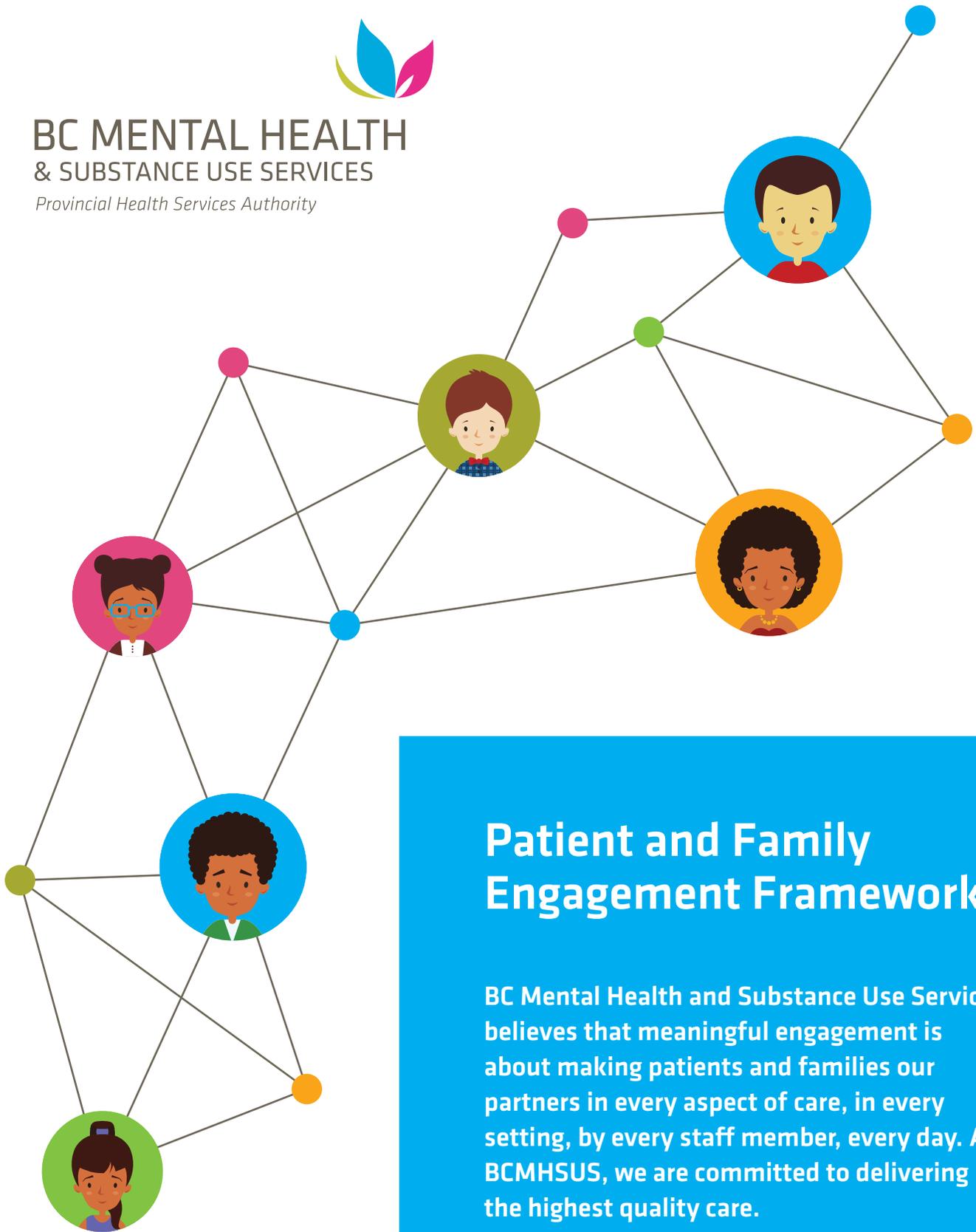




BC MENTAL HEALTH & SUBSTANCE USE SERVICES

Provincial Health Services Authority



Patient and Family Engagement Framework

BC Mental Health and Substance Use Services believes that meaningful engagement is about making patients and families our partners in every aspect of care, in every setting, by every staff member, every day. At BCMHSUS, we are committed to delivering the highest quality care.



“Including clients and families as part of our team is a no brainer to me. It means we have more experience and perspective at the table, and that means we’ll come up with better ideas faster and make better decisions. Mental health and substance use are complex health and social issues and we cannot begin to address them without the people who are living them.”

Becky, BCMHSUS Staff Member



“Being a patient partner has allowed me to transform my experiences into opportunities to engage and improve the healthcare system. Working with BCMHSUS on their hiring committee was an amazing experience since my voice contributed to developing a team that works with patient and community engagement. The hiring panel team was welcoming and allowed me the space to express my point of view. I felt heard, respected and valued.”

Anita, BCMHSUS Patient Partner



“Our journey, although unique, shares many aspects of what all families are going through and it’s often hard to feel anything but exhausted. For us, finding meaningful ways to give back has brought us surprising healing. Participating in groups that help shape services for anyone who suffers from mental illness and addiction has renewed our spirits and given us hope.”

Lisa, BCMHSUS Family Partner

What you'll find in this package:

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Introduction

BC Mental Health and Substance Use Services believes that meaningful engagement is about making patients and families our partners in every aspect of care, in every setting, by every staff member, every day¹. At BCMHSUS, we are committed to delivering the highest quality care.

Part A:

BCMHSUS Patient and Family Engagement Framework is a foundational document to guide the engagement of patients and families in planning, delivering, and evaluating health care and research at BCMHSUS. It outlines:

- How we define patient and family engagement and why it is needed for exceptional care
- The Spectrum of Engagement, based on international best practices and customized for BCMHSUS

A

Part B:

Putting the Framework into Action is a practical tool outlining the approach we use to plan effective engagement. It provides:

- Practical steps for meaningful engagement
- Lists of additional resources, tools, and supports available to assist you when engaging patients and families

B

Together, this package can be applied to support patient and family engagement in a wide range of projects across BCMHSUS, including:

- Site and organizational policies
- New programs and services
- Improvements to existing programs and services
- Research projects
- Health literacy projects
- Individual patient care plans



Who is this framework for?

This tool is for all staff, physicians, and researchers. At BCMHSUS, it is everyone's role to work together with patients and families to create policies, programs, projects, and practices.

Part A: BC Mental Health and Substance Use Service (BCMHSUS) Patient & Family Engagement Framework

Why a Patient and Family Engagement Framework?

Patient- and family-centred care is a priority of our province and health care system, as seen in the vision, mission, and values of the BC Ministry of Health², the Provincial Health Services Authority³, and the BC Mental Health and Substance Use Services⁴.

This framework is designed to guide the process of reaching this common vision. It is based on decades of evidence and worldwide best practices for patient and family engagement^{5,6} that have been endorsed by the BC Ministry of Health and adapted here for the unique and specialized work we do at BCMHSUS.

Key Concepts

Engagement **is**:

- Working with patients and families to
 - Design a service
 - Create care plans
 - Develop research studies and questions

Engagement **is not**:

- Providing a service to patients and families, such as counselling or a medical appointment
- Conversations between patients and clinical providers about patient health
- Research where patients and families are subjects of the study

Patient and Family Engagement is the **process** of designing, planning, delivering, and evaluating health care together with the patients.

Patient and Family Experience is the **outcome** of positive, quality experiences from all interactions across the continuum of care.

Patient- and Family-Centred Care works **with** patients and families, not **for** them. It values dignity, respect, communication, compassion, collaboration, cultural safety, and humility.



Through meaningful engagement, we aim for a health care system that delivers patient- and family-centred care, resulting in a meaningful experience for patients, families, and staff.

Definitions and visual adapted from the BC Patient Safety and Quality Council.⁷

Defining “Patient” and “Family”

Patient: The person in our care. May also be called the “client.”

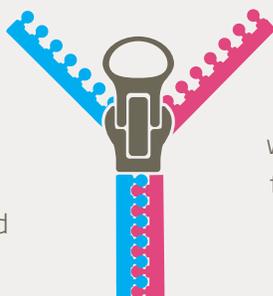
Family: The primary support for the patient, as defined by the patient. This may be their birth, adopted, extended, or street family, and can change over time.

Patient and Family Partners: Current and former patients, family members, and other people with lived and living experience of mental health and substance use (MHSU). They represent the voice of the people we serve. They participate in the organization, service, direct care, and/or research design.

The Zipper Analogy

Project

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



An Example of Engagement in Action at BCMHSUS

BCMHA Partnerships in Care Committee

Partnerships in Care is a peer-led Steering Committee at the Burnaby Centre for Mental Health and Addictions (BCMHA). Families and health care staff meet monthly and as needed to work together to improve quality, patient experience, and patient safety. The committee has created resources for families, launched a monthly support group, and designed BCMHA policies, while continually keeping the family voice in mind. In 2020, the group was recognized nationally by Health Standards Organization as a leading practice.

Why Engage?

Why Patient and Family Engagement is Important

We have a high moral and ethical responsibility to engage those who are impacted by health decisions in making those decisions. This is our ultimate *why* for doing this work.

There are also a number of key benefits to engaging patients and families. For example:

- Patients and families can share how the services and research we think we are delivering compare to their actual experiences and expectations. Working together, we can create a more responsive care system and prevent harms before they occur.
- Engagement can help the health care system better define both the problem and the solution.
- Decisions made in partnership with patients and families are not only more responsive, but more innovative.
- When patients and families are engaged as equal partners in co-creating policies, programs, and services, it creates a shared accountability and increases buy-in and adoption of those initiatives.



Specifically, engaging patients and families at every level has been proven to improve:

- **Health outcomes:** When patients and families take active roles in designing their health care system, treatment outcomes improve.⁸ Patients and families who are involved in their care are also better able to manage their diagnoses.^{9,10}
- **Quality and patient safety:** Services and quality improvement projects that are designed in collaboration with patients and families better meet the needs of patients, resulting in fewer safety-related incidents.²⁰
- **Staff satisfaction and retention:** Health care staff who listen and respond to the insights of patients and families are happier with their work. Adopting a patient and family engagement strategy helps recruit and retain high-quality talent.¹¹
- **Research and knowledge translation:** People are more likely to participate in studies when their ideas and experiences shape the project. Findings can also be directly applied to practice.¹²
- **Equity:** At BCMHSUS, we provide care to some of the most underserved people. Engagement is about equity, diversity, and partnership. This reduces societal stigma.¹³
- **Health care costs:** Patients and families who can manage their own health are less likely to use the care system unnecessarily, which ultimately leads to lower per capita costs.¹⁴

Patients and families have important knowledge and insight. They know their own needs and should play an active role in decisions that impact them. What we think matters to a patient or family member may not actually matter to them. Engagement findings help us leverage this information for the continuous improvement of our health care system.

A Standard of Excellence

The evidence for patient and family engagement is strong, so much so that Accreditation Canada says that it should be standard in how we work. Patient- and family-centred care is important for decision making, health outcomes, patients' experiences, financial management, and safety.¹⁵ Engagement language is found throughout our standards, showing that we are expected to partner with patients and families at all levels in our everyday work. This includes standards for both organizational leadership and clinical excellence.



An Example of Engagement in Action at BCMHSUS

Forensic Psychiatric Hospital Patient Needs Assessment

In 2019, the Forensic Psychiatric Hospital (FPH) hosted a patient needs assessment (PNA) to better understand the care needs at FPH. After completing the PNA, staff hosted a Town Hall on each unit to share with patients what they heard and validate the findings through in-depth group discussions. Staff asked:

What is important to you?

What are you concerned about?

These questions get to the root of what matters. Patients were informed that their priorities and needs will be used to inform the revised Model of Care.



An Example of Engagement in Action at BCMHSUS

Correctional Health Services Information Technology Strategy

In 2018, BCMHSUS hosted a series of focus groups with Correctional Health Services (CHS) clients to identify opportunities to leverage IT to improve care. 50 clients across three correctional centres participated and shared their top priorities. As a result of the engagement, enhancements were made at all correctional centres, including the addition of Telehealth units and increased access to specialist services using virtual health.

BCMHSUS Patient and Family Engagement Framework

This framework shows the full range of engagement across different areas. Moving from left (Inform) to right (Empower) requires increased decision-making with patients and has a greater impact. One level is not better than another as different approaches are required to meet different goals. **When planning your engagement strategy, be sure to refer to this spectrum to identify the level most appropriate for your project and clearly communicate the goal to patients, families, and others involved, including internal decision-makers.**

Spectrum of Engagement with Patients and Families

	 Inform	 Consult	 Involve	 Collaborate	 Empower	
Domains of Engagement	Individual (Point of Care)	Has access to their health information in an uncomplicated, easy, and timely manner	Understands all their care plan options	Helps to inform their care plan by asking questions and sharing their goals and preferences	Co-creates their care plans and health goals and 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 the program	Supported in providing feedback on a draft or concept	Preferences, needs and core elements of person-centred care are understood and used for program design	Co-creates the program or service	Make some or all program-related decisions
	Organization (Policy, Planning & Governance)	Understands the policy and its broader goals	Shares feedback on a draft policy statement	Interests, preferences, needs, and concerns inform the policy	Partners in developing the policy	Makes some or all the decisions about what is included in the policy
	Research (Knowledge Generation & Translation)	Provided with evidence-based information to understand the broader research goals	Provides feedback on the research	Shares information with the researcher to help inform the research question and/or results	Partners with researchers for main aspects of the research	Provides the research question and/or conducts their own research, with researchers' assistance

Adapted from IAP2 Spectrum of Public Participation¹⁶ and BC Ministry of Health Patient, Family, Caregiver and Public Engagement Framework.¹⁷

Part B: Putting the Framework Into Practice

Examples of Engagement Across A Client's Care Journey

The visuals below provides examples of what patient and family engagement might look like at each stage of a typical patient care journey.



Pre-Admission



Inform: Staff share complete and unbiased information, at the right time, in ways that are affirming, useful, accessible, and culturally safe.



Collaborate: Staff invite chosen families to join the care team.

During Care



Inform: Staff wear name tags and explain their roles to patients during new interactions.



Involve: Staff ask patients and families what matters to them, understands their needs and experiences, and build them into the care plan.



Collaborate: Staff work with families on visitation, privacy, and confidentiality procedures, so their needs are met while respecting legal bounds.

An Example of Engagement in Action at BCMHSUS

Heartwood Community Meetings

Every week, residents of Heartwood Centre for Women gather together outside of regular programming to discuss their priorities related to their care and safety. This creates an open and equalizing space for clients to raise key issues, receive immediate feedback from fellow clients/ patients and staff, and collaborate to find solutions.

Pre-Discharge



Inform: Staff educate families on strategies to support their loved one post-discharge in ways that are affirming, useful, and accessible.

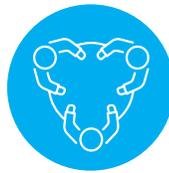


Consult: Staff ask and listen to patient and family feedback on their experience of the program and use the information to improve services.



Collaborate: Staff work with patients and families to create a transition and post-treatment safety plan.

Post-Care



Consult: Staff provide options for how patients and families would like to be engaged post-discharge. Staff invite them to join the BCMHSUS Patient and Family Partner Network, and if available, the Patient and Family Advisory Committee (PFAC) at their site.



Collaborate: Staff work with patients and families on internal committees, using their experiences to improve services.



Empower: Patients and families co-chair committees focused on patient experience; ideate and direct new projects.

Adapted from BC Children's Hospital.¹⁸



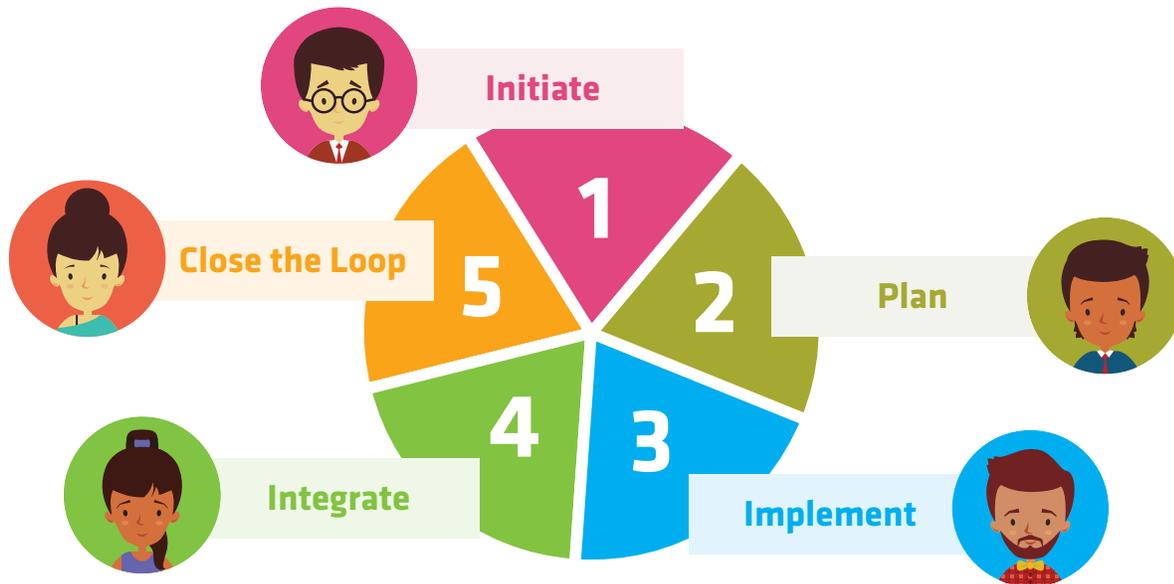
An Example of Engagement in Action at BCMHSUS

Patients on Interview Panels

Patient and family partners are involved in interviewing candidates for leadership positions at BCMHSUS. Their insight into the hiring decision illustrates the importance we place on patient- and family-centred care, helping us to attract and keep the right people and demonstrates our commitment to meaningful engagement.

The Steps of Engagement

For a successful engagement, invite participants to help shape the entire process, bringing their perspective in at “**Initiate**” and keeping them involved through to “**Closing the Loop**.” Doing this will help them feel more invested in the final decision.



Initiate

The **Initiate** phase focuses on developing a clear understanding of your goals, objectives, and overall readiness for engaging patients and families.

1. Clarify the Decision That Needs to Be Made

As a team, discuss why you want to engage and what decision you are trying to make with patients and families.

For example, “By 2020, FPH administration will adopt a revised Model of Care, so that patients receive care that is appropriate for their needs and goals.”

CONSIDER:

- What the project is that you want patient/family participation in
- Who are the key decision-makers in this project
- Timeline (start and end dates)
- Goal (rationale, result, and deliverable)
- Domain of the decision (individual, service, organization, research). See Spectrum of Engagement on page 6.

OUTCOME:

Decision statement that is S.M.A.R.T. (specific, measurable, attainable, realistic, and time-specific)

2. Write the Engagement Objectives

Objectives define your scope of engagement and are specific about who is being engaged. Be sure to include a diverse range of perspectives (include those with both positive and negative experiences).

For example, “During the summer of 2019, patients of FPH are invited to provide input on the development of a revised Model of Care, so that their lived experiences are incorporated into the design of new health services.”

CONSIDER:

- What you hope patients and/or families will bring to the table
- How input will be used and applied
- How long it will take to achieve each objective

OUTCOMES:

- Tangible outputs (e.g., a report, a list of preferences, feedback on a draft)
- Intangible outcomes (e.g., greater understanding of patient priorities, feeling heard, building common ground, re-building a relationship)



3. Determine the Level of Engagement

Use the Spectrum of Engagement on page 6 to select the level that is most appropriate for your objectives.

CONSIDER:

- Context
- Needs of patients and families
- Needs of the final decision-makers

TIPS:

- Assess needs and expectations to manage risks before they occur (e.g., patients expect to be engaged at “Collaborate,” but leaders planned to engage at “Inform”)
- Engage different groups at different levels
- Communicate the level of engagement to patient and family partners so they know what to expect and how their feedback will be used

4. Determine Available Timing, Capacity, and Resources

CONSIDER:

- Time needed to achieve your engagement objective
- Funding needs
- Available resources
- Your team's workload
- Current priorities of the program and organization



5. Gain Leadership and Internal Commitment

CONSIDER:

- Expectations of the final decision-maker(s) and if they align with your engagement objective(s)
- Your team's commitment to gathering and using patient and family feedback
- If the necessary funding and resources are available



TIPS:

- Make sure internal staff understand the roles and responsibilities of patient and family partners
- Create a strong feedback loop to the final decision-maker(s) before beginning engagement



Plan

The **Plan** phase focuses on identifying the most appropriate patient and family partners, designing what the engagement will look like, and outlining the steps and activities needed to reach and measure your objective(s).

1. Who to Engage With

Create a list of patients and family members to engage.

CONSIDER:

- Who will be affected by this decision (directly, indirectly, or unintended impacts)
- How patients and families will perceive the decision
- The cognitive abilities and accessibility needs of your patient and family partners
- Participation needs (e.g., access to technology, living in a certain region, past or current experience of a specific service)



2. Design the Engagement Plan

You've now determined the scope, objective(s), level of engagement, and participant list, and have secured the necessary resources and leadership commitment to move ahead. Your engagement plan brings this all together and describes how you will engage patients and families.

CONSIDER:

- How many steps there are in the decision and how much time is needed between each step
 - *For example: By August 2020, create a list of top patient priorities related to health care. By November 2020, decide on 3 possible solutions to explore for each priority. By January 2021, decide on the solution to implement for each priority.*
- Availability and roles of staff members at each step
- Logistic needs (e.g., space, food)
- Financial impacts of participation (e.g., remuneration for travel, parking, etc.)
- How to raise awareness, invite participants, and encourage their participation
- Visual, tactical, and auditory methods of communication
- How to listen, receive, record, and report information
- Which engagement technique(s) you will use
- How you will define and measure success



Implement

The **Implement** phase focuses on putting your engagement plan into practice. It builds upon key components of the plan in more detail; specifically, communication, facilitation, and evaluation.

1. Communicate Clearly

CONSIDER:

- Information patients and families need to participate
- The current level of understanding among the different groups
- Barriers to understanding and how they can be overcome
- If participants are clear on the scope of the decision before engagement begins
- If participants are clear on their role and how you will use their input

TIPS:

- Match participant expectations to the engagement objective
- Provide information on participation – how expenses will be covered, compensation, travel, etc.
- Use different communication techniques for different audiences
- Use plain language. Avoid jargon, clinical terms, and acronyms

OUTCOME: Clear participant expectations

2. Facilitate the Engagement

CONSIDER:

- How participants are being compensated and/or reimbursed for expenses
- The supports can you provide so they feel valued and are able to participate
- The operating values for a successful session (e.g., community guidelines)

TIPS:

- Ask participants beforehand what supports you can provide
- Pack a Facilitator's Toolkit to ensure you are prepared the day of
- The facilitator should be neutral, unbiased, and impartial to the decision. The decision-maker or expert should not be the facilitator
- Stick to your plan for the day with a printed internal agenda for you and your team
- Plan how notes will be taken (e.g., multiple note-takers, flip chart for group view, etc.)

OUTCOME: Record of patient and family input

3. Debrief and Evaluate

TIPS:

- Use both real-time evaluation (ex: [Δ/+ technique](#)) and post-session evaluation (formal data collection) with patient and family participants
- Debrief with staff immediately after the session
- Talk about any challenges and develop a plan to address them
- Incorporate a practice of self-reflection and improvement

CONSIDER:

- How participants can give feedback (e.g., verbal, paper, real-time, post-session)
- As the facilitator what went well for you and what could have been better
- What could have been better prepared before the session

OUTCOME: Completed participant and staff evaluations. List of lessons learned.

Integrate

The **Integrate** phase focuses on analysing and reporting your findings, and applying the information to help make the final decision.



1. Analyse and Report

CONSIDER:

- Who will ensure the input and recommendations are analysed and connected directly to the decision-making process
- Who will ensure timely and meaningful follow-up with patients and families

TIPS:

- Create a “What We Heard” report to share the input and recommendations of participants. This can be shared with patients, families, and decision-makers right away
- After the decision is made, create a “What We Did” report to share how participants’ input was used or not used and why

OUTCOME: Patients and families understand how and where their engagement contributed to the decision. If it did not, they understand why not. Outputs include a “What We Heard” report and “What We Did” report.

Close the Loop

Close the Loop involves an official acknowledgement of the engagement’s completion and reporting back to patients and families on how their input was used in the final decision. It builds trust and promotes ongoing engagement.

1. Show Impact

CONSIDER:

- What the balance between transparent communication and protecting internal information looks like in your context
- How to acknowledge and express gratitude for your participants’ involvement

TIPS:

- Ensure participants are clear on the decision-making process, including how their input was considered
- Acknowledge **all** issues that were raised. Whether their feedback was or was not incorporated, communicate **why**
- Recognize their contributions and say thank you

OUTCOME: Final communication with patients and families, including sharing of “the What We Heard” and “What We Did” reports

2. Continue the Relationship

CONSIDER:

- Any future opportunities for the patient and family partners to stay involved

TIPS:

- Invite them to join the BCMHSUS Patient and Family Partner Network, a provincial network of experts with lived experience partnering with BCMHSUS staff to make key decisions (see page 18 for more information)
- Invite them to join your program or site’s Patient and Family Advisory Committee, if you have one.

OUTCOME: Sustained connections



Your Resources

Going Deeper

The Patient Engagement Page on PHSA On Demand (POD) is your go-to place for toolkits, resources, and printable templates to make your engagement initiative a success. [Visit](#) for tools such as:

- BCMHSUS Patient and Family Engagement Playbooks
- BCMHSUS Patient and Family Compensation Guidelines
- Stakeholder Mapping Templates
- Assessment Worksheet for Selecting Your Engagement Techniques
- Engagement Evaluation Templates
- Real-time evaluation techniques, such as $\Delta/+$
- Facilitator's Toolkit
- Annotated Agenda Planning Worksheet
- And more

Further Reading

- Accreditation Canada Website: [accreditation.ca](https://www.accreditation.ca)
- BC SUPPORT Unit's Guide to Patient Engagement: bcsupportunit.ca/resources/guide-patient-engagement
- Health Standards Organization (HSO) Standards: [healthstandards.org](https://www.healthstandards.org)
- HSO Leading Practices Library: [healthstandards.org/leading-practices](https://www.healthstandards.org/leading-practices)
- International Association of Facilitators: [iaf-world.org](https://www.iaf-world.org)
- International Association of Public Participation: [iap2canada.ca](https://www.iap2canada.ca)
- Ministry of Health: Patients as Partners Initiative: [gov.bc.ca/patientsaspartners](https://www.gov.bc.ca/patientsaspartners)
- BC Patient Voices Network: [patientvoicesbc.ca](https://www.patientvoicesbc.ca)



BCMHSUS Patient Experience and Community Engagement Team

The Patient Experience and Community Engagement Team is your resource for engagement initiatives. We can help you initiate, design, and implement a successful engagement process for your research, service, program, and quality improvement projects.

Contact us at engage_bcmhsus@phsa.ca.

BCMHSUS Patient and Family Partner Network

This is a provincial network of people with lived experience of mental health, substance use, and/or incarceration. Network members will work in partnership with staff, physicians, and researchers to improve the health care at BCMHSUS. If you are interested in connecting with the network, reach out to the Patient Experience and Community Engagement Team for more information.

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