Patient
Voices
Network

ADMINISTERED BY
HEALTH QUALITY BC

Committee Principles & Guidelines

For Health Care Partners

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About Us

The Patient Voices Network (PVN) connects people who have lived and living experience with those working in health care to improve BC's health system. Supported through funding from the Ministry of Health and administered by **Health Quality BC**, we support all aspects of patient engagement, from recruiting patient partners to offering advice on how they and health care partners can work together to make health care better.

With more than 1,200 patient partners from across the province, our operations and activities are guided, co-designed and supported by an Oversight & Advisory Committee consisting of patient partners and an equal number of representatives from health care organizations and the Ministry of Health. Learn more about our work at PatientVoicesBC.ca.

Introduction

Organizations frequently include patient partners in committees as they strive to improve health care services. Understanding the different types of committees and aligning their purposes with patient partner input is key to meaningful patient engagement. Our committee principles and guidelines resource is designed to:

- Inform you of the different types of committees and their purpose
- Assist with your assessment of including patient partners
- Provide you with key features of patient partner involvement, and
- Address some frequently asked questions

This resource does not provide all the information available about including patient partners on committees. However, it does provide foundational information and refers you to other sources that can help you assess your readiness. Health Quality BC can also help you to move forward with next steps.

Why Do We Involve Patients and the Public?

There are many reasons to involve patients and the public, including:

- To Inform health system decision makers of patient experiences to ensure the perspectives of those receiving services are included in decision-making
- To promote an understanding of different viewpoints
- To provide opportunities for partnership and shared decision-making
- To facilitate effective communication between the health system, patients and community members
- To build trust and partnerships
- To meet Accreditation Canada standards and BC Ministry of Health mandates

The Benefits

Engaging with patient partners to improve health care helps to build connection and benefits everyone involved in many ways.

Patients, family members & caregivers	Organizations	Service Providers
Become involved in the systems that support their own health care	Helps target resources where they are most effective and valued by patients	Supports the provision of person- and family-centred
Improves the understanding of issues and the health care system	Brings diverse perspectives into the planning process	Recognize the important role of other caregivers, such as family and friends
Appreciates involvement, being listened to and having their opinions valued	Demonstrates accountability and transparency	Increases awareness of the barriers encountered by patients
Learns how to advocate effectively	Provides a direct link to patients, families and caregivers	Helps to identify system issues that need to be addressed
Understands how to be an active participant in their own health care	Supports a culture of person- and family-centred care	May improve relationships with patients

Committee Types

There are a variety of health care committees that seek to include patient partners. It is important to determine from the beginning what level of influence patient partners will have over the decisions of the committee. This may also help you determine which committee is the best fit for your initiative.

We have suggested levels of engagement, however, it is recommended that you clarify with your team where your committee fits on the IAP2 spectrum.[1] While you may choose a particular level of engagement for your committee, you may have working groups or other activities under the banner of your committee that have a different level of engagement. The goal is to have everyone on the same page about their roles to align expectations.

Here are some frequent PVN-supported committee descriptions:

Name	Description	Level of Engagement
Advisory	A structured way for patients, families and caregivers to share their perspectives, experiences and ideas with health care partners. This committee does not have governance responsibilities and is relied upon for expert opinions, based on patient partner experiences.	Consult or Involve
Steering	A mixture of health care decision makers and patient partners that collaborate on decisions that lead, prioritize,	Collaborate

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[1] International Association for Public Participation. IAP2 Spectrum [Internet]. [cited 2019 Mar 21]. Available from https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf

	and define the scope of initiatives. They act as a guiding force for health care teams as they seek to improve health care services.	
Working Group	A group of health care and patient partners working together to achieve specified goals. The groups are domain-specific and focus on discussion or activity around a specific subject area. Working groups dissolve once the activity is completed.	Involve or Collaborate
Project	A group of health care and patient partners working on a time-limited quality improvement project. The committee’s purpose is to solve one problem. They typically have a project manager who guides the team. They will only exist for as long as is needed.	Involve or Collaborate

Weighing the Options

Even with the best of intentions, adding a patient partner to a committee may not be the best option. Your goal is to include patients and the public so that **what matters to them** shows up in any improvements made. Keep in mind the phrase “right people, right role” as you explore the possibilities. The impact of patient and public involvement is not determined by quantity, rather, it is the quality of those interactions that matters. Taking the time to go through the options, and talking with your team, is an important part of this process. The **Health Care Partner Readiness Check List** is a great tool to use when weighing your options.

Patient Partner Involvement May NOT Be the Best Method to Achieve Your Goals When:

- ☐ The intention is to “inform” patients or the public (as per the **IAP2 Spectrum of Engagement**)
- ☐ They cannot influence decisions (often referred to as “tokenistic” engagement)
- ☐ There is inadequate support available for their involvement
- ☐ When you want broader public input (other methods may be more effective)
- ☐ A group with a finite term is entering its end stages
- ☐ Other group members may not know how to work with them
- ☐ The group is in transition with its leadership and future direction is unclear

Barriers to Participation

Ensuring inclusion of the voices of all British Columbians takes effort. **Diversity, Equity & Inclusion – Elevating the Voices of All British Columbians** is a guide that can help you and your team reflect on reducing barriers and challenging your own biases as you support patient engagement. We recommend you read this resource as you move forward. Here are some barriers to committee work that you should consider:

Barriers	Facilitators
Computer access or literacy	Offer non-web-based methods for communications (e.g., phone, mail, in person).
Language	Check availability of translation services
Health status	Consider alternative methods of participating on "sick days" (e.g., teleconference).
Physical disabilities	Choose meeting spaces with wheelchair accessibility, hearing and/or visual enhancements and other aids as appropriate.
Family needs	Set meeting times together, including providing or reimbursing for childcare or elder care.
Transportation	Choose meeting locations accessible by transit and reimburse travel expenses.
Health literacy	Remove jargon and avoid acronyms. Give background information where appropriate.
Mistrust of health care system	○ Choose neutral meeting locations. Include professionals who have a previously established positive relationship. ○ Decrease power dynamics by dressing casually and reducing jargon. ○ Balance the number of patient partners and professionals as appropriate. ○ Take the time to build relationships. Connection before content!

Including Patient Partners

We recommend that you build an orientation for new committee members into your engagement planning, including opportunities for them to ask questions.

It is also important that all committee members are prepared in advance that patient partners will be joining the meetings. This provides an opportunity to review the benefits of working in partnership together and to recognize that the first few meetings may involve spending time on context setting, introductions, role clarity and answering questions.

Here are some other important considerations.

Connection before Content:

The patient experience is a human experience. Getting to know each other beyond your roles as patient and health care partners helps to create understanding, builds trust and establishes comfort with each other. It is important to create time to build connections and to have ongoing touch points throughout the life cycle of the engagement.

Connection before content lays the foundation for how all other communication happens in your engagement. Without this step, it is difficult to create a culture of honest dialogue.

First Meeting:

Plan an initial meeting involving patient partners and other members. The first meeting serves as time for relationship-building and an orientation to all group members.

We recommend the agenda include:

- An introduction to one another
- Highlight the role of the patient partner and other members' roles on the project
- A briefing on the committee's purpose, scope and Terms of Reference
- Work that has happened to date (this is particularly important if patient partners are joining a committee after it has been formed or if they are replacing a patient partner who has completed their term)
- A discussion on the planning and coordination of future communications and meetings
- Creating a commitment or Teamwork Agreement on how you would like to work together as a group and have respectful conversations. Having an agreed upon set of rules or commitments makes meetings run more smoothly

For other tips on how to lead a meeting, check out this resource Leading Great Meetings.

To help balance power dynamics and create cohesion, we recommend:

- Using first names rather than titles and clearly displaying names
- Creating an understanding of shared language e.g., pronoun use
- Starting the meeting with a Territorial Acknowledgement
- Avoiding jargon, uncommon medical terminology and acronyms
- Reminding people, as needed, of the Terms of Reference and other group values
- Sharing – in advance – education and information about programs or projects so that patient partners can participate fully in the discussion

Provide Adequate Support to the Patient Partner:

Patient partners have unique perspectives and needs based on their previous experience, their health and other personal circumstances. Initially, a patient partner may feel like an "outsider," coming into a group of people who may already know each other or have worked together previously. They may have questions that they do not feel comfortable asking in a group setting or may not know who the appropriate person is to ask.

The lead health care partner can provide support by debriefing with patient partners before and/or after meetings to help clarify questions and provide additional support, as necessary. They can also advocate for patient partner inclusion during meetings. Based on our experience, the level of support needed usually decreases as patient partners become more integrated into the working group.

Handouts and Background

Include a Term of Reference, previous meeting minutes (if applicable), an agenda and an attendee list.

Patient Partner Introduction

The patient partner will prepare a brief verbal introduction that includes:

- Their name
- Relevant experience they wish to share (professional, voluntary, personal) that illustrates what they can bring to the committee
- Motivations to join the committee

Preparing for Subsequent Meetings

If you have specific areas where you are seeking the patient voice, or even if you do not, be sure to identify ways to have a meaningful role for the patient partner. Where can they have input?

Frequently Asked Questions

Here are some common concerns that have arisen in committees and some ways to overcome them:

Concern 1: The Patient Partner Talking About Personal Experience or Specific Health Care Circumstances.

"The patient partner seems to have their own agenda and often hijacks the conversation to talk about their personal experience. They are focused on their own experience and it does not seem that they represent the voice of the public."

Considerations: Health care can be traumatic. Having the grace, kindness and respect to support patient partners that share their experience through building relationships (connection before content) helps guide a mutually beneficial experience. Personal stories can be powerful as they bring reality to an issue and help others see things from a non-health care provider way.

It is important to understand that just as we would not expect one nurse on a committee to represent the voices of all nurses, we cannot ask a single patient partner to represent all patients. If representing a specific demographic or medical condition is important for your committee, make sure to recruit for that. Or better yet, team up with an organization that has the experience and relationships to help guide you on the best approach to increasing the diversity of voices.

In addition, having more than one patient partner present can help bring a diversity of views and build connections. Appropriate orientation and facilitation can help keep members on track during meetings. Regular check-ins with the committee chair can also help resolve issues and clarify roles and expectations.

Concern 2: The Patient Partner Is Not the Best Fit for the Committee.

"The patient partner seems 'too professionalized,' we are looking for someone to bring a 'rawer' perspective."

Considerations: There are pros and cons to having patient partners with previous health care and committee experience. The benefit is that those people do not need as much orientation to how initiatives work and often feel more comfortable and confident with other professionals. People who have the time and capacity to participate in various initiatives often come from a professional background, may be in good health and are often retired.

If your committee is looking to include perspectives from hardly-reached groups or those with recent or current health issues, you must be prepared to provide them with the appropriate level of support to enable their participation. This could include reminders, regular check-ins, honoraria (money, parking, food) and other supports such as child or elder care. You may need to structure your meetings in a location and at a time that is more accessible.

To achieve a balance between experienced and fresh viewpoints, consider structuring the committee so that members' terms are time-limited and staggered so that only a portion of the committee is new and knowledge is retained.

Recognizing this expectation from the beginning can be helpful to support the healthy dynamics of a committee.

Concern 3: Recruitment/Scheduling/Turnover.

"It has been really hard to get patient and public involvement because other committee members who participate as part of their job would prefer to meet during business hours, and the patient partner cannot take the time off work to accommodate our meetings."

Considerations: Scheduling is an issue for almost all initiatives that bring together people from different workplaces and organizations. Consider holding meetings over lunch hours (and providing lunch if possible) or towards the end of the day to make it easier for patient partners to participate. If this is not possible, and you really would like public involvement, consider giving an honorarium to reimburse patient partners for time lost.

Turnover is inevitable in any committee. Ensure that changes in membership are communicated to the whole committee.

Concern 4: Patient Partners Are Not "Up to Speed" With the Work.

"Having a patient partner slows the meetings down, which can be frustrating."

Considerations: While patient partners may slow down the meeting, it can also provide a great learning opportunity for professionals. Meetings with patient partners are often "slowed down" because professionals are asked to explain their jargon, acronyms and rationale for doing things. By committing to this as a team, you are increasing accountability to the public and helping professionals practice effective knowledge translation techniques.

Connecting as humans, before you get into the content of your committee, can help build relationships. A thorough orientation both for patient partners (background and context of the committee), as well as for committee members (patient partner's role) can also prevent unnecessary backtracking during meetings. Providing all members with agendas, meeting minutes and supporting documents can help ensure patient partners are up to date.

Concern 5: Dealing With Conflict.

"There seems to be ongoing conflict between a patient partner and myself or other committee members. What is the best strategy to resolve this?"

Considerations: The key to minimizing conflict is to set your committee up for success from the beginning. Connection before content, creating core values for working together, providing adequate support, building ongoing communication options and evaluating your efforts are good places to start. Keep in mind that a difference of opinion is often necessary to generate new solutions.

In the event of ongoing or major conflict we suggest the project lead meet one-to-one with the patient partner, as soon as possible.

If they do not feel comfortable addressing the conflict directly, provide support to facilitate a discussion. In many cases, the conflict is due to a misunderstanding and can be resolved through communication and collaboration. However, if the conflict cannot be resolved, the partnership may need to be dissolved or shifted to another opportunity.

Final Thoughts

You may need some support to include patient partners in your health care improvement work. Health Quality BC is here to provide you with:

- Engagement readiness and preparation
- Planning – engagement technique options and role clarity
- Finding a patient partner
- Involving a patient partner
- On-going support
- Closing the Loop – evaluation and measuring outcomes

You can reach us at **www.patientvoicesbc.ca** or 1.877.282.1919