PHIA Review Submission

Newfoundland & Labrador
Centre for
Health Information

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1 Introduction

The current *Personal Health Information Act* (PHIA) was proclaimed five years ago on April 1, 2011. As per section 91 the PHIA is to be reviewed five years after its proclamation.

The NL Centre for Health Information (Centre) is a crown corporation of the provincial government. The Centre's objective is to assist individuals, communities, health service providers and policy makers at federal, provincial and regional levels in making informed decisions to enhance the health and well-being of persons in the province by providing a comprehensive province-wide information system.

The Centre has established many information networks including those that form the provincial electronic health record. The Centre is also responsible for gathering information from other stakeholders in the provincial health system, processing and analyzing information and providing it to key stakeholders.

Protecting the personal health information in the custody or control of the Centre is our top priority. The Centre relies on the CSA Privacy Principles as the framework for our privacy program and PHIA provides clarity on the details of protecting personal health information.

This submission to the PHIA Review Committee was written based on feedback provided by individual employees of the Centre, meetings with departments who interact with the PHIA, and observations by privacy team members.

2 Part 1: Purpose, Interpretation and Application

2.1 Interpretation (s.2)

Information Network

PHIA does not provide an interpretation of what constitutes an "information network". The term, "information network" is introduced in Section 39(4)(c) by specifying that a disclosure of personal health information to an information network is permitted for health related purposes. However, an approach to designating an information network in the regulations is not provided.

The Centre suggests that some consideration be made for providing what constitutes an information network.

Research

The definition of "research" in PHIA is very broad, while the definition in the *Health Research Ethics Act* specifies "health research involving human subjects". PHIA requires research approval by the Research and Ethics Board (REB) before any disclosures of personal health information. For consistency, the definition for research should align.

Evaluation

The term evaluation is used in PHIA in relation to "management, evaluation and monitoring of the allocation of resources, health system planning and delivery of health care services" and also with respect to the evaluation of research. It would be valuable if there was some interpretation provided on what constitutes evaluation, in both instances.

Person

The PHIA refers to "person" but does not offer an interpretation of what is considered a person. The Centre suggests including an interpretation such as that in the *Access to Information and Protection of Privacy Act.*

2.2 Custodian (s.4)

The Centre is a custodian of personal health information in its custody or control as a result of or in connection with the performance of its powers or duties. The Centre looks to its incorporating legislation, the *Centre for Health Information Act,* to clarify what "powers or duties" the Centre is responsible for. Through our interpretation, that would include the creation of information networks that support decision making to enhance health and well-being of persons in the province.

The Centre believes that the designation of custodian is appropriately applied and supports the Centre's vision of improved health through quality health information.

2.3 Personal Health Information (s.5)

Genetic Information

Section 5(1) (a) of PHIA defines personal health information as the physical or mental health of the individual, including information respecting the individual's health care status and history and the health history of the individual's family. The Centre is of the opinion that genetic information should be explicitly included within the definition of personal health information. Other provisions such as 5(1)(c) account for identifying information that relates to the donation by an individual of a body part or bodily substance, including information derived from the testing or examination of a body part or bodily substance. However, the term donation can be interpreted in many ways and may not include genetic information.

The Centre would like the PHIA Review Committee to update the definition of personal health information to include a specific reference to genetic information.

Identifying Information

Generally, when personal health information has been stripped of identifying information, it is referred to as de-identified. However, organizations that retain the de-identification code following this process are considered to hold identifiable information based on the interpretation of identifying information in PHIA[1].

The Centre considers all record-level personal health information to be identifiable. Newfoundland and Labrador has a small population and even de-identified data could potentially be utilized, either alone or together with other information, to identify an individual.

The lack of consistent interpretation of the definition of identifying and de-identified information results in inconsistent safeguarding of data by different custodians.

The Centre proposes that PHIA be modified to take into consideration the nuances for collecting, using, disclosing and retaining information that is considered de-identified.

Similarly, the Centre would like consideration to be given to providing a definition of "aggregate information" and support for the use of aggregate information be included in PHIA. Alberta has included a definition and defined how aggregate information should be treated. [1]

Aboriginal Personal Health Information

The Centre does have custody or control of some personal health information belonging to members of aboriginal communities. The Centre recognizes that aboriginal peoples have unique privacy concerns which may impact the expectations of how personal health information is collected, used or disclosed. It would be valuable if some clarification was provided on addressing the needs of aboriginal people.

3 Part II: Practices to Protect Personal Health Information

3.1 Information Manager (s.22)

Alberta[1], and Saskatchewan[2] have provisions in their legislation that demonstrate that a custodian may act as an Information Manager for another custodian. These provisions specify that when a custodian is acting as an Information Manager they do not become custodian of that information.

The Centre for Health Information has been asked to "manage" information for other custodians in the past including datasets from research, databases of information not related to the Centre's objectives, or other custodians request to use the Centre's technological resources to store data.

The Centre respectfully submits that the Information Management provision in PHIA be modified to reflect these types of relationships. This would facilitate the Centre supporting other custodians and clarify the responsibilities of each party.

4 Part III: Consent

The Centre asserts that the provisions for consent within PHIA support the ongoing establishment of the provincial electronic health record while protecting the privacy of individuals.

5 Part IV: Collection, Use and Disclosure of Personal Health Information

5.1 Disclosure for Health Related Purposes (s. 39)

Electronic Health Record (EHR)

Currently Section 39(4)(c) requires the designation of an information network to facilitate the creation of an electronic record of personal health information. The information networks currently established are:

- Pharmacy Network (Pharmacy Network Regulations)
- Picture Archiving and Communication System
- Laboratory Information System

However, no guidance has been given to define how and when an information network is designated.

Other provinces have provisions for the establishment of electronic health records. This provision in PHIA does not provide the general public information on what an information network is, and what it means to construct or create an integrated electronic record.

Legislation in other provinces, notably, Alberta and Ontario distinctly provision for their provincial electronic health record. These sections clearly outline the collections, and disclosures of information, and consent provisions.

Modifying this provision, or creating a new provision would accomplish several things. Most importantly, it will further enable the Centre to be open and transparent about the electronic health record. The Centre provides information on our corporate website in an effort to educate the public on the EHR. A section dedicated within the legislation to the EHR will ensure that the public and other custodians are aware of

[1] S.66(7) *The Health Information Act*

[2] S.18(5) *The Health Information Protection Act.*

the importance of the EHR, and clarify any confusion on its operation. As the information contained in the EHR becomes more complete, more public interest will be generated.

Registries

Section 39(4)(d) allows for the disclosure of information to a registry. Currently, custodians wanting to create and maintain a registry would need to be designated as such in the regulations, however the regulations do not list any custodians nor additional information about the process.

The Centre recommends the PHIA Review Committee consider adding details within the PHIA or PHIA Regulations around the requirements of establishing, and maintaining a registry.

Disclosure for Evaluation purposes

Section 39(1)(d) states that a custodian may disclose personal health information without the consent of the individual who is the subject of the information for the purpose of delivering, evaluating or monitoring a program of the custodian that relates to the provision of health care or payment for health care. However, if a non-custodian intends to evaluate a program for which they are not the custodian of then this is not permitted under PHIA. The Centre requests that the PHIA Review Committee provide clarity on the role of non-custodians in conducting evaluations of programs for which they are not the custodian.

5.2 Disclosure for Research Purposes (s.44)

PHIA has a very succinct provision relating to disclosure of health information for research purposes. There are many examples of research provisions in health privacy legislation that are more prescriptive in nature.

The Centre would like consideration to be given to expanding the research provision to include specifics such as:

- Requirements for researchers submitting applications to custodians;
- Considerations for custodians prior to disclosure; and
- Requirements for custodians who conduct research using data in their custody or control.

Including specific considerations for the disclosure of personal health information for research will ensure all custodians are treating these requests equally.

Delisting of Custodians

The Centre discloses data to researchers regularly as part of a secondary review process. There are tiers of trust models within the review process and researchers representing other custodians are treated with a higher degree of trust. For example, if a researcher from Memorial University requests data from the Centre, the risk associated with disclosing data to him/her is considered lower than if the data was disclosed to an unaffiliated researcher since custodians are required to protect personal health information in accordance with PHIA. If a custodian designated under PHIA, were to be delisted or if their status changed, that would impact the disclosure of data to researchers affiliated with that organization.

6 Part V: Access to and Correction of a Record of Personal Health Information

The Centre has no concerns regarding the provisions for access to and correction of a record of personal health information in PHIA.

7 Regulations

Currently there are two sets of regulations, Pharmacy Network and Personal Health Information Act. These should be combined for ease of use.

8 Conclusion

The Personal Health Information Act has served the province of Newfoundland and Labrador well over the past five years. There are some provisions that could be amended to better suit the needs of the population and clarifications of what is meant by some provisions would be valuable. Resources to accompany the legislation are needed however, there should be clear direction on the process for becoming an accepted entity in the regulations and why an organization should want this designation. The designation of a registry needs to be clarified not only for organizations but also so that the general public understands the protections that go along with these designations.

PHIA's role is to provide for the protection of personal health information of residents of Newfoundland and Labrador, and any changes to the legislation should be considered with that intent in mind.

Appendix A Sources of Information

The following sources were consulted or used in conducting this submission.

The Centre established working groups composed of a variety of Centre employees to provide their input and express their concerns about PHIA.

The Centre engaged a consultant in the spring of 2016 to provide some preliminary feedback on PHIA for the Centre.

Some of the key informants for this submission include the following.

- Executive Team
- Donna Roche, Manager, Health Analytics and Chair of the Secondary Uses Committee
- Kayla Collins, Director, Information Services
- Ann Vivian Beresford, Director of Data Quality and Standards
- Members of the Privacy Team
- Members of the internal PHIA Review Committee that met during the summer of 2016

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