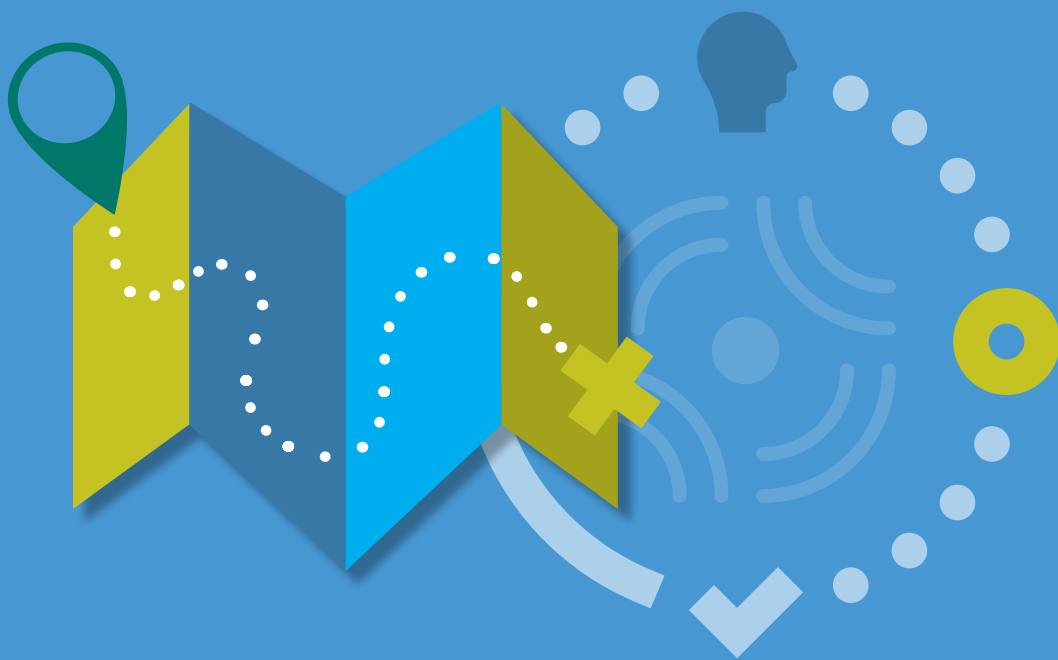


A Guide to Patient Engagement



Patient
Voices
Network

PVN is guided by patient and health care partners and administered by the:



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

A Guide to Patient Engagement

In This Guide:

- 2** Patient Engagement: The Essentials
- 8** Help! How Do I Start Working With Patient Partners?
- 11** Finding the Right Patient Partner
- 13** Where Do I Find Patient Partners?
- 14** We Have a Patient Partner! How Do We Do This Right?
- 16** Preparing the Patient Partner
- 16** Authentic Engagement
- 18** Demonstrating Impact & Saying Thank You
- 21** Resources
- 22** References



Welcome to the world of patient engagement!

We're excited that you're interested in learning about patient engagement and this resource will support you in your journey. By inviting patients, family members and caregivers to work in partnership with your health care team, you are taking an important step to making health care better for all British Columbians. In this resource, we'll cover the essentials of patient engagement, how to prepare for it, where you can find patient partners and how to engage them well.

Patient Engagement: *The Essentials*

Before inviting patient partners into your work, it's important to start with an understanding of patient engagement and the reasons to involve patients.

Key Concepts

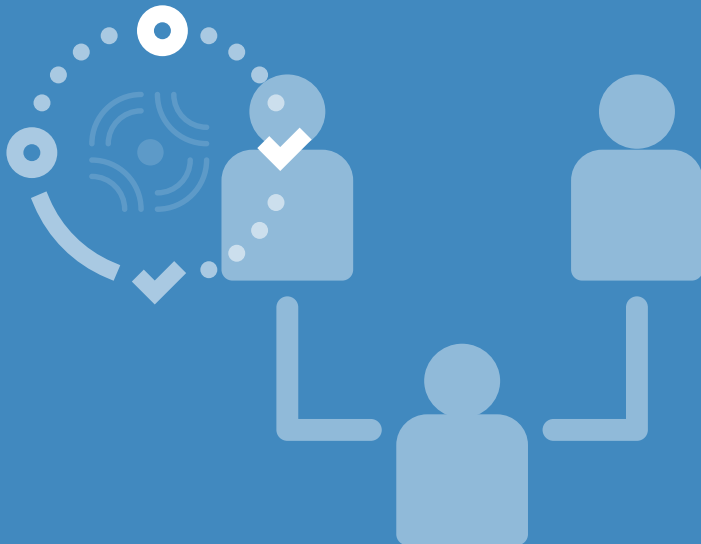
Person-centred care, patient and family engagement and patient experience are all concepts commonly used to discuss engaging with patients. These terms do not all mean the same thing, and it's helpful to understand them, where they overlap and the relationship between them. Cancer Care Ontario has developed a model [1] to illustrate how these concepts work together.



Adapted from Cancer Care Ontario

Patient Partners: In the Patient Voices Network (PVN), patient partners are community members who want to be involved in improving health care. Many patient partners have extensive experience either as a patient, family member or caregiver; others have been part of the health system in a professional manner. They are a diverse group with an array of backgrounds and experiences, but all of them are passionate about improving the quality of care in BC.

Health Care Partners: We define health care partners as individuals or organizations seeking to include patient, family and caregiver voices in an effort to improve BC's health care system. Health care partners can be health authorities, health organizations and non-profit organizations.



Person-Centred Care

The philosophy of person-centred care has many names: it can sometimes be referred to as person- and family-centred care, patient- and family-centred care (PFCC) and client- and family-centred care. In this toolkit we'll use the term person-centred care, meaning “an approach that fosters respectful, compassionate, culturally appropriate, and competent care that is responsive to the needs, values, beliefs and preferences...” [2, p1] of patients and their family members. Person-centred care “shifts providers from doing something to or for the...[patient] — where the health care provider’s perspective is dominant—to doing something with” them in a true partnership. [2, p.1]

What Matters to You?

We are encouraging providers to have **“What matters to you?”** conversations *each and every day* with the people they support or care for. Because patients are the true experts on their own needs and experiences, asking, listening and responding to what matters to them is a key feature of person-centred care, and can help with patient engagement at the bedside or point of care. For more information visit the BC Patient Safety & Quality Council's website, BCPSQC.ca.



Patient Engagement

Patient engagement is the act of involving the patient and their family in decision-making, design, planning, delivery and evaluation of health services. When patients are actively engaged, they can become informed decision makers in their own care and help improve the overall health care system. When health care providers listen to and work with patients and family members, programs, service delivery and policy can be improved by their firsthand knowledge, insight and experience. [3]



Patient Experience

The outcome of person-centred care and patient engagement can be improved patient experience. 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.” [4, p.1] Including patient partners in your work can provide a unique perspective to any decisions being made.

A family presence policy is an excellent example of how patient engagement can lead to improved patient experience. When Providence Health Care reviewed their guidelines, they understood that patients, families and caregivers have firsthand knowledge about the importance of visits from loved ones during hospital stays, the role visitors have in healing and the barriers to people being able to visit. So they worked with patients and family members to change their hospital visiting policy so that it met their needs and those of health care professionals providing care. These changes resulted in improved patient experience as it became easier for family members to visit loved ones in the hospital.

These core principles from the Institute for Patient and Family-Centered Care [5] 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 and families so they can effectively participate in care and decision-making

PARTICIPATION – encourage and support patients and families to participate in care and decision-making at the level they choose

COLLABORATION – collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care



Patient Engagement in BC

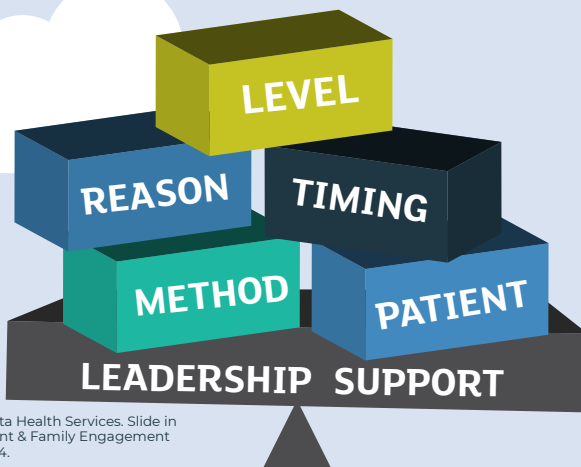
British Columbia's health care system is complex and, in order to provide sustainable high-quality care, it needs a foundation of person-centred care as well as a clear understanding of the patient experience. The BC Ministry of Health has identified that person-centred care is one of our key priorities for health care delivery.

To meet this priority, health care organizations across BC are continuously working to embed the philosophy of person-centred care into all aspects of health care delivery. Although each health authority and organization achieves this priority differently, many organizations have dedicated departments who support opportunities that improve person-centred care.

Unique to BC, the Patient Voices Network (PVN) is a provincial community of patients, families and caregivers working with health care partners to improve the health care system. Administered by the BC Patient Safety & Quality Council, PVN works to connect patients and health care teams to partner on improvement initiatives, program design and service delivery across the province. For more information, or to get involved either as a patient or health care partner, visit our website, PatientVoicesBC.ca.

Help! How Do I Start Working with Patient Partners?


Do you need to connect with patients but don't know how? Are you trying to brainstorm the best way to include patients and families in your work? The BC Patient Safety & Quality Council promotes and develops patient engagement through the Patient Voices Network. We can help you navigate the world of patient engagement and support your team to work authentically with patient partners!



Adapted from: Rees, J, Alberta Health Services. Slide in CFHI Webinar: What is Patient & Family Engagement and Why Do It?, January 2014.

There are a few things you and your team will need to do to get started. As a basis for patient engagement, you need to have **leadership support**. Having support from key leaders and decision makers will ensure your work is successful and sustainable. To build this support, start with your manager or director, and brainstorm how you can form your team to include patients and families. Talk through your assumptions and hesitations. The definitions, frameworks and models in this Guide to Patient Engagement and other PVN resources will help you speak with confidence on why including patients and families will benefit your projects and initiatives.

Involving patients and caregivers directly in quality improvement processes 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, as they are able to see them from the patients' perspectives;
 - 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. [6]



With Leadership Support as Your Base, There Are Five Key Components to Consider:



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 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 and committees? Be creative!



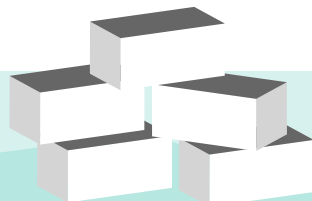
THE TIMING: When do you want to bring patients on board? As a rule of thumb, inviting patients to participate as early as possible is ideal, but this will depend on the context of the project and your organization. Sometimes it can make more sense to bring in different groups of patients using different formats as your work progresses. Patients, 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.



THE LEVEL: Make sure you and your team have considered what you are comfortable promising to patients and families. One valuable tool is the IAP2 Spectrum of Public Participation (see *page 12*). 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? How will your team let the patient know the impact of their time and effort? [7]



Finding the Right Patient Partner

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






Questions to Consider:

- Do you need someone who has accessed your program?
- How many patient partners would you like to invite?
(We recommend at least two partners per opportunity)
- Should the patient or family member have had a specific care experience, or would anyone be welcome?
- Does the patient partner 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 patient or family member 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?
- In order to participate in the opportunity, does the patient or family member need to have any certain skills, or access to any certain technology?
- 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 patient 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 patient partners for an interview to learn more about each other before confirming their participation?
- Will there be any costs or expenses related to participation? How will you, as the sponsoring organization, ensure expenses are paid up front or reimbursed in a timely way?

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. Visit PatientVoicesBC.ca to download numerous resources that can help.

When designing engagements be sure to look at the IAP2 Spectrum of Public Participation so that you can clearly communicate the expectations around engaging to your health care team and patient partner(s). [8]

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

Where Do I Find Patient Partners?

The ideal patient may already be in your waiting room! Talk to the patients and family members who access your services, especially those who have taken the time to share comments or reflections with you about their experiences. Put up posters, leave pamphlets, send out letters or include questions on discharge surveys. Your health authority or organization may have patient experience staff who can help you connect with patients.

You can also reach out to the Patient Voices Network! Depending on your opportunity you can fill out an Engagement Request Form and we can support you through our process of connecting with a patient partner! Or we can share your information as an external opportunity and have patients who are interested connect with you directly.

Benefits of working with the BC Patient Safety & Quality Council and the Patient Voices Network:

PVN has close to 1,000 patient partners eager to be part of your health care system improvement project. PVN patient partners are all oriented, supported by regional Engagement Leaders and passionate about getting involved. If you are looking for someone who can speak to a rare health experience or has a specific background and currently do not know a patient partner who meets the criteria, our team will network with local agencies and your community to find the right person. Finally, as soon as you submit an Engagement Request Form your opportunity will be assigned to an Engagement Leader, who will work with you to help make your engagement a success.

We Have a Patient Partner! How Do We Do This Right?

Preparing the Health Care Team

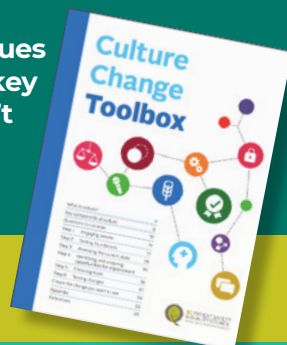
Every team and organization has its own culture. We have more influence over culture individually than we think and we shape it by our interactions with others, how we respond and how we behave. Embedding the patient voice into your team's culture takes work but we're here to help you start!

The key to success in patient engagement lies in setting 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 understands the role of the patient partner.

Here are some helpful hints on how you can prep 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 a defined point of contact 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 language.
- Consider privacy and confidentiality – how will you talk about it and do you need patient partners to sign any confidentiality forms if the information they will be hearing is sensitive?
- 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.

Conflict is not a dirty word. Talking through issues to better understand different viewpoints is a key part of organizational culture change. It doesn't have to be scary! Check out BCPSQC's Culture Change Toolbox: BCPSQC.ca



Preparing the Patient Partner

Before patient partners attend an event or come to their first meeting with you, we suggest that you schedule a call in advance to introduce yourself and discuss key points about your initiative. This conversation might look different depending on whether you interviewed patient partners as part of the selection process, but either way this call can help to build and strengthen the relationship between you and the patient partner. The call is also a wonderful chance to learn what additional background information or supports patient partners might need in order to succeed with your team.

As a general list, an introductory meeting or phone call should cover:

- Who are they and what should you know about them?
 - How they can get in touch with you if needed.
- Review information about the engagement opportunity:
 - Review the scope and expectations;
 - Go over the logistics such as date, time, location, where to park and how expenses will be covered ahead of time (if possible!) or reimbursed.
- Ask them about supports you can provide to ensure they feel included, valued and able to participate:
 - Do they have any accessibility issues (and any specific room requirements) or have any allergies/dietary preferences?
 - How would they like to be acknowledged and made aware of their contributions? In other words, how will you close the loop on the engagement?
- Provide an opportunity for them to ask questions.

Principles of Authentic Engagement

1

Patient partners affected by a decision are involved in the process.

2

Health care partners commit that the patient partners' input will contribute to the final outcome.

3

Sustainable decisions are possible only when the needs of all partners have been recognized.

4

Diverse perspectives are sought out and invited to participate.

5

Patient partners are supported and provided with all necessary information to ensure that they are able to participate fully right away.

6

Patient partners and other participants are kept updated throughout the process about how their input is shaping the final decision.

Simply having a patient partner at the table isn't enough – be authentic! The Auditor General of BC defines engagement as authentic when *“the decision has not been made and the decision-maker commits to be influenced to a specific level that will be communicated in advance.”* [9, p.1] To aid health care partners in authentic engagement, we suggest following the principles on the previous page, which were adapted from IAP2.

Authentic engagement is complex and takes much more time than we can provide in this guide! For more detailed information on how to do successful authentic engagement, please download our resource Demystifying Authentic Patient Engagement from PatientVoicesBC.ca.



Avoid Tokenism

When inviting patients and family members to participate in an engagement opportunity, it is crucial to bring them in early so that they can be part of the discussion before any decisions are made. Inviting patients to participate is not a box to be ticked. Instead it requires time and a commitment to actively partner and listen to patients and family members. The IAP2 Spectrum of Public Participation [8] is a great tool that helps patient and health care partners understand their goal in engaging patients and their promise to the patients who will be involved.

Check-In

Discuss how you are going to check in with patient partners and your team, and set a schedule to do it!

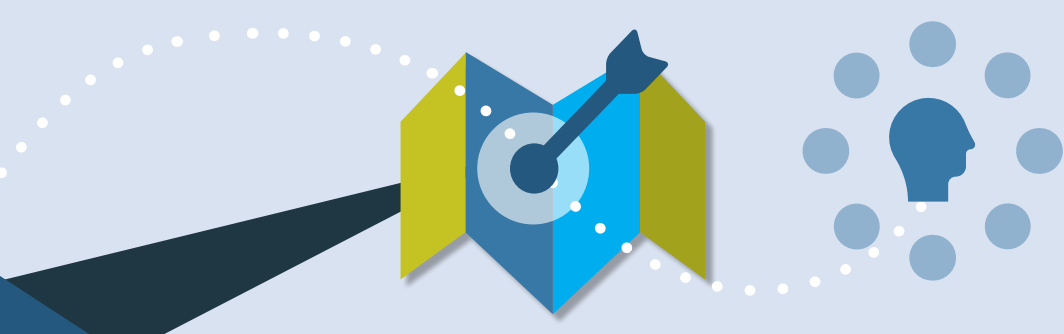
After the initial meeting or phone call, it is good practice to follow up with patient partners their experience participating in the engagement, and whether your team could do anything differently to support them moving forward. Additionally, this is an excellent opportunity to decide what is the best way to check in with each other going forward! Some patient partners are completely comfortable scheduling phone calls or meetings with health care partners, while some are not. Please make sure you discuss what works best for you and the patient partner(s) involved.

Oh No, This Isn't Going as Planned – Don't Panic!

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.

Check-in Surveys: If you recruit patient partners through PVN, we will send short electronic surveys via e-mail to both health care and patient partners within three months of your first meeting. This survey is designed to check in and troubleshoot any concerns that there may be with the partnership. We may follow up with patient and/or health care partners depending on survey results. The goal is to ensure that everyone is on the same page moving forward. With that being said, if at any time during your engagement you have any questions or require additional support, please contact a member of our team.



Demonstrating Impact & Saying Thank You

In some engagements, it can be hard to identify the impact of including a patient perspective. Certain engagements, such as policy changes, can take a long time and the results of including a patient voice might not be demonstrated for months or even years after the opportunity ends. Therefore, it is extremely important to ensure regular, and pre-determined check-ins with the patient partners to update them on the progress and status of any changes. Health care partners need to remember to follow up with decision makers around the status of their recommendations or outputs from engagements and be ready to share the outcomes when they are known. Remember, even an update that there is no update is better than nothing.

How patient partners want to be thanked and recognized for their contributions can be a very personal thing. It is recommended that early discussions take place between the health care and patient partner(s) to understand the best way to close the loop and acknowledge their involvement. Health care partners are encouraged to have conversations with patient partners to understand what they can do to thank them. This might be a phone call, a thank you card, a copy of the final report or materials worked on – it's up to the patient partner!

We designed a Closing the Loop form to help identify the immediate impact of patient engagement.

Closing the Loop

Closing the loop is an essential ingredient to successful patient engagement. Patient partners spend time and energy working on engagement opportunities and sometimes share incredibly personal and emotionally exhausting experiences. After each engagement opportunity, and ideally throughout it, it is crucial that patient partners are informed of how their participation affected and/or contributed to the objective or end result.

Closing the loop is the action of:





COVERING EXPENSES

Patient partners are generously giving their time and energy and therefore should not be out-of-pocket for any expenses. Before inviting a patient partner to participate, make sure you have resources available to support patient partners and are clear in the invitation about which expenses will be covered. If the opportunity involves large amounts of travel such as hotel stays, flights and meal per diems, try to be creative to see how your organization can pay for expenses up front. Perhaps someone on your team can book flights and hotels on a company card or buy a prepaid credit card for meal and transit expenses.

Typically, mileage, parking and transit are reimbursed, but depending on the patient partner, consider whether child care, seniors care or taxis are required. If unable to pay for costs upfront, make sure you have a plan to reimburse the patient partner as soon as possible. The most important thing is to be clear on what you and your organization can provide so that the patient partner can choose whether they will be able to participate.

Resources

There are many websites and resources that seek to advance effective patient engagement, including skill building for patient and health care partners. It is easy to get overwhelmed, so we have laid out a few options to help you get started. Please know that this is not a complete list, but we have tried to include a sample of some of the incredible work.

Alberta Health Services Services' Guidebook for Engaging Patient and Family Advisors

<http://bit.ly/2VU9EJE>

BC Ministry of Health's Patients as Partners Initiative

<http://bit.ly/2JsCUAz>

BC Patient Safety & Quality Council

<https://bcpsqc.ca/>

Canadian Foundation for Healthcare Improvement's Resource Hub

<http://bit.ly/2vMnL52>

Canadian Patient Safety Institute's Engaging Patients in Patient Safety – a Canadian Guide

<http://bit.ly/2H8EjJP>

Health Quality Ontario's Patient Partnering Tools and Resources

<http://bit.ly/2YidJof>

Provincial Health Services Authority's Orientation to Patient and Family Engagement

<http://bit.ly/2Wxm56e>

Patient Voices Network

<https://patientvoicesbc.ca/>

Vancouver Coastal Health's Community Engagement Advisory Network

<http://cean.vch.ca/>

References

1. 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?redirect=true>
2. Accreditation Canada. Client- and family-centred care in the Qmentum program [Internet]. 2015 [cited 2019 Mar 21]. Available from <https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/accreditation-canada.pdf>
3. Baker GR, Judd M, Fancott C, Maika C. Creating 'engagement-capable environments' in healthcare. 2016 [cited 2019 Mar 21]. Available from: <https://www.theberyl institute.org/page/definingpatientexp>
4. Defining patient experience [Internet]. The Beryl Institute. [cited 2019 Mar 21]. Available from: <https://www.theberyl institute.org/page/definingpatientexp>
5. 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>
6. Health Quality Ontario. Engaging with patients and caregivers about quality improvement: A guide for health care providers [Internet]. Available from: <http://www.hqontario.ca/portals/0/documents/qi/qip/patient-engagement-guide-1611-en.pdf>
7. 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/ml-presentation2014v1postweb.pdf?sfvrsn=dc27c344_0
8. 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](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf)
9. Auditor General of British Columbia. Where can organizations start in defining their approach to public participation [Internet]. [cited 2019 Mar 21]. Available from: <http://www.bcauditor.com/online/pubs/394/395>



Patient
Voices
Network

PVN is guided by patient and health care
partners and administered by the:



BC PATIENT SAFETY
& QUALITY COUNCIL

Working Together. Accelerating Improvement.

Connect with us!

Phone: 604.668.8240 / 1.877.282.1919

Fax: 604.668.8220

Email: pvn@bcpsqc.ca

Mail: 201-750 Pender St W, Vancouver, BC, V6C 2T8

PatientVoicesBC.ca | [@PatientVoicesBC](https://www.instagram.com/PatientVoicesBC)

