

Reproductive Genetics Expert Group

Terms of Reference

Background

As part of Ontario's plan to improve genetic testing and clinical genetic services across the province, Ontario Health (OH) has established the Provincial Genetics Program (PGP). The PGP is tasked with ensuring the provision of comprehensive, coordinated, and evidence-based genetic services for Ontarians. The PGP scope of work will encompass genetic testing for rare and inherited diseases (including hereditary cancer), tumour biomarkers, pharmacogenomics, and clinical genetic services. The PGP has prioritized several clinical areas in which genetic services are of high impact, including Neurogenetics, Neurodevelopmental Genetics, Cardiogenetics, Renal Genetics, Reproductive Genetics, and Inborn Errors of Immunity.

Purpose

The Genetic Expert Groups provide expert clinical advice to support the development of evidence-based clinical guidance on comprehensive genetic testing and clinical genetics services. This includes recommending a genetic testing strategy, eligibility criteria, and model of care for identified clinical areas of high impact. The Genetic Expert Groups will facilitate dissemination and implementation of recommendations and ensure that they are kept up to date over time.

This expert group in Reproductive Genetics will advise on genetic testing and clinical genetics services for infertility, assisted reproductive technologies including preimplantation genetic diagnosis and testing, preconception genetic testing, and prenatal diagnosis. This work will be done in collaboration with stakeholders within Ontario Health and those provincially involved in the provision and delivery of reproductive genetic services, including the Better Outcomes Registry & Network (BORN) and Prenatal Screening Ontario (PSO).

Specific Responsibilities

- Using a disease pathway management model, identify priority topics and utilize best available evidence to develop guidance that will be kept up to date.
- Provide advice on key performance indicators related to their specialty area that would support measurement and evaluation of services on an ongoing basis.
- Provide timely advice on responses to information requests from government, media, the public, Ontario Health programs, and others, as needed.
- Facilitate and champion the successful implementation and uptake of clinical practice guidelines
- Contribute to horizon and jurisdictional scanning to ensure that Ontario's genetics system is aware of, and prepared for, emerging knowledge and clinical practices in the field of genetic disorders.

Membership

For each expert group, the membership will include:

- Chair, which will be the Ontario Health Clinical Lead
- 6 - 10 representatives across the province, for example but not limited to:
 - Medical geneticists
 - Certified genetic counsellors
 - Laboratory medicine specialists (e.g. embryology, biochemical, molecular and/or cytogeneticists)

- Adult specialists (e.g. reproductive endocrinologist, maternal-fetal medicine specialist, and/or obstetricians)
- Fetal pathologist
- Research specialists (e.g. translational research)
- Patient and/or family advisors
- Primary care and/or community-based providers (e.g. midwives)

The above membership will be selected to ensure the following representation:

- Geographic representation across the province from both hospital systems and community-based care settings
- Balance of different specialities and/or care settings
- Clinicians working in relevant disease areas that represent a breadth of experience

Ex-Officio

- PGP Manager
- PGP Team Lead
- PGP Senior Specialist
- PGP Analyst
- PGP Provincial Head (ad hoc)
- Director, Integrated Diagnostics and Genetics (ad hoc)

Meeting Schedule

The Genetics Expert Groups will meet 4 - 6 times per year, more frequently as necessary to address specific issues of concern. Meetings will be held primarily by videoconferencing. Members may be asked to review and comment on relevant documents circulated electronically between meetings.

Attendance

Members assume responsibility for attending all meetings. To maintain continuity in discussions, delegates are not permitted. If a member is unable to attend at least 75% of meetings, they will be replaced. A sufficient quorum for each meeting will be determined by the Clinical Lead depending on agenda items.

Guests

Guests are permitted to attend specific meetings only where the subject matter being discussed requires their expertise. Any guests will require prior approval from the Chair, in consultation with Ontario Health.

Accountability

The Expert Group reports through its Clinical Lead to the Provincial Head, PGP. The Vice-President, Clinical Institutes and Quality Programs, Ontario Health, is accountable for the success of the PGP, reporting to the Clinical Institutes and Quality Programs executive team.

Sub-Working Groups

Sub-working groups will be formed as needed, upon approval of the Clinical Lead of the Expert Group and the Provincial Head, PGP. These will support work in focused areas that do not require full Expert Group input at all phases, and when additional expertise is needed. Sub-working groups will report to the Expert Group. The Expert Group will act as a steering committee to determine and guide the work of sub-working groups. Sub-working

groups will develop plans for the accomplishment of key tasks related to their mandate. These plans will be approved by the Chair and Ontario Health as sponsor. The Expert Group and sub-working groups are jointly accountable for fulfilling the mandates.

Meeting Minutes

Minutes will be kept of all meetings by Ontario Health staff and be distributed to all Expert Group members.

Confidentiality

Unless it is generally available to the public, all data and information acquired or prepared by or for the Expert Group should be treated as confidential. Members should keep these data and information confidential and not directly or indirectly disclose them during or subsequent to their term as a member of the Expert Group. Members will be required to complete a Statement of Confidentiality upon joining.

Communication

All communications of the Expert Group and sub-working groups will be managed by Ontario Health

Expenses

Ontario Health will reimburse travel expenses incurred by meeting participants in accordance with Ontario Health's policies.

Conflicts of Interest

Expert Group members must ensure that any actual or potential conflict of interest regarding any matter under discussion by the Expert Group is brought to the attention of the Chair. The Chair will decide what action, if any, is required arising from the conflict of interest and will take appropriate action, including, but not limited to, requesting the member to absent himself or herself from participation in discussion of the matter. Members will be required to complete a Conflict of Interest Declaration upon joining the Expert Group.

Rationale for Recommendations

The Ministry of Health provides strategic direction and system governance to guide program oversight and management by Ontario Health. Ontario Health will oversee the mandate and work of the Expert Group and provide secretariat support to the Expert Group and any sub-working groups that form. The Expert Group's recommendations and overall work, along with those of any sub-working groups, will be reported to the Ministry through Ontario Health. Decisions of the Expert Group and sub-working groups will be made by consensus of the members. If there are any issues on which consensus cannot be achieved, the decision-making approach will be decided upon by the Chair, in consultation with Ontario Health.

Terms of Reference Review

This Terms of Reference (ToR) will continue for a 2-year period starting from the expert group formally convening, exact date to be determined and updated in the ToR. After this time, the ToR will be reviewed and updated to ensure relevancy, seeking input from the Expert Group. All amendments must be approved by the Ministry with agreement from Ontario Health.

Membership Term

The term for all members is 2 years with the potential to extend for an additional 2-year term. Members are asked to commit to a full term upon joining the Expert Group but may withdraw at any time with written notice. Expert Group membership will be reviewed in conjunction with the review of the Terms of Reference to ensure the Expert Group has the appropriate expertise to advise on initiatives and priorities outlined in the ToR.