

# **MCHP Guidelines for Public and Private Sponsorship of Research Projects Accessing the Manitoba Population Research Data Repository (2016)**

## **Background**

The Manitoba Centre for Health Policy (“MCHP”) through the University of Manitoba (the “University”) is the trustee for the Manitoba Population Research Data Repository (the “Repository”). MCHP is a research unit in the Department of Community Health Sciences, Max Rady College of Medicine in the Rady Faculty of Health Sciences at the University of Manitoba.

All data in this Repository is collected by public bodies. Research using this data is permitted by privacy legislation if:

- it is for statistical or research purposes,
- it is in the public interest, and
- the results remain in the public domain.

As a trustee, MCHP is bound by agreement to ensure that the following criteria are met prior to any project specific access of the Repository:

1. the project fits within the framework of the MCHP Mission Statement;
2. the project abides by the MCHP Privacy Code to obtain MCHP approval;
3. the project has obtained all required approvals as outlined on our website under data access and copies of all required approvals are on file at MCHP as per: [http://umanitoba.ca/faculties/health\\_sciences/medicine/units/chs/departamental\\_units/mchp/resources/access.html](http://umanitoba.ca/faculties/health_sciences/medicine/units/chs/departamental_units/mchp/resources/access.html)

Approved research projects will be aimed primarily at establishing facts, principles or generalizable knowledge, which are of social value and intended to be publicly disseminated.

## *Mission Statement*

The Manitoba Centre for Health Policy (MCHP) is a research centre of excellence that conducts world class population-based research on health services, population and public health, and the social determinants of health. MCHP develops and maintains the comprehensive population-based data repository on behalf of the Province of Manitoba for use by the local, national and international research community. MCHP promotes a collaborative environment to create, disseminate and apply its research. The work of MCHP supports the development of evidence-informed policy, programs and services that maintain and improve the health and well-being of Manitobans.

The University of Manitoba's mission is to create, preserve and communicate knowledge, and thereby, contribute to the cultural, social and economic well-being of the people of Manitoba, Canada and the world. MCHP is situated within the University of Manitoba Strategic Plan Framework and the Max Rady College of Medicine Strategic Framework.

## **1. Project Management**

- 1.1 The University shall have sole control, supervision and direction of the project and shall alone be responsible for the manner in which the project is performed.
- 1.2 The sponsor's representative shall be designated in writing. The University's representative, shall be the principal.
- 1.3 The sponsor's representative shall not be a part of, or associated with, the project research team.
- 1.4 All project analysis shall be conducted by University of Manitoba staff or students within the MCHP secure environment.
- 1.5 All members of the research team shall disclose any industry involvement for the past five (5) years.

## **2. Consultation and Reports**

- 2.1 During the term of the project, the sponsor's technical representative and other representatives may have reasonable access to consult with the University's principal investigator regarding the status of the project, personally, electronically, or by telephone.
- 2.2 The University shall provide the sponsor with a final research report, if outlined in the funding contract, sixty (60) days before public release as outlined in under Publication 5. – note that no preliminary outcomes or information will be provided to the sponsor or their representative.

## **3. Confidential Information**

- 3.1 The sponsor and the University may disclose technical, scientific, business or marketing information one to the other to facilitate work under this project. Such information clearly marked as "Confidential", "Protected Business Information" or "Not for Publication" shall be safeguarded and not disclosed to anyone within the sponsor agency or the University without a "need to know". Each party shall also protect such information which has been clearly marked from disclosure to third parties.
- 3.2 The obligation of confidentiality shall not apply to information which:
  - a) is already known to the party to which it is disclosed, as evidenced by written records;
  - b) is now or shall enter the public domain other than by a breach of confidentiality obligations to the disclosing party;
  - c) is lawfully obtained from third parties;

- d) either party can demonstrate that it was developed independently of the information received from the disclosing party;
  - e) must necessarily be disclosed to regulatory agencies, or to clinicians or others in connection with such disclosures;
  - f) must necessarily be disclosed by either party to financial institutions or other funding sources in order to obtain financial assistance, provided that such entities agree to keep the information confidential;
  - g) is required by law to be disclosed;
  - h) is published or presented by or through the University in learned journals or scientific forums, or as part of a thesis.
- 3.3 The obligation of confidentiality shall not apply to professional expertise which the principal investigator or the University has upon execution of the project or which is further developed or enhanced as a result of performing work on the project.

#### **4. Ownership/Licenses**

- 4.1 The University shall retain possession of all original documents and materials used and developed during the course of the project, including but not limited to maps, sketches, notes, reports, data, models and prototypes.

#### **5. Publication**

- 5.1 The sponsor will not use the name of the University, nor of any member of the University's staff, in any advertising or promotional material or publicity release without the prior written approval of the University.
- 5.2 The University will not use the name of the sponsor, nor any employee of the sponsor in any advertising or promotional material or publicity release without the prior written approval of the sponsor.
- 5.3 Nothing herein precludes the University and the principal investigator from including the name of the sponsor as a funding source for purposes of internal reporting, reporting to government and governmental agencies, publications, presentations or in order to obtain financial assistance.
- 5.4 The sponsor will have no opportunity to influence the data analyses or interpretation, study conclusion or contents of any reports or manuscripts.
- 5.5 All research projects must be undertaken with the clear understanding that the University investigators concerned have the full right to publish any results obtained by them, subject only to established safeguards for the protection of privacy or confidentiality of personal data description in reports and journal publications.
- 5.6 Decisions for publication of results will be determined solely by the principal investigator on the basis of the scientific merit of the work.
- 5.7 Authors and order of authorship on any publication are determined by the University principal investigator.

- 5.8 Manuscripts, including the final report of the project, are not open to review by the sponsor prior to completion. A copy of the completed report may be provided to the sponsor sixty (days) before public release (sec. 2.2).
- 5.9 All publications/reports resulting from the project must be submitted to each data provider for confidentiality and accuracy review in advance of submission for publication in accordance with the standard practice for all academic publications using Repository data – the data provider has no right of censorship.
- 5.10 The principal investigator will provide the sponsor with a final research report, if outlined in the proposal. The sponsor will have the right to use such reports after public release, but may not use the University's name in any publication or advertising without the express written consent of the University.
- 5.11 The investigators will provide the data provider(s) the opportunity for verbal presentations regarding the project findings and conclusions, and contents of all reports or manuscripts, at least sixty (60) days in advance of the public release of such reports or manuscripts.
- 5.12 In all publications/reports arising from the research project, the data provider(s) and MCHP will be acknowledged as the source of data and the sponsor as the source of funding.
- 5.13 The following disclaimer will appear in all results obtained, publications or lectures given – *“We acknowledge the financial support of “the sponsor”. The authors acknowledge the Manitoba Centre for Health Policy for use of data contained in the Manitoba Population Research Data Repository under project #\_\_\_ (HIPC#\_\_\_). The results and conclusions are those of the authors and no official endorsement by (insert name of data provider(s)), MCHP and the University of Manitoba or “the sponsor” is intended or should be inferred. Data used in this study are from the Manitoba Population Research Data Repository housed at the Manitoba Centre for Health Policy, University of Manitoba and were derived from data provided by Manitoba Health <and name other data providers>.”*

## **6. Project Proposals and Funding Agreements from Sponsors**

- 6.1 Complete and submit a project feasibility form including a copy of the project proposal and funding contract to MCHP as outlined on the website:  
[http://umanitoba.ca/faculties/health\\_sciences/medicine/units/chs/departamental\\_units/mchp/resources/access.html](http://umanitoba.ca/faculties/health_sciences/medicine/units/chs/departamental_units/mchp/resources/access.html)
- 6.2 Review the MCHP Guidelines for Public and Private Sponsorship of Research Projects (this document).
- 6.3 Provide a copy of the project funding contract to MCHP. Note this agreement or contract must comply completely with the MCHP Guidelines for Public and Private Sponsorship of Research Projects Accessing the Manitoba Population Research Data Repository (2014) (as per section 6.6).
- 6.4 A MCHP committee will review the proposal and funding contract in relation to the Guidelines. If the committee deems it necessary the proposal will be sent out to two (2) independent reviewers to ensure it demonstrates scientific merit. Effective May 17,

2016 a non-refundable fee of \$2,000 is required for all private sector sponsored applications using the Repository. The fee is only to cover the costs of reviewing the proposal and funding agreement, and is not an assurance that a project will receive approval. Applications funded by the public sector (i.e. the Government of Canada, Health Canada, PHAC, Province of Manitoba, etc...) are not subject to this fee.

- 6.5 If the proposal and funding contract comply with Guidelines, the project will receive MCHP approval and can move forward in obtaining the remaining required approvals. All required approvals must be obtained before research can begin.
- 6.6 If the proposal and/or funding contract do not comply with the Guidelines, access to the Repository will be declined. Note that even if all guidelines are met, and approval for access to the Repository is granted, this is **not** a guarantee that approval from other sources (i.e. HIPC, Ethics, data provider(s), etc...) will necessarily be granted.