BCMHSUS Patient and Family Experience Council

## Terms of Reference

***“Dynamic partnerships between patients, families and staff will serve as a catalyst   
toward excellence in the delivery of healthcare for our community.”***

## BACKGROUND

The BC Mental Health and Substance Use Services (BCMHSUS) provides health care services to people across British Columbia with severe mental health and substance use issues, people in custody, and people who have been referred by the courts for assessment and treatment. BCMHSUS also leads knowledge exchange, health promotion, and literacy.

The Patient and Family Experience Council (PFEC) advises the BCMHSUS Senior Operations Committee on policies, practices, planning and delivery of patient- and family-centered care across BCMHSUS.

1. **LEVEL OF ENGAGEMENT**

The BCMHSUS PFEC is a formal group of clients, families, and staff working together at the level of “collaborate” on the [IAP2 Spectrum of Public Participation](https://iap2canada.ca/Resources/Documents/0702-Foundations-Spectrum-MW-rev2%20(1).pdf). The promise to patients and families is that BCMHSUS will look to you for advice and innovation in formulating solutions and incorporate your recommendations into the decisions to the maximum extent possible.

1. **OUR ASPIRATION FOR PATIENT AND FAMILY EXPERIENCE**  
   We are committed to a culture where:

* Patients and families partner with staff and physicians to make informed decisions about their own healthcare, as well as the services and policies that affect them.
* Patients, families and staff feel safe, are treated with respect and dignity, and receive care in an environment that is free of racism and discrimination.
* Patients and families feel the quality of health care they receive is extraordinary.
* Patients and families participate in co-designing research projects that are aligned with their priorities.
* The voices of patients and families are at the centre of all decisions, interactions, and activities at BC Mental Health and Substance Use Services.

1. **OUR DEFINITION OF FAMILY**

Family is the primary support for the patient, as defined by the patient. Whoever the patient sees as their family can change over time.

It is a “person or persons who are related in any way (biologically, legally, or emotionally), including immediate relatives and other individuals in the client’s support network. Family includes a client’s extended family, partners, friends, advocates, guardians, and other individuals.” (Accreditation Canada Standards: Mental Health Services).

## OUR GROUP PURPOSE

The purpose of the BCMHSUS Patient and Family Experience Council (PFEC) is to enhance the delivery of services provided by BCMHSUS to all patients/clients within its care. The PFEC will enable family engagement. The PFEC will also promote the engagement of patients and families as partners in research processes.

This will be achieved by:

* Establishing partnerships between patients, families, staff, physicians and researchers across all services and the research institute.
* Learn from the lived and living experiences of patients and families to create programs and environments that are positive, equitable, trauma-informed, and culturally safe.
* Make recommendations to BCMHSUS senior leadership that will improve the policies, processes and culture.
* Advance person-centered care and patient and family engagement across BC Mental Health and Substance Use Services.

## OUR GOAL

To ensure that every patient and family member who receives services at BCMHSUS experiences treatment that is safe, effective, responsive and equitable. Further, to ensure that BCMHSUS research leads to improvements to services that are evidence-based and improve health outcomes.

We will achieve this by:

1. Identifying and advising on strategies, services, projects, and research directions that improve the diverse experiences of patients, clients, and their families; and
2. Empowering patients, clients, and families to actively participate in establishing the goals, processes, and evaluation of BCMHSUS initiatives.

## THE HOW

This goal will be achieved through regular meetings between patients, families, health care professionals and researchers on the PFEC, in which experiences, ideas, and knowledge are shared. BCMHSUS will also engage patients and families in addition to meetings to plan, implement, and evaluate initiatives that are directed by the PFEC, or support patients and families to lead the work.

## GUIDING PRINCIPLES

## As the PFEC we:

## Share our perspectives, knowledge, worldviews, belief systems, and experiences so that others may learn from them.

* Work in equal partnership.
* Actively listen to each other, suspend judgment, and value all viewpoints.
* Keep others’ stories confidential.
* Honour and promote the diversity of all patients, clients and families within our services.
* Prioritize health equity and social justice within our services.
* Seek best and wise practices everywhere.
* Are open to innovation and encourage healthy and respectful debates to enrich discussions.
* Communicate all activities pertaining to the PFEC in a respectful, inclusive and transparent way.
* Uphold the [PHSA Code of Ethics](http://pod/policies/Conduct/Code%20of%20Ethics.pdf) for all PFEC activities.

We practice or we live these principals in all interactions together.

## MEMBERSHIP

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| Recruitment Principles | * At least 50% + 1 of the PFEC will be Patient and Family Partners. * The composition of the PFEC is guided by the desire to learn and share perspectives from a diverse population and broad cross-section of identities served by BCMHSUS, recognizing the intersectional nature of identities (including but not limited to: culture, gender, health condition, sexual orientation, age, geography). |
| Recruitment Method | * Methods of recruitment include: BCMHSUS Patient and Family Partner Network, BC Patient Voices Network, outreach during special events, and word of mouth. |
| Application Process | * Interested patients and families will contact or be referred to the BCMHSUS Patient Experience and Community Engagement team further screening and discussion. |
| Council  Co-Chairs | * The Council will be co-chaired by *(see Appendix B for Co-Chair role descriptions):*   + One Co-Chair who is a patient or family partner   + One Co-Chair who is an BCMHSUS staff member (Director, Patient Experience and Community Engagement) * These positions will be determined by the PFEC through a nomination process on an annual basis. |
| Orientation | * All new members will receive an in-person or virtual orientation by the BCMHSUS Patient Experience and Community Engagement Team.   + The orientation will include a handbook on how to participate in a PFEC. * The Patient/Family Co-Chair will receive an in-person or virtual orientation by the BCMHSUS Patient Experience and Community Engagement Team.   + The orientation will include a handbook on how to co-chair a PFEC.   + The Patient/Family Co-Chair will receive ongoing support from the Staff Co-Chair and BCMHSUS Patient Experience and Community Engagement Team as needed. |
| Term | * Members shall participate on the PFEC for one year, with the possibility of extension. * Following completion of the term, members who are interested in renewing their membership, can reapply. * Members stepping down will be offered an exit interview by one or both Co-Chairs and/or representative(s) from the BCMHSUS Patient Experience and Community Engagement Team. |
| Additional Criteria | * Patient and family partners must have lived/living experience, or have a loved one with lived/living experience, of correctional health services, forensic psychiatric services, and/or concurrent mental health and substance use. * All members must not have any conflict of interest. * All members must be interested in partnership, rather than individual priorities that are not within the scope of the PFEC. |

## COUNCIL PROCESS

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| Agenda | * Agendas will be collaboratively prepared and reviewed by the Co-Chairs. * An agenda will be distributed 5-7 calendar days prior to each meeting to allow for member feedback. * Agendas will be annotated to provide clarity of the purpose of each item, outlining: the level of engagement and the accountable lead. |
| Minutes | * Minutes will be recorded at each meeting by BCMHSUS staff member. * Minutes will be distributed no later than 5-7 calendar days after the meeting to allow for member feedback. |
| Frequency | * Meetings will occur every month in-person or by Zoom. * Each meeting will be 2 hours in duration. |
| Attendance | * If a patient and/or family representative misses two meetings in a row, the Co-Chairs will check in with the individual using their preferred method of communication. |
| Decision-Making | * The traffic light decision-making process will be applied for all PFEC’s decisions, where members vote individually on whether they agree, can live with or veto the decision. |
| Quorum | * At least 10 members, in addition to the Co-Chairs, of the PFEC shall be necessary to constitute a quorum. * A one-to-one ratio of patient or family partner to health care partner must be upheld for quorum (i.e. minimum of 5 patient and family partners and 5 staff partners). |
| Sub-Committees | * Working groups and/or action teams consisting of additional representation may also be established to support planning and implementation of key PFEC activities. |
| Council  Leadership | * Co-Chairs will meet regularly to debrief successes, challenges, opportunities for improvement, and plan an overall strategy for the PFEC, in alignment with BCMHSUS priorities. |

1. **COUNCIL SCOPE**

The roles and responsibilities of all PFEC members are as follows:

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| Inform | * Be **informed** on all key initiatives, activities, strategies and innovations related to the healthcare and research at BCMHSUS, including relevant timelines, goals, decision pathways, and people and teams accountable. * Be **informed** on all key initiatives, activities, strategies and innovations related to healthcare, research, knowledge exchange, education and health promotion at BCMHSUS, including relevant timelines, goals, decision pathways, and people and teams accountable. * Be **informed** on patient experience measurement findings, which will be regularly collected, monitored, and analyzed by designated staff at BCMHSUS, and be supported to understand the meaning of those findings. |
| Consult | * **Review and provide feedback** on BCMHSUS documents, proposals, and plans. * **Advise** BCMHSUS internal stakeholders (including leaders, staff, researchers and physicians) on policies, practices, planning, and delivery of healthcare services from a patient and family perspective. * **Advise** on key strategies, values, behaviours and actions that improve the experience of patients and families. * **Advise** on the integration of best practices, evidence and new knowledge into BCMHSUS initiatives. |
| Involve | * **Identify** opportunities for improvements in key initiatives, activities, strategies and innovations at BCMHSUS. * **Recommend** strategies and practical ideas for improving patient care and patient-oriented research. * **Contribute** to the development of patient experience metrics and performance measures to evaluate the impact of care. |
| Collaborate | * **Define** the ideal patient experience for BCMHSUS’ diverse patient population, that is inclusive of patients and families who experience inequities and/or are marginalized. * **Collaborate** on the development of tools to support healthcare team members to meaningfully engage with patients and families as partners. * **Discuss** patient experience reports and measurement findings and **recommend** actions to address identified gaps. * **Define** metrics and performance measures to evaluate the impact of PFEC-led initiatives. |
| Empower | * **Oversee and lead** BCMHSUS-wide engagement initiatives that aim to improve patient and family experience. * **Develop and implement** a recruitment strategy for the PFEC. * **Lead** the annual self-review and evaluation exercise for the PFEC, including the Terms of Reference and work plan. * **Design** patient- and family-friendly language in all materials where patients and families are the intended audience. * **Communicate** with BCMHSUS workforce, patients, families, and external stakeholders on the progress and performance of PFEC activities. |

**The following issues are out of scope for the PFEC:**

* Specific issues related to patient-provider interactions, critical incidents, and other unit-level daily operations
* Collective agreements

## ACCOUNTABILITY

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| Members | All PFEC members are personally accountable for:   * Our actions, words, and behaviours, including the way in which we communicate with each other. * Attending PFEC meetings and completing action items. * Informing Co-Chairs if we are not able to attend a meeting. |
| Co-Chairs | Co-Chairs are accountable for:   * Liaising between the PFEC and Quality and Patient Safety Committee, ensuring that PFEC recommendations and progress are communicated in a regular, timely manner. * Regularly closing the loop on engagement, reporting back to patient and family partners on how their input was used in the final decision. |
| Reporting | The PFEC is accountable to the BCMHSUS Quality and Patient Safety Committee.  The Quality and Patient Safety Committee is accountable for:   * Ensuring that PFEC recommendations are reflected in decision-making at BCMHSUS. * Reporting back to the PFEC personally or via the Co-Chairs with progress in following through the recommendations, or reasons for why follow-through was not possible. |
| Partnership | The PFEC will regularly engage with (at the level of “Consult” and “Involve”) to the work of the following BCMHSUS committees:   * BCMHSUS Infection Prevention and Control Committee |

## REMUNERATION

Participation on the Patient and Family Experience Council will be as barrier-free and inclusive as possible. To ensure equity in remuneration for all members:

* + Individuals identifying as a patient or family partner will be compensated at a rate of $25.00/hour, in alignment with BC Centre for Disease Control’s Peer Payment Guidelines. This will include meeting time and work outside of meetings as determined by the PFEC co-chairs. It will not include preparation and follow-up time from meetings, unless specified.
  + Individuals who are employed with BCMHSUS or another organization, for whom participation on the PFEC would be considered an activity that is within their professional role and responsibilities, will not be compensated in addition to their wage or salary.
  + Travel, parking, accommodation, and/or meal expenses will be provided to all members travelling to participate in in-person meetings. Compensation in this manner will be determined at the time of their joining at the discretion of the BCMHSUS Patient Experience and Community Engagement team.

*See the* [*BCMHSUS Compensation Guideline*](http://shop.healthcarebc.ca/phsa/bcmhsus/C-03-07-50504.pdf) *for more information.*

## EVALUATION AND REVIEW

The PFEC shall conduct an annual evaluation and self-assessment of this Terms of Reference and of Council management, effectiveness, performance, resources and partnerships. This process includes:

* Feedback on patient and family member experiences will be collected as part of the annual review, including council management, engagement, impact and value.
* Evaluation process will be determined by PFEC members and implemented by staff.
* Changes made to the Terms of Reference must be approved by the PFEC before being enacted.

**Appendix A: BCMHSUS PFEC Membership**

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| **Name** | **Committee Role** | **Role and/or Department** |
| Anita David | Co-Chair | Patient Partner |
| Kathryn Proudfoot | Co-Chair | Patient Experience and Community Engagement (Director) |
| Bryan Benner | Member | Patient |
| Chris Lamoureux | Member | Patient |
| Mark Brady | Member | Patient |
| Mo Korchinski | Member | Patient |
| Pam Young | Member | Patient |
| Phil Kou | Member | Patient |
| Tonia Robataille | Member | Patient |
| Amber | Member | Patient |
| Anja Lanz | Member | Patient |
| Louise Yeoh | Member | Family |
| Ron Merk | Member | Family |
| Shirley Paulsen | Member | Family |
| Wanda LeBlanc | Member | Family |
| Justine Patterson | Member | Executive Leadership Team (Executive Director, Knowledge, Innovation, and Partnerships) |
| *Vacant* | Member | Executive Leadership Team (Chief Operating Officer) |
| Cassie Michell-Bader | Member | Indigenous Patient Experience and Partnerships (Leader) |
| Katie Mai | Member | Patient Experience and Community Engagement (Leader) |
| Nassim Pezeshkzad | Member | Patient Experience and Community Engagement (Coordinator) |
| Laura Accili | Member | Patient Experience and Community Engagement (Assistant) |
| Ayesha Sackey | Member | Forensic Psychiatric Hospital (Director, Allied Health) |
| Nancy Desrosiers | Member | Correctional Health Services/Forensic Psychiatric Services Regional Clinics (Executive Director) |
| Kam Parmar | Member | Correctional Health Services (Manager, Community Transition Teams) |
| Alyssa Rafferty | Member | Adult Mental Health and Substance Use Services  (Director, Interprofessional Practice) |
| Becky Hynes | Member | Heartwood (Social Work Professional Practice Lead) |
| Deborah Ross | Member | Strategic Initiatives/Research Institute (Director, Strategic Initiatives) |
| Dr. Nooshin Nikoo | Member | Physician Representative |
| Davina Gallagher | Member | Quality and Accreditation Lead |

**Appendix B: PFEC Co-Chairs Role Description**

**Background**

The PFEC Co-Chairs uphold the guiding principles of patient- and family-centered care as outlined by the BC Ministry of Health and Accreditation Canada: “Patients and families are provided meaningful opportunities to engage with care providers and leaders in the continuum of quality improvement, policy and program development, implementation and evaluation.”[[1]](#footnote-1)

**Roles and Responsibilities**

The Patient/Family Co-Chair and Staff Co-Chair will be responsible for specific areas of duties and collaborate on a number of duties. These responsibilities are outlined below.

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| **Shared Responsibilities** |
| ***Meetings***   * Manage and lead PFEC meetings, ensuring dialogue is open, honest, respectful, accessible, and inclusive. * Develop the agenda, identifying appropriate topics for engaging the PFEC and developing activities to elicit meaningful input. *\*Admin assistant will send draft to both co-chairs.* * Determine the level of engagement most appropriate for each initiative discussed at the PFEC, using the annotated agenda as a framework. * Liaise with guest speakers to ensure presentations and materials are ready prior to the meetings. * Review the minutes and ensure the records of meetings are correct. *\*Admin assistant will send draft to both co-chairs.*   ***Membership***   * Screen and select applicants. * Ending membership as needed. * Offer and perform exit interviews with outgoing members. * Ensure the PFEC is performing in accordance with the Terms of Reference. * Manage conflicts within the PFEC, including conflicts of interest. * Ensure the work of the PFEC is meaningful for all members.   ***Communications and Partnerships***   * Communicate effectively with the PFEC on a regular basis. * Work together to respond to external emails received by the public email account (triaged by Patient/Family Co-Chair). * Attend meetings and events on behalf of the PFEC as required (e.g. Lunch and Learns, new hire orientation). * Identify and initiate opportunities for strengthened relationships between the PFEC and other teams across BCMHSUS. |

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| **Patient/Family Co-Chair Responsibilities** | **Staff Co-Chair Responsibilities** |
| * Oversee development and implementation of recruitment strategy for patient and family representatives. * Working with the BCMHSUS Patient Experience and Community Engagement team, provide support and orientation to new patient and family members on the PFEC. * Liaise between external patient and family partners and the PFEC, inviting guests to meetings as needed. * Represent the patient/family voice at BCMHSUS events, such as new staff orientation. | * Engage senior leadership to ensure the necessary buy-in for the PFEC’s initiatives exist, ultimately supporting the sustainment of these initiatives. * Engage senior leadership to ensure that the PFEC recommendations are reviewed, actioned upon, and reported back to the committee. * Provide support and orientation to new staff members on the PFEC. * Liaise between BCMHSUS staff and the PFEC, inviting guests to meetings as needed. * Ensure meeting logistics are fulfilled, including Zoom link, space, food, honoraria, etc. * Ensure committee members are provided with speaker information, materials, and date of presentation as a reminder in advance of meetings. * Maintain accurate attendance for each meeting. |

1. BC Ministry of Health (2015). The British Columbia Patient-Centered Care Framework. [↑](#footnote-ref-1)