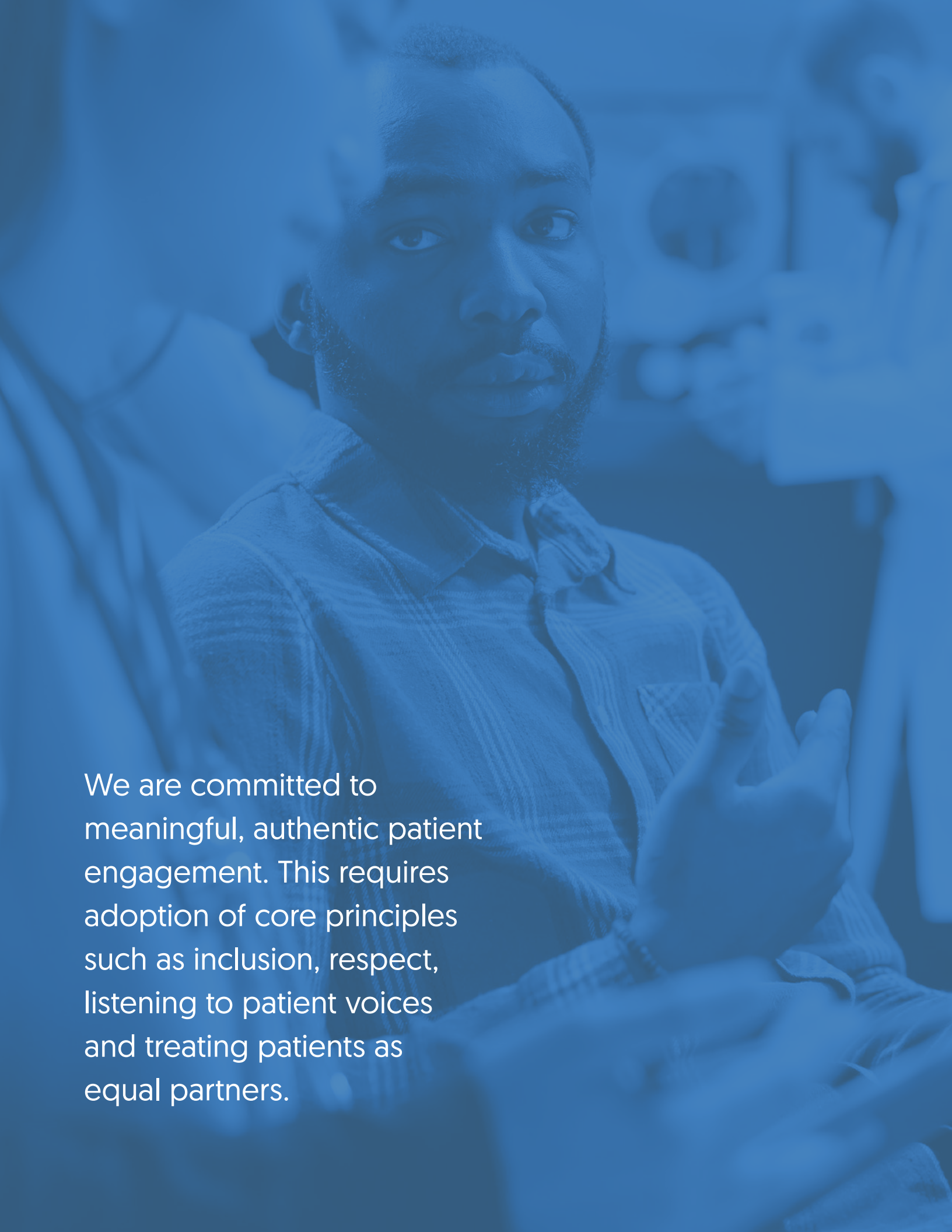


The background of the entire page is a blue-tinted photograph of three people smiling. In the foreground, a woman with dark hair is laughing joyfully, looking upwards and to the right. Behind her, two other people, a man and a woman, are also smiling. The overall mood is positive and collaborative.

# **MEANINGFUL PATIENT PARTNER ENGAGEMENT**

## A GUIDE FOR PROJECTS AND COMMITTEES



We are committed to meaningful, authentic patient engagement. This requires adoption of core principles such as inclusion, respect, listening to patient voices and treating patients as equal partners.

# TABLE OF CONTENTS

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- Using this Guide .....4**
  - Purpose.....4
  - How to read this document .....4
  - Glossary and Definitions .....5
  
- Part 1 · Throughout Engagement .....7**
  
- Part 2 · Recruitment..... 13**
  - Getting the team ready to recruit a patient partner ..... 14
  - Searching for a patient partner ..... 16
  - Meeting with potential patient partners ..... 17
  
- Part 3 · Onboarding ..... 19**
  
- Part 4 · Support .....23**
  
- Part 5 · End of Engagement .....27**

# USING THIS GUIDE

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## Purpose

The purpose of this document is to provide guidance for meaningful patient and family engagement in the context of health care quality improvement efforts. In alignment with the BC Ministry of Health's commitment to patient-centred care, patients need to be seen as key partners and decision-makers in healthcare improvement, in order to strengthen decision-making, quality in care, and patient safety.

This document can be used to promote meaningful patient engagement by:

- fostering positive relationships within quality improvement teams.
- describing a variety of best practices and standards that act as a roadmap for the journey of patient engagement.
- providing a consistent provincial approach for quality improvement initiatives and teams.

This document is a result of the dedication and collaboration of the Patient Partner Engagement Working Group. The Patient Partner Engagement Working Group is comprised of patient partners, staff, and physicians who are passionate about health system improvement and meaningful, authentic patient engagement. The valuable input of each member is reflected in this document, and is a testament to the group's commitment to this work. Readers are encouraged to share this document with teams that work with patient partners.

## How to read this document

This document reflects the range of engagements that patient partners can have in quality improvement projects and steering committees. The content in this document is divided into five main sections, with the first section as an overview of general principles that act as a guide to follow throughout the patient engagement journey. The remaining four sections are ordered chronologically to reflect the general timeline of a patient engagement opportunity, from recruitment to closing.

While we use the term Patient Partner throughout this document, we acknowledge that other groups and organizations may use terms such as Peer/Family/Community/Public and Advisor/Advocate/Mentor.

All sections of the document are considered to be equally important, and we hope that they provide you with the information and tools necessary to positively engage with patient partners in quality improvement.



**LOOK FOR THESE:** Throughout this document, you can find tips and suggestions included within green banners at the bottom of the page.

## Glossary and Definitions

### **Active Listening**

The practice of preparing to listen, observing what verbal and non-verbal messages are being sent, and then providing appropriate feedback for the sake of showing attentiveness to the message being presented ([University of Minnesota Libraries 2016](#)).

### **Cultural Humility**

A process of self-reflection to understand personal and systemic conditioned biases, and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a life-long learner when it comes to understanding another's experience ([First Nations Health Authority 2021](#)).

### **Cultural Safety**

An outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care ([First Nations Health Authority 2021](#)).

### **Decision-Making**

The process of making choices by identifying a decision, gathering information, and assessing alternative resolutions ([Dartmouth 2022](#)).

### **Diversity**

The variety of unique dimensions, qualities, and characteristics we all possess, and the mix that occurs in any group of people. Race, ethnicity, age, gender, sexual orientation, religious beliefs, economic status, physical abilities, life experiences, and other perspectives can make up individual diversity ([Canadian Centre for Diversity and Inclusion 2022](#)).

### **Equity**

Where everyone is treated according to their diverse needs in a way that enables all people to participate, perform, and engage to the same extent ([Canadian Centre for Diversity and Inclusion 2022](#)).

# USING THIS GUIDE

**Health Care Partners** 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 ([Patient Voices Network 2019](#)).

**Inclusion** The act of creating a culture that embraces, respects, accepts, and values diversity. It is a mindful and equitable effort to meet individual needs so everyone feels valued, respected, and able to contribute to their fullest potential ([Canadian Centre for Diversity and Inclusion 2022](#)).

**International Association of Public Participation (IAP2)** Developed by the International Association of Public Participation (IAP2), the spectrum intends to help clarify the role of the public (or community) in planning and decision-making, and how much influence the community has over planning or decision-making processes. It includes five levels of public participation: inform, consult, involve, collaborate, and empower. ([Sustaining Community 2017](#))

IAP2 Spectrum	Inform	Consult	Involve	Collaborate	Empower
<b>Definition</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.

Source: [IAP2 Spectrum of Public Participation](#) 

**Intersectionality** A term to describe how social identities may overlap to create compounding barriers for individuals. It is described as a framework for approaching issues from multiple perspectives and understanding how multiple groups, or individuals with multiple identities, may be affected. For example, approaching feminism with an intersectional lens would involve acknowledging and addressing the unique barriers faced by women of colour, disabled women, or trans women ([Canadian Centre for Diversity and Inclusion 2022](#)).

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**Marginalized populations**

Groups and communities that experience discrimination and exclusion (social, political and economic) because of unequal power relationships across economic, political, social and cultural dimensions ([National Collaborating Centre for Determinants of Health 2022](#)).

**Meaningful Engagement**

Any authentic participation that allows people to make important contributions to the process and the outcome of a change, and deepens their understanding of it, their commitment to it, and their ownership of it ([The Change Kit/Frank 2018](#)).

**“Nothing about us without us”**

A phrase used to convey the idea that nothing should be decided about a group of people, without the full and direct participation of members of the group affected ([Moes 2022](#)).

**Patient Partner**

*[the terms “Patient” and “Partner” in this context are sometimes interchangeable with terms such as Peer/Family/Caregiver/Community/Public and Advisor/Advocate/Mentor]*

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 ([Patient Voices Network 2019](#)).

**Person-First Language**

A linguistic practice that puts a person before a diagnosis, describing what a person “has” rather than asserting what a person “is”. This avoids using labels or adjectives to define someone, (e.g., “person with diabetes” instead of “a diabetic person” ([Perry 2021](#))).

**Respect**

A feeling or understanding that someone or something is important, serious, etc., and should be treated in an appropriate way ([Britannica 2022](#)).

**Safe Space**

A space where people feel psychologically safe and can express honest impressions, thoughts, and attitudes without fear of ridicule. A safe space is one that doesn’t incite judgement based on identity or experience – where the expression of both can exist and be affirmed without fear of repercussion and without the pressure to educate. A safe space can be as small as between two people or can be expanded to include all members of a larger team, network, department, or organization. It can even be an expectation of the organizational culture overall ([Canadian Centre for Diversity and Inclusion 2022](#)).

# USING THIS GUIDE

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## **Stigma**

When someone is perceived in a negative way because of a particular characteristic or attribute (such as skin colour, cultural background, a disability or a mental illness) ([Mayo Clinic 2017](#); [Caddell 2022](#)).

## **Tokenism**

Something that a person or organization does that seems to support or help a group of people who are treated unfairly in society, such as giving a member of that group an important or public position, but which is not meant to make changes that would help that group of people in a lasting way ([Cambridge University Press 2022](#)).

## **Transparency**

The transparency of a process, situation, or statement is its quality of being easily understood or recognized, for example because there are no secrets connected with it, or because it is expressed in a clear way. ([Collins 2022](#)).

## **Trauma-Informed Practice**

A strengths-based framework grounded in an understanding of and responsiveness to the impact of trauma. It emphasizes physical, psychological, and emotional safety for everyone, and creates opportunities for survivors to rebuild a sense of control and empowerment ([Government of BC 2017](#)).

## **Unconscious Bias**

Social stereotypes about certain groups of people that individuals form outside their own conscious awareness ([University of California San Francisco Office of Diversity and Outreach 2022](#)).

Sometimes people are intimidated by the patient and their voice, but you definitely don't have to be. What the patient has to say is valuable and can make a positive difference.

**MICHEL WHITE** · PATIENT PARTNER





# THROUGHOUT ENGAGEMENT

## PART 1 · THROUGHOUT ENGAGEMENT

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During an engagement opportunity with a patient partner, there are numerous principles, practices, and policies that are vital for building and maintaining positive relationships among the team.

### THIS SECTION HIGHLIGHTS THE FOLLOWING KEY AREAS:

- > Values that show respect and appreciation of people's diverse lived experiences.
  - > Ways to determine and communicate different levels of meaningful engagement using the IAP2 Spectrum of Public Participation.
  - > Resources for learning more about anti-oppressive language and practices.
1. Remember that patient partners are volunteers offering their time, as well as a diverse set of experiences, skills, and knowledge. Demonstrate that patient partner perspectives are valued, and always work to fulfill the expectations of the IAP2 engagement level that has been committed to.
  2. Consider the importance of inclusive and diverse representation that is relevant to the work at hand, while keeping in mind that an individual does not represent an entire identity group.
  3. There are many values and skills that are important for building positive relationships with a patient partner. All team members should exercise self-awareness, empathy, and active listening as part of fostering meaningful engagement.
  4. Certain theoretical concepts can help deepen your understanding of different perspectives, and assist with forming more equitable and understanding partnerships. Suggested areas of focus that can be beneficial for health care partners to learn more about include intersectionality, cultural safety and humility, trauma-informed practice, unconscious bias, marginalization, and stigmatization. See the Additional Resources in this section for more information.

“Patient engagement ensures there is a connection between health care planning and the needs of the patient. Nothing about me, without me.”

SANDY KETLER · PATIENT PARTNER



Using Person-First Language can help teams better practice inclusivity. See the Gender Based Analysis Plus (GBA+) framework and the BC Centre for Disease Control (BCCDC) plain language guide in the Additional Resources section for more information.

**5. Consider many ways that patients can provide insight. Use the International Association for Public Participation (IAP2) spectrum to determine which level of engagement is needed with the patient partner. Different levels of patient engagement are possible. Different opportunities will often require different levels of IAP2 engagement, depending on what is suitable.**

- a. In keeping with the concept of "Nothing about us without us", projects or initiatives that affect patients should incorporate perspectives of the patients impacted if and when possible. [For more information about the concept of "Nothing about us without us", please go to the Glossary on page 7].
- b. Health care partners should have conversations with patient partners regarding level of involvement, and whether that level meets both parties' expectations.
- c. It is better to overdeliver than to underdeliver – If you think it will be difficult to engage with a patient partner meaningfully at a Collaborate level, perhaps consider engaging at a level to the left on the IAP2 spectrum, such as Consult.
- d. If the scope of the work changes, it is possible for the IAP2 level to change over the course of the engagement as well. If that occurs, be sure to communicate the change with key partners, and work to manage expectations.
- e. Clearly defined objectives will help determine what decisions need to be made, and what level of influence the patient partners are able to have.

**6. Health care partners should be committed to ongoing support, answering questions and managing expectations. Keep communication pathways open throughout the engagement.**

**7. Practice continuous quality improvement by regularly connecting with patient partners to discuss how they can be best engaged and supported.**

**8. Ensure adherence to the organization's confidentiality agreements and policies such as privacy and freedom of information. Protect patient privacy throughout entirety of engagement.**

- a. Do not share the patient partners' personal information without consent.
- b. Patient partners should keep organizational discussions confidential [i.e. sign a confidentiality agreement].

Following principles of authentic engagement can help ensure that commitments to patient partners are being met, and avoid tokenism. See the IAP2 Core Values table on page 15, as well as the BC Patient Safety & Quality Council's Principles for Authentic Engagement in the Additional Resources section for more information.



# PART 1 · THROUGHOUT ENGAGEMENT

## 9. Build trusting relationships and mutual respect among team members.

- a. Ensure patient partners have an equal voice by encouraging them to share their ideas and voice their thoughts. Provide opportunities for the patient partner to be curious and ask questions.
- b. Demonstrate active listening, without judgment.
- c. Promote transparency, open communication, and the embracing of difficult conversations.
- d. Demonstrate humility and willingness to acknowledge our own biases.
- e. Foster a welcoming, professional, and respectful atmosphere that provides a safe space for all team members.

## 10. Show appreciation and thank the patient partners for their contributions and milestones (i.e. anniversaries, sharing their story and vulnerability, recognizing their part in improving a process, and any other contributions).

### ADDITIONAL RESOURCES

- [Patient Voices Network – Health Care Partner Resources webpage](#), which includes the following helpful resources:
  - [Principles for Authentic Engagement](#) Patient Voices Network 2022
  - [A Guide to Authentic Patient Engagement](#) BC Patient Safety & Quality Council 2022
  - [Committee Principles & Guidelines for Health Care Partners](#) Patient Voices Network 2021
  - [Patient Partner Recognition and Appreciation](#) Patient Voices Network 2022
  - [Culturally Safe Engagement: What Matters to Indigenous \[First Nations, Métis, and Inuit\] Patient Partners?](#) Patient Voices Network 2021
  - [Diversity, Equity & Inclusion: Elevating the Voices of All in British Columbia](#) Patient Voices Network 2021
- [Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit](#) Institute for Patient- and Family-Centered Care 2016
- [Foundations of the IAP2 Spectrum of Public Participation](#) IAP2 Canada 2018
- [Sharing Concerns: Principles to Guide the Development of an Indigenous Patient Feedback Process](#) BC Patient Safety & Quality Council 2022
- [BC Health Authorities' Declaration of Commitment to Cultural Safety and Humility](#) British Columbia Ministry of Health 2015
- [Doctors of BC and First Nations Health Authority's Declaration of Commitment to Cultural Safety and Humility](#) First Nations Health Authority 2019
- [Gender-based Analysis Plus \(GBA Plus, or GBA+\)](#) Government of Canada 2022
- [Valuing All Voices: refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach](#) Roche et al. 2020
- [BCCDC COVID-19 Language Guide: Guidelines for inclusive language for written and digital content](#) BC Centre for Disease Control 2020
- [British Columbia Patient-Centered Care Framework](#) British Columbia Ministry of Health 2015
- [Patients as Partners Initiative: Patient, Family, Caregiver and Public Engagement Planning Guide](#) British Columbia Ministry of Health 2018



# RECRUITMENT

## PART 2 · RECRUITMENT

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**Recruitment of a patient partner should be well-planned, in order to ensure that the team has a clear understanding of the expectations of the engagement. This will help the team select the most suitable candidates, and give the patient partner the necessary information to decide if the engagement is a good fit for them.**

### **THIS SECTION HIGHLIGHTS THE FOLLOWING KEY AREAS:**

- > Questions to help identify readiness within the healthcare team to recruit a patient partner.
- > Steps for developing a role description for the patient partner.
- > Considerations to make when searching for candidates.
- > Tips for holding an introductory conversation with potential patient partners.

### Getting the team ready to recruit a patient partner

- 1. Be clear on your intention to engage with patient partners. This is why it is important to develop a clear reason for why you should to recruit a patient partner. Questions to consider:**
  - a. Does this work affect patients? If so, how?
  - b. What decisions need to be made, and is patient partner influence on those decisions possible?
  - c. At what level of the IAP2 spectrum of public participation might be most fitting for the work in which you'd like to engage a patient partner? Think about your capacity as a health care partner to support the work, and the importance of overdelivering rather than underdelivering on any commitments.
- 2. Ensure there is a shared understanding with your team around the importance of meaningful engagement with patient partners, and the role you are developing. This may mean having a discussion with your team and coming to agreement on the level of engagement and role for the future patient partner together. Work through any assumptions, hesitations, or concerns with them.**



Consider the timing of when the patient partner is being brought into the engagement. While it may not always be possible, early engagement is ideal, so that the patient partner has the opportunity to be fully engaged and offer input from the beginning.

**3. Before you begin to recruit or onboard a patient partner, determine the following details with your team:**

- a. The role of a patient partner within the scope of work occurring.
- b. The IAP2 level of engagement that the team is wanting to commit to. Please see the table on page 18 for examples of what each level may look like for projects or committees.
- c. The duration of the engagement opportunity (e.g. 1-year term).
- d. The frequency and delivery method of meetings and activities (e.g. monthly 2-hour meetings on a videoconferencing software).
- e. Any available resources that may support a patient partner during their engagement opportunity (e.g. financial reimbursement information, background information on the work at hand, etc.). When it comes to payment considerations (e.g. honoraria), connect with your organization for current best practices and policies.

**4. Designate a team member as the patient partner's main contact person. Ensure that there is a clear communication process for how the contact person will be put in touch with the patient partner.**

**Core Values for the Practice of Public Participation**

1. Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.
2. Public participation includes the promise that the public's contribution will influence the decision.
3. Public participation promotes sustainable decisions by recognizing and communicating the needs and interests of all participants, including decision makers.
4. Public participation seeks out and facilitates the involvement of those potentially affected by or interested in a decision.
5. Public participation seeks input from participants in designing how they participate.
6. Public participation provides participants with the information they need to participate in a meaningful way.
7. Public participation communicates to participants how their input affected the decision.

Source: [Foundations of the IAP2 Spectrum of Public Participation](#)

For committee work and some quality improvement projects, it is important to recruit more than one patient partner, if possible. This can create a "buddy" system which can be helpful for patients to feel supported; it can also be helpful for succession planning.



## PART 2 · RECRUITMENT

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### Searching for a patient partner

**5. There are many ways to recruit a patient partner. Please refer to your organization's policy on recruiting existing patients and families for engagement opportunities. The following avenues may be available to you:**

- a. Patient Voices Network (PVN).
- b. Community Engagement Advisory Network (CEAN).
- c. Your local Health Authority support staff (e.g. Patient Experience department).
- d. Community organizations and local support groups (such as Caregivers Support Networks, Juvenile Diabetes).
- e. Existing contacts – if recruiting a patient partner known through a health care partner's clinical practice, it is important to be mindful of unique risks such as confidentiality policies, and potential power imbalances.
- f. You may want to extend an engagement opportunity via multiple avenues.

**6. When recruiting, it is helpful to consider the lived experience, background, and skills of candidates you may be looking for. Skills and experience that might be considered:**

- a. Lived experience related to the engagement work.
- b. Previous experience on a committee or quality improvement project team.
- c. Specific training (e.g. Institute for Healthcare Improvement (IHI) Open School).
- d. Skills in public speaking or speaking in a group, effective collaboration, willingness to provide and receive constructive verbal or written feedback, active listening.
- e. There are unique considerations for meaningful engagement with difficult to reach or marginalized communities. See the Additional Resources in this section for more information.

**7. Recruit with the values of equity, diversity, and inclusion. See Additional Resources in this section for more information.**

- a. Consider the patient population you're looking for when scheduling meetings, transportation, etc., and practice equity. Understand the barriers to patient engagement and be flexible to meet their needs.
- b. Provide access to translation/interpretation services, as needed.



## Meeting with potential patient partners

- 8. Meeting with potential patient partners is an important step in the recruitment process to ensure clarity of the role and commitments, and allow for health care partners to make informed decisions about who they may want to invite into the engagement opportunity. This may look different depending on the situation. For example, this could be in the form of an exploratory conversation if you already know the candidate, or it can be a formal or informal interview when you are deciding between multiple candidates.**
- 9. Ensure the health care and patient partner have the information they need to make a decision. This includes:**
  - a. Background information about the work (e.g. the initiative, why the work is occurring, the structure of the work, etc).
  - b. Outline of the role, expectations, and what is in or out of scope.
  - c. Time commitment (exact time of recurring meetings, length of engagement, frequency and duration of meetings, possible prep time).
  - d. What expenses will be covered, and how.
  - e. Contact information of the health care partner and other team members, as appropriate.
- 10. Avoid jargon and acronyms, as much as possible, when meeting with potential patient partners.**
- 11. Use a list of interview questions that are asked to all candidates.**
- 12. Give the candidate opportunities to ask questions.**
- 13. Provide the candidate with space to reflect on questions before answering, or skip a question.**
- 14. After selecting the candidate, provide them with an opportunity to accept or decline the offer, before they are onboarded.**

### The following questions are recommended, but this is not an exhaustive list:

- Why do you want to be a part of the opportunity?
- What do you hope to get out of the engagement?
- What background, skills, and experiences will you bring to this engagement?
- What do you need from us to ensure that you feel included, valued, and able to participate?
- Acknowledging that disagreement is normal and may be an element of consensus decision-making, can you give an example of when you had to manage a difficult conversation? What did you do?



## PART 2 · RECRUITMENT

IAP2 Spectrum	Inform	Consult	Involve	Collaborate	Empower
<b>Definition</b>	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
<b>Committee Example</b>	A press release distributed to channels viewed by patient partners, that explains why a committee made certain decisions that might affect them.	A townhall held by a committee, where patient partners are able to voice comments and ask questions.	Patient partners are invited as regular guests to committee meetings, where they have the space to give presentations or discuss what's important to them.	A governance committee with voting members who are patient partners.	A committee with decision-making power, comprised solely of patient partners.
<b>Project Example</b>	A pamphlet that explains to a patient partners a procedure that is being tested.	A project that uses a patient partner survey to collect data and feedback on a process.	Inviting patient partners to workshop potential solutions with the rest of the project team.	A project plan that is co-created with patient partners.	A quality improvement project with a patient partner in the lead role.

Source: [IAP2 Spectrum of Public Participation](#) 

### ADDITIONAL RESOURCES

- **[Patient Voices Network – Health Care Partner Resources webpage](#)**, which includes the following helpful resources:
  - [Health Care Partner Readiness Checklist](#) Patient Voices Network 2021
  - [Opportunity Preparation Checklist](#) Patient Voices Network 2021
  - [Improving Health Care Together: Selecting a Patient Partner](#) Patient Voices Network 2022
  - [Selection Process Sample Questions](#) Patient Voices Network 2021
- **[Engaging with Patients and Caregivers about Quality Improvement: A Guide for Health Care Providers](#)** Health Quality Ontario 2016
- **[Tip Sheets for Engaging Different Populations - Patients as Partners Initiative](#)** British Columbia Ministry of Health
  - [Primary Care](#)
  - [Mental Health and Substance Use](#)
  - [Seniors with Complex Medical Conditions](#)
  - [Surgery](#)
  - [Rural and Remote](#)
  - [Intercultural Communities](#)
  - [Family Caregivers](#)
- **[Diversity in Patient Engagement Learning Exchange Case Studies](#)** Canadian Foundation for Healthcare Improvement 2019



ONBOARDING

## PART 3 · ONBOARDING

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**Timely and thorough onboarding of a patient partner at the beginning of an engagement opportunity is essential for success. The onboarding process helps set the tone for the relationship and prepares the patient partner and the rest of the team to work together effectively.**

### **THIS SECTION HIGHLIGHTS THE FOLLOWING KEY AREAS:**

- > Components of an orientation meeting and check-in meetings.
- > Identifying accommodations that a patient partner may need.
- > Documents that should be shared with the patient partner at the start of the engagement.
- > Tips for introducing the team to the new patient partner.

**1. The patient partner’s contact person should meet with the patient partner to provide a structured orientation at the start of the engagement (in-person or virtual). The responsibilities of the contact person include:**

- a. Providing as much context as possible about the engagement to the patient partner.
  - i. Describe the initiative and the work being done.
  - ii. Discuss the patient partner’s role.
  - iii. Reiterate the time commitment asked of the patient partner, including dates and times of upcoming meetings and the length of the engagement.
  - iv. Consider developing and agreeing on shared responsibilities and guiding principles to follow within the team.
  - v. Consider how the patient partner will know when the engagement opportunity is over by reiterating the duration of the engagement opportunity and communicating what will occur at the end. Refer to the “End of Engagement” section of this document for more information.
- b. Asking the patient partner how they may like to participate in check-ins, which can provide space for patient partners to ask questions, give and receive feedback, and learn information before or after a meeting or event. Preferences around frequency, timing, and method of communication may differ between patient partners, and these preferences may also change over time. Having flexibility and open lines of communication will help to best support the patient partner.



If the contact person needs support with facilitating a meet and greet with team members, they are encouraged to reach out to the Patient Voices Network or the Community Engagement Advisory Network.

- c. Asking the patient partner specifically what they need to support their participation. The following are some areas that need to be considered:
- i. Accessibility
    - Ensure that physical accessibility needs are supported (e.g. wheelchair accessible meeting spaces, visual/audio aids).
    - Accommodate for allergies and dietary restrictions.
    - Consider access and equity in regards to technology. When possible, have alternative means available for the patient partner to attend meetings (e.g. calling in, meeting with someone in-person and joining them on a video call, etc.)
  - ii. Psychological safety
    - Health care partners and patient partners should familiarize themselves with their organization's policies, such as those that address respectful workplace, psychological safety, and harassment, to help foster safer spaces.
    - Co-create an environment that is respectful of different identities, experiences, and the systemic barriers that people may face. Consider how people want to be seen as their genuine selves (culture, gender, sexual orientation, etc.) and make relevant considerations (e.g. pronouns, holidays, harassment policies, etc.)
    - Find out how the patient partner wishes to be addressed. Share the names and roles of other people on the committee or project and how they prefer to be addressed. Encourage a first name basis.
    - Make a plan for addressing difficult conversations or situations (e.g. dealing with trauma triggers, providing space to walk away and come back later, or feeling unable to speak up, etc.)
  - iii. Expenses and reimbursement
    - Health care partners should ensure that the patient partner does not have to pay for expenses whenever possible (e.g. conference fees, travel/gas, hotels, printing, or resources). If a patient partner does have to pay for any expenses upfront, it is important that they are reimbursed in a timely manner.
- d. Asking the patient partner how they like to be acknowledged and thanked for their contributions and milestones (i.e. privately or publicly).

**When possible, invite and encourage patient partners to explore training opportunities available to them that may support them in their role.**

*For example, basic quality improvement training may be available to team members engaged in a Specialist Services Committee Physician Quality Improvement (SSC PQI) Learning Action Project.*



# PART 3 · ONBOARDING

**2. It is strongly encouraged to provide supporting resources (e.g. printed, email, or pdf), which should include:**

- a. Context about the scope of the work, including the team's organizational structure and information on work being done.

**For Committees**

- Terms of reference
- Operating guidelines
- Recent minutes (if available), and
- Links to relevant resources

**For Projects**

- History and current state of the project, and
- Relevant documents (e.g. project charter)

- b. Patient partner's role description and IAP2 engagement level description.
- c. Description of common acronyms or terms that may be used during the engagement opportunity.
- d. Existing organizational policies and requirements (e.g. confidentiality agreements, reimbursement policy).
- e. Email address and phone number of the contact person and other key team members.
- f. This guide itself is intended to be shared with all team members, and can also be included in the onboarding package for patient partners.

**3. At the start of the engagement work (e.g. first project/committee meeting), ensure there is a round-table introduction of all team members.**

- a. Share descriptions of each person's role; the purpose and role of the patient partner should be reiterated to the team.
- b. Communicate to the group who the main contact person for the patient partner will be.

**ADDITIONAL RESOURCES**

- [“Other expectations to clarify” on Page 21 of Peer Engagement Principles and Best Practices: A guide for BC Health Authorities and other providers](#) BCCDC 2017
- [Onboarding Guide for Patient Partners new to a Patient-Oriented Research](#) Team Saskatchewan Centre for Patient-Oriented Research 2019
- [Onboarding Guide for New Patient-Oriented Research Teams](#) Saskatchewan Centre for Patient-Oriented Research 2019
- [“Confidentiality Agreements” on Page 1 of Guidelines for Confidentiality Agreements, Service Contracts and Information Sharing Agreements \(for Private Practice Physicians\\*\)](#) Doctors of BC 2017

\*Please contact your organization for more information and resources related to privacy and confidentiality.



SUPPORT

## PART 4 · SUPPORT

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**Supporting the patient partner throughout the engagement builds a strong relationship of trust and collaboration. Creating a safe space provides them with the opportunity to have a meaningful engagement in the team.**

### **THIS SECTION HIGHLIGHTS THE FOLLOWING KEY AREAS:**

- > **Ways to support patient partners to engage in the full extent of their role.**
- > **The importance of providing opportunities to connect with the team.**

#### **1. Support patient partner engagement during meetings**

- Provide meeting materials prior to the meeting, with sufficient time for the patient partner to prepare for any upcoming work (e.g. pre-reading).
  - Provide printed copies of meeting materials at in-person meetings, if requested.
- In a virtual setting, communicate to the patient partner that they may choose to be off-camera, and provide access to the chat function, if available.
- Expand on acronyms when first introducing them. Avoid jargon and acronyms if possible.
- Be tactful when discussing financial matters (e.g. salaries, etc), recognizing that the patient partner is likely a volunteer.
- Provide alternative avenues to participate and give feedback on the work, if the patient partner is unable to attend a meeting.





## 2. Provide check-ins to enhance support, throughout the engagement.

- a. Encourage and be available for check-ins with the patient partner.
- b. Ask if there are any opportunities or resources to support the patient partners in being involved more meaningfully.
  - i. Offer support and training for technology used within the opportunity (e.g. Zoom, adding invites to online calendars, etc.)
  - ii. Encourage patient partner to connect with other patient partners to learn from and ask questions, if possible.
  - iii. Offer additional resources to the patient partner, such as those found in this guide, or on the Patient Voices Network website.
- c. Address and acknowledge any conflicts of interest or points of tension. Ensure there are pathways for conflict resolution. Co-create constructive solutions to any issues that may come up.

## 3. If feedback is requested from a patient partner, ensure that it is acknowledged, and let them know if that feedback might be used or not.

- a. It is a good idea to indicate what IAP2 level a request for feedback might be, so that expectations around participation are understood.
- b. Communicate to the patient partner when their participation in that feedback mechanism is complete.

## 4. Ensure that if the contact person leaves the role, that there is a smooth transition to another contact person.

### Respond to emerging knowledge and skills gaps with training or developing new tools and resources for both the patient and health care partners

- Provide patient engagement training to the healthcare team; involve patient partner in training physicians/staff (e.g. developing training materials).
- Other useful skills to develop as a team might include Cultural Safety & Humility, and having difficult conversations.



### ADDITIONAL RESOURCES

- [Patient Voices Network – Health Care Partner Resources webpage](#), which includes the following helpful resource:
  - [Engagement Opportunity Check-in Checklist](#) Patient Voices Network 2022
- [The Power of the Patient Voice: How Health Care Organizations Empower Patients and Improve Care Delivery](#) New England Journal of Medicine Catalyst 2021





# END OF ENGAGEMENT

## PART 5 · END OF ENGAGEMENT

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**The end of an engagement opportunity is an important phase of a patient partner and health care partner's journey together. During the end of engagement phase, it is important for the team to take the opportunity to share, learn, and celebrate.**

### **THIS SECTION HIGHLIGHTS THE FOLLOWING KEY AREAS:**

- > Tips on how to end an engagement opportunity in a positive way.
- > Ideas on how to share and celebrate the wins that a patient partner has been a part of.
- > Ways to debrief and identify areas that could be improved for future engagement opportunities.

- 1. Patient partners and health care partners share accountability to provide advance notice when they are ending the engagement, if possible.**
  - a. An engagement may end at the time that was planned, or at any time by either party, for a variety of reasons [e.g. project end, committee term, patient partner choosing to end the engagement, etc.]
  - b. There may be mutual agreement to extend the duration of the engagement opportunity. If that is the case, a new duration should be determined.
- 2. Invite the patient partner to an end of engagement conversation. The insights learned from patient partners can help improve the program, and future patient partner engagement.**
  - a. Ensure the patient partner is comfortable with the health care partner facilitating the end of engagement conversation. This may or may not be the contact person and/or other team members.
  - b. Provide an overview of the work's progress and how the patient partner's input was incorporated. Acknowledge the impact of their time and effort, and thank them for their contributions.
  - c. Ask for patient partner's reflections and feedback. Get their insight into what went well and what can be improved for next time.
  - d. Ask the patient partner if and how they want to be involved in the future. Future milestones of the work should be communicated to the patient partner post-engagement, if they wish to stay updated.



Invite the patient partner to celebrations or events related to the work they participated in.

3. Healthcare partners should collect and review patient partner feedback, and incorporate improvement ideas for future engagement opportunities.
4. Include how the patient partners were included and contributed to the work in any final reports or presentations, keeping in mind the patient partner's preference for acknowledgement.

In my experience, it is the patients who ask the very best questions.

DR JOHN GALBRAITH · FORMER PQI STEERING COMMITTEE CHAIR FOR ISLAND HEALTH

**The following examples of questions may be helpful prompts during an end of engagement conversation:**

- What did you enjoy most during this engagement?
- Do you feel the time and input you shared was appreciated?
- Could you tell me about anything that took place during the engagement that was difficult for you?
- Would you like to be kept updated about the project/initiative? If so, what are your expectations for frequency and methods of communication?
- Would you recommend this engagement to others?
- Would you like to be contacted about future opportunities that may arise to participate with this project or another one?
- Was your onboarding sufficient to prepare you?
- Was there anything you wanted to discuss that we haven't covered?
- Do you feel your time in the engagement was well spent?
- Do you feel you benefitted from this engagement, and did you feel that your input benefitted others?



**ADDITIONAL RESOURCES**

- [Patient Voices Network – Health Care Partner Resources webpage](#), which includes the following helpful resources:
  - [Closing the Loop Overview \[PVN-Specific\]](#) Patient Voices Network 2022
  - [Closing the Loop Template \[Word Document\]](#) Patient Voices Network 2022
- [Challenge of Closing the Loop](#) Delaney and Associates Inc. 2017
- [Closing the Loop and the “What We Heard” Process](#) Lethbridge College Centre for Teaching, Learning and Innovation 2020

# NOTES

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\* Please consider the environment by not printing this guide, if possible.