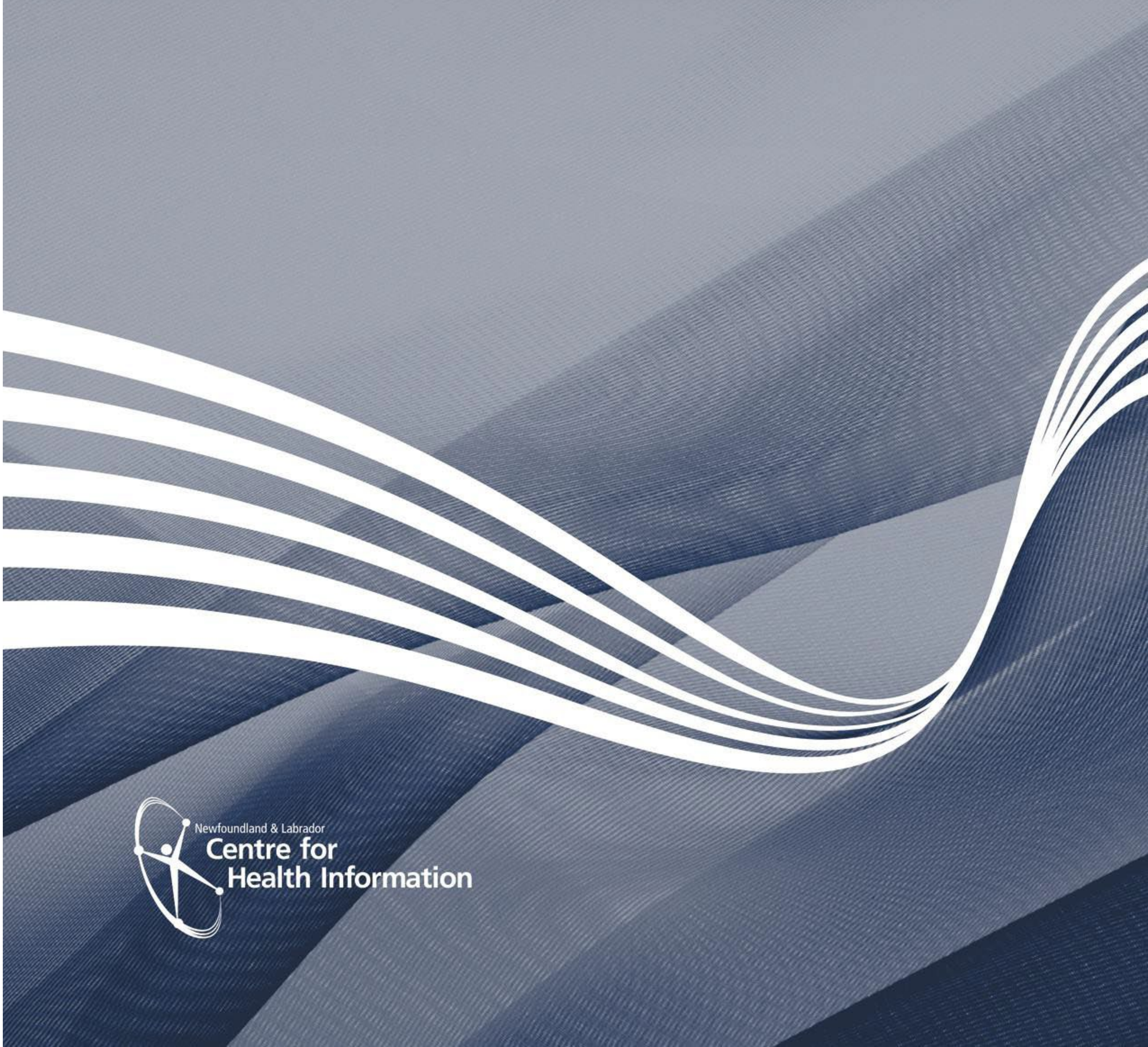
PHIA Review Submission



Newfoundland & Labrador
Centre for
Health Information

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1 Introduction

The current *Personal Health Information Act* (PHIA) was proclaimed on April 1, 2011 and is required to undergo a review once every five years.

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)

Agent

The definition of agent states: "…in relation to a custodian, means a person that, with the authorization of the custodian, acts for or on behalf of the custodian in respect of personal health information for the purposes of the custodian, and not the agent's purposes, whether or not the agent has the authority to bind the custodian, is paid by the custodian or is being remunerated by the custodian;" the Centre suggests greater clarity be provided on if the phrase 'whether or not' applies to pay/remuneration. The definition can be interpreted to mean pay/remuneration is a required aspect of being an agent or that the 'whether or not' phrase applies here.

De-identify

PHIA does not discuss or offer a definition of "de-identify" similar to that in section 2 of the *Ontario Personal Health Information Protection Act, 2004*[1]. Given recent considerations regarding the use of this type of personal health information by regulators such as the Information and Privacy Commissioner of Ontario in PHIPA Decision 175[2] and in its *De-identification Guidelines for Structured Data*[3], the Centre suggests that consideration be given to including a definition of "de-identify" or

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[1] Section 2, S.O. 2004, c. 3, Sched. A.

[2] Information and Privacy Commissioner of Ontario, *Health Information and Privacy - PHIPA Decision 175*, March 25, 2022, PHIPA DECISION 175 - Information and Privacy Commissioner of Ontario (ipc.on.ca).

[3] Information and Privacy Commissioner of Ontario, June 2016, Deidentification-Guidelines-for-Structured-Data.pdf (ipc.on.ca).

"de-identified personal health information" etc. as well as parameters for the use of such data.

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.

Individual

The PHIA refers to "individuals" but does not offer an interpretation of what is considered an individual. The Centre suggests including an interpretation similar to that in section 2 of the *Ontario Personal Health Information Protection Act, 2004*[4]

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.

Minors

There is no definition of "minor" offered in PHIA beyond the description offered in section 7(d). As well, PHIA does not offer guidance to custodians as to what factors to consider in s. 7(d) when assessing whether "in the opinion of the custodian, the minor does not understand the nature of the right or power and the consequences of exercising the right or power". Although the current wording grants the custodian flexibility in assessing whether an individual is a minor, guidance as to the age at which an individual would generally cease to be a minor and/or a list of factors that could be considered for the assessment outlined in s. 7(d) would be helpful to ensure greater consistency among custodians for the release of personal health information. This guidance may be particularly helpful for custodians such as the Centre who do not have a direct relationship with such minors upon which to base the assessment in section 7(d) and are instead assessing against objective information and criteria for the release of personal health information.

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.

2.2 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

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[4] Section 2, S.O. 2004, c. 3, Sched. A.

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.

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.[5]

Indigenous Personal Health Information

The Centre does have custody or control of some personal health information belonging to those who self-identify as Indigenous. The Centre recognizes that Indigenous people 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 Indigenous people.

Registration Information (s. 5(1)(d))

Further details on elements of registration information would be beneficial in this subsection. The Centre has experienced instances where there has been uncertainty if specific data was considered registration information in various contexts. This interpretation holds a significant impact because it determines if the data is personal health information and PHIA applies, or if the data is to be considered personal information and ATIPPA applies.

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

3 Part II: Practices to Protect Personal Health Information

3.1 Security (s. 15)

Subsection 4 of this section states a custodian shall inform the commissioner of a material breach. The Centre is fully committed to the protection personal health information and, in the interest of accountability and integrity, recommends this section be updated so that all breaches of personal health information shall be reported to the commissioner.

3.2 Information Manager (s.22)

Alberta[5], and Saskatchewan[6] 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 Collection of Personal Health Information with Consent (s.29)

Personal Health Record (PHR)

The Centre is currently implementing a PHR strategy. The initial phase enables the viewing of information contained within the existing electronic health record; however, in time, individuals will have the ability to provide information through the PHR such as sharing of key vitals from self-reporting applications, reporting of immunizations, consent, and advanced health care directives. While the information submitted to the PHR will be enabled by the individual, it will be important for the PHIA to consider any implications on the collection, use and disclosure of this information.

5.2 Disclosure where Individual is Deceased (s.38)

The Centre believes that there could be greater clarity regarding the interplay between sections 38, 7(e), 52, 53 and 58(1)(b) of PHIA regarding the access to, and disclosure of, personal health information regarding a deceased individual. Section 38 provides that a custodian may disclose

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

personal health information regarding a deceased without the individual's consent to their personal representative "for a purpose related to the administration of the estate". However, section 7(e) provides that a deceased individual's personal representative may exercise a right or power of that individual under PHIA, including the seemingly unfettered right to access personal health information under sections 52 and 53. The extent to which s. 38 states that such disclosure may only be granted for the limited purposes listed appears to conflict with the broader access rights of sections 52 and 53 available through section 7(e). Relatedly, sub-section 58(1)(b) does not expressly contemplate consent is provided by the personal representative of an individual in accordance with s. 7(e) (or in cases other than a deceased, by another individual with requisite authority to consent to the disclosure).

5.3 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
- Clinical Documents Repository
- Immunizations Record

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 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.

Vital Statistics

The *Vital Statistics Act, 2009* states that all births (s.5), stillbirths (s.14), and deaths (s.15) shall be registered. The Centre requests that the PHIA be amended to state that custodians shall submit information relating to births, stillbirths, and deaths to the registrar general as required.

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. There is an increased interest from third parties to conduct evaluations; however, PHIA does not permit a third party to evaluate a program operated by a custodian. The Centre requests that the PHIA Review Committee provide clarity on the role of third parties in conducting evaluations of programs for which they are not the custodian.

5.4 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

Time of Response (s.55)

Many timelines within PHIA are based on the date of "receipt" however, no definition of "receipt" or "receiving" is offered. For example, section 55 notes the deadline for responding to a request for personal health information is "not more than 60 days after receiving the request." Relatedly, section 54 contemplates incomplete requests but does not speak to whether the timelines for response are triggered upon the "receipt" of the incomplete request and/or whether the timeline for response continues to run while the request is being reformulated to comply with subsection 54(1). There is also no mention of an extension of the timeline for reply in section 55 by reason of an incomplete request.

Duty of Custodian (s. 64)

Section 64 requires a custodian to take "reasonable steps" to be satisfied as to an individual's identity prior to making a record of personal health information available to them pursuant to this Part of PHIA. However, no guideline or direction is provided as to what is deemed "reasonable" for these purposes. Although the current language provides a helpful level of flexibility for custodians to assess what is "reasonable" for their individual procedures in this regard, given the sensitivity of personal health information, some additional direction as to the required standard would be helpful to ensure consistency in the protection and disclosure of personal health information. "Reasonableness" can be quite subjective and what is needed to meet this requirement can be particularly difficult when dealing with more complex situations such as requests for access to personal health information by "Representatives" in accordance with s. 7 (parents on behalf of minors, etc.).

The Centre asks the review committee to recommend PHIA explicitly state a custodian has authority to request from individual's making a request to access or correct personal health information, (1) documentation to confirm identification and (2) proof of authority when acting as a representative as defined in Section 7, including birth certificate, guardianship or custody agreements, letters of probate, or other documentation as necessary to satisfy the custodian.

7 Conclusion

The Personal Health Information Act has served the province of Newfoundland and Labrador well since its proclamation in 2011. 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.

Previous recommendations made by the Centre in 2017 that resulted from established working groups and a third party consultant were considered when drafting the current recommendations.

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

- Executive Team
- Data and Information Services Department
- Director, eHealth Programs – Community and Virtual Care
- Director, eHealth Programs – Acute and Long Term Care
- Privacy Team

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