

Engaging people with lived experience in mental health and substance use decision-making



While people with lived/living experience and expertise (PWLE) of mental health and substance use (MHSU) have played a major role in shaping MHSU systems for decades, this role is increasingly recognized and formalized. The *Supporting Transformation through Research, Evidence, and Action in Mental health (STREAM) Lab* at the *Waypoint Centre for Mental Healthcare* conducted a rapid review of academic literature and published reports, and interviewed experts (most of whom have lived experience) to explore approaches to PWLE engagement in MHSU decision-making. Based on 25 academic articles; over 30 toolkits, resources, and real-world examples; and 17 diverse expert perspectives, we highlight key findings and considerations that may be relevant to decision-makers supporting MHSU systems planning in Ontario.

Impact of PWLE engagement

Evidence suggests that PWLE engagement has impacts at individual, organizational/community, and system levels:

Individual level: engagement can support personal healing and skills-building among PWLE.



Organizational/community level: engagement can build community capacity, balance power dynamics between decision-makers and PWLE, and promote the use of collective knowledge.



Societal level: engagement can support the development of relevant and equitable policies; stigma reduction; and cultural shifts around how we talk about and address MHSU concerns and needs.



Main approaches to PWLE engagement

Seven approaches to engaging PWLE in policymaking were identified:

Deliberative



Dialogues between PWLE, system decision-makers, care providers, researchers, etc. on various policy priority areas.

Committees and councils



May include PWLE embedded into existing advisory bodies or groups consisting solely PWLE.

PWLE-led



Entails PWLE leadership in advocacy and decision-making, often drawing on collective knowledge.

Narrative



Uses stories and personal accounts to influence decision-making.

Digital



Uses social media and digital tools to gather insights from PWLE (e.g., analysis of posts).

Research



Gathers insights from PWLE through research-based methods (e.g., interviews, reviewing existing research).

Translation



Involves translating lived experience into forms that are legible to decision-makers.

Engagement also occurs along a spectrum from more passive forms of participation to those where PWLE actively influence decisions. Different PWLE may want to be engaged to different extents.

Challenges to PWLE engagement

The literature also described four main challenges to engaging PWLE in MHSU contexts:

Perceived legitimacy



Academic expertise may be disproportionately privileged over lay knowledge.

Emotional complexities



Engagement can evoke both painful and positive emotions; pathologizing these emotions can further stigmatize PWLE.

Representativeness



Initiatives may fail to include diverse perspectives, and may raise questions of authenticity and professionalization.

Structural barriers



Stigma, biases, and limited personal resources can restrict PWLE's ability to engage.

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There are several limitations to the evidence presented:

- There was a lack of concrete guidance around engagement of PWLE in MHSU policy contexts; engaging equity-denied groups; and impacts of engagement.
- Our rapid approach to evidence synthesis was not optimized to capture all relevant historical and critical literature on the topic.
- PWLE were not engaged as part of the formal research team.



Considerations for decision-makers:



Align selected approaches with the policy stage



Establish funded leadership roles for PWLE



Recruit PWLE thoughtfully and have clear roles



Tailor processes to the preferences and needs of PWLE



Offer a range of engagement opportunities



Respect emotions - don't pathologize them



Support PWLE and facilitators throughout the engagement



Foster safe spaces for engagement



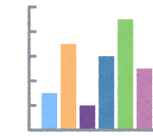
Consider accessibility needs



Reflect on power dynamics & have challenging conversations



Engage diverse PWLE and draw on collective knowledge



Evaluate impact, when possible

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About STREAM Lab

Supporting Transformation through Research, Evidence, and Action in Mental Health (STREAM) Lab is dedicated to meeting the evidence needs of mental health and addictions decision-makers in Ontario and beyond. STREAM products focus on evidence related to health systems, delivering actionable insights that can inform planning and decision-making. STREAM is based at the *Waypoint Centre for Mental Health Care*. The findings in this product should not be taken to represent the views of Waypoint or our funders.