



BC MENTAL HEALTH
& SUBSTANCE USE SERVICES
Provincial Health Services Authority

BCMHSUS

PATIENT AND FAMILY PARTNER HANDBOOK



WELCOME



Whether you're in the process of becoming a Patient or Family Partner at BC Mental Health and Substance Use Services or simply just wanted to learn more about patient and family engagement, we want to say welcome! It is our hope that after reading through this handbook, you have a good understanding of patient and family engagement and feel well equipped to take on this important work.

“

Patient and Family Engagement is a tangible mechanism for providing quality care delivery and service design.

”

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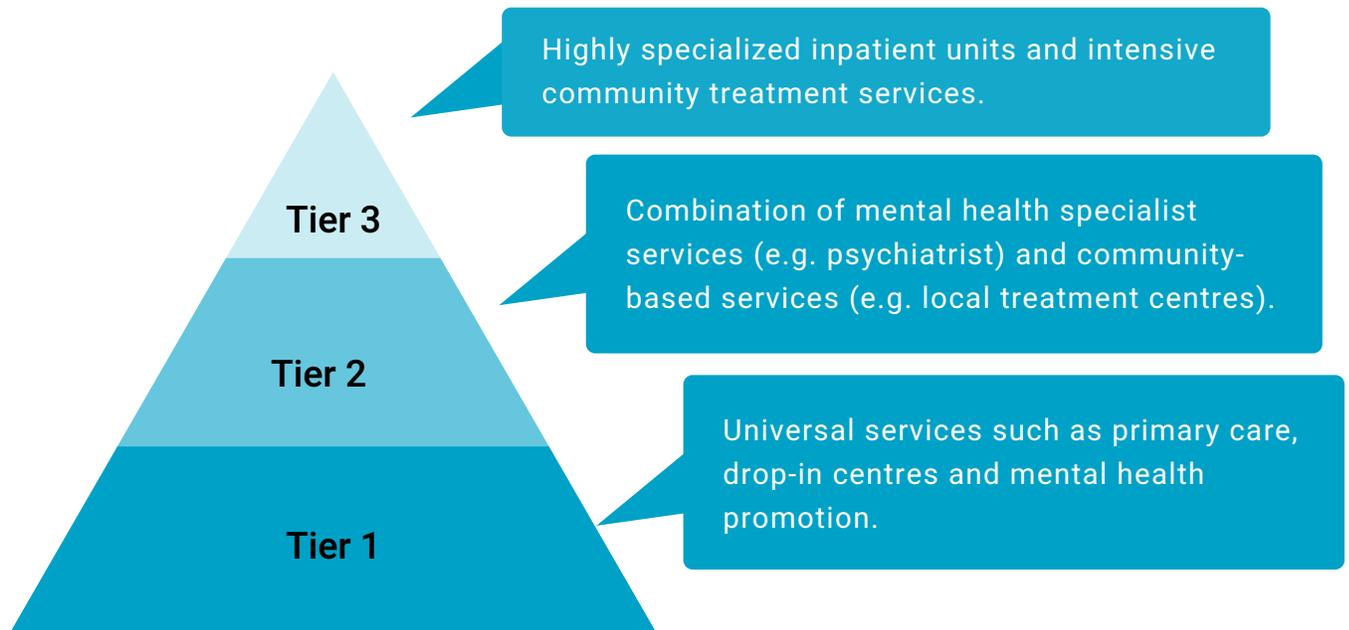
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ABOUT US

BC Mental Health and Substance Use Services (BCMHSUS) is one of the programs offered by the Provincial Health Services Authority. We provide specialized treatment across British Columbia to:

- People with complex mental health and substance use challenges
- People who have been referred to us by the courts for mental health assessment and/or treatment, and
- People in custody

Our clients and patients have needs that go beyond what most people can access within their local communities such as counseling, 12-step meetings, residential treatment for mental health and substance use issues, etc. These community services are considered services in Tier 1 or 2. Our services at BCMHSUS are considered Tier 3 services and are meant to treat the most complex and severe cases of mental health and/or substance use disorders. To be admitted, clients are either referred to us from the health care system (i.e. your addictions physician) or the criminal justice system (i.e. by the legal court).



What is considered complex?

We use the word “**complex**” to describe the severity of the mental health and/or substance use disorder(s) that our clients are experiencing. Oftentimes, this means that there are significant challenges with finding the right healthcare pathway for the individual. One example of a complex illness we treat is a **concurrent disorder**. This means that the person has both a mental illness and substance use disorder. For example, someone with a concurrent disorder might have both schizophrenia and opioid addiction (e.g. heroin, codeine, morphine, oxycodone, fentanyl, etc.), bipolar disorder and an amphetamine addiction (e.g. crystal meth, cocaine, speed, etc.), or depression/anxiety and alcohol. Getting well can be more challenging when multiple disorders are present.

Adding to the complexity of concurrent disorders is the fact that people with this diagnosis often live with other challenges that can further complicate their illness, such as poverty, social barriers, poor health care, unstable housing, and unemployment.

Many of our patients and clients have experienced trauma, including abuse, neglect, sexual assault, or adverse childhood experiences. All of these factors together make treatment for our patients and clients very challenging and require specific assessments, diagnoses, and specialized professionals to help with their care.

Our Vision, Mission and Values

Mission: Provincial health results through caring, leading and learning.

Vision: Province-wide solutions for excellence in health, every time.

Values: Province-wide solutions for excellence in health, every time.



Respect People

We treat people as individuals with unique beliefs, values, lived experiences and cultural norms. We value diversity and seek, listen to and respond to suggestions for improvement. Patients, clients and families are at the centre of all we do.



Be Compassionate

Whether it's caring for a patient, client, family member or colleague, being compassionate is fundamental to the work we do. We care about the health and well-being of one another and those we serve. We believe that simple acts of kindness matter.



Dare to Innovate

As an academic health sciences organization, we achieve excellence through knowledge and innovation. We believe in daring to innovate in all areas of our work to provide the best care for patients and families. We encourage one another to be lifelong learners. We learn from the experiences of patients and families and value their ideas.



Cultivate Partnerships

Our provincial scope means we foster partnerships wherever possible to improve health outcomes. We collaborate with each other; those we serve; and regional, provincial, national and international colleagues. We believe cultivating partnerships also means supporting patients, clients and their families to make the health care decisions that are right for them.



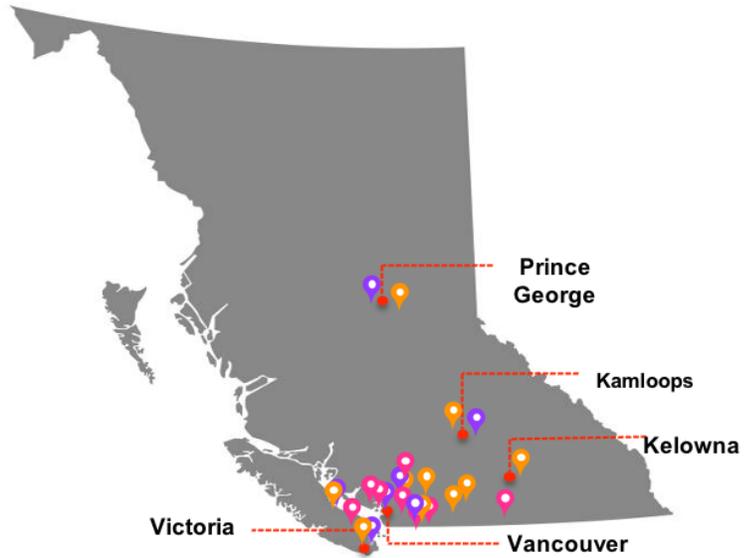
Serve with Purpose

Our shared drive to make meaningful improvements in care helps to guide our services. We find joy through serving others. We believe that making a profound difference in the lives of others is our legacy.

Our Clinical Services

We provide clinical services across the province of British Columbia. Our specialized treatment services fall into three areas:

1. **Adult Complex Mental Health and Substance Use Services**
2. **Forensic Psychiatric Services**
3. **Correctional Health Services**



					
Heartwood Centre for Women	Burnaby Centre for Mental Health & Addiction	Forensic Psychiatric Hospital	Forensic Psychiatric Clinics	Correctional Health Services	BCMHSUS Research Institute
Contracted Services: Coast Rehabilitation & Recovery, Cedars, Phoenix, and others					

Research & Knowledge Exchange	Provincial Planning & Strategic Network	Academic Teaching/ Training	Health Literacy (BC Partners)	Virtual Health
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Adult Complex Mental Health & Substance Use Services

This refers to our inpatient and outpatient services for adults with complex mental health and substance use challenges. These programs are designed for people with severe concurrent disorders whose needs go beyond what their local community or health authority can offer. This includes people who have experienced several relapses and/or have faced significant challenges with treating their illness. Patients attending these treatment centres are either voluntary (choose to be admitted) or involuntary (mandated under the Mental Health Act).

We currently offer two inpatient services:

Burnaby Centre for Mental Health and Addictions

The Burnaby Centre for Mental Health and Addictions is a 94-bed facility that provides treatment for adults (19+) who have been diagnosed with both a severe mental illness AND a substance use disorder (concurrent disorders) in BC. To learn more visit our [website](#).



Heartwood Centre for Women

Heartwood Centre for Women is a 30-bed residential facility located at the BC's Women's Hospital and Health Centre. They provide treatment to women (19+), including transgender women, who struggle with severe substance use and mental health challenges. To learn more about Heartwood visit our [website](#).



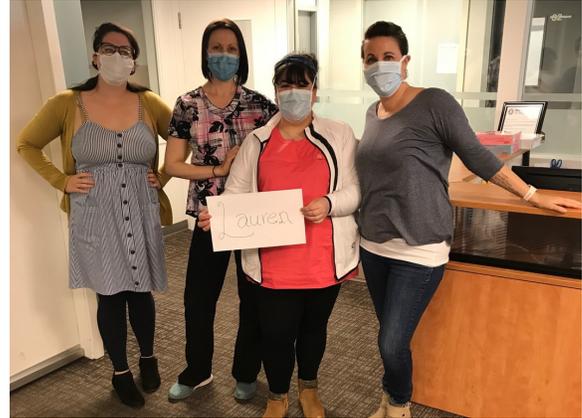
Forensic Psychiatric Services

Forensic psychiatric services are for people who have been referred to or ordered by the BC Criminal Justice System for mental health assessment and/or treatment. Because admission and discharge are mandated by the legal system, they are not voluntary. We provide both inpatient services (Forensic Psychiatric Hospital) and outpatient services (Forensic Regional Community Clinics).



Forensic Psychiatric Hospital

The Forensic Psychiatric Hospital is a 190-bed secure facility located in Coquitlam BC. They treat people who have been found not criminally responsible for a crime or unfit to stand trial due to a mental disorder. The role of the Forensic Psychiatric Hospital is to help patients integrate safely back into their communities when and if possible. To learn more about the Forensic Psychiatric Hospital visit our [website](#).



Regional Community Clinics

There are six Forensic Regional Community Clinics across BC. These provide support and treatment for people that have come in contact with the law who are living with significant mental health and/or substance use issues. Some people have been referred to these clinics by the courts for assessments to determine their ability to stand trial, their criminal responsibility for a crime committed and/or to receive pre-sentence psychiatric and psychological assessments. Others are required to receive treatment at the community clinics as part of their conditional discharge or parole. To learn more about the Forensic Regional Community Clinics visit our [website](#).

Correctional Health Services

We also provide health care, including primary care and mental health and addictions care, to people who are admitted into B.C.'s provincial correctional facilities, where sentences are less than 2 years. There are currently ten provincial correction facilities across the province. We also provide care to those in custody as well as supports and services to help people transition back to community-based care (e.g. community transition teams). To learn more about our Correctional Health Services visit our [website](#).



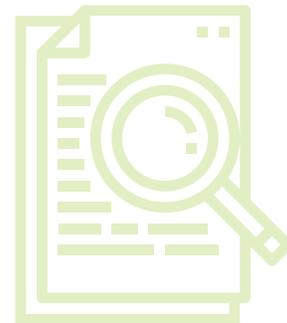
Our Research Institute

In addition to clinical services, we have a research institute located at BC's Women's Hospital and Health Centre. Their role is to continuously improve our understanding of mental health and substance use across a person's lifespan and to investigate different treatment approaches to ensure that we are providing the best evidence-based care to our clients and patients.

Key research areas:

- Cognitive Neuroscience of Schizophrenia Lab
- Provincial Obsessive-Compulsive Disorder Program
- ROAR Canada – Reducing Overdose and Relapse
- Knowledge Exchange

To learn more about our research institute visit the [website](#).



ENGAGING PATIENTS & FAMILIES AS PARTNERS

Delivering high-quality care that is both patient- and family-centred means working with patients and families to promote positive, quality experiences across the continuum of care. At BCMHSUS, we embrace the saying “nothing about us without us” and believe that patients and families should be involved in making the decisions that impact them.

Partnering with patients and families is essential to ensuring safe and effective care. Not only is engaging with patients and families the safe and effective thing to do, but it is also the right thing to do. We recognize that you are the experts of your own experiences, and therefore should have an active role in your own care and care system. Patients and families also bring a unique perspective to decision-making that can result in more innovative and creative solutions! They are experienced health care system users with first-hand knowledge of the care journey, including both the roses and thorns.

Here are some of the ways that partnering with patients and families have made a difference:

HEALTH OUTCOMES

- Improved patient emotional health
- Better symptom management and resolution

EFFECTIVENESS AND APPROPRIATENESS

- Improved care and service delivery after co-design with patients and families
- Reduced re-admission rates to hospital
- Reduced length of stay at hospital

COORDINATED CARE

- Better transitions from and between inpatient, outpatient and community services
- Improved interprofessional teamwork

PEOPLE-CENTRED CARE

- Reduced anxiety and stress with the presence of family and other supports
- Improved communication between patient and care providers
- Better understanding of health, options and individual care plans
- Improved patient and family satisfaction and experience

EQUITY

- Improved cultural awareness and consideration when providing services

SAFETY

- Better medication self-management
- Reduced patient safety incidents
- Increased identification of potential safety issues by patients and families that then prevent future safety incidents

Key Concepts

Before jumping into the nitty gritty of engagement work, let's go over some key concepts:

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

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

Patient and Family Partner: People with lived and living experience who represent the voice of the wide variety of individuals we serve and participate in the organization, service, direct care, and/or research design. They can be current and former patients, family members, or other people with lived and living experience of mental health and substance use (MHSU) and criminal justice involvement.

Patient-and-family-centred care: An approach to care that works with patients and families not for them. It values dignity, respect, communication, compassion, collaboration, cultural safety, and humility.

Patient and family experience: The outcome of positive quality experiences from all interactions across the continuum of care.

Patient and family engagement: The process of involving patients and families in designing, planning, delivering, and evaluating health care together with health care professionals.

Through meaningful patient and family engagement, the health care system can better provide positive patient and family experiences and ultimately deliver patient- and family-centred care.



BCMHSUS PATIENT AND FAMILY PARTNER NETWORK

What is the Patient and Family Partner Network?

The Patient and Family Partner Network is a provincial network of people across BC with lived/living experience with mental illness and substance use, and/or the criminal justice system. Patient and Family Partners work with staff, researchers, and doctors to improve our services at BCMHSUS.



What do Patient and Family Partners do?

Patient and Family Partners use their experience with mental health and substance use and/or involvement with the criminal justice system to provide a patient and family perspective on health care improvements and research. They participate in patient and family engagement opportunities to help make decisions about BCMHSUS services, programs, policies, and research projects. The roles and tasks differ based on the engagement opportunity but generally, the Patient and Family Partner role includes:

- Bringing the patient and family perspective to BCMHSUS staff, clinicians, and researchers.
- Helping health care staff consider patient and family needs in planning and decision-making.
- Sharing your knowledge, skills, experience, and ideas with BCMHSUS staff.
- Learning together from a diversity of perspectives to help make decisions and improve our care at BCMHSUS.

WHAT PARTNERS ARE SAYING



"My experience as a member of the Patient and Family Partner Network has been truly rewarding. As a patient partner, I have an opportunity to assist in improving the patient and family experience by sharing from my own. It's a very special opportunity. I feel valued as a partner and am treated as a respected colleague. Being a part of the Network has contributed to my healing journey."

-Chris, Patient Partner

"For me, being a patient partner is a rewarding aim. It allows me to apply my lived experience with both mental health & addictions challenges to provide input into policy decisions and programmes that address the needs of recovering patients and their families. I also gain the satisfaction that my recovery experience is valued in contributing to these patient care policies and PHSA. I would recommend the role of a patient partner to any individual who seeks to improve the life and well-being of patients in their recovery."

-Mark, Patient Partner



"Being a patient and family partner has been so uplifting. I feel so grateful that I am able to share my lived experience to help someone else have a better healthcare experience."

-Pam, Patient Partner

"The power of partnerships with patients and families lies in having Lived Experience driving future patient care. The result is delivering outstanding patient experience in people's healing journey."

-Ron, Family Partner

Some examples of previous engagements that our Patient and Family Partners have participated in include:

- Providing training to new healthcare providers and leaders by sharing their stories.
- Reviewing policies, resources, and handbooks and giving feedback.
- Participating in committees or working groups.
- Participating in focus groups or one-on-one conversations.
- Interviewing and hiring new staff and leaders.

Who can become a Patient and Family Partner?

Anyone who is living in British Columbia with lived or living experience with both mental health and substance use disorders, forensic psychiatric services, and/or incarceration is welcome to join the BCMHSUS Patient and Family Partner Network!

This includes:

- Past and current patients/clients of Burnaby Centre for Mental Health and Addictions, Heartwood Centre for Women, Forensic Psychiatric Services, and Correctional Health Services.
- Families and friends of past and current patients/clients of the above services.
- People with lived or living experience of both mental health and substance use disorders and their families.
- People with lived or living experience of incarceration and their families.

How do I get involved as a Patient and Family Partner?

If you're interested in becoming a Patient and Family Partner, please send us an email at engage_bcmhsus@phsa.ca. We will set up a meet and greet interview with you to get to know one another, learn about your experience and interests and make sure that our network is the right fit for you!

Approaches to Patient and Family Engagement

Now that we know what patient and family engagement is, let's go over what this actually looks like in practice. When are patients and families engaged? How do you 'do' engagement?

There are four areas in the health care system where patients and families can be engaged:



Next, let's take a look at the activities involved with engagement (i.e. how we 'do' engagement). The table below shows the types of patient and family engagements that can occur at each of the four points in the health care system. Each type of engagement requires different levels of involvement and decision-making. Moving from left (Inform) to right (Empower) requires increased decision-making with patients and families. One type of engagement is not better than another; each uses different approaches to meet different goals.

	Inform	Consult	Involve	Collaborate	Empower
					
Purpose	"Here's what's happening"	"Here are some options, what do you think?"	"Here's a problem, what ideas do you have?"	"Let's work together to solve this problem."	"You care about this issue and are leading an initiative, how can we support you?"
Approach	<ul style="list-style-type: none"> • FAQs • Newsletters • Public health messaging • Fact sheets • Brochures 	<ul style="list-style-type: none"> • Meetings • Open House • Surveys 	<ul style="list-style-type: none"> • Workshop • Dialogies • Focus Group 	<ul style="list-style-type: none"> • Patient Family Advisory Committee • Co-design • Working Groups 	<ul style="list-style-type: none"> • Task Force • Delegate decision to community members
Example	COVID-19 FAQ page outlining visitation, safety and vaccinations for our patients and clients	Presenting a diversity of virtual health initiatives to a group and surveying which are the most popular to shape priorities	Previous clients test out a clinical text messaging platform to assess user experience and identify areas for improvement	Co-design of a welcome handbook for new clients' families written by families	Health Literacy Working group co- chaired by Patients and Families to improve health education and literacy across our organization

NETWORK MEMBERS' RIGHTS AND RESPONSIBILITIES

The engagement spectrum shown earlier is a tool to help ensure you and the Healthcare Partner know what to expect from one another. If you are ever participating in an engagement and are unclear about your role or its scope, please don't hesitate to ask the Healthcare Partner. You can also always contact the Network Coordinator who can help get clarification and address any concerns you might have.

Working Together

The purpose of patient and family engagement is to work together, in partnership with BCMHSUS staff to improve our healthcare services. Here are some guidelines on how we would like to work together:

- Be respectful and open to one another's thoughts and ideas.
- Listen to learn – give one another the space to speak without interruption.
- Actively participate! – We want to hear your thoughts, ideas and opinions.
- Avoid the use of acronyms or abbreviations where possible.
- Respect confidentiality – keep any personal information shared private.
- Respect one another's time by respecting start and end times.
- Take care of yourself and one another. Let others know what they can do to help support you and your participation.
- Remember to enjoy yourself!

A full list of your rights and responsibilities as a Patient or Family Partner can be found in the agreement form in Appendix A.

BENEFITS, SUPPORT, AND RECOGNITION

Compensation and Reimbursement

At BCMHSUS, we recognize that your time, expertise, and experience is valuable and therefore should be equally compensated as that of our staff members. We offer compensation starting at \$25/hr as per best practice standards developed by health care organizations that work with patients and families across Canada including the BC Centre for Disease Control and the BC SUPPORT Unit. These hours will be predetermined and approved alongside the Healthcare Partner. We also provide reimbursement for expenses such as mileage and parking.

All partners are entitled to receive compensation. This can be done either through direct deposit or cheque. You may opt-out and continue volunteering your time as well.

Learning and Development

Resources

Patient and Family Partners bring an incredible amount of knowledge to the table that Healthcare Partners can learn from. However, we want to make sure that as a Patient or Family Partner, your learning is supported as well. For this reason, we have an ongoing commitment to providing opportunities to support your development e.g. trauma-informed practice, peer support training, conferences, health literacy tools and resources, and more. These are circulated through our bi-monthly email communications with the network. We are always open to suggestions to improve our training and education for the network so please let us know what you'd like to see!

References

Patient and Family Partners that have participated in BCHMSUS engagement opportunities can ask for a letter of reference from the Patient Experience and Community Engagement Department. The Director of Patient Experience and Community Engagement will write the letter of reference.

Flexible Options for Participation

Part of promoting meaningful engagement is ensuring that we meet Patient and Family Partners where they are at. This includes working together with Patient and Family Partners to determine how best to support their participation e.g. timing, meeting method (in-person vs. online), location, etc. For example, if you want to be involved in providing feedback but are not comfortable in a group setting, we can arrange to meet you outside of committee meetings.

It is important that you and the Healthcare Partner work together to come up with a plan that works best for both of you. The Patient Experience team is also here to help facilitate this process and make sure that you feel well supported from the start of an engagement to the finish.

Health Literacy and Health Care Jargon

One challenge that Patient and Family Partners commonly face with engagement work is all the healthcare acronyms that can be used. Although we strongly encourage Healthcare, Patient, and Family Partners to avoid using acronyms or health care jargon, they do sometimes slip out. We have created a glossary of common terms and acronyms used at BCMHSUS (there's your first one!). You can find this list in Appendix C on page 31.

HOW DO I PREPARE FOR...

Advisory Committees

First things first, let's discuss what an advisory committee is. An advisory committee is a group of people who come together to provide advice to help work towards achieving a specific goal(s) or objective. Advisory committees may also be called: working groups, steering committees, reference committees, or groups.

The people that make up these committees at BCMHSUS depend entirely on the project or initiative. This may include BCMHSUS staff, administrators, senior leadership, clinicians, doctors, members of partner agencies, and Patient and Family Partners such as yourselves! Typically these committees have a chairperson; someone who leads the committee. Sometimes, more than one person will take on this role in which case they are called Co-chairs of a committee.

Each advisory committee has its own:

- Purpose or goal
- Time and location for meetings
- Meeting frequency
- Length of time expected to complete committee tasks
- Members
- Decision-makers

How to Apply

Before applying to a committee, it's important that you consider whether or not it is the right fit for you! See 'Finding the right fit under the FAQ section on page 28.

Once you've determined that a committee is a good fit for you, you'll likely need to put together an application. Details as to what to submit for each application will be outlined in the Patient Family Partner posting for that committee. As a general rule, applications involve commenting on why you are interested and providing a brief description of any

past or current experience that you think is relevant to the engagement opportunity. This information will then be sent to the Committee lead(s) who will review and select appropriate partner(s).



Your lived experience is always valued! If you have not been selected for an opportunity, it may be that applicant interest exceeded the membership limit or there may be another opportunity that would be a better fit for a Partner's interests and experience.

You've Joined a Committee, Now What?

Once you've joined a committee, you will receive an orientation with either the committee lead(s) or another staff liaison to help introduce you to the committee and their work. You may also be provided with background documents to help bring you up to speed. For example: terms of reference, list of committee members, strategic plans, previous agendas and minutes, etc. If you have questions or feel lost in an information overload, please don't hesitate to ask either the committee lead, staff liaison, or Network Coordinator.

During your orientation, you will also come up with a "check-in plan" with the committee leads. These may occur every 3-months, 6-months, or annually depending on the committee duration and preference! Check-ins are an opportunity for both you and the Healthcare Partner to touch base, discuss what is going well, if/where you need more support, and any other matters that require further discussion. The Network Coordinator can attend these check-ins as well if you'd like to have a neutral person present. You can also always request a check-in directly with the Network Coordinator at any point in time!

Preparing for the first meeting:

 Prepare a brief intro about yourself. Make sure to include:

- Your name
- Your role (Patient or Family Partner)
- Any relevant experience you'd like to share (e.g. professional, volunteer, education, lived experience). This helps show what you bring to the meeting and/or group.

- What motivated you to join the committee, project or initiative?
- Your expectations about the work, how much time you have to give, and any other considerations you'd like to bring up.



Consider bringing the following to the meeting:

- Paper copies of any documents you were sent before the meeting such as the agenda or items for discussion.
* Pro-tip: you may want to create a folder or binder to keep all your papers together!
- Items to take notes with e.g. paper, pen, pencils, whiteboard, computer, etc



Consider asking the Healthcare Partner for the following items to help you prepare for the first meeting:

- Terms of reference
- List of acronyms and key terms
- List of committee members
- Status report (this may be useful if you are joining a pre-existing committee to get a sense of what work has already been done)

Preparing for ongoing meetings:

Here are some tips to help you actively participate and be engaged at future meetings:



Go through the agenda in advance and review items. For each agenda item consider:

- How can I contribute to this discussion?
- What is relevant information to bring to this discussion?
- What could be some possible concerns from the patient/family perspective (if any)?



Jot down any ideas, questions or points you'd like to discuss at the meeting.



Participate at a level you are comfortable with! Remember that your voice is valued so don't be afraid to share your thoughts, ideas, and opinions.

Focus Groups/Focused Discussions

Focus groups are often used at the 'Consult' level of engagement to gather feedback on a project or idea. They usually occur as a one-time meeting to gain insight from Patient and Family Partners on a particular item or topic. For example, collecting Patient and Family Partner feedback to help inform a decision or design a program.

Generally, the facilitator of the focus group will have a pre-determined set of questions to ask partners. Upon project completion, a summary of how your feedback was used is relayed back to you. We refer to this process as 'closing the loop'. All Healthcare Partners are expected to complete the closing-the-loop process in order to ensure meaningful Patient and Family Partner engagement. If you ever run into a scenario where the Healthcare Partner has not 'closed the loop', please let the Patient Experience team know! We will follow up with the Healthcare Partner and ensure they complete this process and connect with you.

Hiring Panel

To help support a patient-centred approach to hiring staff, Patient and Family Partners are often asked to sit on hiring panels for various positions across BCMHSUS. During a hiring panel, a Patient or Family Partner will participate in the interviews as well as provide input to help determine which candidate should be hired. Participating in hiring panels is generally a short-term commitment of a few days of interviews (depending on how competitive the application pool is).

Speaking Opportunities

Conferences, workshops, educational events, and orientation sessions are all examples of speaking opportunities that Patient and Family Partners can be involved in. These may include sharing your story, talking about the importance of patient-centred care or speaking to the patient/family perspective on a specific topic. Not everyone is comfortable public speaking or speaking in front of a group of people – that's okay! But if you do have experience in public speaking or would like to develop skills in presenting or telling your story, please let us know.

CONCLUSION

Thank you for partnering with BC Mental Health and Substance Use Services. Your lived experiences and knowledge can help shape how we deliver health care here. Together, we can ensure that we are providing equitable, safe, and person-centered services to every patient.



Appendix A – Patient and Family Partner Agreement Form

As a Patient and/or Family Partner of BC Mental Health and Substance Use Services (BCMHSUS), you are entitled to certain rights and standards for engagement. Along with these rights come some responsibilities with respect to general conduct and confidentiality. Please review and sign this agreement as part of your commitment to engage with BCMHSUS.

I have the right to:

- Be treated with respect, dignity, fairness and value.
- Feel physically, psychologically, emotionally, culturally safe.
- Confidentiality about your medical conditions, family relations, personal stories, contact information, unless you choose to disclose.
- Be matched with suitable opportunities for engagement, based on my interests, experiences, and knowledge.
- Be provided guidance, orientation, skills development, and ongoing support to participate meaningfully in engagement.
- Be informed by the Healthcare Partner on what types of materials you will be exposed to in advance (e.g. sensitive and/or challenging information) and co-develop strategies to support you in those discussions.
- Be informed about the process and final decision(s) and/or outcome(s) of every engagement you participate in.
- Be recognized and/or compensated for my time and contributions.
- Withdraw from an engagement at any time.
- Take a break from or leave the Patient and Family Partner Network at any time.

I have the responsibility to:

- Respect the rights and views of others, and treat them with respect, dignity, and fairness.
- Not disclose any information of a highly personal nature without the specific permission of the person concerned. This includes medical conditions, contact information (e.g. email addresses), family relations, personal stories, candidate applications.

- Not disclose any information that is confidential to BCMHSUS, without the specific permission of the Healthcare Partner involved. This includes interview tools, unpublished documents and initiatives, financial information, internal correspondence, and documents and discussions that are restricted by law.
- Take all reasonable measures to ensure that information is kept secure and disposed of appropriately after the engagement.
- Notify the BCMHSUS Patient Experience and Community Engagement team and staff partner if I believe I may have inadvertently breached confidentiality.
- Respect the privacy of other Patient and/or Family Partners and BCMHSUS Healthcare Partners.
- Not engage in any form of harassment or discrimination.
- Show commitment to engagement opportunities (e.g. attend meetings, participate in focus group work), and follow through with these commitments to the best of my abilities.

As a Patient and/or Family Partner of BCMHSUS, I consent to:

- Having my contact information (name, phone number, and/or email address) shared with BCMHSUS staff involved with the engagement.
- Being contacted in the future about engagement opportunities that may be of interest.

Adapted from Patient Voices Network, June 2020

Name

Signature

Date

Emergency Contact Information

Name

Phone Number

Appendix B - Frequently Asked Questions

How do I find an opportunity that fits my goals?

Once you've joined the Patient and Family Partner Network we will add you to our mailing list. This is where we circulate upcoming engagement opportunities (internal and external) as well as education and training events. Internal engagement opportunities are those that occur within BCMHSUS while external are those that are hosted by organizations. Instructions on how to apply to each engagement opportunity are included with each posting.

Before you apply to an engagement opportunity, there are a few things you should consider to determine whether or not it is the right fit for you:

- Am I interested in the topic, projects, and/or tasks involved with the engagement opportunity?
- What can I contribute?
- Do I meet the criteria for what the Healthcare Partner is looking for in a Patient and/or Family Partner?
- Do the time and location work with my schedule?
- Can I commit to the number of hours of work including any additional hours that might come out of this opportunity?
- Is there anything about participating in this opportunity that might be triggering for me or difficult for me to talk/think about?

If you're ever unsure, please don't hesitate to send us an email at engage_bcmhsus@phsa.ca and we'd be happy to assist you!

What if I want to stop participating?

Whether life is getting hectic, you need a break, or you're just not enjoying engagement work anymore, we understand. Please make space for yourself and your needs. All we ask is that you let us know as soon as you can by sending us an email. We will also offer to meet you one-on-one if there is anything you'd like to further discuss or debrief as it relates

to you stepping back from engagement work. If you are on a committee, please let the committee leads know as well.

How much time will being a Patient or Family Partner take?

As a Patient or Family Partner, you can choose what engagement opportunities to get involved in. This means that the amount of time and commitment you contribute is completely up to you. Some of our Patient and Family Partners are involved up to ten hours a month while others dedicate a few hours here and there.

What are common challenges experienced by Patient and Family Partners?

Although there are many of benefits to being a Patient and Family Partner, there can also sometimes be challenges with engagement work. Here are some common challenges that may occur while you are participating:

Staff members see you as representing all patients and families

"Sam, what do clients think about this?" Although staff members turn to you to provide the patient and/or family perspective, it is not possible of course for you to represent ALL patients and families on a committee or project. Even if you have worked or know many people with similar experiences to your own, you cannot 'represent' their opinions and experiences.

So what do you do?

Stay firm in your experience, which after all, is your expertise! For example, you could say, "I can't speak for everyone but based on my own experience...."

Things are moving at a snail's pace

Engagement work especially with committees can often feel quite slow. This can be frustrating for Patient and Family Partners that are used to seeing quick turnarounds or more immediate concrete results. However, change takes time. Often it's a marathon, not a sprint. Your role as a Patient or Family Partner is crucial to creating meaningful change by bringing that voice to the table. You may not be able to see the immediate impact but

your role and presence are recognized by others on the team. Collaboration is key to improving patient care. If you see the work is falling off track or coming to a slow, speak to the committee leader. You may be raising an important concern for the group to consider. You can also always reach out to the Network Coordinator and they can help facilitate this conversation as well.

Fear of engagement work impacting you or your loved one's care

Some Patient and Family Partners are concerned that what they share with Healthcare Partners during engagement work could make its rounds and negatively impact the care of their loved ones. Please know that anything and everything you share with Healthcare Partners during engagement work is 100% confidential. This means that under no circumstances will the experiences and input you share be relayed to you or your loved one's care team. Everything you say remains between you and the Healthcare Partner.

Feeling lost or unwelcome on a committee

Joining a committee part way through can be challenging. Many of the members have been working together on an initiative for a while and it can be easy to get lost in all the work that has been done. Before joining a committee, all committee leads are expected to provide Patient and Family Partners an orientation to bring you up to speed. It can also be helpful to ask for a cheat sheet including any common acronyms or key terms members use.

Remember, you have a right to be an active member of the committee just as any other member. The Patient and Family Partner Agreement form helps protect you here to ensure that you are able to participate in engagement work in a way that is meaningful for both you and the Healthcare Partner. If you are ever concerned or feel your voice isn't being heard, please email us at engage_bcmhsus@phsa.ca and we will meet with you to discuss how to best address this.

Appendix C – Acronyms and Health Care Jargon Glossary

PHSA – Provincial Health Services Authority

BCMHSUS – BC Mental Health and Substance Use Services

FPH – Forensic Psychiatric Hospital

CHS – Correctional Health Services

FPS – Forensic Psychiatric Services

RFHC – Red Fish Healing Centre

HW – Heartwood

RHA – Regional Health Authority

CBT – Cognitive Behaviour Therapy

CTT – Community Transition Teams

OAT – Opioid Agonist Therapy

PFAC – Patient and Family Advisory Council

PCQO – Patient Care Quality Office

SUD – Substance Use Disorder

CD – Concurrent Disorders

OD – Opioid Use Disorder

FASD – Fetal Alcohol Syndrome Disorder

MHSU – Mental health and substance use

MOH – Ministry of Health

MMHA – Ministry of Mental Health and Addictions

MSDPR – Ministry of Social Development and Poverty Reduction

PFCC – Patient and Family Centred Care

PSR – Psychosocial Rehabilitation

CoP – Community of Practice

TIP – Trauma-informed practice

MHA – Mental Health Act

Health literacy - The ability to obtain, read, understand, and use health care information in order to make health decisions and follow treatment/care plan instructions.

Knowledge translation - The process of summarizing knowledge or information and sharing/communicating this knowledge and information with others to improve their health and strengthen the health care system. E.g. conferences, presentations, ad campaigns, webinars, infographics etc.