

NEWBORN SCREENING ONTARIO ADVISORY COUNCIL (NSO-AC)

Terms of Reference

The Newborn Screening Ontario Advisory Council (NSO-AC) is responsible for providing advice and guidance to Newborn Screening Ontario (NSO).

Background

Under the stewardship of the Government of Ontario, and with fiduciary responsibility to the Children's Hospital of Eastern Ontario (CHEO) board, Newborn Screening Ontario (NSO) coordinates Ontario's screening program for at least 29 rare diseases including metabolic diseases, congenital hypothyroidism, sickle cell disease, cystic fibrosis and SCID. This includes responsibility for quality assurance, developing and implementing relevant policies, follow-up recommendations, educational programs and materials, medical referrals for follow up care, establishing screening protocols, and performing screening laboratory testing for all babies born in Ontario.

While NSO's work has traditionally involved the use of newborn dried blood spot samples, the Council's scope is not limited to screening targets requiring the use of such samples. For example, the Council will consider and advise NSO if NSO could or should be contributing to systems involving novel screening strategies (e.g. new sample types, point of care tests, non-laboratory based testing, age at screening, etc.)

Purpose

- provide provincial stakeholders a forum to directly influence the direction of current and future NSO programs
- accelerate continuous improvements in NSO program
- guide and provide strategic advice to the NSO program in a changing rare disease and screening landscape
- guide and advise MOHLTC and MCYS on matters related to the NSO program and newborn/childhood screening
- support NSO in achieving its vision of the "best possible health through screening"
- contribute to the best possible screening systems for Ontario children

Specific tasks include

- Review, advise and report on all aspects of NSO program effectiveness and quality, including evaluation of performance indicators and related data. This includes the use of audits as needed.
- Receive, review and approve the Annual Report from NSO
- Receive a consultation from NSO whenever any significant changes to the screening program are considered
- Consider and advise on strategic directions for NSO, and for newborn and childhood screening in Ontario, taking into account new advances including but not limited to new therapies, biomarker/genomic technologies, and information systems/technologies.

- Provide policy and knowledge translation advice for NSO programs including changes to the NSO testing panel, technologies, screening protocols, disclosure of adventitious information, consent, storage and access to residual samples, alignment with other relevant screening systems, etc.
- Identify potential collaborative partners and initiatives to enhance screening and rare disease care for newborns and children in Ontario. The Council may work directly with such bodies or advise NSO to work with them.
- Advise on social, ethical, health system, and scientific issues including research projects related to newborn/childhood screening and NSO programs
- Advise on, and facilitate implementation, of specific newborn and childhood screening protocols, procedures for handling and communication of screen negative and screen positive results (including genetic counselling issues), educational programs for patients and health care providers
- Advise on research necessary to enhance understanding of matters related to program effectiveness.
- Respond to questions referred to the Council by NSO, the Government of Ontario, or other stakeholders.

Membership

The NSO-AC will include ex-officio representatives from:

1. The CHEO board
2. NSO (the NSO Director or designate)
3. The Ministry of Health and Long-term Care
4. The Ministry of Child and Youth Services.

With a goal of no more than 12 additional members, the NSO-AC will be constituted to reflect the expertise required to fulfill the function of the Council. This includes expertise in:

- Target diseases (chair or representative from each disease-specific NSO working group)
 - Screening systems (technical, quality, policy, economics, epidemiology, public health)
 - Perinatal care (e.g. midwifery, birthing hospital roles) and early child development
- Membership will also ensure geographic representation from Children's Hospital of Eastern Ontario, Hospital for Sick Children, Kingston General Hospital, London Health Sciences, McMaster Children's Hospital, and Northern/rural Ontario.

Administrative and resource support persons will be provided by NSO.

Officers and Process for Their Selection:

The Officers of the NSO-AC will be the Chair, NSO Director, CHEO Board member, MOHLTC representative, and MCYS representative. The chair will be elected by the membership of NSO-AC, and will serve a one 3-year term.

Process for Selection of Members:

Members will be identified through a call for letters of interest. The officers of the NSO Advisory Council will short-list the candidates who will then be chosen by a vote of the NSO-AC.

Term

The initial term for membership will be staggered with 1, 2 and 3 year appointments. Thereafter terms will be 3 years, renewable.

Reporting

The NSO Advisory Council is advisory to NSO leadership, MOHLTC, and MCYS. The Council reports annually to the CHEO board.

Disease Specific Working Groups and Task Forces

There shall be Disease Specific Working Groups reflecting the NSO target diseases, and these working groups will report to the NSO-AC. In addition, ad hoc time-limited Task Forces may be struck by the NSO-AC and will be resourced by NSO.

Meetings and Attendance

- As needed with a minimum of four times per year, at least twice in person
- Meeting location will be chosen to minimize cost and maximize participation
- One meeting will be held in conjunction with the NSO symposium
- Tele/Videoconferencing will be used whenever possible to minimize cost
- Members are expected to attend at least 3 meetings per year (75% attendance)

Decision Making and Quorum:

Quorum is set at 50% + 1 of membership for decisions

Decisions will be based on evidence whenever possible, and will always be made with the best interests of the children and families served by the NSO screening system in mind. Decisions will be made by consensus if possible; if consensus is not achieved, then a majority-based decision will be made. If voting is required, all members will have one vote. Decisions are binding and all members will support the decisions and work of the NSO-AC after decisions have been made.

Remuneration

- Chair – honorarium of \$1000 annually
- Travel and accommodation expenses will be reimbursed for all members