

**Guidelines for Student Use of the Population Health Research Data Repository
Maintained by the Manitoba Centre for Health Policy
January, 2003**

The Population Health Research Data Repository (PHRDR) maintained by the Manitoba Centre for Health Policy is an important resource for consideration of a wide range of population-based research. The data repository may also have application to non-population-based research. Historically, students have had an opportunity to work with MCHP researchers on a variety of issues. PHRDR 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 www.umanitoba.ca/centres/mchp.

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

- their research question(s) should be consistent with the mission of MCHP,
- their research question(s) should be answerable using PHRDR,
- their research using PHRDR must be conducted under the direct supervision of a MCHP researcher,
- the MCHP supervising researcher must be on the student's thesis/dissertation committee,
- there are three classes of research in which students may be involved; 1) Deliverables for Manitoba Health, 2) Independent research initiated by a MCHP researcher that is funded from external sources, and 3) Independent research initiated by a student on a full cost recovery basis.

Students are required to obtain approval for their thesis/dissertation project from the University of Manitoba Health Research Ethics Board (HREB) and the Province of Manitoba Health Information Privacy Committee (HIPC), however the proposal must first be reviewed by the MCHP Researcher supervising/advising on the thesis. All approvals must be on file with MCHP prior to starting the project.

Classes of Research Using PHRDR

1) Deliverables for Manitoba Health

A MCHP researcher is assigned as the principal investigator (PI) for the deliverable. If a student is involved directly in the completion of the deliverable, the student should be listed as a co-investigator. If the student uses datasets created in the course of completing the deliverable, but conducts research that extends beyond the scope of the description of the deliverable, permission for use of the dataset must also be sought from the deliverable PI and the MCHP Director. Typically the student will conduct all independent data analyses themselves once the dataset has been created; although depending on the relationship to the deliverable, programming help may be available.

If the student's involvement is limited to taking responsibility for part of the analysis pertinent to the development of an approved deliverable, there are no additional costs

involved, and therefore no costs would be recovered. If the student is conducting independent research using the dataset created for the deliverable, there would be no additional costs, and therefore no costs would be recovered. If the student is conducting independent research based upon the dataset, but additional preparation of the data is required to make it usable for the student, this additional preparation would typically be on a full cost-recovery basis.

2. MCHP Researcher Initiated Projects

If a student is involved as an investigator on an externally funded project initiated by a MCHP researcher, the student may participate in aspects of the project as agreed by the researcher.

As all costs of externally funded research are recovered, there would be no additional costs to be recovered if the student is involved directly in the project. If the student is conducting independent research using the dataset created for the project, there would be no additional costs, and therefore no costs would be recovered. If the student is conducting independent research based upon the dataset, but additional preparation of the data is required to make it usable for the student, this additional preparation would be on a full cost-recovery basis.

3. Student Initiated Research

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. However, due to the complexities of using the database, it is possible to conduct research using PHRDR for projects that are not directly connected to MCHP deliverables or MCHP researcher initiated projects only on a full cost recovery basis. The first step is to identify a MCHP researcher willing to supervise the student's proposed work and then an application should be made to the MCHP Director. In determining whether permission will be granted, the Director will consider the fit of the proposed research to MCHP's mission, the rationale for the project being done independently rather than the research being linked to an already funded project, the complexity of the request and the availability of repository support. Typically the student will conduct all independent data analyses themselves including the creation of the required dataset.

MS Student

Only under exceptional circumstances will it be possible to conduct research using PHRDR for projects that are not directly connected to MCHP deliverables or MCHP researcher initiated projects. This is due to the complexities of using the database, and the fact that programmer costs must be funded from an identifiable source.

If a student desires to conduct research using PHRDR outside of the approved deliverables or an externally funded project initiated by a MCHP researcher, the first step is to identify a MCHP researcher willing to supervise the student's proposed work and then an application should be made to the MCHP Director. In determining whether permission will be granted, the Director will consider the fit of the proposed research to MCHP's mission, the rationale for the project being done independently rather than the research being linked to an already funded project, the complexity of the request and the availability of repository support. It is expected that the student would conduct all data analyses without the direct involvement of

a programmer. It is highly encouraged that students create the dataset(s) which they require for their analysis.

All MCHP programming, dataset creation and repository support costs are provided on a full cost recovery basis.

Special Projects

On an exceptional basis, student initiated projects may be considered to be of such a nature that their work would make a substantial contribution to the Population Health Research Data Repository infrastructure. Under such circumstances, the MCHP Director may provide such programming and repository support as is deemed necessary, without requiring full cost recovery.

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 as well as create their dataset(s). In this document, “full cost recovery” is a requirement for all incremental costs resulting from students’ research. Cost recovery includes both the direct costs for programmer’s time and a share of the cost of the infrastructure that builds and maintains PHRDR. Information concerning the charge for use of PHRDR for graduate student research is available from the Senior Administrator.

Under special circumstances MCHP programmers can be made available for limited file creation, particularly if the project develops out of an ongoing activity at MCHP. If the Director determines that a project is directly relevant to MCHP research initiatives (for example assessing the validity of the approach used to assess waiting times in the province), programmer support may be provided by MCHP. Limited funds are available for student use to defray some of the costs associated with research utilising the PHRDR. Such proposals should be submitted to the Director and will be reviewed internally on an individual basis.

Note that there is no cost recovery for the time spent by a MCHP Researcher in supervising/advising the work of the student.

Additional Information

- Protocol for Conducting Administrative Research:
<http://www.umanitoba.ca/centres/mchp/protocol/>
This site includes the MCHP Orientation Policy and Data Access Request Guidelines and Procedures
- 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/senate/pnp/section_200/238.html

STUDENT PROCEDURE

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

Students wishing to use PHRDR should proceed as follows:

1. Meet with one or more MCHP researchers to discuss research opportunities and identify a proposed research area. Identify a thesis/dissertation advisor and/or a MCHP researcher who is willing to be involved in the research.
2. Have a discussion with the MCHP 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.)
3. Once the MCHP Director has approved a project and a MCHP researcher has agreed to oversee the initiative, the student will be required to sign the MCHP Oath of Confidentiality. The student must also become familiar with the Privacy, Confidentiality and Security Policies and Procedures at MCHP, as well as relevant University of Manitoba policies and procedures.
4. The student is responsible for the submission of their project to the University of Manitoba Health Research Ethics Board (REB) and the provincial Health Information Privacy Committee (HIPC). The proposal must be reviewed by the MCHP Researcher supervising/advising on the thesis prior to submission to REB and HIPC.

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 MCHP researchers 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 data in PHRDR. Projects that require merging multiple files with complex programming requirements are not typically feasible without significant outside financial support.