

MOHCCN DATA ACCESS PROCEDURES V1.2

This document describes the Marathon of Hope Cancer Centres Network (MOHCCN) procedures to ensure data access is provided in a timely manner in compliance with Network agreements and policies. This version focuses on access currently permitted under the Network Master Agreement/Joinder – Phase I.¹ This version is limited to organizational procedures. Technical implementation of approved data access is described in the [Data Sharing Guidelines](#). These data access procedures are maintained by the MOHCCN Data Policies and Standards Committee.

Procedure to Access Network Data	
<p>Scope: These access procedures only apply to:</p> <ul style="list-style-type: none"> Any access and/or transfer of Network Data between Network Institutions (i.e., institution that is a signatory to the Network Master Agreement/Joinder) for an REB-approved Data use study led by an Investigator. Investigators who are individual members of the Network (see Individual Membership Policy) and based at a Network Institution. Access to data no longer subject to the Team Access Embargo period of 0-6 months, or access during the Team Embargo period with voluntary permission of the data-contributing Investigator (see Data Access and Use Policy). Access to controlled-access data only (see Data Privacy Policy). 	
Data-requesting Institution	
A Data-requesting Institution joins as a Network Institution by signing the Network Master Agreement/Joinder. This constitutes institutional acceptance of the “ Terms of Data Access and Use ”, a global legal agreement enabling data sharing for all approved Studies.	
Data-requesting Researcher(s)	
<i>Single PI-led Study</i>	<i>Collaborative Study (Multiple PIs, institutions, and/or provinces)</i>
Designs Study and drafts Protocol (using Platform metadata, open access data, data discovery).	Designs Study and drafts Protocol (using Platform metadata, open access data, data discovery).
Obtains local REB approval for Study. ²	DAC may accept a single REB of record (<i>if permitted by institutional policy</i>).
Submits Data Access Request form to Network DAC.	May submit a single Data Access Request form with multiple lead applicants. Each institution requiring data access must list a lead applicant.

¹ The access procedures will be expanded to cover the broader types of access envisaged by the Network in future phases of MOHCCN.

² “MOHCCN guidance for local REB review” to be developed. Local REB can be directed to consider alignment of the Study with MOHCCN Consent principles.

Network DAC Secretariat Review (expected timeline: 3-5 business days)
<p>Conducts an initial administrative review confirming the following:</p> <ul style="list-style-type: none"> • Completeness and consistency of Data Access Request Form and supporting documents. • Institution of requesting researcher is a Network Institution. • Lead applicant is employed or affiliated with a Network Institution. • Lead applicant is a PI able to take responsibility for research and supervision activities. • All accessing team members (e.g., supervised students and technical staff) are individually listed, affiliated with the same institution as the lead applicant, and under the lead applicant’s responsibility. (After Study approval, members can be added via a Data Access Request Form amendment sent to the DAC Secretariat.)
<p>Circulates compliant requests to Network DAC members for review.</p>

Network DAC Review (expected timeline: 5 business days; max timeline: 1 month).	
<p>Network DAC members review access requests according to review criteria below. <i>Note: These are ‘expedited’ criteria specific to the context of the initial phase and may need to be adapted for subsequent phases (e.g., access outside the Network; commercial access).</i></p>	
<p>Study is “non-commercial academic research”</p>	<ul style="list-style-type: none"> • No production or manufacture of products for general sale. • No commercial exploitation of data. • No data access by for-profit organizations/sponsors (except aggregate results). • May be industry-sponsored. Industry-sponsored studies are required to provide additional information in the data access request form, for review by the DAC, to confirm the study has an academic, non-commercial purpose.
<p>Scientific Feasibility</p>	<ul style="list-style-type: none"> • 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.
<p>Purpose / Ethics</p>	<ul style="list-style-type: none"> • Study aims are compatible with MOHCCN (to advance biomedical research). • Study does not aim to present risks to the reputations of care-providing Sites (e.g., comparative performance research across Sites based on outcomes or quality of care) without express written permission of each Site. • Evidence/applicability of local REB approval.
<p>Data Security</p>	<ul style="list-style-type: none"> • (In the case of data transfers) data recipients will store and analyze data secure computing environment. The request will identify the environment and demonstrate that data security best practices and standards are followed. Requestors using an environment on a pre-vetted list are exempted from this demonstration.
<p>The Network DAC convenes within a week of, and up to a month from, a request and issues a decision (approval, request for clarification, or refusal with written reasons).</p>	

Communication of DAC Approval
<p>An Implementing Email is a formal record of access approval and an instruction to Sites holding data to implement access.³ The Email is sent to the relevant contacts following the Master Network Agreement:</p> <ul style="list-style-type: none"> • Data-hosting Consortium Site Lead, Project Manager and CanDIG Node Admin • Data-contributing Site Lead (if different Site than Consortium Lead) • Data Recipient PI • TFRI MOHCCN Executive Director and Managing Director <p>In light of the existing contractual framework (see above), Network Members are not required to negotiate and execute new data access and use agreements for each specific Study.</p>

Data-Contributing (or Data-Hosting) Institution(s) Implement Approvals (expected timeline to start implementing access/transfer: 15 business days)
<p>Implements permissions for approved user(s) and provides data access.⁴</p> <p>An email should be sent to the DAC Secretariat (mohdatarequests@tfri.ca) to confirm when access has been implemented.</p> <p>The standard timeline envisages the start of transfer for traditional Gold Cohort requests. If there are special requests that require exceptional data management efforts, minor delays are acceptable.</p>

Approved and Authenticated Data Users
<p>A summary of approved data use Studies will be posted on the MOHCCN website. This will demonstrate impact of the Gold Cohort and provide Network researchers with transparency about studies involving data from their Cohorts.</p>
Tracking
<p>The Network DAC shall track duration of access and terminate access (or request data destruction/return) after 2 years (with 30-day notification and potential for renewal). The Data Recipient Institution and Investigator is ultimately obligated to cease access / destroy or return data at the end of the Study to ensure that the data is not used beyond the DAC approval.</p>
<p>The approved Data User will immediately inform the DAC Secretariat of any changes to the Study.</p>

³ If an Institution raises a concern, this will pause the approval procedure. The Data-contributing Institution must provide the Network DAC with a reasoned justification for withholding access (within 5 business days). The Network DAC and data-contributing Institution will attempt to resolve the inconsistency between the approval and the Institution’s inability to provide access. If no consensus is reached, the DAC will respect the Institution’s refusal and inform the requestor of the refusal (to the specific data) and supporting reasons.

⁴ Exceptionally, a Data-Contributing Institution has a right to refuse or withdraw access or transfer of Network Data on reasonable grounds, such as a conflict with legislation, REB, or consent terms (see **Network Master Agreement, Data Access and Use Terms**), though such refusals are expected to be rare. The refusal and supporting reasons and documentation must be reported to the Network DAC and the Requestor (expected timeline: 5-10 business days).

Amendments

Administrative amendments can be approved directly by the DAC Secretariat. Minor amendments may be subject to expedited approval by the DAC Chair (as determined by the discretion of the Chair). A project seeking additional data released from embargo may do so by minor amendment after a reasonable period of time has passed. Significant amendments (e.g., Study aims) may require full DAC review.

Periodic Reporting

The Network DAC periodically reports access metrics to Network Council (e.g., # of requests/approvals/refusals; average time of review; common reasons for refusal; outputs).

Document Revision History

Developed by	Reviewed by	Endorsed by	Effective Date	Policy Version	Summary of revisions
DPSC	Steering Committee	Network Council	27-Feb-26	V1.2	Removal of Advance Notice. Added security and industry-sponsorship review. Changed implementation timeline. Removed “pilot” wording.
DPSC & DAC	Steering Committee	Network Council	1-Aug-25	V1.1	n/a
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