

## **Background Information on the Canadian Institute for Health Information (CIHI)**

### **Who we are**

CIHI was incorporated under the *Canada Corporations Act* in 1994. It has a Board of Directors comprised of sixteen government and non-government members from across Canada.

In 1994, the Federal/Provincial/Territorial Ministers of Health endorsed the establishment of CIHI as an independent, national, not-for-profit organization with the broad general mandate of coordinating the development and maintenance of a comprehensive and integrated pan-Canadian health information system.

CIHI's mandate is:

- to coordinate the development and maintenance of a comprehensive and integrated approach to health information for Canada; and
- to provide and coordinate the provision of accurate and timely data and information required for:
  - establishing sound health policy;
  - effectively managing the Canadian health system; and
  - generating public awareness about factors affecting good health.

Through the work carried out by the Canadian Population Health Initiative (CPHI), CIHI aims to:

- foster a better understanding of factors that affect the health of individuals and communities; and
- contribute to developing policies that reduce inequities and improve the health and well being of Canadians.

Specifically, CIHI:

- identifies health information needs and priorities;
- conducts analysis and special studies and participates in/supports health care system research;
- supports the development of national health indicators;
- coordinates and promotes the development and maintenance of national health information standards;
- develops and manages health databases and registries;
- funds and facilitates population health research and analysis, conducts policy analysis and develops policy options;
- contributes to the development of population health information systems and infrastructure;
- provides appropriate access to health data under controlled conditions;
- publishes reports and disseminates health information; and

- coordinates and conducts education sessions and conferences (relevant to its core functions).

In fulfilling its mandate, CIHI currently manages a total of approximately 25 data holdings which are organized under three broad categories: Health Services Information consisting of ten databases and four registries; Health Human Resources consisting of seven databases; and Health Spending consisting of four databases. A further four data holdings are under development over the next two to three years. Information is received from a variety of sources throughout Canada, including various government ministries and departments of health, hospitals, prescribed entities, continuing care access centres, health professional associations, and other health care organizations.

There are only two registries, the Canadian Joint Replacement Registry (CJRR) and the Canadian Organ Replacement Register (CORR), that collect the individual's name and address. In the case of CJRR, the primary data provider has obtained the express consent of the individual to whom the information relates, to disclose his/her name and address to CIHI. In the case of CORR, the primary data provider discloses information to CIHI in accordance with provincial/territorial privacy legislation.

#### **Legal Authorities Governing CIHI's Collection, Use and Disclosure of Personal Health Information**

The entities noted above, the primary data collectors and providers, are responsible for complying with their applicable privacy legislation. In addition, CIHI complies with very strict privacy and confidentiality policies, procedures and practices regarding the collection, use and disclosure of the information in its custody.

CIHI receives personal information, personal health information and other information from data providers in all provinces and territories, which may contribute to one or more of CIHI's data holdings. These data may be received as summaries of coded personal health information that represent a fraction of the information in the original records of individuals concerned. Although most of these records include some type of a unique identifier, which CIHI uses to facilitate statistical analyses, CIHI cannot readily identify individuals with these unique identifiers because CIHI does not have access to original issuing databases of institutions or health ministries that contain the information that could reveal an individual's identity. That capability for unique identification of an individual remains with the primary data provider.<sup>1</sup> Nonetheless, CIHI protects these data to the same degree as readily identifiable personal health information.

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<sup>1</sup> CIHI does not have a direct relationship with the individual. Nor does CIHI hold sufficient direct identifiers, such as full name and address, to authenticate an individual. Accepted best practice for organizations involved in secondary use and disclosure is to refer individuals back to the original data provider in order to access their information. This is part of CIHI's privacy policy.

CIHI is a prescribed entity for the purposes of section 45(1) of Ontario's *Personal Health Information Protection Act* S.O. 2004, c. 3, Schedule A ("*PHIPA*") and is so designated under section 18 of O. Reg. 329/04.<sup>2</sup> Under *PHIPA*, the Information and Privacy Commissioner/Ontario (OIPC) is required to conduct a review of a prescribed entity's privacy practices every three years. The OIPC has conducted its first review of our organization's privacy policies, practices and procedures and approved them effective October 31, 2005. Moreover, CIHI is an information manager under both section 66 of Alberta's *Health Information Act*, S.A. 2001, c. H-5 ("*Alberta HIA*") and under section 25 of *The Personal Health Information Act*, C.C.S.M. c.P33.5 of Manitoba. Alberta has entered into an information manager agreement with CIHI pursuant to its authority to do so under its relevant legislation. This agreement sets out the terms and conditions for the disclosure of personal health information by the province to CIHI as well as the terms and conditions under which CIHI can use or disclose the personal health information that Alberta provides to CIHI.

CIHI's authority to collect, use and disclose personal information submitted by our data providers is also governed by:

- bilateral agreements with individual jurisdictions, including Newfoundland and Labrador, negotiated under the authority of the respective Ministries of Health, and which contain terms and conditions in compliance with privacy legislation applicable to the respective jurisdiction;
- data sharing agreements also specific to each jurisdiction which outline in more detail the obligations of CIHI and the limitations on our collection, use and disclosure of that information, also in compliance with the applicable privacy legislation. To date, CIHI has concluded umbrella data sharing agreements with Ontario, Alberta and Prince Edward Island. It is negotiating similar agreements with other jurisdictions (not including Newfoundland and Labrador); and by
- CIHI's Privacy Policy titled "*Privacy and Confidentiality of Health Information at CIHI: Principles and Policies for the Protection of Personal Health Information and Policies for Institution-Identifiable Information*", 3<sup>rd</sup> edition, April 2002.

CIHI and the research community are interdependent. Researchers use CIHI data to build on the current body of existing knowledge related to health and to health care. Through their use of CIHI data, regular feedback to CIHI and participation in expert/advisory groups, researchers also contribute to the development and quality of CIHI data and analyses. For its part, CIHI provides data to researchers in accordance with its privacy policies, carries out analytical studies, collaborates with

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<sup>2</sup> For further information on this, please visit the website of the Information and Privacy Commissioner/Ontario located at <http://www.ipc.on.ca/docs/ent-cihi.pdf>.

research organizations and individual researchers, and occasionally commissions research in priority areas.<sup>3</sup>

As part of its mandate and on a case-by-case basis, CIHI provides aggregate or record-level data to those external researchers who are generally associated with academic or health institutions or organizations. The researchers sign confidentiality/non-disclosure agreements that address use, retention, publication and confidentiality of the data before information is released.<sup>4</sup> For example, external researchers must agree not to link the personal information or personal health information with other information, except as approved in advance by CIHI.

Identifiable personal health information or personal information is only disclosed to the facility, health authority, Ministry of Health or other organization that originally provided the personal information/personal health information, or with the consent of the individual to whom the personal information relates, or if the disclosure is required by legislation or an agreement authorized by legislation, or for research purposes provided the researcher submits a research plan and has received research ethics board approval. The President and CEO of CIHI must approve requests that are unusual, sensitive and precedent setting, including requests for identifiable information. Copies of the Client Information Request form for aggregate and record-level information are available on our website located at [http://secure.cihi.ca/cihiweb/en/downloads/reqdata\\_e\\_aggregate.pdf](http://secure.cihi.ca/cihiweb/en/downloads/reqdata_e_aggregate.pdf) and [http://secure.cihi.ca/cihiweb/en/downloads/reqdata\\_e\\_record.pdf](http://secure.cihi.ca/cihiweb/en/downloads/reqdata_e_record.pdf) respectively.

CIHI also discloses personal health information when it is authorized or required to do so under an Act. For example, personal health information is disclosed to Statistics Canada from the Hospital Morbidity Database. Statistics Canada is authorized to collect this information under s. 13 of the *Statistics Act*.

### **CIHI's Privacy Program**

CIHI takes privacy and data protection extremely seriously. Our organization recognized at the outset that to be successful, it not only had to provide objective, valuable and reliable information but also that it was critical to address privacy, confidentiality and security of the information that data providers entrust to us. As such, CIHI put into place a comprehensive privacy program based on the privacy principles<sup>5</sup> of the Canadian Standards Association (CSA) Model Privacy Code (1996) to guide its operations (these principles form the basis of Schedule 1 of PIPEDA). CIHI has regularly updated its policies since then in response to changes in privacy

<sup>3</sup> [http://secure.cihi.ca/cihiweb/disPage.jsp?cw\\_page=research\\_e](http://secure.cihi.ca/cihiweb/disPage.jsp?cw_page=research_e) CIHI—Your Partner in Health Research.

<sup>4</sup> Researchers and other third parties are required to complete the *Client Information Request Form* and to execute a Non-Disclosure and Confidentiality Agreement in order to obtain access to aggregate or record-level data.

<sup>5</sup> CIHI's privacy policies are published in the document *Privacy and Confidentiality of Health Information at CIHI: Principles and Policies for the Protection of Personal Health Information and Policies for Institution-Identifiable Information*. It is available on-line at: [http://secure.cihi.ca/cihiweb/en/downloads/privacy\\_policy\\_priv2002\\_e.pdf](http://secure.cihi.ca/cihiweb/en/downloads/privacy_policy_priv2002_e.pdf).

legislation. CIHI continues to monitor and assess whether further modifications are required.

As mentioned above, we have also entered into bilateral agreements with ministries of health of all jurisdictions, outlining our commitment to abide by relevant health and privacy legislation in the respective jurisdictions and referring to our privacy policies.

CIHI has clearly defined roles with respect to privacy and security. A Privacy Secretariat was established to foster a culture of privacy. The Chief Privacy Officer is a member of the senior management team and has delegated authority from the President and CEO to manage the privacy program. A cornerstone of this program is CIHI's privacy policies referred to above. As part of this initiative, CIHI is committed to conducting a privacy impact assessment (PIA) on each of its data holdings. A PIA assesses the possible privacy-related consequences of systems and practices for the collection, use and disclosure of personal information, including personal health information.<sup>6</sup>

We also established the Privacy, Confidentiality and Security Team (PC&S Team) that includes representation from across the organization, including directors and managers from various departments including information systems, standards, research and analysis, client relations, databases and registries. This team works to enhance the culture of privacy throughout the organization and provides advice on operational issues as they relate to privacy.

In addition, our organization has had a Chief Privacy Advisor for the last seven years. The role of this external advisor is built into the CIHI privacy compliance program. The Chief Privacy Advisor's role is to provide advice to the Chief Privacy Officer and to serve as a resource for the Chief Executive Officer and Board of Directors on privacy complaints. David H. Flaherty, former Information and Privacy Commissioner of British Columbia, has held this position since its inception.

Moreover, CIHI has implemented an internal privacy review program that includes oversight by the Privacy and Data Protection Committee of CIHI's Board of Directors. The terms of reference of the Privacy and Data Protection Committee are the following:

- review and make recommendations on direction of the audit program;
- review the findings of the Privacy Audit Program and formulate recommendations on CIHI's privacy and data protection practices based on the findings of the Privacy Audit Program;
- advise the Board on implications of significant developments in privacy legislation and provide CIHI's position;

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<sup>6</sup> CIHI's PIAs can be found on-line at:  
[http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=privacy\\_e#impact](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=privacy_e#impact) .

- receive reports of major incidents within CIHI that could be seen as constituting a breach of confidentiality; and
- submit an Annual Report to the CIHI Board of Directors.

The Chief Technology Officer is responsible for electronic security and the Manager of Corporate Administration is responsible for the physical security of the facility. CIHI's premises are secured and the data are protected on secured servers.

Finally, all staff must sign a Confidentiality Agreement upon the commencement of their employment, and this Agreement must be renewed on an annual basis.

Attention to these facets of the Privacy Program, as an integral part of the daily operations of CIHI, has resulted in a Privacy Program that is considered to be one of the most comprehensive in the field and promotes a culture of privacy at CIHI.

**For further information about CIHI, please visit our website located at [www.cihi.ca](http://www.cihi.ca)**