PHSA Patient and Family Engagement Framework

Working in partnership with patients and families
to place people at the centre of our health care system

Provincial Health
Services Authority

Quality, Practice &
Clinical Informatics

Spring 2025

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Thank you

A heartfelt thank you to our patient and family partners and colleagues across PHSA programs and services, for sharing your insights, thoughtful edits, and invaluable contributions to shape this framework. Your input has been instrumental in making this document meaningful and impactful.

For additional information, contact:

PHSA Patient & Family Partnerships and Experience
pfp@phsa.ca

Patient and Family Partners at BC Cancer engagement event with the Emily Carr Health Design Lab, 2025

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Land acknowledgement

PHSA provides specialized health care services to communities across British Columbia, on the territories of many distinct First Nations. We are grateful to all the First Nations who have cared for and nurtured the lands and waters around us for all time, including the xʷməθkʷəy̓əm (Musqueam), Sḵwx̱wú7mesh (Squamish Nation) and səl̓ílwətaɬ (Tsleil-waututh Nation) on whose unceded and ancestral territory our head office is located.

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About this framework

This framework offers guidance for PHSA staff involved in planning patient and family engagement for projects, programs, research and health system initiatives.

It builds on existing frameworks within PHSA, as well as provincial and national guidelines. The framework is designed to be flexible and applicable to a wide range of PHSA programs and services.

The framework includes:

- Key concepts in patient and family engagement
- A customized Spectrum of Engagement, based on promising practices and tailored for PHSA
- Steps and resources to support the planning and implementation of meaningful patient and family engagement across different settings

What it does not do:

- Replace existing resources or frameworks for engagement within PHSA programs
- Provide detailed advice for engaging specific populations or communities
- Provide strategies for engaging patients at the point of care (i.e.: doctor/patient conversations and shared decision making over treatment, etc.)

This framework is intended to bring value to all and help strengthen patient and family engagement across PHSA.

Patient partners at the BC Mental Health and Substance Use UNITE event, 2023

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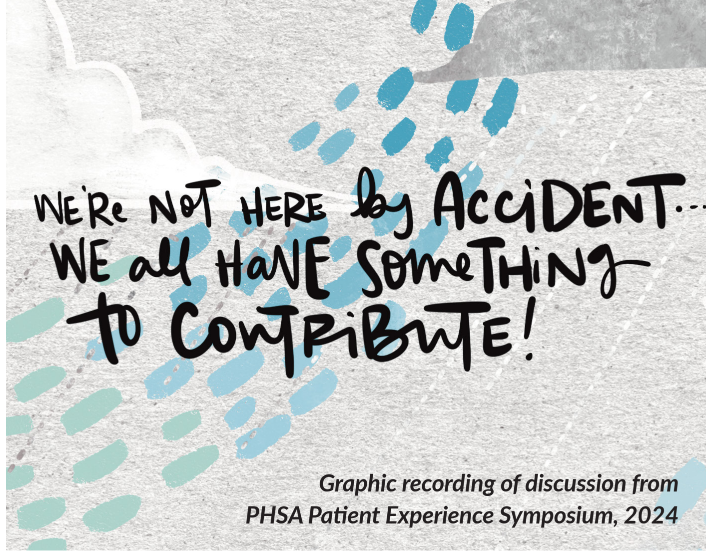
PART A: The Foundation

Background

Placing the people we serve at the heart of the health care system is essential for providing high quality care. Centring each person in their own care journey requires meaningful engagement with the diverse populations we serve in ways that meet their unique needs.



Graphic recording of discussion from PHSA Patient Experience Symposium, 2024

Person- and family-centred care is a priority across the health system. It is widely acknowledged that involving patients and families in health care decisions related to patient care, hospital procedures, health system policies, and programs yields improved health outcomes, higher care quality, reduced health care costs, improved patient experience, and enhanced patient safety.[1–4]

The Provincial Health Services Authority (PHSA) plays a unique role in BC by planning, coordinating, and delivering provincial and specialized health care services. Its programs span multiple areas of health and service delivery, including acute care, ambulatory care, emergency services, public health, laboratory services, and research. Across all these areas, PHSA emphasizes the importance of person-centred care and meaningful patient and family engagement.

The PHSA Patient and Family Engagement Framework aligns engagement practices and supports programs and services to engage patients and families consistently and meaningfully in program, organizational and systems decision making. It encourages an approach rooted in relationality and reciprocity, striving to ensure that those we engage with feel valued, heard, and leave the experience better than when they entered. This framework emphasizes the importance of listening to and learning from patients and families, fostering authentic partnerships, and continuously improving care delivery. When we do this well, it is shown to improve patient experience, enhance joy at work and connect staff to their core purpose. However, it is important to acknowledge that engagement can also be harmful if not approached thoughtfully and respectfully, underscoring the need for intentionality and care in how we involve patients and families in decision-making.

> “Engaging as a Family Partner is a beautifully cathartic and welcomed piece of my healing. To speak openly about our experiences, share examples of our challenges and successes, and work together to improve services/outcomes is a legacy of love and an honouring of my daughter Marni’s life.”
>
> **– Margo Dent, Family Partner, BC Mental Health and Substance Use Services & PHSA**

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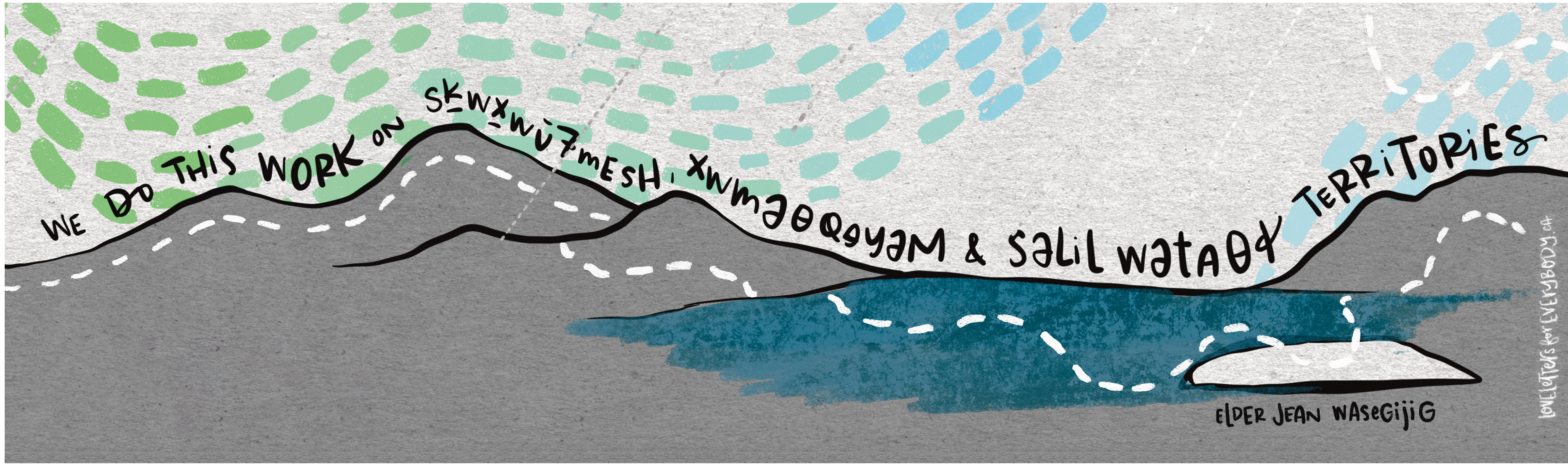
Engagement with Indigenous Peoples (First Nations, Métis and Inuit), organizations, and communities

PHSA acknowledges the Declaration on the Rights of Indigenous Peoples Act (DRIPA) as foundational for all Indigenous engagement. In all Indigenous engagement, PHSA aims to uphold First Nations title and rights and foster Indigenous-specific anti-racism and cultural humility, as PHSA works towards healthcare planning, delivery, and implementation that is equitable, inclusive and culturally safe.

This framework while not Indigenous-specific, offers essential considerations to support thoughtful reflection and preparation for engagement with Indigenous people and communities.

- Before setting out to engage with Indigenous patients, families and communities, read through the foundational documents, provincial commitments and other available resources to ground your next steps in the knowledge and perspectives of Indigenous people that have already been shared
- Connect with Indigenous Health leadership before any engagement to confirm their awareness and seek guidance
- A co-design approach should guide all engagement with Indigenous patients, families, and communities, inviting their input and collaboration from the beginning.



Graphic recording of opening by Elder Jean at the PHSA Patient Experience Symposium, 2024

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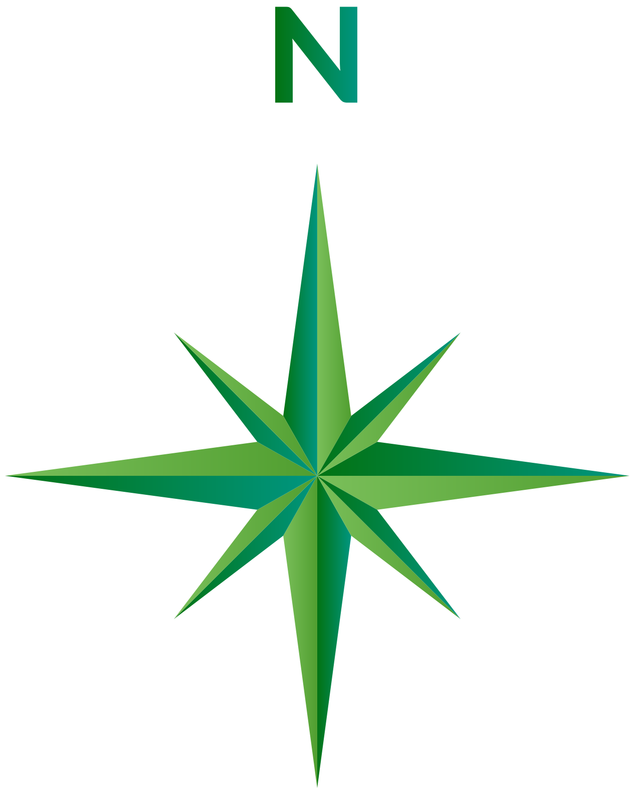
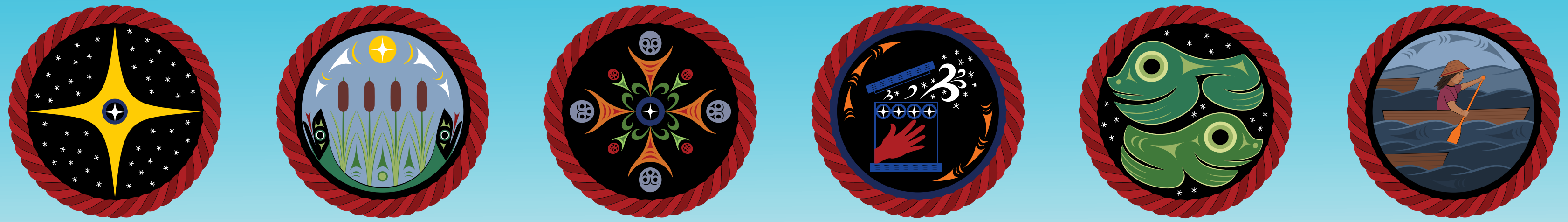
PHSA Vision, Values, Teachings and North Star priorities

The principles of patient and family-centred care are deeply embedded in PHSA's purpose, vision, values, and Teachings. Meaningful engagement with patients and families is essential for building trust and strong partnerships.

PHSA's engagement approach is grounded in the Coast Salish Teachings generously gifted to PHSA by Knowledge Keeper Sulksun, Shane Pointe. These Teachings invite us to reflect deeply on how we carry them into our personal and professional lives. They emphasize the importance of openness to learning, collective wellbeing, and a commitment to community. To truly make them our own, we must take the time to sit with these Teachings, allowing their meaning to take root within us. As you plan and practice meaningful engagement, we encourage you to consider how these Teachings can guide your actions, foster authentic partnerships, and challenge systemic Indigenous-specific racism and discrimination. In doing so, they become not just Teachings we honour and respect but ways of being that shape the care we provide.

Further, by aligning with the PHSA North Star priorities, we commit to ensuring that the practice of engagement is anti-racist and actively supports the creation of equitable and culturally safe health services. Through engagement, we serve with purpose and are accountable to the people and communities we are partnering with as we work to collaboratively transform the health system and support their wellbeing.





Thee eat
"Truth"

Eyhh slaxin
"Good medicine"

Nuts a maht
"We are one"

Whax hooks in shqwalowin
"Open your hearts and your minds"

Kwum kwum stun shqwalowin
"Make up your mind to be strong"

Tee ma thit
"Do your best"

Art by Nash'mene'ta'naht, Atheana Picha, Salish artist from the Kwantlen First Nation

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Benefits of patient and family engagement[i]

There are many benefits to patient and family engagement for the people involved, the projects they partner on, and the organizations and health systems they connect through. These benefits are often interconnected and work together to improve the overall quality and safety of the health care system.

Value to the patient / family / community member

- Encourages meaningful engagement that supports patients' well-being and fosters a sense of value through being heard
- Deepens patients' understanding of the health care system and promotes self-advocacy for themselves and their families
- Supports active participation in care, leading to better outcomes and increased accountability from the health care system
- Helps build patients' trust in the health care system
- Can contribute to healing and recovery
- May offer opportunity to find meaning in a difficult journey
- Reduces discrimination and misunderstandings
- Helps to improve overall patient experience

Value to the program / service / systems

- Targets resources where they are most effective and valued by the community, improving the patient experience
- Brings truths and diverse perspectives into planning and strengthens community partnerships
- Demonstrates accountability and transparency, fostering trust and promoting a culture of patient- and family-centred care
- Provides a direct connection to the people we serve, enhancing community relations
- Supports achievement or organizational objectives such as cost benefit and improved health outcomes
- Promotes equity-driven approaches when engaging communities that experience systemic barriers
- Contributes to continuous quality improvement and patient safety by identifying gaps and suggesting innovative solutions

Value to service providers / staff

- Encourages a patient- and family-centred approach to care and improves relationships with patients
- Raises awareness of barriers patients face and identifies system issues to address
- Enables an opportunity for self-reflective practice
- Increases appreciation for the role of caregivers
- Enhances joy at work and connects to purpose
- Identifies system and point-of-care issues that need to be addressed
- Reduces discrimination, assumptions and misunderstandings
- Increases number of care recipients engaging in health care plans

[i] Adapted from BC Cancer Patient & Family Engagement and Experience Framework, 2017

> “Patients and families are the most under utilized resources. Involve us as your care team.”
>
> **– Louise Yeoh, Patient and Family Partner, BCMHSUS, PHSA & BC Cancer**

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Key concepts and how they all relate

Patient and family engagement:

The participation of patients and families in health and health care system initiatives at the program, organization or system level.

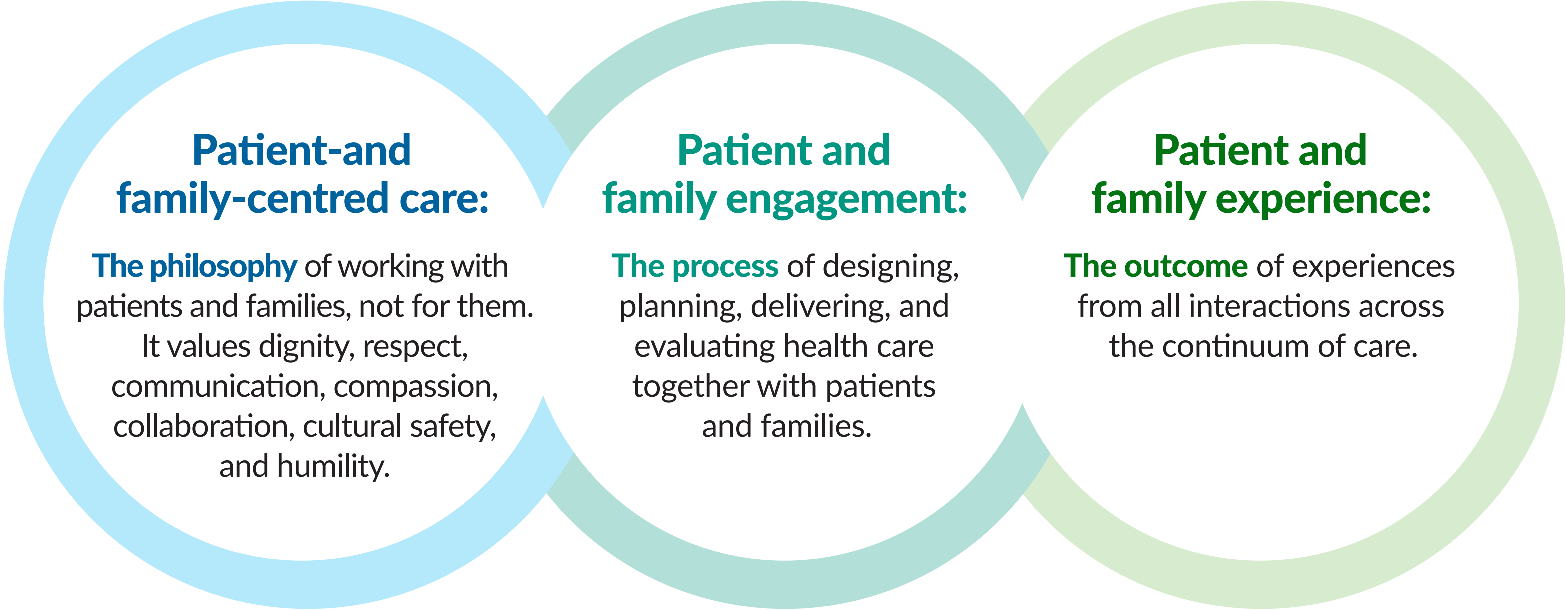
Patient and family experience:

We define the patient experience as the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care.[5]

Patient- and family-centred care:

"An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings."[6]

Patient-and family-centred care is aligned with Accreditation Canada's concept of People-Centred Care: An approach to care that consciously adopts individuals', caregivers' (formal and informal), and communities' perspectives as participants in, and beneficiaries of, trusted health systems that are organized around the comprehensive needs of people.[7]



Patient-and family-centred care:

The philosophy of working with patients and families, not for them. It values dignity, respect, communication, compassion, collaboration, cultural safety, and humility.

Patient and family engagement:

The process of designing, planning, delivering, and evaluating health care together with patients and families.

Patient and family experience:

The outcome of experiences from all interactions across the continuum of care.

ii Adapted from BC Mental Health and Substance Use Services Patient and Family Engagement Framework, n.d.

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Key terms

Patient:

An individual with lived and/or living experience who has, does or might receive health care services. May also be referred to as "client", "service user", "resident", "care seeker", or "community member".

Family:

Refers to individuals who are related by biology, kinship, legal ties, or deep personal connection. This includes caregivers, essential care partners, and chosen family — those who provide physical, emotional, or psychological support to the patient. Family is defined by the patient and can encompass anyone they designate as significant in their care journey, regardless of formal familial relationship.

Patient and family partners:

Any patient or family member who participates in engagement opportunities to bring a patient/family perspective to health system and services initiatives. They represent the voice of the people we serve.

Health care partners:

The individual staff members who seek to include patient and family partner perspectives in projects. We use the term partner to highlight the focus on collaboration, rather than a provider/recipient of care relationship.

BC Children's and Women's Hospital, Sibling Support Centre + Services — Space Race Event, 2024

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Guiding principles for engagement[iii]

At PHSA, we firmly believe that patients and their families should be actively involved in every stage of their health care journey and have opportunities to contribute to the design and functioning of the health care system. For patient and family engagement to be **authentic** and **meaningful**, staff and partners should embrace the following guiding principles:

Partnership:

Our approach to partnering with patients and families is anchored in person-centred care. We support patients and families to actively work alongside health care professionals, ensuring equal voices and shared responsibility for a mutually beneficial partnership rooted in trust, respect, and collaboration.

Responsiveness:

We commit to acknowledging and responding to the perspectives of patients and families. This includes being clear on the purpose of engagement upfront. It also means embracing open and honest communication throughout the entire process.

Support:

We provide adequate support as well as a flexible process for patients and families to contribute. This includes shared learning, training, mentorship, expense reimbursement, offering multiple ways to participate, and honoraria depending on the type of engagement.

Mutual Respect:

We co-create culturally safe, accessible, relevant, and responsive environments. All viewpoints are considered and respected. We all share a vested interest in improving health care.

Equity:

We embrace diversity and strive to create equitable opportunities and conditions for engagement, fostering an environment where partners feel safe, heard, and valued. We respect unique beliefs, values, lived experiences, geographical locations, ethnic and cultural differences. At PHSA, our dedication to equity, diversity, and inclusion drives us to dismantle systemic barriers and guarantee that every individual, regardless of their background, receives fair and just treatment. We hold the belief that every individual has the right to be seen, heard, treated with respect, and provided with appropriate care.

[iii] Adapted from BC Renal Patient & Family Engagement Framework, 2019.

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Indigenous-Specific Anti-Racism & Cultural Safety and Humility:

We recognize that cultural safety and humility are essential to eradicating Indigenous-specific racism and discrimination and ensuring equitable access to high-quality care. We strive to embed Indigenous ways of knowing and being in health care decision-making through Indigenous-specific anti-racism, with a strong focus on cultural safety. Prioritizing Indigenous-specific anti-racism addresses the ongoing impacts of colonization in health care.

Trauma and Violence-Informed:

We understand past and current trauma and violence impacts peoples' lives and behaviours. We take a ***strengths-based and capacity building*** approach to supporting the people we wish to engage, and foster opportunities for choice, collaboration, and empowerment. We strive to create physically, culturally, psychologically, and emotionally safe environments for engagement. We recognize that patient and family partners come from varied backgrounds and experiences and that sharing their lived experience to inform system improvement is a generous offering. We adopt trauma and violence-informed practices to mitigate the harms that can surface during engagement.

Anti-Oppressive:

We strive to dismantle systems of oppression, including racism and Indigenous-specific racism, cisheteronormativity, homophobia, transphobia, ableism, patriarchy, classism, and more, by redistributing power in decision-making and centring the perspectives of those who are historically and presently most marginalized by these systems.

Anti-Racist:

We are committed to identifying, challenging, and dismantling all forms of racism within the healthcare system. By addressing power imbalances, confronting biases, and transforming inequitable structures, we centre the perspectives of those most impacted by racism.

Graphic recording of patient and family partner panel presentation at PHSA patient experience symposium, 2024

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Domains of engagement[8]

Patient and family engagement refers to the active participation of patients and families in decision making and initiatives to improve health and health care.

It can occur across five domains:

Point of Care/Individual:

Patients and families partnering with providers and care teams to share decision making about an individual's health care journey and care plans.

Programs and Services:

Patients and families partnering with health care staff and leaders to develop or improve programs and services.

Organizational:

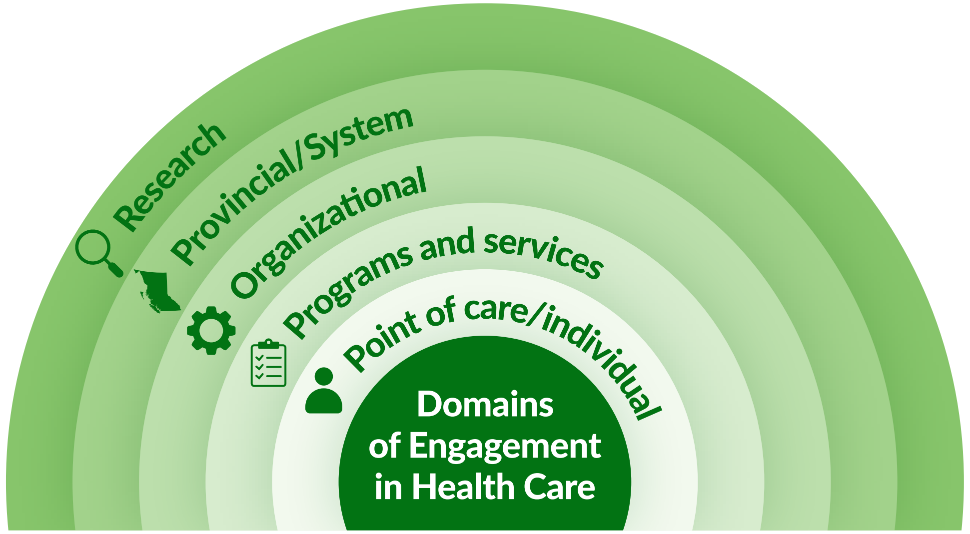
Patients and families partnering with health care staff and leaders to improve health care policies, strategies and governance.

Provincial/System:

Patients and families partnering with networks and health systems to inform province-wide planning, decision making and standards of care.

Research:

Patients and families partnering with researchers to inform research goals, design and conduct studies, analyze data and share findings.



A note on engagement in research:

Incorporating patient and family partners into research efforts offers valuable opportunities to enhance relevance, improve outcomes, and ensure a more patient-centred approach. However, successful partnerships in this field come with unique nuances and specific requirements. For additional guidance and resources, check with your program's Research Office, the CIHR website or BC Support Unit.

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Spectrum of engagement

IMPACT ON DECISION

	INFORM	GATHER**	INVOLVE	COLLABORATE	LEAD**
Our role/ commitment	**Keeping you informed**	**Listening intently**	**Embedding your insights and perspectives**	**Collaborating with you and committing to shared decision making**	**Looking to you for leadership and guidance**
Purpose	To **share** relevant, timely information	To **gather** patient and family perspectives and feedback	To **engage in dialogue** with patients & families to understand and consider their insights and perspectives	To **partner** with patients and families toward a common goal	To recognize and uphold **patients and families as leaders**, with final decision-making authority
Example techniques Keep in mind that many techniques can be applied across multiple levels of the IAP2 spectrum.	• Fact sheets • Websites • Social media blasts • Emails • Newsletter • Open houses	• 1:1 interviews • Focus groups • Surveys • Public meetings • Storytelling	• Workshops • Working groups • World cafés • Document reviews • Developing survey questions • Interview hiring panel	• Advisory committees • Steering committees • Consensus-building activities • Patient journey mapping • Presentations	• Co-design • Delegated decisions • Leading education for staff or leaders • Board member

This spectrum of engagement with applied scenarios is adapted from the International Association for Public Participation's IAP2 Spectrum of Public Participation. It includes adaptations noted in: Healthcare Excellence Canada Patient Engagement Framework, Health Quality BC's Guide to Authentic Patient Engagement, and the BCMHSUS Engagement Framework.

** Following the lead of the Indigenous Engagement and Cultural Safety Guidebook, we have used the terms Gather and Lead rather than Consult and Empower as referenced in the original IAP2 spectrum, as the consultation terminology may have unintended expectations grounded in the common law duty to consult, and the empower language may undermine Indigenous rights to self-determination.

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Spectrum of engagement

IMPACT ON DECISION

What this looks like for patients & families in each domain of engagement:

	INFORM	GATHER**	INVOLVE	COLLABORATE	LEAD**
Individual (point of care)	Has access to their health information in an uncomplicated, easy, and timely manner	Understands all their care plan options and shares their needs	Helps to inform their care plan by asking questions and sharing their goals and preferences	Co-creates their care plans, health goals; collaborates in ongoing self-care and self-management	Supported in deciding what is in/out of their care plan
Programs and Services	Has the information they need to understand, access and navigate the program	Invited to share experiences or provide feedback on a draft or concept	Invited into dialogue to explore and define a problem/opportunity; shares experiences, preferences, and needs to be considered in program design or project plans	Shared decision making. Advice and recommendations are incorporated throughout the project	Makes some or all project-related decisions
Organization (Policy Governance)	Access to policies, strategic plans and organizational goals	Invited to share feedback on draft policy documents, strategies or enterprise models	Interests, preferences, needs and concerns are sought out and used to influence policies, strategies and models	Partners in developing the policy, strategy or model. Sits on board or steering committees	Makes some or all the decisions about what is included in the policy, strategy or model
Provincial/ System	Receives key information about changes or decisions through public websites, social media, press releases, etc.	Public, community and patient input is sought to inform situation analysis, business cases and proposed standards of care	Invited to be a more active part of the process. Working group member or public advisory committee member	Close work with decision-makers, included as task force member or steering committee member with full voting privileges	Makes some or all decisions and has significant control over the process
Research (knowledge generation & translation)	Provided with information to understand broad research goals	Provides feedback on the research plans	Shares information with the researcher to help inform the research questions, methods and/or results	Partners with researchers throughout the research process: developing research questions, study design, analysis, knowledge translation, etc.	Receives advice and assistance from research team to conduct their own research and implement findings

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Engaging with Indigenous Peoples (First Nations, Métis and Inuit), organizations, and communities

There is clear documentation that Indigenous-specific racism and discrimination continues to exist in BC health care services, causing harm to Indigenous patients and families. Together, we must identify and eradicate Indigenous-specific racism to ensure that Indigenous Peoples feel safe seeking care, receive the care they need when they need it, and that PHSA's Indigenous staff and health care workers can practice in a safe and welcoming workplace.

Self-reflective practice is essential to identifying and addressing Indigenous-specific stereotypes, biases, systemic discrimination, and unsafe or inaccessible services. Critical self-reflection creates opportunities for culturally safe and respectful engagement with Indigenous patients, families, and communities. This process involves examining one's own values, assumptions, beliefs, and privileges to understand how they shape interactions and relationships with patients. Through self-reflection, staff can foster open communication, support shared decision-making, and build trust, contributing to more equitable and meaningful patient engagement.

Before engaging with Indigenous patients, families, and communities, consider the following:

- What have Indigenous people already told us?
- Have you reviewed the experiences and evidence already published? *(See legislative obligations and provincial commitments on next page).*
- Why and if their experiences need to be shared?
- What actions have you taken to further your cultural safety and anti-racism learning journey? *(Are you the right person/team to lead the engagement?)*
- Does this support trust building and safe access to care?
- How will you establish trust with those you engage?
- Are you committed to reciprocal accountability *(i.e. validation, reporting back and taking timely and meaningful action in response to engagement)* and the principles of OCAP®?
- Are you committed to an end-to-end co-design approach for your engagement work?

Training & resources

PHSA offers training for staff to advance cultural safety, including:

- San'yas Anti-Racism Indigenous Cultural Safety Training
- Anti-Indigenous Racism Response Training (ARRT)
- Self-Directed Learning Resources

Before engaging with Indigenous patients, families, and communities, you are strongly encouraged to consult your program's Indigenous Health team or PHSA Indigenous Health leadership for guidance and support.

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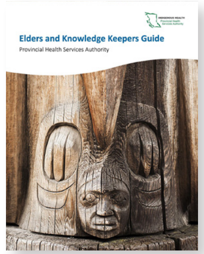
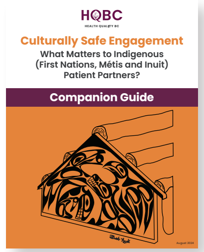
Guides for Culturally Safe Indigenous Engagement


Elders and Knowledge Keepers Guide
Provincial Health Services Authority

- PHSA Elders and Knowledge Keepers Guide

  This guide identifies wise practices for engaging with, and extending invitations to Elders for PHSA programs, services, and gatherings. It outlines guidelines for communicating effectively with, and supporting respectful relationships between Elders or Knowledge Keepers and PHSA.

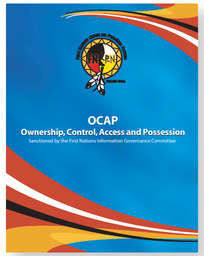

HQBC
Culturally Safe Engagement
What Matters to Indigenous (First Nations, Métis and Inuit) Patient Partners?
Companion Guide

- Culturally Safe Engagement: What Matters to Indigenous (First Nations, Métis and Inuit) Patient Partners? Companion Guide

  This guide outlines key principles and recommended actions to help create conditions for culturally safe patient, family and public engagement.

- Indigenous Engagement and Cultural Safety Guidebook: A Resource for Primary Care Networks — Appendix B: Modified International Association of Public Participation (IAP2)

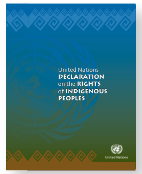
  Use this modified spectrum when meeting with Indigenous partners to determine their level of involvement and what partnership looks like for them.


OCAP
Ownership, Control, Access and Possession

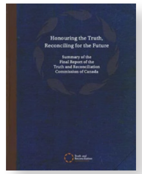
- The First Nations principles of OCAP® (ownership, control, access, and possession) assert that First Nations have control over data collection processes, and that they own and control how this information can be used.

Legislative Obligations and Provincial Commitments

The following reports and commitments guide distinctions-based relationships with Indigenous Peoples in creating culturally safe, anti-racist health care services:



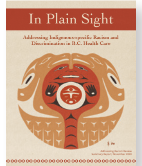
- United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (2007)



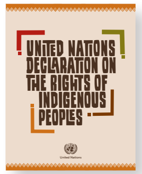
- The Truth and Reconciliation Commission Final Report (2015)


RECLAIMING POWER AND PLACE

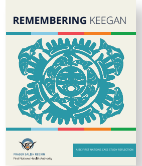
- Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls (2019)


In Plain Sight

- In Plain Sight: Addressing Indigenous-specific Racism and Discrimination in B.C. Health Care (2020)


UNITED NATIONS DECLARATION ON THE RIGHTS OF INDIGENOUS PEOPLES

- United Nations Declaration on the Rights of Indigenous Peoples Act (DRIPA) (2019) & DRIPA Action Plan (2022)


REMEMBERING KEEGAN

- Remembering Keegan: a BC First Nations Case Study Reflection (2022)

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PART B: The Model

The steps of engagement

Meaningful engagement involves careful planning, regular check-ins, follow through, and appropriate closure. These steps will support you in planning a successful engagement.

- **Step 1: Initiate** – Engagement readiness and team preparation
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- **Step 6: Conclude** – Close the loop and evaluate

The *Patient & Family Engagement Plan Template* can be used to document your ideas and progress as you work through the steps. PHSA staff can access the helpful resources and tools on POD. If you do not have access to POD, you may request these tools by emailing pfp@phsa.ca.

> When health care partners follow an engagement guide, all the details will be clear and the engagement will be smooth and effective for everyone!
>
> This guide is their guide to success.
>
> **– Sandy Ketler, Patient Partner, PHSA**

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Step 1: Initiate Engagement readiness and team preparation

Bring your team together and work on developing a clear understanding of your goals, objectives, and overall readiness for engaging patients and families. Dedicate some time to discuss these key areas with your team.

Clearly understand and define your own initiative.

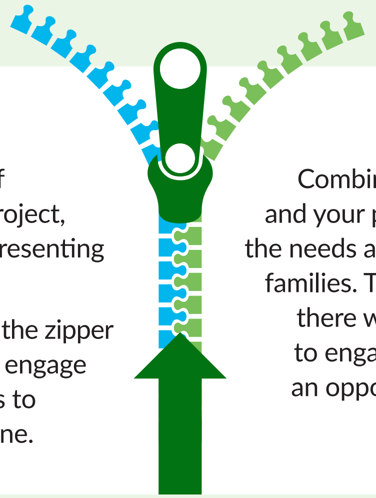
- What is the problem to be solved, opportunity to be explored, or decision to be made?
- How would you describe this project or piece of work to others?
- What are you hoping to achieve?
- Does your initiative directly impact patients?
- Does your initiative impact providers, communities or equity-deserving groups?

Identify engagement opportunities.

- Determine the decision points or milestones in your initiative where the work can be influenced by patient and family participation.

! Invest the time to thoughtfully consider your purpose for engagement and ensure that the project will benefit those you are engaging with.

The Zipper Analogy



Project

Consider one side of the zipper as your project, with each notch representing a project milestone.

On the other side of the zipper are opportunities to engage patients and families to achieve that milestone.

Engagement

Combining an engagement plan and your project plan better meets the needs and wants of patients and families. There may be times when there will not be an opportunity to engage, but there is generally an opportunity to communicate.

Partner on the plan when you can!

Whenever possible, involve patients and their families early in the planning process — even from this "Step 1" starting line. You might want to reach out to a Patient and Family Advisory Council (PFAC) to get their input on the project and ideas for engagement, invite a patient and family partner you already know to join the planning team, or seek the advice of a community leader for your pre-engagement preparations.

Consider the zipper. There may be more than one opportunity for engagement in your project, and different methods to use each time.

> "Early-stage patient engagement is an opportunity to embrace the value that patients bring to health care design and evolution, and to have that value permeate across the health system in ways that improve the experience for patients and providers."
>
> **– Hilary Horlock, Patient Partner, BC Cancer**

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Step 1: Initiate Engagement readiness and team preparation

Obtain leadership support and identify staff member(s) to lead the engagement work.

- What resources will be available, including staff and budget?
  - Is there staff time and capacity to recruit, welcome, and support patient and family partners in the project?
  - Are there funds to offer honoraria and reimburse expenses?
  - Are you clear on the reimbursement process?
- Does your organizational culture support authentic patient engagement aligned with the guiding principles for engagement?
  - If not, consider sharing this Engagement Framework at an upcoming team meeting; host a conversation using the Health Care Partner Readiness Checklist.
- Is the project sponsor aware of and supportive of the engagement?

!

Leadership and organizational support are foundational to the success of your engagement.

Ready your team for engagement.

- Are you clear on your role and responsibilities to support patient and family partners? (e.g. Designated point of contact for the partner).
- Have you mapped out how patient and family partner input will be incorporated into decision making processes?
- Is there a shared understanding of what patients will influence, to what degree, and how this aligns with success measures? Consider the resources below to assess your team's readiness to engage patients and families.

Resource documents:

- Health care Partner Readiness Checklist (Patient Voices Network, HQBC)
- Engaging Patients and Families — Decision Flow Chart
- Engagement Plan Template

Step 1 output:

At the end of step one you should have:

✓ a plain language description of your project
✓ an idea of what pieces of your project are appropriate for engagement
✓ leadership support for engagement
✓ confirmed budget available for patient and family partner honoraria and expense reimbursement
✓ a staff member(s) identified to be a primary contact person for patients and family partners

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Step 2: Plan Engagement objectives, role clarity and activities

This planning phase brings all the key components together to develop a strong engagement plan. Focus on developing a clear understanding of your goals and objectives and describe how and when you will engage with patients and families. Define your team's roles in leading the engagement and the role of the patient and family partners participating. Take the time to communicate this clearly to align expectations and avoid tokenism.

Define engagement objective(s) for each milestone or piece of your initiative where patient and family partners can be meaningfully involved.

- What is the purpose of engaging patients and families in this part of the project?
- Can you fully explain the engagement objective(s) for each milestone?
- Are you clear on how patient and family partner input will be fed into the decision-making process?

Select the level and method of engagement.

- For each engagement objective, consider the spectrum of engagement and select the most appropriate level. Being up front about how much influence over the decision is possible will help to align expectations and avoid misunderstandings.
- For each engagement objective, select the method or activity that would best suit the need.

Clarify the role of the patient and family partners.

- What is the role for the patient and family partner(s)? Be specific in what you are hoping they can do.
- What kind of time commitment will the project require from them?

Step 2 output:

By the end of step two, you should be ready to complete the first half of your engagement plan

- ✓ Background information
- ✓ Engagement objectives
- ✓ Level of engagement
- ✓ Methods/activities
- ✓ Role of patient and family partners
- ✓ Project team and primary staff contact person

NOTE: You may find that Steps 2 and 3 happen at the same time, or require some back and forth. When feasible, it's great to have patient and family partners weigh in on the best engagement method. When you think through the variety of people and groups who may be impacted by the project, you may realize there are additional engagement objectives to add to your plan.

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Step 3: Partner

Finding and inviting patient and family partners

This phase focuses on finding appropriate patient and family partners for the project. For the engagement to be a success, it needs to be a good fit for everyone. Before inviting patients and families to get involved, be clear on who you are hoping to hear from, how you will invite them, and what supports you are able to offer.

Think through who you need to engage.

- Who will be impacted by your project? Consider mapping out all affected groups.
- Have you assessed your patient population to ensure those you are inviting match the population served?
- How many patient and family partners would you like to include?
  - Having several patient and family partners will increase the diversity of perspectives shared, contribute to safety and comfort and help to counter power dynamics in group settings. A minimum of two patient and family partners is recommended.
- Do you have specific eligibility criteria? What skills, experiences, background, interests, passions and visions for the future do you hope they will bring?
- Have you considered seeking representation from different regions and the unique challenges faced by rural, remote or urban populations?
- Are you including the voices of those affected by systems of oppression who bring diverse experiences?
- Are you considering different cultures, backgrounds, and perspectives?
- If you are considering engaging with Indigenous patients, families, or communities, what steps are you taking to ensure the engagement is culturally safe?

! Patient engagement is based on the belief that those who are affected by a decision or project have a right to be involved in the decision-making process.

BC Renal patient partners

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Step 3: Partner

Finding and inviting patient and family partners

Ensure accessibility, equity and safety

To ensure inclusivity, safety, and readiness, it's important to consider the **unique needs and experiences** of participants. While there are many factors to keep in mind, a few key considerations include:

- **Scheduling activities at accessible times** — not everyone can participate during standard business hours.
- **Being mindful of the setting and topic** — hospitals can be triggering environments, and some experiences may be difficult to recall. Participants may need varied supports to fully engage.
- **Providing materials or training** to help participants feel informed, prepared, and confident in their role.

PHSA is committed to advancing the principles of the Accessible BC Act and is dedicated to making meaningful progress by removing barriers, fostering equitable access, and creating environments where everyone feels valued and included.

! Equity-deserving communities will have diverse priorities, accessibility needs and require culturally specific approaches to engagement. Connect with community leaders and organizations to identify additional engagement strategies that may be appropriate.

Accessibility considerations for inclusive engagement:

- **Physical:** Ensure venues are wheelchair accessible and have flexible seating for mobility devices.
- **Geographic:** Account for travel challenges or offer remote participation.
- **Cognitive:** Provide materials in plain language, broken into manageable sections, and offer extra support if needed.
- **Sensory:** Manage lighting, noise, and quiet spaces; provide materials in large print or Braille.
- **Digital:** Ensure online platforms are screen reader-friendly and inclusive (e.g., captions, accessible platforms), offer training or a tech support person.
- **Language:** Offer interpretation or translation services, including sign language.
- **Mental Health:** Create a supportive, non-judgmental space for those with mental health challenges. Peer supports, counsellors, or Elders on site may be appropriate.
- **Time:** Offer multiple time options or asynchronous participation.
- **Financial:** Provide honoraria, transportation support, and food during meetings to reduce financial barriers. Consider child minding options, particularly if engaging with parents and guardians.
- **Cultural/Social:** Offer culturally appropriate materials and work with trusted community organizations to engage diverse groups.

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Step 3: Partner

Finding and inviting patient and family partners

Draft an "Engagement Invitation" to outline your ask.

- Is the invitation language clear? Avoid use of acronyms and jargon.
- Have you outlined:
  - Purpose of the initiative
  - Level of Engagement
  - Eligibility and type of experience you are looking for from a partner
  - Logistics (dates, vacancies, location, commitment)
  - Honoraria and expenses
  - How to express interest and next steps
  - Where they can direct questions

Invite participation.

- How will you find patient and family partners to invite?
- Have you connected with your program's Patient Engagement / Experience department?
- Is there a clinic, unit, family lounge or high-traffic lobby where posters could be displayed?
- Have you connected with local organizations in the community?
- Have you considered Patient Voices Network (a provincial network of patient and family partners, administered by Health Quality BC)?
- Do you have any existing relationships with patient and family partners? Inviting people from one project to join another can help keep them engaged, build on past learnings, and get folks involved quickly. However, be careful not to rely too much on the same group of patient and family partners. Doing so may limit the diversity of ideas and perspectives considered and contribute to patient partner burnout.

Complete a selection process.

- What is your selection process?
- Will you conduct interviews?
- How many patient and family partners will you include? Consider multiple patient and family partners to increase diversity.

Resource documents:

- PHSA Patient & Family Partner Engagement Invitation
- HQBC Selection Process Sample Questions
- HQBC Selecting a Patient Partner
- PHSA Provincial Language Services

Step 3 output:

At the end of step three, you can fill out more of your engagement plan:

✓ Eligibility criteria
✓ Strategy for inviting participation
✓ Resources and supports available

You should also have a clearly articulated engagement invitation that is inclusive and accessible, making a conscious effort to elevate all voices. The invitation is clear so patients and families can make informed decisions about whether they would like to participate.

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Recognizing power and privilege in the health care system

Patient and family engagement is essential for addressing patients' needs and fostering person- and family-centred care. However, systemic oppression — like racism, poverty, sexism, and ableism — often excludes equity deserving communities from these conversations because of existing colonial frameworks embedded in policies, procedures, training, recruitment, and other practices.[9]

Current engagement processes can still unintentionally leave certain groups and entire communities out. This can lead to decisions that only reflect the views of the dominant population, perpetuating health inequities and hindering meaningful change in health care.

At PHSA, we are committed to anti-racist and anti-oppressive practices in all that we do including patient and family engagement. We encourage you to reflect on our North Star priorities and Coast Salish Teachings as a beginning point to think about how you can incorporate equitable practices into engagement.

Patient and family partner panel presentation,
PHSA Patient Experience Symposium, 2024

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Here are a few considerations as you plan your recruitment strategy:

Avoid tokenism.

- Remember that one person cannot represent the experience of an entire group.
- Focus on asking, listening, and responding to patient values, needs, and preferences, not just ‘ticking the box’ that patients have been included.
- Reflect on whose perspectives are missing.

Reflect inward before reaching out.

- Avoid making assumptions about a population’s experiences, preferences, or needs.
- Be aware of your own positionality and privilege. Recognize that your views and realities may not be shared by others.
- Invest in your own learning journey before engaging with people who have been historically excluded from engaging with the health care system.

One size does not fit all. Make it easy for the hardly reached.

- Don’t limit your engagement to people who are easy to reach (individuals who are already connected to and comfortable navigating the system).
- Design your recruitment and engagement activities so that they are inclusive, accessible, and appropriate for those who may feel unwelcome or unsafe when interacting with the health care system. How can you reduce the (financial, emotional, logistical) cost of participating? Do they need to come to your table? Maybe you can go to theirs.

Be mindful of power dynamics, which can sometimes be invisible to those who hold power.

- Power dynamics, including the imbalance between providers and patient or family partners, can affect what participants share. Staff presence may also discourage open expression. To foster a safer, more inclusive environment, it’s important to be mindful of these dynamics and consider using a third-party facilitator, peer facilitator, or co-facilitated session.
- Take a trauma and violence-informed approach to planning. You can build trust by prioritizing adequate time to build relationships and rapport, limit the presence or contributions of professionals, and create comfortable environments that reflect their cultural contexts.[10]
- Be prepared to acknowledge and address situations where conflict or trauma surfaces.
- Acknowledge and reflect on privilege. Recognize how privilege — whether based on professional status, education, cultural background, or other factors — can shape perspectives, influence interactions, and impact the dynamics of engagement.

Helpful resources:

- Health Excellence Canada: Equity, Diversity and Inclusion Virtual Learning Exchange
- Patient engagement in health care planning and evaluation: A call for social justice
- Heard and Valued: Engaging Marginalized Populations (Learning Hub Course)
- Trauma Informed Leadership Series (Learning Hub Courses)
- Peer Engagement Principles and Best Practices

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Step 4: Connect

Welcome and support patient and family partners

This phase focuses on ensuring patient and family partners are welcomed and feel prepared and supported to engage. It's important to make time for connection to start your partnership off in a good way. Engagement is relational!

Plan how to welcome and orient your patient and family partners to the project.

- Book an introductory meeting to get to know each other. This is an essential step for establishing and building relationships.
- Ask how they would like to be supported throughout their involvement and what will help them feel comfortable and prepared.
- Offer proper cultural supports as needed, such as access to Elders, Knowledge Keepers, traditional healing practices.
- Consider accessibility needs, including a review of technology, interpretation services, or alternative formats for materials as needed.
- Offer a high-level overview of PHSA and your specific program; introduce the Coast Salish Teachings.
- Discuss the project and background, provide a glossary of common terms (avoid jargon and acronyms!), go over meeting logistics, clarify their role, and outline how their input will be used.
- Go over the team's roles and responsibilities, including who will be their main contact.
- Share names of other health care staff involved
    - Be mindful of potential conflicts of interest, discomfort, or challenges to a therapeutic relationship that may arise if a patient and family partner unexpectedly finds themselves in a project meeting with a past or current care provider.
- Discuss how and when closing the loop will occur and be most meaningful for all involved (See Step 6).
- Provide opportunities to ask questions.

Patient partners at the BC Mental Health and Substance Use UNITE event, 2023

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Step 4: Connect

Welcome and support patient and family partners

Clarify recognition preferences, how/if honoraria are desired, and if expenses will be reimbursed.

- Look into your program's honorarium and expense reimbursement processes.
- Share this information with patient and family partners, and explore how they would like to be recognized for their contributions.

Discuss privacy and confidentiality needs.

- Review any confidentiality forms or partner agreements required by the project or organization.
    - Explain both health care partner and patient and family partner responsibilities regarding privacy and confidentiality.
- Ask patient and family partners about their preferences for anonymity. They may be comfortable sharing their names and stories with some people or groups but not others. Inquire whether they'd like their name included in meeting minutes, public documents, or how they'd like to be addressed in different settings. Be mindful of any stigma associated with their health conditions.

Step 4 output:

At the end of step four you should have:

- ✓ Welcome Meeting Agenda
- ✓ Plan and process to issue and track honoraria and expense reimbursement
- ✓ Plan to check-in with partners about their engagement experience at regular intervals, particularly for long-term projects

Review the check-in and ongoing support plan.

- Ask about communication preferences (i.e.: phone vs email, group vs 1:1 conversation, etc.)
- Establish a check-in plan for longer term engagements to assess everyone's satisfaction, experiences, and expectations as the project progresses. Consider pre-booking check-in meetings, or setting a calendar alarm to prompt informal check-ins.
- Ask if there are any accessibility needs and other supports you can provide.
- If this group will be working together often, consider co-creating a 'group comfort plan' or 'intentions and agreements' document to guide your work and communication together.

Resource documents:

- Engagement Welcome Meeting Template
- PHSA PFP Privacy and Confidentiality Form
- PHSA PFP Agreement Form
- HQBC Check-in Checklist
- PHSA Honorarium Policy
- Beyond Grateful: a Playbook on Recognition, Expenses and Honorariums for Patient and Family Engagement at PHSA
- POD Guidance: Payments to Elders and Knowledge Keepers & Honorariums

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Step 5: Involve

Facilitate the participation of patient and family partners

This phase focuses on facilitating meaningful engagement, analyzing, and reporting your findings, and applying the information to move the project forward.

Engage with patient and family partners.

At this stage of the engagement, you are ready to go about "engaging" with patient and family partners in whatever ways you had outlined in your engagement plan. Some of the most common patient and family engagement strategies are noted below.

- Survey
- Focus group
- Journey mapping
- 1:1 Interviews
- Advisory committee
- Document review
- Patient speaker
- Co-Presenter

As you develop materials for engagement activities (slide decks, survey or focus group questions, etc.) keep the guiding principles for engagement in mind. Ensure that phrasing and visuals are culturally safe, trauma and violence-informed, plain-language, accessible, etc. Your program's Engagement Team may be able to offer guidance.

> "If someone wants to share, listen. If it's Elders, sometimes there is a long, uncomfortable pause in storytelling, because there is deep thinking going on. It could be about trauma or a language barrier, or how to tell the story in a way the person will understand it."
>
> **– Ḵwa'x̱i'latł (Marsha Dufresne),**
> **Patient and Family Partner, PHSA**

Listen to and integrate feedback.

- **Facilitation Tips:** In group settings, make sure to give patient and family partners a chance to speak and be heard. Listen carefully and be patient with pauses as people take time to find the right words. Offer different ways for people to share their thoughts, like written feedback or one-on-one conversations, since not everyone is comfortable with public speaking.
- **Consider a parking lot:** At the beginning of a project, it's important to clearly define what topics are within scope and what are out of scope. Reminders may be necessary as the project moves forward. If patient and family partners suggest ideas that fall outside the project scope or are beyond the staff's authority to act on, using a 'parking lot' to capture these ideas in the moment can be helpful. Make sure there's a clear process to revisit these ideas — either politely decline them with a clear explanation or redirect them to the right people for follow-up.
- **Collect and Organize Input:** Have a clear process for collecting and organizing the feedback you receive. For example, take notes in focus groups and share them back with patient and family partners to confirm you've captured their thoughts correctly.
- **Integrate and Act on Input:** As you collaborate, regularly reflect on the perspectives, advice, and recommendations shared by patient and family partners, and take action based on their input.
- **Revisit your engagement objectives often.** If the engagement method/approach is not working, try something new.

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Step 5: Involve

Facilitate the participation of patient and family partners

Issue honoraria and reimburse expenses.

- Ensure expense reimbursement and honoraria are issued in a timely manner.

Check in regularly.

- Follow up after the initial meeting about their experience.
- Agree how you want to check in with each other going forward.
- Pause and regroup as needed.

Resource documents:

- HQBC Check-in Checklist
- Patient & Family Partner Engagement: What we heard report template

It's important to connect regularly throughout the engagement. Involving and supporting patient and family partners is an ongoing process.

Step 5 output:

At the end of step five you should have:

- ✓ Completed engagement activities, and records/notes on what was heard and learned
- ✓ Evidence of the project/decision being influenced by the patient and family partner involvement
- ✓ Issued honoraria and reimbursed expenses

Slocan Site Redevelopment Project engagement event. Virtual reality head set to view the latest room designs for the new BC Children's Hospital centre for health complexity, 2025

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Step 6: Conclude

Close the loop and evaluate

This step ensures you have wrapped up your engagement in a good way. Although some of the activities noted below occur at the end of an engagement, consideration and planning for them should start early on — and include the perspectives and priorities the patient and family partners involved.

Debrief and evaluate your process often.

- Follow up with patient and family partners after the initial meeting about their experience.
- Consider building in quick evaluation activities at the end of every meeting (ex: Plus-Delta (Δ/+) Technique).
- Check in with patient and family partners often to see what could be done to improve their experience.
- Talk about any challenges and develop a plan to address them.
- At the end of the engagement, incorporate a practice of self-reflection and improvement, such as an evaluation survey. (i.e. if it was a workshop, or series of engagements, send the survey at the end of the series).
- Report findings to leadership to demonstrate impact and gather support for future initiatives.

! Closing the loop adds value to the time and effort invested and can present an opportunity to further develop the relationships you've built through your project.

Close the loop.

Closing the loop might look different for each project, but it always means officially recognizing when the engagement is done and telling patients and families how their ideas were used in the project. This is important for building trust and keeping people engaged.

Key components of closing the loop include:

- **Appreciation —** Express gratitude to the patient and family partners for their participation at the end of their engagement.
- **Engagement outcome/impact —** share how their input was used and the impact of their involvement.
- **Initiative outcome/impact —** Provide updates on the project's progress, share whether its goals were achieved and provide any provide any meaningful outcomes or results.
  - **Note:** Project outcomes may take months or even years to materialize. It is essential to plan ahead and ensure that the loop is closed with patient and family partners, regardless of any time delays, staff turnover, or changes in project direction.
- **Sustaining connections —** are there any future opportunities to stay involved?

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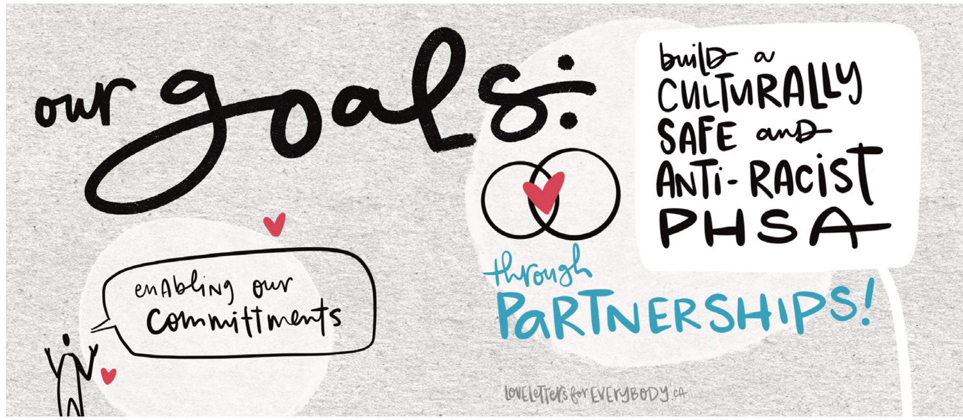
Close the loop and evaluate

Evaluation considerations:

- Consider an evaluation at the end of your engagement, in addition to check-ins along the way.
- Patient engagement evaluation should include the perspectives of both patient and family partners and health care partners. Ideally, the evaluation plan should be co-created, at the start of an engagement. It doesn't need to be fancy or formal!
- How will you define and measure success? What tools do you need? How will you collect data?
- Ask questions about the **process** (what you did and how you did it), and the **outcomes** (individual learnings and influence on the initiative)[iv]
  - **Process Considerations:** Readiness to participate; appropriateness of engagement tactic; role clarity; inclusive and representative participation; communication and information sharing; supports; ability to share views; time and timing; transparent decision-making process; satisfaction.
  - **Outcome Considerations:** knowledge; skills; capacity bridging; empathy and awareness; relationships; trust; team building; decision-making process; influence on project; person and family-centred care; quality of care; patient experience; staff experience; health outcomes; etc.

Resource documents:

- Closing the Loop — Tips & Checklist
- Closing the Loop — Summary Document
- Beyond Grateful: a Playbook on Recognition, Expenses and Honorariums for Patient & Family Engagement at PHSA
- PHSA Patient & Family Partner Engagement Survey Template
- McMaster Public and Patient Engagement Evaluation Tool (PPEET)
- Themes for evaluating the quality of initiatives to engage patients and family caregivers in decision-making in healthcare systems: a scoping review (Hamilton et al, 2021)
- Engage with Impact Toolkit (McMaster)



Graphic recording of goals and hopes at the PHSA Patient Experience Symposium, 2024

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iv Adapted from PVN Patient Engagement Learning Series Measuring the Success & Impact of Patient Engagement — Evaluation and Closing the Loop, 2022.

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Step 6: Conclude

Patient and family partner recognition

Why is recognition important?

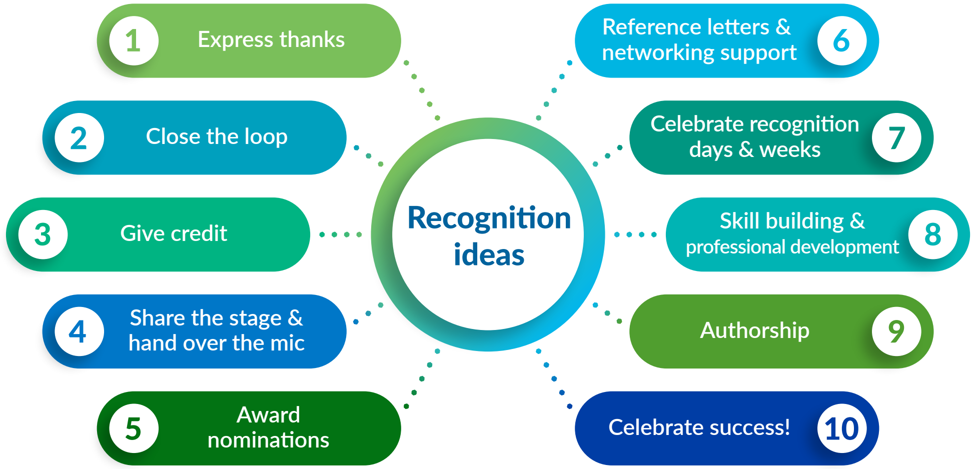
Patient and family partner recognition shows respect and appreciation for the valuable time, insights, and lived experiences they bring, which are often shared without the expectation of compensation. Meaningful recognition can build trust, strengthen relationships, and demonstrate that their contributions are valued and integral to shaping health care solutions.

Honorariums

In addition to demonstrating appreciation for their time and effort, offering honoraria can encourage ongoing involvement, reduce barriers to participation and is increasingly viewed as a best and expected practice in the patient and family engagement space.[11, 12]

Non-monetary recognition

Patient and family partners may have unique preferences for how they wish to be acknowledged; therefore, having an early conversation about their preferred form of recognition is recommended. For further guidance, refer to Beyond Grateful: a Playbook on Recognition, Expenses and Honorariums for Patient & Family Engagement at PHSA.



Recognition ideas

1 Express thanks
2 Close the loop
3 Give credit
4 Share the stage & hand over the mic
5 Award nominations
6 Reference letters & networking support
7 Celebrate recognition days & weeks
8 Skill building & professional development
9 Authorship
10 Celebrate success!

> An honorarium dampens the equity gap between someone on social assistance who provides valuable contributions and those paid a lot more for their attendance in meetings."
>
> **– Anja Lanz, Patient and Family Partner, PHSA**

Step 6 output:

At the end of step six you should have:

- ✓ Fulfilled your commitments to Close the Loop
- ✓ Recognized patient and family partners for their contributions
- ✓ Evaluated your engagement process and impact

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Closing reflections

The perspectives of patients and families are fundamental to quality and safety improvement work and invaluable to our goal of delivering inclusive, equitable, and compassionate care. As we strive to make our health care system more patient- and family-centred, we must consistently and meaningfully engage with the people we serve. Further, we need to do that in a way that respects their diversity, culture, and needs.

Grounded in the Coast Salish Teachings and guided by our North Star priorities, we are reminded of the importance of relationships, interconnectedness, and respect in all that we do. Effective engagement is relational and requires humility, emotional intelligence, honesty, and kindness. It demands time, careful planning, and follow-through — but it is always worthwhile. By involving patients, families, and communities early and often in the development of projects, programs, research, and system redesigns, we can improve health outcomes and create a more meaningful health care experience for everyone involved.

> “By engaging patients and their families at multiple levels of organizational performance, we can not only improve their own health care experiences but also gain valuable insights for actions necessary to improve the health of populations and to extract greater value from our limited health care resources.”
>
> **– Institute for Healthcare Improvement**

Patient partners at the BC Mental Health and Substance Use UNITE event, 2023

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Anti-racism:

The practice of actively identifying, challenging, preventing, eliminating and changing the values, structures, policies, programs, practices and behaviours that perpetuate racism. It is more than just being “not racist” and involves taking action to create conditions of greater inclusion, equality and justice.

Cultural humility:

A life-long process of self-reflection and self-critique. It is foundational to achieving a culturally safe environment. Cultural humility begins with an in-depth examination of our own assumptions, beliefs and privilege embedded in our own understanding and practice.

Cultural safety:

Creating a respectful and inclusive environment where diverse cultural identities, values, and experiences are recognized, valued, and supported. It involves addressing power imbalances, racism, and discrimination to ensure that all participants feel safe, heard, and respected throughout the engagement process.

Diversity:

Means the presence of differences in lived experiences and perspectives – including but not limited to race, ethnicity, colour, gender, gender identity, sexual orientation, ancestry, religion, marital status, family status, ability, age, class, socio-economics.

Engagement:

The initiative, event, or process where patient/client and family partners contribute their perspectives as people with lived experience to inform, design, and/or evaluate health care services.

Equity:

Refers to the process of achieving equality in the distribution of resources, opportunities and outcomes for historically and currently underrepresented and/or marginalized groups. Equity recognizes that each person and group has different circumstances and different needs. It requires the presence of processes that ensure support is provided based on individual and group needs to ensure fair and just treatment and outcomes.

Equity-Deserving Groups:

Are groups/communities that experience barriers to equal access, opportunities and resources due to disadvantage and discrimination and actively seek social justice and reparation.

Honorariums:

A payment generally made as a means of showing appreciation, recognizing knowledge, expertise and lived experience. Honorariums are often given to patient and family partners, and community members, who work with PHSA to share their knowledge, expertise and lived experiences to improve programs and services.

Inclusion:

The practice of fostering a sense of belonging.

Indigenous:

In Canada this is an overarching term that includes First Nations, Inuit and Métis peoples, either collectively or separately. It is the term many Indigenous people in Canada prefer and is part of the title in the United Nations Declaration on the Rights of Indigenous Peoples. One should ask Indigenous individuals which term they prefer to be acknowledged by.

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Indigenous cultural safety:

The process of making spaces, services and organizations safer and more equitable for Indigenous people by considering colonial history and seeking to eliminate structural Racism and Discrimination. Cultural safety is also an 'outcome' based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system; it is when Indigenous people feel safe when receiving Health Care.

Indigenous-specific racism:

The unique nature of stereotyping, bias, and prejudice about Indigenous peoples in Canada that is rooted in the history of settler colonialism. It is the ongoing race-based discrimination, negative stereotyping, and injustice experienced by Indigenous peoples that perpetuates power imbalances, systemic discrimination, and inequitable outcomes stemming from colonial policies and practices.

Lived experience:

For the purpose of this document, lived experience refers to the unique insights and knowledge gained through personal encounters with health conditions, treatments, or the health care system. It includes not only clinical aspects but also thoughts, emotions, challenges, coping mechanisms, and the overall journey. This experience, shaped by personal identities, histories, and realities, goes beyond professional or educational knowledge. Lived experience can be from the past or ongoing.

Reimbursement:

Re-payment for out-of-pocket expenses incurred by patient and family partners while participating in engagement. Reimbursement is different from compensation.

Systemic racism (also referred to as structural or institutional racism):

A form of racism that is embedded and enacted into societal structures, institutions, and systems (e.g., practices, policies, legislation) and results in perpetuating inequities such as profiling, stereotyping, social exclusion, and discrimination for racial groups.

Strengths-based and capacity building:

An approach that focuses on recognizing and building on the existing strengths, skills, and resources of individuals, communities, or organizations. Instead of focusing on problems, this approach emphasizes what is already working well and helps to grow capabilities, confidence, and resilience to achieve goals and overcome challenges.

Tokenism:

Involves incorporating diverse cultural groups, practices, and customs into processes in ways that narrowly focus on superficial engagement while restricting meaningful contributions and decision making.

Trauma and violence-informed:

Recognizes approaches that focus on minimizing the potential for harm and re-traumatization and enhancing safety, control, and resilience for those involved with systems or programs.

Wise practices:

Strengths-based actions, tools, principles, or decisions that are culturally appropriate and community driven. Wise practices recognize the wisdom in each Indigenous community and in the community's own stories of achieving success. The concept of wise practices recognizes that culture matters.

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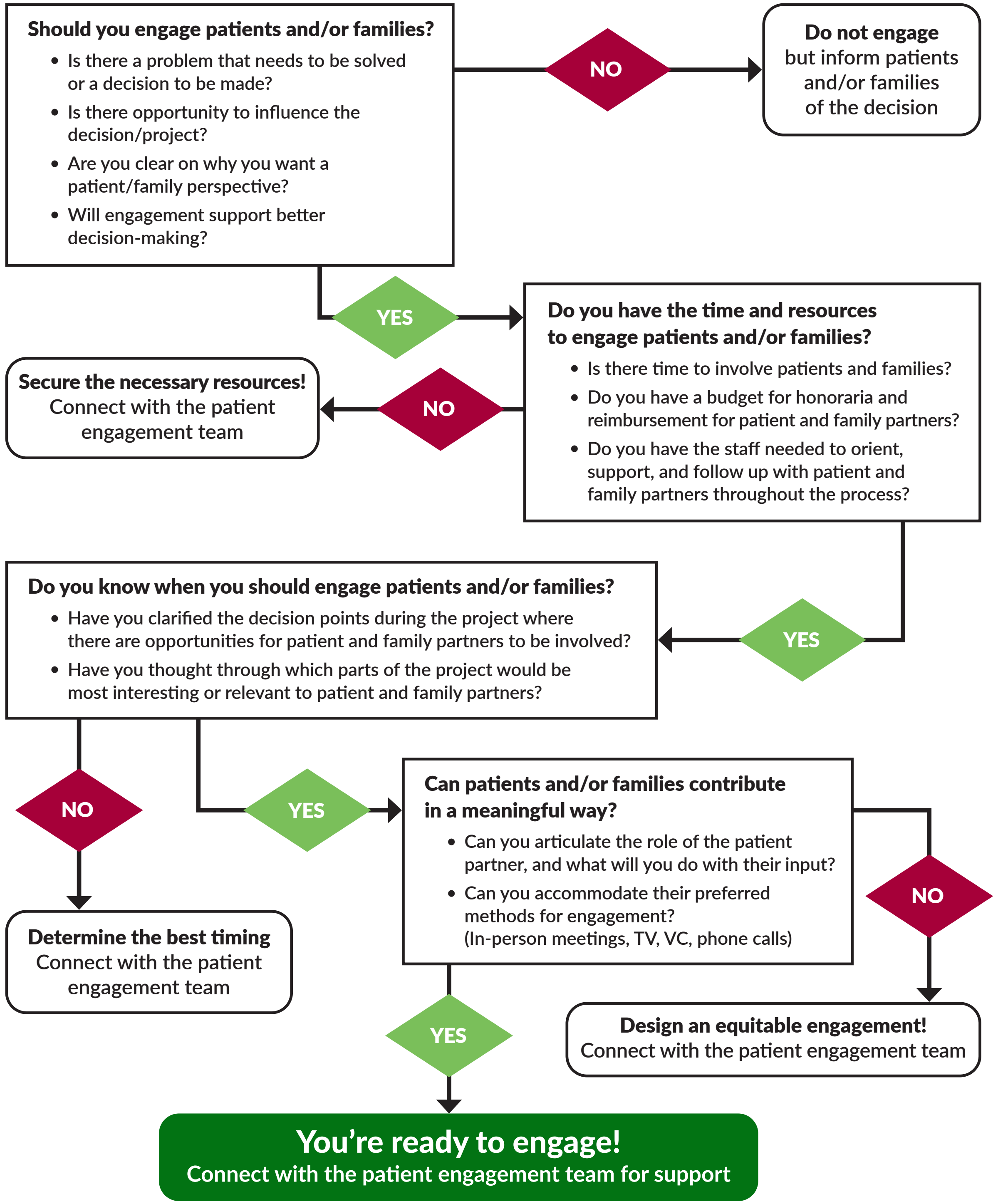
Engaging Patients and Families in Your Project — Decision Flow Chart

Adapted from BCMHSUS



Should you engage patients and/or families?

- Is there a problem that needs to be solved or a decision to be made?
- Is there opportunity to influence the decision/project?
- Are you clear on why you want a patient/family perspective?
- Will engagement support better decision-making?

NO → **Do not engage** but inform patients and/or families of the decision

YES → **Do you have the time and resources to engage patients and/or families?**

- Is there time to involve patients and families?
- Do you have a budget for honoraria and reimbursement for patient and family partners?
- Do you have the staff needed to orient, support, and follow up with patient and family partners throughout the process?

NO → **Secure the necessary resources!** Connect with the patient engagement team

YES → **Do you know when you should engage patients and/or families?**

- Have you clarified the decision points during the project where there are opportunities for patient and family partners to be involved?
- Have you thought through which parts of the project would be most interesting or relevant to patient and family partners?

NO → **Determine the best timing** Connect with the patient engagement team

YES → **Can patients and/or families contribute in a meaningful way?**

- Can you articulate the role of the patient partner, and what will you do with their input?
- Can you accommodate their preferred methods for engagement? (In-person meetings, TV, VC, phone calls)

NO → **Design an equitable engagement!** Connect with the patient engagement team

YES → **You're ready to engage!** Connect with the patient engagement team for support

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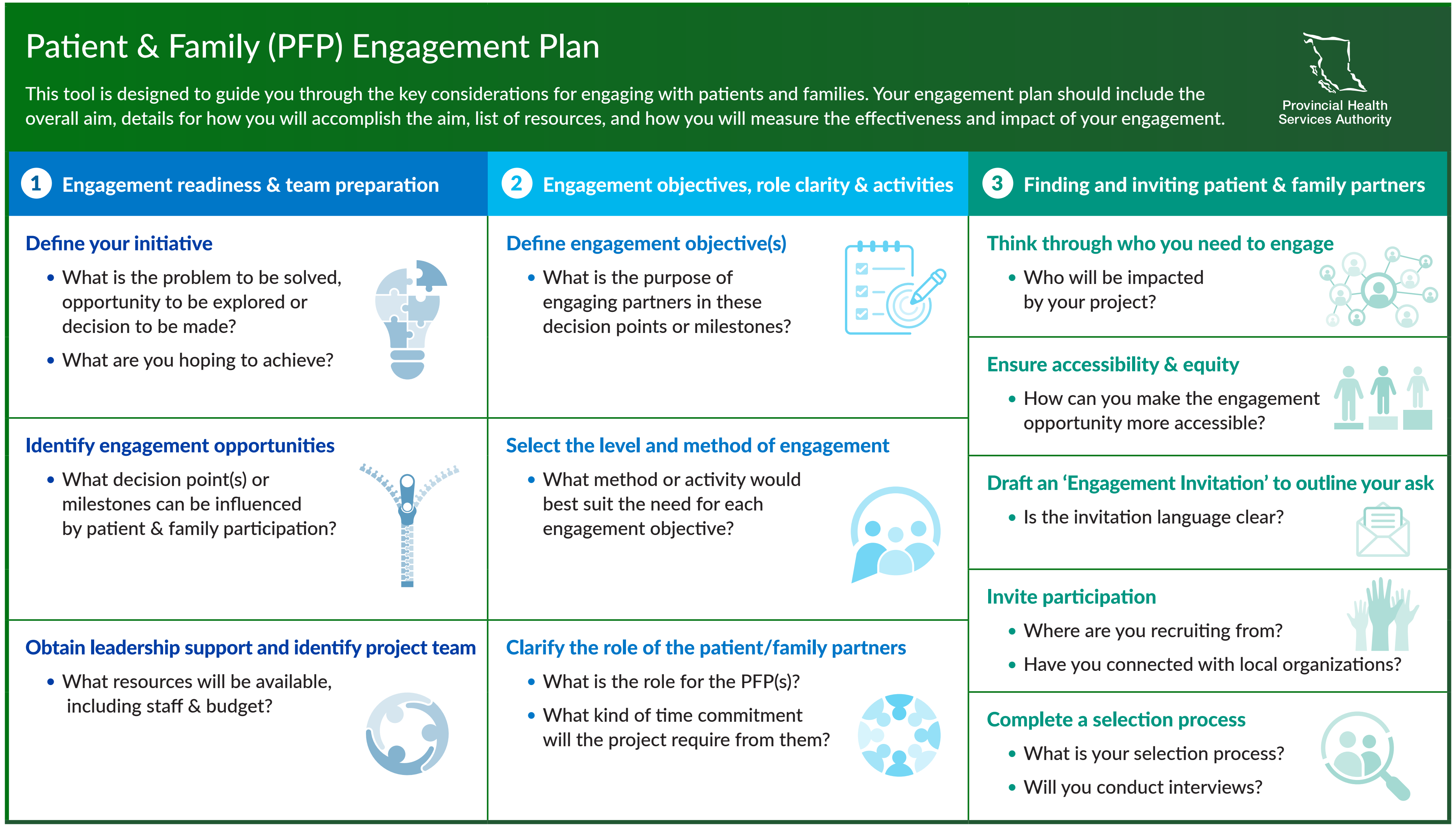
Engagement Plan Template



Patient & Family (PFP) Engagement Plan

This tool is designed to guide you through the key considerations for engaging with patients and families. Your engagement plan should include the overall aim, details for how you will accomplish the aim, list of resources, and how you will measure the effectiveness and impact of your engagement.

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1 Engagement readiness & team preparation

Define your initiative

- What is the problem to be solved, opportunity to be explored or decision to be made?
- What are you hoping to achieve?

Identify engagement opportunities

- What decision point(s) or milestones can be influenced by patient & family participation?

Obtain leadership support and identify project team

- What resources will be available, including staff & budget?

2 Engagement objectives, role clarity & activities

Define engagement objective(s)

- What is the purpose of engaging partners in these decision points or milestones?

Select the level and method of engagement

- What method or activity would best suit the need for each engagement objective?

Clarify the role of the patient/family partners

- What is the role for the PFP(s)?
- What kind of time commitment will the project require from them?

3 Finding and inviting patient & family partners

Think through who you need to engage

- Who will be impacted by your project?

Ensure accessibility & equity

- How can you make the engagement opportunity more accessible?

Draft an ‘Engagement Invitation’ to outline your ask

- Is the invitation language clear?

Invite participation

- Where are you recruiting from?
- Have you connected with local organizations?

Complete a selection process

- What is your selection process?
- Will you conduct interviews?

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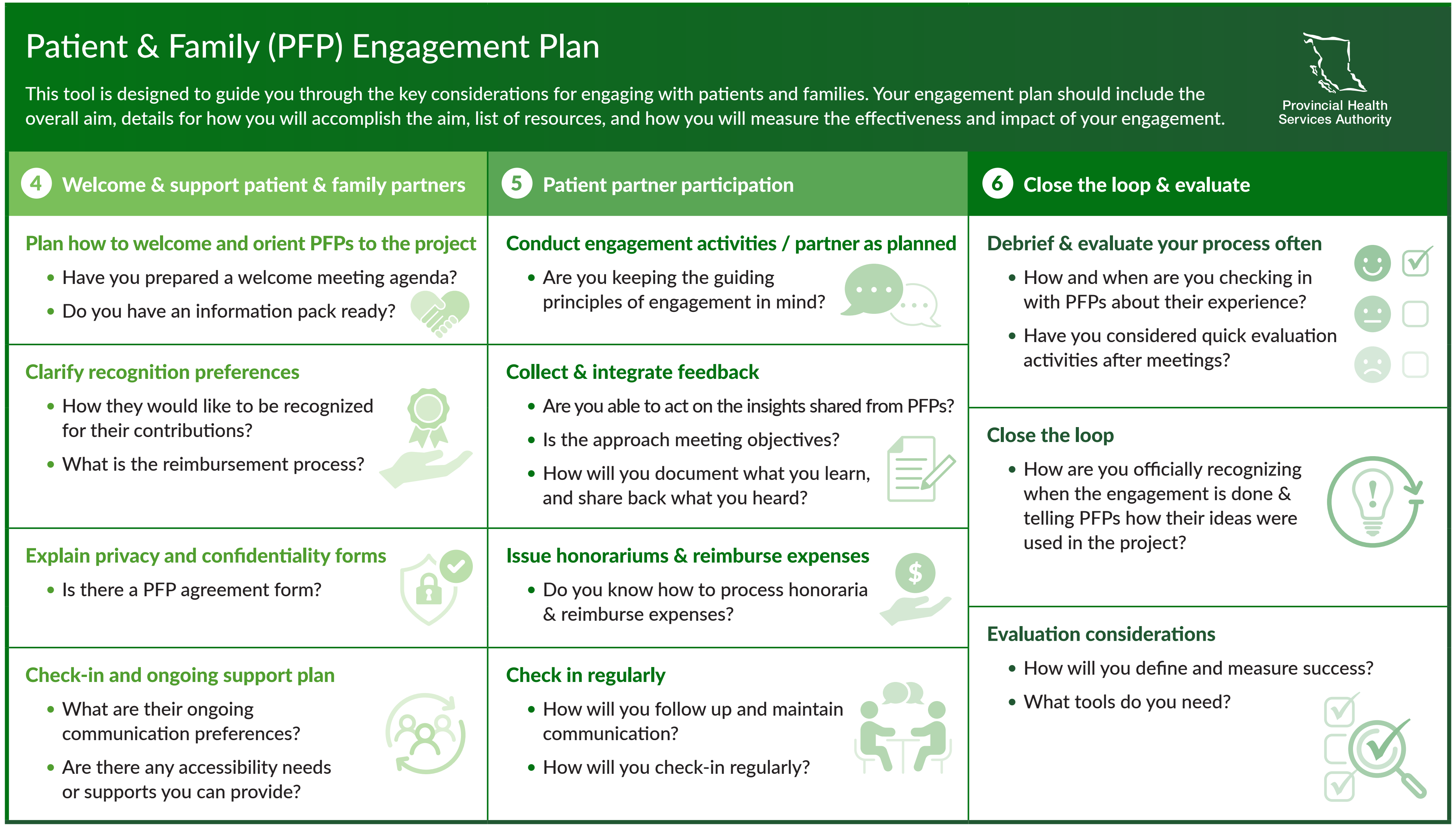
Engagement Plan Template



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4 Welcome & support patient & family partners

Plan how to welcome and orient PFPs to the project

- Have you prepared a welcome meeting agenda?
- Do you have an information pack ready?

Clarify recognition preferences

- How they would like to be recognized for their contributions?
- What is the reimbursement process?

Explain privacy and confidentiality forms

- Is there a PFP agreement form?

Check-in and ongoing support plan

- What are their ongoing communication preferences?
- Are there any accessibility needs or supports you can provide?

5 Patient partner participation

Conduct engagement activities / partner as planned

- Are you keeping the guiding principles of engagement in mind?

Collect & integrate feedback

- Are you able to act on the insights shared from PFPs?
- Is the approach meeting objectives?
- How will you document what you learn, and share back what you heard?

Issue honorariums & reimburse expenses

- Do you know how to process honoraria & reimburse expenses?

Check in regularly

- How will you follow up and maintain communication?
- How will you check-in regularly?

6 Close the loop & evaluate

Debrief & evaluate your process often

- How and when are you checking in with PFPs about their experience?
- Have you considered quick evaluation activities after meetings?

Close the loop

- How are you officially recognizing when the engagement is done & telling PFPs how their ideas were used in the project?

Evaluation considerations

- How will you define and measure success?
- What tools do you need?

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