



This material has
been reviewed
and approved
by patient
partners with the
Patient Voices
Network.



**BC PATIENT SAFETY
& QUALITY COUNCIL**
Working Together. Accelerating Improvement.

A GUIDE TO **Authentic Patient Engagement**





BC Patient Safety & Quality Council

Our work leads to better health care for British Columbians.

We deliver the latest knowledge from home and abroad to champion and support high-quality care for every person in our province. This system-wide impact requires creativity and innovative thinking, which we combine with evidence-informed strategies to shift culture, improve clinical practice and accelerate our partners' improvement efforts.

We also understand that meaningful change comes from working together. We are uniquely positioned to build strong partnerships with patients, care providers, health leaders, policymakers, senior executives, academics and others. These connections enable us to nurture networks, recognize the needs of our health care system and build capacity where it is needed the most.

If you want to improve BC's health care system, visit [BCPSQC.ca](https://bcpsqc.ca) to access programs and resources that can help you start today.

Patient Voices Network

The Patient Voices Network (PVN) connects people who have lived and living experience with those working in health care so they can partner to improve BC's health system. It is supported through funding from the Ministry of Health and administered by the BC Patient Safety & Quality Council, building capacity in the system to support patient engagement.

With more than 1,200 patient partners from across the province, PVN 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 us, sign up as a patient partner or create an engagement opportunity at PatientVoicesBC.ca.



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Welcome to the World of **Patient Engagement!**

We're excited that you're interested in learning about patient engagement and we hope this guide will support you in your journey. This guide has been written for people working in the health care system who are planning or continuing to include patients, families and caregivers in their efforts to improve health care in BC. The engagement concepts explored are for engagement at the program or policy level, not at the point of care.



Definitions

- **Quality** | Quality is defined by seven dimensions that span the full continuum of care: respect, safety, accessibility, appropriateness, effectiveness, equity and efficiency. [2] Learn more in the [BC Health Quality Matrix](#).
- **Quality Improvement** | Quality improvement refers to systematic, data-guided activities designed to bring about immediate improvement in a health care setting. [3]

Involving patients, families and caregivers can:

- Provide important insights and ideas for quality improvement efforts;
- Improve communication between patients and health care providers, leading to improved patient and provider satisfaction;
- Help health care providers embrace potential changes from the patient perspective;
- Ensure that patients are full participants in decisions that affect them;
- Empower patients to become involved in their own health care, rather than being passive participants; and
- Result in meaningful changes to health care services. [1]

This guide shows you the principles and essentials of patient engagement. You can read this guide from cover to cover or focus on the specific sections that are of interest to you. We recommend that you familiarize yourself with the content and keep this guide as a handy reference as you move along your journey of engaging patients.

We have also compiled some key resources and linked them throughout this guide to help support you in your engagement work. While not an exhaustive list, it provides foundational information and reading.



What Matters to You?

If you're looking for ways to engage patients at the point of care, check out the "What Matters to You?" initiative. When providers have conversations with the people they support or care for about what matters, it helps build trust, understanding and empathy. [4] Patients are the true experts on their own needs and experiences and asking, listening and responding to what matters to them is a key element of person- and family-centred care.

For more information visit WhatMattersToYouBC.ca.



Patient Engagement: **The Essentials**

In this section:

Key Concepts

Person– and Family-Centred Care in BC

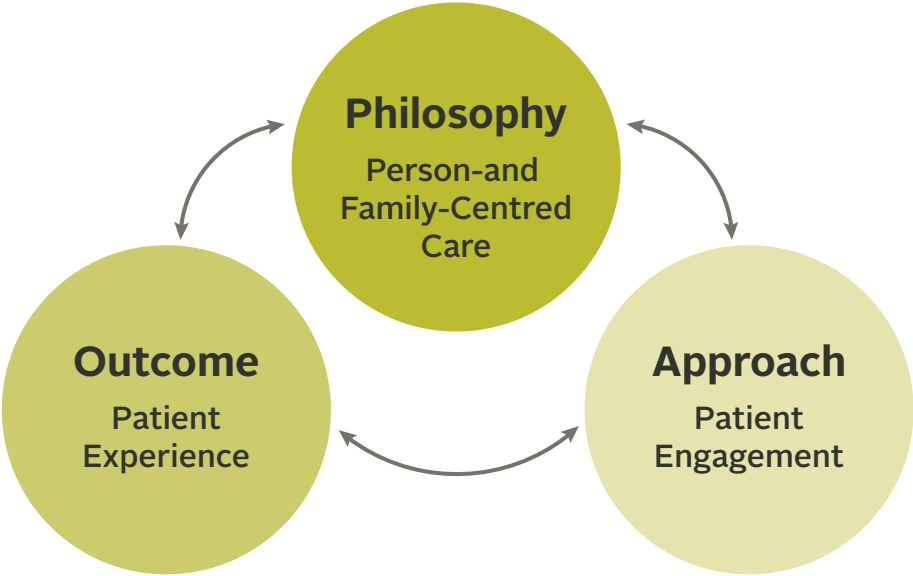


Before we get into the principles of patient engagement, we need to define some key concepts and terms used in this guide.

Key Concepts

Person- and family-centred care, patient and family engagement and patient experience are all concepts commonly used to discuss engaging with patients. These terms don't all mean the same thing and it's helpful to understand them, where they overlap and the relationship between them.

Cancer Care Ontario has developed a model [5] which we've adapted to illustrate how these concepts work together.



Definitions

Patient Partners | The umbrella term “patient partners” is used to refer to anyone who has experience with the health care system as a patient, family and/or caregiver. They have an array of backgrounds and experiences.

Health Care Partners | We define “health care partners” as individuals or organizations seeking to include patient, family and caregiver voices to improve BC’s health care system.

Patient Engagement | In this guide, “patient engagement” refers to the participation of patients, families and caregivers in health care system initiatives at the program or policy levels.

Initiative | In this guide, “initiative” is used to refer to the projects, committees or decisions that “patient engagement” activities are connected to.

In this section:

● Key Concepts

Person– and Family-Centred Care



Person- & Family-Centred Care (The Philosophy)

The philosophy of person- and family-centred care has many names and can sometimes be referred to as patient- and family-centred care as well as client- and family-centred care. In this guide we'll use the term person- and family-centred care (PFCC), meaning “an approach that fosters respectful, compassionate, culturally appropriate and competent care that is responsive to the needs, values, beliefs and preferences” [6] of patients and their families.

PFCC “shifts providers from doing something to or for [patients] — where the health care provider’s perspective is dominant—to doing something with [patients]” [6] in a true partnership.

Patient Engagement (The Approach)

Patient engagement is the act of involving patients, families and caregivers in decision-making, design, planning, delivery and evaluation of health care services. When patients are actively engaged, they become informed decision-makers in their own care and can help improve the overall health care system. When health care providers listen to and work with patients, families and caregivers, programs, service delivery and policy can be improved by their firsthand knowledge, insight and experience. [8]

Patient Experience (The Outcome)

Improved patient experience can be an outcome of person- and family-centred care and patient, family and caregiver engagement. Patient experience can be defined as “the sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.” [9]

In this section:

● Key Concepts

Person– and Family Centred Care

Person– & Family-Centred Care in BC

British Columbia's health care system is complex. A foundation of PFCC and a clear understanding of patient experiences are needed to provide high-quality care.

The BC Ministry of Health has identified PFCC as a key priority for BC's health system [10] so, health care organizations across the province are working to embed it within all aspects of health care delivery.

Did You Know?

These core principles from the Institute for Patient- and Family- Centered Care [7] can be helpful in grounding and setting the tone for patient engagement work:

- **Respect and Dignity** – Listen to and honour patient and family perspectives and choices.
- **Information Sharing** – Communicate and share complete, unbiased information with patients, so they can effectively participate in care and decision-making.
- **Participation** – Encourage and support patient partners to participate in care and decision-making at the level they choose.
- **Collaboration** – Collaborate with patient partners in policy and program development, implementation and evaluation; in health care facility design; in professional education; and in the delivery of care.

“

Working with patient family partners on improvement projects and research helps us stay focused on topics that really matter to patients/ residents and their families.

- Agnes Black, Director, Health Services & Clinical Research and Knowledge Translation, Providence Health Care

In this section:

Key Concepts

- Person– and Family-Centred Care



Principles of **Patient Engagement**

In this section:

Seven Principles of Authentic Engagement

Diversity, Equity and Inclusion (DEI)

Indigenous Cultural Safety and Humility



Authentic patient engagement does not happen by accident – it takes effort and a commitment to working together in partnership throughout the process.

The following seven principles of authentic engagement are based on the [International Association for Public Participation's](#) (IAP2) core values. Consider each of them and ask yourself whether you're engaging patient partners in a way that is of value to you, to them and to our health care system. [11]

1. People affected by a decision are involved in the process.

Acknowledge that it's important for patient partners to have their voices and opinions heard when there's a decision to be made that will impact them in some way.

2. The engagement organizer promises that the patients' input will contribute to the outcome.

Engage patient partners at a point where their input can influence the work and communicate early in the process how this input will be used.

3. Long-lasting and sustainable decisions recognize the needs and interests of all parties.

Engage patient partners in the work from the earliest stages of improvement so you can see where you need to go to achieve a mutually agreeable solution that will best serve everyone's needs. The goal should be to find solutions and improvements that will be supported both now and into the future.



Resources

- [Principles of Authentic Engagement](#)
- [Patient Engagement Learning Series](#)

In this section:

● [Seven Principles of Authentic Engagement](#)

[Diversity, Equity and Inclusion \(DEI\)](#)

[Indigenous Cultural Safety and Humility](#)



In this section:

● Seven Principles of Authentic Engagement

Diversity, Equity and Inclusion (DEI)

Indigenous Cultural Safety and Humility

4. Every effort will be made to ensure that all perspectives are sought out and invited to participate.

Be comfortable hearing from a diverse range of voices – even if they aren't in agreement with what you want to hear. This helps establish a mutually agreeable and widely supported decision.

5. Patient partners' input is sought out in designing their participation in the initiative.

Once you are clear on the engagement objective and which decision points patient partners can influence, it's good practice to create and/or review the proposed engagement activities with patient partners and modify your approach, where feasible, based on their suggestions.

6. All participants are supported and provided with the necessary information to ensure that they can fully participate right away.

Don't assume that patient partners are already well-versed in the technical aspects of health care. While they bring unique perspectives to the work, steps should be taken to ensure that they're given enough support and information to participate in a meaningful way.

7. Patient Partners are kept updated throughout the process about how their input is/has shaped the final decision.

Ensure that patients who are invited into your work receive regular updates on how the decision is progressing and how their input and expertise is used. Closing the loop in a timely manner helps demonstrate the value of their contributions and improves the likelihood of patients volunteering their time in the future.

Diversity, Equity & Inclusion (DEI)

The principles of engagement highlight the importance of hearing from diverse voices. When we think of diversity, we need to consider hard-to-reach voices and diversity in experiences.

Spend some time thinking about who will be impacted by your work now and into the future. How can you involve patient partners in the work now?

Our hope is that you will continue to explore these concepts by taking on further research and asking important questions to help guide your engagements.

These questions might include:

- Does my organization have a DEI policy?
- Have I done my own self-assessment of my knowledge and beliefs towards DEI?
- Are there designated support people inside my organization for DEI?
- Have I accessed training and educational resources to increase my knowledge of DEI principles?
- Have I built enough time into my planning for increasing my knowledge?
- Do I know enough about my community to inform my planning?
- Have I identified and reached out to community partners who could be part of my initiative?

We encourage you to explore how you can make a conscious effort to elevate all voices to improve health care, together.



Did you know?

[Diversity, Equity & Inclusion: Elevating the Voices of All in British Columbia](#) is a resource designed to highlight the importance of this as an engagement best practice.

It will set you on a path to asking important questions and may challenge your own biases as you support patient engagement.

In this section:

Seven Principles of Authentic Engagement

 Diversity, Equity and Inclusion (DEI)

Indigenous Cultural Safety and Humility



Indigenous Cultural Safety & Humility

Cultural safety and humility should be at the core of every engagement involving Indigenous Peoples. Historic and current practices of colonization and oppression contribute to systemic racism towards Indigenous Peoples to this day, including within the health care system. Practicing cultural humility and embedding Indigenous perspectives into quality across the system can lead to cultural safety where Indigenous Peoples feel safe when receiving health care, do not experience racism and discrimination, and are partners in their care.

In [Creating a Climate for Change](#), the First Nations Health Authority provides the following definitions of cultural safety and cultural humility. [12]

Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the health care system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.

Cultural humility is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.

In this section:

Seven Principles of Authentic Engagement

Diversity, Equity and Inclusion (DEI)

● Indigenous Cultural Safety and Humility



Resources

- [Culturally Safe Engagement: What Matters to Indigenous \(First Nations, Métis and Inuit\) Patient Partners – Companion Guide](#)
- [Culturally Safe Engagement: What Matters to Indigenous \(First Nations, Métis and Inuit\) Patient Partners – Pamphlet](#)

For a comprehensive guide on how to engage in a culturally safe way, please see the guide and pamphlet in the resource side bar.

Now that we've defined the key concepts and introduced the principles and need for elevating all voices in British Columbia to be a part of improving health care for everyone, let's get started on the steps to patient engagement!

In this section:

Seven Principles of Authentic Engagement

Diversity, Equity and Inclusion (DEI)

● Indigenous Cultural Safety and Humility



Authentic Engagement in Six Steps

In this section:

Step 1: Engagement Readiness & Preparation

Step 2: Planning Role Clarity for the Patient Partner

Step 3: Finding Patient Partners

Step 4: Involving a Patient Partner

Step 5: Ongoing Support

Step 6: Closing the Loop

Creating a great patient engagement means taking time to plan, check in and close the loop.

We've developed a **six-step process** to help guide you:



In this section:

- **Step 1: Prepare**
- Step 2: Plan
- Step 3: Find
- Step 4: Involve
- Step 5: Support
- Step 6: Close



Step One: Engagement Readiness & Preparation

Making the Decision to Engage

Not all health care decisions and initiatives require patient partner involvement. If your initiative doesn't directly impact patient experience, you may not need the voice of a patient partner.

Engaging patients may add value to your initiative if its scope and goal is to:

- Improve health care service design and/or the process of receiving care
- Ensure appropriate health treatment and care
- Improve health outcomes
- Reduce risk factors and prevent ill health
- Improve patient safety
- Improve patient experience
- Set priorities for action
- Strengthen accountability
- Ensure timely access to treatment
- Improve transitions between health care services

If you don't see your initiative represented in the above, take more time to consider your intention for engaging patient partners to ensure that your initiative will have a direct benefit to those you are engaging with.

In this section:

● Step 1: Prepare

Step 2: Plan

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Leadership Support

Having support from key leaders and decision makers will help ensure your work is successful and sustainable. To build this support, start with your supervisor and explore how you can form a team which includes patient partners. Talk through your assumptions and hesitations. Think about other organizational considerations, such as:

- What resources will be available to you, including staff and budget?
- Do you have the necessary information you need to move the work forward?
- Are you clear on your role and the role of your partners?
- Does your organizational culture support authentic patient engagement?

The definitions, frameworks and models in this guide and other [PVN resources](#) will help you speak with confidence on why engaging patient partners will benefit your initiative.

Five Key Components to Consider:



“ I have learned so much about innovation and capacity building by being part of PVN. I signed up to build my leadership skills, however, I experience benefits for myself, my community and Indigenous peoples throughout the province.

- Cherie Mercer, Patient Partner, New Aiyansh

In this section:

● Step 1: Prepare

Step 2: Plan

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Resources

- [Committee Principles & Guidelines for Health Care Partners](#)
- [Health Care Partner Readiness Checklist](#)

In this section:

● Step 1: Prepare
Step 2: Plan
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With leadership support as your foundation, there are five key components to consider [13]:

- **The Reason** – Why do you want to engage patients? 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 patient partner and what will you do with their input?
- **The Method** – How are you going to include patient partner voices? Are you going to send them a survey, invite them as speakers to share their experiences or integrate them into your committees?
- **The Timing** – When do you want to bring patients on board? Inviting patients to participate as early as possible is ideal, as people often feel more invested in a project when they’re involved from the start and have had an opportunity to contribute to its direction. However, the feasibility of doing so will depend on the context of your project and organization. Let the “why” inform your “when.” Think through your project plan to identify opportunities to engage patient partners. You might find that it makes sense to connect with different groups of patients, through different formats, and at different points in your project.
- **The Level** – Make sure you and your team have considered what you’re comfortable promising to patient partners. One valuable tool is the IAP2 Spectrum of Public Participation ([see pages 20-22](#)). It outlines goals and promises for your team which can be used to communicate expectations to patient partners about the engagement opportunity.
- **The Patient** – 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 for meetings?

Considering these five components will help your engagement be successful. They're embedded within the steps to engagement we outline on the next few pages. Be mindful that the more complex and multi-faceted the initiative, the more detailed your engagement plan will need to be.

Hesitations for Engagement

When you first begin engaging patient partners, it's understandable to be hesitant. We've compiled some answers to commonly raised concerns in the Appendix.

We encourage you to get together with your team to assess your readiness to engage patient partners. To help guide these conversations, ask a series of questions suggested in our [Health Care Partner Readiness Checklist](#).

If you answer “no” to any of these questions, you may need more time to discuss things before adding a patient partner to your initiative. Your teams' readiness to support this type of relationship sets the stage for a successful partnership.



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Step Two: Planning Role Clarity for the Patient Partner

It's important that the role of each team member is clearly defined and communicated. This aligns expectations and helps avoid tokenism. Inviting patients to participate is not a box to be ticked; it requires time and a commitment to intentionally partner and listen to them.

Patient partners can contribute through a variety of ways – each initiative is unique. You can include patient partners on your team or engage with them at different points of your initiative. When establishing roles for patient partners, we recommend you use the [IAP2 Spectrum of Public Participation on the following page](#) [14].

The IAP2 Spectrum of Public Participation is a great tool that you can use to differentiate between levels of participation depending on the goals of your engagement and can provide clarity to everyone involved about what level of engagement is expected.

In this section:

Step 1: Prepare

● Step 2: Plan


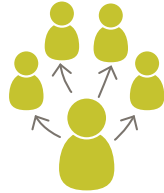
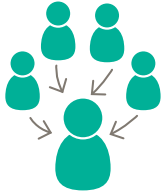
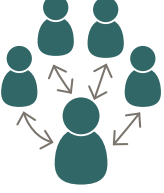
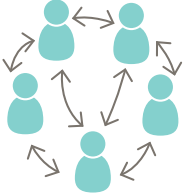
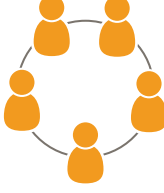
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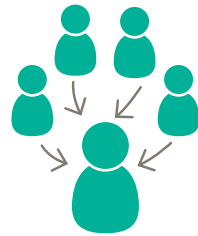
Step 6: Close

IAP2 Spectrum of Public Participation

					
	Inform 	Consult 	Involve 	Collaborate 	Empower 
Public Participation Goal	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.
Promise To The Public	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.
Example Techniques	<ul style="list-style-type: none"> • Fact sheets • Web sites • Open houses 	<ul style="list-style-type: none"> • Public comment • Focus groups • Surveys • Public meetings 	<ul style="list-style-type: none"> • Workshops • Deliberative polling 	<ul style="list-style-type: none"> • Citizen advisory committees • Consensus-building • Participatory decision-making 	<ul style="list-style-type: none"> • Citizen juries • Ballots • Delegated decision

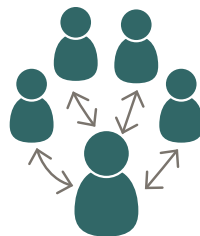


Typically, patient engagement falls into three areas of the spectrum: consult, involve or collaborate. One level of engagement is not better than another and your initiative can have multiple levels throughout its time.



Consult

Consult is the minimum opportunity for patient partners to give input into a decision. There is no invitation to sit down and work together. You're simply asking patient partners for their opinions and then considering their input. This often occurs at set points in an initiative and does not provide an ongoing opportunity for engagement. The promise to patient partners is to consider their input and provide feedback as to how it influenced the decision.



Involve

At the involve level, patient partners are invited into the process, usually from the beginning, and are provided multiple, if not ongoing, opportunities for input as an initiative progresses. However, the health care partner is still the decision-maker and there is no expectation of building consensus or providing patient partners with high-level influence over the decision.

The promise to patient partners is that they'll be provided the opportunity to give input throughout the process and will receive direct feedback on how their input helped to influence the decision.

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Step 1: Prepare

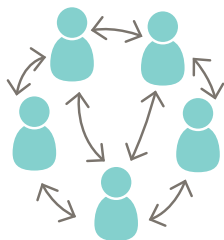
● Step 2: Plan

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Collaborate

At this level, patient partners are directly engaged in decision-making. It often includes an attempt to find consensus solutions within the team, but the degree to which consensus will be sought and how much decision-making authority the health care partner is willing to share must be made clear.

The promise to patient partners is that they'll be engaged in all key activities and decisions, and their input will be incorporated to the maximum extent possible.

Did You Know?

The [Opportunity Preparation Checklist](#) will help you think about what you need to consider before moving forward. It helps ensure that patient partners are prepared and supported to participate in a meaningful way.



Resources

- [IAP2 Spectrum of Public Participation](#)
- [Tamarack: Index of Community Engagement Techniques](#)

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Step Three: Finding Patient Partners

Finding the Right Patient Partners

For an engagement opportunity to be successful, it needs to be a good fit for both the patient and health care partner. Before inviting patient partners to get involved, you and your team should discuss who the ideal patient partners are for your initiative.

Questions to consider:

Do you need someone who has accessed your program or service?

How many patient partners would you like to invite?

We recommend at least two patient partners per opportunity, for a few reasons:

- Diversity – Patient partners can't be expected to speak on behalf of all patients. Inviting two or more patient partners to participate ensures at least two different perspectives are included.
- Safety and Comfort – Participating as a sole patient partner in a group of health care partners can feel uncomfortable or intimidating. Inviting two or more patient partners can help to level the playing field and provide opportunities to support each other.
- Support and Coverage – Patient partners may be navigating personal health care challenges, so they may miss meetings now and then. Having two or more patient partners can help ensure at least one patient partner is in attendance.

Should the patient partner have a specific care experience, or would anyone be welcome?

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Does the patient partner 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 BC’s population?

To participate in the engagement, does the patient partner need to have any specific skills or access to technology?

What days and times will the engagement take place? Does the patient partner need to be available during business hours, Monday to Friday? Is there flexibility on your team to consider their schedule?

Does inviting a specific patient partner to an engagement create ethical dilemmas around their current or future care encounters with, care providers who may be on the team?

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

Will there be any costs or expenses related to participation? How will you ensure expenses are paid up front or reimbursed in a timely way?

It can be helpful to meet with interested patient partners before confirming their participation so that everyone can know if the opportunity is a good fit. We’ve compiled some **Selection Process Sample Questions** for you to use when meeting with patient partners. We recommend that you choose between four to six questions to help you understand the patient partners’ skills and backgrounds.


“
The Patient Voices Network allows me to engage and educate others on various health-related topics. By sitting on various committees and taking part in many activities, I can create real change in health care for everyone.

- Pamela Jessen, PVN Patient Partner, Langford

In this section:

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Resources

- [Selection Process Sample Questions](#)
- [Selecting a Patient Partner](#)

In this section:

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Remind patient partners that they should only disclose what they're comfortable sharing and their answers will be confidential. And keep in mind that this is also a chance for them to ask questions, ensuring that this is a great fit for both of you.

Where Do I Find Patient Partners?

Another consideration is where to recruit patient partners. This could include:

- A patient engagement or experience team within your organization
- The Patient Voices Network
- Local community organizations
- Within your worksite, be mindful that this may pose conflicts of interest for staff and discomfort for patients because of perceived power imbalances

Patient Voices Network

PVN patient partners receive a brief orientation to the BC health care system and key concepts of patient engagement, sign a [patient partner commitment document](#), and are supported by Engagement Leaders at the BC Patient Safety & Quality Council.

The benefit of recruiting patient partners through PVN is that you will have access to patient partners with diverse experiences from across the province and access to skilled engagement professionals.

Step Four: Involving a Patient Partner

Preparing Your Team

The key to success in patient engagement lies in setting and aligning expectations for both the patient partners and your team. Before bringing patients into any meetings, take the time to make sure everyone is ready, comfortable and aware of each other's roles.

Here's how you can prepare your team:

- Discuss what it means to have patient partners working with you and ensure a clear understanding of their role and how you intend to use their input.
- Identify someone who will provide meeting invitations, send key documents and potentially mentor the patient partners.
- Prepare background documents to share (e.g., Terms of Reference and past meeting minutes).
- Prepare the team to use plain language. Avoid jargon, acronyms and technical terms. It's also a good idea to provide a glossary of common terms/abbreviations.
- Consider privacy and confidentiality. Do you need patient partners to sign any confidentiality forms? Be mindful that patient partners may have confidentiality requests of their own for the team to adhere to.
- Acknowledge that there may be tensions around differing opinions and perceptions. Working through this will make your team stronger.
- Address your team's concerns. Talk about any potential challenges in advance and develop a plan to address them.



Resources

- [Tips on Effective Communication](#)
- [Leading Great Meetings](#)
- [Working Together Virtually](#)
- [Blending Virtual with In-Person Meetings \(The Hybrid Model\)](#)

In this section:

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Resources

- [Patient Partner Preparation](#)

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Preparing the Patient Partner

Once you’ve assessed the readiness of your team, it’s time to consider how you will begin to build a relationship with your patient partners. 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 while working together. We call this “connection before content.”

Before patient partners come to their first meeting, we suggest that you schedule a time to connect to get to know each other and discuss your initiative. This conversation might look different depending on whether you met with patient partners as part of the selection process, but either way this meeting can help to build and strengthen relationships. It’s also a chance to provide additional background information and learn what the patient partners might need to successfully partner with your team.

An introductory meeting should cover:

- Introductions – Take the time to get to know each other.
- Communication preferences – How often would you like to touch base? What is the preferred method of communication?
- Information about the engagement opportunity:
 - » Review the scope of the work and clarify the role of the patient partner so that expectations are aligned;

- » Review any work that has happened to date and/or specific concepts that will be discussed so that patient partners can actively participate in the engagement opportunity moving forward (this might include providing background documents, previous meeting minutes, project charters, Terms of Reference, etc.);
 - » Flag if the work has been ongoing and the patient partner is joining midway through your initiative (maybe replacing a former patient partner);
 - » Provide access to all the documents needed to participate in the engagement opportunity in a central location;
 - » Go over the logistics such as date, time, location and how expenses will be covered ahead of time or reimbursed;
 - » Provide information and introductions to other key individuals or organizations involved in the work; and
 - » Discuss two-way confidentiality needs and requests.
- Are there any accessibility needs to consider for both in-person and virtual participation? If in-person, are there any allergies/dietary preferences you need to be aware of?
 - How would the patient partner like to be recognized for their contributions?
 - How will closing the loop be meaningful for all involved? (See Step 6)
 - Provide an opportunity for questions.



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Reimbursement & Compensation

Patient partners are generously giving their time and energy and they should not incur any expenses. Before inviting patient partners to participate, make sure you have resources available to support them and be clear from the beginning what expenses can and can't be covered. If the opportunity includes significant expenses, such as travel requiring hotel stays, flights and meal per diems, see how your organization can pay up front and, if it can't, plan to reimburse the patient partners as soon as possible.

Common costs to reimburse include:

- Transportation costs (mileage, bus fare, taxi, parking, etc.)
- Caregiving costs (child care, care of an older adult, etc.)
- Printing expenses
- Phone, data or internet charges

Practices vary across organizations regarding honoraria or compensation for patient partners' time. Providing an honorarium can help reduce financial barriers associated with participation and allow for more diverse patient partner participation. Some organizations provide gift cards and other small gestures of thanks. The BC Centre for Disease Control also has a [guidance tool](#) you can refer to. [15]

The most important thing is to be clear on what your organization can provide so that the patient partners can decide whether they want to participate.

Step Five: Ongoing Support

Check in Regularly

After the initial meeting, it's good practice to follow up with patient partners about their experience participating in your engagement and if you can do anything differently to better support their and others participation moving forward.

Additionally, this is an excellent opportunity to decide the best way to check in with each other going forward. Some patient partners are comfortable scheduling meetings with health care partners, while others aren't. Make sure you discuss what works best for you and the patient partners involved. At a minimum, have a conversation about the engagement experience two to three months after the work has started.

Engagements can also span months or even years, so it's good practice to connect with patient partners and your team regularly to see how things are going. Discuss how you'll check in with patient partners and your team and set a schedule to do it.



Resources

- [Check-In Checklist](#)

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“

It has been so rewarding to go from an idea to working with such a great group of dedicated people from so many different organizations towards a very fun and rewarding project.

- Laura Parmar, Physician
Quality Improvement Coach,
Northern Health


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If Things Aren't Going as Planned, Don't Panic!

Even the 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:

Take a Pause and Regroup

Revisit your goals for engaging patient partners and see if they need to be tweaked.

Check In

Bring the team, including patient partners, together and check in on their experiences to date.

Ask for Help

Sometimes a fresh set of eyes can help you sort out where you're at in the process.

Talk, Talk and Talk

Clear communication is the key to a successful engagement. Make sure this is a priority to minimize any concerns. As a bonus, you'll always learn something new.

Release the Pressure

It's okay to start and stop. Readjust your expectations.

“

It is more and more becoming the norm to include patients in the design, delivery and evaluation of health services. PVN education and supports have enabled us to develop the capacity to include the patient voice to make care better and achieve better health outcomes.

- Jeanette Foreman, Northwest Quality Improvement Lead,
Quality and Innovation, Northern Health

Perfection 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 this approach.

Try Again

Your first attempt may not have gone so well. That's okay. Try again.

Help for Health Care Partners

Planning and facilitating engagements aren't always easy and you don't have to figure it out alone. We're here to help and support you. The [PVN website](#) has some great tools and resources to help you get started and your organization may also have people and resources to support you.



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Step Six: Closing the Loop

Evaluation

Although we mention it as part of Step Six, ideally you should start thinking about your evaluation needs when you're first crafting your engagement strategy. This will help you plan for any necessary data collection activities along the way.

Evaluating patient engagement efforts helps to identify and document the benefits of including patient partner voices in health system initiatives. Evaluation activities can also help everyone to reflect on their experiences and identify areas for improvement.

There is no one-size-fits-all evaluation strategy for patient engagement. Here are some general principles to help you think about an approach that meets your needs:

- **Start Early** – Evaluation should be part of your engagement plan.
- **Include All Team Members** – Different people might want to know about different aspects of the engagement. Build an evaluation plan together. When people participate in evaluation design, they're more likely to participate in data collection activities and act on the findings.
- **It Doesn't Have to Be Formal** – You might decide that surveys, structured interviews or focus groups are necessary. Frequent and informal check-ins over the course of an engagement are also very effective to ensure objectives and expectations are being met.

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- **Consider Engagement Process and Outcomes** - Engagement process refers to the “what we did and how we did it.” Was the engagement well designed and executed? Are patient partners satisfied and did they have good experiences? Engagement outcomes and impact refer to the “so what and then what.” Were the engagement objectives met? What was the result of this engagement? How was it applied to the broader initiative? What new skills, awareness or relationships were built?
- **Don't Just Sit on It - Move Your Evaluation into Action** – Share, discuss, learn and grow from what you find! If you aren't going to use the information you're collecting, then reconsider why you're doing it.

This table, adapted from the IAP2 Planning Guides [16], can help you think through and map out an evaluation plan.

Evaluation Steps	Process Topics	Outcome Topics
1. What is success? What do we want to know?		
2. What will we use to measure success? What are the indicators?		
3. How will we gather data? Questions, tools, activities, timing?		
4. What does the data mean and how will we use it? Who will we share it with? How will we learn/adapt from it?		

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Resources

- [Closing the Loop](#)
- [Top 10 Tips for Closing the Loop](#)
- [Closing the Loop Template](#)
- [Closing the Loop Engagement Notes Template](#)
- [Patient Partner Appreciation & Recognition Guide](#)

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Evaluation topics and indicators could include:

Process Topics	Outcome Topics
<ul style="list-style-type: none">• Readiness of partners to participate• Appropriateness of engagement tactic selected• Role clarity and clearly defined tasks• Inclusive and representative participation• Communication and information sharing between partners• Support available to enable participation• Ability of participants to share views• Timing of engagement activities• Transparency of decision-making process• Partner satisfaction and experience with engagement	<ul style="list-style-type: none">• New knowledge, skills and capacity building among partners• Increased empathy and awareness of issues, problems or opportunities• Stronger relationships, trust and team building• Stronger decision-making process• Patient partner influence on initiative or decision• More person- and family-centred care• Better quality of care• Stronger culture of patient engagement• Improvements to the Quadruple Aim [17]: Patient Experience, Staff Experience, Health Outcomes and Cost Effectiveness/Savings• Improvements to the seven dimensions of quality: respect, safety, accessibility, appropriateness, effectiveness, equity, efficiency.

Closing the Loop

Patient partners share their time, energy and sometimes personal and challenging experiences when participating in engagements. They do so because they hope to see health care improve for everyone. Closing the loop creates value for the time and effort spent.



At the end of an engagement, closing the loop involves three key components:

1. **Appreciation** – Recognize the end of the engagement and thank patient partners for their participation.
2. **Engagement Outcome or Impact** – Share how their contributions influenced the initiative. Be specific! Share concrete and personalized examples.
3. **Initiative Outcome or Impact** – Share whether the initiative met its aim. Share outcomes, impacts or progress made to date. Provide a tangible outcome of the work. Send copies of final reports, materials or policies that were developed through the initiative. Invite patient partners for a tour of a new space or to attend a launch event, etc.

There is no one right way to close the loop. It could be a written summary of the engagement or you could host a meeting with patient partners to discuss lessons learned, outcomes and impacts of the engagement and the initiative. The PVN [Closing the Loop](#) template can help you prepare a written summary of the engagement to share with patient partners.

For more ideas, check out our [Top 10 Tips for Closing the Loop](#).

A Note on Appreciation

How patient partners want to be thanked and recognized for their contributions is personal. It's recommended that you discuss this early with them so that you understand the best way to close the loop and recognize their involvement. This might be a phone call, a thank you card, a copy of the final report or materials worked on.

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Final Remarks



We're excited that you're interested in learning more about patient engagement! You're building your knowledge on how you can include patient partners to improve the quality of health care in BC. Here are a few final thoughts as you embark on this journey of patient engagement:

- **Be Kind to Yourself** – with an open heart and mind. You aren't expected to know everything and there may be bumps along the way. Being vulnerable and willing to acknowledge what you don't know will only help you on this journey.
- **Connection Before Content** – be human first. Lean into getting to know each other before you get into your project. This approach can create comfort and cultural safety.
- **Define Roles** – everyone has a purpose for being there. Being clear from the start helps partners contribute and achieve shared goals.
- **Plan, Plan and Plan Some More** – build an engagement plan. Engage early and communicate often. Take advantage of the supports out there to help you.
- **Close the Loop** – share how patient partners influenced the project. Sharing the important work you're doing with the patient partners and your colleagues increases the evidence that these partnerships work!

Stay up to date with the
Patient Voices Network!

For more information visit
PatientVoicesBC.ca

Congratulations again for taking on these exciting partnerships,
and thank you for helping to improve health care in BC!

Dreaming big
& reaching for the
impossible!



CHANGING, creating &
"winning" JT

Appendix: Hesitation in Engagement

What if the patient partner's suggestions are complicated or would require too much time and money?

Patient partners are, for the most part, aware of the challenges faced by health care leaders and decision makers, and they realize that they must balance quality of care, system constraints and increased costs. To ensure a good understanding of those limitations, setting out clear parameters and a clear overview of the current state will assist you in making the engagement meaningful.

What if people on my team don't see the value? We are so busy.

It is important to recognize that the successful engagement of patient partners will take deliberate effort and commitment from your team, which can involve more time and energy up front in the engagement planning process. However, there are many valuable reasons for involving patient partners in your work. Ultimately, when health care providers listen to and work with patient partners, their programs, services and policies can be improved by the first-hand knowledge, insights and experiences shared. This ultimately results in care being aligned with the priorities of patients which leads to better health outcomes and patient experience. Additional benefits may include a reduction in cost and/or waste and efficiencies being created which can save provider time in the long run [18]. We have created a [Readiness Checklist](#) that you can explore with your team.

What if the patients' health care experiences were negative and they are struggling to move forward?

Most patients want to ensure that their negative experiences don't happen to others, and they're thrilled to have an opportunity to share how they were impacted, in a teachable moment. It's an opportunity to share lived experiences and perspectives in order to contribute to broader and bigger picture conversations and efforts to improve quality of care and the patient experience.

We discuss confidential information. How do we know that this will be kept in-house?

All health care partners are encouraged to have discussions with patient partners at the start of an engagement opportunity to ensure the importance of respecting the sensitive nature of the conversations that take place and of the information being shared. There may be additional documents that need to be signed as per your own organizational policies.

References

1. Health Quality Ontario. Engaging with patients and caregivers about quality improvement: A guide for health care providers. [Internet]. Queen's Printer for Ontario; 2016 [cited 2022 May 20]. Available from: <http://www.hqontario.ca/portals/0/documents/qi/qip/patient-engagement-guide-1611-en.pdf>
2. BC Patient Safety & Quality Council. BC Health Quality Matrix. [Internet]. 2020 Feb 26 [cited 2022 May 20]. Available from: <https://bcpsqc.ca/resource/bc-health-quality-matrix/>
3. BC Patient Safety & Quality Council. EPIQ Teaching Toolkit. [Internet]. BC Patient Safety & Quality Council; 2018 [cited 2022 May 20]. Available from: <https://bcpsqc.ca/wp-content/uploads/2018/03/TeachingToolkit-Full-revised.pdf>
4. BC Patient Safety & Quality Council [Internet]. Vancouver (CA) [date unknown]. What Matters to You? [date unknown] [cited 2022 May 20]. Available from: <https://bcpsqc.ca/advance-the-patient-voice/what-matters-to-you/>
5. Person-centred care [Internet]. Cancer Care Ontario. 2015 Jun 17. [cited 2019 Mar 21]. Available from: <https://www.ccohealth.ca/en/what-we-do/general-health/person-centred-care>
6. Accreditation Canada. Client- and family-centred care in the Qmentum program. [Internet]. Canadian Foundation for Healthcare Improvement; 2015 [cited 2019 Mar 21]. Available from <https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/accreditation-canada.pdf>
7. Johnson BH, Abraham MR. Partnering with patients, residents, and families: A resource for leaders of hospitals, ambulatory care settings, and long-term care communities. [Internet]. Bethesda, MD: Institute for Patient- and Family-Centered Care; 2012 [cited 2019 Mar 21]. Available from: <http://www.ipfcc.org/about/pfcc.html>
8. Baker GR. Patient Engagement: Catalyzing Improvement and Innovation in Healthcare [Internet]. Longwoods Publishing Corporation; 2016. Introduction, Creating 'engagement-capable environments' in healthcare. [cited 2019 Mar 21]. Available from: <https://www.longwoods.com/content/24908/books+/creating-engagement-capable-environments-in-healthcare>
9. Defining patient experience [Internet]. The Beryl Institute. [cited 2019 Mar 21]. Available from: <https://www.theberylinstitute.org/page/definingpatientexp>
10. Ministry of Health. Setting Priorities for the B.C. Health System. [Internet]. 2014 Feb. [cited 2022 Mar 10] Available from: <http://www.health.gov.bc.ca/library/publications/year/2014/Setting-priorities-BC-Health-Feb14.pdf>
11. The International Association of Public Participation. IAP2 Core Values for the Practice of Public Participation. [Internet]. [cited 2022 May 10]. Available from: https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/2017_core_values-24x36_iap2_.pdf
12. Cultural Safety & Humility: Key Drivers and Ideas for Change. [internet]. First Nations Health Authority; [date unknown] [cited 2022 Feb 23]. Available from: <https://www.fnha.ca/Documents/FNHA-Cultural-Safety-and-Humility-Key-Drivers-and-Ideas-for-Change.pdf>
13. 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 14; cited 2019 Mar 21]. Available from: https://www.cfhi-fcass.ca/sf-docs/default-source/on-call/m1-presentation2014v1postweb.pdf?sfvrsn=dc27c344_0
14. BC Patient Safety & Quality Council. IAP2 Spectrum of Public Participation. [Internet]. 2017 Oct 18 [updated 2022 May 13; cited 2022 May 20] Available from: <https://patientvoicesbc.ca/resources/iap2-spectrum-public-participation/>
15. Becu A, Allan L. Peer payment standards: For short-term engagements. [Internet]. BC Centre for Disease Control; 2018 Feb. [cited 2022 May 20]. Available from: http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf
16. International Association for Public Participation. Foundations in Effective Public Participation: Planning for Effective Public Participation. IAP2 International Federation 2016. 100p. [cited 2022 May 05]
17. Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. Ann Fam Med. 2014;12(6):573–6.: <https://www.annfammed.org/content/12/6/573>
18. Patient Voices Network. Demystifying authentic patient engagement: Practical tips for success. [Internet]. Patient Voices Network; 2018. [cited 2022 May 20]. Available from: <https://patientvoicesbc.ca/wp-content/uploads/2018/09/PVNTipsBaltimore.pdf>



Connect with us.

604.668.8210 | 1.877.282.1919
info@bcpsqc.ca | pvn@bcpsqc.ca

201-750 Pender St W, Vancouver, BC, V6C 2T8
[BCPSQC.ca](https://bcpsqc.ca) | PatientVoicesBC.ca

@BCPSQC    
@PatientVoicesBC  

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