





Primary Health Care Voluntary Reporting System Privacy Impact Assessment, January 2013



Our Vision

Better data. Better decisions. Healthier Canadians.

Our Mandate

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.

Our Values

Respect, Integrity, Collaboration, Excellence, Innovation

CIHI is pleased to publish the following Privacy Impact Assessment pursuant to its Privacy Impact Assessment Policy:

Primary Health Care Voluntary Reporting System Privacy Impact Assessment

Approved by:

Jean-Marie Berthelot Vice President, Programs Anne-Mari Phillips

Chief Privacy Officer & General Counsel

Table of Contents

Те	n Quic	k Facts About the Primary Health Care Voluntary Reporting System	. III
1	Introd	luction	1
2	CIHI's	s PHC VRS	1
	2.1	Background	1
	2.2	Description of PHC VRS Data Elements	2
3	PHC	VRS Data Collection Overview	4
4	Priva	cy Analysis	5
	4.1	Authorities Governing CIHI and the PHC VRS	5
	4.2	Principle 1: Accountability for Personal Health Information	6
	4.3	Principle 2: Identifying Purposes for Personal Health Information	7
	4.4	Principle 3: Consent for the Collection, Use or Disclosure of Personal Health Information	8
	4.5	Principle 4: Limiting Collection of Personal Health Information	8
	4.6	Principle 5: Limiting Use, Disclosure and Retention of Personal Health Information	10
	4.7	Principle 6: Accuracy of Personal Health Information	13
	4.8	Principle 7: Safeguards for Personal Health Information	13
	4.9	Principle 8: Openness About the Management of Personal Health Information	14
	4.10	Principle 9: Individual Access to and Amendment of Personal Health Information	14
	4.11	Principle 10: Complaints About CIHI's Handling of Personal Health Information	14
5	Conc	lusion	14
Αp	pendix	:: PHC VRS Data Set	15

Ten Quick Facts About the Primary Health Care Voluntary Reporting System

- Consistent with its mandate, the Canadian Institute for Health Information (CIHI)
 collaborates with jurisdictions, regions, clinicians and researchers to improve the availability
 of comprehensive and comparable primary health care (PHC) data through the Primary
 Health Care Voluntary Reporting System (PHC VRS), a pan-Canadian PHC data source,
 to support PHC performance measurement and health system improvement.
- 2. The PHC VRS collects a minimum data set of patient data extracted from the PHC electronic medical record (EMR) systems of PHC VRS participants. In the PHC VRS, data represents a range of PHC services delivered at the point of care, including information about demographics, care processes and outcomes in the areas of prevention, chronic disease management, patient safety and utilization. PHC VRS participants include PHC physicians, nurse practitioners and other team members.
- 3. One of the goals of the PHC VRS is to support and inform the implementation of the pan-Canadian PHC EMR Content Standard (PHC EMR CS) and Data Extract Specifications, which are in the process of being adopted by jurisdictions across Canada. The PHC VRS will align with this standard as it evolves to address stakeholders' priority PHC information needs.
- 4. The PHC VRS uses existing data from EMRs, so clinicians are not required to collect new data to participate.
- 5. Data is submitted directly to CIHI by PHC practices (representing clinicians), PHC networks, EMR vendors or jurisdictions (on behalf of PHC VRS participants).
- Each data provider is responsible for preparing his or her EMR data and securely submitting
 it to CIHI in compliance with CIHI's PHC VRS Submission Guide for Electronic Medical
 Record Content Standard 2.0, applicable legislation and his or her own policies.
- CIHI identifies what data is to be submitted, provides secure and appropriate methods of data submission and is responsible for any CIHI-related data management activities once data is received.
- 8. Data submission occurs through CIHI's secure electronic Data Submission Services (eDSS).
- 9. The PHC EMR CS includes 106 data elements that clinicians typically capture in their EMRs. These data elements support both primary uses of patient information (such as patient care) and health system uses (such as statistical analysis).

10. CIHI will use the PHC VRS data in accordance with its mandate to

- Support health system improvements at the practice, regional and jurisdictional levels;
- Inform the evolution of the pan-Canadian PHC EMR CS and support jurisdictional efforts to upgrade EMRs to an agreed set of specifications;
- Improve the availability, quality, comparability and meaningful use of EMR data for clinicians, jurisdictions and researchers; and
- Promote primary and health system use of EMR data that leads to practice- and system-level improvements.

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 and other health facilities, regional health authorities, medical practitioners and governments, including personal health information about patients and residents, and registration and practice information about health professionals.

The purpose of this privacy impact assessment (PIA) is to examine the privacy, confidentiality and security risks associated with the collection of primary health care (PHC) data, in both deidentified and identifiable form. 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 Primary Health Care Voluntary Reporting System (PHC VRS).

A preliminary PIA was completed in October 2010, which was specific to the pilot phase of the PHC VRS project. As a result of the success and growth of the PHC VRS, this formal PIA was completed to describe the collection of data in the pan-Canadian PHC VRS.

2 CIHI's PHC VRS

2.1 Background

CIHI's Primary Health Care Information program leads a number of initiatives, including the PHC VRS, to address priority PHC information needs by establishing new pan-Canadian data sources that can be used to better understand aspects of PHC across Canada, report on PHC indicators and inform health policy- and decision-making at various levels. CIHI collaborates with jurisdictions, regions, clinicians and researchers to improve the availability of comprehensive and comparable PHC data through the PHC VRS, a pan-Canadian electronic medical record (EMR) data source, to support PHC performance measurement and health system improvement.

Phase 1 of the PHC VRS project (January to March 2009) successfully engaged 50 PHC physicians, received and analyzed more than 70,000 unique de-identified records, pilot tested the PHC EMR Content Standard (PHC EMR CS) v1.0 and disseminated confidential feedback reports to participating PHC VRS clinicians.

Subsequently, Phase 2 of the project (ended March 2011) achieved key targets that included increasing PHC VRS participation to more than 200 physicians, resulting in a quarter of a million patient records. This phase enhanced the availability and use of EMR data through analytical products and presentations at national conferences. Lessons gathered since the inception of the project have informed the evolution of the PHC EMR CS, jurisdictional EMR specifications, quality feedback reports and future phases of the PHC VRS.

Phase 3 involves further collaboration with jurisdictions, regions, clinicians and researchers to

- 1. Increase PHC EMR data availability across Canada to support priority intra- and inter-provincial/-territorial PHC information needs and capacity;
- 2. Evolve the PHC VRS to support the implementation and refinement of the pan-Canadian PHC EMR CS;
- 3. Improve the availability, quality, comparability and meaningful use of EMR data by jurisdictions, regions, clinicians and researchers;
- 4. Promote the value of using PHC VRS data, in clinical and health system settings, which leads to support of health system planning, evaluation and improvements;
- 5. Support priority quality initiatives at the jurisdictional, regional and practice levels;
- 6. Promote adoption of the PHC VRS through analytical products (such as CIHI's eReporting tools);
- 7. Make available data and tools that add PHC quality improvement capacity; and
- 8. Respond to emerging collaborative opportunities and stakeholder information needs.

Phases 1 to 3 of the PHC VRS have focused on the collection of de-identified PHC EMR data. The collection of identifiable PHC data is planned to start in 2013 to support privacy-appropriate data linkages. Only the minimum required amount of identifiable data (such as health card number, date of birth and postal code) will be collected for linkage purposes. Potential identifiers will be anonymized prior to being used for analysis. Data submission and reporting processes have been developed and validated to ensure the safe and secure collection, processing and dissemination of both de-identified data and identifiable PHC data in accordance with CIHI's mandate.

2.2 Description of PHC VRS Data Elements

CIHI'S PHC VRS is an emerging pan-Canadian EMR data source that collects a subset of clinical and administrative data. PHC VRS participants provide CIHI with a subset of EMR data that aligns with the PHC EMR CS. This voluntary program was developed in collaboration with clinicians, jurisdictions and researchers to support improvements in PHC and the health of Canadians. Over time, the PHC VRS will continuously improve the availability of PHC information for use by jurisdictions, regions, clinicians and researchers. Currently, the PHC VRS holds data on more than 500,000 patients from more than 300 providers across multiple provinces.

The PHC EMR CS is made up of 106 data elements that are commonly captured in EMRs. The PHC VRS data represents a range of PHC services for which data can be collected and stored at the point of care in EMRs. The PHC VRS captures information about demographics, care processes and outcomes in the areas of prevention, chronic disease management, patient safety and utilization. These data elements are required to support the many facets of PHC, including treatment of illnesses, health promotion and disease prevention. These same data elements are also essential to support a range of health system management processes and improvements.

CIHI, jurisdictions and Canada Health Infowayi developed the PHC EMR CS to help PHC EMRs capture data discretely, so that high-quality, high-priority PHC data can be made available to support both patient care and health system management needs. The *Draft Pan-Canadian* PHC EMR Content Standard, Version 2.1 and PHC Reference Sets are part of an ongoing effort to support improvements in PHC. CIHI, in collaboration with Canada Health Infoway, released an implementation guide, Data Extract Specifications (DES) and data models (conceptual and logical) related to the PHC EMR CS. These products include information on the Reference Sets developed by Canada Health Infoway to support interoperability. The Reference Sets provide vendors and EMR users with a list of standardized, coded terms and values that can be stored in and extracted from EMR systems in the PHC setting; they make up part of the PHC EMR CS. These Reference Sets can also be leveraged by other clinical applications such as eReferrals, chronic disease management and electronic health records (EHRs). The implementation guide and data models are available on CIHI's website and Canada Health Infoway's Infocentral website. The DES is also available on Infocentral for members of the Infoway Standards Collaborative. Efforts are now under way to maximize the implementation of the PHC EMR CS in PHC EMRs across Canada.

The appendix provides an overview of the EMR data set submitted to CIHI's PHC VRS.

Collecting de-identified PHC data means that

- 1. The health card number (HCN) is replaced with a meaningless EMR system—generated number at the time of extraction;
- 2. The date of birth is truncated to month and year;
- 3. The postal code is truncated to the first three characters; and
- 4. Health care providers are assigned meaningless EMR system–generated identifiers.

Collecting identifiable PHC data means that the PHC VRS will include

- 1. Clients' HCNs, full dates of birth and postal codes; and
- 2. Health care providers' identifier numbers in accordance with the PHC EMR CS.

The PHC VRS will continue to evolve to support future iterations of the PHC EMR CS and in response to stakeholders' needs.

i. Other stakeholders include clinicians, standards organizations, vendors and researchers.

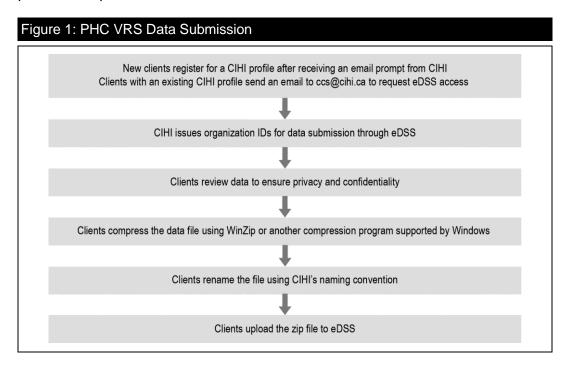
3 PHC VRS Data Collection Overview

Prior to PHC VRS data submission, a data sharing agreement with the participating clinician or site is established, following which CIHI works with each data provider to assess the availability and alignment of his or her EMR data to those elements identified in the *PHC VRS Submission Guide for Electronic Medical Record Content Standard 2.0*. This document was developed to support the data extraction, verification and submission processes for the PHC VRS.

A subset of priority EMR data deemed important by clinicians, jurisdictions, regions and researchers is extracted from existing EMR systems, in accordance with the PHC EMR CS; therefore, clinicians are not required to collect new data to participate in the PHC VRS. Participating clinicians gain access to their own EMR data and comparative reports to assess multiple dimensions of quality for patient care, quality improvement and practice management.

Data is submitted to CIHI directly by PHC practices (representing clinicians), networks, EMR vendors, regions or jurisdictions (on behalf of the PHC VRS participants). Each data provider is responsible for securely preparing and submitting his or her EMR data to CIHI in compliance with the submission guide, applicable legislation and his or her own policies. In some cases, PHC practices/networks may have their EMR vendors submit data to CIHI. CIHI identifies what data is to be submitted (see the appendix), provides secure and appropriate methods of data submission and is responsible for CIHI-related data management activities once data is received.

Data submissions occur through CIHI's secure electronic Data Submission Services (eDSS). To access eDSS, primary health care organizations (practice sites or networks/jurisdiction delegates) register for a CIHI profile prior to submitting PHC VRS data. The steps required for PHC VRS data submission are outlined in Figure 1. These steps are consistent with CIHI's policies and processes.



4 Privacy Analysis

4.1 Authorities Governing CIHI and the PHC VRS

General

CIHI adheres to its *Privacy Policy on the Collection, Use, Disclosure and Retention of Personal Health Information and De-Identified Data, 2010 (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.

While collecting non-identifiable data generally does not raise any privacy issues, as CIHI moves forward with collecting identifiable PHC data, specific legislative authority for this collection will be determined in consultation with the relevant bodies.

Agreements

Data collection agreements are currently in place between CIHI and data providers who submit PHC data to the PHC VRS. These data collection agreements establish the responsibilities of CIHI and each data provider regarding data collection, use and disclosure, in compliance with privacy best practices.

With respect to the collection of personal health information in Ontario, CIHI has been designated as a prescribed entity for the purposes of Section 45(1) of Ontario's *Personal Health Information Protection Act, 2004* (PHIPA). This designation allows CIHI to receive and use personal health information in accordance with PHIPA in Ontario. This designation carries strict responsibilities regarding CIHI's adherence to its privacy policies, practices and procedures regarding the collection, use and disclosure of personal health information in its custody.

As a prescribed entity, CIHI is subject to the oversight of the Information and Privacy Commissioner of Ontario. As part of this oversight, the commissioner audits CIHI's information practices every three years. CIHI's data sharing agreements, such as the one with participating PHC VRS clients, are included within the scope of the commissioner's audit.

In addition to the above, the commissioner also establishes a variety of requirements that prescribed entities must meet. These requirements address many aspects of a prescribed entity's activities, including its data sharing agreements.

Specifically, when a prescribed entity enters into a data sharing agreement that governs the collection, use or disclosure of personal health information in Ontario, the commissioner requires that the agreement contain certain provisions:

- A. When collecting, using or disclosing personal health information under an agreement, CIHI shall comply with PHIPA and the PHIPA regulation.
- B. As a prescribed entity, CIHI may
 - i. Collect personal health information pursuant to Section 45(5) of PHIPA;
 - ii. Use personal health information for the purposes for which CIHI received it, pursuant to Section 45(6) of PHIPA; and
 - iii. Disclose personal health information to the data provider who collected the personal health information from the individual, pursuant to Section 18(5) of the PHIPA regulation.

Before PHC VRS data providers in Ontario begin submitting personal health information, as described above, they will sign a new data collection agreement that reflects Ontario's rules for the collection, use and disclosure of personal health information as well as de-identified PHC data. As clinicians outside of Ontario begin submitting personal health information, new or updated data collection agreements will be required and implemented appropriately.

Where necessary, CIHI has service agreements with EMR vendors on behalf of PHC VRS clinicians that outline vendors' responsibilities for confidentiality with respect to data extraction and submission.

4.2 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 PHC VRS is managed by the Director, Primary Health Care Information and Clinical Registries, within CIHI's Programs division.

The following table identifies positions within CIHI with responsibilities for the PHC VRS 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 PHC VRS	
Director, Primary Health Care Information and Clinical Registries	Responsible for strategic and operational decisions about the PHC VRS and for ensuring its continued successful development and operational maintenance	
Manager, Primary Health Care Information	Responsible for the development and ongoing management of the PHC VRS, making operational decisions about the PHC VRS, supporting the director and the PHC VRS Steering Committee, and consulting internally and with PHC VRS clients, as appropriate	
Project Leads, PHC VRS (Operations and Analytics)	Responsible for the development, implementation and operations of the PHC VRS; supporting the manager, director and PHC VRS Steering Committee; and consulting internally and with PHC VRS clients and vendors, as appropriate	
Vice President and Chief Technology Officer Responsible for the strategic direction and overall operations/implement of CIHI's technological and security solutions		
Chief Information Security Officer	Responsible for leading CIHI's Information Security program, consistent with the corporate Strategic Plan, and CIHI's Privacy Program to ensure that the organization's security principles, policies, procedures and practices support the protection of the organization's information	
Chief Privacy Officer	Responsible for the strategic direction and overall implementation of CIHI's Privacy Program	
PHC VRS Internal Project Steering Committee	Provides the PHC VRS team with overarching strategic guidance, ensures stakeholder interests are addressed and discusses/resolves operational issues, as required	
PHC VRS Participants and Data User Community	Provide input to PHC VRS studies, reports and methodologies	

4.3 Principle 2: Identifying Purposes for Personal Health Information

The PHC VRS is an emerging pan-Canadian EMR data source that promotes

- The use and understanding of the PHC system in connection with the broader health system across Canada; and
- The production of PHC indicators to support decision-making at various levels.

The collection of personal health information will enable clinicians and health system decision-makers to gain insight on the relationships between PHC and the outcomes of this care, such as avoidable hospitalizations, readmissions and primary care—sensitive conditions. Identifiable data is necessary to enable linkage for health system analysis across the care continuum and to expand reporting back to clinicians and others (such as on equity, access to care and predictive risk analysis). For more information, please refer to CIHI's PHC web page.

These purposes are stated in more detail on CIHI's PHC web page, as well as in this PIA.

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

CIHI obtains data for purposes of the planning and management of the health system, including statistical analysis and reporting, under specific legislative authority and/or by legal agreements governing the flow of data. PHC VRS data providers may disclose de-identified data to CIHI without individual consent. In the case of identifiable data, where legislative authority exists for the disclosure of personal health information without consent, data providers may provide identifiable PHC data to CIHI's PHC VRS for use consistent with its mandate and core functions.

4.5 Principle 4: Limiting Collection of Personal Health Information

4.5.1 Data Minimization

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 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 pan-Canadian PHC EMR CS helps CIHI apply the data minimization principle to the PHC VRS. The PHC EMR CS directly supports patient care improvements through both the development of more effective EMRs and health system use of EMR data. The standard was developed through a broad consultation process that engaged clinicians, jurisdictional representatives, standards experts, researchers and vendors to obtain their valuable expertise and insight on the PHC EMR CS and its implementation.

The PHC EMR CS includes 106 data elements that clinicians already commonly capture in EMRs. These data elements support both primary uses of patient information (such as patient care) and secondary uses (such as statistical analysis).

Many of the data elements in the PHC EMR CS are necessary for populating and reporting on a subset of the PHC quality indicators to improve the understanding of PHC across the country and to inform health policy- and decision-making at various levels. Examples of how PHC indicators can be used at the system level include

- Supporting population-based policy development and planning;
- Assessing the performance of the health care system;
- Monitoring changes over time and variations across health regions;
- Providing evidence to inform health programs, policies and funding decisions; and
- Identifying levels of and gaps in the health and well-being of a population and community.

At the organization and practice levels, indicators can be used to support the development and evaluation of quality improvement initiatives. Users of PHC indicators at these levels include jurisdictional ministries of health, regional health authorities and health system planners, provincial health quality councils, PHC providers, PHC organizations, professional associations that include PHC providers, and health researchers. For these users, PHC indicators

- Provide a basis for comparison;
- Support quality improvement programs, planning and evaluation;
- Support program management and performance measurement; and
- Identify opportunities for improvement (for example, gaps in the health and well-being of the practice population).

In addition to the data elements needed to support quality improvement reporting, some data elements provide an understanding of the practice's context and inform clinical care and patient program planning for high-risk populations. These data elements are intended to enable further understanding of how specific socio-economic factors, such as income or homelessness, affect chronic disease—related outcomes. Such information is important to health care policy development and health system planning; these data elements include Client Highest Education, Client Housing Status, Client Language, Service Delivery Location, Encounter Data, Family History Data and Allergy Data.

The PHC EMR CS includes Patient Identifier as a data element. During the de-identified data phases of the PHC VRS project, data providers created a meaningless EMR system—generated number as the Patient Identifier. As data providers begin submitting identifiable PHC data, CIHI will collect patients' HCNs, full dates of birth and postal codes; however, names and addresses will not be collected. Prior to analyzing data at CIHI or releasing data, identifiers will be removed or de-identified.

With respect to information that identifies health care providers, CIHI plans to collect a unique provider identifier. During the de-identified data phases of the PHC VRS project, data providers created a meaningless EMR system—generated number as the health care provider identifier.

4.5.2 Free-Text Data Collection: Current Form

All EMR systems support data capture in free-text fields. The properties of these fields vary within and across vendor systems in terms of system-enforced input restrictions.

Data collected in the PHC VRS includes the content of some of these free-text fields. CIHI is working with clinicians and jurisdictions to reduce the need to extract free text for the PHC EMR CS data elements, such as health conditions, reasons for encounters and interventions. CIHI is collaborating with jurisdictions to support the adoption and implementation of the pan-Canadian PHC EMR CS and use of the PHC VRS to demonstrate the value of standardized, structured data. Implementing the PHC EMR CS will increase the value and quality of EMR data across Canada while also reducing the reliance on free-text data in this priority data source.

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

4.6.1 Limiting Use

CIHI limits the use of personal health information to authorized purposes; only authorized users have access. CIHI uses PHC VRS data in a manner consistent with its mandate and core functions, as follows:

- CIHI collects only personal health information and de-identified data that is reasonably required for clinical management and health system uses, including statistical analysis and reporting; and
- CIHI collects only personal health information and de-identified data that is reasonably
 required 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 will use the data collected through the PHC VRS to

- Improve the availability, quality, comparability and meaningful use of EMR data for jurisdictions, regions, clinicians and researchers;
- Support quality improvement at the practice, regional and jurisdictional levels;
- Inform the evolution of the pan-Canadian PHC EMR CS and support jurisdictional efforts to upgrade EMRs to an agreed set of specifications; and
- Promote primary and health system use of EMR data that leads to practice- and system-level improvements.

CIHI limits access to and use of the PHC VRS data for authorized purposes; only authorized CIHI staff and authorized external users have access to this data. PHC VRS staff are permitted to access and use data holdings containing de-identified EMR data for the purposes identified in the data collection agreement only. Access to and use of EMR data by other CIHI staff outside of CIHI's PHC VRS team, which may be required to conduct CIHI's data quality assessments, analysis and reporting, or application development, is done in compliance with CIHI's *Privacy Policy, 2010* and related procedures. Prior to granting access to other CIHI staff, justification for use and manager approval is required. Employee access to the PHC VRS is reviewed and validated annually by the program manager. External users of PHC VRS data follow processes consistent with CIHI's data access management for other CIHI data sources.

Data Linkage

Data linkage is an important technique in the development, production, evaluation and analysis of statistical data that will shed light on important health and health system issues facing Canadians. For the PHC VRS, CIHI may link personal health information with information from across health care sectors via data holdings available at CIHI. These linkages are necessary to gain a better understanding of the delivery and outcomes of PHC services in relation to the broader health system. When performing data linkages, CIHI complies with its *Privacy Policy*, 2010. Linkage is facilitated through the use of CIHI's Client Linkage Index, which is based on an encrypted HCN.

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 perform the procedure without using names or unencrypted personal HCNs. 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 sections 23 and 24 of CIHI's *Privacy Policy*, 2010, as follows:

- 23. The individuals whose personal health information is used for data linkage have consented to the data linkage; or
- 24. All of the following criteria are met:
 - a. The purpose of the data linkage is consistent with CIHI's mandate;
 - b. The public benefits of the linkage significantly offset any risks to the privacy of individuals;
 - c. 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;
 - d. 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; or
 - e. 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; and
 - f. The data linkage has demonstrable savings over other alternatives or is the only practical alternative.

Section 28 of CIHI's *Privacy Policy*, 2010 sets out the requirement that CIHI will destroy personal health information and de-identified data in a secure manner, using destruction methodologies appropriate to the format, media or device, such that reconstruction is not reasonably foreseeable.

Section 29 of CIHI's *Privacy Policy, 2010* further requires that, for linked data, secure destruction will 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. For linked data resulting from an ongoing program of work at CIHI, secure destruction will occur when the linked data is no longer required to meet the identified purposes, in a manner consistent with CIHI's Information Destruction Standard. This requirement applies to data linkages for both CIHI's own purposes and third-party data requests.

4.6.2 Limiting Disclosure

Section 37 of CIHI's *Privacy Policy*, 2010 states that CIHI discloses health information and analyses on Canada's health system and the health of Canadians in a manner consistent with its mandate and core functions. These disclosures typically fall into one of four categories:

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

Prior to disclosure, CIHI reviews the requests to ensure that the disclosures are consistent with Section 37 of its *Privacy Policy*, 2010, and meet the requirements of applicable legislation.

For the PHC VRS, participating sites will receive comparative feedback reports (containing prevalence rates, clinical process measures and other indicators on quality of care) for the purposes of improving quality of care and optimizing practice management. Jurisdictions may receive aggregate population-level reports for the purposes of health system management and planning. Analytical reports may be released to the public to provide a high-level view of particular aspects of PHC in Canada. A typical analysis could include an overview of the complexities of care for patients with diabetes and other comorbid conditions. Furthermore, the PHC VRS supports the implementation of the PHC EMR CS and offers lessons for jurisdictions and vendors.

CIHI will respond to requests for record-level and aggregate data per its third-party data request process. In addition, requests for record-level PHC VRS data will be considered on a special case-by-case basis until such time as most of the data complies with the PHC EMR CS, which will ensure higher data quality and consistency.

4.6.3 Limiting Retention

The PHC VRS database forms part of CIHI's information holdings; consistent with its mandate and core functions, CIHI retains such information for as long as necessary to meet the identified purposes. Specifically, the Primary Health Care Data Collection Agreement states that CIHI shall retain the personal health information only for as long as necessary to meet the purposes of the program under the agreement and in accordance with CIHI's *Privacy Policy*, 2010.

4.7 Principle 6: Accuracy of Personal Health Information

CIHI has a comprehensive data quality program, as described in the *CIHI Data Quality Framework*. This framework provides an objective approach to applying consistent data-flow processes that focus on data quality priorities, assessing the data quality of a data holding and producing standard data holding documentation with the ultimate goal of continuous data quality improvement for CIHI's data holdings.

4.8 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 PHC VRS are highlighted below.

System Security

CIHI has created preferred methods of data collection that set out standard practices for the secure submission of data. All PHC VRS data is submitted to CIHI electronically in accordance with CIHI's Health Data Collection Standard. In accordance with their agreements with CIHI, each data provider is responsible for extracting data before electronically submitting it to CIHI through eDSS.

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, annual 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 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, 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.

4.9 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 on its corporate website. As well, this PIA will be accessible on CIHI's website (www.cihi.ca).

4.10 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.

4.11 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.

5 Conclusion

This PIA summarizes CIHI's assessment of the privacy implications of the PHC VRS. No privacy risks have been identified.

Appendix: PHC VRS Data Set

Stakeholder engagement and input continues to inform and refine the pan-Canadian PHC EMR CS. Future versions of the PHC EMR CS will inform the direction of EMR data extractions and submissions to the PHC VRS.

PHC VRS Data Elements and Corresponding Definitions

Number	Common Name	Definition
1	Patient Identifier	A unique identifier assigned to the Client.
2	Patient Identifier Type	The type of Client identifier (for example, jurisdictional health care identifier).
3	Patient Identifier Assigning Authority	The legal entity/organization responsible for assigning the Client identifier.
4	Patient Date of Birth	The Client's date of birth.
5	Patient Gender	The reported gender category of the Client at a given point in time; used for administrative purposes.
6	Patient Highest Education	The highest level of education completed by the Client.
7	Patient Housing Status	The housing status of the Client.
8	Patient Primary Language	The preferred spoken language of the Client.
9	Patient Status	Whether or not the PHC Provider considers the Client to be actively seeking PHC services through him or her.
10	Patient Date of Death	The Client's date of death.
11	Patient Rostered Start Date	The date the Client was included on the roster.
12	Patient Rostered End Date	The date the Client was removed from the roster.
13	Patient Ethnicity	The self-reported ethnic group to which the Client belongs; used for administrative purposes. As such, Patient Ethnicity refers to a person's roots and should not be confused with his or her citizenship or nationality.
14	Patient Postal/Zip Code	The postal code of the Client's permanent residence.
15	Clinician Last Name	The Provider's legal family name.
16	Clinician First Name	The Provider's legal given name.
17	Clinician Middle Name	The Provider's middle name.
18	Clinician Identifier	A unique identifier assigned to the Provider.
19	Clinician Identifier Type	The type of Provider identifier.
20	Clinician Identifier Assigning Authority	The legal entity responsible for assigning the unique identifier to the Provider.
21	Clinician Role	The role of the Provider in relation to his or her participation in a specific health care event.
22	Clinician Expertise	The expertise of the Provider.
23	Service Delivery Identifier	The unique identifier of the practice (Service Delivery Location) where the Client received care.
24	Service Delivery Name	The name of the practice (Service Delivery Location) where the Client received care.
25	Service Delivery Type of Services	The type of location (Service Delivery Location) where the Client received care.

Number	Common Name	Definition
26	Service Delivery Postal Code	The postal code of the Service Delivery Location where the Client received the PHC service.
27	Appointment Creation Date	The date on which an appointment was created for the Client by the Provider (or his or her staff).
28	Reason for Visit	The reason for the encounter, as conveyed by the Client.
29	Visit Date	The date the Client had an encounter with the Provider.
30	Visit Type	A description of the type of contact between the Provider and the Client for a registered encounter or visit.
31	Payment Source	The source of Provider payment for the encounter.
32	Payment Type	The type of reimbursement paid to the Provider for the encounter.
33	Billing Code	The jurisdictional billing code.
34	Family Member Health Concern	The relevant health concerns of a person sharing common ancestry with the Client.
35	Family Member Social Behaviour(s)	The relevant social behaviours of a person sharing common ancestry with the Client. This can include risk factors such as tobacco use, alcohol use and abuse of illicit or prescription drugs.
36	Family Member Interventions (Treatments)	The relevant interventions performed on a person sharing common ancestry with the Client.
37	Family Member Relationship to Patient	The relationship between the Client and a person who shares common ancestry.
38	Family Member Health Concern, Intervention or Social Behaviour Age at Onset	The age of the family member (in years) when the health concern, intervention or social behaviour started.
39	Family Member Health Concern, Intervention or Social Behaviour Start Date	The date on which the health concern, intervention or social behaviour started for the family member.
40	Family Member Health Concern, Intervention or Social Behaviour End Date	The date on which the health concern, intervention or social behaviour ended for the family member.
41	Family Member Deceased Date	The date on which the family member died.
42	Family Member Cause of Death	The clinical cause of death of the family member.
43	Family Member Ethnicity	The ethnicity of the family member.
44	Health Concern	The Client's relevant clinical problems, conditions, diagnoses, symptoms, findings and complaints.
45	Health Concern Date of Onset	The date on which the Client's health concern started.
46	Health Concern Date of Resolution	The date on which the Client's health concern ended.
47	Social Behaviour	A type of Client social behaviour that increases the possibility of disease or injury for the Client. This can include risk factors such as tobacco use, alcohol use and abuse of illicit or prescription drugs.
48	Social Behaviour Date of Onset	The effective date the Client started the social behaviour.
49	Social Behaviour Date of Resolution	The effective date the Client ceased the social behaviour.
50	Allergy/Intolerance Type	The type of allergy or intolerance a Client has.
51	Allergy/Intolerance Agent	The specific allergen or other agent/substance to which the Client has an allergic reaction.
52	Allergy/Intolerance Severity	The level of severity a Client has in relation to an allergy or intolerance.
53	Allergy/Intolerance Status	Whether an allergy/intolerance is active or inactive.

Number	Common Name	Definition
54	Allergy/Intolerance Date of Onset	The date on which the recorded allergy/intolerance is considered active.
55	Allergy/Intolerance Date of Resolution	The date on which the recorded allergy/intolerance is no longer considered active.
56	Systolic Blood Pressure	The Client's systolic blood pressure value (in mmHg), as measured. The unit of measure (mmHg) is implied when representing the value.
57	Diastolic Blood Pressure	The Client's diastolic blood pressure value (in mmHg), as measured. The unit of measure (mmHg) is implied when representing the value.
58	Blood Pressure Body Location	The anatomical location where blood pressure was measured on the Client's body.
59	Blood Pressure Body Position	The position the Client's body was in when blood pressure was measured (such as standing, sitting or lying).
60	Blood Pressure Representative Reading	Whether the Client's blood pressure reading is representative of the Client's current health condition.
61	Height	The height of the Client, as measured.
62	Height Unit of Measure	The unit of measure used to capture the Client's height.
63	Weight	The weight of the Client, as measured.
64	Weight Unit of Measure	The unit of measure used to capture the Client's weight.
65	Waist Circumference	The waist circumference of the Client, as measured.
66	Waist Circumference Unit of Measure	The unit of measure used to capture the Client's waist circumference.
67	Clinician Assessment	The Provider's professional opinion of the most relevant clinical findings related to the Client's encounter. The most relevant clinical findings for the encounter can include diagnoses and symptoms.
68	Intervention (Treatment)	The services/activities performed or intended to be performed by the PHC Provider, as well as interventions performed by other Providers for the Client (referral).
69	Intervention (Treatment) Date	The date the intervention was performed or intended to be performed by the Provider for the Client.
70	Intervention (Treatment) Refusal Reason	The reason the Client refused an intervention.
71	Lab Test Ordered	The lab test ordered by the Provider for the Client.
72	Lab Test Ordered Date	The date the lab test was ordered by the Provider.
73	Lab Test Performed Date	The date the lab test was performed.
74	Lab Test Name	The name of the lab test performed.
75	Lab Test Result Value	The result of the lab test.
76	Lab Test Result Unit of Measure	The unit of measure used for the lab result for the lab test performed.
77	Lab Test Result Low Range	The low end of a normal reference range for a lab result for a particular test performed in a particular lab.
78	Lab Test Result Unit of Measure	The unit of measure associated with the Lab Test Result Low Range number.
79	Lab Test Result High Range	The high end of a normal reference range for a lab result for a particular test performed in a particular lab.

Number	Common Name	Definition
80	Lab Test Result Unit of Measure	The unit of measure associated with the Lab Test Result High Range number.
81	Diagnostic Imaging Test Ordered	The type of diagnostic imaging test ordered by the Provider for the Client.
82	Diagnostic Imaging Test Ordered Date	The date the diagnostic imaging test was ordered by the Provider.
83	Diagnostic Imaging Test Performed Date	The date the diagnostic imaging test was performed.
84	Referral	The type of service required for the Client.
85	Referral Requested Date	The date the referral request was created by the PHC Provider.
86	Referral Occurred Date	The actual date the Client had the encounter with the referred-to Provider.
87	Prescribed Medication	The medications prescribed (or intended to be prescribed) to the Client.
88	Prescription Date	The date the prescription for the medication was created for the Client.
89	Prescription Expected Completion Date	The date the prescribed medication is expected to be finished.
90	Prescription Stop Date	The last date the Client took the prescribed medication.
91	Medication Strength	The potency of the drug/chemical, usually measured in metric weight (for example, micrograms, milligrams or grams) and described as the strength of the product's active (medicinal) ingredient.
92	Medication Strength Unit of Measure	The unit of measure for Medication Strength.
93	Medication Dosage	The measured portion of a drug to be taken at any one time; pertains to the drug prescribed.
94	Medication Dose Unit of Measure	The unit of measure of a drug dose taken at any one time.
95	Medication Form	The physical configuration, presentation or state of matter of any given drug product; the dosage form in which the medication is administered (for example, tablet, liquid, suppository or solution).
96	Medication Frequency	The number of occurrences within a given time period that a dose of a drug is to be administered.
97	Medication Route	The part of the body on which, through which or into which a drug product is to be introduced. A drug product can have more than one route of administration.
98	Medication Number of Repeat(s)/Refill(s)	The number of times the prescription can be used to refill the prescribed medication.
99	Medication Not Prescribed Reason	The reason why a preferred medication was not prescribed to a Client.
100	Medication Compliance	Whether or not the Client has been administering the prescribed medication(s) as instructed.
101	Medication Dispensed	The medication that was dispensed to the Client.
102	Medication Dispensed Date	The date the medication was dispensed to the Client.
103	Vaccine Administered	The name of the vaccine that was administered to the Client.
104	Vaccine Administered Date	The date the vaccine was administered to the Client.
105	Vaccine Administered Lot Number	The batch identification number of the vaccine.
106	Reason Vaccine Not Given	The reason a vaccine was not administered to a Client.

All rights reserved.

The contents of this publication may be reproduced unaltered, in whole or in part and by any means, solely for non-commercial purposes, provided that the Canadian Institute for Health Information is properly and fully acknowledged as the copyright owner. Any reproduction or use of this publication or its contents for any commercial purpose requires the prior written authorization of the Canadian Institute for Health Information. Reproduction or use that suggests endorsement by, or affiliation with, the Canadian Institute for Health Information is prohibited.

For permission or information, please contact CIHI:

Canadian Institute for Health Information 495 Richmond Road, Suite 600 Ottawa, Ontario K2A 4H6

Phone: 613-241-7860 Fax: 613-241-8120

www.cihi.ca copyright@cihi.ca

© 2013 Canadian Institute for Health Information

Cette publication est aussi disponible en français sous le titre Évaluation des incidences sur la vie privée du Système de déclaration volontaire des soins de santé primaires, janvier 2013.

Talk to Us

CIHI Ottawa

495 Richmond Road, Suite 600 Ottawa, Ontario K2A 4H6 Phone: 613-241-7860

CIHI Toronto

4110 Yonge Street, Suite 300 Toronto, Ontario M2P 2B7 Phone: 416-481-2002

CIHI Victoria

880 Douglas Street, Suite 600 Victoria, British Columbia V8W 2B7

Phone: 250-220-4100

CIHI Montréal

1010 Sherbrooke Street West, Suite 300 Montréal, Quebec H3A 2R7 Phone: 514-842-2226

CIHI St. John's

140 Water Street, Suite 701 St. John's, Newfoundland and Labrador A1C 6H6 Phone: 709-576-7006

