MARATHON OF HOPE CANCER CENTRES NETWORK
RÉSEAU DES CENTRES D'ONCOLOGIE DU MARATHON DE L'ESPOIR

# RETURN OF RESULTS WORKING GROUP (ROR) TERMS OF REFERENCE

## Background

The vision of MOHCCN is to bring together leading Cancer Centres across Canada to collaborate on precision medicine to benefit cancer patients and drive innovation. The goal of the Network is to apply advanced technologies such as genomics and other omics, high-powered imaging, and artificial intelligence (AI) to advance precision oncology and improve cancer diagnosis and management.

When the funding for the MOHCCN was announced by the Federal Government in March 2019 it was determined that the MOHCCN should operate according to agreed standards and guidelines recommended by nominated Expert Working Groups (WGs). Seven WGs were established: Scientific Questions, Patients, Data, Technology, Data Platform, Health Technology Assessment, and Agreements. Additional WGs were since created.

## 1. Mandate of WG

The WG is focusing on immediate priorities for MOHCCN Gold Cohort approvals and data preparation for submission to digital platforms, in close collaboration with designated sites and MOHCCN/TFRI leadership.

**The mandate of the WG is to:**

- **WG Responsibility:** To provide recommendations on a structure to return cancer-related germline results and to develop a platform to provide an option for MOHCCN cohorts to return results. In the future, to provide recommendations to return somatic results.

- **WG Strategy:** Socialization of draft policies among the WG members to identify areas of question/concern, followed by discussion of the feedback for integration and finalization of the policies.

## 2. Reporting Structure

**Document Initiation and Development:** For the development of the draft policy, any documents including any initial draft developed will be socialized, usually through a onemonth comment period, with the WG. The drafts will live in a shared folder in TFRI's OneDrive that will allow for real-time tracking of edits and comments from all WG members. Feedback will be integrated and harmonized by MOHCCN Staff in collaboration with WG leadership. It is expected that WG members will consult with the individual designated Consortiums/programs and initiatives and cohorts for input.

**Draft Finalization:** MOHCCN Staff will submit, usually via email, the draft policy to the Steering Committee along with a briefing note (BN). The BN will indicate the history of the development of that policy, including details on feedback received and any remaining areas of concern that were raised by WG members.

The Steering Committee will review, usually electronically, the policy and associated documents and provide their comments. When done electronically, a review template will be provided. Any contentious issues raised by Steering Committee will be addressed by the WG or MOHCCN Staff.

**Document Endorsement:** Finalized draft policy will be submitted for endorsement to Network Council along with a summary of the reviews provided by the Steering Committee and the relevant responses provided by the WG or MOHCCN Staff. Remaining issues will be outlined.

## 3. Composition

The membership of the WG will reflect the interests, philosophy, and strategic direction of the Network. It is composed of experts from each consortium member. This includes an effort to align with the 50-30 Challenge[1] to support gender parity and significant representation of under-represented groups.

**The WG membership**

Membership will be provided through the following process:

**a. Chair/Co-chair appointment:** Existing chairs from already active working groups would be asked to continue chairing the WG or for their suggestions on a replacement to MOHCCN/TFRI Staff. The formation of new WGs will be discussed at Network Council to seek their recommendations.

[1] The 50 – 30 Challenge is an initiative co-created by the Government of Canada, civil society and the private sector that aims to attain gender parity and significant representation (at least 30%) of under-represented groups on boards and senior management positions in order to build a more diverse, inclusive, and vibrant economic future for Canadians.

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**b. Membership**: Each working group/committee will include representation from designated Consortiums/programs and initiatives. Members are proposed to a WG by designated Consortiums/programs and initiatives or MOHCCN/TFRI Staff, considered by the Chair/co-Chair and if approved, endorsed by the Network Council. Voting Members are MOHCCN Project Leaders and Researchers. Non-voting members may include Centres staff and outside advisers, based on the specific expertise required for the activities of a Working Group.

**c. Membership Changes**: Any additions or changes in membership will be reflected on the table below and communicated to Network Council for endorsement.

| **Chairs** | **Institutions** | **From** | **Until** |
|---|---|---|---|
| Janessa Laskin | BC Cancer | May-2022 | |
| George Zogopoulos | MUHC | May-2022 | |
| **BC2C** | | | |
| Intan Schrader | BC Cancer | May-2022 | |
| Holly Longstaff | PHSA | May-2022 | |
| **PR2C** | | | |
| Shantanu Banerji | U of Manitoba | Feb-2023 | |
| **OCC** | | | |
| Raymond Kim | UHN – Princess Margaret Cancer Centre | May-2022 | |
| Yvonne Bombard | Unity Health Toronto | Jun-2023 | |
| Lauren Hughes | OICR | Sep-2023 | |
| **MOH-Q** | | | |
| William Foulkes | McGill | 2019 | |
| Ma'n Zawati | McGill and PROFYLE | July-2022 | Feb-2024 |
| **ACC** | | | |
| John Thoms | Eastern Health | July-2022 | |
| **PROFYLE** | | | |
| Caron Strahlendorf | BC Children's | NOT ACTIVE | Jan-2024 |
| Anita Villani | SickKids | NOT ACTIVE | Jan-2024 |
| Stephanie Grover | SickKids | May-2022 | |
| Julie Shiu | SickKids | Jul-2024 | Apr-2025 |
| **Patient Partners** | | | |
| Nicole Beauchemin | McGill | May-2022 | Jun-2025 |
| Jennifer Graham | | Apr-2024 | |
| Kirsten Efremov | | Apr-2024 | |
| **Guests** | | | |
| Marc Clausen | Genetics Adviser | Jan-2024 | |
| Jordan Lerner-Ellis | Mt Sinai | May-2024 | |
| Selina Casalino | Mt Sinai | May-2024 | |
| Andrea Secord | Genetics Adviser | May-2025 | |

Last Updated: July 2025

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## 4. Management and Administration.

**Quorum –** A quorum of voting members (50% plus one) is required as a voting mechanism for WG decisions when needed. The vote may be requested by e-mail when not all members are present at a meeting, usually with a two (2) week deadline to hear back. Different perspectives are expected, and consensus is not necessary at the early stage. Any contentious issues can be escalated for further feedback to the Steering Committee. The WG cycle might be iterative and if it comes to an impasse, then the Steering Committee or the Network Council could be asked to help resolve the problem.

**Time commitment –** The WG will usually meet at least four (4) times per year. Meetings may occur by teleconference, the duration of which shall be approximately 1-hour. One (1) meeting shall be held in-person each year if possible. Changes in the frequency of the meetings are expected as the mandate of the committee is fulfilled.

**Term of membership –** WG Chairs shall rotate on a two (2) or three (3) years provision. WG members shall serve for a minimum term of two (2) years. Centres can suggest a successor if at any point a member can no longer commit to their membership.

**Meeting Facilitation –** TFRI through MOHCCN Staff will facilitate the various WG meetings to ensure good integration of all activities. Responsibilities include pre-meetings with the Chairs, preparation of agendas and meeting minutes, socialization of materials for feedback and reporting to TFRI leadership.

## 5. Confidentiality and Conflict of Interest

All information provided to WG members in paper or electronic format during discussions shall be considered CONFIDENTIAL and must be treated in that manner. Conflicts of interest must be disclosed to the WG Chairs and addressed.

## 6. Remuneration

For some Working Groups, a remuneration model may be developed according to the WG's nature. That remuneration model will be approved by Network Council and included as an appendix to the WG Terms of Reference. Other reasonable expenses necessarily incurred by the member to attend meetings will be covered.

## 7. Terms will be Updated and Reviewed

WG terms will be modified and reviewed as needed, to reflect the evolution of the project. They will be reviewed annually and approved by the Network Council.