

Request for Access to Health Information Held by the Government of Manitoba

An Example Submission Prepared at MCHP Focusing on Fields Relevant for Projects Using the Population Health Research Data Repository*

Annotations and Examples Highlighted in Yellow Recommended Responses in Blue Font

Instructions: Please submit the original plus 10 copies of the completed application form and all supporting documentation. For more detailed information, please see the ['Guidelines for Completing a Request for Access to Health Information Held by the Government of Manitoba'](#).

Date of Request (MM/DD/YYYY): <date>

Title of Research Project: <The title should be the same as the title for the HREB submission.>

I. Researcher Information

Principal Investigator (PI): <full addresses. Note that for UM REB, the PI must be a U of M investigator.>

Affiliation:

Address:

Email:

Phone:

Fax:

Academic Advisor (if PI is a student):

Affiliation:

Address:

Email:

Phone:

Fax:

II. Co-investigators

Please list all co-investigators, their affiliation and role in the proposed research project. <ALL co-investigators who will have actual access to the data need to be identified here. This does not need to include all authors for planned manuscripts; however, once the first author has been determined, this should be sent to HIPC and copied to the Research Access Coordinator at MCHP.>

Role – e.g., provide clinical expertise regarding...; e.g., conduct data analysis, data collection, etc. (The more specific, the better.)

Access to data - is typically checked off as "aggregate">

1. **Name:**
Affiliation:
Role:
He/she will have access to line-level () or aggregate () data.
2. **Name:**
Affiliation:
Role:
He/she will have access to line-level () or aggregate () data.
3. **Name:**
Affiliation:
Role:
He/she will have access to line-level () or aggregate () data.
4. **Name:**
Affiliation:
Role:
He/she will have access to line-level () or aggregate () data.

III. Description of the Research Project

- (a) Is this project part of a program of research? Yes No *<Typically No>*
If yes, has the program of research already received HIPC approval-in-principle? Yes No
↳ HIPC File Number:

(b) Please provide a general description of the research project, including its purpose and the proposed methodology. (This may be added as an attachment)

(c) Please list and describe the specific research questions, objectives, and/or hypotheses that will be tested. For programs of research, please list and describe the planned research projects within the program.

<Provide attachment indicating "Please see attached document" OR provide a summary paragraph plus specific objectives, which should be consistent with the Research Ethics Board submission. Note: any publications arising from the project need to relate back to the objectives.>

- (d) Will the study involve direct access to potential study participants? Yes No
If yes, include copies of the introductory letter(s) that will be sent to the potential participants, as well as the informed consent forms, questionnaires and any other materials that potential participants will receive.

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IV. Specific Data Required

- (a) Indicate the databases to be accessed, years of data required, and the variables of interest. Please be as specific as possible as the Personal Health Information Act requires that only the minimum information necessary to accomplish the purpose of the research project be released to researchers.

<This section (a) refers to Manitoba Health and Healthy Living (MHHL) data. Non-MHHL data is described in section d). Rationale for requesting a given database should be spelled out in the proposal>
 <Note: It is recommended to use general categories or descriptive requirements for Fields of Interest. If specific fields are listed the wording may be prefaced with "for example", "including", "such as", or similar phrasing. Otherwise, you may only use the fields you specify, and a HIPC Protocol Amendment form will need to be submitted for approval; this also applies to descriptions contained in the study protocol and in the HREB submission>.

Database	Years of Data Required*	Fields of Interest
Manitoba Health Insurance Registry	April 1, 2007 to March 31, 2008	Birth, death, coverage status, sex, location of residence, relationship to family head
Hospital Abstracts	April 1, 2007 to March 31, 2008	Hospitalizations, diagnoses, procedures, services & providers, length of stay, hospital & case characteristics
Medical Services (Physician Billings)	April 1, 2007 to March 31, 2008	Services, diagnoses, facility, location, group, physician characteristics
Provider Registry	April 1, 2007 to March 31, 2008	Physician characteristics (specialty, age, location of training, years of practice), practice characteristics, payment methods, workload, group
Drug Data	April 1, 2007 to March 31, 2008	Prescriptions, drugs, characteristics (type, dose, quantity, class), carriers, prescribers, providers, pharmacy
Home Care (MSSP)	April 1, 2007 to March 31, 2008	Users, admissions, services, providers, characteristics
Long Term Care	April 1, 2007 to March 31, 2008	Users, admissions, services, wait times, level of care, characteristics, facilities
Immunization (MIMS)	April 1, 2007 to March 31, 2008	Immunizations, providers, timing
Management Information System (MIS)	April 1, 2007 to March 31, 2008	Statistical & financial data on staff and services provided

* Fiscal years: April 1st, YYYY through March 31st, YYYY

† If data prior to 1985 is required, please consult the HIPC Coordinator.

- (b) Inclusion/exclusion criteria (e.g. age, gender, region of residence, diagnoses, etc.) N/A

- (c) Is a control group required? Yes No

If yes, please describe the matching criteria for the control group:

- (d) Will data held by a department or agency of the Government of Manitoba be linked/merged with data from another department or external source(s)?

Yes No : <usually yes, and specify the categories of databases as well as the linkage key(s)>

If yes, please describe the nature of the linkage (e.g. the data/databases that will be linked).

e.g.

a) non-MHHL data: In order to link database records across data files (e.g., Income Assistance data with health data and education data), MHHL has undertaken the translation process, where all personal identifiers have been removed and numeric identifiers encrypted. Although postal code is required to link census use data to database records, presentation of data at the individual postal code will not be done.

b) MHHL data: Using the scrambled PHIN numbers provided by MHHL, data extracted from the physician's electronic medical record (EMR) will be linked to patient records in the repository at MCHP. This will allow a validation process of the administrative data and facilitate the indicator development.

Note: If the external database(s) contains individual-level data, permission from the trustee is required and a copy of this permission must be submitted to the HIPC. If the external database is a clinical patient registry, please provide a copy of the informed consent form requesting the patient's permission to link data in the clinical registry to other data sources. If informed consent was not obtained, please explain.

V. Level of Intrusion

(a) Please indicate the level of intrusion associated with the proposed research project. Indicate only the highest level of intrusion. <Note: for studies using only MHHL data, the most common level is #2b; if non-MHHL data are also being used, 2d would be more appropriate. An example of #5 would be First Nations analyses or children at risk for poor outcomes.>

- 1. Minimal or no intrusion:** Aggregate statistical information or person specific information with no individual identifiers or record linkages, which could potentially identify individuals.
- 2. Potential intrusion:** Person specific information in anonymized form with data linkages that create the risk of identification of individuals. The degree of risk increases with the type of data linkage as follows:
- 2a.** minimal linkage or specificity of use within Manitoba Health data, which create no potential for the identification of individuals;
- 2b.** multiple linkage or specificity of use within Manitoba Health data which may create the potential for identification of individuals;
- 2c.** linkage of Manitoba Health data files to other publicly available and aggregate level data sources (e.g. neighbourhood-level data from the census) where all individual identifiers have been removed or modified;
- 2d.** linkage of Manitoba Health data files to other person-specific data files where individual identifiers have been removed or modified, or in the case of surveys, no direct contact with the individual will be made (eg National Population Health Survey from Statistics Canada). *(Does not include cases where the population group or information concerned falls within category 5)*
- 3. Moderate intrusion:** Person specific information such as patient charts, surveys or personal interviews will be used but the individuals affected will be asked for their consent prior to the disclosure of any personal health information to the researcher. *(Does not include cases where the population group or information concerned falls within category 5)*
- 4. High intrusion:** Person-specific information involving linkage of Manitoba Health data files to other person-specific files for which the researcher has access to individual identifiers without consent, for example, patient information collected in clinical settings, specialized programs, and disease registry files with identifying information. *(Does not include cases where the population group or information concerned falls within category 5)*
- 5. Highly Sensitive:** Requests for information which would otherwise fall into categories 2b or higher where the population involved is vulnerable or dependent (e.g., minors, First Nations, etc.) or where the nature of the information is highly personal and sensitive (e.g. persons with mental disabilities, sexually transmitted diseases, etc).

(b) Please provide a rationale for your choice and discuss the importance of this research in relation to the level of intrusion.

This project will involve secondary analysis of de-identified data files only, with linkages to other files where identifiers have been removed or scrambled. <e.g. Education data, Family Services Data, National Population Health Survey, Canadian Community Health Survey>. The research will provide valuable results to provincial and regional planners, to help guide policy and program initiatives to optimize population health and health service organization.

e.g. Level 2a, 2b: The project will involve de-identified data only, with linkages of various MHHL data files. The datasets to be used will not contain identifiable personal information.

e.g.'s Level 2b, 2c:

- a) The project will involve de-identified health care utilization data housed at MCHP, with some linkage to public-use census files for measures such as neighborhood income. The datasets to be used will not contain identifiable personal information.

- b) The project will involve linkages of de-identified MHHL data, as well as public use Census files.

e.g. Level 2d: The data we extract from the EMR will have all identifiers removed before the data is transferred to MCH for linkage. The linkage will be made using PHINs which will be scrambled by MHHL.

VI. Data Security

- (a) Please indicate where the data will reside.
Address (including room/office number if applicable):

All of the analyses will be conducted within the secure computer environment of the Manitoba Centre for Health Policy (MCHP) located at 408 - 727 McDermot Avenue, Winnipeg, Manitoba R3E 3P5.

- (b) How will the confidentiality of the data be protected by the researcher(s)? Please include a discussion of the security measures, how and when the data will be destroyed, and other relevant data protection issues. Be specific and use as much space as necessary.

MCHP operates according to rigorous standards regarding security, privacy, and confidentiality of data files contained in the Population Health Research Data Repository. Physical measures include restricted, alarm-protected, access to the facility. Electronic measures include multiple levels of passwords, electronic firewalls, encryption of transmitted information, and other security measures.

Repository data is in the form of de-identified computer files, securely stored at the University of Manitoba, and accessed via the MCHP Unix system at the Bannatyne Campus. Privacy of information is protected through a number of measures, most notably that no files at MCHP contain names or addresses, and that identifiers (e.g., Personal Health Information Number (PHIN) and Registration Number) are changed by MHHL to be not recognizable.

Access to, and use of, the data are carefully controlled and monitored on an ongoing basis. All MCHP staff sign a Confidential Information Agreement and comply with terms related to the use and dissemination of information derived from the data repository. Analyses involving 5 or fewer events or persons are suppressed. Publications generated from database analyses are reviewed by Manitoba Health and Healthy Living prior to release.

Security measures to protect the privacy and confidentiality of individuals are described in MCHP policies and procedures documents (available upon request), and are based on the Data Sharing Agreement in place between Manitoba Health and Healthy Living and the University of Manitoba and are compliant with legislative requirements.

All study associated data and programming code will be archived at the time of study completion and removed from MCHP's analysis system. Study completion is identified by the principal investigator or by the submission of a final REB notification of study completion. Consistent with University of Manitoba protocols, archives will be maintained at MCHP for a period of at least seven (7) years and no more than ten (10) years after completion to allow time for questions and clarifications of publications and then all study associated data will be destroyed. The programming code may be retained indefinitely.

- (c) Will the data be accessed remotely? Yes No No
If yes, by whom?
Where is the remote terminal located?
What level of data (i.e. aggregate vs line-level) will be accessed?

Describe the specific security measures in place to ensure that data security is not compromised by remote access.

VII. Publication of Study Results

(a) Who will be receiving the study results?

e.g., The results will be shared with the participating clinics and physicians, MHHL, and the Manitoba Centre for Health Policy. Academic papers may also be written for publication in journals.

(b) Will there be any publication of the study results? Yes No

If yes, a copy must be sent to Manitoba Health prior to publication (please see the Guidelines for timelines associated with manuscript and presentation submissions and approvals.)

We anticipate several articles will be published as a result of this project. Any papers or reports prepared for publication or distribution will be submitted to MHHL prior to publication to ensure that the use of the data meets provincial standards.

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VIII. Other Information

Please describe any other information relevant to this application.

IX. Attachments

<If approvals for data access are being sought from non-MHHL agencies, it should be specified here - e.g., Social Services data, Education data, Aboriginal Health data. 'Pending' will typically be checked since submissions for approvals are all done around the same time (HIPC, HREB, other agencies) >

The following documentation is attached:

- Ethics Committee approval.* <refers to UM Health Research Ethics Board>
 Pending
- Proof of research funding.*
 Pending
- Assembly of Manitoba Chiefs – Health Information Research and Governance Committee (HIRGC).
 Pending
- Institutional Research Review Board approval (please specify).
 Pending
- Other institutional or research review board approval (please specify).
 Pending
- Other institutional or research review board approval (please specify).
 Pending
- Other institutional or research review board approval (please specify).
 Pending

Note: Projects will not receive final approval until the appropriate documentation is received by the HIPC Coordinator.

* Required for every HIPC submission.

Comments:

X. Declaration

I declare that:

- a) This research complies with The Personal Health Information Act of Manitoba.
- b) The information received will only be used for the purposes of this study.

- c) The information requested is the minimum necessary to accomplish the purpose.
- d) The protocol ensures the security of the personal health information and its destruction when finished.
- e) All reports, publications, and presentations resulting from this project will be submitted to the Health Information Management Branch of Manitoba Health for review prior to distribution or publication (in accordance with the timelines described in the 'Guidelines'), to assure that the anonymity of the study cohort is preserved and that any references to Manitoba Health, or other trustees, are factually correct.
- f) A copy of all published reports and articles will be provided to the Health Information Management Branch of Manitoba Health for its records.

Date	Signature of Principal Investigator <i>An MCHP co-investigator can sign on behalf of a non-UM principal investigator*</i>
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Date	Signature of Academic Advisor (if PI is a student)
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**The Researcher Agreement must, however, be signed by the PI..*

For projects requiring identifiable personal health information:

Where identifiable health information is requested, I declare that this research cannot be done without using identifiable personal health information, and that it is impossible or impractical to obtain consent from the people the personal health information is about.

<Normally not completed, unless the study links to information from clinical registries, surveys, etc.>

Date	Signature of Principal Investigator
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