

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

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The Manitoba Population 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. Historically, students have had an opportunity to work with MCHP on a variety of projects for partial fulfillment of their graduate thesis. The Repository may also be used for Resident and undergraduate projects with some limitations. 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 review the information on the MCHP Applying for access and use web pages and the database information in the Data List and Data Descriptions tools, and to talk with researchers experienced with using the Repository.

Students interested in using the Repository should consider the following:

- their research question(s) must be consistent with the MCHP mission.
- their research question(s) must be answerable using the Repository.
- An MCHP-affiliated researcher who is deemed knowledgeable about the Repository must be on their thesis committee as supervisor, co-supervisor, or under exceptional circumstances a committee member. The MCHP-affiliated researcher must have completed the current MCHP Accreditation and have been a lead researcher or PI on a research project using the MCHP Repository within the last five years. If the student's supervisor or co-supervisor is not the MCHP-affiliated researcher, then the supervisor/cosupervisor should also complete the current MCHP accreditation.
- there will be costs incurred to access the Repository.
- students must have their project approved by their committee (i.e., passed their proposal defense) prior to submitting to the University of Manitoba (UM) Health Research Ethics Board (HREB) and the Provincial Health Research Privacy Committee (PHRPC) for approvals.
- students must complete the <u>MCHP Accreditation</u> session prior to applying for access to the Repository. It is highly recommended the student take this session prior to writing their proposal, to familiarize themselves with the available data, MCHP policies and protocols.
- graduate student thesis projects must be an independent research project. Students must obtain their own set of approvals before they can access the data (gaining approvals by amending a faculty member's set of approvals does not meet this requirement).
 - The Manitoba Centre for Health Policy requires that trainees who access and analyze the data housed in the Manitoba Population Research Data Repository -- as

part of their thesis project -- apply for and secure their own approvals, including: PHRPC, HREB, relevant data providers and other relevant partner organizations.

- This policy exists to provide students with a comprehensive learning experience and protect students' intellectual property.
- Resident and undergraduate student projects typically must be done as part of an ongoing and approved project due to time constraints; the student must be identified as a collaborator on the project (e.g., on the PHRPC/HREB approvals). Under exceptional circumstances, a Resident with appropriate analytic and programming skills may submit a project following a process similar to a graduate student.

Access and use of data in the Repository along with disclosure of the derived research results 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.

Graduate students wishing to use the Repository should proceed as follows:

- 1. Meet with one or more researchers that are experienced using the Repository to discuss research opportunities and identify a proposed research area. Identify an MCHP- affiliated researcher that is willing to supervise, co-supervise or, under exceptional circumstances, be a committee member
- 2. The student will be required to complete the MCHP Accreditation. The student must also become familiar with the Privacy, Confidentiality, Disclosure, Publication and Security Policies and Procedures at MCHP (see <u>Applying for access and use</u>), as well as relevant University of Manitoba policies and procedures.
- 3. Have a meeting with the proposed supervisor and the Associate Director, Data Access and Use outlining the proposed research, how it fits within a MCHP or other funded project, and how the research is proposed to be accomplished using the Repository (including any necessary file creation and programming requirements). The student should complete a **MCHP Feasibility form** and submit their proposal to confirm the feasibility of the project, identify any questions or potential problems, and obtain a financial cost estimate for the use of MCHP resources to create and make available their project specific data.
- 4. Once the MCHP-affiliated researcher has agreed to be the supervisor or committee member, and the proposal has been reviewed and funded, the student will be required to obtain all required approvals for their project including the University of Manitoba Health Research Ethics Board (HREB), the Provincial Health Research Privacy Committee (PHRPC), and any other required approvals as identified in the feasibility review. The project must be approved by the student's committee and supervisor (i.e., passed their proposal defense) prior to its submission to HREB and PHRPC.

Prior to the project starting, all approvals and proof of funding must be on file with MCHP along with a Researcher Agreement signed by the supervisor and student. A MCHP Analyst will be assigned to the project to extract the required data from the Repository and provide some data and analytic support. The Analyst will meet with the student before the data is pulled to confirm data and analytic requirements. MCHP will notify the student when their project specific dataset

has been pulled and made available to them through the Remote Access System (RAS).

It is usually expected that the student will conduct all data analyses themselves.

Cost Recovery

The use of administrative data for research can be an expensive undertaking. In general, graduate students are expected to become familiar with SAS and complete their own programming. SAS training sessions are available to students through MCHP (check with the Associate Director, Data Access & Use for dates). For a student's research project, cost recovery includes the costs for a programmer's time to pull the necessary data and any ongoing support or questions about the data, analyses, or SAS programming. Specific statistical advice should be sought from the student's committee or the University's Biostatistical Consulting Unit (BCU). 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 feasibility review. The MCHP Finance group will invoice the student on a cost-recovery basis, at the student rate. System access costs are typically waived for graduate students working on their own project.

To be considered for a reduced student rate at MCHP the student must be enrolled in an academic degree granting program and be the identified PI on their thesis project.

Undergraduate and Resident Projects

Due to time constraints and the level of programming/data knowledge required it is usually impractical for a Resident or Undergraduate student (e.g. BSc Med) to complete a research project on their own. It is possible for these students to be involved with an existing research project as part of their training.

A Resident or undergraduate project may be completed as part of their training under the following additional conditions:

- the project must be an active project currently in progress at MCHP;
- the student must be identified as a collaborator on the research project;
- because of programming complexities, typically an MCHP or RAS analyst will complete the programming necessary, and funding must be in place to pay for the analysis required at the regular MCHP hourly rate for analysis; and
- the PI on the project must be involved with supervising the Resident or undergraduate project.

Under exceptional circumstances a Resident with sufficient time may do their own analysis and be treated as a graduate student with regard to approvals and costs. To be considered for a reduced student rate the Resident must be enrolled in an accredited Residency program within Manitoba, be doing their own analysis, and apply for their own project approvals.

Additional Information

Further information on the MCHP Data Repository and access process can be found on the MCHP website. This site provides information about the Data Repository; the Research process, including how to access the Repository, policies on use and disclosure, and checklists for developing and managing your proposal; and Research Tools that are available, including the Concept Dictionary and Glossary, and study design and methods considerations. This information is available through the following web page: <u>The Manitoba Population Research Data Repository</u>.

Additional information is available through the following links:

- University of Manitoba (UM) Health Research Ethics Board (HREB) <u>Submission</u>
 <u>Requirements</u>
- Provincial Health Research Privacy Committee (PHRPC)
- <u>UM Use of Computer Facilities</u>

Students are advised to:

- take the MCHP Accreditation session before writing their proposal;
- develop their skills in SAS. MCHP has self-tutoring courses in SAS that can be made available and MCHP also offers SAS training courses. The Epidemiology of Health Care course, usually taught in the fall term, also provides an opportunity to learn basic SAS skills.
- make their interest known early to a Repository-experienced researcher, in case an
 opportunity arises to become involved in an ongoing research project and developing a
 focus which could be used for their thesis research. They should also work with their
 thesis or dissertation supervisor to develop a research question that can be addressed
 using the Repository data.