CLINICAL DATA STANDARDS SUB-COMMITTEE (CDS) 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.

The CDS has been set up as a subgroup of the Data Policies and Standards Committee.

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: Provide recommendations on developing the MOHCCN clinical and omics data models and ontologies.

WG Responsibility:

- Collect timely and complete clinical data and metadata.

- Harmonize data across cohorts to promote uniform analysis.

- Share the data with members of the network and the research community in a manner that respects priority for publication and IP capture.

- Promote sharing with other international cancer genomic initiatives and standards (e.g. ICGC-ARGO, mCODE)

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 one-month 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 Consortium/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 Council 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.

b. **Membership**: Each working group/committee will include representation from designated Consortiums/programs and initiatives. Members are proposed to a WG by a designated Consortium/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 in the table below and communicated to Network Council for endorsement.

Chairs	Institutions	From	Until
Lincoln Stein	OICR, Ontario Institute for Cancer Research	Nov-2021	
OCC			
Tran Truong	UHN – Princess Margaret Cancer Centre	Nov-2021	
Phillippe Bedard	UHN – Princess Margaret Cancer Centre	Mar-2022	
Hardeep Nahal-Bose	OICR, Ontario Institute for Cancer Research	Mar-2022	
Lillian Siu	UHN – Princess Margaret Cancer Centre	Mar-2022	
Anna Dodd	UHN – Princess Margaret Cancer Centre	Mar-2022	
Emily Van de Laar (PM)	UHN – Princess Margaret Cancer Centre	Aug-2022	
Edmund Su	OICR, Ontario Institute for Cancer Research	Sep-2023	
Linda Xiang	OICR, Ontario Institute for Cancer Research	Sep-2023	
Roxana Bucur	UHN – Princess Margaret Cancer Centre	May-2025	
BC2C			
Dean Regier	BC Cancer	NOT ACTIVE	Mar-2023
Jessica Nelson (PM)	BC Genome Sciences Centre	Nov-2021	
Balvir Deol	BC Cancer	Nov-2021	On leave
Shira Yair Sabag	BC Cancer	Jan-2025	
MOH-Q			
Anne Marie Mes-Masson	CHUM	Mar-2022	
Veronique Ouellet	CHUM	Nov-2021	Mar-2023
Nicolas Luc	CHUM	Jun-2022	
Pascal St-Onge	CHUM	NOT ACTIVE	Mar-2023
Kip Brown	CHUM	NOT ACTIVE	Mar-2023
Ksenia Zaytseva	McGill	NOT ACTIVE	Mar-2023
David Bujold	McGill	Mar-2022	
Christine Caron (PM)	CHUM	Apr-2023	
PR2C			
Winson Cheung	Alberta Health Services	NOT ACTIVE	Jan-2024
Jennifer A. Chan	University of Calgary	Jun-2022	
Marshall Pitz	Cancer Care Manitoba	Jun-2022	
Carolyn-Ann Robinson (PM)	University of Calgary	Apr-2023	
PROFYLE			
Anita Villani	The Hospital for Sick Children	Jun-2022	Jan-2024
Rod Rassekh	University of British Columbia	Jun-2022	NOT ACTIVE
Stephanie Grover	The Hospital for Sick Children	Apr-2023	
ACC			
Sidney Croul	Dalhousie Biobank	Jun-2022	
Alexi Surette	Dalhousie University	Jun-2022	

Selena Oakes	Horizon Health Network	Feb-2025	
CanDIG			
Karen Cranston	UHN	Mar-2022	

Last Updated: May 2025

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.

[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.