’s Panel</li> <li>▪ Hackathons (collaborative innovation on one problem/issue)</li> <li>▪ Participatory budgeting (public engagement in policy decisions and spending)</li> </ul>
<p><b>Collaborate</b> To partner with stakeholders in each aspect of the decision from development to solution.</p>	<ul style="list-style-type: none"> <li>▪ Large group meetings (around a particular issue)</li> <li>▪ Document co-creation (co-own a document to develop, edit)</li> <li>▪ Online communities (common interests, working together over the ‘net, over time)</li> <li>▪ Open Space (participants plan agenda, set priorities within the meeting)</li> <li>▪ Committees /Working groups / study circles</li> </ul>
<p><b>Empower</b> Shared Leadership of community-led projects with final decision making at the community level</p>	<ul style="list-style-type: none"> <li>▪ Decision-making platform (electronic consensus)</li> <li>▪ Citizen committees (public advisory committees with decision making capacity)</li> <li>▪ Citizen juries (Participate in democratic decision-making)</li> <li>▪ Community Indicator Projects (indicators developed and evaluated by the community itself)</li> <li>▪ Asset-Based Community Development (sustainable development based on strengths and potentials)</li> </ul>

For further information, please see:

<https://cdn2.hubspot.net/hubfs/316071/Resources/Tools/Index%20of%20Engagement%20Techniques.pdf>

Adapted from Engagement Framework and Toolkit, Capital Health, Nova Scotia, 2011

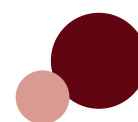
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## ANTICIPATING BARRIERS TO PARTICIPATION

Many obstacles that prevent or limit participation can be overcome with simple strategies. Review the chart below to help you assess whether you can accommodate these strategies for your initiative.

Barriers	Facilitators	Can we accommodate?	
		Yes	No
Computer Access/Literacy	Offer non-web based methods of communication between meetings (e.g. phone, mail, in person).		
Language	Check availability of interpreters (verbal) and translation (written) services or find out if there is a family member who can interpret.		
Health Status	Consider alternative methods of participating on 'sick days' (e.g. by teleconference).		
Physical Disabilities	Choose accessible meeting spaces.		
Employment and Family Needs	Collaboratively set meeting times that meet everyone's needs.		
Transportation	Choose meeting location that is accessible by public transit and consider reimbursement for travel, or offer alternative methods of participating e.g. by teleconference.		
Health and Health System Literacy	Minimize use of jargon and avoid acronyms. Provide background information where appropriate.		
Mistrust of Health Care System	Choose neutral meeting locations. Consider the inclusion of staff with previous experience and demonstrated positive relationships with patients, families and the public.		

*Adapted from Vancouver Coastal: How to Engage Patient and Public Advisors: A Guide for Staff, October 2015.*



## PREPARING YOUR TEAM FOR ADVISORS

So you've decided to have advisors join your team!\* Working with advisors as team members will be new for many staff. Take time as a team prior before integrating advisors to discuss the following:

- 1 What are some the benefits and value that will be added by integrating advisors on your team?
- 2 What are some of the concerns people have about integrating advisors on your team? Don't shy away from this question- it's important for the group to be honest about their fears.
- 3 Who will be the primary contact for the advisor to provide logistical support (ie parking, compensation, orientation, etc)?
- 4 Who will be responsible during meetings for greeting, sitting alongside to answer questions and debriefing with the advisor?
- 5 How will you do things differently at your meetings to make this experience successful for everyone? For example:
  - Spend extra time on introductions at the beginning of a meeting
  - Avoid using jargon or acronyms. Explain technical terms when used.
  - As much as possible, avoid distractions by putting phones and laptops away during meetings.
  - Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care. (See Patient Story Guidelines on the Health Provider Site
  - Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
  - Stay focused on the agenda and avoid side conversations about the workplace, the organization, etc.

\*at least 2 advisors are recommended for any team.

*Adapted from the Institute for Patient and Family Centered Care, Bethesda Maryland*




# IAP2 SPECTRUM OF PUBLIC PARTICIPATION

## IAP2 Spectrum of Public Participation



IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION 					
	<b>INFORM</b>	<b>CONSULT</b>	<b>INVOLVE</b>	<b>COLLABORATE</b>	<b>EMPOWER</b>
<b>PUBLIC PARTICIPATION GOAL</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
<b>PROMISE TO THE PUBLIC</b>	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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International Association for Public Participation [www.iap2.org](http://www.iap2.org)

# DETERMINING THE ADVISOR'S ROLE AND SCOPE

This form can be used to clarify the objectives of the engagement

Program/Project : \_\_\_\_\_  
 Site : \_\_\_\_\_  
 Contact Person : \_\_\_\_\_  
 Phone # : \_\_\_\_\_  
 Email : \_\_\_\_\_

Volunteer Advisors provide insight, perspectives and feedback to help inform decisions within the health system. The role of the Health Care Advisor is not to advocate for specific individual needs, a specific community's needs, or to speak from a health care provider perspective if this is their professional background.

## Description of Engagement Opportunity

*(What are the goals, activities, and deliverables? What is the start date and the length of the Advisor's term?)*

## Required Skills and Attributes of Advisors

*(Consider demographic representation, particular experiences, abilities needed and the number of Advisors required. NB, at least 2 Advisors per committee is recommended.)*

## Benefits to Advisors

*(What will the volunteer gain from this experience?)*

## Expectations of Advisors

*(Anticipated length of commitment, time and frequency of meetings, role of Advisors within and outside of meetings, teleconferencing options, working from home)*

## Designated Advisors Contact

*(Who will orient and support Advisors?)*

## Do you have someone in mind for this role?

*(Name, contact info, has this person(s) been in other advisor roles?)*

## Supports for Advisors' Participation

*(Budget for transportation, alternative caregiver/child care, special accommodations such as translator, note taker, access to amplification, etc.)*

## Evaluation and Termination Plan

*(How will you determine if working with the Advisors was successful for the program and for the Advisors?)*

# FINDING THE RIGHT ADVISOR

For an engagement opportunity to be successful, it needs to be the right fit for both the advisor and the team they will be working alongside. Before inviting advisors to get involved, you and your team should discuss who the ideal advisor would be for your initiative.

## Questions to Consider:

Do you need someone who has accessed your program?

---

How many advisors would you like to invite? (We recommend at least two advisors per opportunity)

---

Should the advisor have had a specific care experience, or would anyone be welcome?

---

Does the advisor need to reflect a certain population that you serve?

---

Who are the people or population that your project is going to affect? How will you involve them?

---

Does the advisor need to come from a certain geographic region, speak a certain language, or have a specific cultural background? How will you reflect the diverse experiences of your catchment area?

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In order to participate in the opportunity, does the advisor need to have any certain skills, or access to any certain technology?

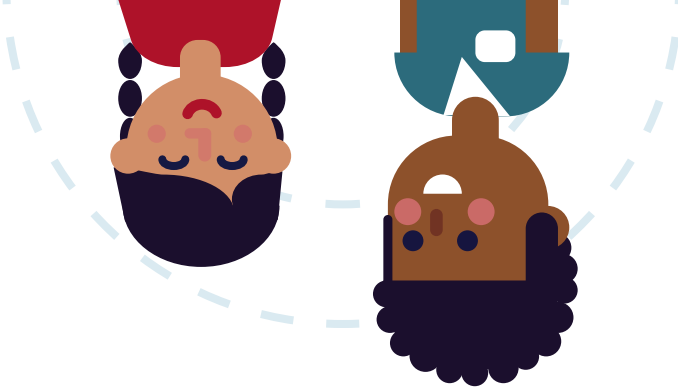
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What days and times will the engagement take place? Does the person have to be available during business hours, Monday to Friday? Is there flexibility to consider their schedule?

---

Does inviting this advisor to this particular initiative create ethical dilemmas for their future care or any other members of the team?





If participating in this opportunity brings up a need for any emotional or psychological supports, are those services available?

Would you or your team like to invite potential advisors for an interview to learn more about each other before confirming their participation?

Will there be any costs or expenses related to participation?

Will your program/service be able to reimburse any out-of-pocket expenses?

### Compensation Guidelines in Manitoba

#### Advisors' Expenses

It is expected that you will reimburse of out of pocket expenses that are incurred while advisors are participating on your committee at rates consistent with your organization. These expenses can include: Bus fare, parking, mileage, hotel and meals if travelling is required, childcare. Advisors are also eligible for incentives such as access to training, conferences, and corporate staff discounts where feasible.

No other compensation is possible.

It is expected that you will attempt to minimize participation expenses where possible by use technology or digital forms of communication.

In some situations, it can be really helpful to have conversations or informal interviews with interested patient partners before confirming their participation. This can help to ensure that it will be a good fit for all involved.

*Adapted from Winnipeg Regional Health Authority and CancerCare Manitoba*

## ADVISOR RECRUITMENT TIPS

Ask other patients and families who are already involved if they have a friend who might be interested in participating.

Ask providers to identify patients and families.

Contact patient or family networks, support groups, or advocacy organizations.

Post notices in appropriate languages on bulletin boards in community locations such as:

- reception areas in clinics and in hospital emergency rooms
- educational, recreational, and social service programs/agencies
- large employers
- churches / places of worship
- housing projects
- gas stations, convenience or grocery stores

Include information about opportunities for patients and families to participate as advisors in the program's or hospital's consumer satisfaction surveys.

Create a webpage for the Patient and Public Engagement to include recruitment information, and link this to the host organization's website, as well as other relevant community websites.

Develop radio and TV public service announcements in the language of the communities you are trying to reach.

Place a story in community newspapers.

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 religious leaders.

Send notices to social and cultural clubs in the community.



## Recruiting for Diversity

For patient engagement to be effective in shaping healthcare service design and delivery, those involved need to reflect the diverse lived experience of the people the organization serves and the broader community. Providers need to deliver culturally appropriate healthcare and be sensitive to social, language, and cultural differences and preferences.

To increase diversity, consider the following characteristics:

- Age, sex/gender, income variety, education, differing neighbourhoods, and/or disability
- Languages, ethno-racial communities, and cultures
- Lifespan perspectives (e.g., elderly vs. young family)
- Family structures and roles (e.g., single, married, caregiver, friend)
- Different experiences with health issues and healthcare (e.g., short- or long-term contact with your organization or service)

Consider barriers that different groups may have to participating:

- Avoid recruiting only those with certain capacity, skills, and experience (e.g., being articulate, well educated, able to represent others from their group).
- Use different outreach and engagement methods to include those who are not typically involved or are more vulnerable or marginalized.

To learn more about why diversity matters, kinds of diversity, removing barriers to participation, tips and tools for reaching out, and case examples, see Health Quality Ontario's Recruiting for Diversity <http://www.hqontario.ca/Portals/0/documents/pe/recruiting-diversity-en.pdf>

*Adapted from Jeppson, E. & Thomas, J. (1994). Essential Allies: Families as Advisors. Institute for Patient- and Family-Centered Care, Bethesda, MD. and Engaging Patients in Patient Safety: A Canadian Guide, Canadian Patient Safety Institute, 2017.*



## PREPARING ADVISORS FOR THEIR ROLE

Preparing both your team and the advisor for their role will ensure the highest likelihood of success. Here are a few ideas to consider:

**1** Ensure that you have discussed the importance of confidentiality and PHIA with appropriate training provided.

Provide orientation:

- 2**
- About the organization
  - About the history of the team they will be joining
  - Offer Terms of Reference and previous meeting notes
  - About current team membership and activities

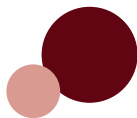
**3** Be clear about expectations. Advisors are there to contribute personal reflections and observations, and not to speak on behalf of a group. Ideally, advisors help provide a well-rounded patient perspective and offer solutions that can benefit patients, families and staff.

**4** Encourage advisors to ask questions before, during and after meetings. Health Care Advisors are committee members like everyone else and they should feel comfortable asking as many questions as they need to in order to help them contribute to the group.

5 Communicate, communicate, communicate! For example: meeting locations and times, parking, preferred method to receive information prior to meetings, who to talk to with questions, evaluating how things are going, etc. Keep advisors informed as much as possible throughout the process.

6 Be honest with advisors. If this is the first time your team has had a patient advisor at the table, explain how everyone will be learning together and to expect a few bumps along the way. Tensions and different opinions are to be expected and respected by all committee members.

*Adapted from the Patient and Family Care Institute, Bethesda Maryland*



# SETTING UP FOR SUCCESS

## Preparation for Meetings

- 1 Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.
- 2 Send agenda and minutes ahead of time to all committee members, remembering to allow time for material to reach patients and families (they may not have fax machines, email, etc.).
- 3 Provide a list of committee members with a brief description of each person.
- 4 Offer a mentor, an experienced advisor or another committee member, to support a new advisor.
- 5 Consider having a trusted person come to the first meeting with a new member and debrief afterwards.
- 6 Remember that this type of collaboration is new for many people so preparation and orientation is important for staff, as well as patients and family members.
- 7 Plan for compensation of time, expertise, and expenses for patients and families. For some this may not be necessary. See Compensation Guidelines.
- 8 Designate one staff member to be responsible for reimbursement and other practical or logistical issues for advisors.

## During Meetings

- Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.
- Provide clear information about the purpose of the committee and the roles and responsibilities of individual members.
- As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together about how to work in new ways. Convey the importance of regularly discussing how the process is working.
- Avoid using jargon. Explain technical terms when used.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care. (See Patient Story Guidelines)

- Acknowledge that there will be tensions and differing opinions and perceptions.
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- If a personal story becomes very prolonged, acknowledge the power and importance of the story, suggest that some policy implications can be learned from the story and that there may be other more appropriate forums where this story should be shared.
- When there are extreme differences in opinions or perceptions, consider:
  - › appointing a sub-committee for further study of the issue;
  - › asking the opinion of other groups (e.g., another committee or patient/family advisory group); or
  - › delaying a decision and considering at a future meeting.

### Anticipate Illness Demands

- Advisors may not be able to attend every meeting. There are other demands on their time and stamina.
- Acknowledge to patients and families themselves and to the committee as a whole that their presence was missed and their participation is valued when they are able to participate. Mailing the minutes and future agendas helps reinforce that their participation is valued.
- Having shared memberships for patients and family members on the committee may help.
- Consider having a “patient and family leave policy” so that advisors can choose an inactive role but maintain their membership should there be circumstances that require some time off.
- Creating a variety of ways for patients and families to participate in the consideration of issues may be useful (e.g., conference calls, written review of materials).

*Adapted from Institute for Patient and Family Centered Care, Bethesda Maryland*

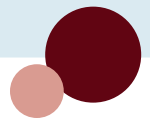




## WHEN THINGS DON'T GO AS PLANNED

Even our best laid plans don't always work out. Patient engagement involves many moving parts and personalities. Here are some tips to consider when things don't go as planned:

- 1 Take a Pause and Regroup** – revisit your goals and objectives for engaging patient partners and see if they need some tweaking.
- 2 Check In** – bring the team together (including patient partners) and check in on their experience to date.
- 3 Ask for Help** – sometimes a fresh set of eyes can help you sort out where you are at in the process.
- 4 Talk, Talk and Talk** – clear communication is the key to a successful engagement. Making sure this is a priority will minimize any concerns and the bonus is you always learn something new.
- 5 Release the Pressure** – It's okay to start and stop. Readjust your expectations.
- 6 Perfect is Not the Goal** – continuous improvement involves letting go of perfection. Being vulnerable is a sign of a good leader. Your team will benefit from that approach.
- 7 Try Again** – your first attempt may not have gone so well. That's okay. Try again.



## EXIT SURVEY QUESTIONS FOR ADVISORS

We are continually striving to improve our programs and services. As one of our volunteers, we would appreciate your help and honesty in receiving your feedback as to your experience with us. We hope with the information we receive, we will be able to make improvements to our program.

**Which team are you a member of?**

**Overall, how would you rate your experience with us?**

- exceeded expectations
  met expectations
  did not meet expectations

**What did you like best about participating on this team?**

**Indicate your level of agreement with the following statement: I felt needed & useful.**

- strongly agree
  neither agree nor disagree
  strongly disagree

**The number of meetings and expectations were...**

- just right
  too much
  too little

**Were there any aspects of the role that you did not enjoy?**

**Was there any information about the role that we did not tell you about, that you would have liked to know?**

**How well did you feel the staff you interacted with in this role treated you?**

- very well
  well
  not well

**Why have you decided to leave?**

- I have completed my term  
 I am moving out of the region  
 It wasn't at all what I expected  
 Other: \_\_\_\_\_

**Do you have any suggestions for improvements?**

On behalf of the Board of Directors and staff of Southern Health-Santé Sud, we thank you for your participation and appreciate the time you have taken to help improve health services and experiences in the region.