



Canadian Multiple Sclerosis Monitoring System
Privacy Impact Assessment, September 2013



Canadian Institute
for Health Information

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d'information sur la santé



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Healthier Canadians.

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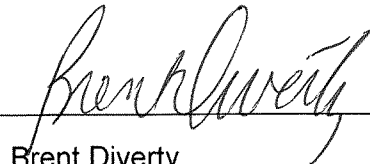
Our Values

Respect, Integrity, Collaboration,
Excellence, Innovation

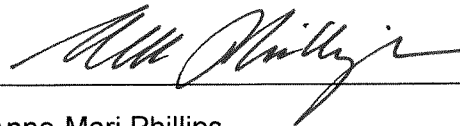
The Canadian Institute for Health Information (CIHI) is pleased to publish the following privacy impact assessment in accordance with its *Privacy Impact Assessment Policy*:

- Canadian Multiple Sclerosis Monitoring System Privacy Impact Assessment, September 2013

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Ottawa – August 2013

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Quick Facts About the Canadian Multiple Sclerosis Monitoring System

1. The Canadian Multiple Sclerosis Monitoring System (CMSMS) was established to
 - Record, measure and monitor the evolution and treatment of multiple sclerosis (MS) in Canada;
 - Increase understanding of MS disease patterns across Canada, variation in use of treatments and long-term patient outcomes;
 - Provide a minimum data set and data standards for MS, adding quality and value to current data collection and analysis capabilities; and
 - Fill an important information gap about MS by providing longitudinal data that is pan-Canadian and comparable across jurisdictions and that enables sound policy and effective health system management that improve health and health care.
2. The Canadian Institute for Health Information (CIHI) began developing the CMSMS in April 2011 through collaboration with an extensive network of experts, including people living with MS and their caregivers, the MS Society of Canada, the Canadian Network of Multiple Sclerosis Clinics, clinicians, researchers, international experts and various governments.
3. Since September 2012, the CMSMS has been ready to receive data from MS clinics across Canada, extracted from their local data sources and submitted via CIHI's secure web-based file submission service. As of April 2013, CMSMS data may also be supplied to CIHI via the secure Online Data Entry Tool.
4. Information is collected during the initial enrolment assessment and subsequent patient visits as a by-product of delivering services to persons living with MS. A subset of this information—including patient demographic, diagnostic, clinical, treatment and outcome information—is supplied to the CMSMS.
5. In the future, CIHI may examine the feasibility of collecting data from community neurologists and family physicians who care for people living with MS, as well as additional patient-reported outcomes provided directly by people living with MS.

Executive Summary

The purpose of this privacy impact assessment (PIA) is to examine the privacy, confidentiality and security risks associated with the Canadian Multiple Sclerosis Monitoring System (CMSMS) operated by the Canadian Institute for Health Information (CIHI). The CMSMS will measure and monitor the evolution and treatment of multiple sclerosis (MS) in Canada.

This PIA is an update to the previous assessment of CIHI's CMSMS, which was published in July 2012. The scope of the current assessment covers the original operational system as well as the implementation of the new secure Online Data Entry Tool for the CMSMS, which became available in April 2013.

CIHI's PIA published in July 2012, and the current updated assessment of the CMSMS, concluded that mitigation measures currently in place for any identified risks are appropriately managed by CIHI and its data providers. There are no recommendations at this time. In keeping with its privacy policies, CIHI will update or renew this assessment when significant changes are made to the CMSMS.

1 Introduction

The Canadian Institute for Health Information (CIHI) collects and analyzes information on health and health care in Canada. Its mandate is to lead the development and maintenance of comprehensive and integrated health information that enables sound policy and effective health system management that improve health and health care. CIHI obtains data directly from hospitals and other health facilities, long-term care homes, regional health authorities, medical practitioners and governments. This data includes health information about services provided to patients, residents and clients; registration and practice information about health professionals; and health expenditure information.

The purpose of this privacy impact assessment (PIA) is to examine the privacy, confidentiality and security risks associated with the Canadian Multiple Sclerosis Monitoring System (CMSMS). The assessment 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 development of the database and methods for submitting data to the CMSMS.

The CMSMS will record, measure and monitor the evolution and treatment of multiple sclerosis (MS) in Canada. Its aim is to increase the understanding of MS disease patterns across Canada, variation in use of treatments and long-term patient outcomes. The CMSMS is a relatively new system at CIHI, and new functionality was recently added. The primary driver for this PIA is compliance with CIHI's [Privacy Impact Assessment Policy](#).

2 The Canadian Multiple Sclerosis Monitoring System at CIHI

2.1 Background

An estimated 93,500 Canadians are living with MS.¹ Much is unknown about MS, and Canada is estimated to have one of the highest MS rates in the world. Therefore, it is important to understand MS, its progression and the use of treatments.

To address gaps in information and better understand this disease, at the request of the Public Health Agency of Canada, CIHI developed the CMSMS. The new system was established to

- Record, measure and monitor the evolution and treatment of MS in Canada;
- Increase understanding of MS disease patterns across Canada, variation in use of treatments and long-term patient outcomes;
- Provide a minimum data set and data standards for MS, adding quality and value to current data collection and analysis capabilities; and
- Fill an important information gap about MS by providing longitudinal data that is pan-Canadian and comparable across jurisdictions.

CIHI worked in collaboration with an extensive network of experts, including people living with MS and their caregivers, the Multiple Sclerosis Society of Canada, the Canadian Network of Multiple Sclerosis Clinics, clinicians, researchers, international experts and various governments to develop and design the CMSMS.

The CMSMS is a multiphase initiative, with an initial focus on obtaining data from MS clinics across Canada. The CMSMS contains patient demographic, clinical, diagnostic, treatment and outcome information.

This PIA is an update to the previous assessment of CIHI's operational CMSMS, which was published in July 2012. The scope of the current assessment covers the operational system as well as the implementation of the new secure CMSMS Online Data Entry Tool, which became available in April 2013.

2.2 Data Flow

CIHI is a secondary data collector of MS information. It relies on the submission of data collected by MS clinics responsible for providing health care services to persons living with MS in Canada. The data that is submitted, for the most part, is required by MS clinics to do their business, which is to plan, conduct and manage the delivery of health care services for persons living with MS. Initially, data will be collected from MS clinics that are located in, or associated with, hospitals across Canada.

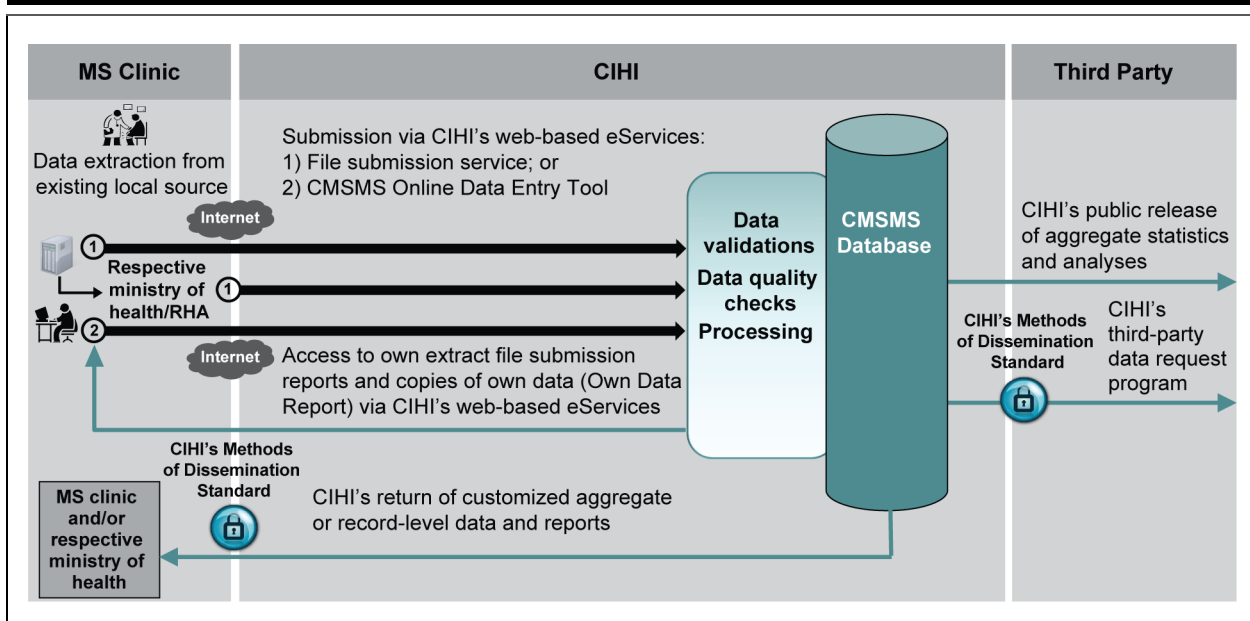
MS clinics extract a minimum data set from their existing data sources and prepare the data for submission in a format that meets CIHI's specifications. CIHI refers to the set of data elements to be collected by the CMSMS as the minimum data set.

Submission of data to CIHI for storage in the CMSMS is expected to conform to CIHI's submission and editing specifications. CIHI provides detailed data submission specifications to participating MS clinics prior to their submission of data. All CMSMS data is submitted through CIHI's secure web-based file submission service or via the secure Online Data Entry Tool; the data is subsequently processed by the CMSMS application. CIHI's web-based file submission service permits the submission of files containing multiple individual records, whereas the Online Data Entry Tool allows submission of individual records.

Figure 1 illustrates the high-level data flow for the CMSMS. Data that has been extracted from existing data provider data sources is submitted to CIHI using two methods:

1. Data is compiled from existing data sources into submission files and submitted to CIHI using CIHI's secure web-based data submission service. Some data providers may supply CMSMS data to their respective ministry of health or regional health authority, which in turn submits the data to CIHI using this secure method. After the data files have been submitted using CIHI's secure web-based file submission service, the data will be processed by the CMSMS system, and extract file submission reports will be produced for the data provider to access via CIHI's web-based eServices. Extract file submission reports describe the outcome of the file submission, including data quality concerns identified during processing. The data provider is responsible for reviewing data quality feedback from CIHI and resubmitting any rejected records or corrections, as required.
2. Data from existing data sources is entered directly into the CMSMS Online Data Entry Tool, allowing data providers to submit individual records directly to CIHI through a series of data entry screens on CIHI's secure website. Online Data Entry Tool users are required to respond to real-time feedback regarding data quality errors and warnings as they work their way through the tool's screens to fill in all of the encounter information. Once all information has been provided and all errors and warnings have been addressed, a record can be submitted to the CMSMS.

Figure 1: Data Flow, Canadian Multiple Sclerosis Monitoring System, September 2013



3 Privacy Analysis

3.1 Authorities Governing CIHI and the Canadian Multiple Sclerosis Monitoring 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. This 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, New Brunswick, 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 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 in Section 2.2, the data will flow directly to CIHI from data providers, such as provincial and territorial ministries of health, MS clinics and other entities responsible for the delivery and/or administration of health care services. For the most part, these data flows will be governed by CIHI's [Privacy Policy, 2010](#), existing legislation in the jurisdictions and existing data-sharing agreements with the provinces and territories. The data-sharing agreements set out the purpose, use, disclosure, retention and disposal requirements of personal health information provided to CIHI, as well as any subsequent disclosures that may be permitted. The agreements also describe the legislative authority under which personal health information is disclosed to CIHI. Where required, existing data-sharing agreements have been updated to include the provision of MS data to CIHI.

Only authorized and registered external users will be able to access the CMSMS file submission service, Online Data Entry Tool and reports via CIHI's restricted web-based eServices applications. These applications are accessed via secure sessions that are encrypted according to industry standards. MS clinic, ministry of health and regional health authority staff who access CIHI's eServices are subject to the terms of service agreements between CIHI and the associated hospital and/or appropriate jurisdictional authority (such as a ministry of health). With each use of an application or service, the user must agree to the online terms and conditions of use.

User profiles will be set up to limit access to the services and data required for the person's job requirements.

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 Committee of its Board of Directors and an external chief privacy advisor.

Organization and Governance

The following table identifies key internal senior positions with responsibilities for the CMSMS in terms of privacy and security risk management:

Position/Group	Roles/Responsibilities
Vice President, Programs	Responsible for the overall operations and strategic direction of the CMSMS.
Director, Acute and Ambulatory Care Information Services	Responsible for strategic and operational decisions about the CMSMS.
Manager, CMSMS	Responsible for ongoing management and uptake of the CMSMS. Makes day-to-day operational decisions about the CMSMS and supports the CMSMS Advisory Committee.
Chief Information Security Officer	Responsible for the strategic direction and overall implementation of CIHI's Information Security program.
Chief Privacy Officer	Responsible for the strategic direction and overall implementation of CIHI's Privacy program.
Manager, ITS Health Information Applications	Responsible for ensuring that technical requirements for ongoing operations and enhancements for the CMSMS are met. Responsible for acting as system administrator for the CMSMS.
Manager, Central Client Services	Responsible for managing external client access to restricted web-based services.

Advisory Committee

The CMSMS Advisory Committee provides CIHI with expert input and advice to support the implementation and uptake of the CMSMS across Canada. The committee provides CIHI with the additional knowledge, expertise and insights necessary to support sound decision-making on matters related to the direction and delivery of the CMSMS operational program. In playing an advisory role, the committee focuses on being anticipatory and strategic in its provision of guidance, thus facilitating and enabling the ongoing success of the program.

3.3 Principle 2: Identifying Purposes for Personal Health Information

The CMSMS collects and reports on patient demographic, diagnostic and administrative information collected from MS clinics in Canada.

As stated previously, the purposes of the CMSMS are to

- Record, measure and monitor the evolution and treatment of MS in Canada;
- Increase understanding of MS disease patterns across Canada, variation in use of treatments and long-term patient outcomes;
- Provide a minimum data set and data standards for MS, adding quality and value to current data collection and analysis capabilities; and
- Fill an important information gap about MS by providing data that is pan-Canadian and comparable across jurisdictions.

These purposes are clearly stated on CIHI's website.

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

CMSMS data is disclosed to CIHI for purposes of planning and managing the health system, including statistical analysis and reporting, under specific legislative authority or by legal agreements governing the flow of data. CIHI is a secondary collector of data and will not have direct contact with the data subjects. CIHI relies on the data providers to meet their data collection, use and disclosure rules and responsibilities, including those related to consent and notification, as outlined in jurisdiction-applicable laws, regulations and policies.

3.5 Principle 4: Limiting Collection of Personal Health Information

CIHI is committed to the principle of data minimization. Per sections 1 and 2 of CIHI's [Privacy Policy, 2010](#), CIHI collects from data providers only the information that is reasonably required for health system uses, including statistical analysis and reporting, in support of the management, evaluation or monitoring of the health care system.

CIHI limits its collection of personal health information to that which is necessary to support authorized data quality and analytical activities. CIHI developed the CMSMS beginning in April 2011 in collaboration with an extensive network of experts, including people living with MS and their caregivers, the Multiple Sclerosis Society of Canada, the Canadian Network of Multiple Sclerosis Clinics, clinicians, researchers, international experts and various governments. A critical deliverable for the development of the CMSMS was identifying the information that is to be collected by this system.

CIHI adopted a systematic method to identify and further refine the information that will be collected by the system. Efforts early in the project were designed to understand very broadly the priority information needs for MS and the environment. These efforts included

- A comprehensive environmental scan of national and international MS activities and data systems;
- A workshop that brought together 29 subject matter experts from across Canada to develop a list of priority clinical and policy questions to inform development of CIHI's CMSMS minimum data set;
- Site visits and assessments of current data collection activities already under way in MS clinics across Canada; and
- Further consultation with the two project advisory committees, as well as federal, provincial and territorial governments, to determine how the CMSMS data set and system development aligned with jurisdictional MS-related information needs.

The environmental scan and initial stakeholder consultation process supported CIHI's development of a draft minimum data set for the CMSMS. The draft data set was then subjected to several rounds of additional scrutiny by the two project advisory committees, as well as broader validation through an external field review. The final minimum data set for the CMSMS reflects the minimum information necessary to address its purposes.

Examples of the types of information collected by the CMSMS follow below, and a sample of data elements that could present an increased risk of direct or indirect identification of an individual is provided in the appendix, along with the rationale for their collection:

Technical Data Elements

- Record Typeⁱ—Indicates whether this is an initial enrolment record, face-to-face follow-up record or non-face-to-face follow-up record

Identifiers

- Health Card Numberⁱ—The person's health card number as assigned by the provincial or territorial government of residence
- Health Care Provider Identifier—The unique identification number of the person's primary health care provider, as assigned by the participating organization for the visit
- Organization Client Identifierⁱ—For example, a chart number
- Source Organization Identifierⁱ—CIHI-assigned unique identifier for the organization at which the visit took place or services were received

i. Data providers are encouraged/recommended to supply all data elements; however, only these data elements are currently mandatory to submit. To ease the initial burden of data collection, if any of the remaining data elements are missing or do not adhere to the specifications, the entire record will still be accepted into the CMSMS database.

Administrative Information

- Service Dateⁱⁱ
- Reason(s) for Service

Demographics

Personal Attributes of Person Living With MS

- Birthdate
- Current Employment Type and Status
- Current Living Arrangement(s)
- Current Usage of Cigarettes/Tobacco Products

Geographic Attributes of Person Living With MS

- Postal Code of Primary Residence
- Location of Birth

Clinical Information

- Date of Diagnosis
- Current Type/Course of MS
- Comorbid Condition(s)
- Treatments
- Disease-Modifying Therapy

Outcome Measures

- Expanded Disability Status Scale—A standardized measure of global neurological impairment in MS
- Health Utilities Indexⁱⁱⁱ—A multi-attribute health-status classification

A complete list of data elements that are collected by the CMSMS is available on CIHI's website.

ii. Data providers are encouraged/recommended to supply all data elements; however, only these data elements are currently mandatory to submit. To ease the initial burden of data collection, if any of the remaining data elements are missing or do not adhere to the specifications, the entire record will still be accepted into the CMSMS database.

iii. © Health Utilities Inc., Dundas, Ontario, Canada

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

Limiting Use

CIHI will limit the use of data in the CMSMS to authorized purposes, as described in Section 3.3. These include comparative analyses within and among jurisdictions; trend analyses to assess/monitor the impact of differences in policy, practices and service delivery; as well as statistics to support planning, management and quality improvement. CIHI staff 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 conducting 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 they are subsequently required to renew their commitment to privacy yearly.

Since 2009, data sets used for internal CIHI analysis purposes do not contain direct identifiers, such as unencrypted health card numbers. Health card numbers in an unencrypted form are available to CIHI staff on an exceptional, need-to-know basis only, subject to internal approval processes, as set out in CIHI's *Privacy Policy Procedures, 2010*.

Data Linkage

At the time of this assessment, there were no planned data linkages for the CMSMS. In the event that data linkages are required, the CMSMS will comply with sections 14 to 31 of CIHI's *Privacy Policy, 2010*, which govern linkage of records of personal health information.

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 not considered a disclosure; rather, it is considered a use. CIHI may return CMSMS data via its web-based eServices, which permit authorized and restricted users to access CMSMS data via industry-standard, encrypted, secure socket layer (SSL) sessions. CMSMS users may access the following:

- CMSMS extract file submission reports—Record-level reports that provide details about the outcome of file submission and data quality issues that exist in a particular submission file. Through web-based eServices applications, CIHI makes available to data providers routine reports on the outcome of their data submissions to internal CIHI applications. Only the minimum amount of data required to notify, investigate and correct the error is included in these reports. The reports are available to clients for 180 days only.

- CMSMS Online Data Entry Tool—Users may search, view, print and export their own data retained within the CMSMS. Submitted health card numbers are fully masked within the interface, except where displaying the health card number is necessary to meet the purposes of the CMSMS. Users may also generate CMSMS Own Data Reports, which are complete single-year or multi-year record-level downloads of own data retained in the CMSMS. Report generation is initiated within the CMSMS Online Data Entry Tool; however, CMSMS Own Data Reports can be retrieved only through a separate eService process requiring additional authorization. The reports are available to clients for seven days only.
- Customized record-level and aggregate data files—CIHI will provide, when requested, 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 Procedures, 2010](#) and CIHI's Methods of Dissemination Standard.

Limiting Disclosure

Public Release of CMSMS Data

As part of its mandate, CIHI publishes aggregate data only in a manner designed to minimize any risk of identification and residual disclosure. Aggregate statistics and analyses are made available on CIHI's website. This generally requires a minimum of five observations per cell.

Third-Party Data Requests

Customized de-identified record-level and/or aggregate data from the CMSMS may be requested by a variety of users, such as various levels of government, health care decision-makers and researchers.

CIHI administers a third-party data request program that contains and ensures appropriate 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. When aggregate data is not sufficiently detailed for the intended purpose, record-level 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 disclosing 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.

Data requestors are required to submit a written request. They must also sign an agreement wherein they agree to use the data for only the purpose 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 cell sizes less than five; and
- Strong encryption technology that meets or exceeds CIHI's standards where mobile computing devices are used.

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 data request form and data protection agreement signed with CIHI.

Limiting Retention

The CMSMS 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 will be addressed by the data provider or documented in data limitations documentation, which CIHI makes available to all users.

Similar to other CIHI data holdings, the CMSMS will be subject to a data quality assessment on a regular basis, based on CIHI's *Data Quality Framework*. The process of completing the framework includes numerous activities to assess the accuracy of the CMSMS data.

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. Key aspects of CIHI's system security with respect to the CMSMS are highlighted below.

System Security

CIHI has created preferred methods of collection that set out standard practices for the secure submission of data. All CMSMS data will be submitted to CIHI electronically in keeping with the *Health Data Collection Standard*.

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 made 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, securing its data holdings and protecting information with administrative, physical and technical security safeguards appropriate to the sensitivity of the information. Audits are an important component of CIHI's overall Information Security program; they are intended to ensure that best practices are being followed and 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 *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. Requests from individuals seeking access to their personal health information will be processed in accordance with sections 60 to 63 of CIHI's *Privacy Policy, 2010*.

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, who may direct an inquiry or complaint to the privacy commissioner of the jurisdiction of the person making the inquiry or complaint.

4 Privacy Assessment Summary and Conclusion

CIHI's PIA published in July 2012, and the current updated assessment of the CMSMS, concluded that mitigation measures currently in place for any identified risks are appropriately managed by CIHI and its data providers. There are no recommendations at this time. In keeping with its [Privacy Impact Assessment Policy](#), CIHI will update or renew this PIA when significant changes are made to the CMSMS.

Appendix

The following table describes personal identifiers and other data elements that could present an increased risk of direct or indirect identification of an individual, including data element definitions, information about when this data is collected and a rationale for its collection.

Element	When Collected	Reason for Collection/Comments
Organization Client Identifier ^{iv} —The person's unique identification number as assigned by the health care organization (for example, a chart number or registration number). A person with multiple records within an organization will have the same Organization Client Identifier for each record.	Initial enrolment assessment, face-to-face follow-up visits and non-face-to-face follow-up interactions	To uniquely identify a person within a source organization and to be able to link multiple records to one person.
Health Card Number ^{iv} —The person's health card number as assigned by the provincial or territorial government of residence.	Initial enrolment assessment, face-to-face follow-up visits and non-face-to-face follow-up interactions	To identify unique persons within the province or territory for the purposes of statistical analyses.
Birthdate—The year, month and day on which a person was born or is officially deemed to have been born.	Initial enrolment assessment	To calculate the onset of specific MS events, comorbidities and changes in outcomes and to track these over time; also to enable correct linkage to other data holdings in the future.
Sex—The biological sex of the person.	Initial enrolment assessment	To analyze differences in disease outcomes and to monitor disease progression according to sex.
Postal Code of Primary Residence—The postal code (assigned by Canada Post) of the person's primary residence. Primary residence can be a home or a facility.	Initial enrolment assessment and face-to-face follow-up visits	To support regional-level analysis related to health service utilization and access to services.
Health Care Provider Identifier—The unique identification number of the person's primary health care provider, as assigned by the participating organization for the visit.	Initial enrolment assessment, face-to-face follow-up visits and non-face-to-face follow-up interactions	To provide a means for the participating organization to enable reporting at a health care provider level.

Reference

1. Statistics Canada. Canadian Community Health Survey (CCHS). Ottawa, ON: Statistics Canada; 2010–2011.

iv. Data providers are encouraged/recommended to supply all data elements; however, only these data elements are currently mandatory to submit. To ease the initial burden of data collection, if any of the remaining data elements are missing or do not adhere to the specifications, the entire record will still be accepted into the CMSMS database.

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