



NETWORK DATA ACCESS COMMITTEE (DAC)

TERMS OF REFERENCE

Background

This Network Data Access Committee (DAC) Terms of Reference is a pilot and will be adapted through consultation and piloting of the Network data access procedures. The elements of this terms of reference are derived from the Global Alliance for Genomics and Health, [Data Access Committee Guiding Principles and Procedural Standards Policy](#) (2021), and informed by a review of best practices in access governance across Canada and internationally, as well as consultation with MOHCCN stakeholders.

1. Mandate

The Network DAC reviews and approves data access requests/Studies to ensure timely access to Network data (data made available for sharing across the Network) and compliance with Network policies and agreements.

2. Governance

The Network DAC is established by Terry Fox Research Institute (TFRI) in consultation with Network Council, with appropriate input from the broader Network. This responsibility includes establishing these Terms of Reference, as well as appointing the initial DAC Chair and members. The Terms of Reference shall be periodically reviewed and revised depending on the volume and complexity of requests.

3. Independence

The decisions of the Network DAC are generally binding on data-contributing institutions and researchers, who have agreed (through the Network Master Agreement and policies) to implement Network DAC approvals. Each data-contributing institution will be responsible for granting the corresponding user permissions for their data to the requesting institutions in a timely manner.

4. Principles for Reviewing Access Requests

The DAC will strive to make access decisions in a timely, consistent, transparent, and fair manner. Review criteria and timelines shall reflect the context of sharing coded genomic and related health data (no biospecimens). General review criteria include the following (which can be further specified for specific contexts in the **Data Access Procedures**).

General	The Study is compatible with the objectives of MOHCCN (to advance biomedical research and improve cancer prevention, diagnosis, and care)
PI bona fides	PI is a bona fide researcher (e.g., qualifications, affiliation, track record).
Scientific feasibility	The Study is scientifically sound. The scope of the Study is sufficiently defined to permit review (and may be exploratory, hypothesis-generating research). Access to Network Data is necessary to conduct the Study.
Ethics	Evidence of local REB approval for the Study, which should consider: - Compatibility of Study objectives with Network consent principles. - Minimal risk of privacy to individuals or stigmatization of communities.
Privacy/security	List of research team members (under PI responsibility) to have access to data.

5. Composition

The DAC shall consist of a minimum of **7** active members with different forms of expertise/experience (minimum 2 bioinformaticians, 2 clinical researchers, and 2 ethical/legal experts). Aside from the Chair, not all members need to attend each meeting/review each request (see Quorum below). This membership composition ensures alternative members are available to review requests at any given time. Membership should also reflect the regional diversity of the Network. The DAC may request input from (non-voting) invited experts (including patient representatives) to review particular Studies. Members will participate voluntarily as part of their Network participation; no funds are available to compensate members. The DAC may be expanded to include 1-2 patient representatives as (voting) members, conditional on appropriate training and support.

Individual DAC Member Responsibilities:

- To be familiar with the Network Data resource and the Network agreements and policies.
- To handle data access requests and communications confidentially.
- To carry out reviews and other responsibilities in a timely manner.



- To declare any real or perceived conflicts of interest, in recognition of the MOHCCN Code of Conduct, future Network policies, and community standards. Members will not participate in discussion or voting where they have conflicts.
- a. Appointment:** The DAC Chair and members will be appointed by TFRI with endorsement from Network Council for a term of 2 years (renewable). TFRI may request nominations from the Network, e.g., from the DAC, Steering Committee, Network Council, and/or Network leadership. An effort will be made to stagger terms so not all members are replaced at the same time. Regional representation shall be considered when making appointments.
- b. Membership Changes:** Any additions or changes in membership will be reflected on the table below and communicated to Network Council for endorsement.

Chair	Institution	From	Until
Holly Longstaff	PHSA	Apr-2024	
Bioinformatics			
Touati Benoukraf	MUN	Apr-2024	
Inanc Birol	BC GSC	Apr-2024	
Benjamin Haibe-Kains	U of Toronto	Apr-2024	
Clinical Research			
Enrique Sanz-Garcia	UHN	Apr-2024	
Erica Tsang	UHN	Apr-2024	
Ethics & Legal			
Darlene Homonko	Lunenfeld	Apr-2024	
Lesley Rapaport	UHN	Apr-2024	
Secretariat			
Kaitlin Hong Tai	TFRI	Apr-2024	

Membership Table Last Updated: April 2024

6. Management and Administration

Review - Data access requests will be circulated to the Committee in advance to facilitate off-line review. Each request will be reviewed by 3 members (one reviewing member may be the DAC Chair). One expert of each type must review each request. The DAC Chair shall ensure that a sufficient number and diversity of reviewers are assigned to a particular request. This permits the DAC to divide up requests to multiple sub-committees. Recommendations may range from approval, refusal (with written reasons), or request for more information. Consensus recommendations may be approved directly by the Chair off-line in a timely manner. Where there is no consensus, or at request of any reviewing member, requests will be put for discussion at a DAC meeting.



Meeting Quorum - Meeting quorum will be the DAC Chair plus **3** members, attending online or submitting written recommendations. Meeting quorum **must** include at least 1 expert of each type: clinical research, bioinformatician and ethical/legal. The DAC Chair may fulfill the expertise requirement in his/her area of expertise. A substitute meeting Chair may be appointed by the DAC Chair if the Chair cannot attend or participate.

Meetings - The DAC will meet on an as-needed basis, with a minimum monthly meeting (by web conference or similar means) if there are unresolved requests, to respect a maximum review timeline of 1 month. Members unable to attend a meeting may participate in advance by reporting their recommendations and comments in writing. The Chair will facilitate declaration and handling real or perceived conflicts of interest. Decisions will be made by consensus (or in case consensus can't be reached by the Chair).

Data Access Secretariat - The DAC will receive appropriate administrative support from a Data Access Committee Secretariat e.g., with handling requests and managing meetings. This Secretariat role may be fulfilled by TFRI staff or may be delegated to a separate organization at TFRI's discretion.

7. Standard Operating Procedures

The DAC will follow the **Data Access Procedures** developed by the Data Policy and Standards Committee (DPSC), covering the receipt and review of access requests, communication, and implementation of access decisions, as well as the tracking of access approvals.

8. Periodic Reporting

The DAC will report metrics quarterly to TFRI to support Health Canada reporting, and annually to Network Council to support periodic review (e.g., number of requests/approvals/refusals; average time of review; common reasons for refusal; Study outputs). Reports may also be used to develop guidance for requestors (e.g., most common reasons for refusal).

9. Appeals

Where an application is rejected by the DAC, the requestor may request a review by the DAC, providing appropriate details. If further review is required, the DAC may consult TFRI and Network Council, who may recommend additional resources or external reviews.



10. Conflicts of Interest

Conflicts of interest are generally left to the responsibility of DAC members to assess, declare and manage. DAC members may contact the DAC Chair for support where needed.

Members of the DAC can request access to Network data (but cannot review their own requests).

Members of the DAC may generally review access requests coming from their own institution, as long as they are not directly involved in the data use study.

Members of the DAC may generally review access requests concerning data from their own institution or Cohort.

11. Terms will be Updated and Reviewed

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.