



MOHCCN Data Access Procedures (January 31, 2024)

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"> • Studies led by an Investigator who is based at a “Network Institution” (i.e., institution that is a signatory to the Network Master Agreement/Joinder). • Investigators who are individual members of the Network (see Individual Membership Policy). • Access to data no longer subject to the Team Access Embargo period of 0-6 months (see Data Access and Use Policy). • Access to controlled-access data (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)	
Single PI-led Study	Collaborative Study (Multiple PIs, institutions, and/or provinces)
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

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.

	institution requiring data access must list a lead applicant.
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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 on request to Secretariat.]
Circulates compliant requests to Network DAC members for review.

Network DAC Review (expected timeline: 2 weeks-1 month).	
<p>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”	<p>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.</p>
Scientific Feasibility	<p>Study is scientifically sound. Study is specific enough to constitute a single project. Access to Network Data is necessary to conduct the Study.</p>
Purpose / Ethics	<p>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>
The Network DAC convenes at least monthly and issues a decision (approval, request for clarification, refusal with written reasons).	
For approvals, the Network DAC or Secretariat sends an Implementing Email (TBD) to the relevant parties. 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 Institution(s) Implement Approvals (expected timeline: 3-5 business days)
Implements permissions for approved user(s) and provides data access. ³
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 and Data-Contributing Institution(s) shall track duration of access and terminate access (or request data destruction/return) after 2 years (with 30-day notification and potential for renewal). Data Receiving Institution and researcher will also be obligated to cease access / destroy or return data at the end of the Study (see Data Access and Use terms).
Approved Data User will immediately inform 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
DAC periodically reports access metrics to Network Council (e.g., # of requests/approvals/refusals; average time of review; common reasons for refusal; Study outputs).

³ Exceptionally, a Data-Contributing Institution has a right to refuse 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).