## Health Information Privacy Committee

## Request for Access to Personal Health Information

## Held by the Government of Manitoba

**Complete ALL questions on the application form. Application forms that are not completed in full will not be reviewed by the HIPC. One (1) copy must be submitted by email to the HIPC Coordinator at** **HIPC@gov.mb.ca****. Ten (10) hard copies must be delivered to the HIPC Coordinator at 4043 - 300 Carlton Street, Winnipeg, Manitoba, R3B 3M9.** **For more detailed information, please see the ‘Guidelines for Completing a Request for Access to Personal Health Information Held by the Government of Manitoba’ and ‘Submission Requirements’ on the HIPC website.**

**Date of Request (MM/DD/YYYY):**

## Title of Research Project:

I. Researcher Information

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| Principal Investigator (PI):        |
| Affiliation:       | Phone:       |
| Email:       | Fax:       |
| Address:       |
| Academic Advisor (if PI is a student):        |
| Affiliation:       | Phone:        |
| Email:       | Fax:       |
| Address:       |

II. Co-investigators

List all co-investigators, their affiliation and *specific* role (e.g., data analyst, statistical or clinical consultant, data collection) in the proposed research project. If the PI is a student, please list all Advisory Committee Members. Attach a list of co-investigators if more space is needed.

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| **Name** | **Affiliation** | **Primary role** | **Line-level data access? Yes/No** |
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III. Conflict of Interest

1. **Do you or the co-investigators have multiple roles/access to information within the context of this research or relationships with other organizations which may present a possible conflict of interest?**

**Yes [ ]  No [ ]**

**If yes, please complete the Conflict of Interest Disclosure Form accessible through the HIPC website**.

IV. Description of the Research Project

1. **What is the anticipated duration of this study (month/year)?**

**From:**         **To:**

1. **Is this project part of a program of research? Yes** **[ ]  No** **[ ]**

If yes, has the program of research already received HIPC approval-in-principle?

Yes [ ]  No [ ]

**HIPC File Number:**

**Briefly summarize the program of research:**

1. **Please describe the purpose of the research project and list the specific research questions, objectives, and/or hypotheses that will be tested.**

1. **Please provide a description of the research project, focusing on the proposed methodology.**

*Note: The description should include the context and/or background, design, methods and analysis plan, variables of interest, anticipated results and significance of the study. Limit the description to one page and do not refer to the protocol and/or attachments.*

1. **Will the study involve direct access to potential study participants? Yes** **[ ]  No** **[ ]**

If yes, provide one (1) emailed copy and ten (10) hard copies each of the introductory letter that will be sent to the potential participants, the Information and Consent Form, questionnaires and any other materials that potential participants will receive.

1. **Will the study involve correspondence with potential participants that is mailed out? Yes [ ]  No [ ]**

If yes, will Manitoba Health, Seniors and Active Living be asked to facilitate a blind\* mail-out?

 Yes [ ]  No [ ]

*\*The researcher would not know the identity of those who are mailed letters.*

V. Specific Data Required

1. Please attach a Data Extraction Form (unless only one database is requested) to indicate ALL databases to be accessed, years of data required, the variables of interest, and the rationale for such requests. Please be as specific as possible. The Data Extraction Form template has been provided below.

*Note: The Personal Health Information Act (PHIA) requires that only the minimum information necessary to accomplish the purpose of the research project be released to researchers.*

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| **Data Extraction Form Template** |
| **Database** Name of database requested **e.g.,**Hospital Discharge Abstract | **Years** Years of data requested **e.g.,**April, 2000– March, 2012 | **Data Fields / Variables** Specific information or data fields required from a database **e.g.,**Admission date, Separation date, Diagnoses, Procedures | **Rationale** Describe in general terms how the information to be collected relates to the study purpose, hypotheses and study questions. If the information does not relate directly to these, provide explanation as to why the information is being collected. **e.g.,**To develop indicators of health status, health services use and health risk |
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\* Manitoba Health, Seniors and Active Living administrative data is organized according to fiscal years beginning April 1st through March 31st.

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

\* The HIPC will not prospectively approve access to data beyond that which is currently available. Updates must be submitted as a protocol amendment request to the HIPC when such data does become available.

\* Please mention specific years for the in the data extraction form (asking for the “latest available” is not acceptable).

1. Inclusion/exclusion criteria (e.g. age, gender, region of residence, diagnoses)

1. Is a control group required to be extracted for this study? Yes [ ]  No [ ]

If yes, please describe the matching ratio and criteria for the control group and provide a rationale for the specific parameters requested:

1. Will First Nations, Métis or Inuit populations be a focus of interest and/or is there intent to stratify analyses or outcomes by First Nations Metis or Inuit populations?

Yes [ ]  No [ ]

If yes, provide a copy of the letter of support from the Manitoba First Nations Health Information Research Governance Committee and/or other First Nations, Métis or Inuit partners as appropriate.

1. Will data held by a department or agency of the Government of Manitoba be linked or merged with data from another department or external source(s)? Yes [ ]  No [ ]

If yes, please describe the nature of the linkage (e.g. the data/databases that will be linked), including the process for linking data from varied sources.

*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 Information and 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.

VI. Level of Intrusion

Please indicate only the highestlevel of intrusion associated with the proposed research project.

**[ ]  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, Seniors and Active Living data, which create no potential for the identification of individuals (e.g. linking the Hospital Abstracts and the Medical Claims databases with aggregate level data for a certain geographic location within a Regional Health Authority);

**[ ]**  **2b.** Multiple linkage or specificity of use within Manitoba Health, Seniors and Active Living data which may create the potential for identification of individuals (e.g. linking the Hospital Abstracts, Medical Claims, and DPIN databases);

**[ ]**  **2c.** Linkage of Manitoba Health, Seniors and Active Living data files to other publicly available and aggregate level data sources where all individual identifiers have been removed or modified (e.g. linking the Hospital Abstracts, Medical Claims, and DPIN databases with outside neighborhood level data from the census);

**[ ]**  **2d.** Linkage of Manitoba Health, Seniors and Active Living 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 (e.g. linking the Hospital Abstracts, Medical Claims, and DPIN databases with data from Statistic Canada’s Canadian Community Health Survey). *This 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. *This 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, Seniors and Active Living 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. *This 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), where the nature of the information is highly personal and sensitive (e.g. persons with mental disabilities, sexually transmitted diseases), or where there will be a focus of interest and/or an intent to stratify outcomes by First Nations, Métis or Inuit populations.

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

*Note: PHIA, 24(3) requires that the HIPC must determine that the research is of sufficient importance to outweigh the necessary intrusion into privacy from the disclosure of personal health information.*

VII. Data Security

1. Please indicate specifically where the data will reside:

 **Complete address (including room/office number):**

1. 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 (e.g., physical, technical and administrative controls and safeguards).

1. Will the data be accessed remotely? Yes [ ]  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.

VIII. Publication of Study Results

**(a) Who will be receiving the study results?**

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

If yes, a copy must be sent to Manitoba Health, Seniors and Active Living for review prior to publication.

*Note: At least thirty (30) calendar days prior notice is required for every intended publication in learned journals or thesis presentation; at least ten (10) calendar days prior notice is required for every poster or oral presentation where such presentation material will be released.*

IX. Other Information

Please describe any other information relevant to this application.

X. Attachments

The following documentation is attached:

**[ ]  Proof of research funding**

*\*\*\* Required for every HIPC submission.*

**Please specify funding source:**

*\*\*\* All funding sources must be specified. Please submit a copy of a letter of support from the granting agency. If grant funding has not been awarded at the time of submission, a letter of support for alternative funding must be attached. For example, if internal departmental funds will be used in lieu of grant funding, a letter of support from the department head is required.*

**Is the research being funded by Private Industry? Yes [ ]  No [ ]**

*\*\*\* If the study is funded by Private Industry, please review the guidelines on Private Industry-Sponsored Research by Manitoba Health, Seniors and Active Living. These Guidelines are available upon request from the HIPC Coordinator.*

**[ ]  Research Ethics Board approval**

 **Pending** **[ ]**

*\*\*\* Required for every HIPC submission.*

**[ ]  Letter of Support from the Manitoba First Nations Health Information Research Governance Committee and/or other First Nations, Métis or Inuit partners as appropriate**

 **Pending [ ]**

**[ ]  Organization or Institutional Research Review Committee approval (please specify):**

 **Pending [ ]**

**[ ]  Organization or Institutional Research Review Committee approval (please specify):**

 **Pending [ ]**

**[ ]  Organization or Institutional Research Review Committee approval (please specify):**

 **Pending [ ]**

**[ ]  Organization or Institutional Research Review Committee approval (please specify):**

 **Pending [ ]**

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

XI. Declaration

I declare that:

1. This research project complies with *The Personal Health Information Act* of Manitoba.
2. The information being requested will only be used for the purpose of the research project outlined in this application.
3. The information being requested is the minimum amount necessary to accomplish the objectives of the research project outlined in this application.
4. The security safeguards outlined in this application reasonably ensure the security and confidentiality of the personal health information and its destruction when the research project is finished.
5. All reports, publications, and presentations resulting from this project will be submitted to the Information Management and Analytics Branch of Manitoba Health, Seniors and Active Living 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, Seniors and Active Living or other trustees, are factually correct.
6. A copy of all published reports and articles will be provided to the Information Management and Analytics Branch of Manitoba Health, Seniors and Active Living for its records.

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| **Date** |  | **Signature of Principal Investigator*****Please print name*:**       |
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| **Date** |  | **Signature of Academic Advisor**(if PI is a student)***Please print name*:**       |

XII. Declaration for Use of Identifiable Personal Health Information

***To be signed only when identifiable personal health information is being 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.

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|       |  |       |
| **Date** |  | **Signature of Principal Investigator*****Please print name:***       |