

# Patient and family engagement at CAMH





# Letter from the CEO: Patient and family engagement

CAMH has a longstanding commitment to patient and family empowerment. We know that there are many benefits for robust patient and family engagement, which include high-quality, safe and more efficient health care, as well as improved patient outcomes and higher patient, family, staff and physician satisfaction. That is why we believe that it's important to include patients and families in all aspects of our work.

CAMH has paid particular attention to meaningful spaces for patients and families within our redevelopment. I'm thrilled to highlight the recent opening of the RBC Patient and Family Learning Space (PFLS), with a door that opens onto Queen St. The PFLS is a safe, welcoming, child-friendly interactive hub for patients, families and the community to access reliable information about mental health, substance use and recovery, CAMH programs and community-based services. It is also the new home of the Family Resource Centre, a service that provides tailored mental health and addictions system navigation support and family-specific educational resources. Located in a bright new space on the ground floor of the new McCain Centre for Complex Care and Recovery at 1025 Queen Street West, the teams offer services and resources in-person and virtually. Patients, families and community members can take part in monthly interactive workshops, webinars and clinics. An advisory committee with patients and family members contributed to the design and development of the space and this committee continues to guide PFLS programming.

The talent, ideas and expertise within our organization is unparalleled. Thank you to the teams who are supporting important patient and family engagement work, including the Patient and Family Advisory Committees, Lived-Experience Research Committee, Family Research Advisory Committee, and Youth Advisory Group.

I returned to CAMH because I believe that mental illness is the most important health issue of our lifetime. The world needs CAMH now more than ever. We're caring for even more patients, and through research and education are pushing our mental health work to new heights. Our advocacy has begun to change societal discourse about mental illness. We're forever grateful for the role patients and families play in making CAMH and the mental health system the best that we can be.



Sarah Downey,  
President and CEO, CAMH



# Patient and family engagement at CAMH

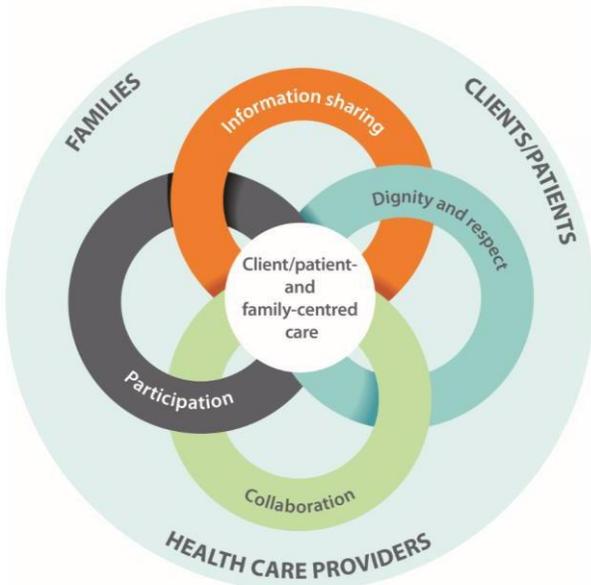
Patient and family engagement at CAMH means patients, family and health care professionals are actively collaborating to improve health care quality, both at direct care and hospital system levels. CAMH is committed to providing an excellent patient and family experience, which includes the following outcomes:

- Better quality and safe health care
- More efficient care
- Improved patient outcomes
- Higher patient and family satisfaction



## Our philosophy: Patient and family-centred care (PFCC)

There are four core concepts of PFCC (Johnson & Abraham, 2012):



- **Dignity and respect:** Health care practitioners listen to and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information sharing:** Health care practitioners share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.
- **Participation:** Patients and families are encouraged and supported in participating in care and decision-making at the levels they choose.
- **Collaboration:** Patients, families, health care practitioners and health care leaders collaborate in policy and program development, implementation and evaluation, in research, in facility design and in professional education, as well as in the delivery of care.

CAMH practices PFCC through a model of engagement (Patient and Family Engagement Framework) to ensure excellent patient and family experiences.

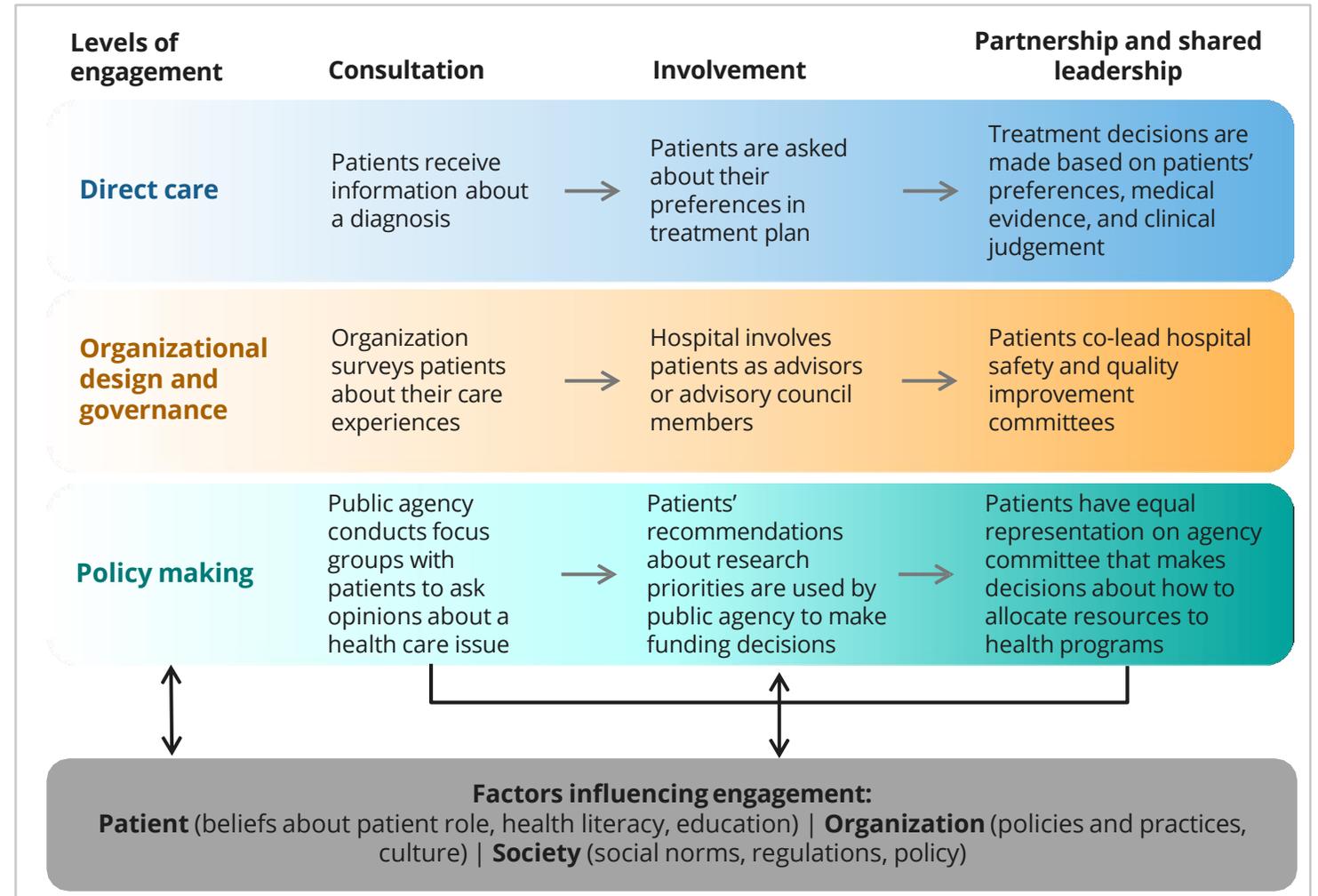
# Patient and family engagement at CAMH

## Our approach: Patient and family engagement

CAMH uses the Patient and Family Engagement Framework (Carman et al., 2013), which outlines three levels of patient and family engagement that exist along a continuum, from consultation to partnership and shared leadership:

- The direct-care level focuses on the level of patient and family involvement and decision-making in their treatment and discharge plans.
- At the organizational level, the patient and family draws upon their experience of care to provide feedback or partner in making improvements to the delivery of care and services.
- Policy making is the third level, and comprises engaging patients at the network, regional or provincial levels of health care services.

This booklet highlights examples of activities that fall into each of the three categories of engagement and where they fall on the continuum, with the hope that they will inspire you and your teams to continue to engage patients and families in meaningful ways. (Please see the appendix on pages 18-20 for a more extensive, but not exhaustive, list of engagement activities across the hospital).



# Patient and family engagement at CAMH

## Our outcomes: Patient and family experience

### Patient and Family Engagement Roadmap:

In 2018, a working group was established by executive leadership team sponsors to develop our systematic, multi-year strategic plan for patient and family engagement. The working group consisted of stakeholders including staff, patients, Family Advisory Committee members, and the Empowerment Council executive. The Ontario Perception of Care Tool for Mental Health and Addictions (OPOC-MHA) and other experience data also informed the working group. The roadmap consists of specific measurable activities and outcomes that fall into six key domains:



# Direct Care



## The RBC Patient and Family Learning Space (PFLS) and Family Resource Centre (FRC)

In October 2022, CAMH's RBC Patient and Family Learning Space (PFLS) held its grand opening, which included the in-person re-opening of the Family Resource Centre (FRC). The PFLS is an interactive hub for patients, families and the community to access reliable information about mental health, substance use and recovery. The FRC supports family members in navigating the mental health and addictions system, shares information about CAMH and community programming, and offers family-facing educational materials. These services are the result of years of planning by the CAMH Patient and Family Education and Patient and Family Experience teams, in partnership with patients and families.

*"Thank you so much for all these excellent, thought-out resources. I'm sure they will make a big difference in my ability to support my partner. Thanks for the wonderful work you do for people like me."*

■ **Consultation**

■ **Involvement**

□ Partnership and Shared Leadership

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## Keeping Connected

Keeping Connected is a weekly group aimed at providing seniors experiencing mood and anxiety challenges with behavioural activation, cognitive stimulation, and engagement with community. This group is intended to help patients overcome feelings of loneliness and isolation through conversation, learning, and shared problem-solving with peers in an informal, non-therapy setting. Patients played a key role in shaping the development and delivery of this program. Keeping Connected was made possible through a generous Estate donation and co-collaboration of the Geriatric Mental Health Outpatient Program and the Patient and Family Experience team.

■ **Consultation**

□ Involvement

■ **Partnership and Shared Leadership**

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# Direct care



## Hope by CAMH

Hope by CAMH is a free smartphone app that provides suicide prevention information, tools and resources to support and guide individuals when they are experiencing thoughts of suicide. One of the key features of this app is the ability for individuals to create a personalized suicide safety plan.

■ **Consultation**

■ **Involvement**

□ Partnership and Shared Leadership

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## Collaborative Learning College

The Collaborative Learning College is a recovery college that offers non-clinical-based education and training programs to people who have lived/living experience of mental health and/or substance use challenges, and who feel ready to set goals, gain skills and make social connections as part of their personal journey. In keeping with an internationally adopted approach to recovery-oriented education, the courses offered at the Collaborative Learning College are:

- created or co-created and led or co-led by people with lived/living experience of mental health and/or addiction challenges and/or social services use
- offered free of charge
- adaptable to local needs and resources
- open to people who have experienced mental health and/or addiction challenges and/or social services use.

□ Consultation

■ **Involvement**

■ **Partnership and Shared Leadership**

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# Direct care



## The CAMH Bill of Patient Rights

The CAMH Bill of Patient Rights (the Bill) was originally passed by CAMH's Board of Trustees in 2004. The Bill was developed through extensive work with patients, CAMH staff, and members of other interested organizations, and was created in collaborative partnership between the Empowerment Council and CAMH. The Bill underwent further revision in 2023, again in consultation with patients, CAMH staff, and other stakeholders, with the objective of more fully and accurately asserting and promoting the dignity and worth of all those who use the services of the organization. As such, the Bill now more fully and accurately expresses the truth that patients possess the same fundamental human rights extended to all Canadians, and that CAMH is committed to upholding of those rights therein. The patients, families, and staff of CAMH who have worked together to develop the Bill understand it to be a living document that will grow and change as it helps to foster an organizational culture of mutual respect. CAMH commits to ensuring that every patient is offered a written copy of, and assistance in understanding, the complete Bill, and to posting its 10 core principles at CAMH's main entrances and other places across the organization where patients receive services.

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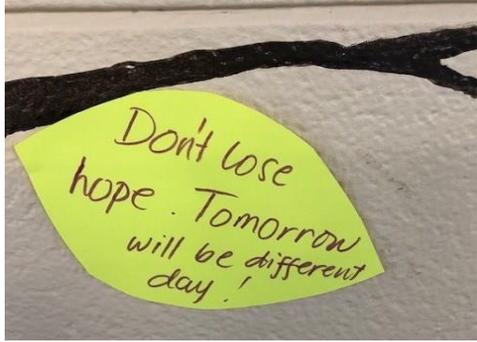
■ **Consultation**

■ **Involvement**

■ **Partnership and Shared Leadership**

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# Organizational design and governance



## Trauma-Informed De-escalation Education for Safety and Self-Protection (TIDES) Program Expansion

One of CAMH's top priorities is ensuring a safe environment for patients, families, staff and physicians. In September 2018, CAMH launched the Trauma-Informed De-escalation Education for Safety and Self-Protection (TIDES), a hands-on training program to help all staff and physicians work safely and effectively with patients. Patients, care providers and representatives from the Office of Family Engagement and the Empowerment Council were key members in the design and implementation process. A key collaboration has been engaging service user educators to co-facilitate the CAMH staff training. In 2022, the Patient and Family Experience team began partnering with the TIDES team to incorporate patient-and-family-centred care content into new employee orientation for non-clinical staff, because all staff can make a difference to patient and family experience.

■ Consultation

■ Involvement

□ Partnership and Shared Leadership

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## Family Research Advisory Committee

The Family Research Advisory Committee is a standing committee at CAMH comprised of family members (or carers, caregivers, family of choice, etc.) of people with lived or living experience of mental health and substance use challenges. The committee is representative of the wide range of populations that CAMH serves, and advise on high-level or cross-hospital research elements.

Committee members share their perspectives to inform and shape future research directions at CAMH, and help guide research goals, activities and outcomes to better reflect the needs of the community that CAMH serves.

■ Consultation

■ Involvement

■ Partnership and Shared Leadership

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# Organizational design and governance



## Patient Portal

Patients registered at CAMH can access a patient portal that is fully integrated with I-CARE, thus providing them with a free and easy way to view components of their health record online. Patient representatives were involved in the design process. Building upon patient portal evaluation findings from previous patient engagement initiatives, new resources were added to CAMH's patient portal in January of 2023. Specifically, mental health and addictions educational resources and digital mental health tools (i.e. apps), were added to the patient portal. These tools were added in hopes of better supporting CAMH patients in navigating and accessing evidence-based resources that they may otherwise not be aware of.

*"I commend the teams who have worked so hard in collating and building these expansive lists in a format that makes the tools visually appealing and easy to understand."  
- Client Participant 1*

■ Consultation

■ Involvement

□ Partnership and Shared Leadership

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## The Patient and Family Partners Program

The Patient and Family Partners Program (PFPP) enhances the spread and scale of patient and family engagement at CAMH. The PFPP recruits and orients patient and family partners and matches them with a wide array of research, quality improvement, and product development projects and initiatives across the organization. It is the result of a collaboration between the Patient and Family Engagement in Research and Patient and Family Engagement teams.

■ Consultation

■ Involvement

■ Partnership and Shared Leadership

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# Organizational design and governance



## Constituency Council

The CAMH Constituency Council is a provincial voluntary advisory council made up of 50-70 stakeholders tasked with providing advice, insight, and feedback to the organization, its strategic plan and its Board of Trustees. The council has designated spots for representation from people with lived experience and family members. The council was recognized as an Accreditation Canada Leading Practice in 2016, and leverages CAMH's Community Engagement Framework in their practices. The group has been a great resource for development discussions at the hospital, information and resource sharing with local communities and guiding the work of CAMH.

■ Consultation

■ Involvement

□ Partnership and Shared Leadership

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## Phase 1D Secure Care & Recovery Building

As planning is underway for the Phase 1D project of the Secure Care & Recovery Building, patient and family representatives on a broad range of user groups have been integral to the development of a new paradigm developed for the space to:

1. Inspire hope, healing and a sense of being valued
2. Support patient choice, autonomy and personalized recovery
3. Enable positive staff and family interactions and connections with patients
4. Provide spaces where privacy, dignity and safety are valued
5. Ensure optimal long term flexibility and adaptability to accommodate future patient needs and/or changes in service delivery models

*"I suggested that plants be placed in the entranceway and lobby of the building. Engaging in this project allowed me to learn more about how this simple idea moves from conception to reality through the various production steps required to make this happen."*

■ Consultation

■ Involvement

□ Partnership and Shared Leadership

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# Organizational design and governance



## Ontario Perception of Care Tool for Mental Health and Addictions (OPOC-MHA)

Every year we ask patients and families to complete the OPOC-MHA survey to provide us with valuable feedback about many aspects of their experiences of care at CAMH. This helps us understand what we are doing well and where we can do better and is a crucial component in our ongoing quality improvement efforts. The survey is administered by surveyors with lived experience engaged through CAMH's Employment Works! Program (learn more about Employment Works! on page 15). Surveyors visit inpatient units, outpatient clinics, in-person and virtual treatment groups, and waiting rooms, to connect with as many patients and families as possible. Having surveyors with lived experience helps patients feel at ease and empowers them to speak openly.

The results of the survey are used to inform both immediate and long-term changes at the hospital, to best support the needs of patients and families. Survey results are also shared with patients and families on the camh.ca website and through in-person and virtual information and feedback sessions, held by the Patient and Family Experience team.

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■ **Consultation**      □ Involvement      □ Partnership and Shared Leadership

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## Lived Experience Research Committee (LERC)

The Lived Experience Research Committee is a standing committee at CAMH comprised of people with lived or living experience of mental health and substance use challenges. The committee is representative of the wide range of populations that CAMH serves, and advise on high-level or cross-hospital research elements. Committee members share their perspective to inform and co-create research at CAMH, and help guide research goals, activities and outcomes to better reflect the needs of the community that CAMH serves.

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■ **Consultation**      ■ **Involvement**      ■ **Partnership and Shared Leadership**

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# Organizational design and governance



## Brain Health Data Bank

The BrainHealth Databank (BHDB) is creating a Learning Health System that will improve patient care and enable discovery and innovation. The BHDB has worked together with advisors representing patients, family, and people with lived experience (PFLE). One example was a consultation series of five interactive workshops to engage stakeholders across the hospital to gather user requirements. Members of the clinical and research patient and family advisory committees were invited to participate and were provided onboarding on technical aspects. PFLE advisors participated at each workshop accounting for 21.5% of stakeholder engagement. Their participation led to a project to co-design the treatment trajectory dashboard for patients. The project was co-led by a patient advisor and involved developing questions for semi-structured interviews with patient and family advisors and clinicians. This produced a formal project report, a presentation to BHDB stakeholders, and a wireframe prototype of the dashboard. As a consequence of the work in these projects, the role of BHDB patient and family advisors evolved to formally joining the BHDB Steering Committee. Their participation in the Steering Committee allows patient and family perspectives to be represented first-hand and to directly influence decision-making.

- Consultation
- Involvement
- Partnership and Shared Leadership

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## Patient and Family Advisory Committees

The Patient Advisory Committee (PAC) is a partnership between CAMH staff and patients affected by mental illness and/or addiction. The PAC engages with patients, community members and care providers in order to improve patient care and enhance the experience of patients at CAMH.

The Family Advisory Committee (FAC) is a partnership between CAMH staff and family\* affected by a loved one's mental illness and/or addiction. The FAC works to ensure that the family perspective is always considered and incorporated in organizational activities, events and decision making.

\*"Family" is defined broadly as meaning a relative, partner, close friend or supportive person.

- Consultation
- Involvement
- Partnership and Shared Leadership

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# Organizational design and governance



## Employment Works!

CAMH Employment Works! supports the employment goals of people with lived experience with mental health and addiction services. Employment Works! offers job application support, resume counselling, interview preparation and employment coaching. The support provided is based on the needs and aspirations of the individual, and Employment Works! has helped hundreds of people achieve their work-related goals. Examples of goals that people have pursued with the assistance of Employment Works! include part-time and full-time opportunities at CAMH, employment opportunities that require lived experience, and pursuing promotions and more senior opportunities.

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### ■ Consultation

□ Involvement

□ Partnership and Shared Leadership

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# Policy making



## Provincial System Support Program (PSSP)

The Provincial System Support Program (PSSP) works with communities, service providers, and other partners across Ontario to move evidence to action and create sustainable change in Ontario's mental health and addictions system. With expertise in knowledge mobilization, implementation, evaluation, equity, lived experience engagement, and data management, PSSP is on the ground collaborating with stakeholders to build a better system.

PSSP acknowledges the importance of being guided by lived experience as evidence, analysis and expertise through meaningful engagement practices. In particular, we value approaches to engagement that center anti-racism and anti-oppression. Here are a few key examples of our work:

- 1) Gathering evidence and advice on PSSP-supported projects from a panel of diverse people with lived experience/family members from across the province.
- 2) Building capacity for equity-thinking and meaningful engagement through tools, resources and educational workshops on anti-racism, anti-oppression, critical thinking, and collaborative partnerships.
- 3) Embedding engagement as a key component in provincial projects like the Substance Abuse Program for African Canadian and Caribbean Youth (SAPACCY) by convening a Provincial Black Youth Advisory Panel (PBYP) that provides guidance on program design, implementation, evaluation knowledge exchange and the strategic direction of the program.
- 4) Collaboratively mobilizing knowledge through initiatives, resources, and activities that bring together communities, service providers, researchers, clinicians, people with lived experience, caregivers, system leaders and policymakers to identify and respond to knowledge needs and evidence gaps.

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■ **Consultation**

■ **Involvement**

■ **Partnership and Shared Leadership**

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# Policy making



## Public Policy Office

CAMH has a long history of advocating for evidence-based public policies that are responsive to the needs of people with mental illness and substance use disorders. The Public Policy Office develops positions on a range of topics including cannabis, criminal justice, opioids, supportive housing and alcohol. All public policy positions are developed in consultation with stakeholders. Frequently, this includes CAMH patients and others with lived experience of mental illness. For example, the Public Policy Office has partnered with CAMH's Empowerment Council to co-develop recommendations for improving police interactions with people with mental illness. The office sought input from CAMH's Youth Advisory Group on different topics and engaged with family members for input on cannabis and alcohol work.

### ■ Consultation

□ Involvement

□ Partnership and Shared Leadership

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## Empowerment Council

The Empowerment Council (EC) is an independent organization operated by people with experiential knowledge of the mental health and addictions systems. The EC advocates on behalf of CAMH patients and, in addition to advocacy, works within three additional broad domains: education, research, and engagement. The EC was integral to creating the CAMH Bill of Patient Rights, and reviews all of CAMH's clinical policies advocating consistently for a patients' rights orientation. It has been through engagement with theory, empirical research, methodological approaches, justice frameworks, and collaborative learning with a variety of audiences and stakeholders, including psychiatry residents, clinicians, university students, inpatient and outpatient groups, and international service user organizations, that the EC has broadened its impact. Numerous academic colleagues, patients, student placements and volunteers with lived experience have contributed to the foundation and identity of the EC over a 30-year period. And it has been through this work that the EC has developed leadership, advocacy, and critical analysis skills aimed at challenging sanism and prejudice in favour of equality, intersectionality, respect for disability history, and anti-oppressive practices.

### ■ Consultation

■ Involvement

■ Partnership and Shared Leadership

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# Appendix:

Additional examples of patient and family engagement in initiatives, programs and services across CAMH

Direct care		
Consultation	Involvement	Partnership and shared leadership
<ul style="list-style-type: none"> <li>• Patient-oriented discharge summaries (PODS)</li> <li>• Safety and comfort plans</li> <li>• Patient and Family Experience Flash Workshops</li> <li>• New Employee Orientation</li> <li>• Patient Journey Mapping (Medical Withdrawal Service)</li> <li>• Psychosis Recovery and Treatment Family Group</li> <li>• “Supporting Family Partners” information guide</li> <li>• University of Toronto Acute Navigation Service</li> <li>• Infection Prevention and Control patient survey about isolation protocols</li> <li>• Clozapine booklet inpatient focus group</li> <li>• Virtual Urgent Care portal</li> <li>• Standards and Measures Advisory Committee</li> </ul>	<ul style="list-style-type: none"> <li>• Patient-oriented discharge summaries (PODS)</li> <li>• This is ME</li> <li>• This is My Family</li> <li>• Patient Journey Mapping (Medical Withdrawal Service)</li> <li>• Psychosis Recovery and Treatment Family Group</li> <li>• “Supporting Family Partners” information guide</li> <li>• Clozapine booklet inpatient focus group</li> <li>• Virtual Urgent Care portal</li> <li>• Standards and Measures Advisory Committee</li> </ul>	<ul style="list-style-type: none"> <li>• “Supporting Family Partners” information guide</li> <li>• Patient Journey Mapping (Medical Withdrawal Service)</li> </ul>

# Additional examples of patient and family engagement across CAMH

Organizational design and governance		
Consultation	Involvement	Partnership and shared leadership
<ul style="list-style-type: none"> <li>• Integrated Care</li> <li>• Mental Health Justice Hub Knowledge Advisory Committee</li> <li>• Accreditation Mock Surveys – patient surveyors</li> <li>• Updates to camh.ca</li> <li>• Patient and Family Experience Week</li> <li>• Fair &amp; Just CAMH Steering Committee</li> <li>• Digital Health Strategy Steering Committee, and Digital Health Strategy Patient and Staff Engagement Working Group</li> <li>• Medication Safety Committee</li> <li>• Program Quality Councils and working groups</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated Care</li> <li>• Mental Health Justice Hub Knowledge Advisory Committee</li> <li>• Accreditation Mock Surveys – patient surveyors</li> <li>• Updates to camh.ca</li> <li>• Patient and Family Experience Week</li> <li>• Clinical Care Committee policy review working groups</li> <li>• Fair &amp; Just CAMH Steering Committee</li> <li>• Digital Health Strategy Steering Committee, and Digital Health Strategy Patient and Staff Engagement Working Group</li> <li>• Medication Safety Committee</li> <li>• Program Quality Councils and working groups</li> </ul>	<ul style="list-style-type: none"> <li>• Integrated Care</li> <li>• Patient and Family Experience Week</li> </ul>

# Additional examples of patient and family engagement in initiatives, programs and services across CAMH

Policy making		
Consultation	Involvement	Partnership and shared leadership
<ul style="list-style-type: none"><li>• Mental Health Justice Hub Knowledge Advisory Committee</li><li>• Fair &amp; Just CAMH steering committee</li></ul>	<ul style="list-style-type: none"><li>• Mental Health Justice Hub Knowledge Advisory Committee</li><li>• Fair &amp; Just CAMH steering committee</li></ul>	

## References

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Johnson, B.H. & Abraham, M.R. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

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