Requesting Data From CIHI for Research Purposes

Who needs to read this?

This document is for researchers or research teams affiliated with a Canadian health facility, university or other public research body who are interested in requesting data from CIHI to facilitate health or health services research and/or analysis.

What's it about?

It contains information about the types of disclosures of health data CIHI may facilitate and where there may be conditions restricting or prohibiting disclosure of certain types of data.

Background

CIHI's mandate

CIHI's mandate is to deliver comparable and actionable information to accelerate improvements in health care, health system performance and population health across the continuum of care.

Flowing from its mandate, and in accordance with all applicable legislation, CIHI's core functions include

- Identifying health information needs and priorities;
- Coordinating and promoting standards and data quality;
- Developing comparable measures of health system performance;
- Conducting analyses in the areas of population health and health services;
- Developing national health indicators; and
- Building capacity and conducting education sessions.

Canadian Institute for Health Information
Institut canadien d'information sur la santé

Disclosures

General

Disclosures of health data are governed by CIHI's *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data*.

CIHI discloses health information and analyses on Canada's health systems and the health of Canadians in a manner consistent with its mandate and core functions. These disclosures typically fall into 1 of 4 categories:

- Disclosures to parties with responsibility for the planning and management of the health care systems to enable them to fulfill those functions;
- Disclosures to parties with a decision-making role regarding health care system policy to facilitate their work;
- Disclosures to parties with responsibility for population health research and/or analysis; and
- Disclosures to third-party data requesters to facilitate health or health services research and/or analysis.

De-identified data

CIHI data disclosures are made at the highest degree of anonymity possible while still meeting the research and/or analytical purposes. This means that, whenever possible, data is aggregated.

Where aggregate data is not sufficiently detailed for the research and/or analytical purposes, data that has been de-identified using various de-identification processes may be disclosed to the recipient on a case-by-case basis and where the recipient has entered into a data protection agreement or other legally binding instrument with CIHI.

Some restrictions may apply to the disclosure of de-identified data; where these exist, they are set out in the jurisdictional data-sharing agreement and researchers will be advised accordingly.

Only those data elements necessary to meet the identified research or analytical purposes may be disclosed.

Researchers who have approval from the research ethics board of the institution/facility with which they are affiliated must provide this documentation to CIHI.

Personal health information

Disclosures of personal health information by CIHI are subject to the specific jurisdictional legislation and agreement under which the data was originally collected and shared with CIHI.

CIHI has limited ability to disclose personal health information, other than in the case of consent-based disclosures. The exception is personal health information that CIHI obtains as a prescribed entity under Ontario's *Personal Health Information Protection Act, 2004* (PHIPA). In this case, CIHI may disclose personal health information for research purposes under Section 44 of PHIPA. The requirements that must be met for such disclosures are prescribed either in the act itself or in the associated regulations. CIHI will provide researchers with a document setting out those requirements.

Consent-based research studies

CIHI is seeing an increasing number of consent-based research studies involving requests for access to CIHI's data holdings. In cases where the intent is to link study data for the cohort with data from CIHI's data holdings, researchers require study participants' consent for disclosure to CIHI of identifying information, usually in the form of health care number, so that CIHI can identify the relevant health records for the cohort of individuals in its data holdings.

Because the resulting linked data set would be considered personal health information, even where the health care number on the file has been replaced with a unique study number, CIHI would also require the study participants' consent to disclose their personal health information to the researcher.

Some jurisdictions have also set out the requirement that disclosures of personal health information — and this includes consent-based disclosures — must be approved by the ministry of health. This is currently the case for New Brunswick, Manitoba, Alberta and the Northwest Territories.

CIHI has prepared a consent checklist and template for researchers to ensure that they obtain the appropriate consent for CIHI to receive and to disclose personal health information for purposes of the identified research study. Email privacy@cihi.ca to request a copy.

As well, Health Data Research Network Canada has published Guidelines: Informed Consent Wording for Administrative Data Linking.

Research ethics boards

Section 43 of CIHI's Privacy Policy, 2010 requires that prior to the disclosure of personal health information for research purposes, the requester will provide CIHI with evidence of the requisite research ethics board (REB) approval. Researchers must demonstrate that they meet the requirements of any applicable jurisdictional legislative requirements related to their study.

For de-identified data only, where third-party data requesters indicate that REB approval was not requested or obtained, the requester must provide evidence of consultation with their REB.

For research studies that use personal health information, REBs, in some circumstances, may waive the requirement for researchers to obtain consent for their study. This, however, does not impact the requirement for researchers to have the requisite legal authority for the *disclosure* of personal health information. This would be the case, for example, where the researchers would be disclosing health care numbers to CIHI for linkage purposes. Researchers must also demonstrate that they meet any applicable jurisdictional legislative requirements related to their study.

See Research studies involving requests for data linkage with researcher-provided cohorts.

Similarly for CIHI, legal authority must be in place for CIHI to disclose personal health information to researchers.

Research studies involving data linkage

For research projects that involve data linkage — within a single CIHI data holding, across CIHI data holdings or between 1 or more CIHI data holdings and a researcher-provided cohort — linkage approval must be obtained from the CIHI Privacy, Confidentiality and Security Committee. CIHI staff working with researchers on their requests will prepare the required documentation for submission to the Committee.

Research studies involving requests for data linkage with researcher-provided cohorts

Research projects involving data linkage between CIH data and a researcher-provided cohort raise a number of possible privacy issues that will need to be addressed before determining whether the linkage can proceed and if so, how, and under what legislative authority the results could be disclosed to the researchers. In many cases, depending on how the project has been organized, the resulting linked data set is considered to be personal health information even though the CIHI records disclosed to the researchers are identified only by unique study identification number. This is the case where the researcher has established the health care number/unique study identification cross-walk file used for linkage purposes, and is thus able to re-identify the linked records.

Also, see Consent-based research studies.

Outside of Canada

In certain cases, disclosures of personal health information or de-identified data outside of Canada may be prohibited. This includes situations where data will be remotely accessed by persons located outside of Canada.

Research networks

CIHI is seeing the creation of a number of research networks in Canada. Research networks connect researchers who are physically separated to facilitate sharing of expertise and resources, and to exchange valuable skills. However, most of these networks are not legal entities with which CIHI could sign a data protection agreement or other legally binding instrument relating to the disclosure of de-identified data or personal health information.

As such an agreement is required by CIHI before releasing either de-identified data or personal health information, researchers will need to consider what institution or facility will sign the CIHI agreement and thus become subject to the terms of the agreement.

Indigenous-identifiable data

CIHI's policy on the release and disclosure of Indigenous-identifiable data requires that requests for Indigenous identifiers be accompanied by evidence of approval from appropriate First Nations, Inuit and Métis authorities (i.e., governments, communities and/or organizations involved at the level of reporting).

The policy aligns with principles of Indigenous data sovereignty (the collective and individual rights of Indigenous peoples to the self-governance and management of their data), such as the First Nations principles of Ownership, Control, Access and Possession (OCAP®). Establishing policies and procedures that respect principles of Indigenous data sovereignty is a key focus of CIHI's Indigenous health strategy. The intent of the policy is to increase the appropriate use of data and to support the health data priorities of Indigenous communities and organizations. Learn more about our work with First Nations, Inuit and Métis.

Audits

The data protection agreement you sign with CIHI will authorize CIHI to conduct an audit of your compliance with that agreement, particularly your organization's use and management of CIHI data. CIHI may conduct the audit on site or remotely. The scope of the audit will include any information technology service organization that provides your organization with information technology services relating to CIHI data.

For more information

If you have questions, please send them to privacy@cihi.ca.

If you're interested in making a request for CIHI data, please complete the online Data Inquiry Form.

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