



Approved By	Date
Revision Date(s):	

# Terms of Reference Advisory Committee

## Background

Screening is the systematic population-based application of a test or inquiry to individuals who do not have symptoms of a specific disease or condition in order to identify those who warrant further investigation and/or intervention to achieve better outcomes. The pillars of systematic screening include education, (offer of) enrolment, test administration, retrieval, treatment or intervention, evaluation and quality assurance/improvement.

Prenatal Screening Ontario (PSO) is housed within BORN Ontario, and is funded by the Ministry of Health (MOH). Its mandate is to coordinate and oversee the operations of prenatal screening services in Ontario, in order to maintain an integrated program that operates as a "system of care".

PSO depends on input from experts and advisors from relevant fields to support the screening program, upholding the principles considered essential to a provincial prenatal screening system:

- 1. Pregnant individuals across the province should have access to the same safe, fast, high-quality prenatal screening service, regardless of their location.
- 2. Pregnant individuals and their families should receive the counselling and support they require in order to make an informed decision.
- 3. The prenatal screening system should deliver high quality and appropriate services that are costeffective.
- 4. Pregnant individuals should have access to newer, safer and more efficient technology in a timely fashion.

#### Mandate and Scope

The Prenatal Screening Ontario Advisory Committee (PSO-AC) has been established to:

- Provide provincial stakeholders a forum to have input on the direction of current and future PSO activities
- Provide recommendations to PSO and to the MOH on new conditions amenable to systematic population screening
- Consider and advise on strategic directions for MOH, and for prenatal screening in Ontario, taking into account new advances including but not limited to new therapies, biomarker/genomic technologies, and information systems/technologies

- Receive a consultation from PSO whenever any significant changes to the screening program are considered
- Provide policy and knowledge translation advice for PSO including changes to the conditions for which systematic prenatal screening is coordinated by PSO, technologies, screening protocols, alignment with other relevant screening systems, etc.
- Identify potential collaborative partners and initiatives to enhance screening for pregnant people in Ontario.
- Advise on social, ethical, health system, and scientific issues that affect prenatal screening in Ontario
- Provide advice and guidance to PSO regarding operationalizing and sustaining the prenatal screening system quality framework
- Respond to questions referred to the PSO-AC by PSO, the Government of Ontario, or other stakeholders.

As needed, task-specific and time-limited *ad hoc* working groups may be formed to work on an item recommended by the Advisory Committee.

## Accountability and Reporting

The PSO-AC is advisory to PSO leadership and the MOH, and reports to PSO. PSO will report on this work through BORN Ontario to the Ministry of Health (MOH). The committee will interact with other internal and external bodies as required to accomplish its tasks.

## Membership

The membership will be interdisciplinary and the following areas of expertise may be represented. Members will be chosen to meet the required content expertise and, where possible, to also provide geographic/regional/subspecialty representation. The committee will be comprised of up to 12 members, including the Co-Chairs. Representation will include expertise in:

- Conditions for which Ontario currently screens (eg. expertise in maternal-fetal medicine, genetics)
- Screening systems (eg. technical, quality, policy, economics, epidemiology, public health, ethics)
- Antenatal care (e.g. ultrasonography, primary care, midwifery)
- Laboratory medicine

Membership includes voting and non-voting members. The non-voting members may include ex-officio representatives from the MOH, PSO staff and any representatives who may be invited as subject experts. All other members, including the Co-Chairs, are voting members. Membership should be reviewed on a yearly basis and periodic rotation of members should occur. PSO will provide a supportive secretariat function.

Administrative and resource support persons will be provided by PSO.

PSO will issue a general call for Expressions of Interest for membership on the PSO-AC. A nominations committee established by BORN will review all submissions and will nominate individuals based on the aforementioned membership criteria, excluding any individuals with conflicts of interest (as detailed below).

#### Term

The inaugural Co-Chairs will have a term of three years. At the end of the initial three years, the Chair structure of the PSO-AC will evolve to match that of all BORN Ontario committees, and the Terms of Reference will be amended at that time. Each of the inaugural Co-Chairs may remain as a committee member after the term is completed, and may return as Chair for another term after a cycle of a different Chair.

Members of the committee will generally have terms of three years, renewable once. Renewed appointments will normally be for another 3 years, however, after the inaugural three years of the committee, some renewals will be for 1 or 2 years, to ensure continuity among the membership. Additional renewal may be possible to allow a member to assume the chair or vice-chair role, if requested. Members are expected to attend a minimum of 50% of meetings per year to maintain membership. Members are requested to withdraw membership if unable to attend meetings on a regular basis.

## Condition-Specific Expert Groups and Working Groups

There shall be Condition-Specific Expert Groups that reflect the conditions for which systematic screening is coordinated by PSO. These expert groups will report directly to PSO, and recommendations will be brought to the PSO-AC in accordance with the PSO-AC Scope and Mandate.

Ad-hoc Working Groups may be struck by the PSO-AC and will be resourced by PSO and BORN.

#### Meetings and Procedures

Face-to-face meetings will be held at the call of the chair no more than two times a year. Other business will be conducted by teleconference and email, with no interval between meetings of more than 4 months.

The advice and recommendations developed by the Advisory Committee should reflect the consensus of the whole group. Decisions will be based on evidence whenever possible, and will always be made with the best interests of the pregnant individuals and families served by the PSO screening system in mind. The Co-Chairs will facilitate a consensus decision-making process that is inclusive and provides enough time for evaluation, discussion, proposed options, identification of concerns, and acceptable resolution of the items and/or issues under consideration.

The Members will agree to support a consensus decision or course of action and be willing to carry it out. Where Members are unable to reach consensus, then a majority-based decision will be made.

Decisions are binding and all members will support the decisions and work of the PSO-AC after decisions have been made.

### Quorum

Quorum shall be 50 percent of voting members, either present in-person or via telephone-conference.

## Conflict of Interest

Members will not include any person whose personal or professional activities constitute a conflict of interest. Any potential COI must be disclosed to the Co-Chairs. Such activities include, but are not limited to, direct ties to private industry and personal interests in developing related technologies, including patents and patents pending. Incumbent and existing members will disclose to the chair, without delay, any actual or potential situations that arise which might be reasonably interpreted as either a conflict of interest or a potential conflict of interest.

The Co-Chairs have the right to excuse any member with a COI that is perceived to interfere with the deliverable.

## Confidentiality

Every member will respect the confidentiality of matters brought before the committee or any of its working groups. Meeting materials, including slides, are all to be considered confidential and may not be used outside committee work and may not be disclosed or shared with non-committee members. If such material is no longer confidential and may be circulated externally, the committee will be notified by the Co-Chairs.

#### Compensation

Serving as a committee member is voluntary. Meetings will typically be held by teleconference, but should travel expenses be incurred to attend meetings, members will be reimbursed for those expenses as per the BORN Travel Reimbursement Policy and Procedure.

#### Administrative Support

PSO administrative staff will provide administrative support for the committee.