Home Care Reporting System—Privacy Impact Assessment
Who We Are

Established in 1994, CIHI is an independent, not-for-profit corporation that provides essential information on Canada’s health system and the health of Canadians. Funded by federal, provincial and territorial governments, we are guided by a Board of Directors made up of health leaders across the country.

Our Vision

To help improve Canada’s health system and the well-being of Canadians by being a leading source of unbiased, credible and comparable information that will enable health leaders to make better-informed decisions.
CIHI is pleased to publish the following Privacy Impact Assessment pursuant to its Privacy Impact Assessment Policy:

HOME CARE REPORTING SYSTEM
PRIVACY IMPACT ASSESSMENT

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10 Quick Facts About the Home Care Reporting System

1. The Home Care Reporting System (HCRS) is a national source of standardized data about individuals who are referred to, screened by and/or accepted into publicly funded home care programs across Canada.

2. The HCRS contains demographic, clinical, functional and resource utilization information on clients who are served by publicly funded home care programs in Canada. It also collects information about the organizations that deliver home care services and the characteristics of the home care programs themselves.

3. The information collected by the HCRS minimum data set consists of 781 data elements. The clinical data standards for the HCRS were developed by interRAI, an international research network, and modified with its permission for Canadian use. The interRAI Resident Assessment Instrument—Home Care (RAI-HC)© is used to identify the preferences, needs and strengths of long-term home care clients. It also provides a snapshot of their formal and informal services. The interRAI Contact Assessment (interRAI CA)© captures a brief profile of all people served by screening or home care intake processes.

4. The HCRS contains 11 years of data from the RAI-HC, going back to the year 2000. Data submissions to the HCRS-CA (using the interRAI CA) had not begun at the time of writing.

5. Currently, 24 organizations participate. The breakdown per province/territory is as follows:
   - Yukon (entire territory);
   - British Columbia (5 regional health authorities);
   - Ontario (16 community care access centres);
   - Nova Scotia (entire province); and
   - Manitoba (1 regional health authority).

6. Health service administrators, policy-makers, governments, researchers and others use HCRS data to do the following:
   - Determine accountability for home care access and quality (for example, federal, provincial and territorial accountability reporting on comparable health indicators of access, outcomes and service utilization);
   - Conduct home care program benchmarking, quality improvement and system-level planning and management;
   - Identify accurate and timely comparative information on characteristics of home care populations, service utilization and outcomes (for management decision-makers);
Generate instantaneous results for clinical algorithms and indicators to improve referral and care planning protocols (for front-line service providers); and

Produce clinical, quality-of-care and policy analysis and research.

7. The HCRS supports the collection, sharing and analysis of data about clients who receive publicly funded home care services in Canada and the characteristics, utilization and outcomes of publicly funded home care programs.

8. HCRS data comes from a variety of sources, reflecting the variation in the way publicly funded home care services are delivered across Canada. Data providers include, for example, provincial or territorial ministries of health, regional health authorities and other entities, such as community care access centres in Ontario.

9. In 2010, CIHI enhanced the HCRS to allow for the capture of clinical data on all short- and long-term clients at intake or screening using the interRAI CA, meaning that the HCRS will now collect information about individuals who are screened/assessed for home care and receive short-term care related to a time-limited, acute condition, as well as about clients who require longer-term support to enable them to remain in a community setting. It also means that CIHI will collect information on individuals for whom the only home care service received was an assessment to determine the need for home care services or placement in residential care.

10. Recent studies produced by CIHI using data from the HCRS include an Analysis in Brief titled Caring for Seniors With Alzheimer’s Disease and Other Forms of Dementia.
1 Introduction

The Canadian Institute for Health Information (CIHI) collects and analyzes information on health and health care in Canada. Its mandate is to provide timely, accurate and comparable information to inform health policies, support the effective delivery of health services and raise awareness among Canadians of the factors that contribute to good health. CIHI obtains data directly from hospitals, regional health authorities, medical practitioners and governments, including personal health information about patients and registration and practice information about health professionals.

The purpose of this privacy impact assessment is to examine the privacy, confidentiality and security risks associated with the Home Care Reporting System (HCRS). It includes a review of the 10 privacy principles set out in the Canadian Standards Association’s Model Code for the Protection of Personal Information as they apply to the database.

This privacy impact assessment updates one completed in 2006. The primary drivers for this privacy impact assessment are

- Compliance with CIHI’s Privacy Impact Assessment Policy; and
- Planned implementation of expanded HCRS collection of personal health information via the interRAI Contact Assessment (interRAI CA).

2 The Home Care Reporting System at CIHI

2.1 Background

In 2004, CIHI initiated the HCRS development project to fulfill two needs: to respond to a request from the Ministry of Health in British Columbia for CIHI to build a repository for B.C.’s home care data; and to provide standardized pan-Canadian information on the home care sector in response to the 2002 Romanow report’s description of home care as “the next essential service.”

Phase 1 of the HCRS was launched in 2005, with administrative data standards for all home care clients and a clinical data standard for longer-term home care clients. This clinical standard was interRAI’s Resident Assessment Instrument—Home Care (RAI-HC). In 2008, CIHI launched Phase 2 development to allow for the capture of clinical data on all short- and long-term clients at intake or screening using the interRAI CA. This module was ready to accept data in May 2011.
The HCRS is designed to capture information on home care services that are provided by provincial and territorial governments, including where publicly funded home care programs use private-sector agencies to deliver care.

The HCRS is a national source of standardized data about individuals that are referred to, screened by and/or accepted into publicly funded home care programs across Canada. This includes individuals who receive short-term care related to a time-limited, acute condition and clients who require longer-term support to enable them to remain in a community setting. It also includes individuals for whom the only home care service received was an assessment to determine the need for home care services or placement in residential care.

The HCRS also collects information about the organizations that deliver home care services and the characteristics of the home care programs themselves.

The system does not capture data on clients who receive only privately funded home care, informal care and/or voluntary care. Nor does the system currently collect information on home care services delivered directly by the federal government, such as home care services for members of the Canadian Forces and the RCMP and eligible veterans.

The HCRS database is longitudinal and, as such, is structured to reflect a profile of the clients, their clinical and demographic characteristics, their resource use and their outcomes over time. The information captured in the HCRS includes:

- Demographic information;
- Administrative data, such as referral and discharge information;
- Service data, including service and provider type, frequency and duration;
- RAI-HC assessment data, including health, cognitive and functional status, formal and informal care, and medications; and
- interRAI CA data, including key health and functional information required for intake and screening.

A key approach in developing the HCRS was to ensure that the data is a by-product of the processes of care wherever possible. To this end, the bulk of HCRS information is collected by clinicians at the point of care using standardized assessment forms, primarily (but not exclusively) interRAI’s client assessment instruments. interRAI is a not-for-profit collaborative network of researchers in more than 30 countries that is committed to improving health care for persons who are elderly, frail or disabled. The interRAI instruments that form the majority of the HCRS data collection standards, used under license by CIHI, are the RAI-HC and the interRAI CA.
The interRAI CA is a brief, standardized clinical assessment that is designed to inform home care intake and screening of vulnerable populations in hospital emergency departments or other community settings. The form is designed to gather only the essential information needed at the time of intake to support decisions regarding the need for more comprehensive assessment (for example, using the RAI-HC), the urgency for home care service provision and the need for specialized services (such as rehabilitation). Information includes client demographic information (for example, sex, birthdate, postal code of usual living arrangement and primary language) as well as intake/history and clinical information designed to support effective discharge planning and/or referral for clients at greatest risk of negative outcomes.2

The RAI-HC, by comparison, is a comprehensive, standardized assessment tool that is used to assess home care clients who are expected to be on service for 60 days or more or those being assessed for residential care placement. The RAI-HC is designed to evaluate the needs, strengths and preferences of home care clients and can inform and guide comprehensive home care planning. The foundational component of the RAI-HC is the client assessment instrument, which collects client demographic information (for example, sex, year and month of birth and postal code of residence) and data elements relating to health conditions, cognitive and physical functioning, behaviour, medication use, nutritional status, special treatments and procedures.

In addition, both the interRAI CA and the RAI-HC derive value-added information from client assessment data. Certain combinations of responses are defined as triggers, which identify clients who could benefit from further evaluation of specific problems and risks for functional decline. Other algorithms derive summary measures of clients’ status and clinical outcomes, case-mix classification systems and quality indicators.

The HCRS data set consists of 781 data elements; 486 relate to collection based on the RAI-HC and 295 relate to collection based on the interRAI CA. The HCRS focuses on the individual home care client’s demographic and clinical information (approximately 303 data elements associated with the RAI-HC and 253 data elements associated with the interRAI CA). The remaining data elements provide contextual or administrative information that is associated with the home care organization that delivers services, the services provided, the vendor involved in data submission or characteristics of the provincial/territorial or federal home care program itself. Some data elements, such as unique organization and client identifiers, are common to both the HCRS and HCRS-CA. Data elements that provide details about the organizations that participate in the HCRS and HCRS-CA are submitted only once (typically annually), even if the organization is submitting both HCRS and HCRS-CA data. Other common data elements are submitted to both systems.
Since 2006, there have been no significant changes in the HCRS, with the following notable exceptions:

- Planned expansion of HCRS data collection to include the interRAI CA; and
- Planned expansion of HCRS data collection to include clinical data associated with clients who have been referred to and screened by, but ultimately not accepted into, publicly funded home care programs across Canada.

The expansion to collect clinical data on clients screened by but ultimately not accepted into a publicly funded home care program (using the interRAI CA) has been long planned and was largely driven by clinical and health policy requirements on the part of the stakeholders who provide home care services and the ministries that mandate such data collection. This module captures a core set of information to support the home care intake process in community or hospital inpatient settings, allowing for the collection of comparable information on all referrals to home care wherever people are served, from urban hospitals to remote community outposts. Further information on the purpose of the data collected is outlined in Section 3.3.

Currently, 24 organizations participate in the HCRS. The breakdown per province/territory is as follows:

- Yukon (entire territory);
- British Columbia (5 regional health authorities);
- Ontario (16 community care access centres);
- Nova Scotia (entire province); and
- Manitoba (1 regional health authority).

The earliest data in the HCRS goes back to the year 2000; however, data is not available for all organizations for every year.

### 2.2 Data Flow Diagram

HCRS data is supplied by a variety of sources, reflecting the variation in the way publicly funded home care services are delivered across Canada. Data providers include, for example, provincial or territorial ministries of health, regional health authorities and other entities, such as community care access centres in Ontario.

There may be several sources of data for the HCRS within a data provider organization, including the following:

- Data collected as a product of completing an interRAI assessment. If the assessments are conducted electronically, submission to CIHI may occur through the use of software purchased by the home care organization from an independent software vendor.
• Data collected through other systems that are used to capture demographic, administrative and resource data (which may be developed in-house or by independent software vendors).

Submissions to the database are expected to conform to CIHI’s submission and editing specifications. Data specifications and other associated documentation, such as file layouts, are supplied to the key stakeholders in electronic format. Software vendors must be licensed with interRAI to gain permission to develop software for the collection of RAI data. Additionally, those that have developed data collection software must also be licensed with CIHI to receive system specifications, and they must successfully submit test data to CIHI prior to the submission of live data.

Some jurisdictions have faced challenges conforming to CIHI’s full specifications for the HCRS. When this occurs, CIHI, on an exceptional basis, will accept files that do not meet the HCRS submission and edit specifications (for example, the files have missing data in mandatory data elements or the file is a different structure). These files are submitted through CIHI’s secure electronic Data Submission System (eDSS) and are stored in a secure, restricted-access folder that is accessible to selected program area staff and IT Operations only. Prior to processing by the program area, the health card number is encrypted by IT Operations. This step is performed regardless of whether the health card number submitted to CIHI was encrypted by the data provider prior to submission. The files are then manually processed, and the data quality and utility of the data are evaluated. After passing the data quality checks, the data is incorporated into the HCRS analytical files and data mart. Once an organization is capable of conforming to HCRS specifications, direct submission to the production system is expected.
The HCRS data and information flows are set out in the following flowchart:
3 Privacy Analysis

3.1 Authorities Governing CIHI and the Home Care Reporting System

General

CIHI adheres to its Privacy Policy, 2010, and to any applicable privacy legislation and/or agreements.

Legislation

CIHI is a secondary data collector of health information, specifically for the planning and management of the health system, including statistical analysis and reporting. Data providers are responsible for meeting the statutory requirements in their respective jurisdictions, where applicable, at the time the data is collected.

All provinces and territories have public-sector privacy legislation in place. Canadian privacy legislation includes provisions that authorize public bodies covered by the acts to disclose person-identifiable data, without the consent of the individual, for statistical purposes. Alberta, Saskatchewan, Manitoba, Ontario and New Brunswick (legislation pending in Newfoundland and Labrador and Nova Scotia) also have health information–specific privacy legislation with express lawful authority to use and disclose personal health information, without individual consent, for the purposes of managing the health system, including statistical analysis and reporting.

For example, CIHI is recognized as a prescribed entity under the Personal Health Information Protection Act of Ontario. Custodians in Ontario may disclose personal health information to CIHI without patient consent pursuant to Section 29 as permitted by Section 45(1) of the act.

Agreements

As indicated above, data flows directly to CIHI via existing applications/systems from data providers, for example, from provincial and territorial ministries of health, regional health authorities and other entities responsible for delivering and/or administering publicly funded home care programs. For the most part, these existing data flows are governed by CIHI’s Privacy Policy, 2010, existing legislation in the jurisdictions and data-sharing agreements with the provinces and territories or organizations. The data-sharing agreements set out the purpose, use and disclosure and retention requirements, as well as any subsequent data sharing that may be permitted.
CIHI requires each participating organization to sign a service agreement to access HCRS reports, and only authorized and registered external users are able to access aggregate HCRS reports via CIHI’s restricted web-based applications. These applications are accessed via secure sessions that are encrypted according to industry standards. To become a registered user, the chief executive officer (or designate) of an organization must sign the service agreement that governs the use of the data by authorized individuals at the organization. The agreement stipulates, among other privacy requirements, that the users must not attempt to identify any specific individual using HCRS information. User profiles are set up to limit access to the statistics and reports required for the person’s job requirements. With each use of the application, the user must agree to the online terms and conditions of use.

The service agreement limits HCRS participant organizations’ rights to use and disclose confidential information, including personal health information and organization-identifiable information, obtained through HCRS reports. Participating organizations are able to see unique client identification numbers (excluding health card numbers) from their own organizations on submission reports that they receive for the purposes of correcting submission errors and resubmitting the data. Specifically, participant organizations and their users are permitted to use such data solely for internal, non-commercial, local/regional evidence-based decision-making, planning and analytical purposes. Confidential information cannot be disclosed by the participating organization to any third party, except as expressly permitted in the service agreement or as required by law. Publication or disclosure outside of the participant organization is permitted only when all reasonable attempts to prevent the identification of individuals are employed and there are no cell sizes with fewer than five units of observation. Organization-identifiable information cannot be released by the participating organization unless the written consent of each organization identified in the information, or its respective ministry of health, has been obtained prior to release. Participants assume responsibility for ensuring that users of HCRS reports within their organizations are aware of the terms and conditions of the service agreement. All users must review and agree to the terms and conditions outlined above each time they log in to the HCRS system.
Participant organizations agree to immediately notify CIHI of any unauthorized access or use or any other breach of confidentiality or security of which they become aware. In addition, the service agreement sets out the following specific requirements and responsibilities with respect to usernames and passwords:

- Each user must create a user profile (name, title and email address), username and password on CIHI’s website, as instructed by CIHI.
- Participant organizations and their users must be aware that usernames and passwords are confidential and not to be shared.

Participant organizations are fully responsible for all activities that occur under their means of access.

A license agreement was signed with interRAI in May 1996, which grants CIHI an exclusive right and license to use interRAI’s assessment instruments for the purposes of national statistical reporting. The license agreement also commits CIHI to supply interRAI with one annual copy, in de-identified form, of the RAI data gathered by CIHI from its member health organizations for the previous year. The flow of de-identified data from CIHI to interRAI is governed by non-disclosure/confidentiality agreements that are signed annually.

**Advisory Committees**

The Home and Continuing Care Advisory Committee is made up of ministry of health representatives from across Canada. The purpose of the committee is to provide CIHI with advice, recommendations and support on pan-Canadian implementation and continuous improvement of the reporting systems and our services to participating jurisdictions.

### 3.2 Principle 1: Accountability for Personal Health Information

CIHI’s president and chief executive officer is accountable for ensuring compliance with CIHI’s Privacy Policy, 2010. CIHI has a chief privacy officer and general counsel, a corporate Privacy, Confidentiality and Security team, a Privacy and Data Protection subcommittee of its Board of Directors and an external chief privacy advisor.

**Organization and Governance**

The HCRS is managed by the Home and Continuing Care departments, under CIHI’s directorate of Methodologies and Specialized Care.
The following table identifies key internal senior positions with responsibilities for the HCRS in terms of privacy and security risk management:

<table>
<thead>
<tr>
<th>Position/Group</th>
<th>Role/Responsibilities</th>
</tr>
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<tbody>
<tr>
<td><strong>Vice President, Programs</strong></td>
<td>The vice president, programs, is responsible for the overall operations and strategic direction of the HCRS.</td>
</tr>
<tr>
<td><strong>Director, Methodologies and Specialized Care</strong></td>
<td>The director is responsible for strategic and operational decisions about the HCRS and ensuring its continued successful development.</td>
</tr>
<tr>
<td><strong>Manager, Home and Continuing Care (two positions)</strong></td>
<td>The manager is responsible for ongoing management, development and dissemination of the HCRS. The manager makes operational decisions about the HCRS, supports the advisory committee and consults internally and with CIHI’s HCRS clients as appropriate.</td>
</tr>
<tr>
<td><strong>Vice President and Chief Technology Officer</strong></td>
<td>The vice president and chief technology officer is responsible for the strategic direction and overall operations/implementation of CIHI’s technological and security solutions.</td>
</tr>
<tr>
<td><strong>Chief Privacy Officer</strong></td>
<td>The chief privacy officer is responsible for the strategic direction and the overall implementation of CIHI’s privacy program.</td>
</tr>
<tr>
<td><strong>Manager, ITS Operations</strong></td>
<td>The ITS Operations manager is responsible for ensuring that technical requirements for the ongoing development and maintenance of the HCRS are met. The ITS Operations team is responsible for acting as the system administrator for the HCRS.</td>
</tr>
<tr>
<td><strong>Manager, eReporting and Enterprise Data Warehouse (EDW) Services</strong></td>
<td>The eReporting and EDW manager is responsible for the HCRS data mart (as part of CIHI’s data warehouse) and the development, maintenance and enhancement of the HCRS eReports.</td>
</tr>
</tbody>
</table>

### 3.3 Principle 2: Identifying Purposes for Personal Health Information

The HCRS collects and reports on clinical, administrative, functional and resource utilization data from publicly funded home care programs in Canada. Also collected is information on transitions of home care clients to and from hospitals or emergency rooms.

The information, gathered electronically at the point of care, provides real-time decision support for front-line care planning and monitoring. The HCRS provides participating organizations with HCRS eReports, which contain profiles of their populations, services and outcomes, including quality indicators. These reports are used by clinical quality champions, managers and policy-makers for planning, quality improvement and accountability. Standard tables of aggregate data (Quick Stats) and analytical reports to inform the public about home care issues are available publicly on CIHI’s website.
Through the collection and use of information on both referrals to home care and home care clients, stakeholders are able to

- Identify gaps between the needs of clients referred to home care or screened in emergency departments and the services provided through their home care programs;
- Predict the need for admission and designation as long-stay and/or alternate level of care (ALC); and
- Improve coordination between acute care hospitals and community care agencies with respect to the discharge of frail elderly persons from emergency departments to the community.

These purposes are clearly stated on CIHI’s website, in the HCRS reports and bulletins, and in this privacy impact assessment.

3.4 Principle 3: Consent for the Collection, Use or Disclosure of Personal Health Information

HCRS data is disclosed to CIHI without individual consent for the purposes of the planning and management of the health system, including statistical analysis and reporting.

3.5 Principle 4: Limiting Collection of Personal Health Information

CIHI is committed to the principle of data minimization. As per sections 1 and 2 of CIHI’s Privacy Policy, 2010, CIHI collects from its data providers only that personal health information and de-identified data that is reasonably required for health system uses, including statistical analysis and reporting, in support of the management, evaluation or monitoring of the allocation of resources to, or planning for, the health care system in Canada, including support for the improvement of the overall health of Canadians.

CIHI limits its collection of personal health information to that which is necessary to support authorized data quality and analytical activities. The data elements collected and their purpose were identified in consultation with appropriate stakeholders, including the Home and Continuing Care Advisory Committee.

The personal health information and de-identified data collected in the HCRS are founded on the interRAI CA and RAI-HC assessment tools. However, the RAI-HC and interRAI CA collection forms contain additional data elements that are collected during the assessment but not submitted to CIHI (for example, names of clients, caregivers and assessors). CIHI’s adoption of the interRAI assessment tools as the basis for HCRS data collection means that the data elements, in particular those of a clinical nature, have been carefully selected.
based on the best available evidence of utility and specificity in addressing the identified purposes. Each version of an interRAI assessment instrument represents the results of rigorous research and testing to establish the reliability and validity of items, outcome measures, assessment protocols, case-mix algorithms and quality indicators.3

3.6 Principle 5: Limiting Use, Disclosure and Retention of Personal Health Information

3.6.1 Limiting Use

CIHI limits the use of data in the HCRS to authorized purposes, as described in Section 3.3. This includes comparative analyses within and among jurisdictions; trend analyses to assess/monitor the impact of differences in policy, practices and service delivery; and statistics to support planning, management and quality improvement. Staff from the HCRS program area are permitted to access and use data on a need-to-know basis only, including for data processing and quality management, the production of statistics and data files, and the conducting of analyses. All authorized users are made aware of their obligations and responsibilities for privacy and confidentiality. All CIHI staff are required to sign a confidentiality agreement at the commencement of employment and are subsequently required to renew their commitment to privacy yearly.

Since 2009, data sets used for analysis purposes do not contain direct identifiers, such as unencrypted health card numbers and street addresses (patient names are not collected in the HCRS). Health card numbers in an unencrypted form are available to CIHI staff on an exceptional, need-to-know basis only.

Data Linkage

Sections 14 to 31 of CIHI’s Privacy Policy, 2010, govern linkage of records of personal health information. Pursuant to this policy, CIHI permits the linkage of personal health information under certain circumstances. Data linkage within a single data holding for CIHI’s own purposes is generally permitted. Data linkage across data holdings for CIHI’s own purposes and all third-party requests for data linkage are subject to an internal review and approval process. When carrying out data linkages, CIHI will generally do so without using names or personal health numbers. The linked data remains subject to the use and disclosure provisions in the Privacy Policy, 2010.
Criteria for approving data linkages are set out in Section 24 of CIHI’s Privacy Policy, 2010, as follows:

1. The individuals whose personal health information is used for data linkage have consented to the data linkage; or

2. All of the following criteria are met:
   - The purpose of the data linkage is consistent with CIHI’s mandate;
   - The public benefits of the linkage significantly offset any risks to the privacy of individuals;
   - The results of the data linkage will not be used for any purpose that would be detrimental to the individuals that the personal health information concerns;
   - The data linkage is for a time-limited specific project, and the linked data will be subsequently destroyed in a manner consistent with sections 28 and 29 of CIHI’s Privacy Policy, 2010; or
   - The data linkage is for purposes of an approved ongoing program of work at CIHI, where the linked data will be retained for as long as necessary to meet the identified purposes and, when no longer required, will be destroyed in a manner consistent with sections 28 and 29 of CIHI’s Privacy Policy, 2010; and
   - The data linkage has demonstrable savings over other alternatives or is the only practical alternative.

Section 29 of CIHI’s Privacy Policy, 2010, further requires that secure destruction of linked data occur within one year after publication of the resulting analysis or three years after the linkage, whichever is sooner, in a manner consistent with CIHI’s Information Destruction Standard. This requirement applies to both data linkages for CIHI’s own purposes and to third-party data requests.

### 3.6.2 Return of Own Data

Section 34 of CIHI’s Privacy Policy, 2010, establishes that the return of data to the health care facility that originally provided it to CIHI is considered not a disclosure but a use. CIHI returns HCRS data in the following ways:

- **HCRS Submission Reports**: Record-level reports provide details on data quality issues that exist in a particular submission file. CIHI makes available to data providers reports on the outcome of their data submissions, including details of records that contain errors for these organizations to investigate and, where necessary, correct and resubmit. Experience to date with the HCRS has highlighted the challenge that some jurisdictions face in identifying data in their systems that has been corrected or updated since their last submission to CIHI. This challenge prevents an organization from identifying, extracting and submitting the specific records required to update previously submitted data. To accommodate this challenge, the CA module has
additional functionality that allows an organization to delete and resubmit all of the data in CIHI’s database for a particular period of time. This delete and refresh process allows a jurisdiction to provide updates and corrections by resubmitting all records and eliminates the need for them to identify the specific records that should be updated. A similar process can also occur with any manually processed files, as a jurisdiction may resubmit all of its data when sending in a new file to be processed. The interRAI CA module will allow data submitters to request reports that will verify records that have been successfully submitted to the enhancement application. These verification reports will provide data submitters with an additional means of determining the success of their prior data submission and correction efforts.

- **Customized record-level and aggregate data files:** When requested, CIHI provides data cuts (copies of the record-level data) back to the original data providers and their respective provincial or territorial ministries of health. Such data cuts may contain personal health information and are returned to the original data provider in accordance with CIHI’s Privacy Policy, 2010.

- **Test data (vendors):** At the discretion of the vendor, test data submitted to CIHI may include personal health information, de-identified data or fabricated/dummy data that was generated for test purposes. Privacy management for the vendors is the responsibility of the data provider, in adherence with applicable privacy laws. Vendors receive submission reports following the processing of their test files. These reports are the same as those received by data submitters from the HCRS production system outlining the overall success of their submission and the errors that require correction. Test data is stored in the vendor test system from year to year.

- **Test data (CIHI):** To help vendors ensure that their algorithms to derive aggregate outputs from RAI data are calculating correctly in their software, the HCRS program area also generates test data sets for each algorithm for the vendors to use. These data sets include the expected derived value for each test case. The data sets are generated using a random number generator to eliminate the risk of releasing personal health information that might otherwise occur by anonymizing existing client data.
3.6.3 Limiting Disclosure

Disclosures to Data Provider Community

The HCRS makes data available to the data provider community via HCRS eReports, a secure web-based application that allows authorized users to view aggregate comparative data (statistical reports) that can be customized to meet the user’s needs. CIHI creates and discloses statistics based on the HCRS to registered clients: organizations that participate in the HCRS and their respective provincial or territorial ministries of health. These reports include aggregate de-identified information on client characteristics, clinical outcomes, service utilization and quality and performance indicators. They include organization-specific reports and reports comparing information across organizations, but they do not contain any person-identifying information. The reports are accessed through a secure, web-based business intelligence tool that allows users to view and customize reports to suit their business needs. It is important to note that clients do not have access to the names, health card numbers, dates of birth or full postal codes of recipients of health care services through CIHI’s e-Reporting service. A privacy impact assessment on CIHI’s e-Reporting strategy was completed in March 2011.

Under the terms of the license agreement between CIHI and interRAI, every year CIHI provides interRAI with a de-identified version of the record-level HCRS RAI data (RAI-HC and interRAI CA) for the previous year. This file is provided to the research sites of interRAI located at the University of Waterloo and the Hebrew Rehabilitation Center for Aged in Boston, Massachusetts. interRAI uses this data to allow researchers to conduct research and analysis that will provide new insights on clinical practice, improve the quality of home care and further refine the instruments and their associated applications. Data is disclosed to interRAI, in compliance with CIHI’s Privacy Policy, 2010, using CIHI’s third-party data request process, request forms and agreements.

Public Release of HCRS Data

As part of its mandate, CIHI publishes aggregate data only in a manner designed to minimize any risk of identifiability and residual disclosure. Aggregate statistics and analyses are made available on CIHI’s website. This generally requires a minimum of five observations per cell. These publications include Quick Stats tables and Analysis in Brief reports, such as Caring for Seniors With Alzheimer’s Disease and Other Forms of Dementia, which was released in 2010.
Third-Party Data Requests

Customized record-level de-identified data and/or aggregate information from the HCRS is periodically requested by a variety of users, such as the federal government, health care decision-makers, researchers and the media. As discussed previously, interRAI also receives de-identified record-level RAI-HC and interRAI CA data from the HCRS through CIHI’s third-party data request process.

CIHI administers a third-party data request program, which contains and ensures tight privacy and security controls within the recipient organization. Furthermore, as set out in sections 45 to 47 of CIHI’s Privacy Policy, 2010, CIHI’s data disclosures are made at the highest degree of anonymity possible while still meeting the research and/or analytical purposes of the requester. This means that, whenever possible, data is aggregated. Where aggregate data is not sufficiently detailed for the intended purpose, data that has been de-identified may be disclosed to the recipient on a case-by-case basis, when the recipient has entered into a data protection agreement or other legally binding instrument with CIHI. Only those data elements necessary to meet the intended purpose may be disclosed.

In 2009, CIHI adopted a complete lifecycle approach to data management. As part of that lifecycle, Privacy and Legal Services (PLS) developed and is responsible for the ongoing compliance monitoring process, whereby all data sets that are disclosed to third-party data recipients are tracked and monitored for secure destruction at the end of their lifecycle. Prior to the disclosure of data, third-party recipients sign a data protection agreement and agree to comply with the conditions and restrictions imposed by CIHI relating to the collection, purpose, use, security, disclosure and return or disposal of data.

As of January 2011, in addition to the compliance monitoring process, which leverages data captured to monitor compliance with data destruction requirements, PLS contacts third-party data recipients on an annual basis to certify that they continue to comply with their obligations as set out in the third-party data request form and data protection agreement signed with CIHI.
Data requestors are required to submit a written request. They must also sign an agreement wherein they agree to use the data only for the research specified. All data protection agreements with third parties specify that receiving organizations must keep de-identified record-level data strictly confidential and not disclose such data to anyone outside the organization. Moreover, CIHI imposes obligations on these third-party recipients, including

- Secure destruction requirements;
- CIHI’s right to audit;
- Restriction on the publication of cells with fewer than five observations; and
- Strong encryption technology that meets or exceeds CIHI’s standards where mobile computing devices are used.

3.6.4 Limiting Retention

The HCRS forms part of CIHI’s information holdings and, consistent with its mandate and core functions, CIHI retains such information for as long as necessary to meet the identified purposes.

3.7 Principle 6: Accuracy of Personal Health Information

CIHI has a comprehensive data quality program. Any known data quality issues are addressed by the data provider or documented in data limitations documentation, which is made available to all users.

Similar to other CIHI data holdings, the HCRS is subject to an annual data quality assessment, based on CIHI’s Data Quality Framework. The process of completing the framework includes numerous activities to assess the accuracy of the HCRS data. As well, preliminary counts and indicator values for each jurisdiction are shared with each provincial and territorial ministry of health for their review and confirmation before the data is released to the public.
3.8 Principle 7: Safeguards for Personal Health Information

CIHI’s Privacy and Security Framework

CIHI has developed a Privacy and Security Framework to provide a comprehensive approach to privacy and security management. Based on best practices from across the public, private and health sectors, the framework is designed to coordinate CIHI’s privacy and security policies and provide an integrated view of the organization’s information management practices. The framework is designed to enable the effective integration and coordination of CIHI’s privacy and security policies and to provide CIHI’s decision-makers, privacy and security officers, and entire governance structure with a holistic view of the organization’s information management practices. Key aspects of CIHI’s system security with respect to the HCRS are highlighted below.

System Security

All HCRS data is submitted to CIHI via CIHI’s secure web-based eDSS. Physical, technological and administrative safeguards are in place to protect HCRS data during transmission, to store it securely and to limit access to authorized staff at CIHI. The eDSS application uses a secure, 128-bit encrypted SSL (secure sockets layer) session between CIHI and data providers for the purpose of data transfer. This level of encryption is considered the industry standard and is used for most internet banking and e-commerce applications. The encrypted file transmission from eDSS is received on a file transfer protocol (FTP) server on a segregated section of CIHI’s network and moved promptly into the protected area, where it is decrypted. The protected area has additional firewalls and is not linked to external-facing servers.

The HCRS files reside on a secure server that is maintained by CIHI’s ITS department. While a threat risk assessment has not been conducted specifically on the HCRS, the database’s security features have been updated on numerous occasions in conjunction with CIHI’s corporate IT security updates since 2006.

When data providers submit data, they do so according to a predetermined record layout of data elements. The process of transferring data into the HCRS within CIHI is carried out electronically, thereby ensuring that only the data that is part of the record layout is transferred from the original data holding to the database. Electronic transfer also limits the number of people with access to the data.
More generally, CIHI has established physical, technical and administrative security practices to ensure the confidentiality and security of all of its data holdings. Moreover, CIHI’s employees are aware of the importance of maintaining the confidentiality of personal health information through a mandatory privacy and security training program and through ongoing communications about CIHI’s privacy and security policies and procedures.

CIHI is committed to safeguarding its IT ecosystem, to securing its data holdings and to protecting information with administrative, physical and technical security safeguards that are appropriate to the sensitivity of the information. Audits are an important component of CIHI’s overall Information Security program and are intended to ensure that best practices are being followed and to assess compliance with all information security policies, procedures and practices implemented by CIHI. Audits are used to assess, among other things, the technical compliance of information processing systems with best practices and published architectural and security standards, CIHI’s ability to safeguard its information and information processing systems against threats and vulnerabilities, and the overall security posture of CIHI’s technical infrastructure, including networks, servers, firewalls, software and applications.

An important component of CIHI’s audit program is regular third-party vulnerability assessments and penetration tests of its infrastructure and selected applications. All recommendations resulting from third-party audits are tracked in the corporate risk register, and action is taken accordingly.

3.9 Principle 8: Openness About the Management of Personal Health Information

CIHI makes information available about its privacy policies, data practices and programs relating to the management of personal health information. Specifically, CIHI’s Privacy and Security Framework and the Privacy Policy, 2010, are available to the public on its corporate website (www.cihi.ca).

3.10 Principle 9: Individual Access to, and Amendment of, Personal Health Information

Personal health information held by CIHI is not used by CIHI to make any administrative or personal health decisions affecting the individual. An individual seeking access to his or her personal health information will be processed in accordance with sections 60 to 63 of CIHI’s Privacy Policy, 2010. It should be noted that over the five years since the original privacy impact assessment was completed, there have been no cases of an individual approaching CIHI to request access to, or amendment of, his or her personal health information in the HCRS.
3.11 Principle 10: Complaints About CIHI’s Handling of Personal Health Information

As set out in sections 64 and 65 of CIHI’s Privacy Policy, 2010, complaints about CIHI’s handling of personal health information are investigated by the chief privacy officer. The chief privacy officer may direct an inquiry or complaint to the privacy commissioner of the jurisdiction of the person making the inquiry or complaint.

4 Conclusion

CIHI’s assessment of the HCRS did not identify any privacy risks.
Appendix

The following table describes personal identifiers and other data elements that could be considered sensitive, including data element definitions, information about when this data is collected and a rationale for collecting it.

<table>
<thead>
<tr>
<th>Element</th>
<th>When Collected</th>
<th>Reason for Collection/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unique Source Organization Client Identifier</strong></td>
<td>All records</td>
<td>A unique number, other than the health card number, is assigned to a client by the home care organization. This client identifier remains unchanged across multiple admissions and discharges within a given organization. As not all clients have a valid provincial or territorial health card number, an administrative identifier (captured in this data element) is also required to uniquely identify records for individual persons within an organization when they do not have a valid health card number. This number is used by CIHI as a primary key to connect records for a given client, within a single episode of care and across multiple episodes, within the same organization. It is also used as the client identifier in the HCRS submission reports for organizations to identify which person’s records need to be investigated, corrected and resubmitted.</td>
</tr>
<tr>
<td><strong>Unique Provincial Client Identifier</strong></td>
<td>All records (if available)</td>
<td>Some provinces and territories are instituting jurisdiction-wide client registries that assign a single identifier (other than the health card number) to an individual to be used across the continuum of care (for example, Alberta’s unique lifetime identifier). If such identifiers are used, they can be submitted to the HCRS as this data element. This data element, if available, will allow the connection of individuals’ records across multiple organizations within a province or territory, even if the person does not have a valid provincial or territorial health card number. If available, it can be used to connect individuals’ episodes of care across multiple organizations and potentially across the continuum of care. This will ensure more accurate access and utilization estimates at a provincial level, since in highly urban areas there can be relatively high proportions of clients who are served by more than one home care organization.</td>
</tr>
<tr>
<td>Element</td>
<td>When Collected</td>
<td>Reason for Collection/Comments</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>-------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Health Card Number (HCN)</td>
<td>interRAI CA: on admission; RAI-HC: if available and if changes occur</td>
<td>This number allows for the connection of records that relate to the same individual, particularly across organizations. For this reason, it is often used as the principal identifier by health care organizations. However, not all home care clients have a valid provincial or territorial health card number (for example, members of the Canadian Forces and RCMP and residents of other countries). If available, it can be used to connect individuals’ episodes of care across multiple organizations and potentially across the continuum of care. This will ensure more accurate access and utilization estimates at a provincial level, since in highly urban areas there can be relatively high proportions of clients who are served by more than one organization. The health card number is encrypted and removed from analytical data sets.</td>
</tr>
<tr>
<td>Postal Code of Residence</td>
<td>interRAI CA: on admission; RAI-HC: on admission and if changes occur</td>
<td>The postal code is used to assign clients to health regions to report on region-specific access, utilization and outcome indicators, which are used for planning purposes and population health initiatives. The geographic boundaries of health regions are not static; they change with time and health system restructuring. CIHI needs one constant, unique, geographic variable to be able to validate that health data belongs within a specific location. Postal codes can be mapped to standard geographic regions using Statistics Canada’s Postal Code Conversion File. These standard geographic regions can then be converted to health regions using Statistics Canada’s health region–to–census geography correspondence files. Census geography does not recognize provincial health region boundaries (and vice versa), and neither geographical system falls neatly into Canada Post’s assignment of postal codes to mailing addresses. Correspondence files provide the linkage between these geographic units and require all six characters of postal codes for accurate mapping. Although all six digits of the postal code are required for accurate mapping to health regions, data released by CIHI in response to external data requests will typically include only geographic identifiers such as large census subdivisions, health regions and provinces, which are mapped from the postal codes.</td>
</tr>
</tbody>
</table>

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i. Statistics Canada has established these correspondence files as a standard way of converting postal code information to an appropriate geographical region across Canada that suits the requirements of data users. It could be, for example, the geographical expanse of a regional health authority in British Columbia.
## Home Care Reporting System—Privacy Impact Assessment

<table>
<thead>
<tr>
<th>Element</th>
<th>When Collected</th>
<th>Reason for Collection/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>interRAI CA, RAI-HC: on admission</td>
<td>Sex is coded <em>male</em> or <em>female</em>. It may be left blank (for example, in B.C., it will be validated by the Ministry of Health against its personal health number registry, which has some missing values due to past data quality issues). It is checked against other personal identifiers (Health Card Number, Unique Source Organization Client Identifier and Birth Date) to ensure the longitudinal integrity of the database (that is, that only records related to an individual client are connected to each other). It will be used to produce key analyses of access, utilization, health status and outcomes by sex and for age and sex standardization.</td>
</tr>
</tbody>
</table>
| **Birth Date**   | interRAI CA, RAI-HC: on admission   | This is used to calculate age, which is required for analysis of indicators by age and for age and sex standardization. With the addition of the interRAI CA to the HCRS, the full date of birth is included as opposed to month and year only, as is the case for basic HCRS information. This decision was made to  
- Ensure consistency with interRAI’s new suite of tools, which includes full date of birth; and  
- To make the data element more valuable as a unique client identifier check.  
It is checked against other personal identifiers (Health Card Number, Unique Source Organization Client Identifier and Sex) to ensure the longitudinal integrity of the database (that is, that only records related to an individual client are connected to each other).  
In response to external data requests, CIHI typically releases only year of birth, derived age or age grouping. |
<p>| <strong>Primary Language</strong> | interRAI ED, interRAI CA, RAI-HC: on admission and if changes occur | This data element can be used to identify clients who are potentially underserved due to an inability to speak the language or to cultural differences. The list of possible languages that can be coded is large, which is likely to result in small numbers of clients being coded to less-frequently spoken languages. Language codes with small numbers are aggregated into larger categories for analysis and release within data requests; typically, languages other than English and French will be categorized as <em>other</em>. |
| <strong>Marital Status</strong> | RAI-HC: on admission and if changes occur | This captures self-reported marital status (that is, the assessor does not check any legal records to complete this data element). The client’s marital status is critical to understanding the client’s support network, which is an important aspect of care planning and an important factor in recovery after an illness and being able to remain in a community environment. It can affect the amount of informal and formal services the client receives. Collecting information on marital status will assist in understanding variations in informal caregiving and caregiver burden. It will also enable analysis of the impact of changes in marital status on formal service utilization. |</p>
<table>
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<tr>
<th>Element</th>
<th>When Collected</th>
<th>Reason for Collection/Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Record Number</td>
<td>interRAI CA,</td>
<td>This is a number assigned by the home care organization, usually to differentiate an individual's episode of care. It cannot identify an individual on its own.</td>
</tr>
<tr>
<td></td>
<td>RAI-HC</td>
<td></td>
</tr>
<tr>
<td>Aboriginal Identity</td>
<td>RAI-HC</td>
<td>This is required for aggregate analysis of health status and outcomes for a vulnerable population. The RAI-HC clinical assessment requires that the clinician ask the client or family whether the client identifies himself or herself as a member of an Aboriginal community (First Nations, Inuit or Métis). Understanding populations is critical to providing appropriate access and service quality; it is particularly important to understanding and meeting the needs of vulnerable populations. There is considerable research to indicate that Aboriginal populations are at risk for particular diseases, illnesses or injuries. Both Health Canada and Statistics Canada collect information on Aboriginal identity for a variety of purposes. This data element will provide a unique perspective on Aboriginal people who receive home care services outside of Health Canada's First Nations and Inuit Health Branch programs. It will allow for analysis of health and functional status, access to services and health outcomes across populations that have unique health needs. It will be critical in the development of valid, comparable indicators that support quality improvement initiatives. This data element is released in external data requests only following approval from the vice president of Programs (responsible for CIHI’s First Nations and Inuit Health Information program).</td>
</tr>
<tr>
<td>Responsibility for</td>
<td>RAI-HC</td>
<td>This is required to determine funding sources for home care services.</td>
</tr>
<tr>
<td>Payment</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Event Dates             | RAI-HC, start and end of service, on admission, at discharge | Event dates include  
  • Date case opened/reopened;  
  • Date of acceptance to home care;  
  • Assessment date;  
  • Discharge date;  
  • Service start date;  
  • Service end date;  
  • Facility admission date; and  
  • Date assessment signed as complete.  
  Event dates permit the creation of an episode of care and are critical to the evaluation of waiting times, duration of service and outcomes of care. |
<table>
<thead>
<tr>
<th>Element</th>
<th>When Collected</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Highest Level of Education</td>
<td>RAI-HC</td>
<td>Level of education, along with a wide range of other factors, has been shown to have an impact on health: higher levels of education are associated with better health. Collecting information on a client’s level of education will allow for analyses of the impact of his or her level of education (relative to other client characteristics) on health and functional status, service utilization and outcomes. For example, research has shown a direct association between level of education and measures of cognitive performance. It is therefore important to understand the relationship between education and cognitive performance when trying to analyze the impact of cognitive performance on other client characteristics, outcomes, etc.</td>
</tr>
<tr>
<td>Physically Abusive</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Bladder Continence ii</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Disease Diagnosis</td>
<td>interRAI CA</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Dementia Other Than Alzheimer’s</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Any Psychiatric Diagnosis</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>HIV Infection</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Client Had to Have Drink First Thing in a.m., Was in Trouble Due to Drinking</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Prognosis of Less Than Six Months to Live</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Neglected, Abused iii</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Alcohol/Drug Treatment Program</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Hospice Care</td>
<td>RAI-HC</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Referral for Palliative Services</td>
<td>interRAI CA</td>
<td>Example of sensitive information collected.</td>
</tr>
<tr>
<td>Expected Residential/Living Status</td>
<td>interRAI CA</td>
<td>Example of sensitive information collected.</td>
</tr>
</tbody>
</table>

ii. In this instance, the Canadian RAI-HC manual4 instructs assessors to “[m]ake sure that your discussions are held in private. Control of bladder function is a sensitive subject, particularly for clients who are struggling to maintain control.”

iii. The Canadian RAI-HC manual4 specifies that the “client should be interviewed in private, away from family, friends and caregivers.”
References


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