

Health Quality Ontario

The provincial advisor on the quality of health care in Ontario

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Role and Responsibilities of Patients and Caregivers on the Ontario Genetic Advisory Committee

Let's make our health system healthier



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About Health Quality Ontario and the Ontario Health Technology Advisory Committee

Health Quality Ontario (HQO) has a legislated mandate to make evidence-based recommendations to the Minister of Health and Long-Term Care regarding the Government of Ontario's provision of funding for medical devices and health care services including genetic and genomic testing. Health Quality Ontario fulfills this part of its mandate through the Ontario Health Technology Advisory Committee (OHTAC), a Committee of the Health Quality Ontario Board of Directors. In making recommendations with respect to genetic and genomic tests, the Ontario Genetic Advisory Committee, a sub-committee of OHTAC, will advise OHTAC on the clinical utility, validity, and value for money of new and existing genetic and genomic tests in Ontario.

Attributes of the Patients and Caregivers with Lived Experience

A Lived Experience member is anyone who uses their health care and other lived experiences to provide guidance to health organizations. As a member of the Ontario Genetic Advisory Committee, the Lived Experience member will be required to review and synthesize considerable amounts of information. They will have had experience with the Ontario health care system as a patient or an informal care giver and have an interest or understanding of the concept of using evidence to inform recommendation development about genetic testing. The Lived Experience member brings forward the lived experience of patients receiving health care in Ontario specifically with respect to genetics. However, they do not represent any specific interest, group, or organization.

The Lived Experience member must live in Ontario and be at least 18 years of age.

In addition, the lived experience member shall demonstrate the following attributes:

- Have received care or had a loved one receive care in Ontario within the last two years.
- Can work respectfully in partnership with a variety of other people.
- Take a constructive approach to discussing concerns and ideas about genetic testing in order to address them.
- Have an interest in genetic and genomic testing and health care within the Ontario health care system.
- A willingness to learn about the mandate of Health Quality Ontario, OHTAC, the Ontario Genetic Advisory Committee and its role in the Ontario health care system
- Ability to relate to and respect a diverse range of values and beliefs
- An ability to think critically in a broad fashion beyond their immediate health condition and participate in complex committee discussions with a range of others of various expertise
- An interest in, and willingness to collaborate with all other members on issues related to genetic testing and the allocation of public health care resources, and an ability to share these perspectives at the Committee meetings
- Not currently or recently employed (last 2-5 years) in the health care sector or within the pharmaceutical, genetic, laboratory, or medical device industries.
- Previous experience providing feedback to improve healthcare design and delivery, such as serving on a Committee or Board of Directors is considered an asset

Expense Reimbursement

Expenses incurred by members of the Ontario Genetic Advisory Committee in the course of performing their duties will be reimbursement, in accordance with the HQO travel, hospitality, and meals policy. Members will be reimbursed for cost of travel, accommodation, and caregiving supports as outlined by the Patient, Family and Public Engagement Travel, Accommodation and Other Supports Protocol.

Time Commitment and Location of Meetings

The Ontario Genetic Advisory Committee meets approximately 4 to 8 times per year. Meetings are generally 4-6 hours in duration. Preparation for the meeting will include reviewing word documents and power point presentations. All meetings will be held in Toronto at Health Quality Ontario, 130 Bloor St. West, 10th Floor. Teleconference options will be available.

Supports

Lived Experience Members will be supported throughout the duration of their participation by HQO in terms of being on-boarded and prepared for meetings, as well as receive regular check-ins to better understand how their needs can be met and their participation can be supported.