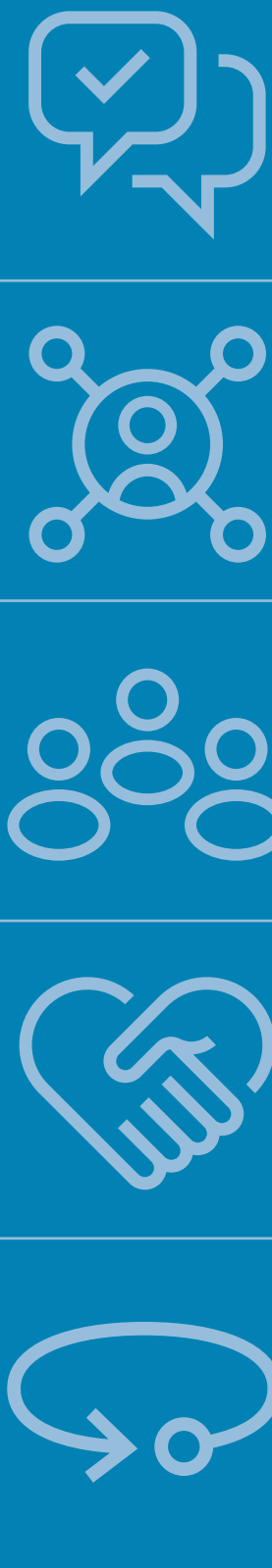
JCC Joint Collaborative Committees

# JCC Engagement Guide: Patient, Family, and Caregiver Partners

## How to engage meaningfully with people who have lived experience of the health care system



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doctors of bc

A Partnership Between the Province of British Columbia and Doctors of BC

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The Joint Collaborative Committees (JCCs) are dedicated to meaningful, authentic engagement with people and their families who have lived experiences with the health care system. Engagement is built on the principles of inclusion, respect, listening to patient voices, and partnership.

# About this guide

## This guide helps health care teams meaningfully engage patients, families, and caregivers in Joint Collaborative Committee (JCC) activities such as quality improvement projects, advisory groups, and committees.

It supports meaningful engagement by:

- Providing information to help team members work together more effectively.
- Describing best practices and standards.
- Outlining a consistent approach to engagement.

This guide updates the Specialist Service Committee's (SSC) 2022 Meaningful Patient Engagement Guide, originally developed by staff from SSC, Shared Care Committee (SCC), patient partners, health system partners, and physicians. After receiving positive feedback, a new version of the guide that supports patient engagement across the diverse work of the JCCs was requested, incorporating the perspectives of representatives from the Family Practice Services Committee (FPSC), Joint Standing Committee on Rural Issues (JSC), and Rural Coordination Centre of BC (RCCbc). The valuable contributions of all engaged in the guide's development are reflected throughout its content.

Teams engaged in JCC initiatives are encouraged to share and use this guide in their work.

### A note about language

While patient partner is used most frequently throughout this guide, other terms, such as people with lived experience of the health care system, may be more relevant in different situations. Words like peer, family, caregiver, public, or community may also be applicable. Instead of partner, some people may choose advisor, advocate, mentor, or other terms.

Throughout this guide, you'll find tips and suggestions included within blue boxes shown alongside this lightbulb icon.

> *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

# Part 1
# Engagement principles

Many principles, practices, and tools can help build and maintain positive team relationships throughout the journey of engaging with patient partners.

### The importance of meaningful engagement

- Following the principle of "nothing about us, without us", the perspectives of patients, families, and caregivers should be incorporated into the solutions that affect them whenever possible.
- For more information about the concept of "nothing about us, without us", please see the glossary on pages 16-19.
- Consider the importance of inviting multiple diverse perspectives to the work, remembering that one individual does not represent an entire group.
- Get to know the IAP2 Spectrum of Public Participation and the IAP2 Core Values; these frameworks are key to effective engagement.
    - Please note that the level of engagement on the IAP2 Spectrum of Public Participation determines how patient partners are recruited, onboarded, and supported. For example, partners at the "Collaborate" or "Empower" levels may need more support than those at the "Consult" level.
- Remember that patient partners contribute valuable experiences, skills, knowledge, and time. Show that their perspectives are valued by incorporating their ideas into solutions to the maximum extent possible and expressing appreciation for their contributions.

| IAP2 Public Participation Goal[1] | | | | |
|---|---|---|---|---|
| Inform | Consult | Involve | Collaborate | Empower |
| 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. |

1 https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf

## IAP2 Core Values[2]

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 thelr input affected the decislon.

## Creating a safe space for engagement

- Encourage patient partners to share their ideas, thoughts, and questions by fostering a welcoming, professional, and equitable environment for all team members:
  - Demonstrate empathy and active listening.
  - Practice self-awareness, humility, and a willingness to acknowledge your own biases.
  - Promote healthy communication, transparency, and an openness to difficult conversations.
- Build positive relationships with patient partners (and others) by deepening your understanding and application of important concepts such as strengths-based approaches, intersectionality, cultural safety and humility, Indigenous-specific anti-racism (ISAR), trauma-informed practice, and gender-based analysis plus (GBA Plus).

## Protecting privacy

Protecting patient privacy is essential throughout the engagement journey.

- Don't share patient partners' personal information, stories, or experiences without their consent.
- Ask patient partners to keep discussions confidential. Depending on the level of engagement, this may include asking patient partners to sign a confidentiality agreement.
- Review your organization's privacy policies and ensure you're following all required processes.

> *Patient engagement ensures there is a connection between health care planning and the patient's needs. Nothing about me, without me.*
>
> **Sandy Ketler** · Patient Partner

2 https://iap2canada.ca/resources/Documents/NEW-Foundations-Core-Values-MW-rev1.pdf

# Part 2 **Recruiting**

The first steps in patient partner engagement are foundational for ensuring success throughout the engagement opportunity. By doing the work upfront, you can enhance shared understanding and support for patient partner engagement within the team, and support patient partners to make informed decisions about their participation.

## Before recruiting a patient partner

At the outset of your work, it is important to be able to clearly communicate your intention to engage patient partners. Before starting recruitment, discuss these questions with your team:

- How could this work affect patients, families, and/or caregivers, both directly and indirectly?
- What decisions need to be made, and is patient partner influence on those decisions possible?
- What level of the IAP2 Spectrum of Public Participation makes most sense to engage patient partners in, considering the work you are doing? Think about how much support your team can realistically provide and commit to a level you can deliver on. It's better to start at a level such as "Consult" than to overpromise at "Collaborate".
- Does your team share an understanding of the importance of meaningful engagement with patient partners and the role you are developing? Consider discussing any assumptions, hesitations, or concerns together.
- Is your team ready? Review the Patient Voices Network Health Care Partner Readiness Checklist before starting any recruitment or onboarding.

There are many ways to recruit patient partners. The following options may be available to you:

- Patient Voices Network (PVN)
- Community Engagement Advisory Network (CEAN)
- Your local organization' or health authority's support staff (e.g. patient experience team)
- Community organizations and local support groups
- Your contacts – Please note there are risks that must be mitigated when engaging past or current patients, family members, or caregivers from your clinic or health facility. Follow your organization's policies when addressing challenges such as power imbalances and protecting confidentiality.

Consider when engagement begins compared to the work's progress. Are patient partners being engaged early or later? While not always possible, early engagement is always encouraged.

### Developing a patient partner role

Clearly describe the engagement opportunity for success during recruitment and afterward. Organizations that support patient partners, such as Patient Voices Network (PVN) and Community Engagement Advisory Network (CEAN), will ask you to confirm details such as:

- A description of the patient partner role.
- The level of engagement you're committing to on the IAP2 Spectrum of Public Participation (page 17).
- The number of patient partners you're recruiting.
- The lived experiences, background, or skills you are looking for, if applicable.
- Background information on the work (such as the purpose, objectives, and information about the organization and team).
- The engagement timeline and duration, including start and end dates.
- How often meetings and activities happen, and where/how they are held (e.g. monthly two-hour meetings on Zoom or Teams).
- Resources and information available to support patient partners during their engagement, especially any best practices and organizational policies related to patient partner expenses.

It can be helpful to consider the lived experiences, background, and skills of patient partners you would like to engage. While a patient-centred perspective is key, patient partners may have additional relevant skills unrelated to their medical journey, such as:

- Lived experience related to the engagement work. There are unique considerations for meaningful engagement with difficult-to-reach communities or communities facing marginalization. See section resources for more information.
- Previous engagement experiences.
- Skills such as public speaking, effective collaboration, providing and receiving constructive verbal or written feedback, and active listening.

Recruiting more than one patient partner can create a supportive "buddy" system that also assists with the team's succession planning.

## Identifying a main contact

- Designate a team member to act as the main contact throughout the engagement journey. The main contact should either be the healthcare partner (such as the committee chair or the project's physician lead) or another key staff person (such as a project coordinator or administrative assistant).
- Ensure early on that there is a clear process for how the main contact will work with patient partners, including how they will provide them with logistical support (e.g. sending meeting invitations), foster opportunities for connection and debriefing (e.g. providing pre- or post-meeting check-ins), and ensure safe spaces for engagement.

## Connecting with a potential patient partner

- Meet with potential patient partners during recruitment to clarify their role and the intended level of engagement. This allows both health care partners and patient partners to make informed decisions about the engagement opportunity.
- Determine how you will connect with potential patient partners, depending on the context. For example, you might have an informal conversation if you already know the patient partner or the engagement level is "Consult". You might use a more formal process, like a brief interview, if the engagement level is "Empower" and you're choosing between applicants.
- Identify a few questions to ask potential patient partners. While not an exhaustive list, the following questions are recommended:
    - Why are you interested in this engagement opportunity?
    - What background, skills, and experiences do you bring to this engagement opportunity?
    - How can we support you to feel included, valued, and fully able to participate?

The above questions can be given ahead of the conversation to allow potential patient partners time to reflect on them.

- Give potential patient partners time to reflect before answering questions or let them skip questions if they want.
- Provide opportunities for potential patient partners to ask questions throughout the process.

In both formal and informal recruitments, provide a safe, welcoming space for potential patient partners and demonstrate equity, diversity, and inclusion at every step.

- Ask potential patient partners how you can best support their participation in an initial discussion or interview. Are there barriers that might limit their participation? Consider clarifying the following:
  - Preferred way of meeting (in person, over the phone, or virtually).
  - Accessibility needs (e.g. translation or interpretation services, wheelchair access, transportation, closed captioning on Zoom, etc.).
  - Any potential costs that could be avoided or covered up front.
  - Flexibility with scheduling an initial discussion.
  - Considerations around a potential patient partner's location and time zone.
- Communicate any changes as early in advance as possible.
- Reflect on who will be part of the first conversation or interview, and how this may impact the experience of potential patient partners.
  - Avoid interviewing potential patient partners in front of large groups. Limit the group size so patient partners feel comfortable asking and answering questions.
  - Treat any personal stories or sensitive information shared by potential patient partners with respect and confidentiality.
- Use clear, plain language and avoid jargon or acronyms when meeting with potential patient partners.
- Check for explicit and implicit biases that may be coming up for you and/or the team when deciding who to invite as a patient partner. See glossary and section resources for more information.

A local patient partner may be ideal for some engagement opportunities, but it isn't required, especially for virtual engagements or work that isn't tied to a specific location.

### Inviting a patient partner to participate

After choosing a patient partner, reach out to them using their preferred contact method. When inviting patient partners, share a summary of the engagement so they can make an informed decision on whether to participate. This should include:

- A description of the patient partner role.
- The IAP2 Spectrum of Public Participation level of engagement you are committing to (page 17).
- Background information about the work and other relevant information (e.g. purpose, objectives, etc.).
- The time commitment, including the engagement's duration, meeting schedule, whether it's virtual or in-person, and any required preparation time.
- The financial policies and processes (e.g. honoraria, stipends, expense reimbursement).
- The email and phone number of the assigned main contact, and other team members as needed.

After inviting a patient partner to participate, give them a chance to accept or decline the invitation before starting the onboarding process.

> *In my experience, it is the patients who ask the very best questions.*
>
> **Dr John Galbraith** · Former SSC-ISLH QI Steering Committee Co-Chair

# Part 3: **Onboarding**

Providing patient partners with timely and thorough onboarding is essential for successful engagement. It sets the tone for the relationship and prepares team members for working together effectively.

## Welcome and orientation

The assigned main contact should meet with incoming patient partners to provide a structured orientation at the start of the engagement (in-person or virtually). The responsibilities of the main contact include:

- Providing context to patient partners about their new engagement opportunity:
  - Describe the work being done.
  - Discuss the roles of the patient partner, health care partner, main contact, and other team members.
  - Repeat the time commitment, including meeting dates, times, and the length of the engagement.
  - Clarify how patient partners will know when the engagement ends by restating its duration and what happens at the end. Refer to the "Ending an Engagement" section of this document for more information.
- Considering the co-development of shared team responsibilities and guiding principles.
- Asking patient partners how they prefer to participate in check-ins before or after meetings or events. This allows them to ask questions, give and receive feedback, and enhance their understanding of the work. Preferences about how often, when, and how to communicate may vary between patient partners, and can also change over time. Maintaining flexibility and open communication will help to best support patient partners.
- Asking patient partners how they prefer to be acknowledged and thanked for their contributions (i.e. privately or publicly; verbally or in writing).
- Ensuring a smooth transition to a new main contact, if the role is changed during the engagement opportunity.

If the main contact needs support in facilitating a meet-and-greet with team members, they're encouraged to reach out to the Patient Voices Network (PVN) or the Community Engagement Advisory Network (CEAN).

- Documents to share during onboarding:
  - Patient partner role description and the agreed-upon level of engagement.
  - Supporting documents for the work (e.g. project charter, committee terms of reference, recent minutes, links to resources, list of common acronyms/terms).
  - Email and phone number for the main contact and other key team members.
  - Relevant organizational policies (e.g. expense policy).
  - Documents the patient partner needs to sign or acknowledge (e.g. confidentiality agreement).
  - **Tip:** You're encouraged to share this guide with all team members. Consider including it in the orientation package for patient partners and new team members.

## Reducing barriers to participation

Confirming what patient partners need to participate is an important step in the onboarding process. The following are areas to consider and discuss with patient partners.

### Accessibility

- Ensure that physical accessibility needs are supported (e.g. wheelchair-accessible meeting spaces and visual/audio aids).
- Accommodate allergies and dietary restrictions.
- Consider the meeting time and ask patient partners for their preference (e.g. pain levels may be higher at certain times of day, or some patient partners may be at work during usual meeting hours).

### Psychological safety

- Before introducing new patient partners to the rest of the team, ask them how they want to be addressed.
- Start engagement work (e.g. at the first meeting) with a roundtable introduction of all team members, describing each person's role and restating the patient partner's role to the team. Encourage the use of first names amongst all team members.

- Create a respectful team culture that values diverse identities and experiences, and honours authentic self-expression through considerations such as pronouns, holidays, and safe/neutral spaces.
- Consider strategies for addressing difficult conversations or situations (e.g. trauma triggers, team conflicts, or feeling unable to speak up).
- Ensure that health care partners and patient partners review the organization's policies on respectful workplaces, psychological safety, and harassment to help create safer spaces.

**Expenses, reimbursement, and compensation**

- It is encouraged that expenses for patient partners (e.g. conference fees, hotels, printing, resources) are covered upfront whenever possible. If patient partners do have to pay out of pocket, it is important to reimburse them quickly.
- Account for potential patient partner expenses in your budget.
- Please review and follow your organization's patient partner compensation policies.
- For JCC-funded activities, a JCC Patient Partner Compensation Policy and Guide is available. Please contact JCC@doctorsofbc.ca for more information.

**Technology**

- Consider access and equity regarding technology. Ensure patient partners have the technology (hardware and software) they need to participate in the engagement.
- Address technology challenges caused by geography (e.g. in rural and remote communities) and problem-solve issues as they arise.
- Offer patient partners alternative options for participating if needed (e.g. by telephone, meeting a team member in person and then joining the group by video, providing feedback over email, etc.).

When possible, encourage patient partners to explore training (preferably free or virtual) that would support them in their role, and cover their costs or expenses. For example, basic quality improvement training may be available to team members engaged in some Specialist Services Committee programs.

# Part 4: **Supporting**

Providing ongoing support for patient partners throughout the engagement builds trust, improves collaboration, and helps them participate fully.

## Enabling full engagement

**During meetings or events:**

- Share materials (e.g. pre-reading) before meetings or events, giving patient partners enough time to prepare.
    - Provide printed materials to patient partners on request during in-person meetings or events.
    - Remind patient partners in virtual meetings or events that they can choose to be on or off camera.
- Use plain, clear language, avoid jargon, and spell out acronyms the first time you use them.
- Tactfully discuss financial matters (e.g. salaries, sessional rates, etc.), recognizing that patient partners may be volunteering their time.
- Offer alternative ways for patient partners to participate if they miss a meeting.
- Credit patient partners for created or co-created materials, such as listing them as co-authors on publications.

**Check-ins:**

- Use check-ins to build trust and collaboration, especially before or after meetings and events. Check-ins can provide:
    - Meaningful context for patient partners who may be less familiar with the work or environment.
    - Opportunities for ongoing feedback about the engagement opportunity.
    - Clarity about how they would like to be credited or acknowledged for their contributions.
- Ask patient partners if there are opportunities or resources that would help them engage more meaningfully.
    - Offer support and training for technology used during the engagement opportunity (e.g. Zoom, online calendar invitations, etc.).
    - If there are other patient partners on the team or within the organization, suggest connecting with other patient partners for peer support and relationship building.
    - Offer additional resources to patient partners, such as those included in this guide.

When material is created or co-created by patient partners, provide opportunities to credit/acknowledge their contributions appropriately and in a way that they are comfortable with (e.g. listing them as co-authors on a publication, providing a shoutout during a presentation, etc.).

### Working through challenges

- Practice active listening and empathy to build healthy team dynamics, address tension or conflicts early, and co-create constructive solutions to any issues that arise.
- Address challenges early, work together to find a resolution, and use supports from your organization's patient experience department.
- Build team skills and strategies for having difficult conversations.

Provide access to training, tools, and resources to address emerging knowledge and skill gaps for health care partners and patient partners.

# Part 5
# Ending an engagement

The end of an engagement opportunity is an important phase in the patient partner engagement journey. Take this time to 'close the loop' on the engagement opportunity, show appreciation for patient partner contributions, and celebrate the team's accomplishments.

## Closing the loop

- Invite patient partners to an end-of-engagement conversation to gather insights for improving the program and future patient partner engagements.
  - Ask patient partners if they're open to an end-of-engagement conversation, and who they prefer to speak with. Health care partners often facilitate this discussion, but patient partners may prefer talking to their main contact or another team member.
  - Share progress, show how patient partner input was used, acknowledge their impact, and thank them for their contributions.
  - Ask for patient partner reflections and feedback to gather their insights on what went well and what to improve for next time. Consider providing anonymous pathways to provide feedback or improvement suggestions (e.g. launching an anonymous survey to multiple patient partners).
  - Ask patient partners if they'd like to be invited to participate in future engagements. Share the work's future milestones with them, if they wish to stay updated.
- **Note:** Sometimes an engagement opportunity will need to end early, or there may be mutual agreement to extend it.
  - Ending an engagement opportunity early: Provide advance notice if needing to end an engagement opportunity earlier than originally planned. Health care partners and patient partners share accountability for communicating any changes to the engagement opportunity.
  - Extending an engagement opportunity: Set a new duration for the engagement opportunity and clarify the role if there is mutual agreement to extend it.

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

- What did you most enjoy during this engagement?
- Could you tell me about any challenges you faced during this engagement that we could have better supported you with?
- Did your onboarding help you to feel prepared?
- 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?
- Do you feel the time and input you shared was appreciated?
- Would you like to be updated on the work? If so, how would you like to receive updates, and how frequently?
- Would you like to be contacted by our team about future engagement opportunities?
- Was there anything you'd like to discuss that we haven't covered?

## Showing appreciation

- Follow the patient partner's lead on how they wish to be acknowledged for their contributions throughout the engagement journey.
- Provide private acknowledgement to patient patients who prefer it, using a personal gesture like a letter of appreciation.
- Offer appreciation through ways such as:
  - Crediting patient partners who contributed to the work in final reports and presentations, with their consent.
  - Inviting patient partners to celebrations or events related to the work. Make efforts to include them in in-person activities when possible.
  - Obtain patient partners' consent before including them or their contributions in any media coverage. Check your organization's media relations policy for more information.

# Glossary

### Active listening

Active listening includes demonstrating respect and inclusivity, key aspects of productive dialogue. Practicing active listening means asking questions to understand, avoiding interrupting, belittling, or using inflammatory language, and being mindful of diverse communication styles and perspectives (UBC Equity & Inclusion Office 2025).

### Cultural humility

Cultural humility is 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 lifelong learner when it comes to understanding another's experience (First Nations Health Authority 2021).

### Cultural safety

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 (First Nations Health Authority 2021).

### Diversity

Diversity is the range of social identities, lived experiences, and perspectives of people that may include race, ethnicity, colour, ancestry, place of origin, political belief, religion, marital status, family status, physical disability, mental disability, sex, gender identity or expression, sexual orientation, age, class, and/or socio-economic situations (UBC Equity & Inclusion Office 2023).

### Family caregiver

A family caregiver is an individual who provides care and support to someone living with a disease, disability, or frailty due to aging. The role of family caregiver is mutually determined by the person providing care and support, and those receiving it (Family Caregivers BC).

### Gender-based analysis plus (GBA Plus)

GBA Plus is an intersectional analysis that goes beyond biological (sex) and socio-cultural (gender) differences to consider other factors, such as age, disability, education, ethnicity, economic status, geography (including rurality), language, race, religion, and sexual orientation (Government of Canada).

### Health care partner

A health care partner is an individual or organization seeking to include patient, family, and caregiver voices to improve BC's health care system (Health Quality BC 2023).

### Health equity

Equity is the absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically, or by other means of stratification (World Health Organization 2026).

### IAP2 Spectrum of Public Participation

Developed by the International Association for Public Participation (IAP2), the IAP2 Spectrum of Public Participation clarifies the role of the public in planning and decision-making, and the extent of the public's influence over these processes. It includes five levels of public participation: inform, consult, involve, collaborate, and empower (Patient Voices Network 2023).

### Inclusion

Inclusion is 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 2024).

### Indigenous-specific anti-racism

A practice of identifying, challenging, preventing, eliminating and changing the values, structures, policies, programs, practices and behaviours that perpetuate Indigenous-specific racism. This approach relies on re-centering Indigenous ways of knowing and being, as well as Indigenous Peoples' inherent rights (In Plain Sight Report 2020).

### Intersectionality

Intersectionality describes how social identities may overlap to create compounding barriers for individuals. It is a framework for approaching issues from multiple perspectives and for 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).

### Marginalization

Marginalization occurs when people are excluded based on social identities such as race, gender, sexuality and social class as well as the inequitable distribution of social, economic, physical and psychological resources. Individuals and communities are marginalized by, live in marginalized conditions, or are forced into marginalization rather than being labelled as marginalized people/populations/groups (National Collaborating Centre for Determinants of Health 2022).

### Meaningful engagement

Meaningful engagement includes 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 2023).

### "Nothing about us, without us"

"Nothing about us, without us" is a principle that nothing should be decided about a group of people, without the full and direct participation of members of the group affected (United Nations 2004).

### Patient engagement

Patient engagement is the participation of patients, families, and caregivers in healthcare system initiatives at the program or policy levels. It is the act of including patients, families, and caregivers in decision making, design, planning, delivery, and evaluation of health are services. Authentic patient partner engagement does not happen by accident. It takes effort and a commitment to working together in partnership throughout the process (Health Quality BC 2023).

### Patient partner

A patient partner refers to anyone who has experience with the health care system as a patient, family member, and/or caregiver. They have an array of backgrounds and experiences (Health Quality BC 2023). *Please note: the terms patient and partner in this context are sometimes used interchangeably with other terms, such as person with lived experience, peer, family, caregiver, community member, or member of the public, and advisor, advocate, or mentor.*

### Person-first language

Person-first language is a way to emphasize the person and view the disorder, disease, condition, or disability as only one part of the whole person. It includes describing what the person "has" rather than what the person "is." Person-first language avoids using labels or adjectives to define someone (e.g. "a person with diabetes" rather than "a diabetic") (National Institutes of Health 2025).

### Safe space

A safe space is an environment where people can express honest impressions, thoughts, and attitudes without fear of ridicule. A safe space can be as small as between two people or can be expanded to include all members of a larger group (i.e. team, department, unit, organization). It can even be an expectation of the organization's overall culture (Canadian Centre for Diversity and Inclusion 2019).

### Stigma

Stigma is 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

Tokenism is 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

Trauma-informed practice is 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
(British Columbia Ministry of Health 2020).

### Unconscious bias

Unconscious, or implicit bias, is a systematic way of thinking that can cloud our judgment and impact our decision-making. It refers to attitudes based on stereotypes that we have been taught which affect our understanding, actions, and decisions in an unconscious manner. The attitudes and beliefs are often involuntarily and outside of our awareness or intentional control. Everyone holds unconscious beliefs about various social and identity groups, and these biases stem from our tendency to organize social worlds by simplistic categorization (UBC Equity & Inclusion Office 2021).

# Resources

## Part 1: Engagement principles

**Health Quality BC's Patient Voices Network Health Care Partner Resources (2024):**

- Principles for Authentic Engagement
- A Guide to Authentic Patient Engagement
- Committee Principles & Guidelines for Health Care Partners
- Patient Partner Appreciation & Recognition Guide
- Culturally Safe Engagement: What Matters to Indigenous (First Nations, Métis and Inuit) Patient Partners Pamphlet
- Diversity, Equity & Inclusion: Elevating the Voices of All in British Columbia

**Engaging Indigenous partners:**

- Guide for respectful Indigenous engagement (Doctors of BC 2025)
- What we stand for: Truth and Reconciliation (Doctors of BC 2026)
- Sharing Concerns: Principles to Guide the Development of an Indigenous Patient Feedback Process (Health Quality BC's Patient Voices Network 2024)

**Additional resources:**

- IAP2 Core Values (IAP2 Canada 2026)
- IAP2 Spectrum of Public Participation (IAP2 Canada 2026)
- Gender-based Analysis Plus (GBA Plus) (Government of Canada 2025)
- Inclusive language and terms (Government of Canada 2025)
- CMA Patient Voice Guide: Trauma Informed Engagement & Resources (Canadian Medical Association 2020)
- 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)
- Doctors of BC Privacy Toolkit (Doctors of BC 2026). Please contact your organization for more information and resources related to privacy and confidentiality.
- Patient, Family, Caregiver and Public Engagement Planning Guide (British Columbia Ministry of Health 2018)
- Partnering with Patients and Families to Enhance Safety and Quality: A Mini Toolkit (Institute for Patient- and Family-Centered Care 2016)

## Part 2: Recruiting

**Health Quality BC's Patient Voices Network Health Care Partner Resources (2024):**

- Health Care Partner Readiness Checklist
- Improving Health Care Together: Selecting a Patient Partner
- Selection Process Sample Questions

**Additional resources:**

- Diversity in Patient Engagement Learning Exchange (Canadian Foundation for Healthcare Improvement 2019)
- A Guide for Health Care Providers (Health Quality Ontario 2016)
- Tip Sheets for Engaging Different Populations – Patients as Partners Initiative, BC Ministry of Health

## Part 3: Onboarding

- Peer Engagement Principles and Best Practices: A guide for BC health authorities and other providers (BC Centre for Disease Control 2017)
- For patient partners: Onboarding guide for Patient Partners new to a Patient-Oriented Research Team (Saskatchewan Centre for Patient-Oriented Research 2019)
- For health care partners: Onboarding Guide for New Patient-Oriented Research Teams (Saskatchewan Centre for Patient-Oriented Research 2019)

## Part 4: Supporting

- Check-in Checklist (Patient Voices Network 2024)
- The Power of the Patient Voice: How Health Care Organizations Empower Patients and Improve Care Delivery (New England Journal of Medicine Catalyst 2021)

## Part 5: Ending an engagement

- Closing the Loop Overview (PVN-Specific) (Patient Voices Network 2022)
- Closing the Loop Template (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)

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The Joint Collaborative Committees are a partnership between Doctors of BC and the BC Government.

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JCC Joint Collaborative Committees

**115-1665 West Broadway, Vancouver BC V6J 4A4**

JCC@doctorsofbc.ca

collaborateonhealthbc.ca