

Manitoba Population Research Data Repository

Data Inclusion and Guidelines

June 11, 2018



This document provides information regarding the inclusion of data in the Manitoba Centre for Health Policy (MCHP) Manitoba Population Research Data Repository. There are three groups of data housed at MCHP: Repository data, Inactive Repository data, and Project Specific data. The identification of Inactive Repository data is at the discretion of the MCHP executive. Data housed at MCHP is de-identified prior to disclosure and use of the data requires explicit research approvals, and researcher agreement.

More information about the Manitoba Centre for Health Policy and the Manitoba Population Research Data Repository is available on-line through the following hyperlinks:

- [Manitoba Centre for Health Policy website](#)
- [Manitoba Population Research Data Repository - Overview](#)

Data Group Definitions

1. **Repository Data:** data housed at MCHP for research purposes that is disclosed to MCHP under a data sharing agreement rather than a particular project approval. MCHP takes responsibility for requesting, maintaining, and documenting this data at a level sufficient for researchers and analysts to understand and use the data.

The data is routinely updated and installed in one of the primary data domains on the MCHP data server. In general access to this data is limited to MCHP analytic staff; approved project specific data tables are generated from core repository data tables.

A list of Repository data is maintained on the MCHP website, including a high level overview information, years available, data scope, and approval requirements. Internally a detailed metadata dictionary is maintained including field names, types, value distributions, and additional field information. The meta data information is accessible from MCHP offices, Remote Access Site connections, and the MCHP training lab.

2. **Inactive Repository Data:** rarely used repository data that may not be updated or maintained routinely. MCHP, at its discretion, may choose to install and complete documentation for rarely used resources at the time of an approved data request. The cost for installation and documentation of this data is charged back project requesting the specific data on a first request basis.

A list of Inactive Repository databases is available on the MCHP website, including the years of data available and who the Data provider is – see the [Inactive Repository Data](#) glossary term for more detailed information. An estimated cost for installation and update will be provided as part of the MCHP feasibility review. The metadata dictionary is updated on an as needed basis. The meta data information is accessible from MCHP offices, Remote Access Sites, and the MCHP training lab.

3. **Project Specific Data:** data housed at MCHP for specific research projects/programs that is either disclosed as part of a defined research project, or derived from Repository data for a specific research project. This data is installed in the MCHP PROJECT domain and is identified or associated with an identified research project or program. Approvals from the Provincial Health Research Privacy Committee (PHRPC), UM Health Research Ethics Board (HREB) and other data providers (if appropriate) must be in place prior to any disclosure or derivation of data. Data sharing agreements for disclosure and use of data is the responsibility of the research project staff. MCHP is identified as the location where the data is housed and secured; agreements are between project principle investigator and data provider. MCHP may provide support for disclosure and use agreements along with data transfer on a cost recovery

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basis. The following hyperlink contains a summary of what MCHP will provide for individual projects: [Repository Data vs Non-Repository Data](#), available at:

http://mchp-appserv.cpe.umanitoba.ca/data/Non_Repository_data.pdf

MCHP Responsibilities for Repository Data

Funding for Core Repository data comes out of the ongoing Manitoba Health Deliverable contract, as a portion of the Fee-for-Service analytics, or the system access fees for individual research projects. MCHP takes on the following responsibilities with regard to Repository Data.

- Negotiation of disclosure and use requirements with data providers.
- Development and implementation of data sharing agreements.
- Development, support, and tracking of an approval for use process.
- Documentation of the Repository data (Metadata, collection of background and user documentation).
- Providing End user support with regard to data content, use, and general questions/queries.
- Completing a standard data quality assessment with every data disclosure and update.
- Requesting initial and subsequent data updates.
- Installation of data into a format accessible and usable at MCHP (data server).
- Linkage support where necessary.
- As necessary, provide data extraction and consultation on database structure, extraction and transfer processes with the data provider.
- Develop and maintain 'concepts' associated with repository data.
- On a cost recovery basis develop or provide access to data or subsets for approved research projects.
- Maintain confidentiality and security of the data with regard to access and use.

Requirements (Repository Data)

To be included as part of the Core or Inactive Repository data there are a number of requirements that must be met:

- The authority to disclose and use data must be clearly defined, usually as part of a data sharing agreement. This includes the any relationship between data manager and data provider (trustee).
- The purpose of the primary data collection does not limit the disclosure to MCHP and subsequent use in research.
- There is buy-in and support from the providing agency, trustee, and program. In the form of a signed data sharing agreement from the disclosing trustee.
- Although any use of the data must be approved by the data provider (trustee), there is no restriction of the use of the data for bona fide research.
- Data is de-identified to the satisfaction of the MCHP executive prior to transfer of any data to MCHP.
- Database structure is consistent and stable [over time].
- There is a clean linkage key, singly (e.g. PHIN) or through a combination of fields.
- There is funding support for the initial negotiations, disclosure, and installation. Typically, this is supported through a government sponsored 'Deliverable'.
- There is long-term funding support for the data including updates and maintenance. In the case of Inactive Repository data, the associated costs will be recouped from the research project(s) requesting use of the data.
- The data has been identified as part of a specific Deliverable including initial development (note the Deliverable may be from Manitoba Health or another government department or Ministry).

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- The data represents a 'whole' data system, or at least the whole client/patient component, if it is population based.
 - The data provider has and will provide supporting documentation for the backend system as well as user documentation.
 - MCHP Executive supports the inclusion of the data in the repository including the associated costs, negotiations, and data management requirements.

Requirements (Project Specific Data)

- The authority to disclose and use data must be clearly defined. This may be part of a data sharing agreement or be identified as part of the research approval/agreement with the trustee and associated impact committee(s). In either case, the responsibility is with the researcher to obtain the appropriate agreements/approvals.
- The purpose of the primary data collection does not limit the disclosure to MCHP and subsequent use in research.
- Data is de-identified to the satisfaction of the MCHP executive prior to the transfer of any data to MCHP. The de-identification process is done by Manitoba Health Information Management and Analytics staff.
- The Researcher takes responsibility for all costs and documentation associated with the data.
- MCHP takes responsibility for providing a secure storage and computing environment. Access to project specific data is limited to the individuals identified as having line level access on appropriate approvals for the project.

For more detailed information, please read the document [Data Request Guidelines for Project Specific Data](#).

If you have any further questions about the Manitoba Centre for Health Policy or the types of data in the Data Repository, please contact us at:

info@cpe.umanitoba.ca