Health Equity Advisory Group – Terms of Reference

Background on BORN

BORN was created by CHEO and the Ministry of Health and Long-Term Care in 2009. It is a prescribed person under PHIPA established for the following purposes:

- To build and manage the pregnancy, birth, and childhood registry
- To build a source of accurate and timely pregnancy, birth, and childhood information for facilitating and improving the provision of health care to pregnant individuals and children in Ontario
- For analysis of pregnancy, birth, and childhood data to support decision making by health-care providers and planners.[1]

Health information custodians may disclose personal health information to BORN for the purpose of "facilitating or improving the provision of health care."[2] As such, BORN is a secondary collector of personal health information. PHIPA, however, imposes limits on BORN's ability to use and disclose the personal health information that it receives. BORN may use personal health information as if it were a health information custodian in limited circumstances:

a. Use personal health information for the purpose of conducting research;
b. Disclose personal health information to researchers;
c. Disclose to a prescribed entity; and
d. Disclose de-identified personal health information to the Minister of Health.[3]

As a recipient of personal health information, BORN may also use and disclose the personal health information it receives for the same "purpose for which the custodian was authorized to disclose the information under this Act" pursuant to s. 49(1)(a).[4] This is a limited right of further disclosure as BORN may only do so for the custodian's purposes, such as disclosures related to the provision of health care to the custodian's patient, rather than BORN's own purposes.

BORN is also required to publish a plain language description of its functions and purposes.[5] In its statement, *P-07: Statements of Purpose for Data Holdings Containing Personal Health Information*, BORN identified seven purposes related to facilitating and improving the provision

[1] BORN Privacy and Security Plan: *P-07: Statements of Purpose for Data Holdings Containing Personal Health Information*.
[2] *PHIPA*, s. 39(1)(c)
[3] *PHIPA*, s. 37(1)(j), s. 44, s. 45, and s. 47 (respectively)
[4] *PHIPA*, s. 49(1)(a)
[5] *PHIPA Regulations*, O.Reg. 329/04 General, at s. 13(3)
[6] BORN Privacy and Security Plan: *P-07: Statements of Purpose for Data Holdings Containing Personal Health Information*.

of health care.[6] The statements of purpose may be amended and are not intended to be an exhaustive list of the purposes for which BORN uses and discloses personal health information.

BORN's Seven Purposes:

1. Identify individuals or settings where appropriate care has not been received and facilitate access to care and treatment for pregnant and birthing individuals, infants, and children.
2. Facilitate continuous improvement of health-care delivery tools to minimize adverse outcomes.
3. Determine where pregnancy, birth, and/or newborn outcomes are clinically or statistically discrepant with accepted norms and raise alerts where necessary.
4. Enable health-care providers to improve care by providing information & tools to compare their outcomes and performance with peers and/or benchmarks.
5. Identify areas where best practice evidence needs implementation (knowledge translation strategies) to improve the quality and efficiency of care for pregnant and birthing individuals, and children.
6. Create reports that can be used to provide the Ministry of Health, Local Health Integration Networks and Public Heath Units with comprehensive and timely information for pregnant and birthing individuals, infants, and children.
7. Facilitate the provision of health care to a pregnant individual and/or child through the pre-population of personal health information n used by or between health information custodians within the circle of care of a pregnancy and/or resulting delivery (including postpartum care and newborn care).

Health Equity Advisory Group

BORN's mandate is to facilitate and improve care for pregnant and birthing individuals, children, and families. The Health Equity Advisory Group (HEAG) provides guidance, recommendations, and support to BORN with a lens on equity.

 A health equity approach recognizes that health is not distributed equally. Addressing health inequities starts with data.

The collection and use of race-based data is important in order to enable BORN to meet its mandate to facilitate or improve the provision of health care for all individuals. This may also include other social factors that may impact health such as age, language, ethnicity, immigration status, disability, socio-economic status, sexual orientation, gender, religion, education, food insecurity and others.

BORN's approach should be a responsible and ethical one, where we will measure, monitor and report on health inequities with careful consideration of the systems that enable inequities

rather than focus on individual identities. As an example, race is not a barrier to optimal health, but systemic racism can be.

Overall, neither Anti-Racism Act (ARA), its regulations, nor the ARA Data Standards will be directly applicable to BORN and its programs. However, BORN will be mindful of the principles outlined in the ARA Data Standards, and the ARA to the extent that they identify the appropriate questions to include or use when collecting race-based personal information.

Indigenous data will have other considerations, for example but not limited to OCAP principles. With Indigenous partners, BORN is developing an Indigenous engagement strategy to better inform and support the use and governance of Indigenous people's data in a respectful, culturally safe, accessible way that ensures individual privacy and confidentiality and is responsive to the needs of individuals and communities. This work is part of a separate portfolio to the work being carried out by the Health Equity Advisory Group.

Objectives

The HEAG has the following two objectives:

1. Review the collection of race-based data and other social determinants of health data in the BORN Information System (BIS) and provide guidance on appropriate collection, use, storage and governance of race-based data and other social determinants of health data to facilitate and improve care.
2. Provide recommendations to leadership on how BORN can align or implement equity-guiding and anti-racism principles to all work and operations.

Composition

External Advisory Group: The Voices that will Shape our Plan

BORN will seek out expertise from those with lived experiences and for whom the data collected affects. It is crucial that the voices of those who are impacted are centred in all the decisions, to ensure efforts reflect what is meaningful to individuals facing inequities.

Equity-seeking groups are communities that face significant collective challenges in participating in society. This marginalization can be created by attitudinal, historic, social, institutional, and environmental barriers based on age, ethnicity, disability, economic status, immigration status, race, sexual orientation, gender, religion, etc.

Given that it is vital that this be a space where the goal is to create an environment where members can discuss freely, safely, and respectfully engage with each other, members of the *External HEAG* will ideally identify as belonging to at least one equity-seeking group.

Ideally, this advisory group will be composed of approximately 15 members plus a BORN chair (or two co-chairs). The number of members is not such a concern rather than diversity of lived experiences and representation, from the following areas:

1. Pregnant and birthing individuals
2. HICs (Hospitals, MPGs, Birth Centre and other organizations)
3. Prenatal Screening
4. Obstetrics
5. Midwifery
6. Family Physician
7. Neonatal
8. Indigenous Health
9. Nursing
10. Community organizations that serve equity-seeking groups
11. Researcher/Epidemiology
12. Public Health
13. MNOC representative

Ex officio

14. CIHI representative
15. PCMCH representative
16. Ontario Health representative

Internal Advisory Group (BORN Members): Moving the Work Forward

A small group of BORN staff will be selected, who will represent various domains across our organization. The internal HEAG group will be responsible for moving the work forward within BORN and ensuring that the opinions and expertise of our External HEAG are championed.

Ideally, this group will be composed of about 10 members, plus a chairperson, and have representation from:

1. Clinical Content Specialists
2. Data Analysis & Research Team
3. Data Quality
4. Indigenous Wellness
5. Provincial Perinatal Engagement Team
6. Privacy
7. Prenatal Screening Ontario
8. Tech/Reporting
9. Leadership
10. Management/Executive

The BORN chair(s) of both committees should be the same individual(s). Since the BORN chair(s) will facilitate and attend the meetings of the external group, they must also identify as a member of at least one equity-seeking group if they are to attend the External HEAG. The role of the BORN staff member(s) present at the External Group is to provide resources to the committee and to relay discussion points back to the Internal HEAG members.

Selection

External Advisory Group: The Voices that will Shape our Plan

A call for members will be circulated annually. Existing members will be asked to indicate their interest in renewal of their term, as per the terms of membership. Interested new members will be asked to submit a statement of interest.

Members of the Internal Advisory Group (BORN staff) will select committee members who will best fulfill its purpose and responsibilities while ensuring diverse lived experience and representation. Advice from the external chair will also be solicited for new member selection. Management will review and submit to Executive for final approval.

Given that it is vital that this be a space where the goal is to create an environment where members can discuss freely, safely, and respectfully engage with each other, members of the External HEAG will ideally identify as belonging to at least one equity-seeking group.

Internal Advisory Group (BORN Members): Moving the Work Forward

A call for members will be circulated to all staff and interested members will be asked to submit a statement of interest. An internal advisory group will select committee members who will best fulfill its purpose and responsibilities. Management will approve and submit to Executive as an informational item.

Terms of Membership

All members are expected to participate in at least 3 meetings per year of 2 hours each and participate in projects between meetings. All members are to inform the chair(s) if they will miss a meeting. To maintain historical knowledge, diversity of membership and member preferences within the advisory group, membership appointments will be staggered within a timeframe of 1-3 years. When joining, members will be asked for their preference of a 1, 2, or 3 year term. Specific assignments can be revisited by the co-chairs as needed at the request of a member. Terms can be held for a maximum of 3 years. Additional renewal may be possible to allow a member to assume the chair role, if requested.

Meetings

The External and Internal HEAG will generally meet via teleconference. Meetings will be scheduled as required.

Responsibilities and Tasks

External HEAG: The Voices that will Shape our Plan

- Recommend which health equity data variables will be collected
- Provide guidance and feedback on the development of a Data Governance plan to prevent misuse and misinterpretation of the data (e.g., policies directed at how those determinations are made).
- To recommend and advise on data use and analysis, ensuring that the context and interpretation of data on equity-seeking groups is carefully presented
- Other tasks, as needed

Internal HEAG (BORN Members): Moving the Work Forward

- Staff members of the Internal HEAG should be responsible to promote equity, diversity, and inclusion in compliance with all applicable laws and CHEO's policies.
- Develop an implementation strategy including educational tools and guiding documents with partner organizations who submit data to BORN (e.g., hospitals, MPGs, birth centres and other organizations).
- Devise a meaningful, humanistic, statement that shows BORN's commitment to health equity and responsibility for guarding this information. It should also include actions taken, or to be taken, to support the statement.
- Submit a proposal to the Data Holdings Committee of data elements to be edited, removed or added, with the evidence and rationale (for any new data elements requested for collection).
- Align with CHEO's efforts to address equity and diversity.
- Consider or make any proposals to amend to the Privacy & Security Management Plan to improve alignment with social determinants of health data collection/use. For example, our policies for data collection might be revised to expressly consider a factor directed at whether the collection will improve health equity.
- Provide recommendations on the use and sharing and reporting of such data, including any recommendation on how perinatal health disparities can be known in Ontario.
- Other tasks, as needed

Accountability

Recommendations on all matters relating to the first objective of this group should be reported to BORN's Data Holdings Committee (DHC). Recommendations on all matters relating to the second objective of this group should be reported to Executive.

The External HEAG will meet and will advise the Internal HEAG. Advice and recommendations proposed by the HEAG will be based on the lived experiences and expertise of these groups and

given the barriers that equity-seeking groups face, it is very important that these recommendations remain as undiluted as possible. The Internal HEAG will have a critical role in describing the External HEAG's message to the DHC.

Decision Making

Decision making by the HEAG will be by consensus. If a vote is necessary, the outcome will be determined by a simple majority of Working Group members in attendance. A majority of the voting members of the HEAG (50% plus one) shall constitute a quorum.

Self-Reflection

Members will be encouraged to sign a commitment to self-reflection work. Training to support anti-oppression, diversity, equity, and inclusion will be made available to members of all committees, work groups and task forces as required (e.g., relevant webinars may be sent to members).

Confidentiality

Every member will respect the confidentiality of matters brought before the working group. Personal information shared in the group that may or may not be public knowledge like gender or invisible disabilities are considered confidential and not to be disclosed or shared with non-group members. Meeting materials, including slides, are all to be considered confidential and may not be used outside group work and may not be disclosed or shared with non-group members. If such material is no longer confidential and may be circulated externally, the group will be notified by the chair.

Compensation

Service as a group member is voluntary. Meetings will be held virtually but may on occasion be held in person. With the pre-approval of the executive director, members will be reimbursed for expenses incurred to attend meetings to the extent permitted under the CHEO Travel Reimbursement Policy and Procedure.

Amendments

These Terms of Reference will be reviewed annually or as necessary.

APPENDIX A: Self-Reflection Statement

Commitment to Self-Reflection

As a member of the Health Equity Advisory Group (HEAG) with Better Outcomes Registry & Network (BORN Ontario) you may be working with many individuals who face significant collective challenges in participating in society. This marginalization can be created by attitudinal, historic, social, institutional, and environmental barriers based on age, ethnicity, disability, economic status, immigration status, race, sexual orientation, gender, religion, etc.

It is an enormous privilege to listen to experiences and to collect data on individuals who may be impacted by systemic oppressions, but we must ensure that we are attune to and aware of the systems that enable inequities. When individuals are aware of their own individual biases, and concerned about the consequences of their biases, it is then that we can work towards negating them to achieve equitable outcomes for all.

Self-reflection helps you discover values, beliefs, myths, and stereotypes that you may hold.

We ask that each member commit to their own personal self-reflection. Please sign below to indicate you agree with the value of this process.

_____   _____

Committee Member Signature   Date

APPENDIX B: Document History

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