

Guidelines for Student Use of the Population Health Research Data Repository Maintained by the Manitoba Centre for Health Policy

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The Population Health Research Data Repository (Repository) maintained by the Manitoba Centre for Health Policy (MCHP) is an important resource for consideration of a wide range of population-based research. The Repository may also have application to non-population-based research. Historically, students have had an opportunity to work with MCHP on a variety of projects. The Repository contains complex databases, and students who seek to understand the content of the databases and the process of conducting research with administrative data are encouraged to consult the MCHP website at <http://umanitoba.ca/medicine/units/mchp/>

Students interested in using the Repository for completing their thesis or dissertation should consider the following:

their research question(s) should be consistent with the mission of MCHP

<http://umanitoba.ca/medicine/units/mchp/>,

their research question(s) should be answerable using the Repository,

their research using the Repository must be conducted under the direct supervision of a researcher experienced using the Repository, and

the supervising researcher should be a member of the student's thesis/dissertation committee.

there will be costs incurred to access the Repository (see below for further description of how these could be funded)

Students are required to obtain approval for their thesis/dissertation project from:

MCHP Review committee (starting with the MCHP project feasibility and data access quote request form – available at:

<http://umanitoba.ca/faculties/medicine/units/mchp/resources/access/proposals.html>

the University of Manitoba Health Research Ethics Board (HREB) and

the Province of Manitoba Health Information Privacy Committee (HIPC).

All approvals and proof of funding must be on file with MCHP and a Researcher Agreement signed prior to the project starting.

There are three categories of research in which students may be involved:

- 1) Manitoba Health Deliverables
- 2) Independent research initiated by the supervising researcher, where the research is fully funded through the researcher's external sources (i.e., granting agency); or
- 3) Independent research initiated by a student, which is fully paid for by the student or funded through external sources granted to the student.

Categories of Research Using the Repository

1. Manitoba Health Deliverables

A researcher is assigned through MCHP as the principal investigator (PI) for a Deliverable – this is a contracted research project between Manitoba Health and MCHP. A PI may chose to involve a student directly in the completion of the Deliverable. The student will then be listed as a co-investigator of the Deliverable.

If the student uses datasets created in the course of completing the Deliverable to conduct research that extends beyond the scope of the description of the Deliverable for their thesis or for another project, then permission for use of this dataset must be obtained from the PI, the MCHP Director, Manitoba Health. In addition, the student MUST also obtain separate permissions from HIPC and HREB, so that their proposal is identified separately from the Deliverable. The student is expected to conduct all of the independent data analyses for their thesis themselves from the created dataset. As the dataset was created for the Deliverable, there is no cost recovery to the student for the use of this data.

If the student requires additional preparation of the data to make it usable for their thesis, this additional preparation would be completed by a MCHP programmer on a full cost-recovery basis, for which the student would be responsible.

2. Researcher-Initiated Projects

If a student is conducting their thesis/dissertation research using data created for a researcher's project, it is expected that the project will cover the additional expenses required to make the data useable and accessible by the student. The total cost is provided in the feasibility quote prior to the start of the thesis project. Funding to cover the total costs must be identified prior to the start of the project. The student will also be required to obtain separate permissions from HIPC and HREB, in accordance with the graduate requirements of the Department, and sign a separate Researcher agreement.

3. Student-Initiated Research

Only with prior approval from the MCHP Director or the MCHP Associate Director, Research is it possible for a graduate student to conduct their thesis research using the Repository on a project that is not directly connected to a MCHP Deliverable or a fully funded MCHP Research Scientist initiated project. This is due to the complexities of using the Repository, and the fact that programmer costs must be funded from an identifiable source.

PhD Student

We recognize that graduate students enrolled in PhD programs are expected to conceive and execute their dissertation research independent of their supervisors or other faculty members, although their dissertation research may be part of a larger project. The student is expected to conduct all of their own analyses, and obtain separate HIPC and HREB approvals. Access to project specific data will be done on a full cost recovery basis. The total costs are provided to the student

in the feasibility and quote stage of the process. Full funding must be identified prior to any data access.

The first step for this student is to identify a researcher willing to supervise the student's proposed work with the Repository. Once a researcher has agreed to supervise the student, then a research proposal is developed and sent to the MCHP Repository Access Coordinator for review and processing.

MSc Student

If a student desires to conduct their thesis research using the Repository outside of Deliverables or an externally funded project, the first step is to identify a researcher willing to supervise the student's proposed work. Once a researcher has agreed to supervise the student, then a research proposal is developed and sent to the MCHP Repository Access Coordinator for review and processing.

It is expected that the student would conduct all data analyses themselves and will have secured funding in place to cover the full costs of access and use of the Repository prior to the start of the project.

Cost Recovery

The use of administrative data for research can be an expensive undertaking. In general, students are expected to become familiar with SAS and complete their own programming. In this document, cost recovery includes both the direct costs for programmer's time and a share of the cost of the infrastructure that builds and maintains the Repository. Information concerning the charge for use of the Repository for graduate student research will be provided to the student at the completion of the proposal review. The MCHP Finance will invoice the student on a cost-recovery basis, at the student rate.

Additional Information

MCHP Research Resources (this site provides information on the Repository; Research Process including data access, policies on use and disclosure, and checklists for developing and managing your proposal; and Research Tools including concept dictionary, glossary, and design and methods):

<http://www.umanitoba.ca/faculties/medicine/units/mchp/resources/index.html>

University of Manitoba Health Research Ethics Board:

<http://www.umanitoba.ca/faculties/medicine/research/ethics/index.htm>

Provincial Health Information Privacy Committee:

<http://www.gov.mb.ca/health/hipc/index.html>

Use of Computer Facilities:

http://www.umanitoba.ca/admin/governance/governing_documents/community/252.htm

STUDENT PROCEDURE FOR ACCESS AND USE OF THE POPULATION HEALTH RESEARCH DATA REPOSITORY

June 2, 2010

Access and use of data in the Repository and disclosure of research results derived are governed by provincial legislation and established policies and procedures of the University of Manitoba and MCHP to protect the confidentiality, privacy and security of sensitive personal health information.

Students wishing to use the Repository should proceed as follows:

1. Meet with one or more Repository experienced researchers to discuss research opportunities and identify a proposed research area. Identify a thesis/dissertation advisor and/or a Repository experienced researcher who is willing to be involved in the research.
2. Have a discussion with the MCHP Director or Associate Director outlining the proposed research, how it fits within a MCHP or other funded project, and how the research is proposed to be accomplished with the database (including any necessary file creation and programming requirements). The student should complete a MCHP Feasibility form (available on the website) to obtain a financial quote for the use of MCHP resources to create and make available their project specific data.
3. Once a Repository experienced researcher has agreed to oversee the initiative and the proposal has been reviewed and is fully funded, the student will be required to obtain all required approvals for their project including the University of Manitoba Health Research Ethics Board (REB) and the provincial Health Information Privacy Committee (HIPC). The project must be reviewed by the Repository experienced Researcher supervising/advising on the thesis prior to its submission to HREB and HIPC.
4. When the student receives all required approvals, they should provide copies of these to the Repository Access Coordinator. MCHP will notify the student when their project specific dataset has been pulled and made available to them through an assigned space in T-155.
5. The student will be required to complete MCHP Accreditation, prior to receiving a key to T-155 to access and analyze their project specific data. The student must also become familiar with the Privacy, Confidentiality, Disclosure, Publication and Security Policies and Procedures at MCHP, as well as relevant University of Manitoba policies and procedures.

Students are advised to:

- develop their skills in SAS. MCHP has self-tutoring courses in SAS that can be made available. The Epidemiology of Health Care course usually taught in the fall term also provides an opportunity to learn basic SAS skills.
- participate in MCHP offered SAS training courses.
- make their interest known early to a Repository experienced researcher in order that opportunities for becoming involved in an ongoing research project, and developing a focus which could be used for thesis research, are created.
- work with their thesis or dissertation supervisor to develop a research question that can be addressed with Repository data. **Projects that require merging multiple files with complex programming requirements are not typically feasible without significant outside financial support.**