Terms of Reference

Advisory Sharing Circle

The GEM Hub

Executive Summary

Purpose of this document

This document outlines the purpose and functioning of the Advisory Sharing Circle (ASC), and what to expect as a member of the ASC.

Background

When a person nearly misses death, but survives complications during pregnancy, childbirth, or within 42 days after pregnancy, they are said to have experienced a "near-miss event"[1]. The World Health Organization (WHO) has recommended using indicators of serious complications, including near-miss events, to monitor and improve the quality of pregnancy care[2]. In addition, reducing near-miss events is an essential step to reach the WHO's Sustainable Development Goals for pregnancy-related mortality reduction by 2030[3]. Notably, serious complications and mortality in pregnancy disproportionately affect certain population groups, including racialized, immigrant, Indigenous, 2SLGBTQAI+ communities, and individuals residing in rural or lower income areas or living with disabilities[4-13], reflecting multiple ongoing inequities.

Purpose The GEM Hub

This Hub has been created to address pregnancy-related near-miss events and deaths, and to improve the health and wellness of women and gender-diverse people in Canada. The Hub aims to be a place for persons and families with lived experience of pregnancy (including near-miss events), community partners, health care professionals, decision makers, policy makers, and researchers to meaningfully interact and co-create knowledge mobilization activities (see definition below) addressing pregnancy-related near-miss events and deaths in Canada. These will include research priority setting activities, as well as the co-development of material by Hub members and collaborators within working groups to improve the quality of pregnancy-related care. Progress on activities will be shared within the community of the Hub and the general Public throughout the duration of the project.

Description of the GEM Community

The Hub community is composed of:

Advisory Sharing Circle

The Tripartite leadership (Rohan D'Souza, the Canadian Perinatal Programs Coalition, and Isabelle Malhamé), and members of the Hub.

Working Groups

Members of the GEM community and external collaborators.

GEM Community

All members.

For detailed explanation of our community review the Expression of interest document here

[1] *An Interim Steering Council convened by the Tripartite Leadership and stakeholders with expertise in EDI, Indigenous Health, Health Equity Research, and Patient and Public Engagement co-developed the first ASC. The Interim Steering Council will dissolve once the first ASC is developed.*

Key definitions

Knowledge mobilization: a broad umbrella term encompassing a wide range of activities related to the production and use of knowledge, including knowledge synthesis, dissemination, transfer, exchange, co-creation, and co-production by researchers and knowledge users (e.g., clinicians, policymakers, persons with lived experience of pregnancy, their family, support persons and others)[14].

Goals

To advise Working Groups on the co-creation of knowledge mobilization activities.

To make recommendations to ensure that principles of EDI (Equity, Diversity, and Inclusion), OCAP (Ownership, Control, Access, and Possession), and EGAP (Engagement, Governance, Access, and Protection) are adhered to across activities of the Hub.

To make recommendations to ensure that activities of the Hub center on the voices of persons with lived experience of pregnancy (including near-miss events).

Members

Size of the ASC:

- The ASC will bring together a group of 10 to 15 individuals per meeting.
- The ASC will seek multisectoral input from individuals with cultural or spiritual knowledge, experiential knowledge, and/or mainstream or academic knowledge.

Recruitment:

- New and continuing membership will be sought periodically from within the GEM community, existing networks of GEM community members, and the Public.
- Guidelines will be created by ASC members to determine recruitment practices for new Hub and ASC Members.

Representation:

- We will seek to bring together the perspective of diverse stakeholders with cultural or spiritual knowledge, experiential knowledge, and/or mainstream or academic knowledge, including but not restricted to the following prioritized groups:

    - Persons, family members, and carers of those with lived experience of pregnancy and/or pregnancy-related near-miss events and deaths
    - Gender non-conforming/Diverse/2SLGBTQIA+ communities
    - First Nation, Métis, Inuit communities
    - Racialized communities, newcomers, refugees, persons with non-permanent status
    - Persons with disabilities
    - Persons with lived experience of a “high-risk pregnancy”
- Intersectional identities will contribute to expanding representation within the ASC.
- We will strive to recruit 2 or more individuals within each prioritized group.
- We will strive to put into place a backup system with 2-3 individuals per stakeholder group and prioritized group as designated alternates to optimize representation at each meeting.

Term’s Length:

- Membership will consist in a renewable 2-year commitment, with the possibility of having alternate years of joining.

Meetings Frequency :

- The ASC will meet once every 4 months (3 times per year).

Leadership

- The tripartite leadership of the Hub will continue to have inclusive leadership practices, including co-building of different structures/processes of the Hub.
- Leadership of ASC meetings will be rotated.
- ASC members will be offered the opportunity to facilitate meetings.

Decision making

- A consensus-based decision-making approach will be the preferred approach for the Tripartite Leadership and members will be provided information about its Indigenous and global origins.
- Within this approach, a process will be put into place for individuals to be able to maintain their stance without holding back the decision-making process.
- The ASC will agree on a mechanism for how to interpret the absence of responses.
- The Tripartite Leadership will make final decisions with input.

Appreciation payments

- Persons with lived experience and non-academic ASC members will receive an appreciation payment for their time according to their level of engagement and in keeping with Appreciation Payment Guidelines, found in the ASC google folder available to members.

Striving for equity within co-creation

- We acknowledge that various power differences exist within the ASC, and the leadership team of the Hub will hold a responsibility to be transparent in identifying variations in access to power within the Hub spaces.

Organizers are expected:

- To set meeting dates, discussion points, and agenda ahead of time with ASC members.

- To ensure availability of all documents and meeting notes in a shared location.
- To provide sufficient explanations for all ASC members to understand the topic at hand.
- To agree on meeting times that are consistent and mindful of members' other engagements.
- To put mechanisms into place for people to engage and say what they need to say even if they are not able to attend the meeting.
- To provide updates of KM activities and changes to the Hub.
- To highlight where and how contributions from members are being applied within the Hub and in KM activities.

Members are expected:

- To read and adhere to the Group Norms for working together.
- To complete the following free online training modules (The trainings with ** are strongly suggested, but all trainings are offer valuable perspectives and are encouraged):
    - Tri-council policy statement
        - Core 2022 (Course on Research Ethics) **
    - Toronto Academic Health Science Network
        - Anti-Black Racism eLearning modules**
    - Queens University (Open Access Version)
        - Indigenous Community Research Partnerships**
    - Trans Care BC - The Education Centre
        - Intro to Gender Diversity Expanded**
        - Indigenous Gender Diversity**
    - Sex and Gender Considerations in Research
        - Course 2
        - Course 3
    - CIHR - Research Involving First Nations, Inuit, and Métis Peoples of Canada
        - Chapter 9

- To attend a minimum of 2 out of 3 x 90-minute meetings and attend one event per year.
- To read provided material ahead of time in preparation for the meetings.
- To provide anonymous feedback on any issues that may arise, including harmful dynamics such as racism, colonial legacies, discrimination, sexism, transphobia and homophobia.

Advisory Sharing Circle Member's Name

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Date

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References

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