

MOHCCN DATA ACCESS PROCEDURES V1.1

Introduction

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 “Pilot” version focuses on access currently permitted under the Network Master Agreement/Joinder – Phase I, in order to support the launch of initial Network data-sharing activities.¹ This version is limited to organizational procedures, which will be piloted and linked to technical infrastructure development as part of Pathfinder activities. These data access procedures are maintained by the MOHCCN Data Policy and Standards Committee.

Pilot Procedure to Access Network Data	
<p>Scope: These pilot 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	
Data-requesting Institution joins as Network Institution by signing 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 (if <i>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. • Confirm data requested are no longer subject to 0-6 month Team Embargo period, or that the data-contributing Investigator voluntarily permits access. • 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 on request to Secretariat.)
Circulates compliant requests to Network DAC members for review.

Network DAC Review (expected timeline: 1 week; 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 pilot phase and may need to be adapted for subsequent phases (e.g., access outside the Network; commercial access).</i></p>	
Study is "non-commercial academic research"	<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.
Scientific Feasibility	<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.
Purpose / Ethics	<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.
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).	

Communication of DAC Approval

For approvals, the Network DAC or DAC Secretariat sends an advance notice of the approval to all data-contributing Institutions. Data-contributing Institutions have 3 business days to inform the DAC of any concern.³

After the 3-day notice period expires, an **Implementing Email** is sent to the relevant parties (data-Contributing Institutions and/or Data Repository Institutions). 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.

Data-Contributing (or Data Repository) Institution(s) Implement Approvals (expected timeline: 3-5 business days)

Implements permissions for approved user(s) and provides data access.⁴

Approved and Authenticated Data User

If data is still subject to Network Access Period (6-18 months), Data User shall post a description of a proposed cross-cohort analysis to the Network mailing list 1 week in advance. Data User is expected to give Data-contributing teams notice of planned cross-cohort data analyses.

Tracking

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.

The approved Data User will immediately inform the DAC Secretariat of any changes to the Study.

Lay summaries of approved Studies are published on the MOHCCN website.

Amendments

Administrative amendments can be approved directly by DAC Secretariat. Minor amendments may be subject to expedited approval by the DAC Chair (as determined by the discretion of the Chair). 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).

³ If an Institution raises a concern, this will immediately pause the approval procedure. The data-contributing Institution must provide the Network DAC with a reasoned justification for withholding access (within 5 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: 3-5 business days).

Document Revision History

Developed by	Reviewed by	Endorsed by	Effective Date	Policy Version	Summary of revisions
DPSC & DAC	Steering Committee	Network Council	1-Aug-25	V1.1	n/a
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