Manitoba Centre for Health Policy

Accreditation 2024

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Territory Acknowledgement

The University of Manitoba campuses are located on original lands of Anishinaabeg, Ininewuk, Anisininewuk, Dakota Oyate and Denesuline, and on the National Homeland of the Red River Métis.

We respect the Treaties that were made on these territories, we acknowledge the harms and mistakes of the past, and we dedicate ourselves to move forward in partnership with Indigenous communities in a spirit of Reconciliation and collaboration.

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Introduction

MCHP Accreditation

- MCHP Manitoba Population Data Repository
  - Primarily Administrative Data
  - Basic knowledge of MCHP data holdings, and location of additional information and resources;

- An understanding of the process for starting and running a research project;

- Expectations around limits on access, use, and publication of data; and

- Time and cost estimates to start and execute a project.

MCHP Accreditation webpage

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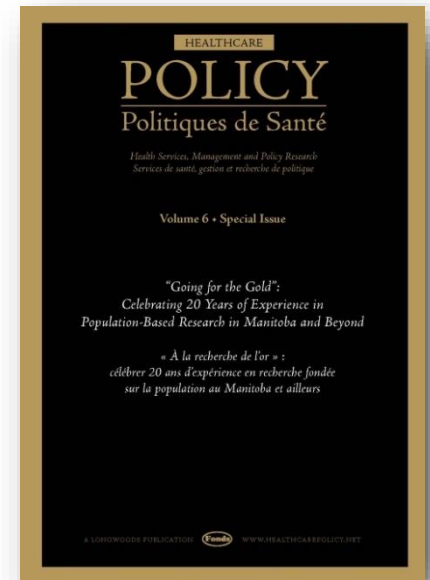UM | Rady Faculty of Health Sciences

MCHP Accreditation

- Who

  - MCHP Staff, PIs on all research projects, people with access to MCHP computer network.

- When

  - Before or at the time of starting project or work

  - Re-certification required annually (web-based since spring 2011)

MCHP Accreditation webpage

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U of M Research Unit

- "MCHP is a research unit within the Department of Community Health Sciences in the Max Rady College of Medicine, Rady Faculty of Health Sciences at the University of Manitoba."

- Formed in 1991 administrative data has been housed and collected representing health services data since 1970, and expanded to include Education, Social, Justice data.

- Supporting ~250 ongoing research projects

MCHP Home

Research at MCHP - Deliverables

- Deliverables
  - Several major projects annually (deliverables)
  - Knowledge translation through the Evidence to Action (E2A) Annual Workshop
  - Examples: Primary Care Projections, Methamphetamine consumption, Immigrant Health, First Nation health, Gastrointestinal Endoscopy Utilization, Transitions in Care, ICU use predictions, overlaps in Child Welfare with Justice and Education and Surgical Procedures.

MCHP Deliverables
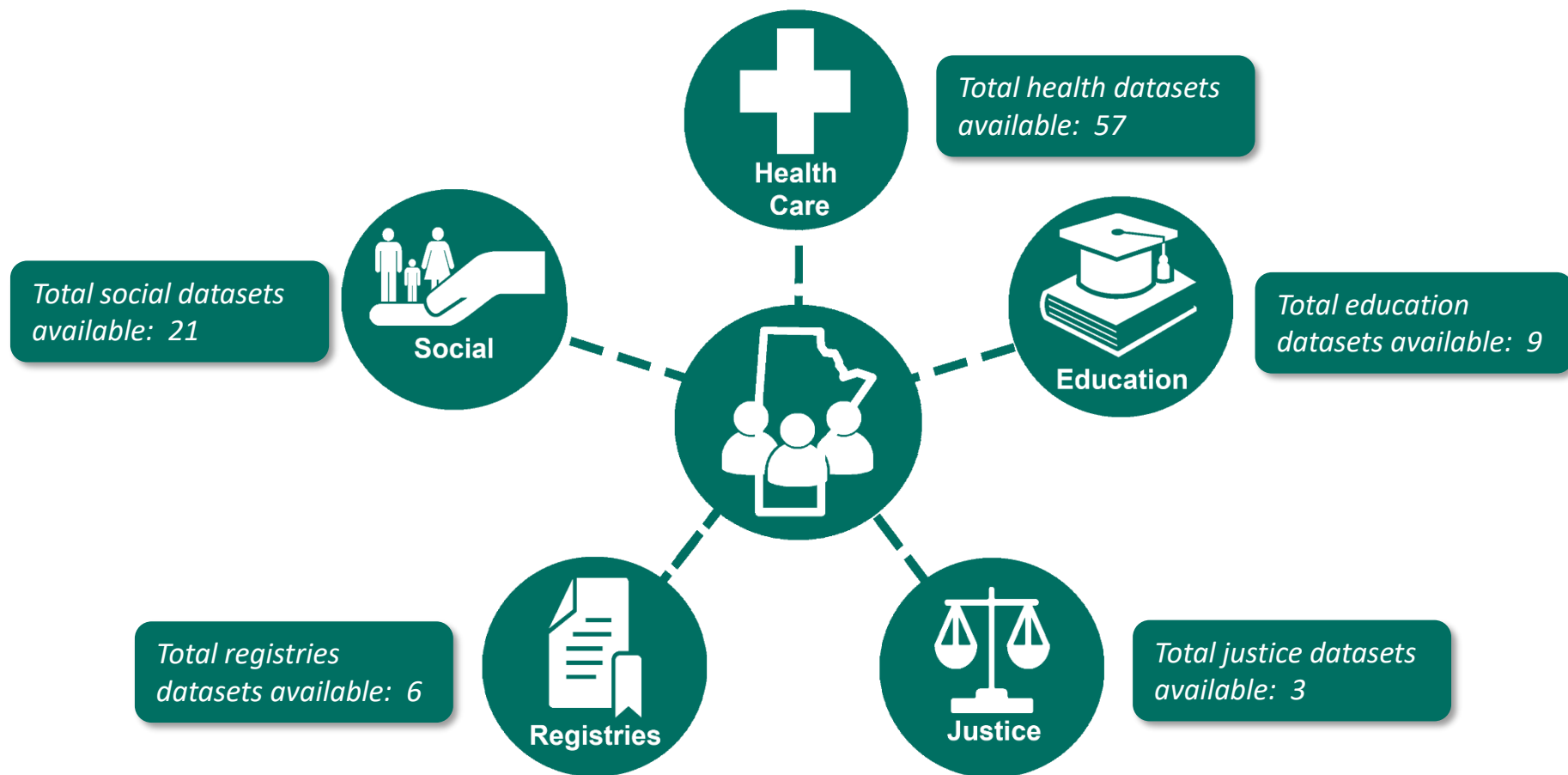
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Research at MCHP - Investigators

- Research Projects
  - Researcher driven & funded projects
  - Cost recovery – not for profit
  - Possible topics include: COVID-19 modeling and outcomes, prescription medication or antibiotic use, cardiac surgery follow-up, IBD, ICU recovery, educational achievement, child welfare involvement, justice system involvement and overlaps, mental health, program evaluation, First Nation and Métis, validation studies, maternal and child health, osteoporosis, immunization and vaccine uptake, Multiple Sclerosis treatment, illicit drug use, immigrant health

Research at MCHP

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Manitoba Population Research Data Repository

Total health datasets available: 57

Total social datasets available: 21

Total education datasets available: 9

Total registries datasets available: 6

Total justice datasets available: 3

Health Care

Social

Education

Registries

Justice

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Scope and Coverage

- Represents whole Manitoba Population

- Data are installed/updated after year end files are closed

- Data are de-identified with a common encrypted ID

- Linkable – but not maintained in a linked format.

- Can be used only for approved research project

- Project Specific Data (Survey, RCT, Clinical)

Data Repository

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Data Information

- [MCHP's Data List](#)

Data Repository

Detailed Data Dictionaries

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Internal MCHP Data Dictionaries

Concept Dictionary/Glossary
Methodological/Algorithms

1. **Intellectual Disability (ID) (Mental Retardation) / Developmental Disability (DD) / Developmental Disorders / Intellectual or Developmental Disability (IDD)**

   This concept briefly describes the conditions of intellectual disability (mental retardation) / developmental disability / developmental disorders, and provides operational definitions used in research that utilizes the Manitoba Centre for Health Po...

2. **Involvement Type Indicator - Justice System**

   This concept contains information about an indicator that was developed to provide information about involvement with the Justice system. The indicator is derived from the Justice Prosecution Information and Scheduling Management (PRISM) data avail...

3. **High School Completion / Graduation and Grade 12 Attainment**

   High school completion / graduation is frequently used as an outcome measure for a child's level of educational attainment. Attainment of Grade 12 by a certain age, such as 17 years old, provides a similar measure. This concept describes the genera...

Concept List

Data Equity?

Data Equity is a set of principles and practices to guide anyone who works with data (especially data related to people) through every step of a data project through a lens of justice, equity, and inclusivity. And equity is not just an end goal, but also a framing for all data work from start to finish... (data.org, April 25, 2024)

It underscores marginalized communities' unequal opportunities to access data and, at times, their harm from data's misuse. Data equity pushes us to consider the ways that data can reinforce stereotypes, exacerbate problems like racial bias, or otherwise undermine social justice. (jliconsultinghawaii.com, July 19, 2020)

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Data Equity

- Data are not objective
    - Requires historical and cultural context, especially as we confront racism, colonialism, ableism, gender inequities and other systemic forms of discrimination
    - What data are collected or are not collected reflect the values of the system
        - In the case of admin data, the data gathered are the information that provincial /federal govt values
        - Though we have "whole population" level data, there is lots of information missing.

- Data can do harm
    - Research using admin data provides us an excellent window into the past; however, the past cannot inform future policy without reflecting on the contexts mentioned above – high probability of repeating mistakes without taking past structures into account.

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Data Access and Use Process

Accreditation → Project Proposal Review and Approval Costing and Feasibility → Governance

Governance → PHRPC, HREB, Indigenous Partnerships, Others, RA

Governance → Project Start Notification → Account & Project Provisioning → Data Analysis → Vetting/Output Request (small N) → Publication Review → Project Completion → Project Archival

Project Start Notification → Training/Orientation (project specific) → Account & Project Provisioning

Data Analysis → Additional Training Consultation → Training/Orientation (project specific)

Audit

Approvals, Amendments, and Extensions

Initial Approvals

- Health Research Ethics Board (HREB)

- Provincial Health Research Ethics Committee (PHRPC) & CHIPER

- Others may be required (e.g. Shared Health, Education, CCMB, HIRGC, etc…)

- Research Agreement (RA) with UofM & MB Gov

Amendments/Follow-up

- REB Annual Renewal

- RA Expiration and Extensions

- Please note, other data providers and data may also have deadlines, and/or expiration dates

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Limited Use and Results Reporting

- Use of data is limited within each project to the approvals obtained

- Data cells representing 1-5 individuals or events must be suppressed. Some data providers (IRCC) require 10-20.

- Copy of publication or presentations must be sent to data providers and MCHP a minimum of 30 days prior to release

- Vetting and transfer of aggregated data and results for external researchers/analysts

- Ethics, Privacy, and Impact reviews must be kept current

- Inactive or expired projects will be archived.

- When a project is complete, a Final Study Status Report must be submitted

- Projects will be archived for 7 to 10 years

Data Use Guidelines

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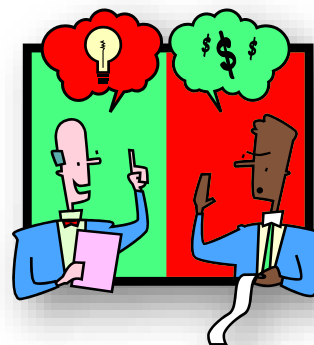
Publication/Presentation Review Time Frame - Days

Type	Manitoba Health (PHRPC)	MCHP	Other Providers (some specific DAS may have further requirements)
Articles (publications, thesis, new release)	30 days	30 days	Prior to public release
Presentations (with handout, abstract or compendium)	30 days	30 days	Prior to public release/presentation
Oral Presentation only	10 days	10 days	Prior to public presentation

Publications/presentations based on Manitoba Health Deliverables require special permission prior to release.

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MCHP Provided Support Remote Access Sites

- VPN access from desktop – in Manitoba currently. Resolving with province to allow access externally.

- Requires currently patched Windows, and Anti-Virus running – compliance tested with each login.

- Feasibility provides cost estimate. MCHP invoices monthly based on hours of time spent working or supporting projects

- There is an initial project startup cost with a subsequent annual supporting fees

- If RAS is being used there is a prorated annual user access free

- Projects with an identified student PI then RAS fee direct support rate is reduced.

- Student Guidelines

- Private Sector/Contract Guidelines

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MCHP: Audits and Reviews

- Ensure compliance and protection

    - Approvals (U of M, MHSC, others….) ongoing

    - Data access

    - System access

    - Publication review

    - Forms (RA, Confidential Data)

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Access Audits and Follow-up

- Breach
  - Individual records or personal information released/disclosed
    - Within system/MCHP
    - Externally
  - Individual records or personal information used or accessed outside of approvals
  - Integrity of data is compromised
  - Small numbers released/disclosed
  - Release of results outside of process (e.g. published without review)

- Reporting
  - Notification of direct supervisor/MCHP
  - Review/Extent
  - Notification of UofM/Gov - Access and Privacy Office, MB Gov Dept/MH
  - Review - what was the breach; is further investigation necessary
  - Correction/Follow-up
  - Documentation

Data Use Guidelines

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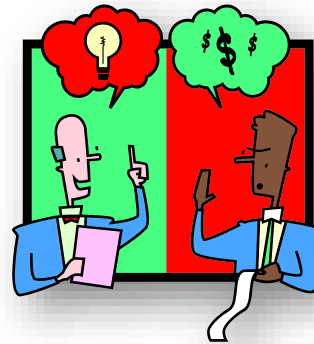
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U of M Pledge of Confidentiality

- Required for everyone with access to Personal Health Information, MCHP staff, project PI, and individuals with MCHP system access.

- Required to be completed for HREB submission

- Completion of the U of M MCHP Associated PHIA Orientation material and corresponding Pledge of Confidentiality is required

- U of M PHIA & Pledge of Confidentiality must be completed even if PHIA orientation has been completed with a different organization (e.g. WRHA, Province of Manitoba).

**U of M PHIA
Training Page**

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Thank you/Questions

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