

*Personal Health Information Act (PHIA)*  
Statutory Review

Final Report

May 2017

(Amended September 2017<sup>1</sup>)

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<sup>1</sup> Non-material edits of a grammatical/typographical nature have been made to this report (in September 2017) since the original submission in May 2017.

## Executive Summary

### About the Review<sup>2</sup>

Under Section 91 of the *Personal Health Information Act* (PHIA), the Minister Responsible for the Department of Health and Community Services must refer the Act to a committee for review every five years. Though portions of the Act were proclaimed into force in 2009, the majority of the Act was proclaimed into force in 2011, making the Act due for review in 2016. The Minister of Health and Community Services initiated the first review of the Act in late November 2016. This document constitutes the report of the findings of the Review, in accordance with the Terms of Reference found in Appendix B.

The Review Committee was comprised of the following members:

- David Morgan, Committee Chair
- Marian Crowley, Committee Member
- Jeannie House, Committee Member
- Daryl Pullman, Committee Member
- Blaine Edwards, Committee Coordinator
- Michael Bannister, Ex Officio

The approach to the Review was primarily developed by the Committee Chair and Committee Coordinator in consultation with other committee members and the Communications and Public Engagement Branch of the Government of Newfoundland and Labrador (CPE). In addition to a thorough reading and examination of the text of the Act, a review of related Acts, and a review of literature and comparable Acts from other jurisdictions to consider select topics, the Review featured the following key elements:

- A Review Website ([www.phiareviewnl.ca](http://www.phiareviewnl.ca)). The Review website served as a central clearing house of information relating to the Review.
- Stakeholder Email Lists. The email lists were relied on heavily to communicate information prior to the launch of the website.
- A Half-Day Workshop at the provincial *Access, Privacy, Security, and Information Management 2016* conference held in late November 2016 in St. John's. This workshop was used to "kick-off" the process, and gather preliminary feedback from members of the information access, privacy, security, and information management community regarding topics of interest. Over 40 people participated in the workshop, which was facilitated by CPE and the Committee Coordinator.
- A Web-Based Survey designed to gather input from members of the general public and people associated with organizations that handle health information. The PHIA Review Survey was made available from early February to mid-March 2017. The survey had 77 respondents.

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- A three-round, responsive written submission process. The written submission process was designed to get input from both individuals and organizations. A list of the written submissions can be found in Appendix C. In total, 23 written submissions were received, seven of which were in response to earlier submissions.
- A Public Forum to hear from members of the general public, as well as people in health information organizations. The public forum was scheduled for March 8, 2017 in St. John's, with telephone/web conferencing as required depending on the location of registrants. Though registration for the public forum was limited, it proceeded; however, none of the registered participants attended, except a representative of the Office of the Information and Privacy Commissioner.
- Focus Groups to hear from people within groups that may were poorly represented through other participation methods, namely members of the general public and individual clinicians. Despite active efforts to recruit participants to these focus groups, there was not sufficient interest to proceed with meaningful sessions.

The Review was conducted in an open, transparent, and respectful manner. Moreover, the privacy of individuals was maintained throughout the course of the Review; notably, individuals were invited to make anonymous submissions. As a general rule, all submissions were to be posted on the Review website; however, individuals were informed that, in exceptional circumstances, submissions would not be shared publicly, if requested (no such requests were received).

Unfortunately, the Review was not able to meet its mandated timeline to have the final report submitted to the Department of Health and Community Services by March 31, 2017. The main reasons for not meeting this timeline are related to delays in launching the website, and the amount of time required to analyze and discuss the breadth of topics covered by the written submissions. However, the Review was able to complete its work within the allocated budget. With extensions to the timeline, the Review has been able to prepare a comprehensive and well-considered report that addresses the majority of topics that were raised for consideration.

Key findings of the PHIA Review Survey and literature/jurisdictional reviews on various topics are interspersed throughout the report, according to the discussion(s) with which they relate. The results from the PHIA Review Survey have been provided to the Department of Health and Community Services along with this report.

## **Conclusion**

Based on the results of the PHIA Review Survey, and the written submissions made by stakeholders, it would appear that PHIA is not a fundamentally flawed piece of legislation in need of a major overhaul. Notably, many of the written submissions spoke to how PHIA has improved the protection of personal health information in Newfoundland and Labrador.

Instead of a complete overhaul, PHIA simply needs some fine tuning in order to reflect the experience gained over the past five years. Though this report makes nearly 100 recommendations (see Appendix D), the majority of these recommendations represent minor corrections to address the challenges faced

by stakeholders, as well as the lessons learned. However, some of the recommendations address fundamental concepts, such as “custodianship”, group practices, academic institutions, privacy impact assessments, contractual requirements, oaths of confidentiality, working students, privacy of the deceased, duty to assist, offences, and penalties. As well, the report recommends a change in oversight powers of the Information and Privacy Commissioner to align with the *Access to Information and Protection of Privacy Act, 2015*.

In deciding whether or not to adopt the recommendations found in this report, there are risks in taking an “a la carte” approach. Not every recommendation must be accepted in order to improve the Act; however, many of the recommendations work together to ensure a fulsome legislative health privacy regime for the province. In some cases, accepting one recommendation but not another would be akin to erecting scaffolding with a few missing pieces – it might stay upright for a while, but will eventually start to fail.

Many of the written submissions called for additional education and the development of supporting resources. In some cases, this work is well-suited to government institutions, such as the Office of the Information and Privacy Commissioner and the Department of Health and Community Services; yet, in many cases, custodians and their supporting professional associations simply need to buckle down and do this work, collaborating with their peers and prioritizing as necessary in order to ensure that the work gets done.

Because limited resources were available to conduct the Review, there were some topics that the Review could not tackle in full; moreover, some of the recommendations stop short of suggesting specific wording for amendments to the Act, instead leaving that work for those who are experts in drafting legislation. However, this limited resourcing required the Review to “think outside the box” in an attempt to maximize reach and engagement while minimizing cost and effort. Despite little participation from faith communities and the community sector, the level of engagement by stakeholders was very high. Use of social media to promote the PHIA Review Survey resulted in very strong survey participation, and the introduction of a “responsive” round of written submissions resulted in respectful public dialogue and debate amongst stakeholders without the need for in-person sessions and travel. It is hoped that some of the creative solutions used in the Review might work for future legislative reviews conducted by the province.

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## 1 Introduction

### 1.1 About the Review<sup>3</sup>

Under Section 91 of the *Personal Health Information Act* (PHIA), the Minister Responsible for the Department of Health and Community Services must refer the Act to a committee for review every five years. Though portions of the Act were proclaimed into force in 2009, the majority of the Act was proclaimed into force in 2011, making the Act due for review in 2016. The Minister of Health and Community Services initiated the first review of the Act in late November 2016. This document constitutes the report of the findings of the Review, in accordance with the Terms of Reference found in Appendix B.

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- A Review Website ([www.phiareviewnl.ca](http://www.phiareviewnl.ca)). The Review website served as a central clearing house of information relating to the Review. The Review website, which was hosted by the Office of the Chief Information Officer of the Government of Newfoundland and Labrador, was launched in late January 2017.
- Two Stakeholder Email Lists. One email list was comprised of very broad representation of stakeholder groups that might have an interest in the Review. The second email list was comprised of stakeholder contacts that self-identified as wanting to be provided regular updates over the course of the Review. The larger email list was contacted with 2-3 updates of major importance, while the smaller email list was contacted more often regarding smaller developments. The email lists were relied on heavily to communicate information prior to the launch of the website.

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- A Half-Day Workshop at the provincial *Access, Privacy, Security, and Information Management 2016* conference held in late November 2016 in St. John's. This workshop was used to "kick-off" the process, and gather preliminary feedback from members of the information access, privacy, security, and information management community regarding topics of interest. Over 40 people participated in the workshop, which was facilitated by CPE and the Committee Coordinator.
- A Web-Based Survey designed to gather input from members of the general public and people associated with organizations that handle health information (for example, health clinics, private healthcare practices, hospitals, government programs, Workplace NL, and Memorial University). The PHIA Review Survey was made available from early February to mid-March 2017. The survey had 77 respondents, and was promoted through the website, email lists, and social media.
- A three-round, responsive Written Submission Process. The written submission process was designed to get input from both individuals and organizations. Organizations were encouraged to use the written submission process to highlight the strengths and weaknesses of the Act that they have identified over the past five years, to showcase issues that challenge their ability to comply with the Act, and to identify future challenges that they felt the Act may need to address. Individuals were also encouraged to highlight these strengths and weaknesses, and share personal experiences relating to the Act. A list of the written submissions can be found in Appendix C.
  - In Round 1, any individual or organization was welcome to make submissions on any aspect of the Act, or an experience relating to the Act. More than one submission was allowed from each individual and organization. Round 1 was launched in mid-December 2016; due to delays in launching the website, the deadline for Round 1 submissions was extended to February 14, 2017, though some late submissions were accepted. In total, 16 submissions were received in Round 1.
  - Prior to the start of Round 2, the Committee Chair reviewed submissions from Round 1. In Round 2, select individuals and organizations could provide clarification at the invitation of the Committee Chair; however, no clarifications were required or invited. Round 2 was held between February 16, 2017 and February 22, 2017.
  - Because individuals and organizations could not anticipate all of the topics that others might comment on during Round 1, Round 3 provided an opportunity to respond. In Round 3, any individual or organization was welcome to make submissions in response to submissions from Round 1 and Round 2. Individuals and organizations did not need to have made a submission in Round 1 in order to make a submission during Round 3. As with Round 1, more than one submission was allowed from each individual and organization. Submissions made during Round 3 were not permitted to explore topics that were not related to the topics presented in Round 1 submissions, and were reviewed prior to acceptance to ensure that they were related to Round 1 submissions. Round 3 was held between February 23, 2017 and March 8, 2017, though some late submissions were accepted. In total, seven submissions were received in Round 3.

- A Public Forum to hear from members of the general public, as well as people in health information organizations; however, official representatives of health information organizations were also welcome to attend to provide organizational perspectives. The public forum was scheduled for March 8, 2017 in St. John's, with telephone/web conferencing as required depending on the location of registrants. Though registration for the public forum was limited, it proceeded; however, none of the registered participants attended, except a representative of the Office of the Information and Privacy Commissioner.
- Focus Groups to hear from people within groups that may were poorly represented through other participation methods, namely members of the general public and individual clinicians. Despite active efforts to recruit participants to these focus groups, there was not sufficient interest to proceed with meaningful sessions.

The Review was conducted in an open, transparent, and respectful manner. Moreover, the privacy of individuals was maintained throughout the course of the Review; notably, individuals were invited to make anonymous submissions. As a general rule, all submissions were to be posted on the Review website; however, individuals were informed that, in exceptional circumstances, submissions would not be shared publicly, if requested (no such requests were received). The Review was contacted informally by some members of the general public – when they were asked if they wished their emails to be considered written submissions to the Review, none accepted the offer.

Unfortunately, the Review was not able to meet its mandated timeline to have the final report submitted to the Department of Health and Community Services by March 31, 2017. The main reasons for not meeting this timeline are related to delays in launching the website, and the amount of time required to analyze and discuss the breadth of topics covered by the written submissions. However, the Review was able to complete its work within the allocated budget. With extensions to the timeline, the Review has been able to prepare a comprehensive and well-considered report that addresses the majority of topics that were raised for consideration.

## **1.2 Organization of the Report**

For the most part, the report follows the organization of the Act, which addresses foundational matters up front, then considers particulars, and concludes with matters relating to the powers of the Information and Privacy Commissioner.

Key findings of the PHIA Review Survey and literature/jurisdictional reviews on various topics are interspersed throughout the report, according to the discussions with which they relate. The results from the PHIA Review Survey have been provided to the Department of Health and Community Services along with this report.

A list of acronyms found in the report can be found in Appendix A.

## 2 Purposes of the Act

PHIA defines itself as “an Act to provide for the protection of personal health information”. The purposes of the Act are further articulated in Section 3 as follows:

*“(a) to establish rules for the collection, use and disclosure of personal health information that protect the confidentiality of that information and the privacy of individuals with respect to that information; (b) to provide individuals with a right of access to personal health information about themselves, subject to limited and specific exceptions set out in this Act; (c) to provide individuals with a right to require the correction or amendment of personal health information about themselves, subject to limited and specific exceptions set out in this Act; (d) to establish mechanisms to ensure the accountability of persons having custody or control of personal health information and to safeguard the security and integrity of the personal health information in their custody or control; (e) to provide for an independent review of decisions and resolution of complaints with respect to personal health information in the custody or control of custodians; and (f) to establish measures to promote the compliance with this Act by persons having the custody or control of personal health information.”*

Many of the written submissions spoke to the positive impact that the Act has had on the protection of personal health information in the province. More importantly, none of the written submissions challenged the articulated purposes, and there were no comments received during the PHIA Review Survey to suggest that the articulated purposes needed closer examination.

It would appear that there is no need to consider any revision of the purposes articulated in Section 3 of the Act.

### 3 Custodianship

As anticipated at the outset of the Review, the written submission process elicited many comments on Section 4, the section of the Act that imparts “custodian” status on certain individuals and organizations. The concept of “custodianship” is central to the entire Act: besides imparting powers on the Information and Privacy Commissioner, the majority of the Act speaks to either what a custodian “must do” (mandatory), “must not do” (mandatory), or “may do” (discretionary).

We address the majority of custodianship-related matters in this section of the report, reserving some custodianship-related discussion for other sections. When considering custodianship, it is helpful to first consider some of the key custodianship-related concepts reflected in the Act.

- With limited exception, the Act does not contemplate “contextual” custodianship – that is, whether or not an individual or organization is a custodian does not generally depend on the context. The present definition of custodian only includes five cases where a “person” (defined in Section 2 of the Act to include both individuals and organizations) is or is not a custodian depending on the context. Specifically, Section 4 of the Act defines a “custodian” as *“a person ... who has custody or control of personal health information as a result of or in connection with the performance of the person’s powers or duties or the work described in that paragraph”*. The limited exceptions in which custodianship depends on the context are as follows:
  - Section 4(1)(c): *“a department created under the Executive Council Act, or a branch of the executive government of the province, when engaged in a function related to the delivery or administration of health care in the province”* (emphasis added);
  - Section 4(1)(d): *“the minister, where the context so requires”* (emphasis added);
  - Section 4(1)(e): *“a health care professional, when providing health care to an individual or performing a function necessarily related to the provision of health care to an individual”* (emphasis added);
  - Section 4(2)(j): *“a person referred to in section 7 [is not a custodian], when acting in the capacity described in that section”* (emphasis added); and
  - *Personal Health Information Regulation 4(a): “a department of the Nunatsiavut government when engaged in a function related to the delivery or administration of health care in Nunatsiavut”* (emphasis added).
- The Act appears to contemplate custodianship with respect to specific “records” of personal health information – that is, a person is not simply a custodian, but a custodian with respect to specific records. Specifically, this concept is demonstrated by way of Section 4(3) of the Act which says *“... a custodian does not cease to be a custodian with respect to a record of personal health information until...”*.
- The Act appears to try to eliminate “nested” custodianship – that is, the Act tries to eliminate situations where a person who might otherwise be a custodian is accountable to another custodian.
  - Section 4(2)(a): *“an employee of a custodian when acting in the course of his or her employment [is not a custodian in respect of personal health information he or she may*

- collect, use, disclose or dispose of while performing the powers or duties described]*" (e.g. a physician who is an employee of a regional health authority).
    - Section 4(2)(h): *"an information manager [is not a custodian in respect of personal health information he or she may collect, use, disclose or dispose of while performing the powers or duties described]"* (e.g. a company providing document storage services for a regional health authority).
    - Section 2(1)(j): *"health care professional' means... but does not include an employee of a health care professional when acting in the course of his or her employment"*.
  - The Act does not appear to contemplate "joint" custodianship – that is, the Act does not contain any language that suggests that more than one person (whether a "natural" person or not) is a custodian in the same context, or with respect to the same record (e.g. that a massage therapist and a physiotherapist, who are custodians in their own right, have equal custodianship of shared patient files).

### 3.1 Custodians, Subordinate Roles, Group Practices and Other Business Relationships

#### **Custodians as Information Managers**

In their written submissions, NLCHI and the OIPC highlighted issues arising with the relationships between "custodians" and "information managers". Section 2(1)(l) of the Act defines an "information manager" as *"a person or body, other than an employee of a custodian acting in the course of his or her employment, that (i) processes, retrieves, stores or disposes of personal health information for a custodian, or (ii) provides information management or information technology services to a custodian"*.

Specifically, NLCHI and the OIPC both raised the point that there are situations where custodians are providing information management services to other custodians with respect to specific records and the custodian providing information management services does not arguably have custody or control of the records. Yet, NLCHI and OIPC point out that the Act does not offer clarity about whether the custodian providing information management services is an information manager, and not a custodian, with respect to those specific records. Notably, NLCHI has been established as a central resource for electronic health information in this province, so it occasionally provides data storage, extraction, and analytics services to other custodians despite having no vested interest in the records being managed – NLCHI simply manages and interacts with the records according to the direction of the custodian to whom they are providing services.

According to the definition of "information manager", there is, at first glance, nothing that prevents a custodian from being an information manager. The problem arises from the fact that Section 4(2)(h) of the Act can easily be interpreted to understand that designation as a custodian (in some circumstance) precludes designation as an information manager (in any circumstance). Specifically, Section (4)(2) says, *"except as otherwise provided in the Act or the regulations, a person described in one of the following classes shall not be considered to be a custodian in respect of personal health information he or she may collect, use, disclose or dispose of while performing the powers or duties described ... (h) an information manager"*. However, another equally valid interpretation of this phrasing is that playing the role of

information manager with respect to certain records simply precludes playing the role of custodian with respect to those same records.

The written submissions demonstrate that the differing interpretations of Section 4(2) of the Act, with respect to custodians and information managers, are not simply theoretical. Anecdotally, those on both sides of the argument often have trouble understanding the other argument; unfortunately, this matter has not yet been tested in the courts, so there is no definitive interpretation.

Furthermore, the OIPC raised the issue of whether or not a custodian (that is, a custodian with respect to some records) might be designated an “information manager” with respect to records in the custody or control of a party that is not designated as a custodian (with respect to those records) under the Act. For example, NLCHI could manage records for a smoking cessation clinic excluded from the definition of custodian by way of Section 4(2)(g) of the Act. In this situation, the records remain in the custody or control of the clinic. Though possible, it would seem to be inappropriate to have NLCHI designated as an “information manager” with respect to those records, as such designation would result in NLCHI being given accountabilities and responsibilities under the Act (with respect to the clinic’s records) even though the clinic to whom NLCHI is providing services has not been given accountabilities and responsibilities under the Act.

#### **Clarifying Powers and Duties that Preclude Custodianship**

A closer inspection of Section 4(2) of the Act exposes the fact that there are actually several persons for which the “powers or duties described” are not specified and must be implied. This lack of clarity may lead to confusion or inconsistent interpretation in other scenarios that were not raised during the Review. To borrow a phrase used by the OIPC throughout their submissions, the lack of specified powers or duties is not “user-friendly”, and should be clarified.

#### **Group Practices, Ownership Structures, and other Relationships that Preclude Custodianship**

In addition to the need to clarify powers and duties that preclude custodianship in Section 4(2) of the Act, there is an opportunity for further clarification within Section 4(2) with respect to relationships in order to eliminate the potential for real or perceived situations of “nested” or “joint” custodianship.

It is hard to imagine a scenario in which a person subordinate to a custodian (e.g. acting under the direction of a custodian or for the custodian’s purposes) would reasonably be considered to be in custody or control of records – for example, the typical subservience relationship between employees and employers would suggest that custody and control would rest with the employer. Section 4(2)(a) of the Act appears to be respecting this subordinate relationship by precluding “*an employee of a custodian when acting in the course of his or her employment*” from being a custodian in that context.

One could argue that Section 4(2)(a) (employees are not custodians) is unnecessary because it is unlikely that an employee would ever be considered to have control or custody of records in an employment context; however, Section 4(2)(a) offers clarity, and eliminates any risk of “nested” custodianship in this context. Though Section 4(2) provides some clarity in the context of subordinate relationships by precluding employees and information managers from being custodians, this section can provide even further clarity.

Notably, the written submission of the CMTNL put forward some very important questions regarding group practices that were also highlighted in submissions from the OIPC. The questions posed are of equal interest in any situation where the relationship amongst health care providers/professionals deviates from one of obvious subordination.

Consider, for example, where a massage therapist, physiotherapist, and chiropractor have come together in an informal partnership, using a common location to provide services in an arrangement where clients pay the individual practitioners<sup>4</sup> according to the services used, but the practitioners rely on a single patient file to support and document care. As indicated by the OIPC, these practices generally operate well until there is a breach or until someone decides to leave the practice – only then do issues of custodianship (e.g. who is accountable, who makes decisions, who has rights to records) become apparent.

In this example, there is an informal partnership that has been created. According to Section 4(2)(e), the individual professionals are custodians of the patient file and there do not appear to be any other elements of Section 4 that otherwise preclude this custodianship based upon the partnership – certainly, there is no employment structure to bring Section 4(2)(a) of the Act into play. Yet, there is a very reasonable argument that, according to the definitions of “health care provider” and “person” found in Section 2, the partnership constitutes a “person” that is a “health care provider”.<sup>5</sup> In turn, the partnership is a custodian according to Section 4(1)(f), and there do not appear to be any other elements of Section 4 that otherwise preclude this custodianship. This situation presents complications in terms of both “nested” and “joint” custodianship. The same is also true if the practitioners are brought together (e.g. recruitment) by another person as part of some arrangement, as opposed to coming together in a partnership.

A closer review of Sections 2 and 4 of the Act suggests that the failure to adequately address custodianship in group practices results from Section 4(2) not adequately eliminating the possibility of “nested” and “joint” custodianship established through Sections 4(1)(e) through 4(1)(g). This issue is further complicated by the definitions of “health care professional” and “health care provider” found in Section 2 not being limited to “natural persons” and Section 4(1)(g) creating significant exceptions on non-natural persons that might otherwise be custodians.

Specifically, Section 4(1)(g) includes in the list of custodians “*a person who operates (i) a health care facility, (ii) a licensed pharmacy as defined in the Pharmacy Act, 2012, (iii) an ambulance service, or (iv) a centre, program, or service for community health or mental health, the primary purpose of which is the provision of health care by a health care professional or health care provider*”. Subsections (i) through (iii) are very comprehensive, but Subsection (iv) offers many exceptions by way of the restriction to “community health or mental health” that would otherwise capture group practices, or other

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<sup>4</sup> To avoid excessive use of the cumbersome phrases “health care professionals and health care providers” and “health care professionals or health care providers”, which precisely use terms defined by the Act, the report will occasionally refer to “practitioners”.

<sup>5</sup> Arguably, most people familiar with PHIA would implicitly perceive a “health care provider” as being a natural person; however, the definition does not specify that it is a natural person.



arrangements in which the relationship between practitioners deviates from one of obvious subordination.

These shortcomings in Section 4(1)(g) can be addressed by eliminating the exceptions, and explicitly referring to group practices, thereby clearing capturing group practices and making the “person who operates” the enterprise the custodian, regardless of whether or not they are a natural person. In the case of a group practice, an examination of the operating/ownership structure or informal partnership can then be relied on to determine who is the custodian (in some cases, it might be the partnership created by all the participants in the group practice). The elimination of the phrase “community health or mental health” from Section 4(1)(g)(iv) is not problematic, as the definition of “health care” in Section 2 adequately covers community health care and mental health care.

To ensure further clarity with respect to custodianship in group practices, the Act could require that a person who is designated a custodian by way of operating a group practice must communicate in writing with each practitioner participating in the group practice that the person operating the group practice is the custodian with respect to the records of the group practice, not the practitioner.

Moreover, while eliminating the exceptions found in Section 4(1)(g)(iv), the exclusion associated with “centres, programs or services ... *the primary purpose of which is the provision of health care...*” (emphasis added) could also be eliminated to ensure sufficient accountability and responsibility when the provision of health care is simply a purpose, but not the primary purpose. This change may result in additional persons being covered by the definition of custodian, but it will be to the betterment of health information protection in the province.

Finally, in order to more effectively eliminate the possibility of “nested” and “joint” custodianship through Section 4(2), this section should not simply preclude custodianship where a person is subordinate to a custodian. This section should also preclude custodianship where a practitioner is providing health care as part of a facility, pharmacy, service, centre, program, or group practice identified in 4(1)(g) – the person operating the facility, pharmacy, service, centre, program, or group practice is a custodian, and should remain accountable and responsible for actions of the people providing health care as part of their endeavour, providing sufficient direction to ensure that these activities are conducted in a way that represents their values. Extending this preclusion to persons who provide services for or on behalf of any custodian would be problematic, as it could possibly create an unwanted chain reaction of preclusion (e.g. a dentist provides dental services as part of a program operated under the auspices of a regional health authority who is arguably providing services on behalf of the Minister of Health and Community Services or the Department of Health and Community Services).

***Recommendation 1*** Provide further clarity on custodianship and information management within the Act, and eliminate the potential for “nested” or “joint” custodianship.

***Recommendation 1a*** To eliminate the potential for “nested” or “joint” custodianship, to eliminate the restrictions to community health and mental health in Section 4(1)(g)(iv), and to clearly address group practices, amend the Act as follows: (a) limit the definitions of “health care provider” and “health care

*professional” found in Section 2(1) to natural persons; and (b) rephrase Section 4(1)(g)(iv) as “a centre, program, service, or group practice, the primary purpose of which is the provision of health care by a health care professional or health care provider”.*

***Recommendation 1b*** Consider offering further clarity with respect to custodianship in the context of group practices by amending the Act to require that a person who is designated a custodian by way of operating a group practice must communicate in writing with each health care professional or health care provider participating in the group practice that the person operating the group practice is the custodian with respect to the records of the group practice, not the health care professional or health care provider.

***Recommendation 1c*** To provide further clarity on custodianship and information management, and to eliminate the potential for “nested” or “joint” custodianship, amend Section 4(2) of the Act to clearly identify those persons which: (a) cannot be considered custodians under any circumstance; and (b) are not custodians with respect to specific records in specific contexts. Moreover, in amending Section 4(2), ensure that: (a) custodians designated under the Act can play the role of information manager to other custodians with respect to specific records; (b) any custodian designated under the Act who plays a subordinate role to another custodian with respect to specific records (e.g. employee, contractor, information manager) is clearly precluded from being considered the custodian with respect to those records; and (c) any health care professional or health care provider who provides or undertakes health care as part of a facility, pharmacy, service, centre, program, or group practice identified in 4(1)(g) is clearly precluded from being considered the custodian with respect to records they engage with (e.g. “collect, use, disclose or dispose of”) in that context .

***Recommendation 2*** Consider broadening the list of designated custodians through elimination of the “primary purpose” limitation found in Section 4(1)(g)(iv) by amending the Act to replace the phrase “the primary purpose of which is the provision of health care by a health care professional or health care provider” with “a purpose of which is the provision of health care by a health care professional or health care provider”.

### **3.2 Custodianship in Multi-Organization Information Systems**

In its written submission, Eastern Health raised a scenario in which it is particularly difficult to identify who is, or should be, playing the role of custodian with respect to specific records. Notably, records found in hospital information systems of the regional health authorities (who are custodians designated under Section 4(1)(a)), are contributed by way of the practitioners interacting with the system. In many cases, a practitioner has access to a hospital information system by way of their employment with the regional health authority, so it is clear from Section 4(2)(a) that the regional health authority is the custodian of the records contributed; however, in other cases, the practitioner is not an employee of the regional health authority and so the practitioner is arguably the custodian with respect to the records they have provided, and the regional health authority is simply an information manager of those records. In such situations, the final conclusion regarding who is the custodian with respect to the specific records must come down to an analysis of “custody or control”.

Although not raised as part of Eastern Health’s written submission, this lack of clarity exists for other health information systems in the province. For example, the regulations to PHIA highlight the “Pharmacy Network”, “Picture Archiving and Communication System”, and “Laboratory Information

System” as information networks to which personal health information must be disclosed under Section 39(4)(c) of the Act. The regulations specify that NLCHI “operates” or “administers” these systems, but are silent on whether or not NLCHI is the custodian with respect to the records found in these systems. Because the records found in the Pharmacy Network and the Laboratory Information System are copies of records from source systems, NLCHI is generally understood to be the custodian of the records in the Pharmacy Network and the Laboratory Information System; however, the Picture Archiving and Communication System is the information system used in the province for digital imaging purposes – the images found in the system are entered and accessed primarily by regional health authorities and their staff (as well, as some of the “independent” practitioners discussed above), so exactly who the custodian is with respect to the records in this system is not so clear.

This lack of clarity associated with custody of specific records within information systems that operate beyond the bounds of a single organization is similar to the lack of clarity associated with group practices discussed in Section 3.1 of this report. In the interest of clarity, it would be far easier to address these situations directly.

In its written submission, Eastern Health puts forward the idea of some sort of “joint” custodianship with a “primary” custodian, or using some sort of designation that falls “between” custodian and information manager. Unfortunately, the concepts of “custodian” and “information manager” do not sit on a linear continuum for which there is an “in between”. At best, a third role could simply have some characteristics of each; however, the introduction of a third role would likely make the Act and its interpretation more confusing with little reward. Moreover, the idea of “joint” or “shared” custodianship with respect to specific records would run contrary to the idea that accountability best resides with a single person.

It would seem that a simpler solution would be, where possible, to place all the records within a multi-organization health information system under the custodianship of a single custodian; however, given the trend towards the shared use of common provincial health information technology platforms, this approach is a bit too simplistic. Consider, for example, the provincial Client Safety Reporting System (CSRS; also known as the “Occurrence Reporting” system) which is used by all four regional health authorities to record occurrence outside the scope of normal operations, but which is operated by a single health authority, Eastern Health. To better accommodate such shared infrastructure, this approach might be “relaxed” to place classes of records within a multi-organization health information system under the custodianship of a single custodian – in the case of CSRS, each regional health authority might be designated as the custodian of all the records originating from that health authority, thereby eliminating any potential confusion relating to custodianship.

Obviously, the effort required to develop such regulations to the contentment of multiple stakeholders might be significant in some cases; however, the approach will offer clarity (where there is presently little) to those who are willing to undertake the effort. For those who might seek to clarify legislative accountability and responsibility using this approach, it is important to recognize that having legislative accountability and responsibility for all the records, or a class of records, in an information system reside with a single person does not preclude the establishment of governance structures that ensure that

stakeholder voices are heard and factored into decisions that are discretionary under PHIA (e.g. disclosure for research purposes).

***Recommendation 3*** *To ensure clarity of custodianship with respect to records in multi-organization health information systems, amend the Act to establish a mechanism whereby classes of records within a health information system can be placed under the custodianship of a single designated custodian using regulations to the Act. For greater clarity, such a mechanism must also facilitate the placement of all the records within a health information system under the custodianship of a single designated custodian.*

### 3.3 Health Professions

In its written submission, Central Health highlights the fact that the definition of “health care professional” found in Section 2(1)(j) only includes those subject to specific health profession acts, such as the *Chiropractors Act, 2009* and the *Denturists Act, 2005*, and overlooks those professions which are addressed by way of the *Health Professions Act* (e.g. acupuncturist, audiologist).

In many cases, members of the professions governed by the *Health Professions Act* would be considered “health care providers” under Section 2(1)(k) of the Act, given that they are “*paid by [the Medical Care Plan], another insurer or person, whether directly or indirectly or in whole or in part, to provide health care services to an individual*”. However, it would seem unusual that these practitioners, who by the very name of the *Health Professions Act* would undoubtedly be considered “professionals”, are only governed by PHIA in a secondary way, possibly allowing some to not be governed by PHIA in some contexts.

The obvious solution is to designate members of the professions listed in the *Health Professions Act* as “health care professionals” under PHIA, thereby making them custodians. As a matter of practicality, situations which might present “nested” or “joint” custodianship would be addressed by Recommendation 1 made in Section 3.1 of this report.

***Recommendation 4*** *To better ensure legislative protection of personal health information by those practitioners regulated by the Health Professions Act, amend the Personal Health Information Act to designate all members of the professions listed in the Health Professions Act as “health care professionals” under Section 2(1)(j).*

### 3.4 Home Support

In its written submission, Central Health highlighted the need for clarity regarding the applicability of the Act to home support agencies and independent home support workers. It would seem that, depending on the type of care provided and barring partnerships or other arrangements that might complicate matters, most independent home support workers are providing some form of “health care” according to the definition found in Section 2, and would fall under the definition of “health care professional” or “health care provider”; therefore, they would be custodians according to Section 4(1)(e) or (f). Similarly, depending on the care offered, home support agencies would also be captured by the current definition

of “health care provider” (which is not limited to natural persons) and are also custodians.<sup>6</sup> This interpretation was supported by the responsive written submission of the OIPC; however, the OIPC suggested that clarity is welcome. It is hoped that any partnerships or other arrangements that might introduce “nested” or “joint” complicate custodianship with respect to home support are addressed by Recommendation 1.

Over and above the matter raised by Central Health, the OIPC raised the question of whether or not independent home support workers employed directly by individuals should be held to the same expectations and standards placed on other custodians by the Act, particularly if they are not doing so as a “health care professional”. To quote the OIPC in their written submission, *“their employment may be long term or short term. There is no education standard, or even literacy standard, which must be attained by these workers in order to accept this employment”*. To borrow a phrase from the submission of Memorial University on an unrelated topic, the question at hand is whether designation of these home support workers as custodians is necessary in order to enable the objectives of PHIA to be met in a way that ensure the burdens are offset by the benefits.

Given the mixed nature of the work done by these home support workers, the lack of education and literacy standards that must be met, and the ever-increasing importance of these workers in response to the aging demographics of the province, it would seem that the burdens currently imposed on custodians under the Act might indeed be too great to justify designating these workers as custodians. In the words of the OIPC submission, *“it may not be realistic to expect that these individuals are aware of PHIA, or have the capacity to understand and comply with it”*. The designation of these workers as custodians imposes desirable accountability, responsibility, and local oversight based upon a legislative framework that is working well; however, in practice, it will likely only improve the protection of health information through a marginally increase in awareness of the importance of confidentiality amongst these workers. In some cases, those individuals whose connection to the profession is tenuous might choose (or may have chosen) to leave the profession after giving serious consideration to the implications of custodianship, and those considering entering the profession (or who have considered) might choose not to for the same reasons. Anecdotally, many who engage in this profession do so not “for the money”, but rather because they consider it a “calling”.

As an alternative, the OIPC proposes that these home support workers *“be exempted from most of the requirements, roles and obligations of custodianship in PHIA except that they be subject to an overall confidentiality requirement as well as subject to the offense provisions”*. This approach seems reasonable: by doing so, there would a mechanism to ensure some local oversight, and pursue violations of confidentiality outside of those that exist through the *Privacy Act* and the federal *Personal Information Protection and Electronic Documents Act*. However, this approach might require significant legislative customization of the Act that introduces further complexity, and has the potential to open a “Pandora’s Box” as other groups might also seek the same exemptions. Further, the OIPC suggests that

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<sup>6</sup> Should Recommendation 1a and Recommendation 2 be accepted, the home support agency would likely be considered a custodian by being a person operating a health care service.

the only reasonable alternative is to exempt them from the Act all together. This suggestion that there is only one reasonable alternative would also seem to be correct.

Though the written submissions of Central Health and the OIPC are highly valued, and the OIPC considers the matter in some detail, neither submissions present this topic using tangible examples that indicate anything beyond a hypothetical issue; moreover, the written submission process, public forum, and call for focus groups did not hear from any individuals or organizations involved in home support, or from their supporting associations. The submissions on the topic of home support suggest that the application of the Act to home support has likely “flown under the radar” over the last five years, and the Review has not significantly changed this low profile. Unfortunately, the Review had little commentary to go by in considering this matter, and did not have the time or resources to explore this issue more deeply, so the associated recommendation does not forcefully suggest a deviation from the status quo.

***Recommendation 5*** Amend the Act to make it clear that home support agencies are custodians.

***Recommendation 6*** Consider further exploration of the issue of custodianship by independent home support workers who are not considered “health care professionals” according to the definitions found in Section 2 of the Act. Specifically, determine if the burden of custodianship requirements, roles, and obligations on these workers outweighs the resulting benefit to the protection of personal health information in this province. Should further evidence suggest that the burden outweighs the benefit, consider exempting these workers from the Act by way of regulation, or by amending the Act to more appropriately balance the burden and benefit.

### **3.5 Custodianship within Academic Institutions and the Health Research Community**

Several of the written submissions spoke to custodianship in the context of post-secondary academic institutions and the level of protection for personal health information within the research community. In considering these topics, it is important to first understand how the province’s legislative health information protection framework currently applies to post-secondary academic institutions and health research.<sup>7</sup>

First, it should be noted that all health research in the province is subject to scrutiny by way of the *Health Research Ethics Authority Act* (HREAA). Because information protection is a component of research ethics, HREAA is plays an important role in the province’s legislative health information protection framework. However, as discussed in more detail later in this section, the focus of HREAA is research ethics, of which information protection is only one consideration. Therefore, the primary legislative responsibility for ensuring protection of personal health information lies with PHIA, not HREAA.

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<sup>7</sup> The provincial legislative health information protection framework is about far more than requiring custodians to safeguard personal health information (and, in the case of researchers, conducting ethical research). Among other things, the framework ensures complaint mechanisms for the public, rights of access by an individual to personal health information about them, and oversight of the privacy rights of citizens.

With respect to post-secondary academic institutions, there are four faculties and schools of Memorial University which are explicitly established as custodians under the Act (via Section 4(1)(j)): the Faculty of Medicine, the School of Nursing, the School of Pharmacy, and the School of Human Kinetics and Recreation. The Act also establishes the Centre for Nursing Studies (operated by Eastern Health in partnership with Memorial University) and the Western Regional School of Nursing (operated by Western Health in partnership with Memorial University) as custodians by way of Sections 4(1)(k) and (l). In the case of health research activities, these faculties, schools, and centres are fully participant in the province's legislative health information protection framework because they are subject to HREAA and are custodians under PHIA. In the case of non-research activities (e.g. teaching, community knowledge transfer, speaking, contribution to public debate, administration), they are fully participant in the framework as custodians under PHIA.

The Act does not impart custodianship based on participation in health research. However, many health researchers<sup>8</sup> in the province are affiliated with the Centre for Nursing Studies, the Western Regional School of Nursing, and the four designated faculties and schools of Memorial University. As well, some researchers are affiliated with other custodians, such as the regional health authorities and NLCHI. Because custodians are fully-participant in the province's legislative health information privacy framework, any health researcher who is affiliated with a custodian in a subordinate role (e.g. employee, service provider) is also fully-participant in the framework when undertaking work as part of that affiliation.

However, not all researchers have such subordinate relationships with custodians. For example, one of the organizations who made a written submission, Sequence Bio, is a for-profit corporation which anticipates significant future participation in health research using personal health information, collected both directly and indirectly, based upon consent from participants. Some of Sequence Bio's health research may be undertaken through affiliations with Memorial University, while some may not. Moreover, there is nothing that prevents a member of the general public from independently conducting health research approved by a health research ethics board or body. In the case of researchers who are not operating as a subordinate to a custodian, they are not fully participant in the province's legislative health information privacy framework because they are not subject to PHIA.

### **Custodianship of Memorial University and other Post-Secondary Academic Institutions**

The written submission of Memorial University was, in short, a request to have its four custodian faculties/schools "de-listed" as custodians. No representations were made by Memorial University, Eastern Health, or Western Health to modify the status of the Centre for Nursing Studies or the Western Regional School of Nursing.

Memorial's argument is based on the following key points.

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<sup>8</sup> Section 2(1)(y) of the Act defines a "researcher" as "*a person who conducts research*"; therefore, a researcher need not be a natural person. Where this report assumes that a researcher is a natural person, it will do so explicitly.

- Memorial’s primary functions are education and research. The delivery of health care services does not fall within Memorial’s mandate.
- Several units at Memorial deliver health care (e.g. Student Health Clinic, University Counselling Centre) and each such unit should be considered custodians. They are actively working to ensure compliance with the Act in these contexts.
- Memorial has reached arrangements with health care organizations whereby students engaged in student placements in clinical settings are subject to the policies and procedures of those organizations. Imposing requirements that Memorial ensure the security of personal health information by students in this context by way of PHIA is duplicative.
- Memorial has reached an arrangement with health care organizations whereby cross-appointed faculty (e.g. faculty with appointments in both the Faculty of Medicine and Eastern Health) engaged in the work of the health care organization do so in their roles as practitioners and are subject to the policies and procedures of those custodians. Faculty who wish to conduct research using personal health information encountered or obtained by way of their work for the health care organization must obtain the approval of the health care organization (as well as necessary ethics approval in accordance with HREAA).
- Health research involving personal health information is already subject to legislative and ethical requirements by way of HREAA and obligations to the Tri-Council Agencies.<sup>9</sup> Imposing requirements on research data by way of PHIA is unnecessarily duplicative. Moreover, in doing so, PHIA potentially *“creates impediments to research and the development of intellectual property”* and undermines practices around custody and control of research data bearing on academic freedom and the trust between researcher and research subject. Specifically:
  - Research data is subject to mandatory disclosures by way of the Act (in turn, Memorial highlights a recent court case in which a claim of academic freedom by researchers blocked a search warrant for research information in their possession).
  - Because of guarantees of academic freedom, academic researchers at Memorial *“should not be regarded as being under the direction and control of their employer to the same degree as an employee who does not enjoy such freedom”*. Moreover, *“researchers at Memorial who are guaranteed academic freedom are generally regarded as having custody and control of research data they collect”*.
  - *“Subjecting research data to PHIA also potentially creates impediments to research generally by imposing obligations on researchers at Memorial that are not imposed on researchers in private industry in the province (and elsewhere) or on other institutions with which Memorial collaborates.”*
  - *“...applying PHIA to research data could also threaten the commercial viability and value of intellectual property generated in the course of such research”* by way of mandatory disclosures set out in the Act (in turn, Memorial highlights the fact that *“research is*

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<sup>9</sup> The Tri-Council Agencies are made up of the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC) and the Social Sciences and Humanities Research Council of Canada (SSSHRC). Together, they have developed the *Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans* (TCPS2), which forms the basis of ethical reviews of health research by research ethics boards across Canada, including those established by the *Health Research Ethics Authority Act*.



*specifically excluded from the scope of the province's Access to Information and Protection of Privacy Act, 2016 [sic] for this very reason" and that similar exclusions are found in similar access and privacy legislation across Canada).*

- The Ontario *Personal Health Information Protection Act* does not name universities or academic units as custodians.

Furthermore, with respect to its mandate for teaching, Memorial *"submits that it is inappropriate, in light of the historical practices of and current teaching arrangement in place between Memorial and health care organizations, to apply PHIA to Memorial's four named faculties" and that "doing so creates unnecessary administration and confusion and, accordingly may actually serve to heighten the risks to the security of personal health information that are intended to be mitigated by the legislation"*.

In making its arguments, Memorial also notes issues with Regulation 3 of the *Personal Health Information Regulations* established under the Act. This matter will be addressed in Section 8.6 of this report.

Memorial's request was anticipated by both NLCHI and OIPC, whose written submissions countered Memorial's position. NLCHI, an organization which is regularly called upon to disclose health data without consent for research purposes (a discretionary disclosure under Section 44 of the Act), indicated that Memorial researchers associated with faculties/schools that are designated as custodians benefit significantly from this designation. Specifically, *"the risk associated with disclosing data to [a researcher affiliated with a custodian organization] 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"*. Moreover, NLCHI goes on to say that *"if a custodian... were to be delisted or if their status changed, that would impact the disclosure of data to researchers affiliated with that organization"*. The OIPC, in its submission, highlighted an article authored by several Memorial researchers and a representative of the Office of the Privacy Commissioner of Canada in the Journal of the American Medical Informatics Association which speaks highly of the existing framework struck by HREAA, PHIA, and Memorial's custodial designations under PHIA. The OIPC contends that *"this article essentially concludes that a delicate balance has been struck which establishes appropriate regime to facilitate important research while ensuring appropriate privacy protection" and that "the value of the current model is predicated on the fact that the four schools/faculties at Memorial are custodians. It does not work as intended if they are not custodians"*.

The responsive written submission of the OIPC countered Memorial's submission more directly. In the words of the OIPC, *"although Memorial... has played a positive role in the promotion of access to information and protection of privacy, there have been occasions where we have been critical of Memorial's position on certain matters, and there have also been areas of profound disagreement. The [issue of "de-listing" Memorial's custodian schools/faculties] is fairly placed in the latter category"*. Specifically, the counter argument of the OIPC is based on the following key points.

- HREAA and PHIA are intended to operate *"interdependently"*. If Memorial were not subject to PHIA in any way, *"there would be no legislated requirement for information security policies and*

*procedures; no complaint mechanism for the public if someone believes their information has been collected, used or disclosed improperly in the course of research activities; and no real oversight of the privacy rights of citizens whose information is used in research activities”.*

- Under past legislative regimes, Memorial has denied the Commissioner access to documentation demonstrating approval by a research ethics board in response to a privacy breach involving researchers employed by Memorial.
- Memorial’s argument that its academic researchers should not be seen as being under the direction of their employer to the same extent as an employee without academic freedom, and in turn records associated with its researchers’ activities are with the custody or control of the researcher and not Memorial, is invalid for the following reasons.
  - Research funding applications made by Memorial researchers are processed and administered through Memorial’s Office of Research.
  - Faculty members are required to engage in research as part of their collective agreement with Memorial.
  - Researchers seeking ethics board approval generally *“present themselves as having all of the institutional support of Memorial behind them”*, including *“elements such as data storage and security, and policies and procedures to protect the data from unauthorized access, use, disclosure, loss, theft, and to ensure its secure destruction under terms required by the research ethics board”*.
- Memorial graduate students and faculty switch institutions over their career. If researchers indeed have independence from Memorial to the extent that custody and control of research data rests with the researcher, establishment of custodianship is a useful guarantee in ensuring that the research data stays subject to the province’s legislative framework.
- To the knowledge of the OIPC, custodianship has not interfered with the beneficial goals of the recently launched Translational Personalized Medicine Initiative of Memorial. Rather, the OIPC suggests, *“the interconnected statutory regime of PHIA and HREA [sic] ensures that there are standards in place which establish clear lines of accountability”*.
- Other custodians have indicated that de-listing has the potential to jeopardize disclosures of personal health information to Memorial for research purposes under Section 44 of the Act. Approval by the research ethics board is a prerequisite for consideration by the organization contemplating the disclosure – the *“status of custodian... provides a level of assurance that the information will remain secure and that there is accountability for maintaining that security”*. The research ethics board process *“while having elements of data security..., is not explicitly a privacy review”*.<sup>10</sup>
- Whether or not health care services falls within Memorial’s mandate is irrelevant. The purposes outlined in Section 3 of the Act make no mention of about protection of personal health information solely in the context of delivery of health care services.
- Memorial’s claim that the Act *“potentially creates various impediments to research and the development of intellectual property and undermines existing practices in academia around*

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<sup>10</sup> The HREB themselves argue that the research ethics board process is not intended as a review with respect to PHIA, so custodians should still conduct their own review in deciding to disclose under Section 44 of the Act.

*research data custody and control*” are not backed by their submission. Moreover, even if the Act does have an impact on these existing practices, the OIPC contends that *“it is not at all clear that such impacts are substantial or even negative”*, as demonstrated by the indications that other custodians place trust in Memorial’s ability to safeguard information in part because of the custodial designations.

- The Memorial submission did not present examples of how the Act has negatively impacted research at Memorial over the last six years. Specifically, it does not provide examples of how the Act has undermined academic freedom, created impediments to research, threatened the commercial viability of research, or reduced the value of intellectual property. With respect to academic freedom, the OIPC asserts that *“PHIA is no more an impediment to academic freedom than the Health Research Ethics Authority Act”*.
- The Act helps Memorial researchers establish trust between researcher and research subject in situations where research is being conducted without consent. The Act provides the research subject with assurances of safeguards, oversight, and accountability.
- Section 71 of the Act ensures that the power of the Commissioner to compel information from custodians is used sparingly and there have not yet been any demands from the OIPC for research information. Moreover, any related investigations by the Commissioner would be in the interest of protecting privacy interests and not hindering academic freedom.
- Comparison to the legislative regimes in Ontario are not “apples to apples” as the Ontario *Personal Health Information Protection Act* *“provides for a completely different regime for the protection of privacy in the course of research, and... does not have an equivalent to the Health Research Ethics Authority Act”*.
- A very recent publication of the Organisation for Economic Co-operation and Development (OECD)<sup>11</sup> recommended principles on health data governance that align with the responsibilities and best practices associated with PHIA custodianship and are presented at the institutional level. These recommendations were developed by an expert group that included prominent Canadian privacy leaders and health research ethicists, and have been *“welcomed by Health Ministers”* representing OECD member countries.

Furthermore, in its written submission, Eastern Health suggests that the custodian designation should be extended to other educational institutions who participate in health research. Though much of the research in this province involving health data occurs at Memorial, it also happens under the auspices of other institutions. This sentiment is supported by the responsive written submissions of the HREB and the OIPC as well.

Memorial’s observation that health research at Memorial is already subject to legislative and ethical requirements by way of HREAA and obligations to the Tri-Council Agencies is indeed valid. However, Memorial’s submission significantly misses the mark with respect to its role in the overall framework established by PHIA, with respect to the relationship between PHIA and the HREAA, and, to some

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<sup>11</sup> Canada is a member country of the OECD.

degree, with respect to the actual considerations given by the Health Research Ethics Board when evaluating research protocols during the ethics review process.

The intent of HREAA is to ensure that health research conducted in this province is done in an ethical manner – protection of personal health information, which is the goal of PHIA, is only one ethical consideration; moreover, the articles of the TCPS2 contemplate an assessment of the protection of personal health information that is limited in scope and does not extend beyond a researcher and their supporting research institution – it does not extend to a larger system/framework in which the researcher and their supporting research institution exist. In contrast, PHIA establishes a framework for information protection that is reflective of the entire province and all the stakeholders and activities within it. Although PHIA achieves many of its objectives by way of requirements placed on individuals and organizations, it also establishes structures and mechanisms that are much bigger, such as rights of access and complaint resolution through a provincial oversight body.

Specifically, the objective in applying the TCPS2 during the ethical review, according to the TCPS2, is “*to strike an appropriate balance between recognition of the potential benefits of research, and protection of participants from research-related harms*”. The TCPS2 is very clear that “*researchers are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants*”. A research protocol for a project that does not involve new data collection, that indicates that the data will only be accessed by the principal research on a single encrypted computer in a locked office, and is backed by the support of Memorial, would likely pass “*information-protection-muster*” when considered by a research ethics board; but the research ethics board does not consider the broader benefit of PHIA, including complaint mechanisms for the public and oversight of the privacy rights of citizens.

In its submission, Memorial rightly points out that a central question in any regulatory scheme is whether the benefits outweigh the burdens. In terms of “*burdens*” imposed on custodians by the Act, the primary considerations are the following:

- develop policies and procedures relating to the protection of personal health information (Section 13);
- ensure that those individuals engaged within the organization take oaths of confidentiality, are aware of the Act, and are aware of the custodian’s policies and procedures relating to the protection of personal health information (Section 14);
- ensure reasonable safeguards and respond appropriately to incidents and breaches (Section 15);
- designate a decision-maker and contact person (Sections 17 and 18);
- advise individuals of information practices and their rights (Sections 19 and 20);
- establish agreements with information managers (Section 22);
- facilitate withdrawals of consent, as appropriate (Section 28); and
- support the rights of access and correction, as appropriate (Part V).

Arguably, these “burdens” are simply matters that an organization should be attending to regardless of their status as a custodian under the Act, as they help ensure that their work is being done in a privacy-respectful manner.<sup>12</sup>

In the case of Memorial, an organization that collects, uses, and discloses vast amounts of personal health information as part of its education and research mandates, the “burdens” on the institution as a custodian are decidedly outweighed by the benefits gained by their fulsome participation in the province’s legislative health information privacy framework. Again, this framework includes complaint mechanisms for the public, oversight of the privacy rights of citizens, and deeper consideration of information protection than that offered by a research ethics board. Moreover, by being fully participant in this provincial framework and compliant with the Act, Memorial can demonstrate their leadership, and contribute to the privacy leadership that the province has shown through the establishment of a robust legislative scheme for health privacy and health research ethics. Memorial’s participation in this legislative scheme makes the legislative scheme even more robust.

In short, Memorial should be the custodian with respect to all activities conducted under its teaching and research mandates. Memorial’s constituent schools/faculties/units should not be custodians in this context, nor should Memorial’s faculty or staff. Custodianship is better placed with the institution itself, with the institution providing necessary and sufficient direction to those participating in or undertaking those activities in order to ensure that personal health information is protected.

The same is also true of other post-secondary educational institutions that use personal health information as part of their education, training, and research mandates. Moreover, to not designate these other organization as custodians under the Act would be unfair to Memorial as it would result in these organizations being less regulated than Memorial. As well, it would be unfair to the other institutions that should be afforded the same opportunity that Memorial has to demonstrate their leadership. Specifically, it would seem both advantageous and appropriate to ensure that the College of the North Atlantic is designated as a custodian under the Act. However, it might be more appropriate to consider custodianship of private training institutions on a case-by-case basis, according to the nature of their operations.

In designating other academic institutions as custodians, they may need some extra time to develop policies, procedures, and other structures in order to be compliant with the Act. As well, consideration should be given to establishing exception mechanisms in the Act to eliminate the need for specific personnel considerations (e.g. oaths of confidentiality, awareness of the duties under the Act) in settings where there is little or no engagement with personal health information. This matter is addressed in more detail in Section 6.6 of this report.

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<sup>12</sup> Generally speaking, the requirements placed on custodians by the Act simply give legislative effect to things that should be done as part of conducting operations in a privacy-respectful manner. In an ideal world, they would be doing them even without privacy legislation – by doing so, they maintain public trust in their organizations and the health system as a whole. Many of the custodian organizations who participated in the Review are to be commended for developing privacy programs before the establishment of provincial privacy legislation.

The arguments put forward by Memorial suggest the need to ensure that academic freedoms are maintained with respect to mandatory disclosures without consent to third parties under the Act (i.e. mandatory disclosures other than those relating to access and correction requests by individuals).<sup>13</sup> Unfortunately, the Review had little commentary to go by in considering this matter, and did not have the time or resources to explore this issue more deeply. It would seem prudent that the Act provide an exemption for research data in all mandatory disclosures except those in response to a summons, subpoena, warrant, demand, order or similar requirement issued by a court, or in response to a rule of court concerning the production of personal health information in a proceeding – in these situations, the judicial system is capable of balancing academic freedoms against other interests.

Interestingly, the fact that only four Memorial schools/faculties were designated as custodians when the Act was first drafted would seem to have artificially limited Memorial's fulsome participation in the province's robust legislative framework (which, to some degree, compromises the robustness of the framework). Of similar interest is the fact that the Centre for Nursing Studies and the Western Regional School of Nursing were designated as custodians even though they are part of regional health authorities who are custodians in their own right; that being said, at no point in the Review did anyone raise the designation of these two nursing schools as custodians separate from their respective regional health authorities as being problematic.

***Recommendation 7*** *Broaden the application of custodianship within the post-secondary academic community.*

***Recommendation 7a*** *Amend the Act to replace the custodial designations associated with Memorial University (i.e. the four schools/faculties currently designated under the Act) with custodial designation of the entire institution with respect to all activities conducted under its teaching and research mandates. For greater clarity, Memorial's constituent schools/faculties/units should not be custodians in this context, nor should Memorial's faculty or staff.*

***Recommendation 7b*** *Amend the Act to designate all public post-secondary institutions operating in the province as custodians under the Act with respect to all activities conducted under their teaching and research mandates.*

***Recommendation 7c*** *Consider amending the Act to designate all persons operating a private training institution under the Private Training Institutions Act as custodians under the Act with respect to all activities conducted under their teaching and research mandates.*

***Recommendation 8*** *To ensure the protection of academic freedoms in the context of mandatory disclosures without consent, consider amending the Act to provide an exemption for research data in all mandatory disclosures except those in response to a summons, subpoena, warrant, demand, order or similar requirement issued by a court or in response to a rule of court concerning the production of personal health information in a proceeding.*

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<sup>13</sup> Where the Act makes a disclosure discretionary, there are no concerns relating to academic freedom – Memorial can simply choose not to disclose.

**Custodianship within the broader Research Community**

In its written submission, the HREB raised an important question as to whether personal health information is adequately protected after disclosure by a custodian for research purposes. There are actually two much broader questions that deserve consideration: is personal health information adequately protected in research settings within the province? and, as was contemplated for Memorial University and other post-secondary academic institutions, would the province's legislative health information privacy framework be more robust if researchers were more fully participant?

As discussed previously, it is important to recognize that many health researchers are subordinate to custodians, and thereby obligated to safeguard personal health information under the Act – indeed, increasing the number of health researchers who are subordinate to custodians is part of the motivation behind Recommendation 7. However, not all health researchers are affiliated with custodians, so the protections envisioned by PHIA are not assured with respect to these researchers, even though these researchers may have made various commitments to a health research ethics board or to custodians who have disclosed information to the researcher. It is to this group of researchers that the existing framework might be expanded.

One possible solution which is common to most Canadian health privacy legislation is to bind health researchers to information protection commitments by way of some sort of agreement. In essence, HREAA is already using this approach by way of the research protocol submitted to a research ethics board or body – where a research project deviates materially from the approved protocol, it can be shut down, and other sanctions can be applied. However, as previously discussed, the focus of HREAA is health research ethics, of which information protection plays only one part. Again, the primary legislative responsibility for ensuring protection of personal health information lies with PHIA, not HREAA.

In considering how such agreements might be leveraged in PHIA, it is important to recognize that PHIA is “custodian-centric” – nearly all the material clauses in the Act that speak to what one can, must, or cannot do, apply solely to custodians. The only context in which research and researchers come into play is via Section 44 of the Act which permits custodians to disclose personal health information without consent for research purposes, provided the research project has been approved by a research ethics board or body under HREAA. To require such agreements be put in place when disclosures are made under Section 44 would do nothing to address the majority of situations in which the health research project only involves personal health information collected directly from patients. Ensuring the protection of health information across the health research community in all situations requires a “re-think”.

The obvious solution is to make all health researchers custodians. As discussed with respect to Memorial University, the advantages to ensuring that all stakeholders engaging with personal health information are fully participant in the province's legislative health information privacy framework are myriad, and far outweigh the supposed “burdens”. In fact, this approach of making health researchers custodians is already being used in New Brunswick and Prince Edward Island.

By having all health researchers in the province participate fully in the province's legislative health information privacy framework (through custodianship), and comply with the Act, health researchers can demonstrate their leadership and contribute to the privacy leadership that the province has shown. As a matter of practicality, situations which might present "nested" or "joint" custodianship in a health research context (e.g. Memorial faculty, staff of an independent research institute, collaboration between two research institutes) would be addressed by Recommendation 1 made in Section 3.1 of this report.

Further, making health researchers custodians addresses the matters raised in the written submission of Sequence Bio, a for-profit corporation participating in health research subject to the federal *Personal Information Protection and Electronic Documents Act* but not PHIA.<sup>14</sup>

***Recommendation 9*** *To ensure legislative protection of personal health information across the health research community, amend the Act to designate all health researchers as custodians (whether or not the health researcher is a natural person).*

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<sup>14</sup> In short, Sequence Bio was proposing an arrangement whereby one could opt-in to oversight by the OIPC, but not necessarily be a custodian. This option would facilitate Sequence Bio's efforts within the province, which rely heavily on public trust, by ensuring provincial privacy oversight of their work. Several other written submissions spoke to the uniqueness of Sequence Bio and their proposed mechanism.



## 4 Personal Health Information

As with the question of custodianship, the Review also anticipated that the written submission process would also elicit many comments on Section 5, the section of the Act that defines “personal health information”.

### 4.1 Definition of “Record”

The written submission of the NLASW called for clarification that “texts” and “emails” are considered records of personal health information under the definition found in Section 2(1)(s) of the Act. The OIPC suggested that this clarification was worth considering.

Section 2(1)(s) of the Act clearly indicates that a “record” is “*in any form*”. To specifically include certain forms in the definition has the potential to make the definition less clear, as it dilutes the impact of the phrase “*in any form*”.

However, a close examination of the definition of “record” is self-referencing. This poor composition should be corrected.

***Recommendation 10*** *To ensure clarity of the definition of a “record” of personal health information, do not amend the Act to indicate specific forms which are included in the definition of “record”.*

***Recommendation 11*** *To ensure clarity of the definition of a “record” of personal health information, amend the Act to eliminate the self-reference included in the definition of “record”.*

### 4.2 Donation of Body Parts and Bodily Substances

The written submission of the OIPC suggested expanding the definition of “personal health information” to better address collection of body parts and bodily substances. Specifically, by way of Section 5(1)(c) of the Act, the definition of personal health information includes information about “*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*”. The OIPC notes that such collections are not always associated with “donations”.

The OIPC is correct to point out that this limitation to donations is unnecessary. However, in considering more appropriate phrasing, it is worth noting that the terms “collection” and “donation” typically have specific use with respect to body parts and bodily substances (e.g. “collect a blood sample”; “donate a kidney”), so care must be taken in choosing new wording.

***Recommendation 12*** *To broaden the definition of “personal health information” to include information about any collection of body parts and bodily substance, amend the Act to replace the phrase “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” found in Section 5(1)(c) with the phrase “the collection, whether as part of a donation or not, of a body part or bodily substance, including information derived from the testing or examination of a body part or bodily substance”.*

### 4.3 Protection of Samples

As well, the written submission of the OIPC suggested that the Review give consideration to the matter of privacy and confidentiality with respect to “tissue samples”. Indeed, this is a very important topic which the OIPC highlighted in a submission to the 2014 ATIPPA Review. As the technological capacity to turn samples into information increases, protection and oversight of biological samples must evolve. However, as the Review considered this topic, it became clear the PHIA is currently well-framed to protect information, but not the biological samples from which information is derived or to which information is attached.

Reframing PHIA to also address the protection of privacy and confidentiality in the context of biological samples would be a challenging task – the handling of biological samples as part of health care comes with a unique set of considerations that are foreign to many who are experts in the handling of health information and vice-versa.<sup>15</sup> The role of PHIA is to protect any information attached to a sample (which might be made more identifiable by way of the sample), or to protect any information derived from a sample. By expanding PHIA to address biological samples, its ability to protect information would be compromised. The legislative duty to protect privacy and confidentiality in the context of biological samples is better addressed by way of amendments to other legislation, or the creation of new legislation.

***Recommendation 13*** Further explore legislative protection of privacy and confidentiality in the context of biological samples.

***Recommendation 13a*** To ensure that the protection of personal health information is not compromised in an effort to legislatively protect privacy and confidentiality in the context of biological samples, do not establish legislative protection of privacy and confidentiality in the context of biological samples by way of amendments to Personal Health Information Act.

### 4.4 Genetic Information

The written submissions of NLCHI and the OIPC both recommended that “genetic information” be explicitly included in the definition of personal health information in order to ensure absolute clarity on the matter. This sentiment was echoed by the HREB in their responsive submission.

At face value, the inclusion of “genetic information” in the definition of personal health information would seem like a good idea; however, with this inclusion comes the challenge of identifying exactly what to define and how to define it. Unfortunately, none of the submissions propose a definition for “genetic information”, likely because it is a difficult concept to capture. Neither the Nova Scotia *Personal Health Information Act*, the Ontario *Personal Health Information Protection Act*, the Alberta *Health Information Act*, nor the Saskatchewan *Health Information Protection Act*, use this term.

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<sup>15</sup> It should be noted that privacy and confidentiality in the context of biological samples does get some consideration in the provincial legislative framework by way of the *Health Research Ethics Authority Act*. The HREAA essentially commits to the application of the *Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans* (TCPS2) and the *International Conference on Harmonization of Technical Requirements for the Registration of Pharmaceuticals for Human Use Guidance E6: Good Clinical Practice: Consolidated Guideline*, both of which speak to the collection, retention, and use of biological samples in the research setting.

Moreover, the Manitoba *Personal Health Information Act*, the Prince Edward Island *Health Information Act*, and the New Brunswick *Personal Health Information Privacy and Access Act* include “genetic information” in the definition of personal health information, but neither defines “genetic information”. Some of the complexity that comes with a specific reference to “genetic information” arises from the fact that it is difficult to identify what “genetic” information is actually “personal” information: does the fact that an individual’s great grandfather had Alzheimer’s disease bear significantly on the individual – perhaps it does if the grandfather and father in the lineage also did as well.

Ostensibly, one could turn to Section 5(1)(d) of PHIA for help in defining “genetic information” because this section includes “registration information” in the definition of personal health information; however, upon closer inspection, one notices that this section is, along with Section 5(1)(g), one of two sections which imprecisely includes “information about information” in the definition of “personal health information”. Rather, it would be better to stick to the approach of articulating exactly what the “information... relates to”, as per the phrasing in Section 5(1). It would seem that the simplest solution, and one that avoids defining “genetic information”, would be to include “information... that relates to genetics”. To ensure that the reader understands that the topic of interest is the genetics of the individual and not the discipline of “Genetics” itself (and to be less terse), some examples might be included to say “information... that relates to genetics, including genes, genetic variation, and genetic heredity”.

***Recommendation 14*** To clearly include information of a genetic nature in the definition of “personal health information”, amend the Act to include the phrase “genetics, including genes, genetic variation and genetic heredity;” as a subsection under Section 5(1) of the Act.

#### **4.5 Information in a Research Context**

The written submission of Eastern Health recommended that the definition of personal health information explicitly include information collected as part of research. This sentiment was echoed by the HREB in their responsive written submission, but the HREB noted that this may already be covered. This matter can be extended further by investigating the need to address not only information collected as part of research, but information in a research context.

Indeed, the definition of “personal health information” established by Section 5 of the Act is primarily focused on the nature of the information and is generally agnostic as to the context in which the information is encountered – the only exception to this neutrality is Section 5(1)(g), which includes “information about the individual that is collected in the course of, and is incidental to, the provision of a health care program or service or payment for a health care program or service”.<sup>16</sup> So as to avoid the risk of creating potential misconceptions about contexts in which certain information might not be considered personal health information, Section 5 should remain as agnostic as possible as to the context in which the information is encountered.

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<sup>16</sup> As discussed in Section 4.4 of this report, this is one of only two subsections of Section 5(1) of the Act that imprecisely includes “information about information” in the definition of “personal health information”.

***Recommendation 15*** *Maintain the agnosticism, with respect to context, of the definition of “personal health information” by not amending the Act in any way that either includes or excludes information from the definition of “personal health information” depending on the context in which it is collected or encountered.*

#### **4.6 Identifying Information**

The written submission of NLCHI spoke to the complexities associated with the definition of “identifying information” found in Section 5(5) of the Act. In its discussion, NLCHI highlighted the fact that they “consider all record-level personal health information to be identifiable”, noting that “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”. Furthermore, they add that “the lack of consistent interpretation of the definition of identifying and de-identified information results in inconsistent safeguarding of data by different custodians”.

NLCHI is quite right to point out that concepts such as “identifying” and “de-identified” are subject to interpretation – even experts in the field cannot agree on a standard definition. Commendably, the Act avoids use of the terms such as “de-identified” and “anonymous”, in favour of “identifying”, for which it offers a definition in Section 5(5). Unfortunately, that definition is also subjective, as it uses the phrase “information that identifies an individual or for which it is reasonably foreseeable in the circumstances that it could be utilized... to identify an individual” (emphasis added).

NLCHI proposes that the Act be “modified to take into consideration the nuances for collecting, using, disclosing, and retaining information that is considered de-identified”, where NLCHI defines information as being “de-identified” when it “has been stripped of identifying information”. This request is actually much larger than it would seem at first glance: information that is not “identifying” is not considered “personal health information” under Section 5 of the Act (and thereby not under the purview of the Act), so for the Act to address nuances associated with information that is “not identifying” (or, as NLCHI calls it “de-identified”) it would need to enter into entirely new regulatory territory. Unfortunately, the Review did not have the time or resources to tackle this challenge; moreover, it is unclear exactly if any benefit would be gained by addressing this category of information in legislation. That being said, NLCHI is to be commended for taking the approach of treating all record-level personal health information as though it were identifiable, as this eliminates the subjectivity of the definition of “identifying information” out of the equation with respect to the standard of protection offered by their organization. Other custodians might benefit from adopting the same position as NLCHI.

In its submission, NLCHI also wanted consideration to be given to addressing “aggregate” information in the Act (e.g. “six patients were diagnosed with coronary artery disease”). This request was also supported by the OIPC in their responsive written submission. Given that PHIA treats all “identifying information” equally (and the earlier discussion does not recommend changes to regulate “non-identifying information”), the question that remains is whether or not there is a way to clarify the definition of “identifying information” by excluding certain aggregate information from being considered “identifying”. Certainly, not all aggregate information is non-identifying, as organizations such as

Statistics Canada have given significant consideration to the privacy implications of “small cell counts”, particularly in small populations and vulnerable populations.

As an example of how aggregate information might be treated legislatively, NLCHI points to the *Alberta Health Information Act*. That Act defines “aggregate health information” as “*non-identifying information about groups of individuals*”. Unfortunately, this definition presumes the information is “non-identifying”; as such, it does not offer value with regards to determining what aggregate information might be non-identifying.

Just as with how PHIA might have regulated “non-identifying” information, the Review also did not have the time or resources to tackle the challenge of precisely articulating what aggregate information should be considered non-identifying; moreover, it is not apparent that further clarity on the definition of “identifying information” could be offered without being inappropriately prescriptive or otherwise jeopardizing the standard of “*information... for which it is reasonably foreseeable in the circumstances that it could be utilized, either along or together with other information, to identify an individual*”

## 5 Other Definitions

### 5.1 Definition of “Agent”

Section 2(1)(a) of the Act defines an agent as *“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”*. Several of the written submissions called for changes to this definition or otherwise highlighted challenges with the definition.

Despite the challenges with this definition, it fits reasonably well within the context of other “actors” relating to a custodian (e.g. employee, contractor, volunteer) – this topic is discussed in further detail in Section 6.1.1 of this report. The responsive written submission of the OIPC suggested that examples might be included to help clarify the definition; however, the nature of the “agent” relationship makes it difficult to identify concise examples that might apply in most circumstances.

### 5.2 Definition of “Minor”

The written submissions of Labrador-Grenfell Health and Western Health both called for clarification on exactly who is considered a “minor” under the Act. As well, Central Health suggested that consideration be given to integrating the concept of “mature minor” into the Act.

Historically, the matter of allowing young people to make health-related decisions, and determining when they have sufficient maturity or capacity to make such decisions, has been the subject of significant debate and study. There is no clear cut direction on which an organization can rely: fixed ages are arbitrarily rigid and do not adequately consider individual situations, yet case-by-case considerations are time-consuming and difficult to apply consistently. The challenges associated with minors in the context of health care extend far beyond the protection of personal health information.

The responsive written submission of the OIPC endeavoured to provide clarity with regards to the definition of “minor”, suggesting that in the absence of any specific reference, the *Age of Majority Act* applies. That is, any individual less than 19 years of age would be considered a minor. Unfortunately, the Review did not have time or resources to properly consider this interpretation, nor did it have the time or resources to explore what guidance might be offered by related acts such as the *Advanced Health Care Directives Act* and the *Child and Youth Care and Protection Act*, as suggested by Labrador-Grenfell Health and Western Health. Moreover, the Review did not have the time or resources to consider how the “mature minor” concept might be worked into the Act, or what the implications might be. Should there be an interest in considering this topic further, the OIPC notes that recent work by Canada Health Infoway on the topic of access to patient portals by “mature minors” might be used as a starting point to understand important considerations.

**Recommendation 16** *In the interest of clarity, consider amending the Act to define the term “minor”.*

### 5.3 Definition of “Guardian”

The written submissions of Central Health and the NLASW, as well as the responsive written submission of the OIPC, suggested the need for clarification on exactly who is considered a “guardian” under the Act. Much like the concept of “personal representative” discussed in Section 8.4.2 of this report, the concept of “guardian” is generally well-understood in common law to be someone legally appointed (and obligated) to provide care. In the interest of clarity it might make sense that the Act define the term; however, it should be noted that other Acts which might be better positioned to define the concept of guardian, such as the *Children and Youth Care and Protection Act*, do not offer a definition.

**Recommendation 17** *In the interest of clarity, consider amending the Act to define the term “guardian”.*

### 5.4 Definition of “Spouse”

The written submissions of Labrador-Grenfell Health and Western Health both called for clarification on exactly who is considered a “spouse” under the Act. Unfortunately, the challenge associated with articulating a mutually agreeable definition of spouse is great, and the Review did not have the time or resources to undertake this effort.

**Recommendation 18** *In the interest of clarity, consider amending the Act to define the term “spouse”.*

#### 5.4.1 Considerations for Cohabiting Partners

Section 7 of the Act establishes a representative who can exercise all the rights or powers of an individual under the Act. In doing so, Sections 7(b) and 7(e) rely on the *Advance Health Care Directives Act* to determine a “substitute decision maker” or “nearest relative”, respectively.

In its written submission, Central Health highlights the fact that PHIA intersects with multiple statutes which contemplate “next of kin” and “nearest relative” in a different way from the *Advance Health Care Directives Act*. Specifically, the *Advance Health Care Directives Act* does not appear to give consideration to a “cohabiting partner”, yet the *Mental Health Care and Treatment Act* and the *Vital Statistics Act* do.

Central Health does make a very good point – it would seem natural that “cohabiting partners” should be considered when identifying a representative who acts on behalf of an individual. However, in the circumstances contemplated by Sections 7(b) and 7(e), it would seem that the *Advance Health Care Directive Act* is the most relevant Act to apply in determining who the representative should be. Notably, other subsections of Section 7 explicitly refer to other Acts as the circumstances warrant: for example, Section 7(g) of the Act considers circumstances where “*where an individual has been certified as an involuntary patient under the Mental Health Care and Treatment Act...*”.

As such, the issue of not considering “cohabiting partners” in determining a “substitute decision maker” or “nearest relative”, as per Sections 7(b) and 7(e) of the Act, is more appropriately addressed by way of amendments to the *Advance Health Care Directives Act*.

**Recommendation 19** *In the interest of clearly outlining the rights of cohabiting partners in health care related decision making in the event of death or other incapacity, consider the appropriateness of*



*including cohabitating partners in the precedence list found in Section 10 of the Advance Health Care Directives Act.*

## 5.5 Definitions of “Research” and “Evaluation”

### 5.5.1 Definition of Research

The term “research” is defined in Section 2(1)(v) of the Act as *“a systematic investigation designed to develop or establish principles or facts or to generate knowledge, or any combination of principles, facts and knowledge, and includes the development, testing and evaluation of research”*. This definition attracted attention during the written submission process. Specifically, NLCHI and the HREB called for a revised definition of “research”.

NLCHI notes that the current definition found in the Act is very broad, and the HREB notes that it is broader than the working definitions commonly used (e.g. the definition of “research” found in the *Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans* (TCPS2), and the definition of “health research” in the HREAA). Indeed, the definition found in the Act is quite broad, presumably because “research” is a very broad concept. The TCPS2 defines research as “an undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation”. The HREAA defines “health research involving human subjects” as *“activities whose primary goal is to generate knowledge in relation to human health, health care and health care systems, and involving human beings as research subjects, health care information respecting human beings and human biological material”*.

In considering the definition used in PHIA, the first matter that must be addressed is whether or not the Act should consider “research” or simply “health research”, or as defined in the HREAA, “health research involving human subjects”. Given that PHIA only contemplates research by a research ethics board or body authorized under HREAA, and that the only such body existing at present is the Health Research Ethics Board, whose mandate is limited to the consideration of health research, there is a reasonable argument to restrict any definitions to “health research”. However, there is no harm, and certainly much greater flexibility, if PHIA considers the broader term – the focus of PHIA is on the protection of personal health information, not the types of research that personal health information might be involved in. As discussed in Section 8.5.8 of this report, there could be situations where personal health information is used in a research project which is reasonably considered to be non-health research. In its responsive written submission, the OIPC argues against harmonizing definitions between PHIA and HREAA, as these Acts have different purposes.

Provided that PHIA chooses to consider “research” (and not simply “health research”), the next matter to consider is how the term is defined. To distill the HREAA definition of “health research involving human subjects” into its non-health components would render a definition something to the effect of “activities whose primary goal is to generate knowledge”. It would seem that the three candidates (the current definition found in PHIA, the definition found in TCPS2, and the distilled HREAA definition) share a common reference to “generating/extending knowledge” – what differentiates them is the additional supporting language. The distilled HREAA definition is the most terse, simply referring to an activity that generates knowledge, and ignoring the “disciplined” and “systematic” elements of the TCPS2 definition.



The current definition found in PHIA incorporates “systematic investigation”, but the phrase “*develop or establish principles or facts or to generate knowledge, or any combination of principles, facts and knowledge*” is a cumbersome way to incorporate the “generating/extending knowledge” concept. Furthermore, the current definition found in PHIA is somewhat self-referencing, including the phrase “*and includes the development, testing and evaluation of research*”, which is problematic.

Given the shortcomings of the current definition of “research” found in PHIA, and the shortcomings of the definition distilled from the definition of “health research involving human subjects” in HREAA, it would seem that the best candidate of the three candidates is the definition found in TCPS2. As a final argument for using the definition found in the TCPS2, it would seem sensible to use a definition crafted by a panel of research ethics experts, despite the expertise that may have gone into crafting the definition of “research” during the drafting of PHIA.

***Recommendation 20*** *Do not amend the Act to replace the definition of “research” with a definition of “health research”.*

***Recommendation 21*** *In the interest of aligning research-related aspects of the Act with key frameworks, consider amending the Act to revise the definition of “research” to align with that found in the “Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2014” (commonly referred to as the TCPS2). Specifically, revise the definition of research to “an undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation”.*

### **5.5.2 Definition of Evaluation**

In its written submission, NLCHI also called for a definition of “evaluation”, a term used throughout the Act in reference to health care programs and delivery, but often confused with “research”. Anecdotally, there are situations where health researchers have incorrectly self-exempted their undertakings from ethical review, claiming that their work is “program evaluation”; similarly, there have been instances where health researchers have brought research protocols to research ethics boards, only to have the research ethics board declare their undertakings as “program evaluation” and not “research”.

Defining “evaluation” within the Act would help to distinguish these two concepts. As expected, the TCPS2 does not contain a definition of “evaluation” or “program evaluation”, as the focus of the TCPS is “research” (as opposed to matters that are not research). However, the Canadian Evaluation Society has expended considerable effort in developing their definition of “evaluation” as “the systematic assessment of the design, implementation or results of an initiative for the purposes of learning or decision-making”. Given the credibility of this professional society and their national efforts, it would make sense to give serious consideration to their definition. Notably, the definition developed by the Canadian Evaluation Society focusses on “learning” and “decision-making”, whereas the TCPS2 definition of “research” focuses on “extending knowledge”.

***Recommendation 22*** *In the interest of clarifying the difference between “research” and “evaluation”, and aligning with key frameworks, consider amending the Act to define “evaluation” to align with the definition developed by the Canadian Evaluation Society. Specifically, define “evaluation” as “the*

*systematic assessment of the design, implementation or results of an initiative for the purposes of learning or decision-making”.*

## **5.6 Definition of “Use”**

The written submissions of both Central Health and the OIPC recommend modifying of the definition of “use” found in the Act. Section 2(1)(aa) of the Act defines “use” as *“to handle or deal with the information or to apply the information, but does not include disclosing the information”*. Both submissions reference the changes found in Ontario’s recent Bill 119 which expand the definition of “use” in the *Personal Health Information Protection Act* to specifically reference “viewing” of information. In the interest of clarity, it would make sense for PHIA to do the same.

**Recommendation 23** *To clearly indicate that viewing of personal health information constitutes “use”, amend the Act to modify the definition of “use” found in Section 2(1)(aa). Specifically, replace the phrase “means to handle or deal with the information” with “means to view, handle or deal with the information”.*

## 6 Practices to Protect Personal Health Information

The written submission process elicited a lot of discussion related to Part II of the Act, which is the part that speaks to practices to protect personal health information. For custodians designated under the Act, Part II is where “the rubber hits the road” in terms of people, processes, and structures that need to be established within an organization in order to maintain compliance.

### 6.1 Existing Actors to a Custodian

The Act currently contemplates seven types of actors who operate under the umbrella of a custodian.<sup>17</sup>

- Employee. Not a defined term under the Act. Using the *Labour Standards Act* as a guide, “a natural person who works under a contract of service for an employer”, in this case the employer being the custodian.
- Volunteer. Not a defined term under the Act. Generally understood to be a natural person who freely gives of their time and effort to assist the custodian.
- Contractor. Not a defined term under the Act. Generally understood to be affiliated with the custodian by way of some sort of contractual service relationship with a non-natural person (i.e. not an employee), such as a corporation, partnership, or sole proprietorship. Written submissions suggest that there is no general consensus on who is a contractor: in some cases, it is perceived to be the non-natural person; in other cases, it is perceived to be the natural person(s) doing the work of the non-natural person (e.g. the employee(s) of the non-natural person engaged in providing the service to the custodian).
- Information Manager. Defined by Section 2(1)(l) of the Act as “a person or body, other than an employee of a custodian acting in the course of his or her employment, that (i) processes, retrieves, stores or disposes of personal health information for a custodian, or (ii) provides information management or information technology services to a custodian”.
- Agent. Defined by Section 2(1)(a) of the Act as “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”.
- Health Care Professionals Treating in Facilities. This group is simply described by reference in Section 14 (“where the custodian is an operator of a health care facility, those health care professionals who have the right to treat persons at a health care facility operated by the custodian”).<sup>18</sup>

<sup>17</sup> Sections 17 and 18 also identify two key groups of actors (designated decision maker; contact persons), but their role is very specific and will be considered elsewhere in this report.

<sup>18</sup> Recommendation 1a proposes changing the definitions of “health care professional” and “health care provider” such that they are natural persons. For the balance of Section 5 of this report, it is assumed that they are natural persons. If the recommendation is not accepted, the recommendations made in Section 5 of this report may need to be adjusted to refer to natural persons in the case of oaths of confidentiality.

- Electronic Means Providers This group is simply described by reference in Section 14(4) (“a person who provides goods or services for the purpose of enabling a custodian to use electronic means to collect, use, modify, disclose, retain or dispose of personal health information”).

Aside from some challenges arising from confusion over exactly who is a contractor, from potential duality of information managers and custodians (see Section 3 of this report), and from determining which category people fit into, this slate of actors does a fairly comprehensive job of capturing everyone who might impact the protection of personal health information by a custodian. That being said, there are some gaps in this slate of actors which unnecessarily limit the protections afforded by Part II of the Act, particularly those afforded by Section 14.

#### **6.1.1 Comprehensiveness of the Definition of Agent**

The definition of “agent” is unnecessarily limited by way of the phrase “*in respect of personal health information*”. Several sections of the Act place obligations on a custodian’s “employees, agents, contractors, and volunteers”, yet the concepts of “employee”, “contractor”, and “volunteer” are not restricted based upon their relationship to personal health information. The definition of agent should not specifically reference personal health information – like employees and volunteers, simply being present in a facility where personal health information is located or using the custodian’s computer systems might expose an agent to personal health information. It would make more sense to define these actors more generally, excluding them from specific requirements depending on their relationship to personal health information in the custodian’s custody or control, as necessary and desirable.

***Recommendation 24*** To eliminate the risk of unintentionally limiting the protections afforded by the Act to only those aspects of a custodian’s activities that directly involve personal health information, groups of actors (with respect to custodians) should not be defined according to their relationship or involvement with personal health information.

***Recommendation 24a*** Amend the Act to remove the phrase “*in respect of personal health information*” from the definition of “agent”.

#### **6.1.2 Comprehensiveness of References to those Treating in Facilities**

Where the custodian is an operator of a health care facility, Section 14 of the Act unnecessarily restricts several requirements to “*health care professionals who have the right to treat persons at a health care facility operated by the custodian*”. Not only does this phrasing limit the requirement to those who “treat” persons, but it also does not include “health care providers”. These references can be made more comprehensive by including these health care providers and using the more inclusive phrase “provide or undertake health care” which leverages, and is consistent with, a comprehensive definition of “health care” found in Section 2(1)(h) and used elsewhere in the Act.

To reduce repetition within the Act and to eliminate the risk of inconsistent phrasing, a definition of these actors should be included in Section 2 of the Act, which can simply be referenced throughout Section 14 as required. The natural choice for this term would likely include the word “provider”; however, use of this word would be confused with the reserved term “health care provider”, so another noun must be used. This Review proposes the term “authorized health care giver”.

***Recommendation 25*** To improve the comprehensiveness of the protections afforded by Section 14 of the Act, amend the Act to replace references to “those health care professionals who have the right to treat persons at a health care facility operated by the custodian” with “those health care professionals and health care providers who provide or undertake health care at a health care facility operated by the custodian”, as appropriate.

***Recommendation 25a*** To reduce repetition within the Act and to eliminate the risk of inconsistent phrasing, amend the Act to: (a) add the following definition to Section 2(1) of the Act: “authorized health care giver’, in relation to a custodian, means a health care professional or health care provider who has the right to provide or undertake health care at a health care facility operated by the custodian”; and (b) reference the definition of “authorized health care giver” throughout the Act as appropriate.

### 6.1.3 Working Students

One of the largest gaps in the existing slate of actors discussed in Section 6.1 of this report is students on educational work placements. Notably, the written submission of the OIPC called for the inclusion of students within the protections afforded by Section 14 of the Act.

The Review has exposed the need to establish clear accountability, responsibility, and oversight for the actions of students on educational work placements (e.g. nurses, physicians, health information management professionals). In its written submission, Memorial University captures the complexity well.

*“The students are located on the premises of these custodians, sometimes as part of the ‘circle of care’. Given that the students are participating in such activities in an educational capacity, it is logical for them to be considered part of the Memorial community. However, such circumstances create the potential for confusion as to which organization is ultimately responsible for the student’s activities and sets up the possibility of conflict between the policies and procedures of the respective organizations”*

Colloquially, one makes reference to people who “wear two hats”. For example, a physician working with Eastern Health might also be a researcher with Memorial. When working with Eastern Health as a physician, they “wear their Eastern Health hat”, operating according to their commitments to Eastern Health and their regulatory college or board. When conducting research, they “take off their Eastern Health hat to put on their Memorial hat”, operating according to their commitments to Memorial University, funding organizations, and research ethics boards. Unfortunately, in the case of students on work placement, they are essentially wearing both hats at the same time – the only reason they are on a work placement with a custodian is because it is part of their educational program. Ultimately, the question that must be answered with respect to these students is “which hat is relevant with respect to the custodian’s accountabilities and responsibilities for information protection?”.

In its written submission, Memorial indicates that they have worked with custodians, such as Eastern Health, to evolve an approach to address these issues. These organizations are to be commended for their efforts to come to a working understanding in the absence of legislative clarity. However, as is the case for health care professionals and providers in group practices (see Section 3.1 of this report),

legislative accountability and responsibility must be clear. The written submission of the OIPC calls for this clarity with respect to oaths of confidentiality contemplated under Section 14(1) of the Act, but oaths of confidentiality are only one consideration.

It would seem natural that the information protection requirements placed on a custodian by the Act that apply to its existing principal actors (employees, volunteers, contractors, information managers, and agents) should also apply to these students. The Act makes the custodian accountable and responsible for personal health information in its custody or control, so the requirements of the Act should be applied to every actor playing a role in the custodian's protection of the information. In short, the objectives of Part II of the Act are compromised if Part II does not, or cannot, bear on these students as actors of the custodian.

As for how to express students on work placements as one of these actors, these students might fall into the category of employee, volunteer, contractor, or information manager from time to time by way of the particulars of their work placement; however, they would not fit any of these categories on a consistent and predictable basis. Notionally, they might fit into the "catch-all" category of "agent", but that necessitates a debate about whether the student is acting "*for the purposes of the custodian, and not the agent's purposes*": the student's personal goals of fulfilling the work placement requirements of their educational program and gaining professional experience are intertwined with the custodian's goals of developing prospective future employees, maintaining relationships with academic institutions, and completing necessary work, so there is a reasonable argument to say that they are not agents.

In the absence of revising the definition of "agent" to better address these students, which might result in unintended consequences, it is best to establish a new definition that applies to these students. A review of other Canadian health privacy legislation highlights that there are a wide variety of terms and language applicable to students on work placement, each with their own nuances, so there is no consistent practice with which PHIA might align.

In articulating this legislative definition, there are a number of considerations:

- To avoid confusion with terms that already have a well-understood meaning, terms such as "practicum", "work term", and "intern" should be avoided.
- It may be advantageous to avoid the term "affiliated" because these students are also affiliated with their respective educational institutions.
- The definition need not be mutually exclusive of the employees and volunteers, as students on work placement may also fall into these categories.
- The definition need not specifically reference student placements, as some education programs might simply require the student to complete a prescribed number of working hours, regardless of whether or not it is done as a volunteer, employee, internship, or other arrangement.
- The definition should not specifically require that the student interact directly with personal health information (see Recommendation 24) – like employees and volunteers, simply being present in a facility where personal health information is located or using the custodian's computer systems might expose a student to personal health information.

- The definition should support the work placements within the educational institution (the educational institution might be a designated custodian).
- The definition should not preclude the possibility that the student works with more than one custodian; rather, it should remain custodian-centric.

***Recommendation 26*** *To support the establishment of requirements that apply to students on work placements with custodians, amend the Act to add the following definition to Section 2(1) of the Act: “working student’, in relation to a custodian, means a student of a post-secondary institution working with, for, or on behalf of, the custodian whether or not the student is being remunerated by the custodian”.*

## 6.2 Direct vs. Indirect Custodian Relationships

Sections 14 and 22 of the Act outline very specific requirements of custodians with respect to their actors, and Section 15 outlines requirements of custodians that likely impact their relationships with these actors. Specifically, custodians must

- ensure that certain actors take oaths of confidentiality (Section 14(1)); and
- make certain actors aware of the duties imposed by the Act and the information protection policies and procedures of the custodian (Section 14(3)).

Furthermore, some of these actors are expected to comply with the Act (Sections 14(2)(a), 14(4), and 22(4)(a)) and information protection policies and procedures of the custodian (Section 14(2)(b)).

It goes without saying that a custodian can readily exercise control over any subordinate, natural or otherwise, with whom they have a direct relationship. Specifically, in the case of employees and volunteers, they might use employment/volunteer contracts, documented policies and procedures, and training sessions. In the case of their service providers, they would likely use business contracts.

However, beyond this direct relationship (i.e. beyond the “first degree of separation”), a custodian can only exercise control by way of requirements placed on a person it has a direct relationship with. For example, Eastern Health might engage a records management company to store health records at an offsite facility. If Eastern Health wants the cleaning staff of the records management company to follow certain practices when working around the records, Eastern Health must do so by way of its contract with the records management company. Those cleaning staff might be employees of the records management company, or the records management company might engage a cleaning company to deliver cleaning services. Most service providers would dislike having a customer provide direct instruction to their employees, let alone their subcontractors.

Moreover, in exercising this control, it is helpful for the custodian to articulate requirements that are not overly prescriptive. In the example above, consider some of the challenges that might present if Eastern Health were to contractually obligate the records management provider to have all the personnel working at the records management facility participate in an Eastern Health privacy training session. Eastern Health and records management provider would need to find a mutually convenient time to run the session(s) and Eastern Health would need to deliver the session on an ongoing basis in order to train

new personnel as they begin working at the facility. It would be much simpler, and likely just as effective, for Eastern Health to contractually obligate the records management provider to ensure that the personnel are trained according to a privacy curriculum set by Eastern Health (Eastern Health would likely need to reserve the right to audit this training, etcetera). The objective is to ensure that personnel working in the facility are sufficiently trained in privacy – exactly how this objective is achieved is not critical.

As discussed in the Eastern Health written submission, requiring a custodian to ensure that the staff of a service provider take an oath of confidentiality (which is legally binding) is a complicated matter. Some employees of the business entity may not interact with the personal health information under the custody or control of the custodian, or they might be one of thousands of employees who might possibly interact with that personal health information (e.g. a call centre). Moreover, if these staff do not live in the province, it becomes more challenging to take an oath in accordance with the *Oaths Act*. And, if the service provider subcontracts the work out to another business entity, the custodian must contractually ensure that obligation to take oaths of confidentiality is passed on in subcontracts.

Attempting to exercise control at a “second degree of separation” is not inherently wrong – indeed having people take oaths of confidentiality assures strong personal accountability – but it does introduce additionally complexity. Attempting to do so is much like fitting the proverbial “square peg” in the proverbial “round hole”. Instead, business relationships require business-level solutions (e.g. contracts), not individual-level solutions (e.g. oaths).

In the case of business relationships, attempting to prescriptively obligate a service provider may mean that the contractual relationship with the service provider cannot be established or must come to an end. The Act must be careful to not require custodians to prescriptively obligate service providers, except where it is absolutely imperative; it is preferable that the Act focus on what information protection objectives needs to be achieved, as opposed to how they need to be achieved.

Section 15 of the Act is the least prescriptive, simply requiring custodians to “*take steps that are reasonable in the circumstances*” to ensure various information protection objectives. Section 22 of the Act, which speaks to information managers, is only slightly prescriptive. In comparison, Section 14 of the Act is more prescriptive than Section 22. In addition to prescriptiveness, Section 14 suffers from a lack of precision: it appears to be trying to place obligations on natural persons (e.g. employees, volunteers), but relies on definitions that include non-natural persons as well as undefined terms that can be interpreted to refer to non-natural persons. Much of the remainder of Section 6 of this report attempts to rework these requirements and obligations such that business-level solutions are used for business relationships, and individual-level solutions are used for natural persons.

### **6.2.1 Clarifying the Definition of “Contractor”**

As discussed in Section 6.1 of this report, “contractor” is not a defined term under the Act. Generally, a “contractor” is understood to be affiliated with the custodian by way of some sort of contractual service relationship with a business entity such as a corporation, partnership, or sole proprietorship (and, more importantly, not an employee or volunteer, as these are not business entities). Written submissions



suggest that there is no general consensus on who is a contractor: in some cases, it is perceived to be the business entity; in other cases, it is perceived to be the natural person(s) doing the work of the business entity (e.g. the employee(s) of the business entity).

This complication arises principally by way of Section 14(1)(a) of the Act, which requires custodians to “ensure that its... contractors... take an oath or affirmation of confidentiality”. Oaths are only taken by natural persons, so there are two possible interpretations:

- A “contractor” must be a natural person.
- The individuals working with/for the custodian by way of business relationships with business entities (the business entities being “contractors”) must take oaths of confidentiality.

The confusion is exacerbated by the definitions of “agent”, “health care professional”, and “health care provider”: according to the definitions found in Section 2(1) of the Act, they need not be natural persons.<sup>19</sup> Yet, “agents”, and in some cases “health care professionals” and “health care providers”, are also expected to sign oaths of confidentiality.

In the absence of convincing evidence to suggest the original meaning intended by “contractor”, there is a consideration that suggests a suitable approach going forward. Where a contract is established with an individual, that individual is either doing so to become a contractual employee or to establish a business relationship as a sole proprietor. In the case of the former, the scenario is already addressed by use of the term “employee” throughout Section 14. As such, the term contractor might be best defined in terms of a business entity.

***Recommendation 27*** *To better support the establishment of requirements that apply to custodians with respect to business entities with whom they engage, amend the Act to add the following definition to Section 2(1) of the Act: “contractor’, in relation to a custodian, means a business entity with whom a custodian enters into a business relationship”.*

### **6.2.2 Agreements for Service**

Section 22 of the Act outlines a set of requirement to ensure that custodians and information managers establish a business relationship that is respectful of health information privacy and compliance. However, as the OIPC rightly points out in the written submission, this protection need not be limited to “information managers”, and should be established for “agents” and “contractors” as well. No opposition to this suggestion was received in the responsive written submissions.

***Recommendation 28*** *To better ensure protection of personal health information in business relationships, amend the Act to extend the requirements of Section 22 (“information managers”) to “agents” and “contractors” whose role, with respect to the custodian, requires them to collect, use, disclose, maintain, destroy, or otherwise interact with or handle personal health information.*

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<sup>19</sup> Recommendation 1a proposes revising to definitions of “health care professional” and “health care provider” to refer only to natural persons.

### 6.3 Oaths of Confidentiality

Section 14(1) of the Act requires custodians to ensure that various actors take an oath or affirmation of confidentiality. In the absence of direction to the contrary, oaths and affirmations need to be taken in accordance with the *Oaths Act* – failing to maintain confidentiality could result in perjury charges in accordance with the *Oaths Act*.

#### **Who should take an Oath of Confidentiality?**

As discussed in Section 6.2.1, oaths of confidentiality can only be taken by natural persons; yet, the definitions of “agent”, “health care professional”, and “health care provider” found in Section 2(1) of the Act includes non-natural persons. As such, Section 14(1) of the Act should be amended to more precisely refer to natural persons.<sup>20</sup> Similarly, this section should be amended to eliminate the reference to contractors (based on the definition proposed in Recommendation 27). Though these amendments are not technically a removal of contractors and non-natural agents from the oath of confidentiality requirement, but rather a clarification to address existing issues with Section 14, these amendments should not significantly lessen information protection or accountability with respect to these actors. The remaining requirements found in Section 14 will still apply to these actors, and the use of contractual obligations to maintain confidentiality when working with contractors and non-natural agents are, arguably, “reasonable” steps that a custodian might take in addressing the requirements imposed by Section 15 of the Act.

Also, “working students” should be included in the actors taking oaths, as they should be accountable for their actions in the same way that employees, volunteers, and agents who are natural persons are.

Finally, in support of Recommendation 25, the actors taking oaths can now leverage the definition recommended in Recommendation 25a.

***Recommendation 29*** *To better ensure the commitment to confidentiality at the personnel-level, amend Section 14(1) of the Act such that custodians must ensure that oaths of confidentiality are taken by its employees, its volunteers, its working students, its agents who are natural persons, and its authorized health care givers.*

#### **Particulars about Oaths of Confidentiality**

Based on the current wording used in Section 14(1) of the Act, the intention of this section appears to be that the oath of confidentiality should apply with respect to all information in all circumstances. In its written submission, Eastern Health recommended clarifying the form of the oath of confidentiality contemplated by Section 14(1) of the Act. Similarly, the OIPC recommended that the elements of these oaths be prescribed in regulations to the Act to “ensure that the oath effectively becomes a commitment by the individual not to do the things outlined in the offence provisions”. As well, the OIPC suggested that oaths be renewed every three years or when someone changes their position within an organization.

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<sup>20</sup> Recommendation 1a proposes revising to definitions of “health care professional” and “health care provider” to refer only to natural persons.

Indeed, the exact phrasing which best achieves a commitment to confidentiality by way of an oath can be debated – anecdotally, the wording used by custodians in their oaths of confidentiality is varied. And, failing to maintain confidentiality could result in perjury charges in accordance with the *Oaths Act*, but might not result in charges or prosecution under the offence provisions found in PHIA – by committing to the offence provisions, there is a greater likelihood of charges and prosecution in cases of inappropriate behaviour.

As suggested by the OIPC, it would seem practical to allow the particulars of the oaths contemplated under Section 14(1) to be specified in regulation if required; moreover, it would seem advantageous to strengthen the ability to prosecute under the offence provisions of the Act through a commitment to the provisions by way of these oaths.

***Recommendation 30*** Amend the Act to allow the creation of regulations that enable the particulars of the oaths and affirmations contemplated by Section 14(1) to be specified.

***Recommendation 30a*** Consider establishing regulations to the Act that require the oath or affirmation contemplated by Section 14(1) to require a commitment to the offence provisions of the Act.

***Recommendation 30b*** Consider establishing regulations to the Act that require the oath or affirmation contemplated by Section 14(1) to be renewed at least once every three years.

#### **6.4 Compliance with Act and Policy**

Section 14(2) of the Act requires various actors (with respect to a custodian) to comply with the Act and as well as the policies and procedures established by the custodian with respect to the protection of personal health information (in accordance with Section 13 of the Act). Essentially, Section 14(2) of the Act embeds compliance with these policies and procedures within the Act, thereby elevating these policies and procedures to law.

The written submission of CNPS argues that this reference to policies and procedures is problematic because there can be a conflict between the Act and these policies and procedures. In its responsive written submission, the OIPC refutes the CNPS claim, arguing that they have not provided any evidence to suggest the problem is anything but theoretical. Moreover, a close examination of Section 13(1) of the Act reveals that these policies and procedures must “ensure compliance with” the Act, arguably invalidating any elements of a custodian’s policy and procedure that conflict with the Act.

Furthermore, in its written submission, CNPS takes exception to the fact that these policies and procedures are elevated to the status of law by way of Section 14(2)(b) of the Act. The elevation of these policies and procedures is an interesting characteristic of PHIA, as it has the potential to establish different legislative standards within different organizations. For example, one organization might require its staff to shred all paper slated for disposal, whereas another organization might require its staff to only shred those documents which are known to contain personal health information (perhaps the former organization has regularly seen personal health information scribbled on newspapers as a matter of convenience). In another example, one organization might ban the use of paper clips, while

another may not (perhaps the former organization has had multiple breaches involving documents that have accidentally gotten attached to one another by way of entangled paper clips).

Even if it does possibly create different standards in different organizations, the elevation of these policies and procedures to law is not necessarily problematic. The Act outlines a set of “motherhood” requirements with which every custodian must comply (e.g. reasonable safeguards) and obligates custodians to establish policies and procedures “to facilitate the implementation of, and ensure compliance with, [the] Act...” (which, at a minimum, address the topics listed in Section 13(2) of the Act). This approach allows the Act to avoid prescriptive statements about how the “motherhood” requirements are achieved (e.g. use of encryption), instead allowing the custodian to meet these “motherhood” requirements through the establishment policies and procedures tailored to the custodian’s specific circumstances. However, in exchange for this latitude, the Act makes non-compliance with these policies and procedures more than simply a human resources or contractual affair – it is a matter of legislative compliance.

Other than the submission from CNPS, which the OIPC effectively counters on most points, there is little evidence to suggest that this clever interplay between statute and policy is causing problems. Notably, in its responsive written submission, Central Health recommended not removing this requirement to comply with policies and procedures, as doing so would downgrade compliance to a human resources issue. And, finally, the OIPC used its written submission to reiterate its standing offer of assistance to custodians who are developing such policies and procedures.

That being said, the set of actors to which Section 14(2) applies should be revised to reflect the newly established and revised groups discussed throughout Section 6 of this report.

***Recommendation 31*** *To better ensure compliance with the Act and organizational policy at the personnel-level, amend the Act such that the current obligations under Section 14(2) are applied to a custodian’s contractors, agents, employees, volunteers, working students, and authorized health care givers.*

## **6.5 Awareness**

The Review did not identify any issues with Section 14(3) of the Act which requires custodians to ensure that various actors are aware of the duties imposed by the Act, as well as the information policies and procedures contemplated in Section 13(1). Nor did it identify any issues related to the role of the “contact person” in respect of this awareness as contemplated in Section 18(2)(b). However, the set of actors to which Sections 14(3) and 18(2)(b) apply should be revised to reflect the newly established and revised groups discussed throughout Section 6 of this report.

***Recommendation 32*** *To better ensure awareness of the duties imposed by the Act and organizational policy at the personnel-level, amend the Act such that the current obligations under Section 14(2) (awareness of duties) and Section 18(2)(b) (“contact persons” role in ensuring awareness of duties) are with respect to a custodian’s contractors, agents, employees, volunteers, working students, and authorized health care givers.*

## 6.6 Exceptions to Personnel-Level Requirements

For most custodians currently designated under the Act, personal health information is pervasive throughout their scope of operations. In the interest of having more organizations participate in the province's legislative health information privacy framework, this report recommends that some additional organizations be designated custodians. For some of these new custodians, personal health information may only be present in a portion of their operations. For example, Recommendation 7 would make Memorial University itself a custodian; however, there are many academic departments of Memorial which are unlikely to encounter personal health information as part of their regular operations.

Consideration should be given to establishing exception mechanisms in the Act to eliminate the need for specific personnel considerations (e.g. oaths of confidentiality, awareness of the duties under the Act) in settings where there is little or no engagement with personal health information. That being said, identifying settings in which there is little or no engagement with personal health information is more difficult than it seems. For example, it might be reasonable to assume that a Memorial faculty member in Classics would not have engagement with personal health information. However, a faculty member in Linguistics might undertake linguistic research related to the impact of speech impediments or facial injuries on various languages or dialects. Moreover, health information is often unintentionally shared with others in a custodian organization by way of incorrectly addressed emails, poor permission setting on shared data stores, misplaced/uncontrolled paper documents, and overheard conversations.

Because it is difficult to identify settings where there is definitively little to no engagement with personal health information, and because health information is often unintentionally shared with others in a custodian organization, there is a valid argument for not establishing such exception mechanisms. Moreover, to alter the status quo without further discussion amongst stakeholders might have unintended consequences.

If an exemption mechanism were to be created for the somewhat prescriptive requirements of Sections 14(1)-(3) in order to prevent their application in setting where there is little to no engagement with personal health information, there is an offsetting measure that can be applied. It would not be unreasonable to expect custodians to document the rationale for such exemptions, as the significant accountability placed on them by way of the Act suggests that they should have a solid understanding of the involvement of personal health information throughout their organization.

***Recommendation 33*** *To reduce unnecessary burdens on custodians, consider amending the Act to establish exception mechanisms that eliminate the need to undertake specific personnel-related protections (i.e. Sections 14(1)-(3) of the Act) in settings where there is little or no engagement with personal health information.*

***Recommendation 34*** *Should the Act be amended to establish exception mechanisms that eliminate the need to undertake specific personnel-related protections in settings where there is little or no engagement with personal health information, further amend the Act to require custodians to document the rationale for why such exceptions should apply in these settings.*

## 6.7 Privacy Impact Assessments

Section 15(1) of the Act requires custodians to “*take steps that are reasonable in the circumstances*” to ensure the security of personal health information in its custody and control. This type of phrasing is common to most Canadian privacy legislation, as it is very difficult to identify exactly what measures should be taken to safeguard personal health information in all circumstances. In some cases, it might suffice to maintain records in a locked filing cabinet in a locked office. In other circumstances, electronic records might need to be encrypted within an access controlled data centre behind strong firewalls.

Naturally, determining what is “*reasonable in the circumstances*” is a subjective process, and most organizations struggle to determine what safeguards to apply. In its written submission, the NLMA highlighted the need for the identification of best practices relating to security, and other custodians used the written submission process to call for guidance on various topics. Exactly who should be providing this guidance is not the focus of this Review; however, it is fair to say that the OIPC, Department of Health and Community Services, and professional associations all play a role.

The question of interest is “what are the best practices related to the safeguarding of personal health information that should and can be prescriptively enshrined in legislation?”. As discussed in Section 6.2 of this report, prescriptive legislative requirements must be introduced judiciously because, despite good intentions, they often present significant implementation challenges.

In its written submission, the OIPC called for one such best practice to be enshrined in the Act: the use of Privacy Impact Assessments (PIA). A PIA is an assessment tool used to evaluate the impact on privacy that results from change to a system, environment, or process; for example, such change might take the form of a revised policy, a software upgrade, or the introduction of new technology. A PIA is conducted by considering the system, environment or process in the context of privacy principles, privacy-related best practices, privacy-related codes of conduct, privacy-related legislation, and relevant privacy-related directives. PIAs serve to inform relevant stakeholders and decision-makers on privacy considerations pertaining to the system, environment, or process; as such, PIAs should be timed so as to allow the findings of the assessment to factor into decision-making processes. PIA reports are “living” documents that should be revisited whenever there is further change to the system, environment, or process.

Use of PIAs is a generally accepted best practice within organizations that are truly committed to privacy, and are prepared to expend the effort necessary to understand how privacy is impacted by their operations and to modify weak practices. Indeed, the OIPC rightly notes that PIAs can “*become part of the analysis in determining whether there has been compliance with section 15 of PHIA*”. Notably, ATIPPA, 2015 enshrines the use of PIAs in very limited circumstances relating to executive government.

However, the OIPC’s call for PIAs attracted numerous comments in the responsive written submissions. The comments spoke to the challenges around who should complete PIAs, when PIAs should be done, whether submission of PIAs to the OIPC should be mandatory, when the OIPC should review PIAs, how quickly the OIPC should review PIAs, and what format PIAs should take. These challenges did not go unnoticed by the OIPC, as the OIPC spoke to them in their written submission, and also took the

opportunity to further address some points in a letter to the Review following the responsive written submissions.

When PIAs are comprehensive, well-timed, and performed by adequately skilled personnel, they can be very helpful. However, the practical questions relating to execution suggest that they not be enshrined as a requirement in legislation. As an alternative middle ground that recognizes PIAs as a best practice while still allowing custodians latitude in execution of PIAs, the policies and procedures which a custodian must establish by way of Section 13(1) can require custodians to address PIAs.

***Recommendation 35*** *The Act should not be amended to establish prescriptive requirements regarding Privacy Impact Assessments, but should be amended to require custodians to address Privacy Impact Assessments by way of policy and procedure. Specifically, amend Section 13(2) of the Act to include policies and procedures to “ensure comprehensive and documented assessment of the privacy impacts, by appropriately-qualified personnel, of all aspects of the custodian’s operations relating to personal health information in their custody or control in order to address: (a) the format of such assessments; (b) the timing of such assessments; (c) the integration of the findings of such assessments into the custodian’s decision-making processes; (d) the submission of such assessments and their findings to the commissioner; and (e) the presentation of such assessments and their findings to the general public”.*

## **6.8 Notification and Reporting of Incidents/Breaches**

Under Sections 15(3)-(7) of the Act, there are certain circumstances in which custodians must notify affected individuals when the security of personal health information about them has been compromised, as well as circumstances in which custodians must inform the Commissioner of such incidents. In the privacy community, these practices are commonly referred to as “breach notification” and “commissioner reporting”, respectively.

### **6.8.1 Commissioner Reporting**

Under the Act, “breach notification” does not necessarily trigger “commissioner reporting”. Specifically, under Section 15(4) of the Act, custodians are only required to notify the commissioner of incidents when the incident meets the threshold of being a “material breach”, which is defined in the *Personal Health Information Regulations* established under the Act.

In its written submission, the OIPC recommended that “breach notification” trigger “commissioner reporting” in all circumstances. In the absence of such an automatic trigger, the OIPC is somewhat hamstrung in its efforts: it cannot effectively track the number and nature of incidents over time in order to target its activities towards maximal impact, and it cannot effectively respond to individuals who might reach out to the OIPC following “breach notification”. As expected, a few of the larger custodians responded to this recommendation in their responsive written submissions: some disagreed with the OIPC recommendation because of the workload implications, and some agreed with the OIPC recommendation but noted the workload implications.

Indeed, the relationship between “breach notification” and “commissioner reporting” is mixed in Canadian privacy legislation, and is a topic commonly discussed in the privacy community. The debates are often predictable, some noting high volumes of seemingly trivial privacy incidents requiring “breach



notification” and excessive “paperwork” associated with “dealing with the Commissioner”, and others seeing the value in having the Commissioner be fully participant in the breach response process.

One of the arguments that often gets less attention has to do with the fact that, although the Commissioner is sometimes required to act as an “enforcer”, a large portion of their time, resources, and energy is spent in helping and empowering stakeholders. If the Commissioner is only working with partial knowledge, they cannot effectively “have their finger on the pulse” of privacy within their jurisdiction, thereby limiting their ability to support stakeholders and build a privacy-conducive environment. Notably, when participants in the PHIA Review Survey were asked to identify “which statement best matches your preference for a clinic or hospital to tell the Information and Privacy Commissioner about privacy breaches?”, 68% of respondents (based on 56 responses) chose the answer “I want the Information and Privacy Commissioner to be notified every time”.<sup>21</sup> Where responses were limited to those not affiliated with health organizations, this percentage rose to 83% (based on 24 responses).<sup>22</sup>

Indeed, there are workload implications associated with helping the Commissioner be fully engaged, but this investment of time, resources, and energy by custodians will benefit everyone in long term – arguably, all larger custodians in the province should be meeting with the OIPC on a regular basis (“breach reporting” only represents one opportunity to ensure the Commissioner is fully engaged and participant). That being said, the OIPC must ensure that processes for engaging with their office are streamlined, valuable, and affirming.

With respect to “breach reporting”, there is an important subtlety in Section 15 that should be addressed. Section 15(5) allows the Commissioner to “*recommend that the custodian... notify the individual who is the subject of the information*” of a compromise that the custodian is not required to notify the individual about. Yet, in the absence of guaranteed “breach reporting” to the Commissioner, the Commissioner might not learn about such circumstances, or make recommendations, until very late in the process, if at all.

***Recommendation 36*** *To better ensure that the Commissioner can more execute their mandate, amend Section 15 of the Act to ensure that the details of incidents involving the compromise of personal health information, and any associated notification of affected individuals, are reported to the Commissioner if: (a) individuals are notified that personal health information about them has been compromised, whether required by the Act or not; or (b) any of the criteria found in Sections 15(3)(a)-(d) are met.*

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<sup>21</sup> The alternative answers to this question were “I want the Information and Privacy Commissioner to be told most of the time, but there might be situations where it is OK to not tell the Information and Privacy Commissioner” (30%), “None of the above” (0%), and “I have no opinion” (2%).

<sup>22</sup> In analyzing the data from the PHIA Review Survey, a respondent was deemed to be not affiliated with a health organization if they responded “no” to the question “Are you currently associated with an organization or facility that handles health information? For example, are you an employee, temporary/casual/contract worker, or volunteer with an organization such as a health clinic, a private healthcare practice, a hospital, a regional health authority, a government health-related program/insurer/corporation, or a health-related department/program of an academic institution?”.



***Recommendation 36a*** *Should Recommendation 36 be adopted, amend the Act to remove the existing “material breach” trigger for Commissioner reporting that is found in Section 15(4) of the Act (Recommendation 36 eliminates the need to consider a “material breach” threshold for reporting incidents to the Commissioner).*

### **6.8.2 Exemptions for Risk of Harm**

Section 15(7) of the Act outlines two scenarios in which the “breach notification” is not required: namely, when the compromise “*will not have an adverse impact upon the provision of health care or other health benefits to an individual... or the mental, physical, economic or social well-being of the individual*”.<sup>23</sup> In its written submission, the OIPC recommended including an exemption in situations where notification “*could reasonably be expected to result in a risk of serious harm to the mental or physical health or safety of the individual who is the subject of the information or another individual*”. This language is consistent with that used in Section 58(2)(d)(i) to establish an exemption to the requirement to provide an individual with access to personal health information about them.

Inclusion of this exemption for health and safety would seem prudent. Indeed, in its responsive written submission, Central Health agreed with the OIPC.

On this point, it should be noted that Eastern Health called for the elimination of the “double negative” structure used in Section 15(7) of the Act, as it is potentially confusing. There is nothing inherently wrong with the negations used in this provision; moreover, current structure is desirable – the default posture is to notify individuals, and Section 15(7) grants exemptions where certain harms are not present.

***Recommendation 37*** *To prevent harming individuals as a result of notification of breaches or exceptional circumstances, amend Section 15 of the Act to include an additional exemption to the requirements of Sections 15(3) (“breach notification”) and 20(3) (exception notification) when notification “could reasonably be expected to result in a risk of serious harm to the mental or physical health or safety of the individual who is the subject of the information or another individual”.*

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<sup>23</sup> In addition to providing exemptions for “breach notification”, Section 15(7) of the Act also provides exemptions for Section 20(3), which requires custodians to notify individuals when personal health information is not collected, used, or disclosed in accordance with the policies and procedures established under Section 13(1). Sections 15(3) and 20(3) are intimately connected: in each case, personal health information has been comprised in some way.

## 7 Consent

Part III of the Act addresses consent. This topic did not attract a great deal of commentary through the written submission process – notably, NLCHI simply noted that, overall, Part III of the Act supports their efforts to develop the provincial Electronic Health Record. However, some of the comments received were certainly of interest to the Review.

### 7.1 Flow of Consent Directives

In its written submission, the NLMA noted that the flow of “consent directives” between information systems is a topic that needs consideration.<sup>24</sup> The OIPC agreed with the NLMA in their responsive written submission, suggesting it be a topic for further discussion.

At the heart of this topic lies the fact that most members of the general public see the health system as being highly interconnected, with substantial integration between points of care. For example, they visit a physiotherapist, who suggests a visit with a family doctor, who makes a referral to a specialist, who writes a prescription, etc. As such, most patients would assume that if they were to set a consent directive with one practitioner, it would be honoured across the health care system (at least in the province). However, most people who are more familiar with the inner workings of the health system know that the information systems that support care are not yet robustly interconnected, and that a consent directive captured in one system might not make sense in another. As a result, patients who want to place consent directives that apply across the health system must do so with dozens of entities and organizations, if not more.

This interconnectedness and passing of consent directives is not something that is presently contemplated by the Act. Instead, the Act focuses on personal health information, primarily telling custodians what they must, cannot, or can do with personal health information based on the consent that has been established. Unfortunately, the Review did not have the time or resources to consider this topic in any detail; moreover, it is unclear what role legislation would play in facilitating the passing of consent directives, whether in electronic form or not. That being said, in order to give the substance of Part III greater effect, it is a topic that needs advancement.

That being said, it is perfectly reasonable to expect a custodian to assist individuals inquiring about control of personal health information. Specifically, they can inform them of what consent options are available within the custodian organization, facilitate any requests for consent directives, inform them that there may be other organizations and facilities with whom they may wish to set consent directives, and provide reasonable assistance in connecting them with these other organizations and facilities. The “duty to assist” is discussed in further detail in Section 9.1 of this report.

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<sup>24</sup> “Consent directive” is a term commonly used to refer to an instruction, given by an individual, to place restrictions on how personal information about them is collected, used, disclosed, or otherwise handled. Most Canadian health privacy legislation allows for individuals to give such instructions, including withdrawal of consent, in various circumstances.

***Recommendation 38*** *In order to give greater effect to an individual’s right to control the flow of personal health information about them as contemplated by Part III of the Act, consider initiating a dialogue amongst stakeholders regarding the passing of consent directives (whether or not they are in electronic form).*

***Recommendation 39*** *To better empower individuals to control the flow of personal health information about them as contemplated by Part III of the Act, amend the Act to require custodians to do the following when an individual inquires about control of personal health information: (a) inform the individual of what consent options are available within the custodian organization; (b) facilitate any requests for consent directives; (c) inform the individual that there may be other organizations and facilities with whom they may wish to set consent directives; and (d) provide reasonable assistance in connecting the individual with these other organizations and facilities.*

## **7.2 Implied Consent and the “Circle of Care”**

For various custodians who are closely connected to the provision of care, Section 24(2) of the Act gives these custodians the ability to rely on implied consent for the use and disclosure of personal health information as part of the “circle of care”. This topic attracted some comments as part of the written submission process.

### **7.2.1 Clarifying the Definition of “Circle of Care”**

Section 24(3) of the Act defines the “circle of care” as “*the persons participating in and activities related to the provision of health care to the individual who is the subject of the personal health information and includes necessarily incidental activities such as laboratory work and professional consultation*”. In its written submission, the NLMA highlighted that the “circle of care” is often interpreted inconsistently, and called for further clarification. This sentiment was echoed by the HREB in their responsive written submission. However, other than a very specific request by the NLMA to include “family physicians” within the “circle of care” unless explicitly excluded by the individual, neither party proposed a clarification.

A close examination of the definition of “circle of care” found in the Act indicates that it does a reasonably effective job of articulating what is intended by this very imprecise concept. Professional associations are encouraged to work with their members and with other associations to ensure that practitioners have a consistent interpretation.

With regards to the NLMA’s request to include “family physicians” within the “circle of care” unless explicitly excluded by the individual, to do so would not be consistent with the privacy-related aspects of the “circle of care”. In considering this matter, it is useful to first consider that the concept of “family physician” is ambiguous in its own right: a “family physician” is simply a physician with whom a patient has a regular or close relationship with – a patient could have more than one such physician (or none at all). Although such a physician can often add value to a circle of care, there might be circumstances where they are not needed and the patient does not want them to be involved. To include someone in the “circle of care” when they are not required to support care, without the patient’s knowledge, would be problematic. Based on this rationale, the OIPC spoke against the suggestion of the NLMA in their responsive written submission.

The March 2017 report of the “All-Party Committee on Mental Health and Addictions” recommended that *“consideration be given to amending the legislation to ensure family members and caregivers providing support to, and often living with, an individual with a mental illness or addiction, have access to the appropriate personal health information necessary to provide that support”*. Indeed, family members and caregivers (which might include spiritual care) play a vital role in providing support and care, whether the care and support be related to mental illness and addiction or not.

To support this work, Section 25(1) of the Act needs attention. This section reads as follows:

*“Notwithstanding subsection 24(1) [which permits consent to be either express or implied], where a provision of this Act requires the consent of the individual to the disclosure of his or her personal health information, the required consent shall be express and may not be implied where (a) a custodian discloses the personal health information to a person that is not a custodian; or (b) a custodian discloses the personal health information to another custodian and the disclosure is not for the purpose of providing health care or assisting in providing health care.”*

In its written submission, the OIPC argues that the current phrasing precludes a custodian from relying on implied consent for sharing personal health information with non-custodians, such as family members, as part of the “circle of care”. This interpretation would appear to be accurate, but even if it is not, the phrasing certainly complicates the matter of relying on implied consent for the sharing of personal health information with non-custodians. Any disclosure for *“the purpose of providing health care or assisting in providing health care”* should be able to rely on implied consent until this consent is withdrawn, regardless of who the information is disclosed to.

***Recommendation 40*** *To ensure that the “minimum necessary” principle is upheld with respect to the “circle of care”, do not amend the Act to automatically include a “family physician” as part of the “circle of care” unless explicitly excluded.*

***Recommendation 41*** *To better support the participation of family members and other non-custodians in care giving, amend Section 25(1) of the Act so that a custodian can rely on implied consent for the disclosure of personal health information for the purpose of providing health care or assisting in providing health care regardless of who the information is disclosed to.*

### **7.2.2 Regional Health Authorities and Implied Consent**

Section 24(2) of the Act gives various custodians who are closely connected to the provision of care the ability to rely on implied consent for the use and disclosure of personal health information as part of the “circle of care”. In their written submissions, Labrador-Grenfell Health and Western Health both noted that the unambiguous exclusion of regional health authorities in this provision appears to have been an error, as these organizations are very involved in care. Their argument is sound, and attracted no rebuttals in the responsive written submissions.

***Recommendation 42*** *Amend the Act to clearly give regional health authorities the ability to rely on implied consent for the use and disclosure of personal health information as part of the circle of care. Specifically, change the phrase “Where a custodian referred to in paragraph 4(1)(e),(f) or (g)” with “Where a custodian referred to in paragraph 4(1)(a),(e),(f) or (g)”.*

## 8 Collection, Use, and Disclosure of Personal Health Information

As anticipated, the sections of the Act addressing collection, use, and disclosure of personal health information attracted significant commentary through the written submission process. Very few comments were made on collection and use – most comments focused on disclosure.

### 8.1 Collection for Analysis

In its written submission, the OIPC highlighted a peculiarity with Section 31(j) of the Act which permits indirect collection of personal health information for analysis of the health care system, but only where *“the person from whom the information is collected has in place practices and procedures to protect the privacy of the individuals who personal health information it receives and to maintain the confidentiality of the information”*. It is not clear why the Act would concern itself with the source a custodian is collecting from. Presumably, the practices of the party from whom information is being collected are governed in some way by Canada’s privacy framework, so this clause is unnecessarily limiting.

***Recommendation 43*** *To eliminate the unnecessary restriction on the collection of personal health information for analysis of the health care system, amend the Act to remove the phrase “and the person from whom the information is collected has in place practices and procedures to protect the privacy of the individuals who personal health information it receives and to maintain the confidentiality of the information” from Section 31(j).*

### 8.2 Extending Rights of Use and Disclosure to Health Care Professionals

In its written submission, the CNPS notes that under Sections 34(g) and 39(1)(g), a custodian is permitted to use personal health information for proceedings, and to disclose for audits, legal services, error management services, and risk management services. CNPS argues that the Act should extend these rights to any nurses practicing as employees of custodians (and, presumably, to any regulated health care professional practicing as an employee).

In situations where a regulated health professional is an employee of a custodian, or otherwise in a subordinate relationship, it would seem that the regulated health professional could simply make a request of the custodian to use or disclose personal health information for these purposes. If denied, they could grieve by way of their professional associations or representatives, or, in a worst-case scenario, could take other legal action obligating the custodian to use or disclose the personal health information, if appropriate. The CNPS has not given any concrete examples of instances where problems have arisen in this regard, so no amendments to Act are recommended.

### 8.3 Scope of Use

Section 35 of the Act requires custodians to limit use of personal health information within their organizations based on the “need to know” concept, but only references employees and agents in doing so. As noted by the OIPC in their written submission, it should apply to all the relevant actors.

***Recommendation 44*** *To ensure that the “need to know” concept is more accurately applied, amend Section 35 of the Act such that limitations on the use of personal health information apply to a*

*custodian's contractors, agents, employees, volunteers, working students, and authorized health care givers who "need to know".*

## **8.4 Deceased Individuals**

The written submissions of the OIPC and several of the regional health authorities raised points related to the privacy of deceased individuals; specifically, matters arising from Sections 7(e) and 38(c) of the Act. These two sections of the Act read as follows.

*7(e) "A right or power of an individual under this Act... may be exercised, where the individual is deceased, by the individual's personal representative or, where there is no personal representative, by the deceased's nearest relative..."*

*38(c) "A custodian may disclose personal health information about an individual who is deceased or presumed to be deceased without the consent of the individual who is the subject of the information to the personal representative of the deceased for a purpose related to the administration of the estate."*

### **8.4.1 Differences between Sections 7 and 38**

A close examination of these two sections reveals that the powers afforded by way of Section 7(e) make Section 38(c) largely unnecessary. If a personal representative exists, then any personal health information that a custodian might disclose to that personal representative under Section 38(c) could, under most circumstances, be obtained by way of information access powers given to the representative under Section 7(e).

The written submission of Labrador-Grenfell Health suggested that clarity should be offered with respect to Sections 7(e) and 38. Anecdotally, it would appear that there has been a degree of misinterpretation relating to these sections, with some believing that Section 38 somehow limits the rights afforded under Section 7(e) to a personal representative or nearest relative. It is not clear how the existing composition is problematic: Section 7 gives sweeping rights and powers to a single representative (essentially making them equivalent to the deceased individual), whereas Section 38 gives custodians discretionary authority to disclose to a broader group of people for various purposes in the event of death.

Furthermore, amending the Act to remove Section 38(c) simply because it is essentially covered by way of Section 7(e) might be problematic. Sections 7 and 38 have very distinct intents, and future changes to Section 7(e) might prevent the important disclosures currently contemplated by Section 38(c) if Section 38(c) is removed.

### **8.4.2 Difference between "Representative" and "Personal Representative"**

As part of its request for clarity, Labrador-Grenfell Health recommended dropping the phrase "personal" from the term "personal representative" in Section 7(e) – this recommendation exposes a specific confusion that can arise when reading the Act. A "personal representative", as contemplated by common law, is someone who administers a deceased person's estate. A "representative", as defined by PHIA, is someone identified under Section 7 of the Act as being able to exercise the rights or powers

of an individual under the Act. Not all “representatives” are “personal representatives”. Where an individual is deceased, Section 7(e) makes the “personal representative” the “representative”. Unfortunately, the term “personal representative” uses the word “representative” – to borrow a phrase from the OIPC written submission, this is not “user-friendly”.

***Recommendation 45*** *In the interest of clarity, consider amending the Act to define the term “personal representative”.*

***Recommendation 46*** *In the interest of clarity, consider amending the Act to replace the defined term “representative” with another term that avoids confusion with the term “personal representative”.*

#### **8.4.3 Additional Disclosures related to Deceased Persons for Insurance Administration**

Furthermore, the OIPC suggested that consideration be given to allowing custodians to also disclose personal health information without consent to a person or an insurance company for the purpose of collecting on an insurance policy. This suggestion would seem to make sense. Not all insurance policies are addressed by way of an estate, nor would they bear on the “personal representative” (e.g. an executor of an estate).

***Recommendation 47*** *Amend the Act to allow custodians to disclose personal health information about an individual who is deceased, or presumed to be deceased, without the consent of the individual who is the subject of the information, to a person or insurer for the purposes of administering an insurance policy.*

#### **8.4.4 Extensive Powers and Rights Afforded after Death**

Perhaps the most significant consideration that arose during the Review, with respect to the privacy of deceased persons, had to do with the near-absolute surrender of privacy to a deceased person’s representative resulting from Section 7(e) of the Act.

In life, the Act affords individuals significant control over most of the personal health information about them. In death, Section 38(d) of the Act allows custodians to disclose the personal health information about the deceased without their consent to “*a spouse, partner, sibling or descendant of the individual where the recipient of the information reasonably requires the information to make decisions about his or her own health care or the health care of his or her child or where the disclosure is necessary to provide health care to the recipient*”. Such disclosures would seem to be reasonable: upon death, any health details that one might have withheld from family members that would otherwise impact their health care can now be released to them.

However, Section 7(e) takes this level of surrender much further. A “personal representative” or, in the absence of a “personal representative”, the deceased’s nearest relative, has all the rights and powers of the deceased individual under the Act. By way of information access rights granted by the Act, this section effectively gives this single representative access to all of the deceased individual’s health details – after death, there can be no secrets from this representative.



A review of other Canadian health privacy legislation reveals that there are very few other acts that have comparable provisions, and that most limit such surrenders to only a personal representative where the right or power relates to the administration of an estate.

***Recommendation 48*** *To reduce the existing wholesale transfer of rights and powers upon death such that they are only given to a personal representative for the purposes of administering the estate, amend the Act to replace the existing phrasing in Section 7(e) of the Act with “where the individual is deceased, by the individual’s personal representative for a purpose related to the administration of the estate”.*

## 8.5 Disclosure for Health-Related Purposes

Section 39 of the Act addresses disclosures without consent for health-related purposes. Given that health-related disclosures are central to the operations of most custodians, this section elicited several comments during the written submission process.

### 8.5.1 Omission of WHSCC

In its written submission, the Workplace Health, Safety and Compensation Commission (operationally known as WorkplaceNL) spoke to its belief that their activities may have been unintentionally excluded under the disclosure provisions of Section 39(1)(a) of the Act. Specifically, this section allows custodians to disclose without consent “*for the purpose of determining of verifying the eligibility of the individual to receive health care or related goods, services or benefits provided under an Act of the province or of Canada and funded in whole or part by the government of the province or of Canada*” (emphasis added).

Many of WorkplaceNL’s activities involve “*determining of verifying the eligibility of the individual to receive health care or related goods, services or benefits provided under an Act of the province*”, but these activities are funded by way of employer premiums and not the government of the province, so they do not meet the conditions of the clause. Yet, WorkplaceNL is a commission established by the government of the province, so its activities would appear to align with the intent of Section 39(1)(a).

No objections to WorkplaceNL’s request were received in the responsive written submissions.

***Recommendation 49*** *Amend the Act to ensure that custodians may disclose personal health information without consent for the activities of the Workplace Health, Safety and Compensation Commission relating to “determining of verifying the eligibility of the individual to receive health care or related goods, services or benefits provided under an Act of the province or of Canada”.*

### 8.5.2 Disclosing for the Benefit of other Custodians

In its written submission, NLCHI highlighted the fact that Section 39(1)(d) limits the ability of a custodian to disclose personal health information without consent “*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*” (emphasis added). That is, a custodian can only make such disclosures without consent for their



own activities.<sup>25</sup> Similar restrictions exist in Section 39(1)(b) (payment), Section 39(1)(e) (review and planning), and Section 39(1)(g) (audit, legal, and related services).

This restriction is problematic for NLCHI, as their broad mandate with respect to provincial health information establishes them as an organization that can support the work of many custodians in the province. NLCHI may have data that can help another custodian in their payment, evaluation, planning, and risk management activities, but is not readily able to support other custodians in this regard because of the restrictions in Section 39(1) – NLCHI can only make such disclosures without consent with respect to their own activities.

In the interest of ensuring that all custodians can effectively participate in self-improvement activities, it would seem reasonable to allow custodians to disclose personal health information for such activities undertaken by any custodian. Such disclosures would remain optional, and accountability for the decision to disclose remains with the disclosing custodian.

Furthermore, there may also be benefit in allowing such disclosures without consent to non-custodians, as there are many non-custodians doing important work relating to health care that could benefit from such disclosures (e.g. NL Alliance for the Control of Tobacco). Though such disclosures can still occur with consent, allowing them to occur without consent may better enable important work. As with any disclosure, custodians are free to put in place whatever mechanisms or restrictions they feel are warranted (e.g. agreements, audits), as they are accountable for the decision to make such disclosures.

***Recommendation 50*** *To better enable custodians to support the work of other organizations, amend the Act to allow custodians to disclose personal health information without consent to any custodian for the purposes contemplated under Sections 39(1)(b), (d), (e), and (g) of the Act.*

***Recommendation 51*** *In the interest of better enabling custodians to support the work of other organizations, consider amending the Act to allow custodians to disclose personal health information without consent to any person for the purposes contemplated under Sections 39(1)(b), (d), (e), and (g) of the Act.*

### **8.5.3 Disclosure to a Successor**

Section 39(1)(j) of the Act allows a custodian to disclose personal health information without consent “to its successor where the custodian transfers records to the successor as a result of the custodian ceasing to be a custodian or ceasing to provide health care within the geographic area in which the successor provides health care and the successor is a custodian”. Furthermore, Sections 39(2) and 39(3) of the Act go on to elaborate on Section 39(1)(j), requiring the custodian to provide notice to people who might be affected, and describing the content of this notice and when it should be given.

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<sup>25</sup> The written submission of the HREB made a comment related to disclosures by a custodian to third-parties for evaluation of the custodian. Given that a custodian would be providing information to deliver, evaluate, or monitor their own activities (i.e. for their own purposes, and not for the purposes of the organization to whom they are providing the information), the “disclosure” currently contemplated by Section 39(1)(j) of the Act would typically be considered a “use”. Generally, any person is free to engage a service provider to support their endeavours. Depending on the circumstances, the service provider might be an “information manager” according to the definition found in Section 2(1)(l) of the Act.

In its written submission, the OIPC points out that the geographic consideration found in Section 39(1)(j) is unnecessarily limiting, which it is. Presuming this unnecessary limitation is eliminated, there are some additional “tweaks” that are warranted in Sections 39(1)(j) and 39(3).

***Recommendation 52*** *To eliminate the unnecessary limitation related to geographic area established by Section 39(1)(j) with respect to disclosures of personal health information by a custodian without consent, amend the Act to: (a) replace the current phrasing in Section 39(1)(j) with “to its successor where the custodian transfers records to the successor as a result of the custodian ceasing to be a custodian or ceasing, in whole or in part, to provide health care and the successor is a custodian”; and (b) replace the current phrasing in Section 39(3) with “that the custodian has ceased or will cease to be a custodian with respect to the personal health information referred to in the notice”.*

#### **8.5.4 Mandatory Disclosure to a Designated Registry**

Section 39(4)(d) requires a custodian to disclose personal health information without consent “to a custodian designated in the regulations who compiles or maintains a registry of personal health information for purposes of facilitating or improving the provision of health care...”. This section of the Act drew attention during the Review, just as it did when custodians were preparing for the Act to come in to force.

The OIPC noted in its written submission that the registry should be designated in the regulations along with custodian. This minor revision makes sense, and aligns with the phrasing “x with respect to y” commonly used in legislation to provide clarifying or limiting context.

However, the question of continued interest with respect to Section 39(4)(d) has been “what makes a registry/custodian suitable for compelling a disclosure from a custodian without consent”. Several submissions remarked on the fact that the Department of Health and Community Services and stakeholders invested significant effort in developing a process for reviewing/credentialing registries, but that none were ever designated under the regulations.<sup>26</sup> Moreover, the OIPC highlighted the fact that there are several important “registries” operating in the province that were anticipated to be subject to such processes and eventually designated under the regulations – until such time that they are designated, such endeavours are potentially non-compliant.

In its written submission, NLCHI called for the Act to provide additional detail around the requirements for designation of registries (e.g. assessment criteria that might be used). This sentiment was supported by both the OIPC and HREB in their responsive written submission. Given the significant compromise associated with mandatory disclosures of personal health information without consent, this idea has merit. Unfortunately, the Review had little commentary to go by in considering this matter, and did not have the time or resources to explore this topic more deeply. At a minimum, the designation of registries should require periodic review. In considering this matter further, one might examine the practices in Ontario because that province has established extensive periodic review processes for various legislative designations.

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<sup>26</sup> The first registry designation under the Act occurred in spring 2017, after the conclusion of the written submission process

***Recommendation 53*** Amend the Act to designate registries and their associated custodians, not simply custodians, to which all custodians must disclose personal health information without consent.

***Recommendation 54*** To support the ability to legislatively enshrine criteria which must be considered when designating registries (and their associated custodians) to which custodians must disclose personal health information without consent, consider amending the Act to allow the establishment of such criteria by way of regulation.

***Recommendation 55*** To prevent undesirable mandatory disclosures of personal health information without consent to registries which evolve over time, amend the Act or establish regulations to ensure periodic review of all designated registries against any criteria that are used to determine suitability of the registry for designation.

### **8.5.5 Mandatory Disclosure to a Designated Information Network**

Section 39(4)(c) requires a custodian to disclose personal health information without consent “to or via an information network designated in the regulations in which personal health information is recorded for the purpose of facilitating: (i) the delivery, evaluation or monitoring of a program that relates to the provision of health care or payment for health care, (ii) review and planning that relates to the provision of health care or payment for health care, or (iii) the construction or creation of an integrated electronic record of personal health information in accordance with the regulations”.

As with the mandatory disclosures to registries discussed in Section 8.5.4 of this report, NLCHI also posed the question of what makes an information network suitable for designation under Section 39(4)(c) of the Act. NLCHI is well-positioned to pose such a question, as the mandatory disclosures facilitated by this section are critical to the continued operation of the provincial electronic health record operated by NLCHI.

Given the significant privacy compromises associated with mandatory disclosures of personal health information without consent, there may be merit in providing additional detail around the requirements for designating information networks under Section 39(4)(c) (e.g. assessment criteria that might be used). Unfortunately, the Review had little commentary to go by in considering this matter, and did not have the time or resources to explore this topic more deeply.

On a related matter, NLCHI suggested that an explicit mention of the provincial electronic health record in the context of Section 39(4)(c) of the Act might be more transparent than placing such designations in regulation. Indeed, explicit references to provincial electronic health records can be found in many health privacy acts across Canada.

In its responsive written submission, the OIPC supported NLCHI’s desire for openness with respect to the provincial electronic health record, but achieving this openness is more complex than it would first appear. Explicitly referencing an omnibus provincial electronic health record in the context of Section 39(4)(c) of the Act makes it clear that there is a provincial electronic health record, but comes with the risk of having new functionality and systems indiscriminately/inappropriately categorized as being part of the provincial electronic health record, thereby compelling mandatory disclosures without consent without proper consideration. In contrast, referencing components of the provincial electronic health

record in a piecemeal fashion (this approach is the one currently being used – it is consistent with the modular creation of the provincial electronic health record over time) is less clear about the existence of the overarching provincial electronic health record, but lessens the risk of having new functionality and systems indiscriminately/inappropriately categorized as being part of one of the constituent systems. How to reference the provincial electronic health record in the context of Section 39(4)(c) of the Act in a way that balances various “openness” considerations may not have a concise solution, and may require references to both the omnibus system and its constituent parts.

***Recommendation 56*** *To support the ability to legislatively enshrine criteria which must be considered when designating an information network to which, or via which, custodians must disclose personal health information without consent, consider amending the Act to allow the establishment of such criteria by way of regulation.*

***Recommendation 57*** *In the interest of openness, consider amending the Act to: (a) explicitly reference the provincial electronic health record operated by the NL Centre for Health Information as an information network to which, or via which, custodians must disclose personal health information without consent; and (b) list the constituent subsystems of the provincial electronic health record.*

#### **8.5.6 Disclosure for Contemplated Proceeding**

Section 41(2)(a) of the Act allows custodians to disclose personal health information without consent “for the purpose of a proceeding or contemplated proceeding in which the custodian is or is expected to be a party or a witness where the information relates to or is a matter in issue in the proceeding or contemplated proceeding”. As part of its written submission, Central Health called for consideration of the creation of a consistent “timing” threshold for such disclosures across all legislation bearing on regulated health professionals, noting that complaints against regulated health professionals are often resolved through “progressive discipline” which might warrant disclosure at some stage, but not an early stage. Furthermore, they suggested considering the addition of qualifiers in such circumstances to specify to whom the information could be disclosed and for what purpose.

Unfortunately, no responsive written submission championed this suggestion by Central Health, so the Review had little additional commentary to go by in considering this matter, and did not have the time or resources to explore this issue more deeply.

#### **8.5.7 Disclosure for Enforcement Purposes**

Section 42 of the Act speaks to disclosures without consent in the context of investigations and the prevention of fraud, abuse, or other offences. Specifically, this section reads as follows.

*“42(1) A custodian shall disclose personal health information, including information relating to a person providing health care, without the consent of the individual who is the subject of the information to a person carrying out an inspection, investigation or similar procedure that is authorized by or under [PHIA], the Child, Youth and Family Services Act, another Act or an Act of Canada for the purpose of facilitating the inspection, investigation or similar procedure.*

*(2) A custodian may disclose personal health information, including information relating to a person providing health care, without the consent of the individual who is the subject of the*

*information to another custodian where the custodian disclosing the information has a reasonable expectation that disclosure will detect or prevent fraud, limit abuse in the use of health care or prevent the commission of an offence under an Act of the province or of Canada.”*

The written submission of Central Health challenged the existing mandatory disclosure contemplated by Section 42(1), suggesting that it might be appropriate to give consideration to the powers that have been granted to the body conducting the “*inspection, investigation or similar procedure*”. Similarly, the OIPC raised the issue of how a custodian confirms that the “*inspection, investigation or similar procedure*” is duly constituted and “*authorized by or under [PHIA], the Child, Youth and Family Services Act, another Act or an Act of Canada for the purpose of facilitating the inspection, investigation or similar procedure*”.

At first glance, it would seem that the provision of a warrant, subpoena, production order, or equivalent would serve to demonstrate the power of the body compelling the disclosure and that the “*inspection, investigation or similar procedure*” is duly constituted. A review of other Canadian health privacy legislation reveals that most acts do require this sort of demonstration, and phrase the clause as an optional disclosure. In the case of Alberta, the Health Information Act Guidelines and Practices Manual published by the Government of Alberta provides additional context on the “*optionality*” of such disclosures, stressing to the need to review the authority associated with orders, warrants, and subpoenas and to ensure that these documents are properly served.

*“Although section 35(1)(i) [of the Alberta Health Information Act] is stated in discretionary language, warrants or subpoenas have the force of law. They should be reviewed carefully as to what specific information they cover. Affiliates of custodians should consult with their legal advisor or the custodian when they receive an order, warrant or subpoena in order to determine whether it provides sufficient authority for the response that is being demanded. This means it must refer to information that is actually in the custody or under the control of the custodian; it must have been granted by a justice or person with proper authority and jurisdiction; and the instrument must have been properly served; among other criteria.”*

The current phrasing found in PHIA would appear to be based on the Ontario *Personal Health Information Protection Act*, which inspired much of the drafting of PHIA. The relevant section of that Act makes such disclosures mandatory, and suggests the importance of warrants but does not explicitly require them, by way of the following phrasing.

*“43(1) A health information custodian may disclose personal health information about an individual,... subject to the requirements and restrictions, if any, that are prescribed, to a person carrying out an inspection, investigation or similar procedure that is authorized by a warrant or by or under this Act or any other Act of Ontario or an Act of Canada for the purpose of complying with the warrant or for the purpose of facilitating the inspection, investigation or similar procedure*

Under the current phrasing of Section 42(1) of PHIA, there is a genuine risk of a mandatory disclosure occurring without sufficient scrutiny by the custodian or without sufficient demonstration of necessity

by the requesting party, under the assumption that an *“inspection, investigation or similar procedure”* is duly authorized and that the requested information is relevant simply because the requestor says so. Given the sensitivity of personal health information, it would make sense to require the requesting party to demonstrate their authority and the necessity of their request via an order, warrant, subpoena, or equivalent if seeking a mandatory disclosure. Legislative language that aligns with such a requirement can be found in Section 41(1)(b) of the Act, which reads as follows.

*“41(1) A custodian shall disclose personal health information without the consent of the individual... (b) for the purpose of complying with a summons, subpoena, warrant, demand, order or similar requirement issued by a court, person or entity, including the commissioner, with jurisdiction to compel the production of personal health information or with a rule of court concerning the production of personal health information in a proceeding.”*

In making such a mandatory disclosure, the custodian must still comply with the “minimum necessary” principle, disclosing only that personal health information which is required to satisfy the order.

However, the possibility remains to have an *“inspection, investigation or similar procedure”* which is duly constituted and *“authorized by or under [PHIA], the Child, Youth and Family Services Act, another Act or an Act of Canada for the purpose of facilitating the inspection, investigation or similar procedure”* that does not readily have tools such as orders, warrants, subpoenas, at its disposal. In such cases the obvious solution is to make the disclosure discretionary. This change has the potential to introduce some delay into investigative procedures; however, such potential delays are outweighed by the increases in accountability placed on the requestor and disclosing custodian.

As well, the OIPC spoke to Section 42(2) of the Act. Specifically, the OIPC raised the matter of whether or not there were mechanisms to allow a custodian to disclose personal health information without consent to law enforcement if they have a *“reasonable expectation that disclosure will detect or prevent fraud, limit abuse in the use of health care or prevent the commission of an offence...”*. The current phrasing of Section 42(2) only allows such disclosures to custodians. The need to address this question was also spoken to by Central Health in its responsive written submission.

A close examination of the Act reveals that there may not be sufficient mechanisms for allowing such preventative disclosures to law enforcement. There are general mechanisms to allow disclosure to *“prevent or reduce a risk of serious harm to the mental or physical health or safety [of an individual]”*, for *“public health or public safety”* (Section 40(1)), in response to an investigation that is already started (Sections 41(1)(b) and 42(1)), or for a proceeding or contemplated proceeding (Section 41(2)(a)), but the provision in 42(2) is not general. It would make sense to allow such preventative disclosures to law enforcement, as it is natural to involve law enforcement where there is a belief that there is, or is likely to be, fraud, abuse of the health care system (potentially a type of fraud), or some other offence.

***Recommendation 58*** *To increase the level of accountability placed on, and due diligence expected of, custodians when making disclosures of personal health information without consent to a person carrying out an inspection, investigation or similar procedure that is authorized by or under the Act, the Child, Youth and Family Services Act, another Act or an Act of Canada for the purpose of facilitating the*

*inspection, investigation or similar procedure, amend the Act to make such disclosures discretionary, except where other provisions of the Act make the disclosure mandatory.*

***Recommendation 59*** *To better support the prevention of fraud and other abuses, amend the Act to allow custodians to disclose personal health information to law enforcement without consent where there is reasonable expectation that doing so will detect or prevent the commission of an offence under an Act of the province or of Canada.*

### **8.5.8 Disclosures for Research Purposes**

Section 44 of the Act allows custodians to disclose personal health information without consent for research purposes where the research project has been approved by a research ethics board or body under HREAA. The interplay between PHIA and HREAA is unique within Canadian health privacy legislation, and has drawn the attention (and envy) of many. However, this interplay is not perfect, as the HREB noted some potential gaps in its written submission.

The *Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans* (TCPS2) forms the basis of ethical reviews of health research by research ethics boards across Canada. The TCPS2 does not require researchers to undergo ethical review for projects that exclusively involve data which is “publicly available”, or data which is “anonymous” and being used for a secondary purpose (i.e. previously collected and part of another initiative, and not collected for the research project under consideration).<sup>27</sup> As such, there may be health research projects that involve data subject to PHIA, but that do not require researchers to seek ethical review under TCPS2. As well, some research projects may involve very limited amounts of health information sourced from custodians, but may not be perceived as health research, so they would be not be reviewed by a research ethics board or body under HREAA.

#### **Research Projects not Requiring a Researcher to seek Ethical Review**

As for research projects not requiring ethical review under TCPS2, there is no material problem with the interplay between PHIA and HREAA. There does not appear to be any suggestion by TCPS2 that these projects cannot undergo ethical review, thereby facilitating disclosures under Section 44 of PHIA. There are three scenarios which require consideration.

1. In situations where the research ethics board or body confirms that the research protocol does in fact not require ethical review under TCPS2, the examination by the board or body can stop there and simply approve the project.
2. In situations where the research ethics board or body identifies that the researcher has mistakenly judged that the research protocol does not require ethical review under TCPS2, the project will have benefitted greatly from the additional scrutiny.
3. In situations where a researcher claims that a research project does not require ethical review, but a custodian from whom personal health information is requested claims otherwise, it is

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<sup>27</sup> The TCPS2 does not define “publically available”, but subjectively defines “anonymous” data as information that never had identifiers associated with it (e.g., anonymous surveys) and risk of identification of individuals is low or very low.

simply a matter of policy as to whether or not the research ethics board or bodies authorized under the HREAA will review a project that a researcher claims does not require ethical review.

Furthermore, with respect to “anonymous” data used for a secondary purpose, there would not appear to be a material complication in this province. In interpreting whether or not the data meets the standard of “anonymous” as per the definition of TCPS2 (thereby, not requiring the researcher to obtain an ethical review), one must assess if “the risk of identification of individuals is low or very low”. It would seem that the standard set by TCPS2 is at least as high as that set by Section 5(5) of the Act because both define “identifying information” using nearly identical language. That is, if data can be assessed as being undeniably “anonymous” under TCPS2, it is likely not “identifying information” and, in turn, not “personal health information” under PHIA. Any researcher who claims that their research project only involves “anonymous” data being used for secondary purposes, but encounters a challenge when making a request to a custodian to disclose such information, should probably seek ethical review simply based on the doubts cast by the custodian. If both the researcher and custodian believe the data to be anonymous, thereby not subject to PHIA, then they are both accountable for their judgement and decision-making.

However, with respect to data that is publically available, there is a legitimate prospect of eliminating unnecessary consideration by a research ethics board or body.<sup>28</sup> Consideration could be given to allowing such disclosures without consent for research purposes; however, this would inappropriately couple PHIA to TCPS2. Being health research ethics legislation, HREAA needs to understand the objectives and structures of relevant ethical frameworks. Being personal health information legislation that contemplates disclosures for appropriate health research, PHIA needs to understand the objectives and structures in HREAA, but does not need to know the frameworks upon which HREAA relies. It is better for PHIA to rely on the health research ethics boards and bodies authorized under HREAA, and leave it at that. Furthermore, by way of Section 44 of the Act, PHIA has placed a perfectly reasonable *de facto* requirement on HREAA to be able to resolve all health research projects as either “approved” or “not (yet) approved” – it is up to HREAA and the structures defined within it to be able to meet that requirement.

***Recommendation 60*** *To maintain appropriate independence between the Personal Health Information Act and the Health Research Ethics Authority Act, do not amend the Act to allow a custodian to disclose personal health information without consent for research purposes and without approval by a research ethics board or body, even if the research only involves publically available information.*

#### **Disclosures of Personal Health Information without Consent for Non-Health Research**

With respect to research projects that involve health information sourced from custodians, but that are not considered health research, it is important to recognize that these projects are still subject to ethical review, albeit not a review by a research ethics board or body authorized under the HREAA because the research falls outside the scope of HREAA.

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<sup>28</sup> Personal health information that is publically available might still be requested from a custodian for research purposes, as the custodian may have the information in a more concise format, or in a format that is more suitable for research.



Unfortunately, a health research ethics board or body would not be qualified to perform ethical review of non-health research, nor would they be qualified to give a “token” approval or endorsement (from an ethical perspective for PHIA disclosure purposes) of non-health research approved by a non-health research ethics board. Moreover, there is no legislative oversight of non-health research in this province upon which PHIA can rely to establish provisions equivalently robust as those established by way of Section 44 of the Act in order to deal with non-health research projects that involve health information sourced from custodians. The clever legislative interplay between PHIA and HREAA does indeed leave a genuine gap with respect to non-health research projects that involve health information sourced from custodians, and there is no immediately obvious way to close it using mechanisms that involve legislative oversight. Unfortunately the Review had little additional commentary to go by in considering this matter, and did not have the time or resources to explore possible solutions.

***Recommendation 61*** Consider further examination of the matter of custodians being allowed to disclose personal health information without consent for non-health research.

#### **Custodian Responsibilities to Give Proper Consideration to Disclosure for Research Purposes**

In its written submission, the HREB spoke about custodians relying too heavily (in some cases, exclusively) on the approval decision of the HREB in deciding whether to disclose personal health information without consent under Section 44 of the Act. In turn, this is closely related to NLCHI’s request to legislatively address what a researcher should provide to a custodian when making a request for such a disclosure. The concerns of the HREB and NLCHI may also be somewhat alleviated by making all health researchers custodians (see Recommendation 9 in Section 3.5 of this report).

As mentioned throughout this report, custodians remain accountable for their decision to make discretionary disclosures. Though legislation can tell people how to go about decision-making, this work is better suited to organizational policy and procedure, supported by guidelines and/or directives from professional associations. As a matter of course, it would seem natural that a custodian understand the research protocol and verify that key details in the research protocol align with those presented to the approving health research ethics board or body (perhaps by reviewing the ethics application, amendments, and any correspondence), and to establish an agreement with the researcher to whom the information is disclosed. In its written submission the OIPC recommended that such agreements be established in support of all disclosures.

***Recommendation 62*** To increase the level of accountability associated with disclosures of personal health information without consent for research purposes, amend the Act to require custodians to establish an agreement with the person to whom the information is disclosed to govern the terms of the disclosure.

***Recommendation 62a*** To ensure that specific protections and restrictions are guaranteed in disclosures of personal health information without consent for research purposes, amend the Act to allow specific requirements relating to agreements governing such disclosures to be specified by way of regulations to the Act.

### 8.5.9 Ministerial Powers relating to the Disclosure of Registration Information

Section 45 of the Act addresses disclosure of “registration information” without consent. “Registration information is defined in Section 2(1)(t) of the Act as *“information about an individual that is collected for the purpose of registering the individual for the provision of health care, and includes a health care number and other identifier assigned to an individual”*. For the most part, Section 45 speaks to various powers that the Minister of Health and Community Services has to provide registration information to support the work of the federal government, provincial governments, and public bodies within this province.

In its written submission the OIPC noted a number of practical questions relating to this section. The questions of the OIPC highlight the fact that this section strives to give the Minister discretion to share registration, but fails to recognize the fact that the Minister may not be in the custody or control of registration information. Instead, this section would be much better served by giving the Minister the power to compel custodians to disclose registration information without consent at his or her direction, or in accordance with agreements entered into by the Minister, subject to the existing restrictions placed on the Minister by Section 45 of the Act.

If it is felt that the Minister should not be able to compel such disclosures without consent from custodians outside the public sector, introducing a limitation to preclude this ability is a reasonable “middle ground”.

***Recommendation 63*** *To empower the minister in a way that more appropriately reflects the trust and accountability associated with the role, amend the Act to support the ministerial disclosures of registration information without consent contemplated by Section 45 by requiring custodians to disclose registration information without consent at the discretion of the minister, or in accordance with an agreement entered into by the minister, subject to the existing restrictions found in Section 45 of the Act.*

## 8.6 Teaching

Under Section 3 of the *Personal Health Information Regulations* established under the Act, instruction as part of a course of study is, subject to some conditions, included as a “health care service” as contemplated under Section 2(1)(h)(viii) of the Act. By including instruction as a health care service, many collections, uses, and disclosures relating to instruction are enabled as they are considered to be part of health care. Specifically, this regulation is phrased as follows.

*“Where a custodian has entered into an affiliation agreement to provide instruction to a student or other person in his or her course of study to become a health care provider or a health care professional, that instruction is a health care service within the meaning of paragraph 2(1)(h)(viii).”*

Anecdotally, many of the health privacy professionals in the province recall that this regulation was established in response to the recognition that the use and sharing of personal health information without consent for teaching purposes was not contemplated by the Act. As regulations were being developed, the inclusion of “instruction” within the meaning of a “health care service” was seen as the most viable mechanism for continuing the well-accepted practice of using personal health information,

or exposing someone to personal health information, as part of instruction in certain circumstances. The introduction of the concept of an “affiliation agreement”, and the restriction to the development of health care providers and health care professionals, were attempts to create a threshold of legitimacy. In colloquial terms, many saw it as a legislative “hack” to allow important health-related instruction to continue.

The weaknesses of this legislative solution were exposed by way of comments made during the written submission process. The NLASW called for the Act to better address students, and both Western Health and Labrador-Grenfell Health noted that the instruction of students training for clerical positions, who would not qualify as health care professionals or health care providers, is also very important.

The simplest solution to address these shortcomings is to simply allow the use and disclosure of personal health information without consent for instructional purposes. Allowing the use and disclosure of personal health information without consent for instructional purposes does not mean that it can be used without restriction, as the Act still enshrines the “minimum necessary” concept in Sections 33 and 49 – if other information can be used, there is an obligation to do so. Though the policies and procedures contemplated under Section 13 of the Act must give consideration to information protection and risk regardless of the context, it is appropriate to highlight the need for such policy in the context of instruction.

***Recommendation 64*** *To better support the use of personal health information for instructional purposes, amend the Act to: (a) allow custodians to use and disclose personal health information without consent for instructional purposes under Part IV of the Act; and (b) remove Regulation 3 of the Personal Health Information Regulations. Moreover, in allowing custodians to use and disclose personal health information without consent for instructional purposes under Part IV of the Act, eliminate the need for “affiliation agreements”, as well as the restriction to the development of health care professionals and health care providers, currently found in Regulation 3.*

***Recommendation 65*** *Ensure that use and disclosure of personal health information without consent for instructional purposes is given adequate consideration by way of policy and procedure. Specifically, amend Section 13(2) of the Act to include policies and procedures to protect the privacy of individuals with respect to use or disclosure of personal health information without consent for instructional purposes.*

## 9 Access and Corrections

Part V of the Act addresses access to, and correction of, records of personal health information. Surprisingly, this part of the Act did not solicit many comments during the written submission process, with most comments speaking to the need for minor clarifications, or to call for small measures to lighten operational burdens. Notably, NLCHI indicated that Part V was working well, and the OIPC used its responsive written submission as an opportunity to stress the importance of patient portals in enabling access, and to highlight the need for special considerations for minors.

### 9.1 Duty to Assist

In its written submission, the OIPC called for modifications to Sections 54(2) and 63 of the Act to better capture a custodian's "duty to assist" members of the general public, along the lines of the language found in ATIPPA, 2015. Under ATIPPA, 2015, a public body "*shall make every reasonable effort to assist an applicant in making a request and to respond without delay to an applicant in an open, accurate and complete manner*". Generally, the concept of "request" in ATIPPA, 2015 refers to a request made by an individual to access or correct personal information about them, or to access a government record.

Though the OIPC made this comment in the context of requests by individuals to access and correct personal health information about them, this "duty to assist" actually goes much further. Currently, PHIA contemplates five principal entitlements related to individuals:

1. Right of access to personal health information about them (Section 52).
2. Right of correction of personal health information about them (Section 60).
3. Right to control the flow and sharing of health about them (commonly referred to as a "consent directives"; Part III)
4. Right to be informed of how custodians use and share information about them (Section 20).
5. Right to make privacy-related complaints regarding personal health information (Part VI).

As well, many custodians will let individuals know who has accessed information about them and to whom that information has been shared, even though these elements are not considered to be "personal health information" under the Act. This information is commonly referred to as an "audit record" or "audit log", and the provision of this information to individuals is often considered an extension of the "right of access" and the "right to be informed". The provision of these audit details is vital in helping larger custodians identify instances of unauthorized activity that might constitute a violation of the Act or other privacy infringement because it helps distribute the audit workload and leverages insights that only the subject of the information can provide. Presently, the Act does not clearly enshrine a "right of audit".

In addition to these entitlements, which serve to empower individuals, the Act establishes two key empowerments related to individuals:

1. The establishment of "contact persons" by custodians (Section 18). Under Section 18(3)(a), these "contact persons" are required to "*facilitate the custodian's compliance with this Act and*

*the regulations*". Other than the obligation established under Section 18(3)(a) to generally facilitate compliance with the Act (which includes very select duties that align with a "duty to assist"), "contact persons" are not specifically obligated to help individuals exercise their entitlements under the Act, but only to "respond" to inquiries and requests.

2. The provision of "written public statements" by custodians (Section 19). Under Section 19 of the Act, a custodian must *"make available to those who are or are likely to be affected by the custodian's activities a written statement that (a) provides a general description of the custodian's information policies and procedures; (b)... identifies the contact person and provides [contact] information [for the contact person]... ; (c) describes how an individual may obtain access to or request correction of a record of personal health information about the individual... ; and (d) describes how a complaint may be made to the commissioner"*.

Overall, the PHIA Review Survey showed that individual awareness of these entitlements and empowerments is strong, both amongst the general public, and amongst those not affiliated with health organizations<sup>29</sup>.

- **Right of Access**

- When asked to respond to the statement "I know that, in many situations, I am allowed to see the health information a clinic or hospital has about me", 84.28% of respondents agreed or strongly agreed with the statement (based on 70 respondents). When considering only those respondents who are not affiliated with a health organization, 84.00% of respondents agreed or strongly agreed with the statement (based on 25 respondents).
- When asked "Have you ever asked a clinic or hospital to show you the health information they have about you?", 30.43% of respondents responded "yes" (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 20.83% of respondents responded "yes" (based on 24 respondents).

- **Right of Correction:**

- When asked to respond to the statement "I know that, in most situations, a clinic or hospital must fix health information about me if I tell them it is wrong", 69.57% of respondents agreed or strongly agreed (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 70.84% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Right of Control:**

- When asked to respond to the statement "I know that, in some situations, I can tell clinics and hospitals who they are allowed to share my health information with (this

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<sup>29</sup> In analyzing the data from the PHIA Review Survey, a respondent was deemed to be not affiliated with a health organization if they responded "no" to the question "Are you currently associated with an organization or facility that handles health information? For example, are you an employee, temporary/casual/contract worker, or volunteer with an organization such as a health clinic, a private healthcare practice, a hospital, a regional health authority, a government health-related program/insurer/corporation, or a health-related department/program of an academic institution?".

instruction is often called a “consent directive”), 73.91% of respondents agreed or strongly agreed (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 66.67% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Right to be Informed:**

- When asked to respond to the statement “I know that clinics and hospitals must tell me what they do with health information”, 71.02% of respondents agreed or strongly agreed (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 62.50% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Right to Complain:**

- When asked to respond to the statement “I know that I can bring privacy complaints and concerns about health information to the Information and Privacy Commissioner”, 89.86% of respondents agreed or strongly agreed (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 91.67% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Audit:**

- When asked to respond to the statement “I know that, if I ask, many clinics and hospitals will tell me who has used their systems to look at my health information”, 44.29% of respondents agreed or strongly agreed (based on 70 respondents). When considering only those respondents who are not affiliated with a health organization, 28.00% of respondents agreed or strongly agreed with the statement (based on 25 respondents).

- **Contact Person**

- When asked to respond to the statement “I know that clinics and hospitals must have a person to help answer my questions about what they do with health information and to help me see or fix my health information (this person is often called a “contact person”)”, 66.67% of respondents agreed or strongly agreed (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 70.84% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Written Public Statement**

- When asked to respond to the statement “I know that clinics and hospitals must tell me how I can reach their contact person”, 75.37% of respondents agreed or strongly agreed (based on 69 respondents). When considering only those respondents who are not affiliated with a health organization, 70.83% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

However, when asked about general impressions of the ease with which one can take advantage of these entitlements and empowerments, as well as when asked about how the Act has improved this level of ease, the results are not as promising. The only area for which general impressions are strong is

the ease with which one can have privacy complaints and concerns seen to. However, people generally believe that health information is protected in the province and that the Act has improved the protection of health information in the province.

- **Right of Access**

- When asked to respond to the statement “It is easy for people to see their health information”, 19.67% of respondents agreed or strongly agreed with the statement (based on 61 respondents). When considering only those respondents who are not affiliated with a health organization, 20.00% of respondents agreed or strongly agreed with the statement (based on 25 respondents).
- When asked to respond to the statement “The Personal Health Information Act has made it easier for people to see their health information”, 42.62% of respondents agreed or strongly agreed with the statement (based on 61 respondents). When considering only those respondents who are not affiliated with a health organization, 36.00% of respondents agreed or strongly agreed with the statement (based on 25 respondents).

- **Right of Correction:**

- When asked to respond to the statement “It is easy for people to fix their health information if it is wrong”, 23.33% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 25.00% of respondents agreed or strongly agreed with the statement (based on 24 respondents).
- When asked to respond to the statement “The Personal Health Information Act has made it easier for people to fix their health information”, 41.67% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 29.17% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Right of Control:**

- When asked to respond to the statement “It is easy for people to control how their health information is shared throughout the health system”, 20.00% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 12.50% of respondents agreed or strongly agreed with the statement (based on 24 respondents).
- When asked to respond to the statement “The Personal Health Information Act has made it easier for people to control how their health information is shared throughout the health system”, 36.67% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 25.00% of respondents agreed or strongly agreed with the statement (based on 24 respondents).

- **Other Rights and Entitlements:**

- When asked to respond to the statement “It is easy for people to know how their health information is shared throughout the health system”, 25.00% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 20.74% of respondents agreed or strongly agreed with the statement (based on 24 respondents).
- When asked to respond to the statement “The Personal Health Information Act has made it easier for people to know how their health information is shared throughout the health system”, 45.74% of respondents agreed or strongly agreed with the statement (based on 59 respondents). When considering only those respondents who are not affiliated with a health organization, 34.78% of respondents agreed or strongly agreed with the statement (based on 23 respondents).
- When asked to respond to the statement “It is easy for people to know what clinics and hospitals do with health information”, 20.00% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 20.83% of respondents agreed or strongly agreed with the statement (based on 24 respondents).
- When asked to respond to the statement “The Personal Health Information Act has made it easier for people to know what clinics and hospitals do with health information”, 43.33% of respondents agreed or strongly agreed with the statement (based on 60 respondents). When considering only those respondents who are not affiliated with a health organization, 29.17% of respondents agreed or strongly agreed with the statement (based on 24 respondents).
- When asked to respond to the statement “It is easy for people to have privacy complaints and concerns about health information seen to”, 50.85% of respondents agreed or strongly agreed with the statement (based on 59 respondents). When considering only those respondents who are not affiliated with a health organization, 39.13% of respondents agreed or strongly agreed with the statement (based on 23 respondents).
- When asked to respond to the statement “The Personal Health Information Act has made it easier for people to have privacy complaints and concerns about health information seen to”, 64.40% of respondents agreed or strongly agreed with the statement (based on 59 respondents). When considering only those respondents who are not affiliated with a health organization, 52.18% of respondents agreed or strongly agreed with the statement (based on 23 respondents).
- **Overall Impression of Protection in the Province:**
  - When asked to respond to the statement “Health information is protected in Newfoundland and Labrador”, 66.10% of respondents agreed or strongly agreed with the statement (based on 59 respondents). When considering only those respondents who are not affiliated with a health organization, 60.87% of respondents agreed or strongly agreed with the statement (based on 23 respondents).
  - When asked to respond to the statement “Health information is better protected in Newfoundland and Labrador because of the Personal Health Information Act”, 65.00%



of respondents agreed or strongly agreed with the statement (based on 59 respondents). When considering only those respondents who are not affiliated with a health organization, 58.33% of respondents agreed or strongly agreed with the statement (based on 23 respondents).

In short, the awareness of entitlements and empowerments under the Act is quite strong, but the impression related to the ease with which one can take advantage of these entitlements and empowerments is not abundantly positive. Moreover, it appears that people do not believe that PHIA has had an overwhelmingly positive impact on the level of ease. These relationships suggest that there is further work to be done in helping people take advantage of these entitlements and empowerments. One way to do this is to establish a very general duty to assist, and to allow the Commissioner to be able to commend successes and admonish failures related to this duty.

***Recommendation 66*** *To improve the level of ease with which individuals can take advantage of the entitlements and empowerments afforded to them under the Act, amend the Act to establish an overall “duty to assist” by: (a) obligating custodians to: (i) use every reasonable effort to assist individuals in taking advantage of all entitlements and empowerments afforded to individuals under the Act; and (ii) respond and interact with individuals openly, accurately, and completely; and (b) allowing the commissioner to bring to the attention of custodians a failure to the fulfil the “duty to assist”.*

## 9.2 Calendar Days vs. Business Days

The NLASW and Central Health asked for clarification as to whether response times found in the Act are in calendar days or business days. It would seem sufficiently clear that, unless otherwise specified, a “day” is a “calendar day”. The responsive submission of the OIPC considers the matter of calendar days versus business days in considerable detail, noting that clarifying to refer to “business days” might be particularly problematic, as the interpretation of working days and holidays in a health care context is challenging. The OIPC does not object to clarifying “day” as “calendar day”, so in the interest of clarity this idea is worth entertaining.

***Recommendation 67*** *Consider amending the Act to clarify that references to “days” are “calendar days”.*

## 9.3 Response to Access Requests

Section 55 of the Act speaks to the amount of time afforded to custodians in responding to a request from an individual to access personal health information about them, as well as the custodian’s responsibilities to individuals when extending time limits.

### 9.3.1 Response Times

The written submission processes was very effective in facilitating a public dialogue and debate on this topic, with the OIPC originally suggesting a reduction in response time, several custodians using the responsive round to argue against a reduction and to propose alternatives, and the OIPC eventually withdrawing their original position by way of further correspondence to the Committee. The OIPC and custodian organizations participating in the debate on this topic are to be commended for taking full advantage of, and respecting, the responsive written submission process.

### 9.3.2 Response Content

In its written submission, the OIPC also suggested that, where custodians extend the time limit for responding to a request from an individual to access personal health information about them, these custodians should be required to let the individual know about their right to complain to the Commissioner about time extensions. Similarly, the OIPC suggested that custodians who charge fees for providing access should be required to let the individual know about their right to complain to the Commissioner about the fees. In both cases, providing this information would be consistent with the “duty to assist”, discussed in Section 9.1 of this report. Moreover, none of the responsive submissions countered this suggestion.

As well, the OIPC noted that Section 56(1)(c) of the Act requires custodians, when refusing individual access requests, to inform the applicant of the reasons for refusal, the right to appeal to the Trial Division, and the right to request a review by the Commissioner; yet, there is no equivalent provision for situations when a custodian takes the position that a record does not exist or cannot be found. In considering this matter, it is important to recognize that the custodian takes the position that the record does not exist or cannot be found – it is possible that they have simply not looked hard enough to find it. Again, providing this extra information to the individual as part of the response would be consistent with the “duty to assist”, discussed in Section 9.1 of this report. Moreover, none of the responsive submissions countered this suggestion.

***Recommendation 68*** To better uphold the “duty to assist”, amend the Act such that custodians who extend the time limits for responding to access requests are required, when notifying the individual about the extension, to inform individuals about their right to complain to the Commissioner about extending the time limits for responding to access requests.

***Recommendation 69*** To better uphold the “duty to assist”, amend the Act such that custodians who charge fees for responding to access requests are required, when notifying the individual about the fees they will have to pay, to inform individuals about their right to complain to the Commissioner about the fees.

***Recommendation 70*** To better uphold the “duty to assist”, amend the Act such that custodians who in response to access request take the position that a record of personal health information does not exist or cannot be found, be required to inform the individual of the following: (a) that the custodian believes that the record does not exist or cannot be found; (b) the reason why the custodian believes that the record does not exist or cannot be found; (c) that the individual may appeal to the Trial Division; and (d) that the individual may request a review by the Commissioner.

## 9.4 Fees

The written submission process received some comments related to the fees that can be charged in response to access requests under Section 57(1) of the Act. Unfortunately, the Review had little commentary to go by in considering the matter of fees related to access, and did not have the time or resources to explore this issue more deeply; however, it would make sense to be able to address any particulars related to fees by way of regulation.

***Recommendation 71*** Amend the Act such that particulars of the fees related to access requests can be addressed by way of regulations established under the Act.

## **9.5 Notifying about Corrections**

When dealing with requests from individuals to correct personal health information, Sections 63(1)(c) and 63(2)(a) of the Act require custodians to provide notification of the correction (or annotation, if the request is refused) to anyone to whom the custodian has disclosed the information “*within the 12 month period immediately preceding the request for correction*”. In its written submission, the OIPC proposes changing this period to the period preceding when the correction or notation was made.

The OIPC is right to highlight the need to address the fact that incorrect, or unannotated, information may have flowed between the time that the request was made and the time that it was addressed. However, consideration should also be given to the fact that the request for correction may have been made by the individual based upon the discovery that incorrect information had been provided to someone. It would seem more appropriate that notifications cover the period between the time the correction is made and the day 12 months prior to the request for correction. Moreover, this period would further encourage custodians to deal with such requests in a timely manner.

***Recommendation 72*** To better address the risks associated with having shared incorrect personal health information, amend the Act to ensure that notifications made in response to a correction also cover the period between the request for correction and the disposition of the request by replacing the phrase “*within the 12 month period immediately preceding the request for correction*” found in Sections 63(1)(c) and 63(2)(a) with “*within the period between when the correction was made and the day 12 months prior to when the request for correction was made*”.

## 10 Commissioner Oversight

Part VI of the Act speaks to the oversight model and powers of the Information and Privacy Commissioner. Naturally, the written submission of the OIPC addressed this part of the Act in considerable detail.

### 10.1 Commissioner Oversight Model

The current oversight model established by PHIA does not give the Commissioner the power to compel compliance with the Act by custodians except in relation to access and correction requests; rather, the Commissioner is only empowered to make recommendations.<sup>30</sup> Prior to ATIPPA, 2015, the same was true in that context. This “recommendation-making power” was found in many provincial legislative frameworks, perhaps inspired by the federal *Personal information Protection and Electronic Documents Act*, which gave the federal Privacy Commissioner recommendation-making power, but not order-making power.

However, there has been an increase in the provision of “order-making power” to Canadian commissioners in recent years. The recent ATIPPA, 2015 did not explicitly give the Commissioner “order-making power”, but instead introduced a “hybrid” oversight model unique within Canada. The hybrid model, in its simplest terms, assumes that a public body will comply with a Commissioner’s recommendations, giving the public body a reasonable, but limited, amount of time to object (thereby initiating a court process). The OIPC argues that the current “ombuds” model with “recommendation-making powers” is not effective, citing the same arguments made during the 2014 ATIPPA review, and recommends amendments to the Act to establish a “hybrid” model.

The arguments made by the OIPC and the ATIPPA Review Committee in 2014 remain equally relevant in the context of health information and PHIA. Moreover, although ATIPPA, 2015 addresses both public records and personal (non-health) information, it does not make sense to have the Commissioner follow one model for personal (non-health) information under ATIPPA, 2015, yet a different model for personal health information (which is a subcategory of personal information) under PHIA. As the OIPC rightly points out, the “hybrid” model used in this province is attracting considerable interest from other Canadian jurisdictions.

In implementing the “hybrid” model a number of legislative changes are necessary, many of which have been outlined in the written submission of the OIPC. As efforts are made to identify the legislative amendments necessary to establish the “hybrid” model, the OIPC should be engaged to make sure it is done correctly.

The OIPC is to be commended for the effort it expended on presenting possible alternatives if its suggestion of the “hybrid” model were not accepted; however, the extra effort was unnecessary.

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<sup>30</sup> The terms commonly used to describe the powers given to privacy commissioners are “recommendation-making powers” and “order-making powers”.

***Recommendation 73*** *To enable the Commissioner to play a more substantive role in the protection of personal health information, amend the Act to establish a “hybrid” oversight model by the Commissioner that parallels the “hybrid” oversight model found in the Access to Information and Protection of Privacy Act, 2015.*

***Recommendation 73a*** *Work with the Commissioner to determine the necessary legislative changes to establish the “hybrid” oversight model.*

## **10.2 Compelling the Production of Records from Non-Custodians**

Sections 69, 70, and 71 of the Act speak to the Commissioner’s entitlements when conducting a review based on a complaint under the Act. One such entitlement relates to the power to compel the production of records and enter premises.

At present, the Commissioner is only able to compel records from custodians, not non-custodians. As the OIPC points out in their written submission, “*privacy breaches, by their very nature, are not strictly confined...* ”. Moreover, they cite several examples where the lack of ability to compel records from non-custodians was problematic. Given that Section 68(1) of the Act generally gives the Commissioner “*the powers, privileges and immunities that may be conferred on a commissioner under the Public Inquiries Act, 2006*”, it is appropriate to allow them to compel the production of records from non-custodians.

Although it would appear that Section 70 allows the Commissioner to enter any premises (subject to some conditions), there is some confounding language in Section 71 that may complicate matters. Specifically, Section 71(b) of the Act is phrased as “*Notwithstanding sections 69 and 70, the commissioner shall not... except where... the commissioner provides a statement to the custodian...*”, which suggests that Section 70 might only apply to the premises of custodians. Section 71(b) must be amended to ensure that the power to compel records applies to anyone, not just custodians. And, Section 71(b) must also be clarified to eliminate any potential ambiguity of authority that might make the Commissioner hesitant to enter the premises of a non-custodian.

The OIPC also indicates that it would be useful if the Act required custodians to keep a copy of any record containing personal health information for one year following creation or disclosure, in order to afford individuals a reasonable opportunity to obtain access to it. Although a similar provision exists in ATIPPA, 2015, it would seem that doing so would violate the well-held privacy principle of “limiting retention” – once a record is no longer needed for its intended purpose, it should not be retained, even if it might help an individual understand more about its creation or deletion, prevent a complaint, or assist the Commissioner in reviewing a complaint. By retaining records longer than necessary, new problems are created.

***Recommendation 74*** *To better enable the Commissioner to undertake reviews, amend the Act to allow the Commissioner to compel records from anyone when conducting a review, whether or not the relevant record or person is subject to the provisions of the Act.*

***Recommendation 75*** *To better enable the Commissioner to undertake reviews, amend the Act to unambiguously allow the Commissioner to enter any premises when conducting a review, by replacing the word “custodian” in Section 71(b) with “person”.*

### 10.3 Sharing Information with Other Commissioners

In its written submission, the OIPC highlighted the fact that the Act does not presently allow the Commissioner to exchange information with Commissioners from other jurisdictions in support of investigations involving more than one jurisdiction. This ability to share information is particularly important in the context of health care in this province because patients are sometimes sent out of province to receive treatments not available here. Such provisions exist in health information privacy legislation in some other Canadian jurisdictions.

***Recommendation 76*** *To better support multi-jurisdictional investigations by Commissioners, amend the Act to allow the commissioner to exchange details about investigations with Commissioners from other Canadian jurisdictions.*

### 10.4 Own Motion Investigations

The written submission of the OIPC noted that ATIPPA, 2015 explicitly allows the Commissioner to conduct “own motion” investigations. PHIA does this indirectly, by not preventing a member of the OIPC from being a complainant. However, it makes much more sense to make it clear that the OIPC can undertake “own motion” investigations.

***Recommendation 77*** *To provide clarity, amend the Act to allow the Commissioner to undertake “own motion” investigations.*

### 10.5 Additional Powers of Commissioner

Section 79 of the Act outlines additional powers of the Commissioner over and above those associated with reviews following a complaint. In short, these powers are as follows:

- Make recommendations to ensure compliance.
- Inform the public.
- Receive comments from the public.
- Comment on proposed legislative schemes, and programs and practices of custodians.
- Comment on record linkage and the use of information technology.
- Consult with anyone with regards to anything related to the Act.

#### 10.5.1 Receiving Comments

In its written submission, the OIPC calls for some refinements to Section 79(c). Specifically, the OIPC would like to see the wording changed from “*receive comments from the public about matters concerning the confidentiality of personal health information or access to that information*” to “*receive comments from the public and custodians about matters concerning the privacy of personal health information or access to that information*”. Though it could be argued that the ability of a custodian to comment is covered by the reference to “public”, it is clearer if they are referenced explicitly. As well,

the term “privacy” is far more comprehensive than “confidentiality”. Furthermore, if edits are being made to this section, it would also be appropriate to reference “correction” in addition to “access”.

***Recommendation 78*** *To improve clarity, amend Section 79(c) the Act to allow the Commissioner to “receive comments from the public and custodians about matters concerning the privacy of personal health information, access to that information, or correction of that information”.*

### **10.5.2 New Additional Powers**

In addition to the minor changes to Section 79(c), the OIPC also called for new “additional powers” to align with those found in Section 95(1)(a) of ATIPPA, 2015. Specifically, the OIPC would like to add the following phrases.

- *conduct investigations to ensure compliance with this Act and the regulations;*
- *monitor and audit the practices and procedures employed by custodians in carrying out their responsibilities and duties under the Act;*
- *consult with any person with experience or expertise in any matter related to the purpose of this Act;*
- *inform the public from time to time of apparent deficiencies in the system, including the office of the commissioner; and*
- *take actions necessary to identify, promote, and where possible cause to be made adjustments to practices and procedures that will improve access to and protection of personal health information.*

As well, the OIPC would like an additional power to bring to the attention of a custodian a failure to fulfil the “duty to assist”. This duty to assist extends beyond requests for access to, or correction of, a health record, but more broadly to all matters in which a custodian should assist a member of the general public in exercising their rights under PHIA. This duty to assist is discussed in more details in Section 9.1 of this report.

Such additional powers are commonly found in other Canadian privacy legislation, and would better allow the Commissioner to play his or her oversight role. In particular, providing audit powers to the Commissioner will significantly improve compliance with Act, and more importantly, improve the protection of personal health information in this province. This sentiment was echoed by the HREB in their responsive written submission. In its submission, the OIPC highlights that it has offered a “short, no-strings-attached privacy check-up in the form of a site visit to physicians’ offices”, but have gotten no uptake. The OIPC also highlights that little has been done by professional colleges to make various demonstrations of PHIA compliance part of registration or recertification (a few have made completion of the online PHIA training a prerequisite). In the absence of substantive voluntary effort to address or improve PHIA compliance amongst smaller custodians over the last five years, non-voluntary options must be considered (e.g. audit, “hybrid” oversight model, increased fines), particularly if the OIPC is willing to support them. As with most new public undertakings, some additional resourcing for the OIPC would likely be required to perform audits.



Naturally, some custodians will be made uncomfortable with the idea that the Commissioner might audit their operations, especially those small to medium sized custodians who have largely “flown under the radar” for the past five years. Those who are made uncomfortable by this new power are encouraged to translate their discomfort into excitement about the opportunity to correct weak practices within their organization and improve the overall level of trust that the public has in the health care system.

As a matter of clarity, the OIPC suggests adding a provision comparable to Section 95(3) of ATIPPA, 2015 to make it clear that the Commissioner’s powers do not simply exist in the context of a review in response to a complaint, but in any context.

***Recommendation 79*** *To better enable the Commissioner to execute his or her oversight role, amend the Act to provide the Commissioner with the following additional powers: (a) conduct investigations to ensure compliance with this Act and the regulations; (b) monitor and audit the practices and procedures employed by custodians in carrying out their responsibilities and duties under the Act; (c) consult with any person with experience or expertise in any matter related to the purpose of this Act; (d) inform the public from time to time of apparent deficiencies in the system, including the office of the Commissioner; (e) take actions necessary to identify, promote, and where possible cause to be made adjustments to practices and procedures that will improve access to and protection of personal health information; and (f) bring to the attention of a custodian a failure to fulfil their duty to assist individuals.*

***Recommendation 80*** *To provide clarity, amend the Act to make it clear that the Commissioner’s powers do not simply exist in the context of a review in response to a complaint, but in any context.*

***Recommendation 81*** *In order to improve compliance with the Act, to improve the protection of personal health information in the province, and to increase public trust in the provincial health care system, provide additional resources to the Commissioner to undertake audits under the Act.*

## 10.6 Timelines for the Production of Records

Section 69(3) of the Act requires custodians to produce records in response to a review by the Commissioner within 14 days. Eastern Health recommended making this 20 business days, citing the varying complexity of such requests. The OIPC was generally against referring to business days, as this introduces several complexities discussed in Section 9.2 of this report, but was not opposed to implementing an “extraordinary circumstances” provision similar to that found in ATIPPA, 2015. The ATIPPA, 2015 provision allows the head of a public body to apply to the Commissioner to have a procedure, including a time limit, changed. The introduction of a similar “extraordinary circumstances” provision in PHIA would seem prudent.

***Recommendation 82*** *To establish a mechanism that allows custodians to be afforded some latitude in procedure, including timelines, amend the Act by way of an “extraordinary circumstances” provision similar to that found in Section 24 of the Access to Information and Protection of Privacy Act, 2015.*

## 10.7 Solicitor-Client Privilege

In its written submission, the OIPC noted that Sections 69(3) and 85(3) of the Act could benefit from a clear reference to “solicitor-client privilege” in order to ensure that this privilege is respected without



question in the contexts contemplated by these sections. The OIPC highlights the fact that recent decisions by the Supreme Court of Canada to uphold this privilege emphasize the need to be clear about the privileges intended when referencing legal privileges. Such clarity would be prudent.

***Recommendation 83*** *To clearly uphold “solicitor-client” privilege, amend the Act by making specific reference to this privilege wherever legal privileges are protected by the Act, including Sections 69(3) and 85(3).*

## 11 Offences and Penalties

Section 88 of the Act speaks to offences and penalties under the Act. During the written submission process, only the OIPC and Eastern Health offered comment on offences and penalties; however, the PHIA Review Survey provided more input to this topic.

### 11.1 Clarifying the Offence Threshold

The OIPC noted that the offence phrasing in Section 88(1)(a) of the Act is very narrow in scope. The current phrasing is “*obtains or attempts to obtain another individual’s personal health information by falsely representing that the person is entitled to the information*”. The OIPC proposes the alternate phrasing “*obtains, uses, views, accesses, collects, discloses or attempts to obtain, use, view, access, collect or disclose another individual’s personal health information without authorization or by falsely representing that the person is entitled to the information*”. This proposed phrasing more comprehensively reflects the various ills that one might participate in, and reflects the new definition of “use” proposed in Recommendation 23.

***Recommendation 84*** *To more comprehensively reflect the actions with respect to personal health information that are offensive, amend the offences listed in the Act. Specifically, consider changing Section 88(1)(a) of the Act from “obtains or attempts to obtain another individual’s personal health information by falsely representing that the person is entitled to the information” to “obtains, uses, views, accesses, collects, discloses or attempts to obtain, use, view, access, collect or disclose another individual’s personal health information without authorization or by falsely representing that the person is entitled to the information”.*

### 11.2 Establishing a Limitation Period

The OIPC noted that this province is only one of three in Canada which has seen prosecutions and convictions for offences under health information privacy legislation. Though the OIPC focusses on recommending best practices and avoiding privacy breaches, sometimes intentional breaches warrant prosecution as a deterrent. Given that the Act is silent on limitation periods for prosecution, the *Provincial Offences Act* dictates that the limitation period is 12 months from the day on which the matter arose.

According to the OIPC, this 12-month limitation period significantly limits the investigations that the Commissioner might undertake with the prospect of making a recommendation of prosecution to the Attorney General. It is quite common that such offences involve electronic records, so months and years may have elapsed between when the offence occurred and when it was detected. After detection, the custodian requires time to conduct an internal investigation before referring the matter to the OIPC. In the words of the OIPC “*if you are assaulted, you know right away and can make a complaint to the police. If your privacy is breached, it may be some time before you become aware of it, even though the effect can be long-lasting and devastating*”.

The OIPC also raised this issue as part of the 2014 ATIPPA review, and 2-year limitation period was added to ATIPPA, 2015. The OIPC recommends the same for PHIA, so as to align with ATIPPA, 2015. The establishment of a limitation period that aligns with ATIPPA, 2015 is prudent.

***Recommendation 85*** *To better reflect the time delays associated with the discovery and preliminary consideration of potentially prosecutable offences involving electronic records, and to align with the Access to Information and Protection of Privacy Act, 2015, amend the Personal Health Information Act to establish a two-year limitation period for offences under the Personal Health Information Act.*

### **11.3 Penalties**

In the words of the OIPC, *“while education and training are clearly the highest priority in terms of preventing and discouraging activities contrary to PHIA, there are occasions when, despite knowing better, individuals have and will continue to willfully violate PHIA”*. Currently, the maximum penalty that can be levied for a conviction under the offence provision of the Act is a \$10,000 fine and six months imprisonment. The two convictions under the Act’s offence provision have resulted in fines of \$1,000 and \$5,000.

When PHIA Review Survey participants were asked to respond to the statement *“In general, the consequences for a clinic or hospital breaking privacy laws are {too high, about right, too low, no opinion}”* 48% of respondents said they were *“too low”*, and 4% of respondents said they were *“too high”* (based on 52 respondents who had an opinion). Similarly, when asked to respond to the statement *“In general, the consequences for a health care worker (for example, a hospital/clinic employee, doctor, pharmacist, dentist, massage therapist, or nurse) breaking privacy laws are {too high, about right, too low, no opinion}”* 33% of respondents said they were *“too low”*, and 2% of respondents said they were *“too high”* (based on 51 respondents who had an opinion). Though many feel the consequence of *“breaking privacy laws”* are *“about right”*, far more believe they are *“too low”* than believe they are *“too high”*.

As the OIPC correctly points out, *“as comparable statutes evolve, [penalties under PHIA] are now considered to be on the low end”*. Ontario has recently amended its *Personal Health Information Protection Act* to increase the maximum fine to \$100,000 for a natural person, and \$500,000 for a party that is not a natural person. In the case of Alberta and Manitoba, the maximum fine is \$50,000 (with some exceptional circumstances in Alberta warranting \$100,000). The maximum fine in ATIPPA, 2015 is \$10,000; however, the OIPC argues that personal health information is more sensitive than much of the information covered by ATIPPA, 2015, so the deterrent put forward by PHIA must be significantly higher. Moreover, the OIPC argues that many health professionals in private practice (many of whom are well-compensated) may not be subject to any other form of discipline resulting of a violation of PHIA (e.g. job loss, loss of licence), so the deterring value of fines under PHIA must be sufficient to address these situations.

The OIPC recommends that the maximum fine be increased to \$50,000. In the interest of a robust deterrent, it would seem that \$100,000 offers courts greater latitude in dealing with particularly egregious offences, as well as offenders for whom \$50,000 does not reflect a significant economic hardship.

Further, the OIPC highlights the issue that there are no penalties or consequences for a person who violates the non-retaliation provision found in Section 89 of the Act. Without a penalty or consequence for violating this provision, it is meaningless. The OIPC recommended that consideration be given to

amendments that might be required to allow an investigation under the Labour Relations Board, similar to that set out in the *Public Interest Disclosure and Whistleblower Protection Act*. It would seem that not all hardships contemplated by Section 89 of the Act (“*dismiss, suspend, discipline, demote, harass or otherwise disadvantage*”) are related to employment, so addressing such situations via the Labour Relations Board might not cover all scenarios. Moreover, the OIPC noted that, being information and privacy specialists, they might not be the most appropriate body to undertake investigations of retaliation. Unfortunately, the Review had little commentary to go by in considering the matter of who might investigate such offences of retaliation, and did not have the time or resources to explore this issue more deeply; however, it would seem reasonable to have the same penalties apply to offences of retaliation as apply to other offences under the Act, as the threat of retaliation has the potential to leave such offences undiscovered and uninvestigated.

***Recommendation 86*** *To make maximum fines a more significant deterrent that allows the justice system to appropriately address the harms resulting from egregious offences, and to better impose economic hardship on those of significant financial means, amend the Act to increase the maximum fines from \$10,000 to \$100,000.*

***Recommendation 87*** *Amend the Act to ensure that offences of retaliation, as contemplated by Section 89 of the Act, are subject to the same penalties as other offences under the Act.*

***Recommendation 88*** *Further explore the matter of who might investigate instances of retaliation as contemplated under Section 89 of the Act, and make amendments to the Act as required to enable such investigations.*

#### **11.4 Notification of Professional Colleges**

In its written submission, the OIPC briefly discusses the issue of mandatory notification of professional colleges by custodians where a member working for the custodian engages unauthorized activity involving personal health information. The OIPC rightly points out that this is a complicated matter, involving privacy, professional practice, human resources, and (often) technology, suggesting that the matter requires deeper consideration. Unfortunately, the Review had little commentary to go by in considering this matter, and did not have the time or resources to explore this issue more deeply, so the associated recommendation does not forcefully suggest a deviation from the status quo.

***Recommendation 89*** *Consider further exploring the implications of mandatory notification of professional colleges by custodians where a subordinate of the custodian engages in unauthorized activity involving personal health information.*

## 12 Other Topics for Further Consideration

### 12.1 Death of a Custodian who is a Natural Person

The written submission of the CPSNL raised an interesting question regarding Section 4(5) of the Act. Specifically, this section says that “where a custodian who is a natural person dies, the duties and powers of a custodian under this Act shall be performed by a personal representative of the deceased until custody and control of the record of personal health information passes to another person who is legally authorized to hold the record”. But what if there is no such personal representative? If there is no “personal representative” and no person yet legally authorized to hold the record, the duties of the deceased custodian are unassigned, so important matters like information protection and individual access rights cannot be assured.

As the CPSNL submission was the only written submission to raise this topic, the Review had little commentary to go by in considering this matter. With no examples of how legislative subtleties around the death of custodians who are natural persons are causing tangible problems, the Review assigned this topic lower priority, and did not have the time or resources to explore this issue more deeply. However, it remains a topic worth considering further.

***Recommendation 90*** Consider further exploration of the matter of assumption of custodial powers and duties upon death of a natural custodian in the absence of a personal representative.

### 12.2 “Direct to Consumer” Genetic Testing and Privacy of the Family

In its written submission, the OIPC suggested the need to study the privacy-related implications of “direct to consumer” genetic testing. In recent years, the number of companies offering such services has increased – two such commonly known companies are “23andMe” and “ancestry.com”. Similarly, consumer uptake has increased, and many services now offer hassle-free testing: the consumer is sent a sample kit, mails a saliva sample or cheek swab in return, and is sent the results a few weeks later. Many of these companies are promoting their services as gifts for various occasions, such as Christmas and Father’s Day.

The OIPC sums up the privacy considerations of direct to consumer genetic testing very well:

*“... genetic information gathered through these tests may be used for secondary purposes, including commercial and other research, beyond this jurisdiction and in fact anywhere in the world. The potential privacy implications are still evolving and may not be fully understood for many years, by which time the data will be long out of the control of affected individuals and beyond any regulatory reach within this Province or Canada.”*

The issues arising from direct to consumer genetic testing are simply the “tip of the iceberg” with respect to privacy of family members.

Consider, for example, where an individual provides a medical history which includes personal health information about their parents (e.g. history of heart disease, Huntington’s disease). Though this

information is about the individual's parents, it is also about the individual, so the Act gives the individual the ability to make decisions about who uses this information, how it is used, and who it is shared with. Yet, their parents might not agree with these decisions, and might not want the information used or shared. PHIA does not require the individual to consider their parents' wishes in making these decisions.

Moreover, PHIA is not unique in this regard. Canadian health privacy legislation is focused on the privacy rights and empowerments of the individual, and not those of the family. To better address the privacy of the family, Canadian health privacy legislation would likely need a complete overhaul. Unfortunately, the Review did not have the time or resources to consider matters of the privacy of families, nor direct to consumer genetic testing; however, these remain topics worthy of further exploration.

***Recommendation 91*** Consider further exploration of the privacy implications of direct to consumer genetic testing.

***Recommendation 92*** Consider further exploration of potential legislative frameworks that can protect health-related privacy of both individuals and families.

### **12.3 Need for Education**

Many of the written submissions called for additional education and the development of supporting resources. In some cases, this work is well-suited to government institutions, such as the Office of the Information and Privacy Commissioner and the Department of Health and Community Services; yet, in many cases, custodians and their supporting professional associations simply need to buckle down and do this work, collaborating with their peers and prioritizing as necessary in order to ensure that the work gets done.

### **12.4 Unique Privacy Concerns of Aboriginal People**

In its written submission, NLCHI noted that it recognizes that Aboriginal people have “*unique privacy concerns which may impact the expectations of how personal health information is collected, used or disclosed*”, and suggested the need for clarification on addressing the privacy of Aboriginal people. As briefly discussed in Section 12.3, the development of resources to support the Act is the responsibility of many parties across the provincial health privacy ecosystem.

### **12.5 Spiritual Care**

In its written submission, Central Health suggest considering the inclusion of “spiritual care” in the definition of “health care” found in Section 2 of the Act. Despite efforts to encourage participation in the Review amongst the faith community, the Review received no further commentary to go by in considering this matter, and did not have the time or resources to explore this issue more deeply, so cannot make any recommendations related to spiritual care.

## 12.6 Application to the Community Sector

The Review received one written submission from members of the community sector, specifically, a submission from Stella's Circle. This submission came after the original written submission deadline and was framed in the context of a responsive written submission. In its written submission, Stella's Circle highlights the following:

*"Stella's Circle has 125 staff with an \$8.2 million budget. Every year, we offer services to 1000 people who face many barriers in their community. These barriers can include mental health issues, addictions, homelessness, poverty and criminal justice involvement... Staff of Stella's Circle include social workers, case managers, mental health workers, housing support workers and employment counsellors."*

Stella's Circle submission is limited to *"a general observation of the lack of clarity around the application of this legislation to community groups"*. Stella's Circle recommends communication and education about the legislation specifically to community groups. As briefly discussed in Section 12.3, communication and education is the responsibility of many parties across the provincial health privacy ecosystem.

## 12.7 Relationship to the ATIPPA, 2015

Section 12 of the Act addresses the relationship with ATIPPA, 2015. In its written submission, the OIPC notes that Section 12 is technically correct, but very cumbersome. Moreover, the recommendations found in this report may impact how the relationship between these Acts must be addressed legislatively. Unfortunately, the Review did not have the time or resources to consider this section of the Act in detail.

***Recommendation 93*** Amend Section 12 of the Act (addressing the relationship between the Personal Health Information Act and the Access to Information and Protection of Privacy Act, 2015) to: (a) simplify and improve readability; and (b) appropriately reflect any changes arising from the review of the Personal Health Information Act.

### 13 Minor Matters

The written submission process was instrumental in identifying minor matters, including typos, which need to be addressed in the Act. These minor matters are listed in Table 1.

As well, the written submission process highlighted several potential issues with the use of “and” and “or” in crafting lists. Notably, submissions indicated that the use of “and” and “or” found in Sections 349(m), 34(o), and 39(4)(e) are unclear and likely in need of change. The comments on the use of “and” and “or” within the Act suggest the need for a thorough review and amendments to ensure that what is intended is actually written.

***Recommendation 94*** Amend the Act to address the minor matters presented in Table 1 of the Review report.

***Recommendation 95*** Review the use of “and” and “or” throughout the Act to ensure that what is intended is actually written, making amendments to the Act as required.

**Table 1: Minor matters needing to be addressed.**

Section	Matter
2(1)(j)(i)	The short title of the professional act applying to chiropractors is “ <i>Chiropractors Act, 2009</i> ”, not “ <i>Chiropractors Act</i> ”.
2(1)(j)(ii)	The short title of the professional act applying to dentists is “ <i>Dental Act, 2008</i> ”, not “ <i>Dental Act</i> ”.
2(1)(j)(ix)	The short title of the professional act applying to physicians is “ <i>Medical Act, 2011</i> ”, not “ <i>Medical Act, 2005</i> ”.
2(1)(j)(xv)	The short title of the professional act applying to registered nurses is “ <i>Registered Nurses Act, 2008</i> ”, not “ <i>Registered Nurses Act</i> ”.
2(1)(j)(ix)	The short title of the professional act applying to physicians is “ <i>Social Workers Act</i> ”, not “ <i>Social Workers Association Act</i> ”.
4(2)(b)	This clause references “health professionals”, but the defined term found in the Act is “health care professionals”.
7(f)	This clause references the “ <i>Neglected Adults Welfare Act</i> ”, but the applicable Act is the “ <i>Adult Protection Act</i> ”.
13(1)	This clause references “personal information”, but it appears that the intended term is “personal health information”.
18(3)(c)	This clause uses the word “inquires”, but it appears that the intended word is “inquiries”.
19(b)	This clause refers to “access information” when speaking about how to reach a contact person designated under Section 18. The more commonly understood phrase is “contact information”.
24(3)	To maintain consistency in legislative structure, the definition of “circle of care” should be moved to the definition section (Section 2).
31(b)	The first instance of the pronoun “it” in this clause is ambiguous. For clarity, this clause should be reworded to remove ambiguity.
84(2)	This clause permits the Commissioner to “ <i>intervene as a party to an appeal under paragraph 83(1)(b) [of this Act]</i> ”. The restriction to paragraph 83(1)(b) would appear to unnecessary.
85(2)	This clause refers to “public body”, which is a term used in ATIPPA, 2015. It would appear



	that the intended term is “custodian”.
90(1)(m)	This clause references “subsection 46(3)”, but it appears that the intended subsection is 45(3).

## 14 Conclusion

Based on the results of the PHIA Review Survey, and the written submissions made by stakeholders, it would appear that PHIA is not a fundamentally flawed piece of legislation in need of a major overhaul. Notably, many of the written submissions spoke to how PHIA has improved the protection of personal health information in Newfoundland and Labrador.

Instead of a complete overhaul, PHIA simply needs some fine tuning in order to reflect the experience gained over the past five years. Though this report makes nearly 100 recommendations (see Appendix D), the majority of these recommendations represent minor corrections to address the challenges faced by stakeholders, as well as the lessons learned. However, some of the recommendations address fundamental concepts, such as “custodianship”, group practices, academic institutions, privacy impact assessments, contractual requirements, oaths of confidentiality, working students, privacy of the deceased, duty to assist, offences, and penalties. As well, the report recommends a change in oversight powers of the Information and Privacy Commissioner to align with the *Access to Information and Protection of Privacy Act, 2015*.

In deciding whether or not to adopt the recommendations found in this report, there are risks in taking an “a la carte” approach. Not every recommendation must be accepted in order to improve the Act; however, many of the recommendations work together to ensure a fulsome legislative health privacy regime for the province. In some cases, accepting one recommendation but not another would be akin to erecting scaffolding with a few missing pieces – it might stay upright for a while, but will eventually start to fail.

Many of the written submissions called for additional education and the development of supporting resources. In some cases, this work is well-suited to government institutions, such as the Office of the Information and Privacy Commissioner and the Department of Health and Community Services; yet, in many cases, custodians and their supporting professional associations simply need to buckle down and do this work, collaborating with their peers and prioritizing as necessary in order to ensure that the work gets done.

Because limited resources were available to conduct the Review, there were some topics that the Review could not tackle in full; moreover, some of the recommendations stop short of suggesting specific wording for amendments to the Act, instead leaving that work for those who are experts in drafting legislation. However, this limited resourcing required the Review to “think outside the box” in an attempt to maximize reach and engagement while minimizing cost and effort. Despite little participation from faith communities and the community sector, the level of engagement by stakeholders was very high. Use of social media to promote the PHIA Review Survey resulted in very strong survey participation, and the introduction of a “responsive” round of written submissions resulted in respectful public dialogue and debate amongst stakeholders without the need for in-person sessions and travel. It is hoped that some of the creative solutions used in the Review might work for future legislative reviews conducted by the province.

## Appendix A List of Acronyms

Table 2 presents a list of acronyms which may appear in the report.

**Table 2: Acronyms which may appear in the report.**

<b>Acronym</b>	<b>Expanded Acronym</b>
ATIPPA, 2015	<i>Access to Information and Protection of Personal Information Act, 2015</i>
CIHI	Canadian Institute for Health Information
CMTNL	College of Massage Therapists of Newfoundland and Labrador
CNPS	Canadian Nurses Protective Society
CPE	Communications and Public Engagement Branch of the Government of Newfoundland and Labrador
CPSNL	College of Physicians and Surgeons of Newfoundland and Labrador
HREAA	<i>Health Research Ethics Authority Act</i>
HREA	Newfoundland and Labrador Health Research Ethics Authority
HREB	Newfoundland and Labrador Health Research Ethics Board
MUN	Memorial University of Newfoundland
NLASW	Newfoundland and Labrador Association of Social Workers
NLCHI	Newfoundland and Labrador Centre for Health Information
NLMA	Newfoundland and Labrador Medical Association
OECD	Organisation for Economic Co-operation and Development
OIPC	Office of the Information and Privacy Commissioner
PHIA	<i>Personal Health Information Act</i>
TCPS2	<i>Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans</i>

## Appendix B Terms of Reference

### Statutory Review of the Personal Health Information Act (PHIA) Terms of Reference

#### Preamble

The Personal Health Information Act, SNL2008, c. P-7.01 (PHIA) came into force on April 1, 2011. Pursuant to section 91 of the PHIA, the Minister Responsible for the Department of Health and Community Services (HCS) is required to refer the legislation to a committee for a review after the expiration of not more than five years after its coming into force and every five years thereafter. This is the first review since the proclamation of the legislation.

#### 1. Overview

The Committee will complete a review of the Personal Health Information Act and provide recommendations arising from the review to the Minister Responsible for the Department of Health and Community Services (the Minister), Government of Newfoundland and Labrador. This review will be conducted in an open, transparent and respectful manner and will engage citizens and stakeholders in a meaningful way. The privacy of those who partake in consultations and share information with the committee will be protected.

#### 2. Committee Members

- David Morgan: Committee Chair
- Jeannie House: Committee Member
- Marian Crowley: Committee Member
- Daryl Pullman: Committee Member
- Blaine Edwards: Review Committee Coordinator
- Michael Bannister: Ex Officio

#### 3. Deliverables

The Committee will prepare a final report for submission to the Minister. The report will include:

- an executive summary;
- a summary of the research and analysis of the legislative provisions and leading practices in similar jurisdictions;
- a summary of the public consultation process including information regarding types and numbers of participants, issues and concerns, emerging themes, and recommendations brought forward by citizens and stakeholders; and
- detailed findings and recommendations for the Minister's consideration.

#### 4. Scope of the Work

4.1. The Committee will conduct a comprehensive review of the provisions and operations of the Act which will include, but not be limited to, the following:

- The PHIA Review Committee will conduct public consultations, review all submissions, as well as provide the analysis and recommendations for the report(s);
- Identify the successes and challenges within the first five years of PHIA;
- Evaluate the provisions of the Act and Regulations;
- Determine if specific intended outcomes regarding the protection of personal health information have been achieved;
- Determine if the Act's provisions concerning privacy breaches and the response to privacy breaches is sufficient;
- Whether the current definitions are appropriate and/or if further classes of persons or entities who handle personal health information are needed;
- Whether the current provisions concerning consent of individuals is sufficient to address current and future needs;
- Assess the operation of the Act and Regulations, including whether custodians of this province have adopted practices that align with PHIA and whether there are gaps that would enable stronger compliance to the Act; and
- Whether there are any additional uses or disclosures of personal health information that should be permitted under the Act.

4.2. Consideration of standards and leading practices in other jurisdictions:

- The Committee will conduct an examination of leading international and Canadian practices, legislation and academic literature related to personal health information legislative frameworks and identify opportunities and challenges experienced by other jurisdictions;
- The Committee will specifically consult with the Information and Privacy Commissioner for Newfoundland and Labrador regarding any concerns of the Commissioner with existing legislative provisions, and the Commissioner's views as to key issues and leading practices.

## **5. Resources and Budget.**

5.1. An amount \$30,000 has been budgeted to support the Review Committee;

5.2. The Department of Health and Community Services will provide administrative support to the Review Committee which will include the Manager of Privacy and Information Security act as the Review Committee Coordinator.

Other resources will be made available as needed.

## **6. Timeline**

6.1. The review committee will aim to have the final report submitted to the Department of Health and Community Services no later than 31st March, 2017.

## **7. Transparency and Accountability**

7.1. All written submissions are to be made publically available.

7.2. The committee will limit non-public consultations only to those who wish to clarify previous submitted written submissions.

7.3. The committee will protect the privacy and confidentiality of submissions from the general public.

## Appendix C Written Submissions

The following organizations made submissions during Round 1 of the written submission process.

- Canadian Institute for Health Information
- Canadian Nurses Protective Society
- Central Health Regional Health Authority
- College of Massage Therapists of Newfoundland and Labrador
- College of Physicians and Surgeons of Newfoundland and Labrador
- Eastern Health Regional Health Authority
- Labrador-Grenfell Regional Health Authority
- Memorial University of Newfoundland
- Newfoundland and Labrador Association of Social Workers
- Newfoundland and Labrador Centre for Health Information
- Newfoundland and Labrador Health Research Ethics Board
- Newfoundland and Labrador Medical Association
- Office of the Information and Privacy Commissioner for Newfoundland and Labrador
- Sequence Bio
- Western Health Regional Health Authority
- Workplace Health, Safety and Compensation Commission (also known as “WorkplaceNL”)

No submissions were invited during Round 2 of the written submission process (clarification round).

The following organizations made submissions during Round 3 of the written submission process (responsive round).

- Central Health Regional Health Authority
- Eastern Health Regional Health Authority
- Labrador-Grenfell Regional Health Authority
- Newfoundland and Labrador Health Research Ethics Board
- Office of the Information and Privacy Commissioner for Newfoundland and Labrador
- Stella’s Circle
- Western Health Regional Health Authority

In accordance with Section 4.2 of the Terms of Reference for the Review (see Appendix B), the Review also received further communications from the Office of the Information and Privacy Commissioner following the written submission process.

## Appendix D Summary of Recommendations

The following are the recommendations made by the Review.

**Recommendation 1** *Provide further clarity on custodianship and information management within the Act, and eliminate the potential for “nested” or “joint” custodianship.*

**Recommendation 1a** *To eliminate the potential for “nested” or “joint” custodianship, to eliminate the restrictions to community health and mental health in Section 4(1)(g)(iv), and to clearly address group practices, amend the Act as follows: (a) limit the definitions of “health care provider” and “health care professional” found in Section 2(1) to natural persons; and (b) rephrase Section 4(1)(g)(iv) as “a centre, program, service, or group practice, the primary purpose of which is the provision of health care by a health care professional or health care provider”.*

**Recommendation 1b** *Consider offering further clarity with respect to custodianship in the context of group practices by amending the Act to require that a person who is designated a custodian by way of operating a group practice must communicate in writing with each health care professional or health care provider participating in the group practice that the person operating the group practice is the custodian with respect to the records of the group practice, not the health care professional or health care provider.*

**Recommendation 1c** *To provide further clarity on custodianship and information management, and to eliminate the potential for “nested” or “joint” custodianship, amend Section 4(2) of the Act to clearly identify those persons which: (a) cannot be considered custodians under any circumstance; and (b) are not custodians with respect to specific records in specific contexts. Moreover, in amending Section 4(2), ensure that: (a) custodians designated under the Act can play the role of information manager to other custodians with respect to specific records; (b) any custodian designated under the Act who plays a subordinate role to another custodian with respect to specific records (e.g. employee, contractor, information manager) is clearly precluded from being considered the custodian with respect to those records; and (c) any health care professional or health care provider who provides or undertakes health care as part of a facility, pharmacy, service, centre, program, or group practice identified in 4(1)(g) is clearly precluded from being considered the custodian with respect to records they engage with (e.g. “collect, use, disclose or dispose of”) in that context .*

**Recommendation 2** *Consider broadening the list of designated custodians through elimination of the “primary purpose” limitation found in Section 4(1)(g)(iv) by amending the Act to replace the phrase “the primary purpose of which is the provision of health care by a health care professional or health care provider” with “a purpose of which is the provision of health care by a health care professional or health care provider”.*

**Recommendation 3** *To ensure clarity of custodianship with respect to records in multi-organization health information systems, amend the Act to establish a mechanism whereby classes of records within a health information system can be placed under the custodianship of a single designated custodian using*



*regulations to the Act. For greater clarity, such a mechanism must also facilitate the placement of all the records within a health information system under the custodianship of a single designated custodian.*

**Recommendation 4** *To better ensure legislative protection of personal health information by those practitioners regulated by the Health Professions Act, amend the Personal Health Information Act to designate all members of the professions listed in the Health Professions Act as “health care professionals” under Section 2(1)(j).*

**Recommendation 5** *Amend the Act to make it clear that home support agencies are custodians.*

**Recommendation 6** *Consider further exploration of the issue of custodianship by independent home support workers who are not considered “health care professionals” according to the definitions found in Section 2 of the Act. Specifically, determine if the burden of custodianship requirements, roles, and obligations on these workers outweighs the resulting benefit to the protection of personal health information in this province. Should further evidence suggest that the burden outweighs the benefit, consider exempting these workers from the Act by way of regulation, or by amending the Act to more appropriately balance the burden and benefit.*

**Recommendation 7** *Broaden the application of custodianship within the post-secondary academic community.*

**Recommendation 7a** *Amend the Act to replace the custodial designations associated with Memorial University (i.e. the four schools/faculties currently designated under the Act) with custodial designation of the entire institution with respect to all activities conducted under its teaching and research mandates. For greater clarity, Memorial’s constituent schools/faculties/units should not be custodians in this context, nor should Memorial’s faculty or staff.*

**Recommendation 7b** *Amend the Act to designate all public post-secondary institutions operating in the province as custodians under the Act with respect to all activities conducted under their teaching and research mandates.*

**Recommendation 7c** *Consider amending the Act to designate all persons operating a private training institution under the Private Training Institutions Act as custodians under the Act with respect to all activities conducted under their teaching and research mandates.*

**Recommendation 8** *To ensure the protection of academic freedoms in the context of mandatory disclosures without consent, consider amending the Act to provide an exemption for research data in all mandatory disclosures except those in response to a summons, subpoena, warrant, demand, order or similar requirement issued by a court or in response to a rule of court concerning the production of personal health information in a proceeding.*

**Recommendation 9** *To ensure legislative protection of personal health information across the health research community, amend the Act to designate all health researchers as custodians (whether or not the health researcher is a natural person).*

**Recommendation 10** *To ensure clarity of the definition of a “record” of personal health information, do not amend the Act to indicate specific forms which are included in the definition of “record”.*

**Recommendation 11** *To ensure clarity of the definition of a “record” of personal health information, amend the Act to eliminate the self-reference included in the definition of “record”.*

**Recommendation 12** *To broaden the definition of “personal health information” to include information about any collection of body parts and bodily substance, amend the Act to replace the phrase “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” found in Section 5(1)(c) with the phrase “the collection, whether as part of a donation or not, of a body part or bodily substance, including information derived from the testing or examination of a body part or bodily substance”.*

**Recommendation 13** *Further explore legislative protection of privacy and confidentiality in the context of biological samples.*

**Recommendation 13a** *To ensure that the protection of personal health information is not compromised in an effort to legislatively protect privacy and confidentiality in the context of biological samples, do not establish legislative protection of privacy and confidentiality in the context of biological samples by way of amendments to Personal Health Information Act.*

**Recommendation 14** *To clearly include information of a genetic nature in the definition of “personal health information”, amend the Act to include the phrase “genetics, including genes, genetic variation and genetic heredity;” as a subsection under Section 5(1) of the Act.*

**Recommendation 15** *Maintain the agnosticism, with respect to context, of the definition of “personal health information” by not amending the Act in any way that either includes or excludes information from the definition of “personal health information” depending on the context in which it is collected or encountered.*

**Recommendation 16** *In the interest of clarity, consider amending the Act to define the term “minor”.*

**Recommendation 17** *In the interest of clarity, consider amending the Act to define the term “guardian”.*

**Recommendation 18** *In the interest of clarity, consider amending the Act to define the term “spouse”.*

**Recommendation 19** *In the interest of clearly outlining the rights of cohabitating partners in health care related decision making in the event of death or other incapacity, consider the appropriateness of including cohabitating partners in the precedence list found in Section 10 of the Advance Health Care Directives Act.*

**Recommendation 20** *Do not amend the Act to replace the definition of “research” with a definition of “health research”.*

**Recommendation 21** *In the interest of aligning research-related aspects of the Act with key frameworks, consider amending the Act to revise the definition of “research” to align with that found in the “Canadian*

*Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, December 2014” (commonly referred to as the TCPS2). Specifically, revise the definition of research to “an undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation”.*

***Recommendation 22*** *In the interest of clarifying the difference between “research” and “evaluation”, and aligning with key frameworks, consider amending the Act to define “evaluation” to align with the definition developed by the Canadian Evaluation Society. Specifically, define “evaluation” as “the systematic assessment of the design, implementation or results of an initiative for the purposes of learning or decision-making”.*

***Recommendation 23*** *To clearly indicate that viewing of personal health information constitutes “use”, amend the Act to modify the definition of “use” found in Section 2(1)(aa). Specifically, replace the phrase “means to handle or deal with the information” with “means to view, handle or deal with the information”.*

***Recommendation 24*** *To eliminate the risk of unintentionally limiting the protections afforded by the Act to only those aspects of a custodian’s activities that directly involve personal health information, groups of actors (with respect to custodians) should not be defined according to their relationship or involvement with personal health information.*

***Recommendation 24a*** *Amend the Act to remove the phrase “in respect of personal health information” from the definition of “agent”.*

***Recommendation 25*** *To improve the comprehensiveness of the protections afforded by Section 14 of the Act, amend the Act to replace references to “those health care professionals who have the right to treat persons at a health care facility operated by the custodian” with “those health care professionals and health care providers who provide or undertake health care at a health care facility operated by the custodian”, as appropriate.*

***Recommendation 25a*** *To reduce repetition within the Act and to eliminate the risk of inconsistent phrasing, amend the Act to: (a) add the following definition to Section 2(1) of the Act: “‘authorized health care giver’, in relation to a custodian, means a health care professional or health care provider who has the right to provide or undertake health care at a health care facility operated by the custodian”; and (b) reference the definition of “authorized health care giver” throughout the Act as appropriate.*

***Recommendation 26*** *To support the establishment of requirements that apply to students on work placements with custodians, amend the Act to add the following definition to Section 2(1) of the Act: “‘working student’, in relation to a custodian, means a student of a post-secondary institution working with, for, or on behalf of, the custodian whether or not the student is being remunerated by the custodian”.*

**Recommendation 27** *To better support the establishment of requirements that apply to custodians with respect to business entities with whom they engage, amend the Act to add the following definition to Section 2(1) of the Act: “contractor’, in relation to a custodian, means a business entity with whom a custodian enters into a business relationship”.*

**Recommendation 28** *To better ensure protection of personal health information in business relationships, amend the Act to extend the requirements of Section 22 (“information managers”) to “agents” and “contractors” whose role, with respect to the custodian, requires them to collect, use, disclose, maintain, destroy, or otherwise interact with or handle personal health information.*

**Recommendation 29** *To better ensure the commitment to confidentiality at the personnel-level, amend Section 14(1) of the Act such that custodians must ensure that oaths of confidentiality are taken by its employees, its volunteers, its working students, its agents who are natural persons, and its authorized health care givers.*

**Recommendation 30** *Amend the Act to allow the creation of regulations that enable the particulars of the oaths and affirmations contemplated by Section 14(1) to be specified.*

**Recommendation 30a** *Consider establishing regulations to the Act that require the oath or affirmation contemplated by Section 14(1) to require a commitment to the offence provisions of the Act.*

**Recommendation 30b** *Consider establishing regulations to the Act that require the oath or affirmation contemplated by Section 14(1) to be renewed at least once every three years.*

**Recommendation 31** *To better ensure compliance with the Act and organizational policy at the personnel-level, amend the Act such that the current obligations under Section 14(2) are applied to a custodian’s contractors, agents, employees, volunteers, working students, and authorized health care givers.*

**Recommendation 32** *To better ensure awareness of the duties imposed by the Act and organizational policy at the personnel-level, amend the Act such that the current obligations under Section 14(2) (awareness of duties) and Section 18(2)(b) (“contact persons” role in ensuring awareness of duties) are with respect to a custodian’s contractors, agents, employees, volunteers, working students, and authorized health care givers.*

**Recommendation 33** *To reduce unnecessary burdens on custodians, consider amending the Act to establish exception mechanisms that eliminate the need to undertake specific personnel-related protections (i.e. Sections 14(1)-(3) of the Act) in settings where there is little or no engagement with personal health information.*

**Recommendation 34** *Should the Act be amended to establish exception mechanisms that eliminate the need to undertake specific personnel-related protections in settings where there is little or no engagement with personal health information, further amend the Act to require custodians to document the rationale for why such exceptions should apply in these settings.*

**Recommendation 35** *The Act should not be amended to establish prescriptive requirements regarding Privacy Impact Assessments, but should be amended to require custodians to address Privacy Impact Assessments by way of policy and procedure. Specifically, amend Section 13(2) of the Act to include policies and procedures to “ensure comprehensive and documented assessment of the privacy impacts, by appropriately-qualified personnel, of all aspects of the custodian’s operations relating to personal health information in their custody or control in order to address: (a) the format of such assessments; (b) the timing of such assessments; (c) the integration of the findings of such assessments into the custodian’s decision-making processes; (d) the submission of such assessments and their findings to the commissioner; and (e) the presentation of such assessments and their findings to the general public”.*

**Recommendation 36** *To better ensure that the Commissioner can more execute their mandate, amend Section 15 of the Act to ensure that the details of incidents involving the compromise of personal health information, and any associated notification of affected individuals, are reported to the Commissioner if: (a) individuals are notified that personal health information about them has been compromised, whether required by the Act or not; or (b) any of the criteria found in Sections 15(3)(a)-(d) are met.*

**Recommendation 36a** *Should Recommendation 36 be adopted, amend the Act to remove the existing “material breach” trigger for Commissioner reporting that is found in Section 15(4) of the Act (Recommendation 36 eliminates the need to consider a “material breach” threshold for reporting incidents to the Commissioner).*

**Recommendation 37** *To prevent harming individuals as a result of notification of breaches or exceptional circumstances, amend Section 15 of the Act to include an additional exemption to the requirements of Sections 15(3) (“breach notification”) and 20(3) (exception notification) when notification “could reasonably be expected to result in a risk of serious harm to the mental or physical health or safety of the individual who is the subject of the information or another individual”.*

**Recommendation 38** *In order to give greater effect to an individual’s right to control the flow of personal health information about them as contemplated by Part III of the Act, consider initiating a dialogue amongst stakeholders regarding the passing of consent directives (whether or not they are in electronic form).*

**Recommendation 39** *To better empower individuals to control the flow of personal health information about them as contemplated by Part III of the Act, amend the Act to require custodians to do the following when an individual inquires about control of personal health information: (a) inform the individual of what consent options are available within the custodian organization; (b) facilitate any requests for consent directives; (c) inform the individual that there may be other organizations and facilities with whom they may wish to set consent directives; and (d) provide reasonable assistance in connecting the individual with these other organizations and facilities.*

**Recommendation 40** *To ensure that the “minimum necessary” principle is upheld with respect to the “circle of care”, do not amend the Act to automatically include a “family physician” as part of the “circle of care” unless explicitly excluded.*

**Recommendation 41** *To better support the participation of family members and other non-custodians in care giving, amend Section 25(1) of the Act so that a custodian can rely on implied consent for the disclosure of personal health information for the purpose of providing health care or assisting in providing health care regardless of who the information is disclosed to.*

**Recommendation 42** *Amend the Act to clearly give regional health authorities the ability to rely on implied consent for the use and disclosure of personal health information as part of the circle of care. Specifically, change the phrase “Where a custodian referred to in paragraph 4(1)(e),(f) or (g)” with “Where a custodian referred to in paragraph 4(1)(a),(e),(f) or (g)”.*

**Recommendation 43** *To eliminate the unnecessary restriction on the collection of personal health information for analysis of the health care system, amend the Act to remove the phrase “and the person from whom the information is collected has in place practices and procedures to protect the privacy of the individuals who personal health information it receives and to maintain the confidentiality of the information” from Section 31(j).*

**Recommendation 44** *To ensure that the “need to know” concept is more accurately applied, amend Section 35 of the Act such that limitations on the use of personal health information apply to a custodian’s contractors, agents, employees, volunteers, working students, and authorized health care givers who “need to know”.*

**Recommendation 45** *In the interest of clarity, consider amending the Act to define the term “personal representative”.*

**Recommendation 46** *In the interest of clarity, consider amending the Act to replace the defined term “representative” with another term that avoids confusion with the term “personal representative”.*

**Recommendation 47** *Amend the Act to allow custodians to disclose personal health information about an individual who is deceased, or presumed to be deceased, without the consent of the individual who is the subject of the information, to a person or insurer for the purposes of administering an insurance policy.*

**Recommendation 48** *To reduce the existing wholesale transfer of rights and powers upon death such that they are only given to a personal representative for the purposes of administering the estate, amend the Act to replace the existing phrasing in Section 7(e) of the Act with “where the individual is deceased, by the individual’s personal representative for a purpose related to the administration of the estate”.*

**Recommendation 49** *Amend the Act to ensure that custodians may disclose personal health information without consent for the activities of the Workplace Health, Safety and Compensation Commission relating to “determining of verifying the eligibility of the individual to receive health care or related goods, services or benefits provided under an Act of the province or of Canada”.*

**Recommendation 50** *To better enable custodians to support the work of other organizations, amend the Act to allow custodians to disclose personal health information without consent to any custodian for the purposes contemplated under Sections 39(1)(b), (d), (e), and (g) of the Act.*

**Recommendation 51** *In the interest of better enabling custodians to support the work of other organizations, consider amending the Act to allow custodians to disclose personal health information without consent to any person for the purposes contemplated under Sections 39(1)(b), (d), (e), and (g) of the Act.*

**Recommendation 52** *To eliminate the unnecessary limitation related to geographic area established by Section 39(1)(j) with respect to disclosures of personal health information by a custodian without consent, amend the Act to: (a) replace the current phrasing in Section 39(1)(j) with “to its successor where the custodian transfers records to the successor as a result of the custodian ceasing to be a custodian or ceasing, in whole or in part, to provide health care and the successor is a custodian”; and (b) replace the current phrasing in Section 39(3) with “that the custodian has ceased or will cease to be a custodian with respect to the personal health information referred to in the notice”.*

**Recommendation 53** *Amend the Act to designate registries and their associated custodians, not simply custodians, to which all custodians must disclose personal health information without consent.*

**Recommendation 54** *To support the ability to legislatively enshrine criteria which must be considered when designating registries (and their associated custodians) to which custodians must disclose personal health information without consent, consider amending the Act to allow the establishment of such criteria by way of regulation.*

**Recommendation 55** *To prevent undesirable mandatory disclosures of personal health information without consent to registries which evolve over time, amend the Act or establish regulations to ensure periodic review of all designated registries against any criteria that are used to determine suitability of the registry for designation.*

**Recommendation 56** *To support the ability to legislatively enshrine criteria which must be considered when designating an information network to which, or via which, custodians must disclose personal health information without consent, consider amending the Act to allow the establishment of such criteria by way of regulation.*

**Recommendation 57** *In the interest of openness, consider amending the Act to: (a) explicitly reference the provincial electronic health record operated by the NL Centre for Health Information as an information network to which, or via which, custodians must disclose personal health information without consent; and (b) list the constituent subsystems of the provincial electronic health record.*

**Recommendation 58** *To increase the level of accountability placed on, and due diligence expected of, custodians when making disclosures of personal health information without consent to a person carrying out an inspection, investigation or similar procedure that is authorized by or under the Act, the Child, Youth and Family Services Act, another Act or an Act of Canada for the purpose of facilitating the inspection, investigation or similar procedure, amend the Act to make such disclosures discretionary, except where other provisions of the Act make the disclosure mandatory.*

**Recommendation 59** *To better support the prevention of fraud and other abuses, amend the Act to allow custodians to disclose personal health information to law enforcement without consent where there is reasonable expectation that doing so will detect or prevent the commission of an offence under an Act of the province or of Canada.*

**Recommendation 60** *To maintain appropriate independence between the Personal Health Information Act and the Health Research Ethics Authority Act, do not amend the Act to allow a custodian to disclose personal health information without consent for research purposes and without approval by a research ethics board or body, even if the research only involves publically available information.*

**Recommendation 61** *Consider further examination of the matter of custodians being allowed to disclose personal health information without consent for non-health research.*

**Recommendation 62** *To increase the level of accountability associated with disclosures of personal health information without consent for research purposes, amend the Act to require custodians to establish an agreement with the person to whom the information is disclosed to govern the terms of the disclosure.*

**Recommendation 62a** *To ensure that specific protections and restrictions are guaranteed in disclosures of personal health information without consent for research purposes, amend the Act to allow specific requirements relating to agreements governing such disclosures to be specified by way of regulations to the Act.*

**Recommendation 63** *To empower the minister in a way that more appropriately reflects the trust and accountability associated with the role, amend the Act to support the ministerial disclosures of registration information without consent contemplated by Section 45 by requiring custodians to disclose registration information without consent at the discretion of the minister, or in accordance with an agreement entered into by the minister, subject to the existing restrictions found in Section 45 of the Act.*

**Recommendation 64** *To better support the use of personal health information for instructional purposes, amend the Act to: (a) allow custodians to use and disclose personal health information without consent for instructional purposes under Part IV of the Act; and (b) remove Regulation 3 of the Personal Health Information Regulations. Moreover, in allowing custodians to use and disclose personal health information without consent for instructional purposes under Part IV of the Act, eliminate the need for “affiliation agreements”, as well as the restriction to the development of health care professionals and health care providers, currently found in Regulation 3.*

**Recommendation 65** *Ensure that use and disclosure of personal health information without consent for instructional purposes is given adequate consideration by way of policy and procedure. Specifically, amend Section 13(2) of the Act to include policies and procedures to protect the privacy of individuals with respect to use or disclosure of personal health information without consent for instructional purposes.*



**Recommendation 66** *To improve the level of ease with which individuals can take advantage of the entitlements and empowerments afforded to them under the Act, amend the Act to establish an overall “duty to assist” by: (a) obligating custodians to: (i) use every reasonable effort to assist individuals in taking advantage of all entitlements and empowerments afforded to individuals under the Act; and (ii) respond and interact with individuals openly, accurately, and completely; and (b) allowing the commissioner to bring to the attention of custodians a failure to the fulfil the “duty to assist”.*

**Recommendation 67** *Consider amending the Act to clarify that references to “days” are “calendar days”.*

**Recommendation 68** *To better uphold the “duty to assist”, amend the Act such that custodians who extend the time limits for responding to access requests are required, when notifying the individual about the extension, to inform individuals about their right to complain to the Commissioner about extending the time limits for responding to access requests.*

**Recommendation 69** *To better uphold the “duty to assist”, amend the Act such that custodians who charge fees for responding to access requests are required, when notifying the individual about the fees they will have to pay, to inform individuals about their right to complain to the Commissioner about the fees.*

**Recommendation 70** *To better uphold the “duty to assist”, amend the Act such that custodians who in response to access request take the position that a record of personal health information does not exist or cannot be found, be required to inform the individual of the following: (a) that the custodian believes that the record does not exist or cannot be found; (b) the reason why the custodian believes that the record does not exist or cannot be found; (c) that the individual may appeal to the Trial Division; and (d) that the individual may request a review by the Commissioner.*

**Recommendation 71** *Amend the Act such that particulars of the fees related to access requests can be addressed by way of regulations established under the Act.*

**Recommendation 72** *To better address the risks associated with having shared incorrect personal health information, amend the Act to ensure that notifications made in response to a correction also cover the period between the request for correction and the disposition of the request by replacing the phrase “within the 12 month period immediately preceding the request for correction” found in Sections 63(1)(c) and 63(2)(a) with “within the period between when the correction was made and the day 12 months prior to when the request for correction was made”.*

**Recommendation 73** *To enable the Commissioner to play a more substantive role in the protection of personal health information, amend the Act to establish a “hybrid” oversight model by the Commissioner that parallels the “hybrid” oversight model found in the Access to Information and Protection of Privacy Act, 2015.*

**Recommendation 73a** *Work with the Commissioner to determine the necessary legislative changes to establish the “hybrid” oversight model.*

**Recommendation 74** *To better enable the Commissioner to undertake reviews, amend the Act to allow the Commissioner to compel records from anyone when conducting a review, whether or not the relevant record or person is subject to the provisions of the Act.*

**Recommendation 75** *To better enable the Commissioner to undertake reviews, amend the Act to unambiguously allow the Commissioner to enter any premises when conducting a review, by replacing the word “custodian” in Section 71(b) with “person”.*

**Recommendation 76** *To better support multi-jurisdictional investigations by Commissioners, amend the Act to allow the commissioner to exchange details about investigations with Commissioners from other Canadian jurisdictions.*

**Recommendation 77** *To provide clarity, amend the Act to allow the Commissioner to undertake “own motion” investigations.*

**Recommendation 78** *To improve clarity, amend Section 79(c) the Act to allow the Commissioner to “receive comments from the public and custodians about matters concerning the privacy of personal health information, access to that information, or correction of that information”.*

**Recommendation 79** *To better enable the Commissioner to execute his or her oversight role, amend the Act to provide the Commissioner with the following additional powers: (a) conduct investigations to ensure compliance with this Act and the regulations; (b) monitor and audit the practices and procedures employed by custodians in carrying out their responsibilities and duties under the Act; (c) consult with any person with experience or expertise in any matter related to the purpose of this Act; (d) inform the public from time to time of apparent deficiencies in the system, including the office of the Commissioner; (e) take actions necessary to identify, promote, and where possible cause to be made adjustments to practices and procedures that will improve access to and protection of personal health information; and (f) bring to the attention of a custodian a failure to fulfil their duty to assist individuals.*

**Recommendation 80** *To provide clarity, amend the Act to make it clear that the Commissioner’s powers do not simply exist in the context of a review in response to a complaint, but in any context.*

**Recommendation 81** *In order to improve compliance with the Act, to improve the protection of personal health information in the province, and to increase public trust in the provincial health care system, provide additional resources to the Commissioner to undertake audits under the Act.*

**Recommendation 82** *To establish a mechanism that allows custodians to be afforded some latitude in procedure, including timelines, amend the Act by way of an “extraordinary circumstances” provision similar to that found in Section 24 of the Access to Information and Protection of Privacy Act, 2015.*

**Recommendation 83** *To clearly uphold “solicitor-client” privilege, amend the Act by making specific reference to this privilege wherever legal privileges are protected by the Act, including Sections 69(3) and 85(3).*

**Recommendation 84** *To more comprehensively reflect the actions with respect to personal health information that are offensive, amend the offences listed in the Act. Specifically, consider changing Section 88(1)(a) of the Act from “obtains or attempts to obtain another individual’s personal health information by falsely representing that the person is entitled to the information” to “obtains, uses, views, accesses, collects, discloses or attempts to obtain, use, view, access, collect or disclose another individual’s personal health information without authorization or by falsely representing that the person is entitled to the information”.*

**Recommendation 85** *To better reflect the time delays associated with the discovery and preliminary consideration of potentially prosecutable offences involving electronic records, and to align with the Access to Information and Protection of Privacy Act, 2015, amend the Personal Health Information Act to establish a two-year limitation period for offences under the Personal Health Information Act.*

**Recommendation 86** *To make maximum fines a more significant deterrent that allows the justice system to appropriately address the harms resulting from egregious offences, and to better impose economic hardship on those of significant financial means, amend the Act to increase the maximum fines from \$10,000 to \$100,000.*

**Recommendation 87** *Amend the Act to ensure that offences of retaliation, as contemplated by Section 89 of the Act, are subject to the same penalties as other offences under the Act.*

**Recommendation 88** *Further explore the matter of who might investigate instances of retaliation as contemplated under Section 89 of the Act, and make amendments to the Act as required to enable such investigations.*

**Recommendation 89** *Consider further exploring the implications of mandatory notification of professional colleges by custodians where a subordinate of the custodian engages in unauthorized activity involving personal health information.*

**Recommendation 90** *Consider further exploration of the matter of assumption of custodial powers and duties upon death of a natural custodian in the absence of a personal representative.*

**Recommendation 91** *Consider further exploration of the privacy implications of direct to consumer genetic testing.*

**Recommendation 92** *Consider further exploration of potential legislative frameworks that can protect health-related privacy of both individuals and families.*

**Recommendation 93** *Amend Section 12 of the Act (addressing the relationship between the Personal Health Information Act and the Access to Information and Protection of Privacy Act, 2015) to: (a) simplify and improve readability; and (b) appropriately reflect any changes arising from the review of the Personal Health Information Act.*

**Recommendation 94** *Amend the Act to address the minor matters presented in Table 1 of the Review report.*

***Recommendation 95*** Review the use of “and” and “or” throughout the Act to ensure that what is intended is actually written, making amendments to the Act as required.