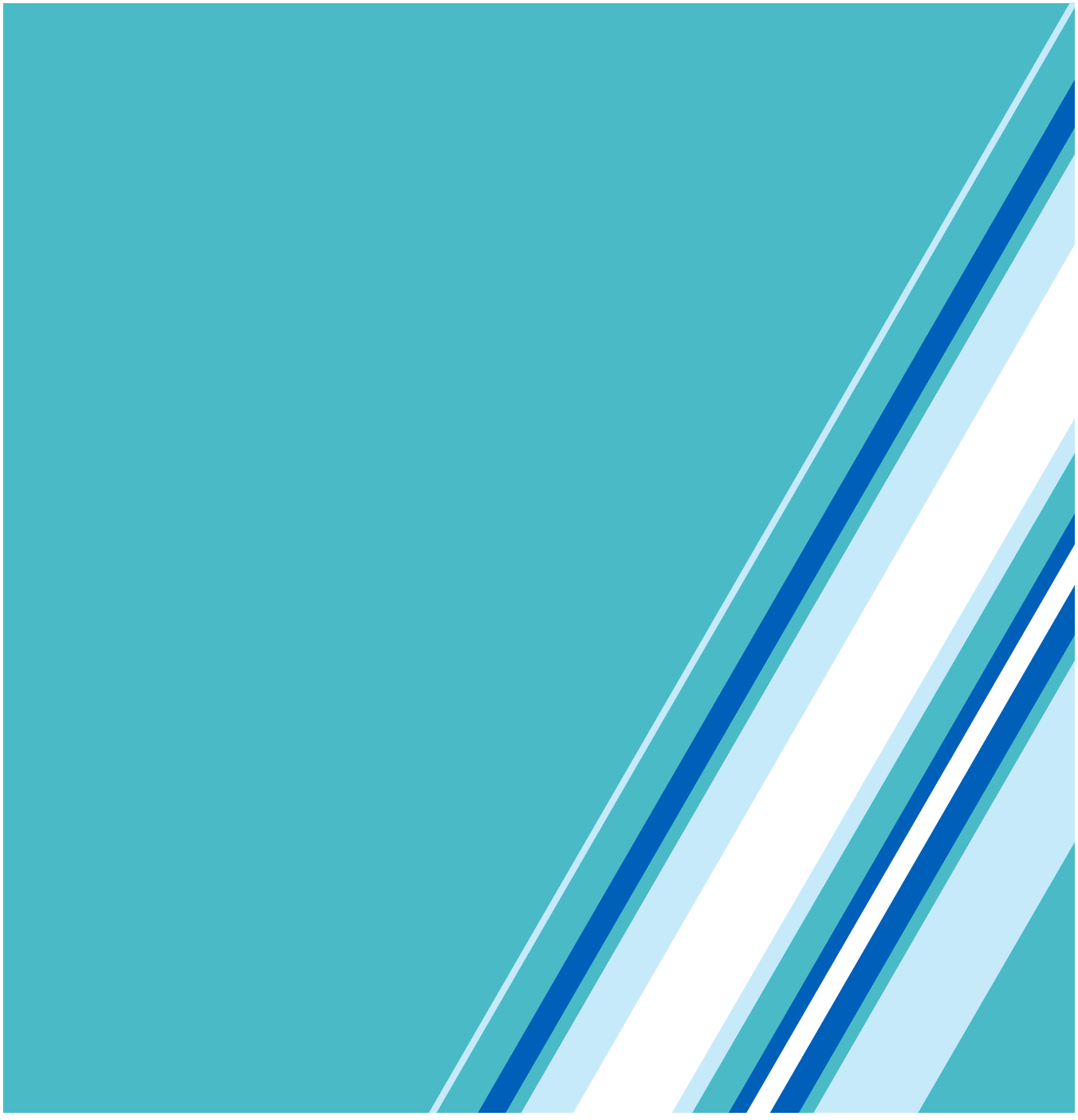
Personal Health Information Act

Three Year Review Findings



NOVA SCOTIA

Personal Health Information Act

Three Year Review Findings

Personal Health Information Act Three Year Review Findings
Department of Health and Wellness

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Executive Summary
Introduction

The Personal Health Information Act (PHIA), which came into force in 2013, establishes a common set of rules for the collection, use, disclosure, retention and disposal of personal health information in the context of health care.

Section 109 of the legislation requires the Minister of Health and Wellness to undertake, with public input, a comprehensive operational review of the Act within three years after the coming into force of the Act.

The mandate of the PHIA review was to understand whether the Act strikes the right balance between the privacy rights of individuals with respect to the protection of their personal health information and the needs of custodians, and examine the purpose, objectives and functioning of the Act to determine if there are any gaps in privacy coverage. The review also included analysis of significant developments in health care and technology that could impact the privacy of and access to personal health information. Finally, the PHIA review included findings on whether amendments should be made to the Act or associated legislation or whether administrative changes are required.

Overall, this review found that PHIA's purpose and objectives are appropriate and the Act is effective and functioning well. There are some areas where public and stakeholder feedback indicated additional clarity is needed. However, the results of the public and stakeholder consultation and the research into Canadian health information legislation supported a finding that the Act is achieving the right balance between protecting the privacy of individuals' personal health information and the need of custodians to collect, use and disclose that information to provide, support and manage health care. The review also noted stakeholder support for addressing privacy concerns associated with future developments in health care that could impact the way personal health information is protected and managed by custodians. The review provides 35 findings, including findings to support the amendment of PHIA, further investigation and consultation, awareness building and no change.

Methodology

The process used to review the Personal Health Information Act included public and stakeholder consultation, the development of a discussion paper and a public survey, and review and research into key areas that were identified during the review process. The approach to engaging stakeholders was developed with input from the PHIA Project Team and the PHIA Advisory Committee.

The primary method of obtaining public feedback on PHIA was through a survey that was promoted via social media channels. Members of the public were invited to complete the survey, which was open to Nova Scotians who have an interest in providing feedback on their personal experiences with aspects of PHIA and any concerns they may have related to personal health information. A total of 243 individuals submitted completed surveys during this time.

The Department of Health and Wellness (the Department) prepared a discussion paper to provide stakeholders and the public with information about the Act and elicit their input and feedback on its operation and impacts. The discussion paper was structured into sections that identify issues raised since the Act came into effect, and asked questions for stakeholder consideration. More than 400 stakeholder groups were provided with an electronic copy of the discussion paper and invited to submit written feedback. Invitations to schedule in-person meetings, in addition to submitting written feedback, were also extended to targeted stakeholder groups. Comprehensive written and/or verbal feedback was received from 24 stakeholder groups representing a multitude of perspectives within the Nova Scotia health care system. The feedback received was of immense value to the review, providing detailed and thorough insight into the functioning of PHIA across the province and across stakeholder groups.

As questions and concerns were noted during the review process, the Department collected and reviewed relevant information to provide context and insight into the analysis and development of the findings. This included a review of Canadian law as it relates to personal health information, and consideration for where Canadian law has been changing in recent years to reflect developments and emerging trends in health care that impact how personal health information is managed.

Attention was also given to previous work conducted to support the original drafting of PHIA in 2013. Reviewing the past PHIA documentation provided insight into the prevailing issues that informed how PHIA was written. This enabled the Department to assess how issues relating to personal health information have evolved or changed provincially and nationally since 2013.

Findings

The Department detailed findings in each topic area raised in the Discussion Paper and several additional topic areas identified by stakeholders or through the survey. The findings are based on an analysis of stakeholder experiences and feedback, research into the personal health information legislation in other Canadian jurisdictions, and in some cases, the Department's own experiences as a custodian under PHIA. In several instances, the Department identified a need for in-depth investigation and further consultation where the issues were significantly complex and/or required additional input from stakeholders.

The 35 findings in this Report are categorized into four areas related to: legislative amendment (8), further investigation and consultation (11), awareness building (6) and no change (10).

Although there are only six formal findings supporting awareness-raising activities, the need for greater knowledge and understanding of PHIA is a key finding from the three-year review of the Act. Misinterpretations of PHIA were not limited to any particular stakeholder group and, in fact, stakeholder feedback revealed a number of opportunities for improved understanding of the Act. The Department recognizes how necessary this is to the continued effective functioning of PHIA across Nova Scotia, and the findings on awareness building are intended to address these areas.

The findings are summarized in the following table.

Findings related to Legislative Amendment

Topic Area and Sections of Act	Findings
Substitute Decision-Makers Sections 21-23	The findings support amending PHIA to: 1. deem persons who are authorized by law to make treatment decisions to be substitute decision-makers under PHIA, if the collection, use and disclosure is related to the care decision. This would clarify that custodians are permitted to disclose personal health information to a substitute decision-maker authorized by law for the purpose of making a treatment decision. 2. clarify that when an individual is deceased, it is the executor or administrator of the individual's estate who would determine the collection, use or disclosure of the deceased individuals' personal health information; and 3. permit substitute decision-makers to exercise any right or power conferred on an individual in circumstances where the substitute decision-maker is authorized to act.
Privacy Breach Reporting Sections 69, 70	The findings support: 4. amendment of PHIA regarding the notification of breaches to (a) include the Commissioner when individuals are notified of breaches with a real risk of significant harm and (b) bring the Act into alignment with requirements in similar legislation across Canada.
Powers of the Privacy Commissioner to disclose personal health information to another Commissioner in the case of investigating or coordinating privacy breaches involving Nova Scotia and at least one other jurisdiction	The findings support: 5. that PHIA be amended to add a provision in section 91(2) to permit the Commissioner to collect and use personal health information needed to participate in a privacy breach investigation that involves Nova Scotia and at least one other jurisdiction.
Recurring Review of PHIA Section 109	The findings support: 6. an amendment to PHIA to require full or partial review of PHIA every five years following the first review, given the anticipated changes in health system information technology to be implemented within the next decade and the unknown impacts this will have on the collection, use, disclosure, storage and retention of personal health information.
Housekeeping items	The findings support: 7. amending section 45, which references a non-existent section 9(2); and 8. amending section 101(1), which refers to itself.

Findings supporting Further Investigation & Consultation

Topic Area and Sections of Act	Findings
Additional Custodians	The findings support: 9. further investigation and consultation with the Dalhousie Dental School on whether the School should be included as a custodian under PHIA.
Multiple Custodians & Electronic Health Records Sections 3(f), 35(1)(ha), 38(1)(u)	The findings support: 10. establishing a Digital Health Privacy Working Group, chaired by the Department of Health and Wellness, to further investigate this topic, engage in additional stakeholder consultation and develop an approach tailored for Nova Scotia. This approach may result in a range of outcomes, from amending PHIA, to developing a framework, policy and guidelines and/or implementing information sharing agreements, as appropriate.
Prescribed Entity Sections 3(t), 38(2-6)	The findings support: 11. the Digital Health Privacy Working Group assess and clarify the roles of custodians, agents and prescribed entities, in the context of the current approach of supporting digital health privacy through the application of PHIA's privacy and access requirements for custodians and their agents and contractual measures.
Mature Minors and Disclosure without consent for administration of a payment	The findings support: 12. further investigation and consultation on how to (1) determine whether the disclosure is reasonably necessary, and (2) ensure only the minimum necessary personal health information is included in billing information. Custodians and the public would benefit from further guidance on how to apply PHIA's provisions in order to continue to achieve the right balance between the privacy of a mature minor and the disclosure of personal health information for the administration of payment.
Disclosure without consent Section 38	The findings support: 13. further investigation and consultation on circumstances for disclosure without consent that could be appropriately included in PHIA, given that a number of stakeholder suggestions and provisions from other jurisdictions merit further consideration. For any new additions to the disclosures without consent, the privacy implications of permitting disclosure of an individual's personal health information without the individual's consent will need to be considered and addressed in order to achieve the right balance between the individual's privacy and the need to disclose this information in the context of health care.
Disposition of health records	The findings support: 14. that the Digital Health Privacy Working Group conduct further investigation and consultation on the disposition of personal health information in health records and outsourcing storage of health records (including storage outside Nova Scotia) and recommend an appropriate approach for Nova Scotia. It will be important to consult with the regulatory bodies of health care professionals as these bodies may have discretionary power to appoint a person to hold, protect and provide access to patient records.
Record of User Activity & Additional Safeguards for Electronic Health Records PHIA Regulations, sections 10-11	The findings support: 15. that the Digital Health Privacy Working Group investigate and conduct further consultation on the record of user activity and additional safeguards for the Electronic Health Record, given the Province's vision and progress toward using electronic health records to improve the delivery of health care to Nova Scotians, the potential gaps in PHIA safeguards and the diverse feedback from stakeholders on these issues.

Topic Area and Sections of Act	Findings
Fees & Exceptions for Access PHIA Regulations, sections 12,16	The findings support: 16. that the Digital Health Privacy Working Group (or a sub-group) be tasked with conducting further investigation and consultation on the topic of fees to determine whether amendment of the regulations as they relate to the exception in section 12(f), record transfers, and section 16 on direct costs is appropriate.
One Person One Record	The findings support: 17. that the Digital Health Privacy Working Group further investigate and consult with stakeholders regarding the privacy and access implications of implementing One Person One Record in Nova Scotia. This work will assist the Department in determining the appropriate approach required to protect the privacy of personal health information in this future system and ensure it is appropriately managed for the health system.
Data linking & matching for research and planning & management within government	The findings support: 18. that the Digital Health Privacy Working Group conduct further investigation and consultation to identify actions to address stakeholder concerns regarding the appropriate collection, use and disclosure of personal health information in data matching and linking for research, and planning and management purposes.
Genetic information	The findings support: 19. further investigation and consultation to determine if (a) PHIA should be amended to include genetic information in the definition of personal health information and/or add more safeguards, or (b) the existing provisions of PHIA are sufficient. The consultation should include representatives from the practice of medical genetics to ensure the unique requirements of these providers and their patients are considered.

Findings supporting Awareness Building

Topic Area and Sections of Act	Findings supporting the Health Privacy Awareness-Building Working Group
Additional Custodians Section 3(f)	The findings support: 20. increasing awareness with the public and custodians about the roles and responsibilities of custodians and agents under PHIA to address various misunderstandings about these terms.
Knowledgeable Implied Consent Sections 12-15	The findings support: 21. that the topic of knowledgeable implied consent be addressed through awareness building measures, such as updating the PHIA Toolkit to include additional information and scenarios, and communication with custodians about the use of this information in any guidelines or educational materials that custodians may have previously developed for their agents.
Disclosure outside Nova Scotia Section 44	The findings support: 22. that there be further awareness building for custodians on the topic of disclosure of personal health information outside Nova Scotia for the purpose of providing health care. Further information and illustrative examples could be added to the PHIA Toolkit to assist in clarifying the form of consent required and what would constitute a reasonably necessary disclosure for this purpose.
Correction of a record of personal health information Sections 85-89	The findings support: 23. that awareness building activities would be appropriate to address concerns with how to apply the provisions for correction in certain circumstances.

Topic Area and Sections of Act	Findings supporting the Health Privacy Awareness-Building Working Group
Research Ethics Boards & Research Sections 52(d) and (e), 55-57	The findings support: 24. that the PHIA Toolkit be augmented to provide additional clarity and direction on questions and concerns about research ethics boards and PHIA that were raised by stakeholders.
Survey Results	The findings support: 25. a promotional campaign be undertaken to raise awareness of individual rights under PHIA. This could be part of a number of awareness-building activities to assist the public and custodians in understanding their rights and responsibilities under PHIA. Other activities could include updating the PHIA toolkit, and communicating about the toolkit and other available resources to promote the public and custodians' understanding of the rules for protecting and managing personal health information.

Findings Resulting in No Change

Topic Area and Sections of Act	Findings
Purpose, objectives & functioning of the Act Section 2	The findings support: 26. leaving the purpose and objectives of PHIA unchanged and continuing to support these objectives and the effective and appropriate functioning of the Act and regulations, given the broad consensus among stakeholders who provided responses on this topic area.
Limited or Revoked Consent Section 17	The findings support: 27. that there be no change to the notification of limited or revoked consent in PHIA as there is general consensus that these provisions strike the right balance between protecting privacy and providing, managing and supporting health care.
Express consent required for use of personal health information for fund-raising and marketing Section 34	The findings support: 28. that there be no change to section 34 of PHIA, as it strikes the right balance between protecting the privacy of an individual's contact information in their health care record and a custodian's wishes to use this information for fund-raising activities, market research or marketing services for a commercial purpose.
Educating Agents Section 33(c)	The findings support: 29. that section 33(c) of PHIA permitting custodians to use personal health information for educating agents to provide health care should remain unchanged to ensure that custodians are able to provide the appropriate education to their agents to provide health care, while following the privacy protections required by the Act.
Disclosure of name and contact information for research requires consent & other research requirements Sections 56, 57	The findings support: 30. that no change to PHIA or sections 56 and 57 is required in relation to disclosure of name and contact information on individuals for research (i.e., this disclosure requires consent) and the PHIA requirements fro disclosure of personal health information for research.
Powers of the Commissioner to compel records; use & disclosure provisions for the Office of the Commissioner; immunity for the Commissioner and staff	The findings support: 31. no change to PHIA to add these provisions for these additional powers for the Commissioner. The authority to augment the power of the Commissioner falls under the jurisdiction of the Minister of Justice, who administers the majority of the privacy legislation for Nova Scotia, including the Privacy Review Officer Act, the Freedom of Information and Protection of Privacy Act, and the Personal Information International Disclosure Protection Act. Amending PHIA alone to add these powers for the Commissioner would lead to a misalignment of the powers of the Commissioner between PHIA and the privacy legislation under the administration of the Minister of Justice.

Topic Area and Sections of Act	Findings
Definition of planning & management of the health system Section 3(s)	The findings support: 32. no changes to the definition of planning and management of the health system at this time.
Definition of record Section 3(v)	The findings support: 33. no change to the definition of record, noting that it can be inferred that the existing definition includes video, given that it states that the record can be in "any form or in any medium" and includes records in electronic form. Although video is not explicitly listed as one of the mediums, the current definition is sufficiently broad to allow for video as a form of record of personal health information.
Multi-jurisdictional Electronic Health Records and information-sharing agreements	The findings support: 34. no change to the provisions of PHIA, in order to preserve the flexibility of custodians to choose the most appropriate approach to protect and manage personal health information in the context of multi-jurisdictional electronic health records. Custodians undertaking the implementation of inter-jurisdictional electronic health records are encouraged to consider information sharing agreements as a best practice, where this approach would be appropriate.
Cloud-computing services & new technologies	The findings support: 35. No change to the provisions of PHIA to add additional safeguards for cloud-based services. PHIA has sufficient safeguards in place to protect personal health information in relation to cloud services or other changing technologies and finds that no change is necessary to PHIA or its regulations at this time. As a best practice and to meet the existing requirements for safeguards in PHIA, custodians should include privacy and security clauses in contracts with cloud service providers.

Part 1
Introduction

1.1 Background, Purpose & Objectives of PHIA

Beginning in the late 1970s, Canadian provinces began enacting legislation to provide access to records and protect personal information held by public bodies. Since that time, the provincial and federal governments have introduced legislation that governs the collection, use, disclosure and retention of personal information in the public and/or private sectors.

Every province has legislation similar to Nova Scotia's Freedom of Information and Protection of Privacy Act (FOIPOP Act), that applies to personal information held by public bodies. More recently, two new areas of information governance have emerged and are now reflected in legislation across the country:

1. protection of personal information held by the private sector; and
2. legislation specific to personal health information that balances the protection of individual privacy with the needs of the health system providers to collect, use and disclose this information to provide, manage and support health care.

Until 2013 with the advent of the Personal Health Information Act (PHIA), the personal health information of Nova Scotians was managed in accordance with many different pieces of legislation, including the Hospitals Act, the Health Protection Act and the FOIPOP Act. Although the former legislative framework did provide protection and accountability, the rules were not always consistent. Additionally, health care provider groups in the private sector (e.g., physicians, dentists, optometrists, etc. in private practice) were covered by federal privacy legislation, the Personal Information Protection and Electronic Documents Act (PIPEDA).

PHIA was developed specifically for Nova Scotia and sets out the rules for the collection, use, disclosure, retention and destruction of personal health information by custodians in the context of health care, regardless of whether it is in the public or private sector. PHIA came into force on June 1, 2013 following a process of public and stakeholder consultation and engagement. The purpose of the Act is described in section 2 of the legislation:

> ...to govern the collection, use, disclosure, retention, disposal, and destruction of personal health information in a manner that recognizes both the right of individuals to protect their personal health information and the need of custodians to collect, use, and disclose personal health information to provide, support and manage health care.

As part of the original drafting process for PHIA, a document entitled "Personal Health Information Legislation for Nova Scotia Discussion Paper (2008)" was developed and circulated for internal and external consultation and engagement. In that Discussion Paper, the following objectives of PHIA were identified:

1. to create a privacy framework that is reasonable to apply and responsive to the current and future realities of health care delivery in Nova Scotia, including electronic health records;
2. to strike a balance between ensuring comprehensive protection of personal health information and allowing the health care sector to manage information appropriately to deliver and improve health care services;
3. to address gaps in privacy coverage and ensure the entire health care sector in the province operates under the same set of rules;

4. to enhance the accountability of individuals who collect, use and disclose personal health information by establishing and enhancing requirements for policies and practices for the protection of personal health information;
5. to provide individuals with the right to receive access to and request correction of personal health information about themselves;
6. to establish and enhance rules for collection, use and disclosure of personal health information in research; and
7. to serve as a solid foundation from which policies, guidelines and standards related to personal health information will flow.

1.2 Application of PHIA

PHIA applies to the collection of personal health information by custodians and the use or disclosure of personal health information by a custodian or a person who is not a custodian and to whom a custodian disclosed the information. Custodians are specifically named in the Act or prescribed by regulation. The term "custodian" is defined as an individual or organization described in the Act who has custody or control of personal health information as a result of or in connection with performing their powers or duties. Custodians include:

- regulated health professionals;
- the Minister of Health and Wellness;
- a health authority (includes the Nova Scotia Health Authority and IWK Health Centre);
- the Review Board under the Involuntary Psychiatric Treatment Act;
- licensed pharmacies;
- licensed or approved continuing care facilities;
- Canadian Blood Services; and
- others prescribed by regulation.

PHIA was declared substantially similar to PIPEDA, the federal privacy legislation that applies to the private sector. As a result, all custodians named in PHIA or prescribed by regulation, including those who were previously covered by PIPEDA, now follow the same rules for the protection of personal health information.

PHIA does not apply to an individual or organization that collects, uses or discloses personal health information for purposes other than health care and the planning and management of the health system. Specifically, PHIA does not apply to:

- an employer;
- insurance company;
- regulated health-profession body;
- regulated health professional who is not providing health care;
- or any individual or organization prescribed by regulation,

although all of these individuals or organizations may have personal health information in their custody or control for various reasons.

It is also noteworthy that PHIA applies within a framework of legislation in Nova Scotia that pertains to personal health information. In several places, PHIA references legislation that governs personal health information in other contexts. For example, PHIA permits disclosure of personal health information to the Nova Scotia Prescription Monitoring Board for monitoring prescriptions pursuant to the Prescription Monitoring Act, to regulated health profession bodies under their Acts regulating the professions, and if the disclosure is permitted or required by law. Some examples of provincial laws requiring mandatory disclosure of personal health information include the Adult Protection Act, the Health Protection Act, the Gunshot Wounds Mandatory Reporting Act, and the Children and Family Services Act.

1.3 Purpose of Review

PHIA is mandated to undergo a legislative review starting within three years of coming into force, to commence at the latest by May 31, 2016. A review report must be submitted by the Minister of Health and Wellness to the House of Assembly within one year after the review is undertaken or such further time as the Assembly may allow.

The PHIA review seeks to determine:

- whether the objectives of the Act (noted above) continue to be the right objectives or whether they should be revised, clarified or strengthened;
- whether the Act is effectively meeting its current objectives;
- whether the Act is functioning effectively and appropriately;

- whether there are any gaps in privacy coverage;
- whether significant developments in public policy, law, technology or priorities have emerged that require a change to the Act;
- whether amendments to the Act, Regulations or to other associated legislation are needed;
- whether the administration of the Act should be changed to improve its functioning; and
- if amendments or changes are supported by the findings, the nature and the objective of those amendments and administrative changes.

Overall, the review of PHIA seeks to understand whether the Act strikes the right balance between the privacy rights of individuals with respect to the protection of their personal health information and the needs of custodians, as defined within the Act, to collect, use and disclose personal health information in the delivery and management of health care services.

1.4 About This Report

This report is structured into six parts. Part 1 of the report provides information on the original objectives for the Personal Health Information Act and explains the methodology that was used to gather feedback from the public and key stakeholders.

Part 2, entitled "Personal Health Information Act Review", contains the main findings from the review. It contains ten sections that reflect the thematic areas that emerged from stakeholder consultation, including:

- Purpose, Scope, and Application of the Legislation
- Custodians & Prescribed Entities
- Consent to Collect, Use and Disclose Personal Health Information
- Collection and Use
- Disclosure of Personal Health Information
- Retention, Destruction, Disposal and De-identification
- Research
- Reporting a Privacy Breach
- Access and Correction
- Review and Oversight

Each theme begins with an overview of the key concerns or questions related to PHIA that emerged from the review process, presented with relevant sections from the Act to support a comprehensive and clear understanding of the issues. Next, a summary of stakeholder feedback is presented, along with a discussion where relevant background context or research findings are presented and considered within the context of the Nova Scotia health care system. Finally, each section concludes with findings supporting how to address the issues. Findings are organized into standard categories including changes to legislation or regulations, further investigation or consultation required, awareness building required, or no change required.

Part 3, entitled "PHIA Regulations" follows the same format and approach as Part 2, focusing on the questions and concerns raised relating the to Personal Health Information Act Regulations. The key themes identified from the Regulations were Safeguards for Electronic Information Systems, Fees, and Cost Implications.

Part 4 considers significant developments that have occurred since the coming into force of PHIA, such as changes in Canadian law as it relates to personal health information. In addition, emerging trends and technological developments that affect the collection, use, disclosure and retention of personal health information are taken into consideration. Four key significant developments were identified during the review process where the use of technologies in the provision of health services and the interaction of health privacy law with other government policy priorities are emerging as issues since the coming into force of PHIA. These topics include electronic health records, data matching and data analytics, genetic information, and cloud computing.

Part 5 presents the results of the online public survey that was administered to gather information on how PHIA has impacted Nova Scotians. The qualitative and quantitative results are presented and interpreted, noting key themes that emerged.

Part 6 provides a summary of findings from the review of the Personal Health Information Act and Regulations.

1.5 Methodology

The process used to review the Personal Health Information Act included public and stakeholder consultation, the development of a discussion paper and a public survey, and review and research into key areas that were identified during the review process.

1.5.1 Public and Stakeholder Consultation

The public and stakeholder groups were engaged and consulted through a variety of means, including a webpage and social media, a survey, a discussion paper, and teleconference or in person meetings.

1.5.1.1 Webpage and Social Media

Feedback was invited from the public and stakeholders through a PHIA 3-Year Review webpage that included an overview of PHIA and the purpose for the review, and links to the online public survey in both French and English. Respondents were also offered the option to fill out, print, and mail in their survey responses by downloading a digital version of the survey. The toll-free telephone number for the Department of Health and Wellness Privacy Access Office was provided for individuals to request a paper copy of the survey.

The webpage also provided a copy of the 2017 Discussion Paper, noting that this document will be part of a broader consultation with health care partners and organizations who need to access the personal health information of Nova Scotians.

The PHIA Review, webpage address, and survey were advertised in a formal news release. A link to the PHIA Review webpage was placed on the Department of Health and Wellness webpage. Social media was used to promote the survey and stakeholders were encouraged to share content through their social media accounts, such as Facebook and Twitter. The number of responses were tracked and a second round of social media promotion was done three weeks after the survey was launched to boost awareness before the survey opportunity closed.

1.5.1.2 Public Survey

Members of the public are impacted by the operation of PHIA. Their feedback is critical to understanding whether the Act has achieved the right balance between protecting the privacy of their personal health information while allowing custodians to manage the information to provide, support, and manage health care.

As noted above, the primary method of obtaining public feedback on PHIA was through a survey that was promoted via social media channels. Located on the webpage containing information about the PHIA 3-Year Review, members of the public were invited to complete the survey, which was offered in French and English. The survey was open to any Nova Scotian with an interest in providing feedback on their personal experiences with PHIA and any concerns related to:

- access to their own personal health information and associated fees;
- access to personal health information for substitute decision-makers;
- sharing personal health information with researchers; and
- awareness of their rights under the legislation.

The survey questions were drafted with input from the PHIA Project Team and the PHIA Advisory Committee, with an objective to collect input on these specific aspects of PHIA that impact Nova Scotians while also providing an opportunity for respondents to comment on any area of concern they felt was important with respect to PHIA and the management of personal health information. The survey contained a mixture of open and closed-ended questions, which allowed respondents to provide written input on each of the topics that the survey introduced. The survey also included three questions that gathered demographic information from respondents. The purpose of collecting demographic information was to provide the Department of Health and Wellness with basic statistical information on the age range, gender and education level of the individuals responding about privacy experiences or concerns in relation to the survey questions. Responses to these questions, and the other questions on the survey, were optional. Individuals were not asked to identify themselves in any way or provide any personal health information about themselves. Please refer to Appendix C to view the survey.

The public survey questions were separated into five broad sections:

1. Access to Your Own Personal Health Information

The Personal Health Information Act gives individuals the right to see and have copies of their personal health information such as test results, specialist reports, and hospital and health care professionals' office records.

Survey questions in this section sought information on individuals' experiences accessing or requesting copies of their own personal health information. The questions focused on respondents' experiences, satisfaction with, and understanding of the processes.

2. Substitute Decision Makers

The Personal Health Information Act describes how Substitute Decision Makers can make decisions about an individual's personal health information. A Substitute Decision Maker is used when an individual is not able to make decisions about their own health care and/or information. This section in the survey focused on the experiences that Substitute Decision Makers have experienced requesting personal health information for someone else when acting in this role.

3. Research

The Personal Health Information Act has rules in place about how personal health information can be used for research purposes in Nova Scotia. However, the Act doesn't cover how, or if, personal health information can be used by researchers in other provinces. This section of the public survey asked Nova Scotians to share their thoughts on the use of personal health information for research purposes inside and outside of the province.

4. Patient Rights

The Personal Health Information Act sets out the rights of patients with respect to:

- accessing their own records;
- controlling who may collect, use and disclose their records;
- making correction to their own records; and
- asking the Privacy Review Officer to review a complaint about privacy, access and correction.

Survey questions focused on whether respondents were aware of their rights under PHIA.

5. Additional Information

The final section of the survey invited respondents to share any additional feedback or concerns relating to PHIA and/or the management of their personal health information.

The survey was available for 4 weeks, between February 3 and March 3, 2017. A total of 243 completed surveys were submitted during this time.

1.5.1.3 Discussion Paper

A discussion paper was prepared as part of the review process to provide stakeholders and the public with information about the Act and elicit their input and feedback on its operation and impacts.

An initial round of stakeholder engagement was conducted, targeting specific stakeholder groups to gather input on PHIA that would inform the basis of the PHIA Three-Year Review Discussion Paper. Four stakeholder organizations were engaged during this phase of the review, including Doctors Nova Scotia, the Nova Scotia Health Authority, the IWK Health Centre, and the Office of the Information and Privacy Commissioner of Nova Scotia. The feedback submitted by each of the four organizations was key to providing a broad and detailed perspective on many of the concerns, issues, gaps, and successes operating under PHIA for the past three years. This created a strong foundation to inform the discussion paper to enable further engagement with all stakeholder groups.

Many of the issues included in the discussion paper were primarily of interest to custodians, individuals and organizations described by PHIA that have custody or control of personal health information, because of, or in connection with performing their duties. Custodians under PHIA have had three years of experience in implementing the requirements of the Act and regulations and their input was an invaluable source of information for the three-year review.

The discussion paper was structured into sections that identify topics raised since the Act came into effect, and asked questions for stakeholder consideration. Based on their experience with the Act over the past three years, stakeholders identified certain areas of the legislation where they experienced a gap or a lack of clarity, leading to confusion or uncertainty over how to meet the requirements of the Act or apply its rules. In discussing these areas of uncertainty, some sections of the discussion paper relied on the direct wording in clauses of the Act, while other sections were based on an interpretation of how the Act applies to a particular set of circumstances.

The discussion document did not address every topic that has been raised over the course of the three years' operation of PHIA. Rather, the topics identified throughout the document were determined to have a high priority for inclusion in the three-year review discussion paper, based on feedback from stakeholders and other factors, such as whether the topic:

- was raised by multiple stakeholders;
- was related to consent;

- highlighted challenges operationalizing the Act;
- was related to safeguarding personal health information or responding to a privacy breach; or
- required more than educational activities to address.

It was noted within the discussion paper that these may not be the only topics warranting consideration, and that feedback was welcome on any topic regarding privacy and access to personal health information as it related to the Act and its regulations.

1.5.1.4 Stakeholder Feedback

Feedback from stakeholders who have had three years of experience in implementing the requirements of the PHIA and its regulations was fundamental to the review process. The approach to engaging stakeholders was developed with input from the PHIA Project Team and the PHIA Advisory Committee, with an objective to balance the high number of potential stakeholder groups impacted by PHIA with the desire to receive meaningful input from those who chose to submit feedback.

A PHIA Three-Year Review Advisory Committee was formed in 2016 with a mandate to assist the review process by providing input and feedback on the engagement process. The Advisory Committee membership was structured to have representation from key stakeholder groups impacted by PHIA, including custodians, agents, and members of the public. The membership included representation from:

- College of Registered Nurses of Nova Scotia
- College of Physicians and Surgeons of Nova Scotia
- First Nations
- Health Association of African Canadians
- Pharmacy Association of Nova Scotia
- McKesson 811
- Private Psychologist
- Department of Health and Wellness Legislative Policy
- 2 members of the public

The Advisory Committee met once in person and following the initial meeting, communicated via email to provide input and direction on both the public survey and the review approach to engaging stakeholders.

As noted previously; Doctors Nova Scotia, the Nova Scotia Health Authority, the IWK Health Centre, and the Office of the Information and Privacy Commissioner of Nova Scotia were contacted to provide input into the PHIA Three-Year Review Discussion Paper. The feedback received was key to establishing the discussion paper required for broader stakeholder review and input.

Following the development of the PHIA Three-Year Review Discussion Paper, a comprehensive list of stakeholder groups was compiled with the input of the Project Advisory Committee, the Project Team, the Department's Health Privacy Office, and established committee networks within the health system. For the purposes of time and efficiency, all identified stakeholder groups were provided with an electronic copy of the discussion paper and invited to submit written feedback. More than four hundred stakeholder groups were invited to provide feedback on PHIA.

As noted above, in addition to the questions contained within the discussion paper, stakeholders were encouraged to provide feedback on any concern related to privacy and access to personal health information as it related to the Act and its regulations. The letters that accompanied the discussion paper asked recipients to consider the following guiding questions:

- Does the objective and goal of the Act continue to be the right objective?
- Is the Act effectively meeting its current objective?
- Is the Act functioning effectively and appropriately?
- Are there any gaps in privacy coverage?
- Do you see any significant developments in public policy, law, technology, or priorities that have emerged that require a change to the Act?

An invitation to schedule in-person meetings in addition to written feedback was extended to targeted stakeholder groups including the NSHA, IWK, the Office of the Information and Privacy Commissioner of Nova Scotia, Doctors Nova Scotia, First Nations Health Directors, the Regulated Health Professions Network, and inter-governmental departments who have been impacted by PHIA. Of these, two meetings were held with First Nations Health Directors. The original stakeholder engagement plan was to consider all other requests for in-person meetings on a case by case basis. One such meeting request was received by the Maritime Medical Genetics Service at the IWK Health Centre, and a meeting was conducted with its representative and a representative of Doctors Nova Scotia on April 5, 2017.

All other feedback for the PHIA review was received in writing between February 3 and April 6, 2017. Comprehensive written or verbal feedback was received from 24 stakeholder groups representing a multitude of perspectives within the Nova Scotia health system, including:

- Association of Psychologists of Nova Scotia
- Canadian Blood Services
- Canadian Institute of Health Information
- Canadian Medical Protective Association
- Canadian Nurses Protective Society
- Cape Breton County Homemaker Agency and Antigonish Homemaker Service
- College of Licensed Practical Nurses of Nova Scotia and the College of Registered Nurses of Nova Scotia
- Cornerstone Psychological Services
- Doctors Nova Scotia (provided written feedback in addition to their initial submission)
- Family 1st Medical Equipment Supplier
- First Nations Health Directors
- Guysborough County Home Support Agency
- Health Data Nova Scotia
- IWK (provided written feedback in addition to their initial submission)
- IWK Medical Genetics
- Northwood
- Nova Scotia Department of Education and Early Childhood Development
- Nova Scotia Department of Internal Services Information Access & Privacy Office
- Nova Scotia Department of Justice
- Nova Scotia Health Authority (provided written feedback in addition to their initial submission)
- Office of the Information and Privacy Commissioner of Nova Scotia (provided written feedback in addition to their initial submission)
- Provincial Dental Board of Nova Scotia
- Provincial Programs (including the Nova Scotia Breast Screening Program, Reproductive Care Program of Nova Scotia, Cardiovascular Health Nova Scotia, Diabetes Care Program of Nova Scotia, Nova Scotia Provincial Blood Coordinating Program, Nova Scotia Renal Program, Program of Care for Cancer)
- Shannex Home Healthcare Service

The content of the written and verbal feedback varied depending on the perspectives and issues experienced by the stakeholder organization. Some responses addressed the discussion paper questions directly, while others focused on the higher-level questions posed within the stakeholder engagement letters. Some stakeholders provided responses to both. Other organizations elected to focus on specific issues and challenges they were concerned with that may not have been addressed in the discussion paper. The feedback received was of immense value to the review, providing detailed and thorough insight into the functioning of PHIA across the Nova Scotia health system.

1.5.2 Review and Research

As questions and concerns were noted during the review process, activities were undertaken to gather and review relevant information to provide context and insight into the analysis and development of findings. This included consideration of Canadian law as it relates to personal health information, and consideration for where Canadian law has been changing in recent years to reflect developments and emerging trends in health care that impact how personal health information is treated.

Attention was also given to previous work conducted to support the original drafting of PHIA in 2013. Reviewing the past PHIA documentation provided insight into the prevailing issues that informed how PHIA was written. This enabled the Department to assess how issues relating to personal health information have evolved or changed provincially and nationally since 2013.

Part 2
Personal Health Information Act

2.1 Purpose, Scope and Application of the Legislation

Sections 2-10 of PHIA outline the purposes of the Act, the definition of various terms used in the Act, and the application of the Act.

2.1.1 Purpose, Objectives & Functioning of PHIA

Section 2 of PHIA states:

> The purpose of this Act is to govern the collection, use, disclosure, retention, disposal and destruction of personal health information in a manner that recognizes both the right of individuals to protect their personal health information and the need of custodians to collect, use and disclose personal health information to provide, support and manage health care.

The *Discussion Paper* identified the objectives of PHIA, as follows:

1. to create a privacy framework that is reasonable to apply and responsive to the current and future realities of health care delivery in Nova Scotia, including electronic health records;
2. to strike a balance between ensuring comprehensive protection of personal health information and allowing the health care sector to manage information appropriately to deliver and improve health care services;
3. to address gaps in privacy coverage and ensure the entire health care sector in the province operates under the same set of rules;
4. to enhance the accountability of individuals who collect, use and disclose personal health information by establishing and enhancing requirements for policies and practices for the protection of personal health information;
5. to provide individuals with the right to receive access to and request correction of personal health information about themselves;
6. to establish and enhance rules for collection, use and disclosure of personal health information in research; and
7. to serve as a solid foundation from which policies, guidelines and standards related to personal health information will flow.

The *Discussion Paper* asked for feedback from stakeholders on whether:

- the objectives of PHIA continue to be the right objectives or whether they should be revised, clarified or strengthened;
- the Act is effectively meeting its current objectives; and
- the Act is functioning effectively and appropriately.

2.1.1.1 Discussion & Findings

Feedback from stakeholder groups was unanimous in stating that PHIA 's objectives continue to be the right ones and that the Act is effectively meeting its current objectives. Stakeholders also indicated that the Act is functioning effectively in the health care environment to protect individuals' personal health information, while permitting health care providers to access the information they need to provide quality health care. One stakeholder provided the feedback that while the Act's objectives are the right ones, some areas require greater clarity to support the functioning of the Act in Nova Scotia.

Given the broad consensus among stakeholders who provided responses on this topic area, the findings support leaving the purpose and objectives of PHIA unchanged and continuing to support these objectives

and the effective and appropriate functioning of the Act and regulations.

In areas where greater clarity may be needed, many of these can be addressed by continuing to build awareness within the public and custodians of the meaning and application of the provisions of PHIA. In addition, it may be necessary to investigate and consult further to fully understand and address stakeholder concerns in specific areas.

2.1.2 Additional Custodians

A custodian is defined in section 3 of the Act to mean an individual or organization described below who has custody or control of personal health information as a result of, or in connection with, performing the person's or organization's powers or duties:

- a regulated health professional or a person who operates a group practice or regulated health professionals;
- the Minister of Health and Wellness;
- a health authority under the Health Authorities Act (includes the Nova Scotia Health Authority and IWK Health Centre);
- the Review Board under the Involuntary Psychiatric Treatment Act;
- a pharmacy licensed under the Pharmacy Act;
- a continuing care facility licensed by the Minister under the Homes for Special Care Act or a continuing care facility approved by the Minister;
- Canadian Blood Services;
- and other individual or organization or class of individual or class of organization as prescribed by regulation as a custodian.

The custodians currently prescribed by regulation include:

- Nova Scotia Hearing and Speech Centres;
- Home care agencies approved by the Department of Health and Wellness that have a service agreement with a district health authority or the IWK Health Centre; and
- Home oxygen agencies approved by the Department of Health and Wellness that have a service agreement with the Department.
- Nova Scotia Hearing and Speech Centres;
- Home care agencies approved by the Department of Health and Wellness that have a service agreement with a district health authority or the IWK Health Centre; and
- Home oxygen agencies approved by the Department of Health and Wellness that have a service agreement with the Department.

Custodians have responsibilities to protect the personal health information of individuals in accordance with PHIA. They also have certain rights to manage personal health information in order to provide or support care to their patients, clients or residents.

Discussion Paper Question

Q1 Should additional organizations that provide health care be included as custodians in the Act or prescribed by regulation (e.g., military hospitals, group homes for youth, or other organizations)?

2.1.2.1 Discussion & Findings

Feedback from stakeholders included both those supportive of including additional organizations that provide health care as custodians in PHIA, and those who recommend maintaining the current custodians named in the Act. The various organizations identified by stakeholders as potential custodians included: Emergency Medical Care Inc., Dalhousie Dental School, vendors of medical equipment, youth group homes, the Nova Scotia Medical Examiner Service, military hospitals and First Nations health centres. In addition, some stakeholders requested clarification of various scenarios where regulated health care professionals are unsure of whether they are acting as custodians or agents.

One of the responses suggested adding as a custodian an organization that already falls within the scope of PHIA as an agent. Emergency Medical Care Incorporated (EMCI) was put forward as a recommended custodian, whereas EMCI currently functions as an agent contracted by the Department of Health and Wellness, a custodian under PHIA.

The Dalhousie Dental School was also noted as an organization that should be considered as a potential custodian under PHIA due to there being an active dental clinic that is involved in diagnosis and treatment activities, including diagnosing some cancers. The Dalhousie Dental School itself is not a custodian under PHIA. The Dental School runs dental clinics where faculty and senior students provide dental care to members of the public.

Faculty who are regulated health professionals are already custodians under PHIA if they are providing dental care. Students providing dental care as part of their educational program are agents of these custodians, if they are acting on behalf of these individual custodians. However, it does appear that the Dental School provides a similar role for dental students to that which the Nova Scotia Health Authority and IWK Health Centre provide with respect to medical students, and they are named custodians in PHIA. As such, the findings support further investigation and consultation with the Dalhousie Dental School on whether the Dental School should be included as a custodian under PHIA.

Section 6 of PHIA states that, unless specifically provided otherwise in the Act, the Act does not apply to an individual or an organization that collects, uses or discloses personal health information for purposes other than health care and the planning and management of the health system. As such, some of the organizations suggested by stakeholders, such as vendors of medical equipment and group homes for youth, do not meet the Act's requirements.

The Nova Scotia Medical Examiner Service investigates deaths of persons who die from criminal violence, by accident, by suicide, suddenly when in apparent good health, when unattended by a physician, in a correctional facility, or in any suspicious or unusual manner. The Medical Examiner Service is not providing health care and, therefore, does not meet the requirements of the Act to become a custodian under PHIA.

Military hospitals are under federal, not provincial, jurisdiction and the federal Privacy Act applies to their collection, use and disclosure of personal health information.

Some stakeholders suggested that First Nations' health centres in Nova Scotia could be prescribed as custodians under PHIA. Regulated health professionals provide on-site health care to individuals within these communities. A number of First Nations' communities have held discussions with the Department of Health and Wellness on this topic and have requested that they be prescribed as custodians. As a result of these discussions, the PHIA regulations are in the process of being amended to include these First Nations Bands as custodians.

Based on the stakeholder feedback and discussion above, the findings support building awareness of the roles and responsibilities of custodians and agents under PHIA. The PHIA Toolkit developed and published on their website by the Department could be revised to include additional scenarios addressing when a regulated health professional or a health care organization is a custodian versus an agent, as requested by stakeholders.

For this Finding, and other awareness-building findings that follow in this Report, a Health Privacy Awareness-Building Working Group should be created and Terms of Reference developed, including roles and responsibilities for acting on these findings.

2.1.3 Multiple Custodians and Electronic Health Records

Nova Scotia has developed a provincial electronic health record system for clinician use (known as SHARE), a personal health record system (MyHealthNS) for patients and their physicians' use, and is in the planning process for the One Person One Record (OPOR) system. The new OPOR system is intended to combine the three existing hospital information systems as part of the ongoing provincial evolution of health care.

Nova Scotia continues to work on providing secure and effective electronic systems to manage health records and to provide and support health services. Many custodians use the provincial electronic health record system and other electronic health records systems in the course of providing and supporting health care.

In many circumstances, there are multiple custodians using one electronic health record system (e.g., in a hospital or a clinic setting). It may not be clear who the primary or most responsible custodian is in this context. It can also be difficult to determine who is a custodian and who is an agent[1]. A lack of clarity over custodianship can create issues with managing individuals' access to their health records and responding to privacy breaches.

Patients may be uncertain who the custodian of their electronic health records is or from whom they should request access or correction. As the province continues to expand electronic databases containing personal health information, clarity is needed on this issue for custodians and patients alike.

[1] See Appendix D for a definition of "agent."

Discussion Paper Question

Q2 Should the Act or regulations define a primary or most responsible custodian when multiple custodians have access to personal health information in an electronic health record system? For example, should s. 5(1)(b) be amended to make clear that prescribed entities are subject to PHIA and to the oversight of the Commissioner?

2.1.3.1 Discussion & Findings

Most stakeholders identified the need for clarity when there are multiple custodians with access to personal health information in an electronic health record system. However, the stakeholder responses varied in how this clarity could be achieved. Some stakeholders indicated that it would be very difficult or not feasible to define a primary or most responsible custodian in PHIA, given the multiple sources of personal health information and lack of uniformity in these systems. They suggested that the use of information sharing agreements is a more practical method of defining the obligations and responsibilities of custodians using these systems. According to one stakeholder:

> Information sharing agreements generally assist in articulating the roles of each participant so that all participants understand who will have access to the information contained in the EHR, and to what extent, as well as who is responsible for the information maintained in the system.

Another stakeholder indicated that, given the number of systems containing personal health information implemented for various custodians, it would be more appropriate to consider a custodian framework outside the legislation to align with the future direction of health care as the Province moves toward a more "shared" electronic health system.

One stakeholder provided the feedback that PHIA be amended to add provisions that assign responsibilities for interoperable databases in use in Nova Scotia to prescribed entities. The stakeholder noted that Ontario recently amended its health privacy legislation to establish a governance framework for a shared provincial electronic health record, including provisions requiring the prescribed organization to maintain, audit and monitor logs relating to the shared electronic health records, respond to access requests, and report privacy breaches.

Section 5(a) of PHIA indicates that the Act applies to the collection of personal health information by a custodian. Section 5(b) states that the Act applies to the use or disclosure of personal health information by (i) a custodian, or (ii) a person who is not a custodian and to whom the custodian disclosed the information. One stakeholder responded that it is worth looking into section 5(1)(b)(ii) and determine whether this section needs to be amended to clarify that prescribed entities are subject to PHIA.

The stakeholder feedback on this topic reveals a desire for clarity with respect to responsibilities under PHIA when multiple custodians have access to personal health information in a shared electronic health record system. The role of a prescribed entity is another area that stakeholders are seeking to understand in relation to electronic health record systems and databases. Recent amendments to Ontario's Personal Health Information Protection Act demonstrate one approach to achieve this clarity. Based on the variety of stakeholder opinions and the future direction of the Province as it moves towards increasing the scope and use of electronic health record systems, the findings support establishing a Digital Health Privacy Working Group, chaired by the Department of Health and Wellness, to further investigate this topic, engage in additional stakeholder consultation and develop an approach tailored for Nova Scotia. This approach may result in a range of outcomes, from amending PHIA, to developing a framework, policy and guidelines and/or implementing information sharing agreements, as appropriate.

2.1.4 Prescribed Entity

Under section 38(1)(j), custodians may disclose personal health information without an individual's consent to a prescribed entity[2], for the planning and management of all or part of the health system, including the delivery of services, if the entity meets the requirements of section 38(2). Section 38(2) authorizes a custodian to disclose personal health information to a prescribed entity that, in addition to any other requirements in the Act, has in place information practices to protect the privacy of individuals whose personal information it receives and to maintain the confidentiality of the information.

The phrase "prescribed entity" is not defined in PHIA. The term "prescribed" is defined in section 3(t) to mean prescribed by the regulations. According to the PHIA toolkit, a prescribed entity may be an organization that is not a custodian but participates in the planning and management of the health system, working with and supplementing the work of the Department of Health and Wellness.

[2] See Appendix D for a definition of "prescribed entity".

In Ontario, prescribed entities include Cancer Care Ontario, the Canadian Institute for Health Information, the Institute for Clinical Evaluative Studies and the pediatric Oncology Group of Ontario. Ontario's Personal Health Information Protection Act (PHIPA) was amended in such a way that a prescribed organization is required to maintain, audit and monitor logs related to the shared provincial electronic health records, respond to access to information requests and report privacy breaches to custodians. To date, there are no prescribed entities in Nova Scotia.

Discussion Paper Questions

Q3 Should the Act or regulations define a prescribed entity and what organizations should be prescribed entities?

Q4 Should PHIA be amended to:

- Assign duties to prescribed entities, including:
  - manage and integrate personal health information received from custodians, ensure proper functions of the electronic health record;
  - ensure accuracy and quality of personal health information;
  - keep an audit log (record of user activity) with prescribed information requirements;
  - keep an electronic record of all instances where a consent directive (s. 17 PHIA) is made, withdrawn or modified, include prescribed information requirements;
  - audit and monitor records it is required to keep (consent directives, audit logs); and
  - make available record of user activity, consent directives and audit logs at the Commissioner's request.
- Require the prescribed entities to:
  - take reasonable steps to limit the personal health information it receives to that which is reasonably necessary for developing and maintaining the electronic health record;
  - prohibit employees from viewing, handling or otherwise dealing with personal health information unless the employee agrees to comply with the restrictions that apply to the prescribed entity;
  - make available to the public and to each health information custodian that provides personal information to it a plain language description of the electronic health record and any directives, guidelines and policies of the prescribed entity that apply to the personal health information; and
  - conduct threat and risk assessments with respect to the security and integrity of the personal health information.
- Set clear standards for prescribed entities for breach identification and notification to affected individuals, health custodians and the Commissioner.

2.1.4.1 Discussion & Findings

A number of stakeholders recommended developing a detailed list of criteria and a definition of a prescribed entity to assist in determining what organizations should be prescribed entities. One stakeholder noted that there is some confusion about the roles of custodians, agents and prescribed entities. Another stakeholder advised that under Ontario's health privacy legislation, several organizations have received prescribed entity status, including the Canadian Institute for Health Information (CIHI), the Institute for Clinical Evaluative Sciences, Cancer Care Ontario, and the Pediatric Oncology Group of Ontario. Distinct from this, Ontario's PHIPA was amended in 2016 to include a prescribed organization for the purposes of maintaining a provincial electronic health record system. The Ontario Act's provisions relating to prescribed organizations enable flexibility in the prescribing of organizations for different purposes and functions, rather than attempting to define a prescribed organization or set out eligibility criteria.

Ontario's PHIPA was amended to include a number of duties and requirements for a prescribed organization to maintain the provincial electronic health record. The amendments authorize the Ontario Ministry of Health and Long Term Care to disclose personal health information to the prescribed organization for this purpose as if the Ministry is the custodian, regardless of the original provider of the information.

Nova Scotia has several organizations that perform similar functions as some of the prescribed organizations in Ontario. Stakeholders have identified Cancer Care Nova Scotia, Health Data Nova Scotia, and the Nova Scotia Health Research Foundation, the Reproductive Care Program of Nova Scotia, CIHI and the Nova Scotia Health Authority (NSHA) as potential prescribed entities under PHIA. However, some of these named groups are not separate legal entities; rather, they are programs under the NSHA or the IWK Health Centre and would not qualify as prescribed entities.

One stakeholder provided the feedback that the prescribing of an entity for provincial electronic health record systems would need to consider any other legislation that governs an entity in order to prevent duplication of functions that may already be in place. This stakeholder recommended the creation of a custodian framework with clearly outlined roles and responsibilities and the development, documentation and dissemination of privacy best

practices for provincial electronic health record systems to demonstrate transparency and build public confidence that personal health information is managed and protected appropriately.

Generally, stakeholders identified the need for greater clarity regarding the roles of custodians, agents and prescribed entities and recommended a variety of organizations and duties that may be considered in this topic area.

The expanding role of provincial electronic health record systems is providing additional impetus to understand the roles for custodians, agents and prescribed entities. Nova Scotia has implemented an approach to supporting digital health privacy through the application of PHIA's privacy and access requirements for custodians and their agents and the development and enforcement of contracts in relation to provincial electronic health records. This flexible approach has been successful in meeting the needs of the health care environment and privacy requirements in Nova Scotia. Ontario's approach to prescribed organizations and provincial electronic health records reflects the structure and requirements of their health care system and population, which are significantly different from Nova Scotia's. Therefore, legislative changes to Ontario's PHIPA that were appropriate for Ontario must be considered carefully in the Nova Scotia context.

The findings support that the Digital Health Privacy Working Group assess and clarify the roles of custodians, agents and prescribed entities, in the context of the current approach of supporting digital health privacy through the application of PHIA's privacy and access requirements for custodians and their agents and contractual measures.

2.2 Consent to Collect, Use and Disclose Personal Health Information

Sections 11-20 of the Act set out the consent requirements that apply to custodians for the collection, use and disclosure of personal health information. PHIA has rules to provide individuals with control over their personal health information, except in limited circumstances, and at the same time authorize appropriate flows of information for custodians to provide and support health care.

2.2.1 Knowledgeable Implied Consent

Pursuant to section 11 of PHIA, a custodian shall not collect use, or disclose personal health information unless the custodian has the individual's consent and the collection, use or disclosure is necessary for a lawful purpose, or required by the Act. Section 12 permits a custodian to accept knowledgeable implied consent, unless the Act required express consent or makes an exception to the requirement for consent. Consent is knowledgeable if it is reasonable in the circumstances for a custodian to believe the individual knows the purpose for the collection, use or disclosure, and that they may give or withhold consent.

PHIA relies on a principle that an individual's personal health information should follow the individual wherever they go in the health care system. This principle is known as the "circle of care." It includes individuals and activities directly related to the health care and treatment of an individual. It may include individuals and activities that provide or support care. PHIA does not include the term "circle of care," although the principle is reflected in the provisions related to implied knowledgeable consent. For example, individuals and organizations involved in providing health care to a patient do not require the express consent of the patient to collect, use or disclose personal health information within the circle of care. Instead, they may rely on knowledgeable implied consent.

Discussion Paper Question

Q5 Is the concept of "knowledgeable implied consent" and how to apply it clear?

2.2.1.1 Discussion & Finding

Stakeholders provided a mix of feedback on whether the concept of "knowledgeable implied consent" and how to apply it is clear. Some stakeholders indicated the concept in PHIA is clear and does not require amendment, but that custodians and agents are unsure of how to apply the concept in certain circumstances or may lack clarity on when to request either written or oral express consent and when to rely on implied knowledgeable consent. Other stakeholders stated that different custodians may not apply the PHIA requirements to similar circumstances in the same way. Several stakeholders discussed the principle of the circle of care and requested that this principle be defined in PHIA and that PHIA explicitly state that it includes out of province health care professionals who are providing the individual with health care. One stakeholder requested that section 33 of PHIA be amended to include agents, in addition to custodians.

Section 12 of PHIA states that unless the Act requires express consent or makes an exception to the requirements for consent (meaning that no consent is required at all), knowledgeable implied consent may be accepted as consent for the collection, use and disclosure of personal health information. Section 44(e) provides that a custodian may disclose personal health information about an individual collected in the Province to a person outside the Province if the disclosure is reasonably necessary for the provision of health care to the individual and the individual has not expressly instructed the custodian not to make the disclosure.

Sections 11 to 18 of PHIA provide direction on the different forms of consent and when they are to be applied. The principle of the "circle of care" is not used in PHIA itself but has been used in the PHIA Toolkit to help describe circumstances where knowledgeable applied consent is the appropriate standard of consent to apply. As noted above, the patient's circle of care is not static. It changes depending on the type of health care a patient is receiving and may also change for each individual episode of care. A definition of "circle of care" would need to be very general in nature to encompass the variety of health care providers and activities that an individual may encounter in the health system. Such a definition would not provide the guidance or certainty that some stakeholders are seeking.

Section 33 of PHIA permits a custodian to use an individual's personal health information for:

(a) the purpose for which the information was collected or created and for all functions reasonably necessary for carrying out that purpose;

(b) a purpose for which this Act, another Act of the Province or of the Parliament of Canada permits or requires a person to disclose it to the custodian; or

(c) educating agents to provide health care.

Section 29(1) of PHIA states that where a custodian is authorized to use personal health information for a purpose, the custodian may provide the information to an agent who may use it for that purpose on behalf of the custodian.

Sections 29 and 33 of PHIA provide the rules for using personal health information and establish the authority for a custodian to provide the information to their agents, who may use it on behalf of the custodian. The addition of agents to section 33 would be redundant and it may potentially be interpreted that the agent could use personal health information for their own purposes and not solely on behalf of the custodian.

PHIA directly addresses the ability of custodians to disclose personal health information outside Nova Scotia for health care purposes and the requirements to do so in section 44(a) and (e). Specifically, a custodian is permitted to disclose personal health information outside Nova Scotia either (1) with the patient's consent, or (2) when the disclosure is reasonably necessary for the provision of health care to the individual and the individual has not expressly instructed the custodian not to make the disclosure.

In light of the questions posed by stakeholders and the confusion regarding how to apply the concept of knowledgeable implied consent in various health care situations, The findings support that this topic be addressed through awareness building measures, such as updating the PHIA Toolkit to include additional information and scenarios, and communication with custodians about the use of this information in any guidelines or educational materials that custodians may have previously developed for their agents.

2.2.2 Notification of Limited or Revoked Consent

PHIA provides patients with the right to limit or revoke consent for a custodian to disclose their personal health information. If the disclosing custodian considers it reasonably necessary for the purpose, the disclosing custodian shall notify the custodian receiving the personal health information, that they do not have consent to disclose all of the information. The custodian receiving the information may determine it is not possible to treat the patient in the absence of the full personal health information.

The right for a patient to limit or revoke consent for a custodian to disclose their personal health information applies except where PHIA permits a custodian to disclose personal health information without consent. For example, pursuant to section 38(1)(d), a custodian may disclose personal health information without the individual's consent when the "disclosure will minimize an imminent and significant danger to the health or safety of a person or a class of persons."

Discussion Paper Question

Q6 Does the notification of limited or revoked consent rule in PHIA strike the right balance between patient privacy and the need for custodians providing health care to have access to personal health information?

2.2.2.1 Discussion & Findings

A majority of stakeholders provided the feedback that the notification of limited or revoked consent in PHIA strikes the right balance between patient privacy and the need for custodians providing health care to have access to personal health information. One stakeholder noted that the health care provider can decide not to offer treatment in the absence of full disclosure where a potential risk to patient safety is identified. Another stakeholder provided the feedback that Section 17 of PHIA allows patients to make an informed choice about who their provider will be and ensures that custodians can access the information relevant to make a decision.

One stakeholder provided the opinion that the Act strikes the right balance but that is it very hard to actually put limited or revoked consent in place in an electronic health system. PHIA addresses this concern in Section 17(3), where a custodian is required to take reasonable steps to comply with an individual's request to limit or revoke consent. Each individual circumstance will determine what is reasonable.

One stakeholder provided the information that PHIA's provisions permitting an individual to limit or revoke consent may impair their ability to fulfil their mandate of collecting and using comprehensive information for their electronic record system performance. It should be noted that under section 11 of PHIA, a custodian shall not collect, use or disclose personal health information about an individual unless

(a) the custodian has the individual's consent under this Act and the collection, use or disclosure is reasonably necessary for a lawful purpose, or

(b) the collection, use or disclosure is permitted or required by the Act.

Section 17(6) states that the revocation of consent does not apply to collection, use and disclosure of personal health information that a custodian is required by law to collect, use or disclose.

The findings support that there be no change to the notification of limited or revoked consent in PHIA because these provisions achieve an appropriate balance between individual privacy and the need of custodians to collect, use and disclose personal health information for providing health care.

2.2.3 Capacity to Consent to Collection, Use and Disclosure of Personal Health Information

Section 18 of PHIA allows any capable individual, regardless of age, to consent or withdraw consent for the collection, use and disclosure of their personal health information. For example, the Act recognizes that where an individual is deemed to have the capacity to consent to the collection, use and disclosure of personal health information, the individual can provide, limit or refuse consent to the disclosure of his or her personal health information to a parent, guardian or substitute decision-maker.

Sections 21-23 of PHIA include provisions for substitute decision-makers, including the authority to consent or refuse to consent to the collection, use and disclosure of personal health information, if an individual lacks the capacity to make the decision. A hierarchical list of substitute decision-makers is also provided in descending order of priority for selecting a substitute decision-maker. If a substitute decision-maker at the top of the list accepts responsibility to make decisions and refuses to consent to the collection, use and disclosure on a patient's behalf, no one else on the list can provide consent (i.e., their decision cannot be overridden by someone else in the list).

Pursuant to section 21(1), a substitute decision-maker is permitted to consent to the collection, use and disclosure of personal health information on behalf of an individual, if the individual lacks the capacity to make the decision. PHIA also recognizes in section 19 that an individual may have capacity at a particular time to consent to the collection, use and disclosure of some parts of personal health information, but be incapable of consenting at another time. In addition, an individual may have the capacity to consent to the collection, use and disclosure of some parts of personal health information, but be incapable of consenting with respect to other parts.

In some circumstances, a substitute decision-maker can have the authority to make a health care decision on behalf of an individual, but the individual may have refused consent to disclose personal health information to the substitute decision-maker. As a result, the substitute-decision-maker is unable to access the personal health information needed to consent to the individual's treatment.

Another issue related to substitute decision-makers is the scope of their authority to exercise an individual's rights under PHIA. Custodians are not prevented from communicating with substitute decision-makers with respect to records of personal health information to which

an individual has a right of access, pursuant to section 80(1)(b) of PHIA. PHIA does not, however, expressly allow a substitute decision-maker to receive a notice of a privacy breach or to exercise the following rights: access, correction, or review.

Discussion Paper Questions

Q7 Should PHIA be amended to permit substitute decision-makers for treatment access to personal health information relevant to the treatment decision?

Q8 Should PHIA be amended to permit substitute decision-makers to exercise any right or power conferred on an individual under PHIA (e.g., rights of access, correction, review or to receive notice of a privacy breach of an individual's personal health information)?

2.2.3.1 Discussion & Findings

With respect to the question of whether PHIA should be amended to permit substitute decision-makers for treatment access to personal health information relevant to the treatment, most stakeholders agreed that this access should be permitted and that PHIA should be amended to specifically authorize this access. Two stakeholders referenced section 5(2) of the Ontario Personal Health Information Protection Act as an example of potential wording that could be used in PHIA.

One stakeholder provided the opinion that although substitute decision-makers should be able to access personal health information relevant to the treatment decision, PHIA did not appear to require amendment to effect this. Another stakeholder referred to section 17 of the Personal Directives Act that specifically grants such access and noted that section 5 of the PHIA regulations could refer to the appropriate Personal Directives Act provisions.

One stakeholder provided the following response related to the ability of a substitute decision-maker to access personal health information for a treatment decision:

> An individual may be assessed to lack capacity to make health care decisions; however, under PHIA the individual must also be assessed to lack capacity to consent for PHIA purposes. If this second assessment is not completed, the individual is presumed to have capacity for PHIA purposes and can, as a result, refuse to consent to disclosure of PHI [personal health information] to their substitute decision-maker for health care decisions. The result is that the substitute decision-maker cannot access to [sic] the personal health information required to make health care decisions for the individual.

Another stakeholder noted that the list of substitute decision-makers in PHIA is different than the lists in other Acts.

One stakeholder asked for clarity regarding consent to the disclosure of personal health information of a deceased individual. This stakeholder proposed that section 21 of PHIA be clarified to state whether a substitute decision-maker may give or refuse consent if an individual is deceased. On this point, the purpose of a substitute decision-maker is to "stand in the shoes" of the individual who lacks capacity and make decisions on the individual's behalf. Once the individual is deceased, the substitute decision-maker's role ends. Section 40 of PHIA addresses the disclosure of the personal health information of a deceased individual.

Section 19(1) of PHIA recognizes that an individual may have the capacity at a particular time to consent to the collection, use or disclosure of some parts of personal health information but be incapable of consenting at another time.

Similarly, section 19(2) recognizes that an individual may have capacity to consent to the collection, use or disclosure of some parts of personal health information but be incapable of consenting with respect to other parts.

Section 20 provides that where an individual is deemed to have capacity to consent to the collection, use and disclosure of personal health information, this capacity to consent includes disclosure to a parent, guardian or substitute decision-maker where applicable.

Section 80(1) of PHIA states that nothing in this Act prevents a custodian from:

(a) Granting an individual access to a record of personal health information, to which the individual has a right of access if the individual makes an oral request for access or does not make any request for access under section 75; or

(b) With respect to a record of personal health information to which an individual has a right of access, communicating with the individual's substitute decision-maker who is authorized to consent on behalf of the individual to the collection, use or disclosure of the personal health information about the individual.

According to section 80(2), nothing in PHIA relieves a custodian from a legal duty to provide, in a manner that is not inconsistent with PHIA, personal health information as expeditiously as is necessary for the provision of health care to the individual.

A key aspect of an individual's capacity to consent is that it is situational and must be considered within the context of each episode of care. When an individual is found to lack capacity to consent to treatment in relation to a health care matter and has a substitute decision-maker for treatment, the substitute decision-maker is, as one stakeholder phrased it, "taking the individual's place in the discussion with the health care provider to find a solution to that specific health care problem."

Section 17 of the Personal Directives Act provides that a substitute decision-maker has the right to access and to be provided with the information and records, including information and records subject to privilege, pertaining to the maker or person represented that are relevant to a decision to be made. PHIA does not refer to the Personal Directives Act directly but does state in section 21(2) that the substitute decision-maker of an individual shall be chosen from a list in descending order, beginning with a person who is authorized by or required by law to act on behalf of the individual. A substitute decision-maker for health care treatment who is authorized by the Personal Directives Act would meet the requirement in PHIA of a person who is authorized by law. Nevertheless, stakeholders are seeking clarity on whether a custodian is permitted under PHIA to disclose personal health information related to the care decision to the individual's substitute decision-maker for treatment.

As such, the findings support amending PHIA to clarify the substitute decision-maker hierarchy by deeming those people who are authorized to make treatment decisions to be substitute decision-makers under PHIA if the collection, use and disclosure is related to the care decision. In addition, the findings support that PHIA be amended to clarify that when an individual is deceased, it is the executor or administrator of the individual's estate who would determine the collection, use or disclosure of the deceased individual's personal health information.

Stakeholders also provided feedback on the question of whether PHIA should be amended to permit substitute decision-makers to exercise any right or power conferred on an individual under PHIA. These rights include:

- To request access to personal health information;
- To request a correction of personal health information;
- To request a review by the Privacy Commissioner; and
- To receive notice of a privacy breach of an individual's personal health information.

The majority of stakeholders agreed that PHIA should be amended to permit substitute decision-makers to exercise these rights on behalf of an individual. One stakeholder noted:

> …there is no express allowance for a substitute decision maker to exercise the rights of access (s. 75), correction (s. 85) or review (s. 91), nor to receive notice of a privacy breach (s. 69). Allowing these four rights is essential to ensuring that Nova Scotians who lack the capacity to consent have the full protection afforded by PHIA. The lack of clarity regarding the authority of the substitute decision maker in these areas puts Nova Scotians who lack capacity at a disadvantage.

Two stakeholders indicated that if these rights are to be extended to substitute decision-makers, the amendment should make it clear that the extension of these rights applies only where the substitute decision-maker is authorized to act.

The findings support that PHIA be amended to permit substitute decision-makers to exercise any right or power conferred on an individual in circumstances where the substitute decision-maker is authorized to act.

2.2.4 Mature Minors and Billing for Health Care Services

PHIA allows mature minors (i.e., an individual under the age of 19 who is deemed to have capacity) to consent or withdraw consent for the collection, use and disclosure of their personal health information. The concept of mature minors is not defined in statute in Nova Scotia; rather it stems from the common law (or judge-made law) in the area of consent for health care treatment. The common law provides that regardless of age, a child is capable of consenting (or refusing consent) if they have the maturity, intelligence and capacity to appreciate the nature and purpose of the treatment and the reasonable foreseeable consequences of giving or refusing consent. If a child meets these requirements then parental consent is not required and does not override the decision of the child. If a child does not meet these requirements then the consent of the parent is required before health care can be provided to the child.

In some cases, a mature minor may have withdrawn consent for the disclosure of their personal health information to a parent. However, the mature minor may not have the legal capacity to enter into a contract for health services that are not covered by publicly funded medical services insurance (e.g., transportation by ambulance).

Section 38(1)(r) provides a custodian with the authority to disclose personal health information that is reasonably necessary for the administration of payments in connection with health care, or for contractual or legal requirements in that connection. This means that the custodian may disclose part of a mature minor's personal health information to a parent if it is necessary for the administration of payment for a health care service. This section does not necessarily authorize the disclosure of all of the mature minor's personal health information related to the service.

Discussion Paper Question

Q9 Does PHIA strike the right balance between the protection of a mature minor's privacy and the need of a custodian to disclose personal health information for the purpose of administering a payment in connection with the provision of health care?

2.2.4.1 Discussion & Findings

Most stakeholders provided the feedback that PHIA strikes the right balance between the protection of a mature minor's privacy and the need of a custodian to disclose personal health information for the purpose of administering a payment in connection with the provision of health care. Two stakeholders indicated that payment should not be the "pivot point" or driver for allowing the disclosure of a mature minor's personal health information without their consent. One stakeholder noted the core issue is the definition of a minor, not the ability to pay. This stakeholder noted that a consideration could be whether a mature minor is emancipated because disclosure of the personal health information of an emancipated minor should meet the same requirements as adults.

Other stakeholders were unsure what constituted a "mature minor" or highlighted the need for education for the public regarding the capacity for youth to consent and the release of information to parents.

Another stakeholder agreed that PHIA strikes the right balance in this area and provided the following comments:

> Critical in this analysis is the "minimum necessary" or limitation principle found at s. 25(1). In the example of a mature minor being transported by ambulance, PHIA authorizes the custodian to disclose the fact of ambulance transportation. Disclosure of any additional PHI is restricted by the "minimum necessary" requirements. The fact that an ambulance transport took place is necessary to ensure payment; the provision is adequate and offers no support for disclosure of the diagnosis information.

Section 25(1) of PHIA states that the collection, use and disclosure of personal health information must be limited to the minimum amount of personal health information necessary to achieve the purpose for which it is collected, used and disclosed. In the example of a mature minor transported by ambulance who does not consent to the disclosure of personal health information to a parent, guardian or substitute decision-maker, PHIA requires the custodian to disclose only the minimum amount of personal health information necessary to achieve the purpose of the administration of the payment.

Based on the variety of stakeholder feedback and the lack of understanding of the application of PHIA to mature minors, the findings support further investigation and consultation on how to (1) determine whether the disclosure is reasonably necessary, and (2) ensure only the minimum necessary personal health information is included in billing information. This may include defining criteria for what constitutes the minimum necessary personal health information on ambulance or other types of health services bills. It may also involve consultation with the Department's agent for the provision of ambulance services, EMC Inc. Custodians and the public would benefit from further guidance on how to apply PHIA's provisions in order to continue to achieve the right balance between the privacy of a mature minor and the disclosure of personal health information for the administration of payment.

2.3 Collection and Use

PHIA requires custodians to collect personal health information only for lawful purposes related to the authority of the custodian, or if it is expressly authorized by PHIA or another Canadian law. Custodians must collect the personal health information directly from the individual, unless PHIA allows indirect collection (collection from a third party).

Custodians are generally required by PHIA to use personal health information for the purpose for which it was collected. There are some circumstances where use for a compatible purpose is permitted and other circumstances where consent is not required for use.

Section 33 of PHIA states that custodians may use an individual's personal health information for:

- the purpose for which it was collected or created and for all functions reasonably necessary for carrying out the purpose;

- the purpose for which PHIA or another Canadian law permits or requires a person to disclose it to the custodian; or
- educating agents to provide health care.

Section 34 requires a custodian to obtain express consent for the collection of personal health information for fund-raising activities and market research or marketing services for a commercial purpose.

2.3.1 Use of Contact Information

Custodians may use an individual's contact information (e.g., name, email address, mailing address, phone number etc.) that is part of their personal health information, only if it is for the purpose for which it was collected or a function reasonably necessary for carrying out the purpose. Custodians may also use an individual's contact information for the purpose for which PHIA or another Canadian law permits it to be disclosed to the custodian.

Depending on the purpose for which contact information was originally collected, the custodian may be able to rely on implied consent to use the contact information or express consent may be required. Consent is not required for a custodian to use personal health information if the purpose is to seek the individual's consent, when the personal health information is limited to the individual's name and contact information.

Express consent would be required to use an individual's contact information from the personal health information record if the purpose is fund-raising activities, market research or marketing services for a commercial purpose.

Discussion Paper Question

Q10 Does PHIA strike the right balance between the protection of an individual's contact information in their health care record and the wishes of a custodian to use contact information for the purposes of fund-raising activities, market research or marketing services for a commercial purpose?

2.3.1.1 Discussion & Findings

Most stakeholders expressed agreement that PHIA strikes the right balance between the protection of an individual's contact information in their health care record and the wishes of a custodian to use contact information for purposes of fund-raising, market research or marketing services for a commercial purpose. Some stakeholders were concerned that if express consent was not required for these purposes, an individual's right to determine how their personal health information is used for non-health care purposes would be eroded. Another stakeholder indicated that PHIA's provisions in this area are consistent with legislation in other jurisdictions, such as section 33 of Ontario's Personal Health Information Protection Act and section 107(2) of Alberta's Health Information Act.

One stakeholder provided the feedback that this balance is a challenge for non-profit organizations where the nature of their business is to communicate with their clients to advocate, educate and invite clients and families to events or to promote services that support health and well-being. This stakeholder noted that they did not believe the contact information should be shared outside the custodian's immediate service spectrum without permission from the client.

Another stakeholder provided the response that express consent should be required to use contact information in a health care record for purposes beyond the original reasons for the collection of the information.

The findings support that there be no change to section 34 of PHIA, as it strikes the right balance between protecting the privacy of an individual's contact information in their health care record and a custodian's wishes to use this information for fund-raising activities, market research or marketing services for a commercial purpose. To achieve that balance, individuals must be asked for consent in order for their personal health information to be used for fund-raising or commercial purposes, whether the custodian is a public body, a private sector organization or a non-profit organization.

2.3.2 Educating Agents

PHIA defines an agent as a person, who 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. Pursuant to section 33(c) of PHIA, a custodian may use personal health information for educating agents to provide health care.

Discussion Paper Question

Q11 Should PHIA be amended to include requirements for the use of personal health information for educating agents to provide health care? If so, what should those requirements include?

2.3.2.1 Discussion & Findings

Stakeholders provided differing opinions on whether PHIA should be amended to include requirements for the use of personal health information for educating agents to

provide health care. Some of those who supported adding privacy requirements for educating agents suggested that these could be similar to the requirements for researchers.

Stakeholders who provided feedback that additional requirements were not needed noted that custodians should have privacy controls in place but that educating agents should be determined by the needs and services of the custodian as long as the nature of the training does not contravene other parts of the Act. Several stakeholders indicated that agents such as students require access to personal health information on a need to know basis and that access is limited to the information necessary to accomplish the purpose of the education. In addition, a number of stakeholders advised that agents who need access to personal health information for the purpose of educating them to provide health care receive training on PHIA and are required to sign confidentiality forms.

Pursuant to sections 61 to 68 of PHIA, custodians are required to protect the confidentiality of personal health information and the privacy of the individual who is the subject of that information, and implement a number of information practices to protect personal health information. The definition of agent in section 3(a) of PHIA states that agents of a custodian are acting on behalf of the custodian in respect of personal health information for the custodian's purposes and not the agents.

Section 24 states that a custodian shall not collect, use or disclose personal health information if other information will serve the purpose of the collection, use or disclosure.

Section 25(1) states that the collection, use and disclosure of personal health information must be limited to the minimum amount of personal health information necessary to achieve the purpose for which it is collected, used and disclosed.

Section 28 of PHIA sets out the requirements for a custodian's agent to collect, use, disclose, retain, destroy or dispose of personal health information in the course of their duties and if it is not contrary to the limits imposed by the custodian, PHIA or another law.

The research provisions of PHIA permit custodians to use or disclose personal health information for research. The key to the additional privacy requirements for research, however, is the purpose for which a custodian may use or disclose the personal health information. Agents are being educated to provide health care. Researchers are not providing health care; thus, they are subject to additional requirements for accessing personal health information for the purpose of conducting research. The additional privacy requirements in PHIA for research, whether carried out by the custodian or another researcher, may not be appropriate for custodians requiring the use of personal information to educate agents to provide health care. Frequently, those agents are directly providing health care to individuals in the course of their education. Sections 24 and 25 of PHIA already restrict a custodian from using personal health information if other information will serve the purpose and require a custodian to use the minimum personal information necessary. These provisions apply to custodians' collection, use and disclosure of personal health information, including the use this information for educating agents to provide health care.

A number of jurisdictions in Canada with personal health information legislation have similar provisions as PHIA with respect to educating agents, including Ontario, New Brunswick, Prince Edward Island and Alberta. The Acts in Newfoundland and Labrador, Saskatchewan, Manitoba, and British Columbia are silent on this issue.

The findings support that section 33(c) of PHIA permitting custodians to use personal health information for educating agents to provide health care should remain unchanged to ensure that custodians are able to provide the appropriate education to their agents to provide health care, while following the privacy protections required by the Act.

2.4 Disclosure of Personal Health Information

Pursuant to section 11 of PHIA, consent is required for the disclosure of personal health information, unless otherwise authorized in the Act. Sections 36 to 46 of PHIA state the requirements for the disclosure of personal health information. Generally, custodians may disclose personal health information only for purposes that are appropriate to their role in providing or supporting care, and which are permitted or required by PHIA or another Canadian law.

2.4.1 Disclosure Outside Nova Scotia

According to section 44 of PHIA, a custodian may only disclose personal health information to a person outside the Province if:

- the individual consents;
- the disclosure is permitted by PHIA or the regulations;

- the disclosure is to a regulated health professional and the disclosure is to meet the functions of another jurisdiction's prescription monitoring program;
- the following conditions are met:
  - the disclosure is for the purpose of planning and management of the health system or health administration;
  - the information relates to health care provided in the Province to an individual who resides in another province of Canada; and
  - the disclosure is made to the government of that other province of Canada; or
- the disclosure is reasonably necessary for the provision of health care to the individual and the individual has not expressly instructed the custodian not to make the disclosure.

A custodian is permitted to disclose personal health information to a person outside Nova Scotia, if the individual consents or if it is reasonably necessary to provide health care to the individual, unless the individual expressly instructed the custodian not to disclose.

Discussion Paper Question

Q12 Should a custodian be able to disclose personal health information to a person outside Nova Scotia for the purpose of providing health care to the individual, unless the individual instructed the custodian not to disclose or should the individual's express consent be required?

2.4.1.1 Discussion & Findings

There was broad support among stakeholders in response to the question of whether a custodian should be able to disclose personal health information to a person outside Nova Scotia for the purpose of providing health care to the individual, unless the individual instructed the custodian not to disclose or should the individual's express consent be required. This disclosure is currently permitted under section 44(1)(e) of PHIA. Custodians can disclose personal health information outside Nova Scotia, based on knowledgeable implied consent, if the disclosure is reasonably necessary for the provision of health care to the individual and the individual has not expressly instructed the custodian not to make the disclosure. However, several stakeholders expressed uncertainty regarding whether this disclosure was permitted without express consent.

The findings support that there be further awareness building for custodians on the topic of disclosure of personal health information outside Nova Scotia for the purpose of providing health care. Further information and illustrative examples could be added to the PHIA Toolkit to assist in clarifying the form of consent required and what would constitute a reasonably necessary disclosure for this purpose.

2.4.2 Balance between Privacy and Disclosure

PHIA contains provisions recognizing the right of individuals to provide consent to the collection, use and disclosure of their personal health information. However, PHIA also recognizes that there are circumstances where the privacy rights of the individual are determined to be secondary to another need, and that disclosure of personal health information without consent is sometimes necessary.

Section 38 of PHIA provides a list of circumstances where a custodian is permitted to disclose personal health information with the individual's consent, including:

- to another custodian to prevent or investigate fraud;
- to a person acting on behalf of the individual;
- to a regulated health profession body to carry out its duties to regulate the profession;
- to any person if the custodian reasonably believes the disclosure will avert or minimize an imminent and significant danger to the health or safety of a person or class of persons;
- to an official of a correctional facility to allow the provision of health care to a detained person;
- to another custodian to ensure quality or standards of care within a quality review program;
- to the Minister of Health and Wellness for planning and management of the health system;
- to the Nova Scotia Prescription Monitoring Board;
- to the Canadian Institute for Health Information for planning and management of the health system;
- to a prescribed entity for planning and management of the health system;
- if the disclosure is required by Canadian law;
- to another custodian to verify an individual's eligibility for insured services;

- for an investigation authorized by Canadian law for complying with a warrant;
- to a proposed litigation or legal guardian of the individual for the purpose of having the person appointed as such or to represent the individual in a proceeding;
- to comply with a summons, order or rules related to the production of information in a proceeding;
- if the disclosure is reasonably necessary for the administration of payment in connection with the provision of health care;
- for risk management or patient safety;
- to the Minister of Health and Wellness for creating or maintaining an electronic health record.

There are occasions where other public bodies who are not named custodians in PHIA or the regulations may request access to personal health information. Examples include the Department of Education, the Department of Community Services, and the Department of Justice, who all may be involved in providing services to a common client or participating in a joint investigation. Unless the circumstances of the request are included in section 38 or another section of PHIA, the disclosure of personal health information would require the individual's consent. There may also be other circumstances not currently included in section 38 that should be considered.

Discussion Paper Question

Q13 Should PHIA be amended to include additional circumstances where disclosure of personal health information should be permitted without consent? If so, what should those circumstances include?

2.4.2.1 Discussion & Findings

Stakeholders provided a variety of feedback on whether there should be additional circumstances where a custodian is permitted to disclose personal health information without consent. Stakeholders identified a number of potential circumstances where they felt that custodians should be permitted to disclose personal information without consent from the individual whose information it is, including:

- to specific public bodies for the purposes of providing services to common clients, research or planning;
- for national reporting and planning on public health;
- to the Department of Community Services regarding risk assessments;
- to law enforcement looking to arrest individuals or trying to locate missing persons;
- expanding disclosure for a quality review program to include multi-custodian, multi-province quality review programs;
- to integrated programs for the purpose of the delivery or a common or integrated program or service;
- to a provincial identity service;
- to a big data institute;
- to Emergency Health Services or Adult Protection;
- for an agent or former agent of a custodian to disclose personal health information for the purposes of a proceeding or contemplated proceeding
- for an agent or former agent to disclose personal health information to a professional advisor for the purpose of providing advice or representation to the agent or former agent;
- clarifying the definition of quality review program and that disclosures for a quality review program include private sector health care custodians;
- for custodians participating organ and tissue donation and transplantation programs to disclose, without consent, living and deceased donor and recipient personal health information to Canadian Blood Services for the purposes of 1) facilitating the donation, procurement and/or transplantation of organs, and 2) organ and tissue donation and transplantation system performance;
- for Canadian Blood Services to collect, use and disclose, without consent, living and deceased donor and recipient personal health information across jurisdictions for this purpose;
- where human life and/or well-being is in jeopardy to a degree that any health care provider would reasonably agree is detrimental to the patient;
- clients providing information to a custodian that they intend to harm themselves or others need to have this shared with the appropriate body;
- add a reference to section 38(1)(s) in section 38(7), such that subsection 38(7) would read: "An agent or former agent who receives personal health information under clauses (1) (n), (o), (p), (q) **or (s)** or under subsection 35(2)…

Other stakeholders provided the opinion that the disclosures already included in PHIA were sufficient. One stakeholder noted that many would like to have access to personal health information but that much of

this information requires expertise to interpret, which does not often exist outside the health care sector.

Some of the suggested additions to the permitted disclosures without consent are already included in section 38 of PHIA. For example, section 38(1)(d) addresses circumstances where a custodian may disclose personal health information to any person if the custodian believes, on reasonable grounds, that the disclosure will avert or minimize an imminent and significant danger to the health or safety of any person or class of persons. Section 38(7) permits an agent or former agent who receives personal health information under various clauses to disclose the information to their professional advisor for the purpose of providing advice or representation to the agent if the advisor is under a professional duty of confidentiality. Some of the suggestions listed above may have been purposely omitted from PHIA originally, as they would not achieve an appropriate balance between individual privacy and the need for disclosure.

A jurisdictional scan of the health information legislation across Canada reveals a variety of provisions [emphasis added in bold] for disclosure without consent, including but not limited to:

Newfoundland Access to Information and Protection of Privacy Act, SNL 2008, c.P-7.01, s.39:

- 39(1)(f) **to an information manager** in accordance with section
- to a **potential successor** of the custodian for the purpose of allowing the potential successor to assess and evaluate the operations of the custodian, on condition that the potential successor first enters into an agreement with the custodian to keep the information confidential and secure and not to retain the information any longer than is necessary for the purpose of the assessment or evaluation;
- 39(1)(i) to a person conducting an **audit** or reviewing an application for **accreditation** or reviewing an accreditation, where the audit or review relates to the services provided by the custodian;
- 39(4)(d) 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 or that relates to the **storage or donation of body parts or bodily functions**
- 39(4)(e) to the **chief medical officer** and other medical officers where the disclosure is required by another Act or an Act of Canada;

PEI Health Information Act, R.S.P.E.I 2014, c.31 (not proclaimed), s. 23:

- 23(11)(b) to a person conducting an **audit** or reviewing an **accreditation**, if the audit or review relates to the services provided by the custodian;
- 23(11)(c) to a custodian who compiles or maintains a **registry** of personal health information for purposes of facilitating or improving the provision of health care or that relates to the **storage or donation of body parts or bodily substances**;
- 23(11)(d) to the **Chief Public Health Officer** if the disclosure is required by an enactment or an Act of the Parliament of Canada;
- 23(13)(h) to a **research data repository** in accordance with the terms of an agreement between the research data repository and the custodian;
- 23(13)(i)to a **potential successor** of the custodian for the purpose of allowing the potential successor to assess or evaluate the operations of the custodian, on condition that the potential successor first enters into an agreement with the custodian to keep the personal health information confidential and secure and not to retain the personal health information any longer than is necessary for the purpose of the assessment or evaluation;
- 23(13)(j) for the purpose of **ensuring the safety of the national blood supply**; and
- 23(13)(k) to the **successor** of the custodian if (i) the custodian transfers records to the successor as a result of the custodian's ceasing to be a custodian or ceasing to provide health care, and (ii) the successor is a custodian.

New Brunswick Personal Health Information Privacy and Access Act, SNB 2009 c.P-7.05, ss. 27, 37. 38:

- 27(2)(ii) if the individual has been admitted to a psychiatric facility as an involuntary patient under the Mental Health Act, or
- 37(6)(b) to a person conducting an audit or reviewing an application for accreditation or reviewing an accreditation, if the audit or review relates to the services provided by the custodian,
- 37(6)(d) 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 or that relates to the storage or donation of **body parts or bodily substances**,

- 37(6)(e) to the **chief medical officer** of health or other medical officers if the disclosure is required by another Act of the Legislature or the Parliament of Canada,
- 38(1)(f) to an information manager in accordance with this Act,
- 38(1)(h) to a **research data centre** in accordance with the terms of an agreement between the research data centre and the custodian,
- 38(1)(h.1) if the custodian is the **Workplace Health, Safety and Compensation Commission**, to the Workers' Compensation Appeals Tribunal established under the Workplace Health, Safety and Compensation Commission and Workers' Compensation Appeals Tribunal Act,
- 38(1)(i) to a potential **successor** of the custodian for the purpose of allowing the potential successor to assess or evaluate the operations of the custodian, on condition that the potential successor first enters into an agreement with the custodian to keep the information confidential and secure and not to retain the information any longer than is necessary for the purpose of the assessment or evaluation, and
- 38(1)(j) to the **successor** of the custodian if 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.

Ontario Personal Health Information Protection Act, SO 2004, c.3, ss.39, 40, 42:

- 39(1)(b) to a person **conducting an audit or reviewing an application** for accreditation or reviewing an accreditation, if the audit or review relates to services provided by the custodian and the person does not remove any records of personal health information from the custodian's premises;
- 39(1)(c) to a prescribed person who compiles or maintains a **registry** of personal health information for purposes of facilitating or improving the provision of health care or that relates to the **storage or donation of body parts** or bodily substances;
- 39(2) (a) to the **Chief Medical Officer of Health** or a medical officer of health within the meaning of the Health Protection and Promotion Act if the disclosure is made for a purpose of that Act;
- 39(2)(a.1) to the **Ontario Agency for Health Protection and Promotion** if the disclosure is made for a purpose of the Ontario Agency for Health Protection and Promotion Act, 2007; or
- 40(2) A health information custodian may disclose personal health information about an individual to the head of a penal or other custodial institution in which the individual is being lawfully detained or to the officer in charge of a **psychiatric facility within the meaning of the Mental Health Act** in which the individual is being lawfully detained for the purposes described in subsection (3).
- 40(3)(b) the placement of the individual into custody, detention, release, conditional release, discharge or conditional discharge **under Part IV of the Child and Family Services Act, the Mental Health Act, the Ministry of Correctional Services Act, the Corrections and Conditional Release Act (Canada), Part XX.1 of the Criminal Code** (Canada), the Prisons and Reformatories Act (Canada) or the Youth Criminal Justice Act (Canada).
- 42 (1) A health information custodian may disclose personal health information about an individual to a **potential successor** of the custodian, for the purpose of allowing the potential successor to assess and evaluate the operations of the custodian, if the potential successor first enters into an agreement with the custodian to keep the information confidential and secure and not to retain any of the information longer than is necessary for the purpose of the assessment or evaluation. 2004, c. 3, Sched. A, s. 42 (1).
- 42 (2) A health information custodian may transfer records of personal health information about an individual to the **custodian's successor** if the custodian makes reasonable efforts to give notice to the individual before transferring the records or, if that is not reasonably possible, as soon as possible after transferring the records. 2004, c. 3, Sched. A, s. 42 (2).

Manitoba Personal Health Information Act, SM 1997, c.51, ss. 22:

- 22(2)(j) to a person who requires the personal health information to carry out **an audit** for or provide legal services to a trustee, if the trustee reasonably believes that the person will not use or disclose the personal health information for any other purpose and will take appropriate steps to protect it;
- 22(2)(l.1) required by **police** to assist in locating an individual reported as being a missing person, if the information disclosed is limited to demographic information;

Saskatchewan Health Information Protection Act, RSS 1999, c.H-0.021, s. 27:

- 27(4)(c) where the disclosure is being made to a trustee that is the **successor** of the trustee that has custody or control of the information, if the trustee makes a reasonable attempt to inform the subject individuals of the disclosure;

Alberta Health Information Act, RSA 2000, c.H-5, s. 35:

- 35(1)(f) to a person authorized to **conduct an audit of the information** if the person agrees in writing (i) to destroy the information at the earliest opportunity after the audit is concluded, and (ii) not to disclose the information to any other person, except as required to accomplish the audit or to report unlawful or improper conduct by the custodian or a health services provider,
- 35(1) (q) to its **successor** where (i) the custodian is transferring its records to the successor as a result of the custodian (A) ceasing to be a custodian, or (B) ceasing to provide health services within the geographic area in which the successor provides health services, and (ii) the successor is a custodian.

Several of the stakeholder suggestions and provisions from other jurisdictions merit further consideration. The findings support further investigation and consultation on suggested circumstances that could be appropriately included in PHIA. For any new additions to the disclosures without consent, the privacy implications of permitting disclosure of an individual's personal health information without the individual's consent will need to be considered and addressed in order to achieve the right balance between the individual's privacy and the need to disclose this information in the context of health care.

2.5 Retention, Destruction, Disposal and De-identification

Appropriate retention, destruction, disposal and de-identification of personal health information are important components of managing this information. Sections 47 to 51 of PHIA require that custodians have in place and comply with information practices for both paper and electronic records containing personal health information, including a written retention schedule.

2.5.1 Disposition of Health Records

Custodians may retire or close their practices before a retention period has expired for the health records of their patients. In some cases, these custodians may transfer the health records to a new custodian. In other cases, there is no new custodian available for transfer of these records. Under these circumstances, there is concern about the custodianship of these records and the accessibility of these records for patients.

While PHIA is silent on these aspects of records disposition, other Nova Scotia statutes dealing with the regulation of health professionals, such as the Medical Act, provide requirements for record disposition as mandated by the relevant College. Health information legislation in some jurisdictions provides specifically for the disposition of personal health information, to clarify the end of a custodian's responsibility and provide rules with respect to outsourcing records storage.

Discussion Paper Questions

Q14 Should a custodian be able to store the personal health information contained in health records outside Nova Scotia?

Q15 If custodians can store health records outside Nova Scotia, should they be required to provide notice to individuals whose personal health information is contained in the records?

Q16 Should PHIA be amended to clarify rules for how custodians handle personal health information when ending their practices, including:

- Clarify that custodianship of records containing personal health information extends until records are transferred to an authorized person;
- Authorize custodians to enter into agreements with information managers to complete disposition of records and require that the agreements be made in writing; and

- Confirm the fees that may be charged by information managers are those set out in PHIA section 82 and the regulations.

2.1.5.1 Discussion & Findings

The majority of stakeholders provided the feedback that custodians should be able to store personal health information contained in health records outside Nova Scotia. They qualified this response by adding that there should be verified controls, conditions and safeguards and the storage must meet the requirements of PHIA or an equivalent provincial or federal law for protection of this information.

On the question of whether custodians should be required to provide notice to individuals whose health records are being stored outside Nova Scotia, there was a mixed response. One stakeholder noted that physicians have an obligation to report the disposition of health records to their College and see it as part of their professional responsibility. Other stakeholders indicated that the location of the health record would not matter to their clients, as long as access to the records was available.

There were also differences in opinion from stakeholders on whether PHIA should be amended to clarify rules for how custodians handle personal health information when ending their practices, with the majority supporting amendment to PHIA to clarify the rules. One stakeholder provided the feedback that embedding procedural rules in PHIA may have a detrimental effect and that it is the role of the regulatory bodies of health professionals to provide guidance to their members. Another stakeholder indicated PHIA should only be amended to address the disposition of health records if other Nova Scotia statutes do not sufficiently address this issue.

Various jurisdictions in Canada have personal health information legislation with provisions for disposition of health records and outsourcing storage of health records, including Ontario, Newfoundland and Labrador, New Brunswick, Saskatchewan, and Alberta, as the following summary[3] illustrates:

Newfoundland Personal Health Information Act, SNL 2008, c. P-7.01:

- Custodianship does not cease until records of personal health information pass to another individual who is legally authorized to hold the records (s. 4(3)).
- Where the custodian fails to carry out his or her duties, the minister may appoint a person to act in place of the custodian (s. 4(4)).
- Custodian may enter into an agreement with an "information manager" to store or destroy records of personal health information. Obligations under those agreements are defined (s. 22).
- Creates a separate category of privacy breach where records are disposed of in an unauthorized manner (s. 15(3)(c)).

New Brunswick Personal Health Information Privacy and Access Act, SNB 2009 c. P-7.05:

- Custodianship does not cease until records of personal health information pass to another individual who is legally authorized to hold the records (s. 54(1)).
- A custodian may enter into an agreement with an "information manager" to store or destroy records of personal health information, pursuant to s. 52(1). Obligations under those agreements are defined, pursuant to s. 52(2), expanded on in Regulations.
- Pursuant to s. 54(2), the custodian or custodian's successor is obligated to advise individuals about the transfer of personal health information, how the individual may request access, and the retention period.

Ontario Personal Health Information Protection Act, SO 2004, c. 3, Sch. A:

- Custodianship does not cease until records of personal health information pass to another individual who is legally authorized to hold the records (s. 3(11)).
- A custodian is permitted to transfer records of personal health information under a confidentiality agreement to a potential successor so that the successor may evaluate the custodian's operations (s. 42(1)).
- A custodian may transfer records containing personal health information to a successor provided the custodian has taken reasonable steps to notify the individuals insvolved (s. 42(2)).

Saskatchewan Health Information Protection Act, SS 1999, c. H-0.021:

- Custodianship does not cease until records of personal health information pass to another individual who is legally authorized to hold the records (s. 22(1)).

[3] Provided by the Information and Privacy Commissioner for Nova Scotia in a September 28, 2016 submission for the PHIA Three Year Review, available on Office of the Information and Privacy Commissioner's website.

- Where the custodian ("trustee") fails to carry out his or her duties, the minister may appoint a person to act in place of the custodian (s. 22(2)).
- A custodian may disclose records containing personal health information to an "information management service provider" to "process, store, archive or destroy" the records. The information manager's uses of the records are restricted by statute (s. 18).

Alberta Health Information Act, RSA 2000, c. H-5:

- A custodian may enter into an agreement with an "information manager" to process, store, retrieve or dispose of personal health information pursuant to s. 66(2). Obligations under those agreements are defined pursuant to s. 66(4) and 66(5) and expanded on in Regulation 7.2.

It is also noteworthy that the Office of the Information and Privacy Commissioner has conducted investigations into improper disposal of health records in dumpsters and health records shipped out of province without notice.

Based on the stakeholder concerns and feedback on the need for clarity and the approach taken in other jurisdictions, the findings support the Digital Health Privacy Working Group conduct further investigation and consultation on the disposition of personal health information in health records and outsourcing storage of health records (including storage outside Nova Scotia) and recommend an appropriate approach for Nova Scotia. It will be important to consult with the regulatory bodies of health care professionals as these bodies may have discretionary power to appoint a person to hold, protect and provide access to patient records. For example, Part 5 of the Medical Practitioner Regulations under the Medical Act authorizes the College of Physicians & Surgeons to appoint such a person (called a custodian) to hold, protect and provide access to a member's or former member's patient records in certain circumstances.

2.6 Research

Sections 52 to 60 of PHIA provide rules for the collection, use and disclosure of personal health information for the purpose of research.

2.6.1 Custodian's Use and Disclosure of Personal Health Information for Research

- prepares a research plan that meets the requirements in section 59;
- submits the research plan to a research ethics board (REB);
- receives the approval of the research ethics board; and
- meets any conditions imposed by the REB.

Even though the personal health information is in the custody and control of the custodian, the custodian is still required to seek the consent of the individuals, unless the REB has determined that consent is not required, or that it is impracticable to obtain consent.

Section 56 of PHIA permits a custodian to disclose personal health information to a researcher if the researcher:

- Submits to the custodian:
  - An application in writing;
  - A research plan that meets the requirements of section 59; and
  - A copy of the submission to and decision of a research ethics board that approves the research plan; and
- Enters into the agreement required by section 60.

Under section 57, custodians may disclose personal health information about an individual to a researcher without the consent of the subject individual if:

- the researcher has met the requirements in section 56;
- the custodian is satisfied that
  - the research cannot be conducted without using the personal health information;
  - the personal health information is limited to that necessary to accomplish the purpose of the research;
  - the personal health information is in the most de-identified form possible for the conduct of the research;

- the personal health information will be used in a manner that ensures its confidentiality, and
- it is impracticable to obtain consent; and

- the custodian informs the Review Officer (now the information and Privacy Commissioner).

Discussion Paper Question

Q17 Should a custodian be able to disclose a patient's name and contact information to researchers without the patient's consent to allow them to contact patients for consent to participate in research, or use their personal health information in research? If so, what requirements should apply to this disclosure? Should the requirements of sections 56 and 57 continue to apply?

2.6.1.1 Discussion & Findings

The majority of stakeholders provided the opinion that a custodian should not be able to disclose a patient's name and contact information to researchers without the patient's consent to allow them to contact patients for consent to participate in research or use their personal health information in research. They also indicated that the requirements for research set out in sections 56 and 57 should continue to apply.

Many stakeholders indicated that the discussion to obtain consent to disclose name and contact information to researchers should occur directly between the custodian and their patients so that an informed decision can be made about the patients' involvement in research and sharing of their personal health information. One stakeholder noted that if this information was disclosed without consent, it could create a perception with patients that their private information is not secure and may prevent patients from seeking medical help.

In other feedback, one stakeholder who is a custodian indicated that they developed a research registry of patients who have consented to disclosure of their contact information and limited personal health information to researchers. This enables them to comply with PHIA's requirements and facilitate research recruitment.

The strong agreement among stakeholder feedback supports the finding that no change to PHIA or sections 56 and 57 is required in relation to this topic.

2.7 Reporting a Privacy Breach

Sections 69-70 of PHIA set out requirements for reporting a breach of an individual's privacy. Specifically, a custodian shall notify the individual at the first reasonable opportunity if the custodian believes on a reasonable basis that:

- an individual's personal health information is stolen, lost or subject to unauthorized access, use, disclosure, copying or modification; and
- as a result, there is potential for harm or embarrassment to the individual.

Pursuant to section 70(1), if the custodian determines on a reasonable basis that personal health information has been stolen, lost or subject to unauthorized access, use, disclosure, copying or modification, but it is unlikely that a breach has occurred or there is no potential for harm or embarrassment to the individual, the custodian is not required to notify the individual.

Section 70(2) states that where a custodian makes the decision not to notify the individual pursuant to this section, the custodian shall notify the Review Officer (now the Information and Privacy Commissioner) as soon as possible.

2.7.1 Notification to the Information and Privacy Commissioner

The wording of sections 69 and 70 results in the notification to the Information and Privacy Commissioner of minor or insignificant breaches, but not breaches where there is a real risk of significant harm. This is not consistent with the breach notification provisions of other Canadian laws, including those of Newfoundland and Labrador, New Brunswick, Ontario, Alberta and the federal government. It could lead to recurrence of systemic breaches, a lack of effective breach prevention strategies, and a failure to notify individuals of their right to an independent review by the Office of the Information and Privacy Commissioner.

Discussion Paper Question

Q18 Should PHIA be amended to:

- Require notification of affected individuals and the Commissioner if it is reasonable in the circumstances to believe the breach creates a real risk of significant harm to an individual;

- Require notification without unreasonable delay;
- Include content requirements for notification to individuals including: specific details about the cause of the breach, the type of data lost or stolen, an explanation of the risks of harm they may experience as a result of the breach, and information about their right to complain to the Commissioner;
- Require maintenance of a record of all data breaches by custodians with specified details available to the Commissioner upon request;
- Remove notification to the Commissioner of minor breaches but add clear authority for the Commissioner to request the breach record maintained by a custodian; and
- Authorize the Commissioner to investigate a custodian's decision not to notify and, if the Commissioner considers it appropriate, to require that the custodian notify the individual of the privacy breach?

2.7.1.1 Discussion & Findings

Most stakeholder responses to the questions on whether PHIA should be amended to address notification of affected individuals and the Commissioner of a privacy breach of personal health information were supportive of the need for amendment. Where responses differed, stakeholders were concerned that any amendments should preserve discretion in the handling of minor breaches or that the custodian should notify the individual of a breach that creates a real risk of significant harm but not notify the Commissioner. Other responses requested clarification of sections 69 and 70 and were looking for guidance as to what factors should be considered in determining the risk of harm. Additionally, one stakeholder wondered how there could be a determination that personal health information was subject to unauthorized access but that it was unlikely a breach occurred (in relation to section 70(1)(a)). Another stakeholder provided the information that the harm or embarrassment algorithm tool (the Privacy Breach Notification Decision-Making Tool) developed by a Working Group of the Department was very helpful.

The majority of stakeholders agreed with the need for amendments to PHIA to address each of the six areas identified in the Discussion Paper question. There were some stakeholders, however, who did not agree that PHIA should be amended to authorize the Commissioner to investigate a custodian's decision not to notify an individual. One stakeholder did not agree that custodians should be required to keep a record of breaches as this would be too onerous. Another stakeholder agreed with the requirement to keep a record but did not believe it should be necessary to provide this record to the Commissioner. One stakeholder provided the following analysis of the need for amendment, as follows:

> Openness and transparency is crucial especially when it comes to breaches. The breach process is an attempt to mitigate the risk resulting from a breach, learn from mistakes and re-gain the trust of the public through close monitoring of strategies and practices. Informing the appropriate individuals is important to communicate our actions, and educate on the steps taken to reduce the risk. It should not be subjective. Whether to report a breach should not be left to the subjective thinking of one individual neither should be one individual responsible to determine what a minor or a major breach is. Reporting all breaches to the Commissioner removes the responsibility of determining the level of harm. Policy based guidelines should help to build criteria to determine risk and harm.

Many jurisdictions across Canada, including the federal government, as well as jurisdictions in Europe, have breach reporting provisions in legislation, as the following summary[4] demonstrates:

Newfoundland Personal Health Information Act, SNL 2008, c. P-7.01, s. 15(4):

- Where the custodian reasonably believes there has been a material breach as defined in the regulations the custodian shall inform the Commissioner.
- Commissioner may recommend that the custodian notify the individual in certain circumstances (s. 15(5)).
- "material breach" – Factors relevant in determining what constitutes a material breach include sensitivity, number of people, whether the custodian reasonably believes that the personal health information involved has been or will be misused and whether the cause of the breach or the pattern of breaches indicates a systemic problem.

New Brunswick Personal Health Information Privacy and Access Act, SNB 2009 c. P-7.05, s. 49(1)(c):

- Notify the individual and the Commissioner at the first reasonable opportunity if personal health information is stolen, lost, disposed of or disclosed to or accessed by an unauthorized person.

[4] Provided by the Information and Privacy Commissioner for Nova Scotia in a September 28, 2016 submission for the PHIA Three Year Review, available on Office of the Information and Privacy Commissioner's website.

- Notification is not required if the custodian reasonably believes that the event will not have an adverse impact on the provision of health care or the individual, or will not lead to the identification of the individual.
- Regulations include information that must be provided in notice.

Ontario Personal Health Information Protection Act, SO 2004, c. 3, Sch. A, s. 12:

- If personal health information that is in the custody or control of a health custodian is stolen or lost or if it is used or disclosed without authority the custodian shall notify the individual at the first reasonable opportunity.
- Custodian must advise the individual of his or her right to complain to the Commissioner.
- Custodian must notify the Commissioner if the breach meets the prescribed requirements.

Alberta Personal Information Protection Act, SA 2003, c. P-6.5 (not yet in force):

- Organization must notify the Commissioner without unreasonable delay where a reasonable person would consider that there exists a real risk of significant harm (s. 34.1).
- Commissioner can require notification of individual where there is a real risk of significant harm (s. 37.1).
- Regulations include detailed list of content for notices.

Alberta Health Information Act, RSA 2000, c. H-5. s. 60.1 (via Bill 12, Statutes Amendment Act, 2014, 2014 c8 s4) (not yet in force):

- Where there is a risk of harm to the individual as a result of a loss of personal health information or any unauthorized access to or disclosure of personal health information the custodian must notify the individual, the Commissioner and the Minister in accordance with regulations.

Canada Digital Privacy Act, SC 2015, c. 32, s. 10.1 requires organizations to:

- Notify individuals and the Privacy Commissioner as soon as feasible of any breach that poses a
- "real risk of significant harm".
- Notify any third party that the organization believes is in a position to mitigate the risk of harm.
- Form and content of notification and identification of risk factors may form part of the
- regulation – consultations currently underway.
- The most recent new reporting provisions include a requirement on the health custodian or public body to also keep a complete record of all breaches (minor and major) available for inspection by the Commissioner.

Canada Digital Privacy Act s. 10.3:

- Requires organizations to keep and maintain a record of every breach of security safeguards involving personal information under its control.

European Union General Data Protection Regulation (GDPR), Article 33.5:

- The organization shall document any personal data breaches including its effects and remedial action taken.
- The documentation must enable the Commissioner (known as the supervisory authority) to verify compliance with the GDPR requirements.

Sections 69 and 70 are not consistent with the breach notification provisions in other Canadian legislation and have resulted in concerns that the Commissioner has insufficient information to (a) evaluate systemic problems, (b) determine whether prevention strategies are effective or if any were implemented, or (c) verify that individuals are, in fact, receiving adequate notification of breaches of their personal health information.

The findings support amendment of PHIA regarding the notification of breaches to (a) include the Commissioner and the individual(s) when notifying of breaches with a real risk of significant harm, and (b) bring the Act into alignment with additional breach requirements in similar legislation across Canada. This will address concerns raised by the Commissioner and other stakeholders.

2.8 Access and Correction

Section 75 of PHIA provides individuals with a right to ask to examine a record, or ask for a copy of a record, of their own personal health information that is in the custody or under the control of a custodian. They can do this by specifying the subject matter of the record and paying any required fees.

2.8.1 Correction of Record of Personal Health Information

Individuals also have the right to request that the custodian correct information contained within their records of personal health information, pursuant to sections 85 to 90 of the Act. The custodian is required to make the correction if the individual demonstrates, to the satisfaction of the custodian, that the record is not complete, accurate, or up-to-date, and gives the custodian the information necessary to enable the custodian to correct the record. However, a custodian is not required to correct a record if:

- it consists of a record that was not originally created by the custodian and the custodian does not have sufficient knowledge, expertise, and authority to correct the record; or
- it consists of a professional opinion or observation that a custodian has made in good faith about the individual.

In some cases, the request for correction may be to correct a factual error. In other cases, an individual may not agree with an opinion or diagnosis on the health record. If an individual does not agree with a professional opinion, the custodian is not required to correct the record, but is required to place a statement of disagreement on the record that outlines the individual's disagreement with the information.

Discussion Paper Question

Q19 Is PHIA clear about who decides what a correction is and if it is warranted?

2.8.1.1 Discussion & Findings

The majority of stakeholders indicated that PHIA is clear about who decides what a correction is and if it is warranted. Of those who disagreed, one stakeholder requested more clarity about when, as a result of a correction request, the information may be deleted as opposed to annotated. Another stakeholder noted there could be more clarity to assist hospitals where the entry was made by a health care professional. A third stakeholder indicated more clarity should be added regarding substitute decision-makers. One stakeholder provided the opinion that section 88(c) has the potential to be onerous for custodians and agents and that section 89 should permit custodians to declare the correction is not warranted or would be fraudulent or untruthful.

Personal health information legislation in Ontario, Newfoundland and Labrador, Alberta and Prince Edward Island all use similar language as PHIA in their provisions regarding correction. Legislation in New Brunswick, Manitoba, Saskatchewan and British Columbia indicates that the custodian/trustee must inform the individual if the personal health information no longer exists or cannot be found. In addition, if the custodian/trustee does not maintain the personal health information, they must inform the individual and provide him or her with the name and address, if known, of the custodian/trustee who maintains it. Otherwise, the legislation in these jurisdictions does not provide reasons why a custodian can refuse to correct the record. All of these jurisdictions require the custodian to notify other custodians or persons of the correction if the previously incorrect information was disclosed to them.

PHIA's provisions on correction are clear to most stakeholders and are aligned with the provisions of a number of other jurisdictions in Canada. However, there does appear to be a need to provide greater clarity for some custodians on how to apply the correction provisions in certain circumstances. The findings support awareness building activities would be appropriate to address this concern. For example, additional information and scenarios on how to respond to a request for correction could be considered in the context of updating the PHIA Toolkit.

2.9 Review and Oversight

Under PHIA the Review Officer, now known as the Information and Privacy Commissioner, provides independent oversight of privacy and access complaints.

2.9.1 Power to Compel Production of Records from Non-Custodian

Section 92(2)(b) permits the Commissioner to initiate an investigation of compliance if there are reasonable grounds to believe the custodian has, or is about to, contravene the privacy provisions, and the subject of

the review relates to the contravention. As part of the investigation, section 99(1) of the Act authorizes the Commissioner to require to be produced and examine any record relevant to the matter that is in the custody or control of the custodian.

In some circumstances, where a privacy breach has occurred, however, relevant records may have been faxed, email or otherwise accessed by a non-custodian. PHIA does not permit the Commissioner to require production of relevant records from a non-custodian. The lack of this power could interfere with the Commissioner's ability to intervene to contain a breach or fully investigate a breach.

2.9.2 Power to Share Information with other Information and Privacy Commissioners

There may be circumstances where a privacy breach involves custodians in Nova Scotia, and custodians in another Canadian jurisdiction. For example, as shared electronic health records are created that enable patients to receive health care no matter where they are in Canada, a privacy breach may require the Commissioner to work with another jurisdiction's Information and Privacy Commissioner to investigate the breach and coordinate activities to prevent future breaches. Other jurisdictions, such as British Columbia and Alberta, have included provisions in their personal and health information legislation to provide for the ability for Commissioners to share information in order to conduct joint investigations.

2.9.3 Restrictions on Disclosure and Immunity for Commissioner and Staff

PHIA does not contain provisions that restrict the Commissioner and her staff from disclosing personal health information except in accordance with the Act. This type of provision is present in some personal health information legislation in other Canadian jurisdictions. Without restrictions on disclosure by the Commissioner and the staff of the Office of the Information and Privacy Commissioner, individuals and custodians may be unclear about the confidentiality, use and disclosure of this information.

Section 105(1) of PHIA provides a general immunity from damages for a custodian and any other person for:

- anything done, reported or said, both in good faith and reasonably in the circumstances in the exercise of good faith of any of the person's powers or duties under this Act; or
- any alleged neglect or default that was reasonable in the circumstances in the exercise of good faith of any person's powers or duties under the Act.

Discussion Paper Questions

Q20 Should PHIA be amended to give the Information and Privacy Commissioner the power to compel production of any relevant record and examine any information in the record, whether or not the record is under in the custody and control of a custodian and/or subject to the provisions of the Act?

Q21 Should PHIA be amended to allow for the exchange of information with extra-provincial commissioners for the purpose of coordinating activities and handling reviews and complaints involving two or more jurisdictions?

Q22 Should PHIA be amended to enumerate the permitted uses and disclosures of information by the Commissioner and her staff?

Q23 Should PHIA be amended to specify the immunity of the Commissioner and her staff?

2.9.3.1 Discussion & Findings

The power and authority of the Commissioner stem from provisions of the FOIPOP Act, the Privacy Review Officer Act, the Personal Information International Disclosure Protection Act (PIIDPA), and sections 91 to 100 of PHIA. Section 3(z) of PHIA also defines the Commissioner (Review Officer) as the Privacy Review Officer under the Privacy Review Officer Act.

The Privacy Review Officer Act was enacted to provide the Commissioner with additional duties and powers with respect to privacy complaints, reviews and investigations. Section 3 of the Privacy Review Officer Act states that it applies to all records in the custody or under the control of a public body to which the FOIPOP Act applies. The Privacy Review Officer Act came into force before PHIA became law.

The Minister of Justice is the Minister responsible for administering FOIPOP, PIIDPA and the Privacy Review Officer Act. The Minister of Health is the Minister responsible for administering PHIA. It is important for the power and authority of the Commissioner to be consistent across all the legislation for which the Commissioner has responsibility for review and oversight. Amending PHIA alone to add these powers for the Commissioner would lead to a misalignment of the powers of the Commissioner between PHIA and the privacy legislation under the administration of the Minister of Justice. For this reason, the findings support no change to PHIA to add these powers.

Of note, section 105(1) of PHIA provides that "no action or other proceedings for damages may be instituted against a custodian or other person [which would include the Commissioner and the Commissioner's staff] for:

(a) anything done, reported or said, both in good faith and reasonably in the circumstances, in the exercise or intended exercise of any of the person's powers or duties under this Act; or

(b) any alleged neglect or default that was reasonable in the circumstances in the exercise in good faith of any of the person's powers or duties under this Act."

There is one area of PHIA, however, that is unique to PHIA and does not exist in the other Acts – the provisions relating to privacy breach (sections 69 and 70). In her submission for the PHIA review, the Commissioner noted the following:

> "With the creation of the electronic health record and the desire across Canada to allow patients to access health care and their health records no matter which Canadian jurisdiction they are in, issues will inevitably arise involving more than one jurisdiction. Privacy breaches know no borders. In order to effectively investigate such breaches the Commissioner requires the clear authority to work together with her regulatory counterparts to investigate these types of breaches and to coordinate activities to help prevent breaches."

The majority of stakeholders also responded that PHIA should be amended to allow the Commissioner to exchange information with extra-provincial commissioners for the purpose of coordinating activities and handling reviews and complaints involving two or more jurisdictions. Both the Alberta Health Information Act and the British Columbia Personal Information Protection Act provide similar power to their Commissioners for this purpose.

In order to ensure the Commissioner has the appropriate authority to collect and use personal health information needed to participate in a privacy breach investigation that involves Nova Scotia and at least one other jurisdiction, the findings support that PHIA be amended to add a provision in section 91(2).

Part 3
PHIA Regulations

The Personal Health Information Regulations provide additional definitions and rules to support the application of PHIA, including:

- prescribing additional custodians;
- designating health care services;
- designating prevailing provisions from other Acts;
- authorization for collecting and using health card numbers;
- processes for addressing complaints;
- additional safeguards for electronic information systems; and
- fees for accessing personal health information records.

3.1 Safeguards for Electronic Information Systems

3.1.1 Record of User Activity

Section 63 of PHIA requires that a custodian create and maintain, or have created and maintained, a record of user activity for any electronic information system it uses to maintain personal health information. The record of user activity related to an individual's personal health information must be made available to the individual who requests it.

The regulations provide additional information for custodians on what should be included in an individual's record of user activity, including the date and time the personal health information was accessed, or if the specific dates and times cannot be determined, a range of dates when the information could have been accessed. The regulations also indicate that a custodian must retain the information that was used to update a record of user activity related to an individual's personal health information for at least one year after each date of access.

3.1.2 Audit and Monitoring

The regulations provide additional safeguards for the electronic information systems used by custodians for maintaining personal health information, including:

- protection of network infrastructure, including physical and wireless networks, to ensure secure access;
- protection of hardware and its supporting operating systems to ensure that the system functions consistently and only those authorized to access the system have access; and
- protection of the system's software, including the ways it authenticates a user's identity before allowing access.

The regulations do not specify any additional safeguards related to audit and monitoring of user access for electronic information systems. However, these safeguards are considered a best practice and are required for many information systems containing personal information or personal health information.

Discussion Paper Questions

Q24 Should the regulations be amended to clarify how long a custodian must retain the information that was used to update a record of user activity?

Q25 Should the regulations be amended to include additional safeguards, such as:

- Safeguards related to audit and monitoring of access to personal health information maintained in electronic information systems;
- Privacy impact assessments or threat risk assessments for new information systems or significant changes to information systems? If these are mandatory, should this be a requirement for all custodians regardless of the size of the custodian or the system;
- Safeguards for custodians who are using personal health information for planning and management of the health system?

3.1.2.1 Discussion & Findings

Stakeholders provided a variety of responses to the questions of whether the PHIA regulations should be amended to clarify how long a custodian must retain the information that was used to update a record of user activity. Some stakeholders were unclear on the intent of this section and indicated there were multiple possible interpretations. Other stakeholders stated that the provision is clear, in that it requires a minimum retention period of one year. However, they noted, the maximum retention period should be based on a reasonable standard such that a custodian would be able to trace back unauthorized accesses by staff that span several years and different patients.

The PHIA Toolkit provides guidance on this topic in Chapter 8 Information Practices: Electronic Health Record and Electronic Information Systems, as follows:

> It is important to distinguish between an "audit log" and a "record of user activity" referenced in section 63 of PHIA:
>
> A record of user activity "*means a report produced at the request of an individual for a list of users who access the individual's personal health information on an electronic information system for a time period specified by the individual*" (PHIA regulation section 11 (1)).
>
> An audit log, if one exists, is an electronic file or record which details, during a given period of time, who has accessed patient information in an electronic information system. The audit log may or may not contain more fields than those required by regulation to produce a record of user activity.
>
> A record of user activity may be generated by taking specific fields from a system's audit log and forming a report that could be provided to an individual. The PHIA regulations require that the audit logs used to generate a record of user activity, if they exist, must be kept for at least one year from the date they were used to create a record of user activity (PHIA regulation section 10(2)). A custodian will determine the retention period for the audit logs on an ongoing basis and this can be included in their written policies.

On the question of whether the PHIA regulations should be amended to include additional safeguards, stakeholders were in general agreement, although several mentioned that additional safeguards may be difficult or onerous to implement for smaller custodians with fewer resources or those in private practice. Two stakeholders noted gaps in PHIA's safeguards for electronic health records compared to similar legislation in other jurisdictions in Canada, such as Ontario. Other stakeholders provided the opinion that privacy impact assessments and threat risk assessments should be a best practice embedded in policy, not legislation, or be limited to electronic health record systems that cross health custodians.

Given the Province's vision and progress toward using electronic health records to improve the delivery of health care to Nova Scotians, the potential gaps in PHIA safeguards and the diverse feedback from stakeholders on these issues, the findings support that these questions be further investigated by the Digital Health Privacy Working Group previously noted in this Report.

3.2 Fees

Pursuant to section 75 of PHIA, individuals are entitled to ask custodians for access to their records of personal health information by meeting three requirements:

- make the request in writing to the custodian that has custody or control of the record;
- specify the subject matter of the record with sufficient information to enable the custodian to locate the record; and
- pay any required fees.

Section 82(1) and (2) provides that a custodian has the right to charge a fee for access, but custodians may not exceed the prescribed amount. In addition, where no amount is prescribed, the fees may not exceed the amount of reasonable cost recovery.

Section 82(3) provides a custodian with the discretion to determine whether to grant a fee waiver. Custodians may waive the payment of all, or any part of, the fee that an individual is required to pay, if in the custodian's opinion, the individual cannot afford the payment or for any other reason it is fair to excuse payment.

Maximum fees are prescribed in the regulations. The regulations provide information on fee exceptions, the general fee for access to records, specific fees and direct costs that a custodian or the custodian's agent may charge.

3.2.1 Fee exceptions

Any authorized individual who makes a request for access to, or a copy of a record, may be charged the fees set out in the regulations, unless the individual falls within one of the fee exception categories set out in the regulations or the custodian grants a fee waiver. The exceptions are described in section 12 of the regulations and include:

- a request made by a solicitor representing a legal aid client;
- a request from an individual for the purposes of appearing before the Review Board under section 68 of the Involuntary Psychiatric Act;
- a search warrant presented by a police officer under section 487 of the Criminal Code (Canada) or a production order presented by a police officer under section 278.7 of the Criminal Code (Canada);
- a request by a police officer or probation officer who is entitled to personal health information in accordance with clause 11(a) of the Act under a consent given by the individual whose personal health information is the subject of the request;
- a request from a regulated health-profession body that is permitted to access personal health information under clause 38(1)(c) of the Act and that is using the information for the purposes of regulating the health profession; and
- a request from a regulated health professional who is entitled to personal health information in accordance with clause 11(a) of the Act under a consent given by the individual whose personal health information is the subject of the request.

Section 11(a) of PHIA states that a custodian shall not collect, use or disclose personal health information about an individual unless the custodian has the individual's consent and the collection, use or disclosure is reasonably necessary for a lawful purpose.

The PHIA Toolkit published by the Department of Health and Wellness on their website includes additional information on the process for charging fees, template forms for providing the individual with a fee estimate, and template forms for individuals to request a fee waiver.

The regulations indicate that a custodian may charge an individual the direct costs of mailing a record to an address outside Canada. However, the authority to charge an individual for the direct cost of mailing a record to an address in Canada is not specified. Some custodians have indicated that this cost is onerous.

A number of custodians have provided feedback that the exception under section 12(f) of the regulations requires clarification. Custodians' understanding of the intent of the exception was that it was intended to prevent one health care professional from charging another health care professional to provide a report, write an in-patient summary, forward the results of a diagnostic report, etc. However, there are two circumstances where confusion has arisen over the application of this section:

1. Patient records that remain when a regulated health professional has retired or otherwise ceased to practice and there is no custodian replacing the exiting custodian.
2. Patient records that are being transferred to the practice of another regulated health professional.

In both of these scenarios, if a patient requests a copy of the health records, the custodian is entitled to charge a fee. However, if the request is from another regulated health professional, stakeholders' understanding is that no fee can be charged. This has the potential to create financial hardship for the regulated health professional who must provide the entire health record needed for the patient's care, but cannot recover any of the costs associated with this effort.

Discussion Paper Questions

Q26 Should custodians be able to charge for the direct costs of mailing a record within Canada? If so, who should pay for these direct costs?

Q27 Should the regulations be amended to clarify that the exception under section 12(f) for a request from a regulated health professional who is entitled to personal health information in accordance with clause 11(a) of the Act under a consent given by the individual whose personal health information is the subject of the request includes:

- Personal health information required for a specific test result or report but does not include providing a copy or transfer of the individual's entire health record to a new custodian?

Q28 Should custodians be able to charge a fee for the transfer of an electronic health record to another custodian?

Q29 Should custodians be able to charge a fee for transferring a paper-based health record to another custodian?

3.2.1.1 Discussion & Findings

On the question of whether custodians should be able to charge the direct cost of mailing a record within Canada and who should be charged, most stakeholders agreed that the custodian should be able to charge a fee and that the individual requesting the record should pay this cost. Some stakeholders felt the former custodian should pay this cost, while others indicated it should be the patient or MSI.

In response to the question about the exception under section 12(f), many stakeholders agreed the exception is unclear, and requested clarification on the intent of this exception.

There were divergent stakeholder responses on the questions of whether custodians should be able to charge a fee for transferring electronic or paper-based health records to another custodian. Several stakeholders provided the opinion charging a fee (or only a fee for direct costs of copying and postage) under either of these circumstances was inappropriate given that no review of the records is required, while others wished to recover the costs associated with the transfer.

In relation to whether a copy of the entire record or a summary of the patient history is needed, one stakeholder stated:

> Add provisions to PHIA that permit physicians (if they so choose) to determine which portions of the health record are actually relevant (if, for example a new physician is taking over the care of a patient) and otherwise provide an overall history/summary. The physician compensation for this work could come from a fee created specifically for this work (and at a minimum should be the equivalent of the fee for a review of the record for third-party information). Alternatively, a fee code could be created for submission to MSI.

Another stakeholder provided the following opinion on fees for accessing personal health information in general:

> The overriding principle for charging fees for individuals accessing their personal health information is that fees should represent the smallest possible barrier to access. The information belongs to the patient and must be portable along with the patient's wishes. This is the fundamental value to Nova Scotian users of the health care system promised by the electronic patient portal.

In 2011, the Department formed a PHIA Working Group on Fees for Access, and developed Terms of Reference for this group. The Working Group was chaired by two representatives of the Department and included additional members from the Department, Doctors Nova Scotia, the IWK Health Centre, Capital District Health Authority, South Shore Health, the Nova Scotia Dental Association, the Nova Scotia College of Chiropractors and the Nova Scotia College of Physiotherapists. The Working Group was mandated to develop the content of PHIA regulations, policies and/or toolkit items related to fees for access charged under PHIA to an individual for access to his or her own personal health information.

The Working Group submitted its final Report and Recommendations to the Department in April 2012. The Working Group conducted a jurisdictional scan of laws in Nova Scotia and across Canada, discussed existing fee practices of health professionals, and reviewed decisions on access fees by the Nova Scotia and Ontario Privacy Commissioners. The Department accepted the Working Group's recommendations and incorporated specific recommendations on the fee structure and exceptions into the PHIA regulations.

Given the concerns raised by stakeholders, including the need for clarity on the exception in section 12(f) and potential fees for transfers of electronic and paper health records, the findings support that the Digital Health Privacy Working Group (or a sub-group) be tasked with conducting further investigation and consultation on the topic of fees to determine whether amendment of the regulations as they relate to the exception in section 12(f), record transfers, and section 16 on direct costs is appropriate.

3.3 Cost Implications

In the Discussion Paper, the Department of Health and Wellness expressed an interest in understanding the cost impact on custodians and individuals of the operationalizing of PHIA and its regulations. Although there were no specific questions included on this topic, custodians, stakeholders and the public were encouraged to provide information relating to the cost impact of the operation of PHIA since it came into effect in 2013, compared to the costs of protecting and providing access to personal health information prior to the implementation of the Act.

Very few stakeholders responded to this topic. The Commissioner, in her September 28, 2016 submission, indicated that her office would require additional resources in order to meet their current and any future additional oversight obligations.

Another stakeholder provided the information that the implementation of section 12(f) of the PHIA regulations on fee exemptions has the potential to cause significant financial hardship for custodians when the request is from another custodian, as this section has been interpreted to mean that no fee can be charged for processing and copying the health record. This is especially the case when a physician has retired or otherwise left the practice of medicine and there is no new physician to take over the practice, leaving "orphaned" health records. In this scenario, the retired physician must pay the costs for processing and sending possibly hundreds or thousands of records to other custodians at their request.

One of the questions on the PHIA survey was about access to personal health information. The survey asked whether those who have requested access to their personal health information were satisfied with the process. Four out of 53 respondents to this question on the survey indicated a concern with the fees associated with accessing personal health information. It is not possible to assess whether the fees charged by the custodians in those four cases were consistent with the fee structure set out in the PHIA regulations. While the Department notes that only 7.5% of respondents to this question were concerned about the fees associated with accessing personal health information, the number and demographics of the survey respondents were limited and may not fully reflect concerns about fees from a more representative sample of the Nova Scotia population.

3.4 Additional Topics

The Discussion Paper invited stakeholders to provide comments on additional topics related to PHIA that were not included in the scope of the Discussion Paper. In this section, a number of these additional topics are identified and discussed, with findings where appropriate.

3.4.1 Changes and/or Additions to PHIA Definition of Planning and Management

Several stakeholders suggested changes and/or additions to the definition of planning and management included within PHIA. One stakeholder noted concerns that the current definition does not adequately cover all program activities, such as surveillance activities, management of disease registries, or quality improvement activities. Another stakeholder indicated that the definition in PHIA does not adequately draw distinctions between processes of planning and management, research, and quality management.

Section 3(s) of PHIA defines "planning and management of the health system" as follows:

- planning and management of the health system" means the analysis of information with respect to
  - (i) the management, evaluation or monitoring of,
  - (ii) the allocation of resources to, or
  - (iii) the planning for all or part of,
- the health system, including the delivery of services

PHIA permits the collection, use, and disclosure of personal health information for the purpose of ensuring quality or standards of care within a quality review program within the custodian's organization (see sections 31(m), 35(c), and 38(f)). Further, the current definition of planning and management of the health system is sufficiently broad to include those activities involving the collection, use, or disclosure of personal health information that would constitute quality management and improvement.

PHIA was structured to incorporate a section that was specific to research, as the collection, use and disclosure of personal health information for the purposes of conducting research is sufficiently different in nature from healthcare planning and management to warrant its own section and requirements in the Act. PHIA defines "research" as:

> a systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research

Although the processes and purposes of planning and management of the health system and research may have some similarities, they are fundamentally different. Planning and management of the health system includes analysis of personal health information with respect to managing, allocating resources to or planning for the health system, including the delivery of health care services. The focus on the health system, including the delivery of services provides a rationale for maintaining separate definitions and rules for planning and management of the health care system as opposed to research activities. There was no evidence suggested by stakeholders to indicate that the existing definition of planning and management of health services or the sections in PHIA concerning quality review are creating barriers to activities such as research, quality improvement, or surveillance. As such, the findings support no changes to the definition of planning and management of the health system at this time.

3.4.2 Retention Schedules

Two stakeholders raised questions relating to retention schedules for personal health information during the stakeholder consultation. One stakeholder requested that the PHIA regulations be amended to set out data retention periods that are consistent with guidance provided by various association bodies in the healthcare system, which could then serve as the written retention schedule that is set out by s.50(1) as follows:

- Every custodian shall have a written retention schedule for personal health information that includes
  - (a) all legitimate purposes for retaining the information; and
  - (b) the retention period and destruction schedules associated with each purpose.

Another stakeholder sought information on the length of time that medical records must be retained, noting a variance in requirements for retaining personal health information for some regulated health professions.

Many custodians have already developed retention schedules, and these and any retention schedules developed in the future to comply with PHIA would depend on the types of records and legal requirements of individual custodians. As such, it would be inappropriate to attempt to incorporate retention schedules into PHIA. The findings support that there be no changes to PHIA in regard to this matter, and that individual custodians and professional bodies should continue to provide guidance and direction to health care providers on the appropriate retention of personal health information.

3.4.3 Role of the Research Ethics Board

A number of questions and comments were submitted by stakeholders regarding the role of the Research Ethics Board (REB) under PHIA. One source indicated that there is a great deal of confusion regarding the role of the REB relative to the authority of the data custodian with respect to scientific review, privacy review and ethical review. This stakeholder specifically noted that there is a need for the research community to understand that the REB approval is not sufficient to allow disclosure of data by a custodian. Sections 55 to 60 in PHIA clearly articulate that it is the responsibility of the custodian to make decisions related to the use and disclosure of personal health information for the purposes of research, whereas the decision of the REB is one element the custodian requires to inform their decision.

One stakeholder requested clarity regarding the Research Ethics Board jurisdiction in cases of research projects where the principal investigator is outside Nova Scotia, but is requesting Nova Scotia data, noting inconsistency in the need for local REB review for different types of research projects. Section 52 of the Act defines a research ethics board as "a research ethics board established and operating in conformity with the Tri-Council Policy Statement." It further states in section 52(e):

> Tri-Council Policy Statement" means the Tri-Council Policy Statement "Ethical Conduct for Research Involving Humans" adopted in August 1998 by the Medical Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council of Canada, and includes any amendments or successor statements.

PHIA is silent on whether the REB is located in Nova Scotia or outside the Province, simply defining it in sections 52 (d) and (e).

Stakeholder feedback was also received on the wording within section 59 of the Act, indicating that PHIA should not direct the REB to accept a research plan or what should be in one for the REB to review, and suggesting alternate wording to reflect this. PHIA sets out the REB review of a research plan as a fundamental requirement to enable custodians to approve the use and disclosure of personal health information for the purposes of undertaking research, stating in section 59(1):

> Before commencing research, a researcher seeking to conduct research utilizing personal health information shall submit a research plan to a research ethics board

The remainder of section 59 lists the elements that should be included in the research plan. The intent of these provisions is to ensure that the proposed use of personal health information within a research plan is carefully considered given the highly sensitive nature of this information, rather than directing the REB to accept a research plan. Section 59 offers a systematic and thorough approach for researchers and custodians to examine the purposes and justification to build a strong case for the use of personal health information in the research project. The requirements in section 59 are not meant to infringe on other information that researchers may need or wish to include in a research ethics submission. The requirements are intended to ensure that proposed use of personal health information is examined, such that the custodian's requirements under PHIA can be met. This is especially the case when individual consent is not being sought. The findings support no changes to section 59 as the reasons for these provisions continue to be relevant for ensuring the protection of personal health information in research.

Similarly, feedback was received that it is not clear that the research plan described in section 59 is for the use of both the REB and the data custodian, where the introduction of the section seems to imply that it is only for the REB. When interpreting the legislation, it is important to read the sections on research as a whole and not one section in isolation. Sections 55 and 56 of PHIA articulate the requirement that the custodian be in receipt of the research plan in addition to other information, including the decision of the REB, making it clear that the research plan is required for the custodian to make a determination of whether to use or disclose the personal health information for the research. Therefore, the Department does not recommend changing the wording in section 59.

Finally, one stakeholder noted that there is nothing in PHIA to distinguish between the REB approval and an exemption. The Dalhousie Research Services online information related to research ethics Frequently Asked Questions , provides the following information on activities that would be exempt from REB:

> Research requires the REB review, but program evaluation, quality assurance and quality improvement activity is exempt from REB review (as per **TCPS 2.5**). The **Panel on Research Ethics** offers more interpretation of this question on its website (Scope – Questions 2 and 7).

> It is often difficult to determine what activities qualify for an exemption from research ethics review. The Dalhousie Research Ethics boards have developed **Guidelines for Differentiating Among Research, Program Evaluation and Quality Improvement**. The guidelines intended to guide researchers and evaluators (including students) as they determine whether their proposed activity constitutes research, program evaluation (PE), or quality improvement (QI), and therefore whether it requires research ethics review or is exempt.
>
> Please note that intent to publish does not in itself determine whether the activity is research (therefore requiring REB review).

It is the Department's understanding that an exemption in this context occurs when the REB determines that a proposed research project does not actually constitute research. As such, projects that are not deemed to be research would need to be assessed by custodians to determine if the work is permitted under a different section of PHIA, as the research provisions would not be applicable.

The findings support that the PHIA Toolkit be augmented to provide additional clarity and direction on the above questions and concerns that were raised by stakeholders.

3.4.4 Recurring Reviews of PHIA

Prior to the enactment of PHIA, personal health information was governed by a mix of federal and provincial legislation, health profession codes, and organizational policies and procedures. The legislation included the Hospitals Act, the Health Protection Act and the Freedom of Information, the Protection of Privacy Act (FOIPOP). PHIA was designed specifically for health care in Nova Scotia, including direct patient care, public health, planning and management of the health system, and research. It provides a comprehensive, consistent and clear approach to the health sector in Nova Scotia to protect personal health information and enable health professionals to provide and manage care. It is also consistent with the approach taken in most other jurisdictions in Canada.

This review has provided an opportunity to hear from a diverse range of stakeholders on the Act and how it has functioned in Nova Scotia. One goal of the review was to identify whether significant developments in public policy, law, technology or priorities have emerged that require a change to the Act. Although not all respondents addressed this specific question directly, a recurring theme in the feedback was that there has been, and continues to be, notable change and evolution within the Nova Scotia health system since PHIA came into force in 2013. For

[5] Provided by the Information and Privacy Commissioner for Nova Scotia in a September 28, 2016 submission for the PHIA Three Year Review, available on Office of the Information and Privacy Commissioner's website.

example, in 2016 a consolidation of services from the Department of Health and Wellness to the Nova Scotia Health Authority led to significant changes in governance, roles, and responsibilities, resulting in the need for the IWK and NSHA to be authorized in the PHIA regulations as organizations who are permitted under PHIA to collect personal health information for the purposes of planning and management of the health care system, where previously only the Minister of Health and Wellness could do so.

Another change on the horizon is the planned implementation of a One Person One Record (OPOR) system to merge all three existing hospital information systems into one system across the province. The development and implementation of OPOR was mentioned by several stakeholders as a key initiative for which there are still many unknowns as it relates to impacts on health system privacy. Additionally, the implementation of shared services was identified as another element of health system change that has the potential to impact privacy as it relates to information sharing across multiple agencies and organizations. One response noted:

> The direction of government is toward shared services and therefore it will be necessary to expand planning and management to other government agencies outside of Health. This should be considered when looking at the proposed changes to PHIA.

In the context of a continually evolving health care system, a request for amendment to PHIA to mandate recurring reviews of PHIA was raised by two stakeholder groups. One response emphasized the need for regular reviews in light of the continuous change in health care technology. Another noted that regular reviews of access and privacy law is a best practice, particularly in a world where new technologies create new opportunities and new challenges for privacy rights, stating:

> With no regular review provision there is no way to ensure that PHIA remains current, incorporates best practices and meets the future needs of Nova Scotians.

There are examples of legislative review provisions from across Canada that include periodic review requirements. For example, the Commissioner's September 28, 2016 submission for the review noted the following laws:

- Alberta Personal Information Protection Act, Chapter P-6.5, s. 63: Review every six years by special committee of the Legislative Assembly. The special committee must submit its final report to the Legislative Assembly within 18 months of beginning the review. Recommendations may result in amendments to the Act or Regulations.
- British Columbia Freedom of Information and Protection of Privacy Act, R.S.B.C. 1996 c. 165, s. 80: Review at least once every six years by special committee of the Legislative Assembly. Within one year of the date of appointment, the special committee must submit a report to the Legislative Assembly. The report may include recommended amendments to the Act or any other Act.
- Newfoundland Access to Information and Protection of Privacy Act, 2015, s. 117: First review not more than five years after the coming into force of the Act and every five years thereafter. Minister responsible for the Act shall refer it to a committee for the purpose of undertaking a comprehensive review. The review must include a review of all exempting provisions.

The Newfoundland Personal Health Information Act, 2008, s.91 also contains a provision for regular reviews, requiring a first review not more than five years after the coming into force of the Act and every five years thereafter.

Given the anticipated changes in health system and information technology to be implemented within the next decade and the unknown impacts this will have on the collection, use, disclosure, storage and retention of personal health information, the findings support an amendment to PHIA to require full or partial review of PHIA every five years following this review.

3.4.5 Housekeeping Items

Stakeholder responses highlighted a small number of instances where they felt "housekeeping" amendments to the Act were required to address minor errors or inaccuracies.

Feedback was received regarding two minor errors in the Act. Section 45 references a section 9(2), which does not exist, and section 101(1) refers to itself. The Department supports amending PHIA to correct these minor errors.

Finally, one stakeholder requested that the definition of a "record" should be amended to include video. Section 3(v) of PHIA currently states:

> "record" means a record of information in any form or in any medium, whether in written, printed, photographic or electronic form or otherwise, but does not include a computer program or other mechanism that can produce a record

The findings support no change to the definition of record, noting it can be inferred that the existing definition incorporates video, given that it states that the record can be in "any form or in any medium" and includes records in electronic form. Although video is not explicitly listed as one of the mediums, the current definition is flexible enough to allow for video as a form of a record of personal health information.

Part 4
Significant Developments Since the Introduction of PHIA

The three-year review of PHIA has also considered significant developments in Canadian health information protection law as it relates to personal health information and technological developments, as well as emerging health and public sector needs that may affect the collection, use, disclosure and retention of personal health information. The Discussion Paper posed questions in four areas where the use of technologies in the provision of health services and the interaction of health privacy law with other government policy priorities are emerging as issues since the coming into force of PHIA.

4.1 Electronic Health Records

4.1.1 Multi-Jurisdictional Electronic Information Systems

The Department of Health and Wellness is participating in the planning and development of pan-Canadian electronic health record systems. These systems will share personal health information across multiple jurisdictions in Canada, to provide more effective health care to individuals no matter where they are located, and to protect public health. As personal health information is disclosed for these purposes, a number of issues will require consideration, including: detecting and reporting privacy breaches, ensuring that appropriate privacy and security safeguards are in place, and providing access for individuals to their personal health information in other jurisdictions.

PHIA contains provisions permitting custodians to disclose personal health information, including disclosure outside Nova Scotia. However, the privacy breach and access provisions do not specifically address multi-jurisdictional electronic information systems.

Discussion Paper Question

Q30 Should PHIA be amended to include provisions related to custodians entering into information sharing agreements to manage inter-jurisdictional electronic health records? If so, what areas of concern should these agreements address (e.g., disclosure, breach notification, and access to personal health information, other)?

4.1.1.1 Discussion & Findings

Stakeholders provided a variety of responses to the question of whether PHIA should be amended to include provisions related to custodians entering into information sharing agreements to manage inter-jurisdictional electronic health records. Some agreed that

PHIA should be amended to require custodians to enter these agreements, including amendments specifically addressing how privacy breaches, disclosures and access would be handled within each jurisdiction. Others viewed information sharing agreements as a best practice for ensuring data sharing is managed securely. Some stakeholders provided the opinion that they were unsure of the need for these agreements, assuming that each jurisdiction has legislation in place protecting privacy and conducts appropriate investigations related to breaches.

Of those stakeholders who supported the need to amend PHIA to include provisions related to custodians entering into information sharing agreements, one indicated that these agreements provide essential protections to citizens and a degree of transparency when these documents are subject to independent oversight. This stakeholder recommended that:

- information sharing agreements be required for any routine sharing of personal health information between custodians in Nova Scotia and bodies outside Nova Scotia;
- authority be provided for the Commissioner to be notified of all agreements and revised agreements; and
- authority provided for the Commissioner to review and comment on these agreements.

One stakeholder wanted to know what the information sharing agreements would look like, while others felt the legislation should specifically allow programs to link their data to multiple sources of data for the purposes of surveillance, disease registries, and quality improvement activities.

As the stakeholder feedback illustrated, there are many situations where personal health information may be shared and in many cases, an information sharing agreement may be best approach to protecting the personal health information and clarifying the rules for its use and disclosure. However, in other circumstances, an information sharing agreement may not be the most appropriate solution. The Department notes that some multi-jurisdictional electronic health records are being implemented under agreed upon formal governance structures and would not require information sharing agreements in this context.

In order to preserve the flexibility to choose the most appropriate approach to protect and manage personal health information in the context of multi-jurisdictional electronic health records, the findings support no change to the provisions of PHIA in relation to this question. Custodians undertaking the implementation of inter-jurisdictional electronic health records are encouraged to consider information sharing agreements as a best practice, where this approach would be appropriate.

4.1.2 One Person, One Record

The Department of Health and Wellness is planning a One Person One Record (OPOR) system to merge all three existing hospital information systems into one system across the province. The development and implementation of OPOR will have significant impacts on a number of areas related to the privacy and access of personal health information, such as:

- the ability of patients to revoke or limit consent for the use and disclosure of their personal health information, also known as the locked box concept or masking, and patient concerns regarding health care professionals knowing there is something in the lock box;
- the ability of custodians to generate a record of user activity or the provision of a central authority to meet this requirement;
- audit and monitoring of access to electronic health records by custodians and their agents;
- determining which custodian is responsible for a privacy breach and any subsequent notification to individuals and the Commissioner;
- providing patients with access to their own personal health information, through the use of patient portals or other means; and
- educating custodians and their agents on the requirements of PHIA.

Discussion Paper Question

Q31 Should PHIA be amended to include provisions related the use of one electronic health information system in all hospitals across the province? If so, what should be included in the amendments?

4.1.2.1 Discussion & Findings

Stakeholders provided a number of different opinions on whether PHIA should be amended to include provisions related to the use of one electronic health record system in all hospitals in Nova Scotia. Some stakeholders did not feel PHIA required amendment because the current provisions in the Act provided the necessary safeguards. Others indicated they were concerned about how multi-custodianship would work and the impact having one system shared by all hospitals on areas such as privacy

breach, audit requirements, record of user activity, consent and access to personal health information.

The role and responsibilities of prescribed entities in relation to one electronic health information system for Nova Scotia hospitals and the governance of large interoperable databases of personal health information were also concerns. The approach taken in Ontario's Personal Health Information Protection Act was cited as a potential model for Nova Scotia to adopt in relation to PHIA. One stakeholder provided the following information:

> There is an urgent need to create clarity around who has control of large interoperable databases. Multiple custodians have access to the data and can add to and amend the data through the life of the patient. From a patient's perspective, he or she may believe that his or her own custodian has complete control over the record or that "the government" has control over the record. Or, he or she may be entirely uncertain who is responsible for the record. The same is true for many custodians who access shared data without having a clear idea who is ultimately responsible for the data. Providing clarity on this issue will assist patients and custodians and will ensure that patients have a meaningful right of access. As electronic health record databases expand, this issue will become more and more of a problem. Addressing it now will create certainty for future e-health projects.

The concerns raised by stakeholders need to be addressed as the Province moves towards using one electronic health record system for all hospitals. The findings support that the Digital Health Privacy Working Group should further investigate and consult with stakeholders regarding the privacy and access implications of implementing One Person One Record in Nova Scotia. This work will assist the Department in determining the appropriate approach required to protect the privacy of personal health information in this future system and ensure it is appropriately managed.

4.2 Data Matching and Data Analytics

As government moves towards more collaborative and integrated planning, management and delivery of services and programs, the Department of Health and Wellness may participate in activities, such as data analytics, which could include matching or linking personal health information (in its custody or control or from other custodians) and data sets from other government departments, such as Education, Community Services, and Justice.

Data analytics is not defined in PHIA, but involves using specialized systems, techniques and processes to examine data sets and draw conclusions about the information they contain, according to organizational requirements. Data analytics is typically used to enable organizations to make informed business decisions based on this information.

Section 52(a) of PHIA defines data matching to mean the creation of individual identifying health information by combining individual identifying or non-identifying health information from two or more databases without the consent of the individuals who are the subjects of the information.

Data linkage is defined in section 2(1) of the regulations to mean the bringing together of two or more records of personal health information to form a composite record.

Section 52(c) defines research as a systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research.

Section 53 states that planning and management of the health system does not constitute research for the purpose of the Act. Planning and management of the health system is defined in section 3(s) as the analysis of information with respect to:

- the management, evaluation or monitoring of,
- the allocation of resources to, or
- planning for all or part of the health system, including delivery of services.

Under section 35 of PHIA, a custodian (including the Department of Health and Wellness) may use personal health information without the individual's consent for planning or delivering programs or services that the custodian provides or funds, allocating resources to them and evaluating or monitoring them. A custodian is also permitted to use personal health information without consent to conduct research if the requirements of section 52 to 60 are met.

Under section 38 of PHIA, the Minister of the Department of Health and Wellness is permitted to disclose personal health information without the individual's consent for the purpose of planning and management of the health system.

Discussion Paper Questions

Q32 Are the definitions of data matching and data linkage clear?

Q33 Are existing PHIA safeguards sufficient for use and disclosure of personal health information for purposes such as planning and management of health system, when the Department of Health and Wellness is matching data sets of personal health information with data sets from other government departments? If not, should there be specific safeguards for these uses and disclosures similar to the ones for research?

Q34 How should external data (i.e. other departments) linked to personal health information be managed and protected? Once linked, is all data considered personal health information?

Q35 What legislation should govern these matched data sets? PHIA and/or FOIPOP?

4.2.1 Discussion & Findings

Stakeholders provided a range of feedback on the question of whether the definitions of data matching and data linkage were clear. Some stakeholders indicated the definitions were clear. However, a majority of stakeholders found the definitions themselves unclear or confusing or they were uncertain about the purposes and contexts for applying the definitions of data matching and data linkage. For example, one stakeholder provided the following comments:

> No they are not clear. Were data matching and data linking meant to be different, or the same things? The reference to data matching is in the Research Section of the Act itself. Matched data (about an individual) results from combining data from two or more databases without consent. The original data may be identifying or non-identifying but, once combined, it identifies an individual. Data linkage results from combining two or more records containing PHI [personal health information] to form a composite record. Data linkage is in the regulations, not in PHIA, and there is no mention of consent. The phrase composite record implies to me that the intent is for health monitoring/ provision of care to an individual rather than for another purpose such as research, educating providers, planning & management, etc. Data matching is for research purposes.
>
> Is the distinction between data matching and data linkage meant to reflect the purpose for combining information, the source of the information (database vs. record), the amount of the information (a dataset or database vs. a single patient record) or all of the above? Although a database would probably not be used to augment a personal health record, a personal health record might be used for research purposes, or a portion of the record might be. The most common occurrence in my experience is a chart review to add details that are not in a database.

Another stakeholder provided the opinion that the definitions were clear but that PHIA does not sufficiently reflect their planned application, noting that data matching defined in section 52 of PHIA is specific to research, which does not include planning and management of the health system, while data linkage is defined in the PHIA regulations. This stakeholder indicated that the subsequent questions on data matching and linkage are related to ways in which the Department of Health and Wellness can link and match data to plan and manage the health system, as well as how it can link and match its own data with that of other public bodies to provide public services.

One stakeholder indicated that data analytics is not research and should be incorporated into the concept of planning and management. In this context, "sharing" of data should be permitted as long as safeguards are in place.

On the question of whether existing PHIA safeguards are sufficient for use and disclosure of personal health information for planning and managing the health system, including matching data sets of personal health information with data sets from other departments, several stakeholders felt the existing safeguards were sufficient. However, some stakeholders provided the opinion that additional safeguards were required. One stakeholder noted the following:

> The safeguards outlined for research could be helpful for planning & management uses but some adjustment would be required. For example, it might be necessary to maintain and add to a matched dataset with no endpoint, whereas a research data set has a specific time frame attached (which might be quite long, I realize). The important features would be some form of review of the purpose for matching data, very careful scrutiny of the technical aspects for matching and some principles for use of the matched data (e.g. used in the least identifying way possible). If databases with different custodian are matched, how is custodianship of the matched data determined?

Another stakeholder provided the opinion that the existing safeguards are insufficient and gave specific examples of potential additional safeguards, as follows:

> No. The sorts of data linking proposed by questions 33, 34 and 35 create significant risks to Nova Scotians' privacy. They need to be approached with an abundance of caution. A critical first step would be significant amendments to rationalize our confusing and outdated network of privacy laws. And while the privacy management framework prescribed by PHIA is superior to that of FOIPOP/MGA, it is still well short of the

> kind of robust, modern, and efficient protections needed for this level of data matching. Mandatory privacy impact assessments, information sharing agreements, review of those documents by the Commissioner, and meaningful and effective breach notification are all critical components of a privacy management framework that enables data matching and data linking in a privacy protective manner. At a minimum, PHIA needs to be amended to require these practices. In addition to review by the Commissioner for privacy considerations, big data analytics of Nova Scotians' personal information and personal health information needs to be subject to review by ethical and human rights experts.

Stakeholders were asked how external data linked to personal health information should be managed and protected, and whether all this data, once linked, should be considered personal health information. On this question, most stakeholders responded that once external data is linked to personal health information, it should be considered to be personal health information. Some stakeholders disagreed and provided the feedback that there should be a way to separate out the personal health information from the non-personal health information. Another stakeholder indicated that privacy best practice is not to leave the data linked. According to this stakeholder:

> No, all data should not be considered personal health information once linked. Privacy best practices for linkages like these are to not leave the data linked. Once appropriate privacy protections are in place, the datasets may be provided by the public body that holds them. The data can be linked in the database and the analysis extracted, and then the involved datasets separated again. Although the linking in the new database may lead to individuals being identifiable, the analysis that is produced must not identify individuals. Performing this kind of analysis by combining provincial government datasets requires either new stand-alone legislation to create a big data institute or substantial amendment to the privacy management framework of PHIA and FOIPOP/MGA.

In response to the question about whether PHIA or FOIPOP should govern these matched data sets, stakeholders provided a mix of responses. Some stakeholders responded that PHIA should govern these data sets. Other stakeholders indicated that the governance of the data should depend on who supplied it, or the purpose for the matched data set (whether for health care or not). Several stakeholders noted that both PHIA and FOIPOP should govern these data sets. One stakeholder provided the following recommendations related to the questions on data matching and linking, as follows:

> In summary then, I recommend the creation of a principled-based legislation governing data linking and big data analytics which could include five core safeguards: (1) creation of a data institute or institutes with expertise in privacy, human rights and ethical issues involved in data integration and analytics; (2) requirement for data minimization; (3) mandatory privacy impact assessments and threat risk assessments; (4) mandatory breach notification and reporting to the IPC and the affected individuals; and (5) order-making and audit powers for the Information and Privacy Commissioner.

An environmental scan of some of the health information legislation in other Canadian jurisdictions revealed that Ontario uses the term data linking in relation to the activities of an approved health data institute but does not define it. New Brunswick uses a similar definition of data matching as PHIA but does not mention consent and indicates that data matching can occur if the custodian has the authority. Manitoba permits data linking under the functions of a health privacy committee but does not define the term. Newfoundland and Labrador permits a custodian to disclose personal health information to a researcher, subject to a number of requirements, including that any record linkage is not harmful to the individuals that the information is about and the benefits to be derived from the record linkage are clearly in the public interest. Alberta's Health Information Act contains a similar definition of data matching as the one in PHIA. In addition, Alberta's Act contains a number of provisions related to data matching, including the following:

27(1) A custodian may use individually identifying health information in its custody or under its control for the following purposes:

(d) conducting research or performing data matching or other services to facilitate another person's research

(i) if the custodian or researcher has submitted a proposal to a research ethics board in accordance with section 49,

(ii) if the research ethics board is satisfied as to the matters referred to in section 50(1)(b),

(iii) if the custodian or researcher has complied with or undertaken to comply with the conditions, if any, suggested by the research ethics board, and

(iv) where the research ethics board recommends that consents should be obtained from the individuals who are the subjects of the health information to be used in the research, if those consents have been obtained;

32(1) A custodian may disclose non identifying health information for any purpose.

(2) If a disclosure under subsection (1) is to a person that is not a custodian, the custodian must inform the person that the person must notify the Commissioner of an intention to use the information for data matching before performing the data matching.

Prohibition

68 A custodian or health information repository must not

(a) collect the health information to be used in data matching, or

(b) use or disclose the health information to be used in data matching or created through data matching in contravention of this Act.

Data matching by custodian or health information repository

69 A custodian or health information repository may perform data matching using information that is in its custody or under its control.

Data matching by custodians or health information repository

70(1) A custodian or health information repository may perform data matching by combining information that is in its custody or under its control with information that is in the custody or under the control of another custodian or health information repository.

(2) Before performing data matching under this section, the custodian or health information repository in whose custody and control the information that is created through data matching will be stored must prepare a privacy impact assessment and submit the assessment to the Commissioner for review and comment.

(3) A privacy impact assessment referred to in subsection (2) must

(a) describe how the information to be used in the data matching is to be collected, and

(b) set out how the information that is created through data matching is to be used or disclosed.

Data matching by custodian or health information repository and non custodian

71(1) A custodian or health information repository may perform data matching by combining information that is in its custody or under its control with information that is in the custody or under the control of a person that is not a custodian or health information repository.

(2) Before performing data matching under this section, the custodian or health information repository must prepare a privacy impact assessment and submit the assessment to the Commissioner for review and comment.

(3) A privacy impact assessment referred to in subsection (2) must meet the requirements of section 70(3).

Data matching for research

72 If data matching is performed for the purpose of conducting research, sections 48 to 56 must be complied with before the data matching is performed.

British Columbia has enacted an E-Health (Personal Health Information Access and Protection of Privacy) Act to govern health information banks (databases that meet the requirements of the Act).

The privacy concerns expressed by stakeholders related to data matching, data linking, and the use of this information by the Department for planning and management of the health system or other public services indicate that this is an area that warrants ongoing attention. Other jurisdictions have taken various approaches to data matching and linking, from including requirements for Commissioner review and privacy impact assessments in their health information legislation, to developing new legislation to govern health information databases. The findings support that the Digital Health Privacy Working Group conduct further investigation and consultation on this topic and provide recommendations for addressing stakeholder concerns about the appropriate collection,

use and disclosure of personal health information in data matching and linking for research, and planning and management purposes.

4.3 Genetic Information

Genetic information is a type of information obtained from biological materials, such as DNA in blood or tissue, and from family histories. Genetic information may be used to predict an individual's risk of developing a disease or other health disorder. PHIA does not address genetic information or biological materials, other than generally through the definition of personal health information. Personal health information is defined in section 3(r) of PHIA as identifying information about an individual, whether living or deceased (in both recorded and unrecorded forms), if the information:

- relates to the physical or mental health of the individual, including information that consists of the **health history of the individual's family**;
- relates to the application, assessment, eligibility and provision of health to the individual, including the identification of a person as a provider of health care to the individual;
- relates to payments or eligibility for health care in respect of the individual;
- **relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance**;
- is the individual's registration information, including the individual's health-card number; or identifies an individual's substitute decision-maker.

The bolded sections of the definition of personal health information may be read to include genetic information that (a) is part of an individual's family history, and (b) is from donated body parts or substances or is derived from genetic testing or examination of the body parts and substances.

Discussion Paper Question

Q36 Should PHIA be amended to include additional privacy protections for genetic information and/or biological material? If so, what requirements or safeguards should be considered?

4.3.1 Discussion & Findings

Stakeholders had differing viewpoints on whether PHIA should be amended to add privacy protections for information and/or biological material and the content of those requirements. One stakeholder provided the opinion that it was premature to define this in PHIA, given that there is no federal or provincial standard or definition in place to cover genetic information. Other stakeholders felt that PHIA's definition of personal health information already included genetic information and/or biological material and the existing protection was sufficient.

Several stakeholders were concerned about the use of genetic and biological material and recommended that PHIA be amended to specifically address the collection, use and disclosure of information for genetic testing, including requiring time-limited express consent. Another stakeholder group indicated that they consulted specifically with medical genetics providers and shared the following information:

> Genetic information should be subject to the same safeguards as other PHI [personal health information]. Feedback from Genetics Team members indicates that genetic testing and DNA banking using blood or other tissue samples already requires express patient consent to be documented by the ordering health care provider. In our practice, we are required to have documented patient consent to retrieve a tissue sample from another health care facility for use in DNA banking or genetic testing. In providing care to genetics patients, we typically describe to them that their genetic information (including the information they provide about their family history) is part of their PHI and will be treated with the same protections as any other PHI.
>
> Under current typical practice, there does not appear to be a compelling reason to treat genetic information differently than other PHI, however, the information provided in the discussion paper is relatively vague and this issue might be better addressed with more specific discussion with the Maritime Medical Genetics team. It would be very helpful in my view to clarify that genetic information is included as personal health information. Caution should be exercised in putting additional security measures in place around genetic information. Either the fundamental principles of PHIA protect health information sufficiently or they don't. Genetic testing is moving so quickly

> that trying to specifically legislate it in the context of privacy would not work. A 'clarification' that genetic information is PHI and is therefore subject to PHIA protections is sufficient. Any desire to legislate further in regard to genetic testing should be done separately and with full consultation.

One stakeholder who is a medical genetics provider, noted that the definition of personal health information in PHIA includes genetic information. This stakeholder also provided the following information:

> Genomics is becoming an even hotter topic, and with the advent of precision care utilizing genetics and genomics at our doorstep, this needs attention. And clinicians and lab scientists should probably be a part of this conversation.
>
> I think that this is a great opportunity to look at what we are currently doing, what might need improvement from a privacy perspective for now and the future, and to look at the PHIA in relation to the practice of Medical Genetics specifically.
>
> We are a small component of the health care system, but we do work "differently" in many regards to other medical professionals in that our scope of care encompasses "Families" rather than Individuals. The PHIA is great to protect the privacy of an individual, but it may be placing barriers on the medical care of families affected by genetic diseases and this legislation may have an impact on how we can provide optimal care.
>
> This then leads to the issue of expansion of the scope of PHIA in genetics/genetics samples/biochemical samples etc., and I strongly discourage any changes without the people in charge having a discussion and feedback from genetics providers, so that this can be done right and avoid leading us to a place where patient care suffers, and needless administrative barriers are enacted that do not improve patient care.

The health information legislation in Ontario contains the same definition of personal health information as PHIA. The health information legislation of New Brunswick, the Yukon, and Prince Edward Island includes both genetic information and body parts or substances. Newfoundland and Labrador's legislation includes body parts and substances but does not specifically include genetic information in the definition of personal health information. Saskatchewan's legislation includes body parts and substances in the definition of personal health information but does not include genetic information. Manitoba's legislation includes genetic materials in the definition of personal health information but does not include biological material or body parts/substances.

Based on the concerns raised in the stakeholder feedback from both a privacy and a health care perspective and the variations in how this topic is addressed in health information legislation across the country, the findings support further investigation and consultation further investigation and consultation to determine if (a) PHIA should be amended to include genetic information in the definition of personal health information and/or add more safeguards, or (b) the existing provisions of PHIA are sufficient. The consultation should include representatives from the practice of medical genetics to ensure the unique requirements of these providers and their patients are considered.

4.4 Cloud Computing

Cloud computing is a form of internet-based computing that provides shared on-demand access to computer resources (e.g., networks, servers, storage, applications and services) and data. Many organizations are turning to cloud computing to decrease costs associated with having to procure and maintain their own dedicated computer resources and to increase the functionality available to them through the cloud.

Typically, an organization enters into a contract with a cloud service provider for the provision of cloud computing resources. Depending on the cloud service provider and the services and resources that are the subject of the contract, the organization's data may be stored on servers controlled by the service provider in Canada or in another country.

There are a number of areas that an organization should be aware of and ensure are addressed in any contract with a cloud service provider, such as:

- ownership of data by the organization;
- collection, use and disclosure of data for the organization's purposes and not the purposes of the service provider;
- obligations for the service provider to keep the data confidential and limit use and disclosure to those employees who need to know;
- notice of compelled disclosure by the service provider to the organization, if the service provider is legally required to disclose the data;
- subcontracting is not permitted by the service provider without written consent from the organization;

- the provision of appropriate security measures to ensure the security and integrity of the data (e.g., encryption, security controls, patch management, etc);
- return of the data to the organization at termination of the contract;
- the right of the organization to require audits for privacy and security compliance throughout the duration of the contract; and
- the governing law of the contract should be the law where the organization is located.

PHIA does not expressly address the use of cloud computing for electronic information systems containing personal health information. However, for custodians who may be considering the use of cloud computing involving personal health information, the rules set out by PHIA for collection, use, disclosure and retention continue to apply. In addition, the required safeguards in the Act and regulations must be met regardless of whether the personal health information is maintained on a local computer system or in the cloud. It is also important to note that custodians who are public bodies are required to follow the Personal Information International Disclosure Protection Act (PIIDPA), which prohibits access and storage of personal information outside Canada, unless certain requirements are met. This law does not apply to custodians who are not public bodies.

Discussion Paper Question

Q37 Does PHIA and its regulations have sufficient safeguards for the protection of personal health information to address the various technologies involved in collecting, using, disclosing and retaining personal health information, or should it be amended to include specific requirements to protect personal health information in relation to cloud computing?

4.4.1 Discussion & Findings

Several stakeholders provided the feedback that PHIA should be amended to include specific requirements to protect personal health information in relation to cloud-based services. One stakeholder specifically noted the need to protect personal health information held in the cloud from surveillance by foreign powers.

Other stakeholders were of the opinion that PHIA has sufficient safeguards in place for protecting personal health information in relation to the cloud or other technologies. One stakeholder highlighted the need for best practices and contract negotiation to address security safeguards, indicating that many new technologies will emerge over the years to come and therefore PHIA's safeguards should not be specific to cloud computing or other technologies in general. Another stakeholder noted that PHIA does not need to specifically provide safeguards for cloud computing and that for any new technology, a Threat Risk Assessment should be conducted to correctly assess the risks. Other stakeholders commented on the value of technology in research or health care delivery but did not provide feedback as to whether PHIA should be amended to include specific requirements to protect personal health information in relation to cloud-based services or computing.

Health information laws across Canada do not include any requirements to protect personal health information specifically in relation to cloud computing.

The Department agrees that PHIA has sufficient safeguards in place to protect personal health information in relation to cloud-based services or other changing technologies and recommends no change to PHIA or its regulations at this time. As a best practice and to meet the existing requirements for safeguards in PHIA, custodians should include privacy and security clauses in contracts with cloud service providers.

Part 5
Survey Results

5.1 Overview of Results

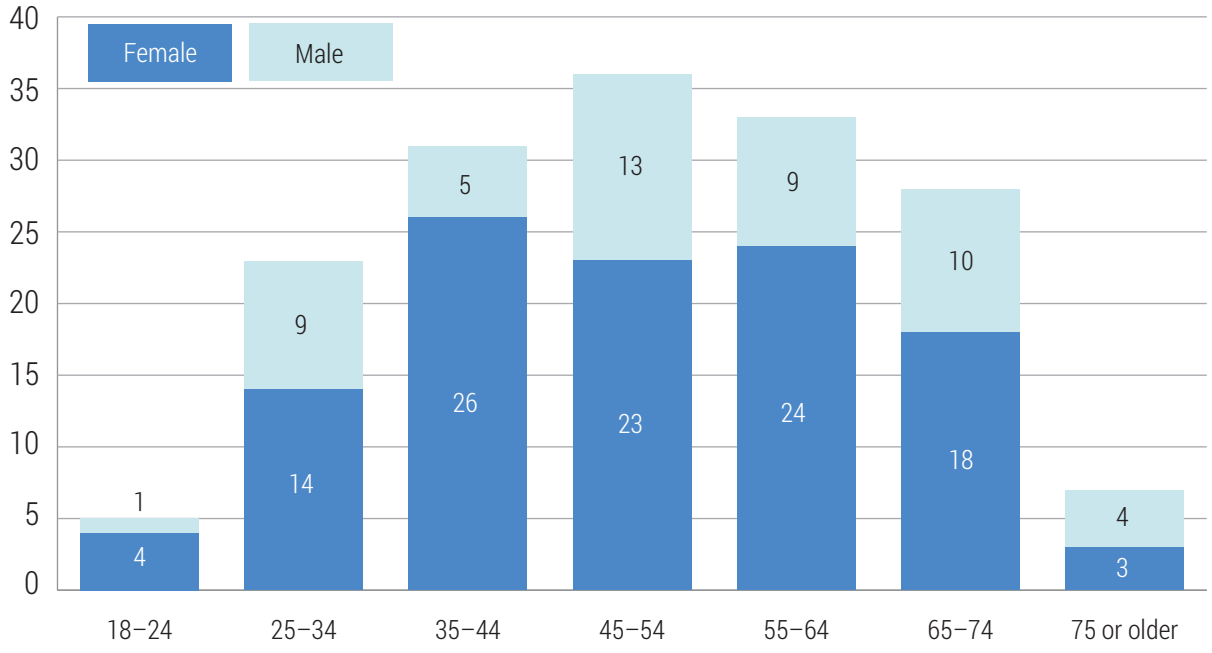
The primary method for obtaining public feedback on PHIA was through an online survey. The survey was made available for a 4-week period during the review and a total of 243 surveys were submitted during this time.

The survey included both closed and open ended questions to allow respondents to provide additional comments on survey questions. There were no mandatory questions, which allowed respondents to respond to the topic areas that were most relevant to their experiences within the health care system. For example, questions relating to the experiences of substitute decision makers would not be relevant to everyone, so respondents were able to skip the questions they did not wish to answer.

5.1.1 Demographic Information

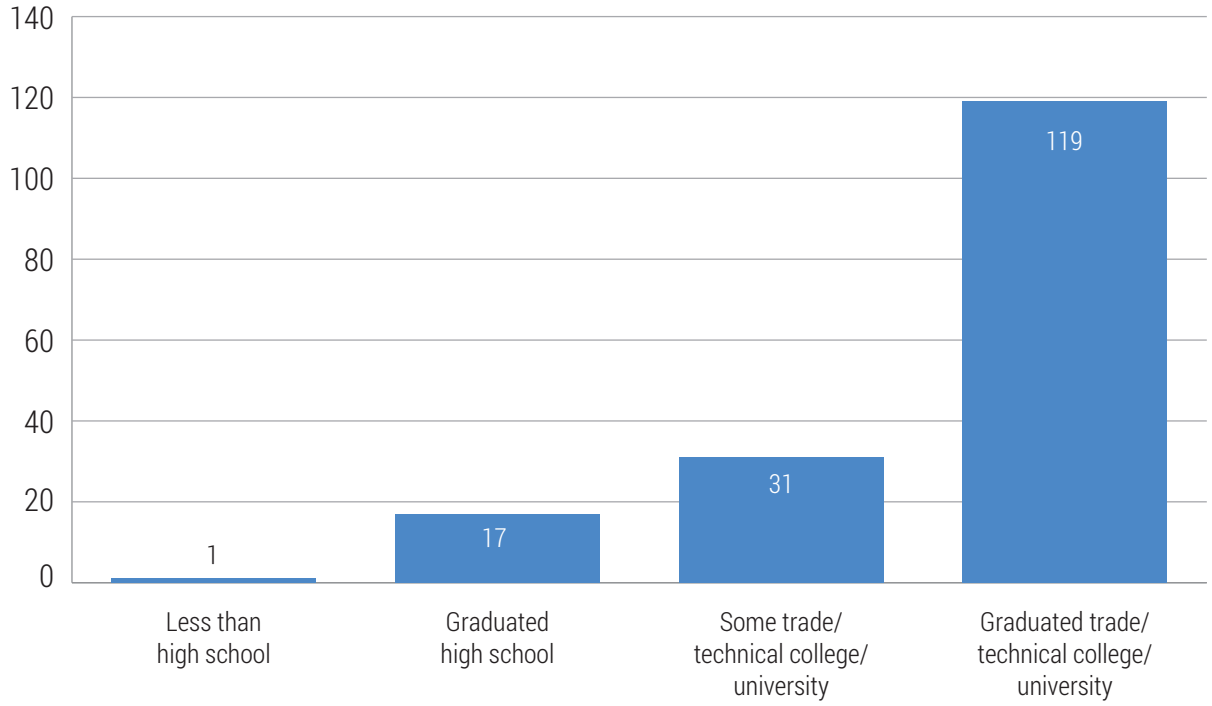
Respondents were asked to provide their age range, gender, and education level in addition to answering the questions within the survey. Based on responses, the following figures show the demographic characteristics for those who responded to the PHIA three-year review survey.

Figure 1: PHIA Survey Responses
Age and Gender



Of the total survey responses, 163 respondents (67%) chose to provide information on their age and gender. Of these, approximately two thirds of respondents were female. Additionally, two thirds of those who provided their age range fell between the ages of 35 and 64.

Figure 2: PHIA Survey Responses
Highest Level of Education



168 respondents, or 69 percent of total survey responses, provided information on the highest level of education they have attained. The graph above shows that that 71% of these respondents had graduated from a trade, technical college, or university. Following this, 18 percent of those who responded have attained some trade, technical college, or university education.

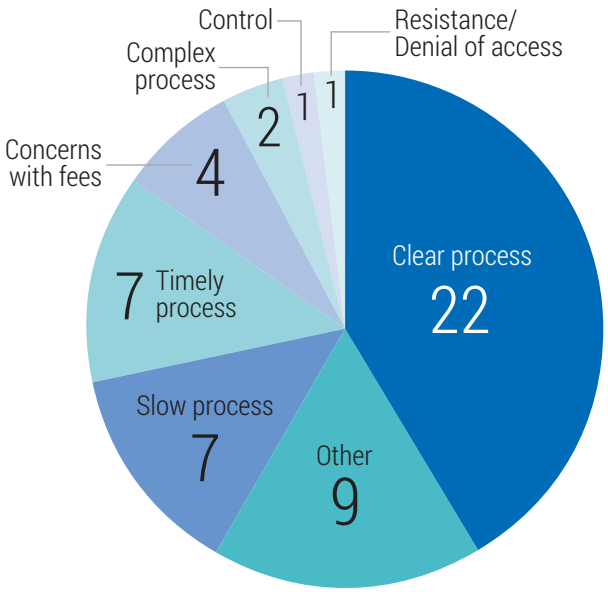
5.1.2 Access to Your Own Personal Health Information

The Personal Health Information Act gives individuals the right to see and have copies of their personal health information such as test results, specialist reports, and hospital and health care professionals' office records. Survey questions in this section sought information on individuals' experiences accessing or requesting copies of their own personal health information.

The survey sought feedback from Nova Scotians who have had to access or request copies of their own personal health information to gain insight on respondents' experiences in terms of satisfaction and process clarity.

A quarter of respondents (N=53) indicated that they have had to access or request copies of their own personal health information. When asked whether they were satisfied with the process of accessing their own personal health information, 71 percent of respondents (N=37) indicated they were satisfied with the process. The following figure depicts the responses received when asked to provide additional information to explain their level of satisfaction with the process.

Figure 3: Level of Satisfaction with Process to Access your Personal Health Information

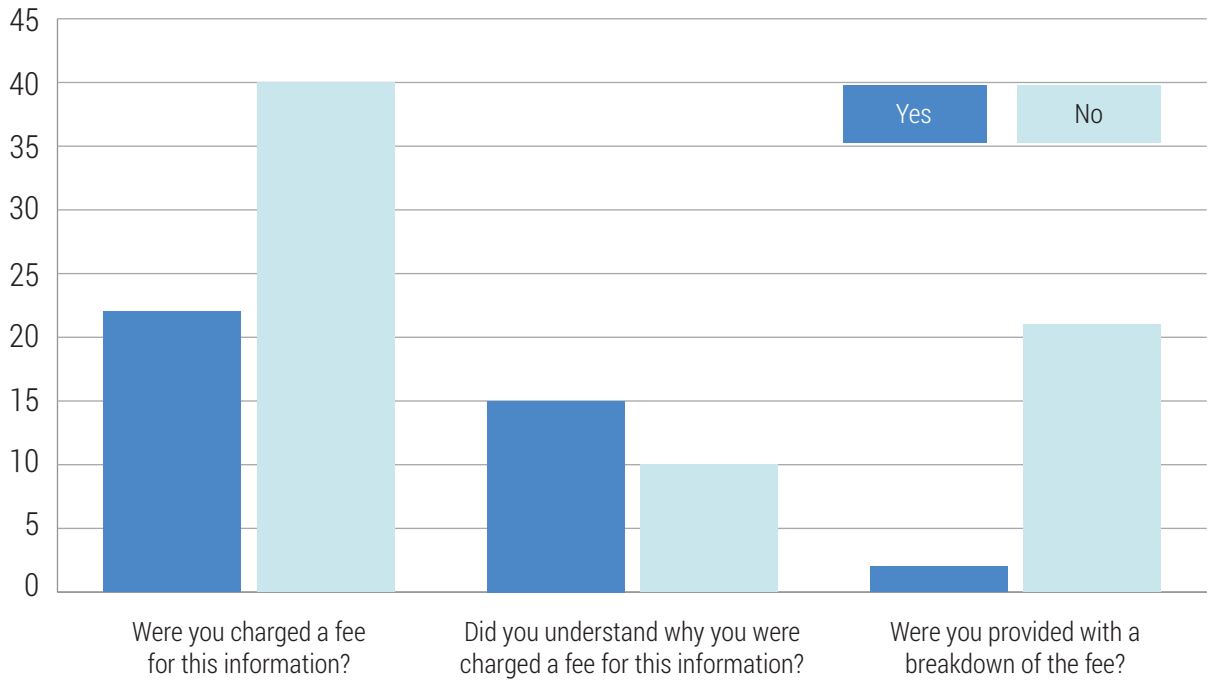


Based on the survey and expressed in the above chart, 42 percent of respondents felt that the process to access or request copies of their own personal health information was clear. 13 percent found the process was timely, and another 13 percent found the process to be slow. Four respondents expressed concerns with the fees associated with these requests, and two respondents indicated they found the process to be overly complicated.

Additionally, 87 percent of respondents indicated that they received all the personal health information they requested.

Under PHIA, doctors can charge an administrative fee to provide personal health information when requested. The maximum fee they can charge is covered under the Act. The following table shows the responses to questions related to fees for these requests.

Figure 4: Fees for Requsting your Personal Health Information



When asked, 35 percent of those who responded indicated that they were charged a fee for their request. For those who had been charged a fee, 60 percent reported that they did understand why they were charged a fee for this information. Only 9 percent of respondents reported that they were provided with a breakdown of the fee.

5.1.3 Access to Personal Health Information for Substitute Decision-Makers

The Personal Health Information Act describes how Substitute Decision Makers can make decisions about individuals' personal health information. A Substitute Decision Maker is needed when an individual is not able to make decisions about their health care and/or information. For example, if an individual has dementia and doesn't understand and remember information to make decisions about their health care and they do not have a Personal Directive, their spouse may be appointed their substitute decision maker. This enables the spouse to be able to bring the individual to their medical appointments and discuss their healthcare with their doctor.

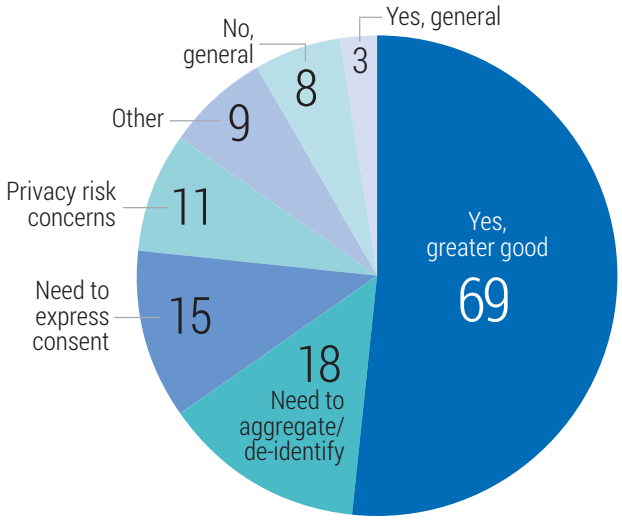
The PHIA three-year review survey sought feedback from Nova Scotians who have been a Substitute Decision Maker for someone and needed personal health information about that person, and to share their experiences doing so. 10 percent of survey respondents (N=16) indicated they had this experience. When asked whether their experience as a Substitute Decision Maker requesting someone's personal health information was satisfactory, two thirds of those who responded (N=11) indicated that the experience was not satisfactory. Only five respondents chose to provide additional written comments on this matter, with two indicating they experienced resistance or denial of their request, and two noting they had concerns with the fees that were charged. Another respondent indicated that the process took a long time.

5.1.4 Sharing Personal Health Information with Researchers

The Personal Health Information Act has rules in place about how personal health information can be used for research purposes in Nova Scotia. However, the Act doesn't cover how, or if, personal health information can be used by researchers in other provinces. The Department of Health and Wellness wanted to hear from Nova Scotians on sharing the personal health information of Nova Scotians with researchers who are located inside or outside of the province, assuming the proper privacy and security measures are in place.

64 percent (N=107) of survey respondents indicated that they think that personal health information should be shared with researchers, providing the proper privacy and security measures are in place. Respondents were invited to provide additional comments to explain their responses to this question. The following chart provides an overview of the 133 comments that were received.

Figure 5: Should Personal Health Information be Shared with Researchers?



52 percent of the comments indicated support for sharing personal health information with researchers based on it being for "the greater good." Many respondents used the phrase "for the greater good," noting that research activities have the potential to improve healthcare knowledge, treatment, and patient outcomes. 14 percent of the comments supported sharing personal health information with researchers under the conditions that the data be de-identified and/or used in an aggregate form. 11 percent of the comments provided called for the use of express consent if personal health information is to be shared with researchers. 8 percent of responses expressed concerns about the potential privacy risks that are associated with sharing personal health information with researchers.

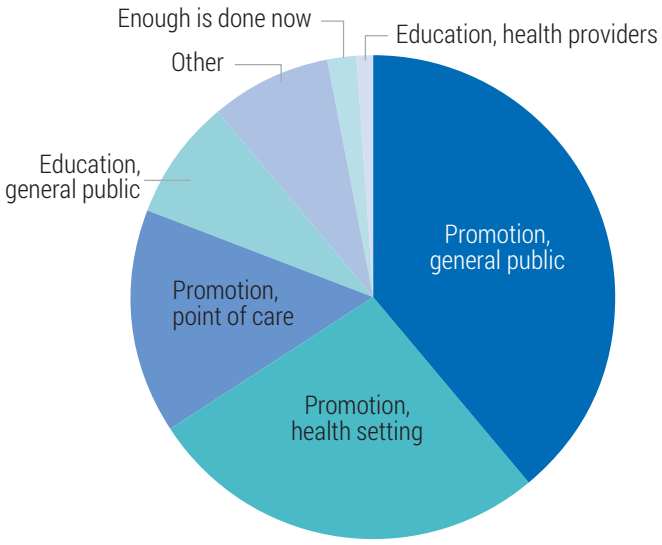
5.1.5 Awareness of Patient Rights Under PHIA

The Personal Health Information Act sets out the rights of patients with respect to:

- accessing their own records;
- controlling who may collect, use and disclose their records;
- making correction to their own records; and
- asking the Privacy Review Officer to review a complaint about privacy, access and correction.

The PHIA three-year review survey asked whether respondents were aware of their patient rights under the Act. Of the 172 responses, 55 percent (N=95) indicated that they were in fact aware of their patient rights under PHIA. A follow up question asked respondents to share their thoughts on what could be done to ensure Nova Scotians are aware of their patient rights under PHIA. The following chart provides a summary of the comments that were received.

Figure 6: How to Ensure Nova Scotians are Aware of their Rights under PHIA (n=127)



Most responses (80 percent) recommended some form of promotional activity to support Nova Scotians being aware of their patient rights under PHIA. Of these, 48 percent suggested that promotion of PHIA to the public would be helpful, such as newspaper and television advertisements that provide information on how Nova Scotians can access their own personal health information. 33 percent suggested that promotion of patient rights should be done primarily within health settings to target individuals who are partaking of health care services. The remaining 19 percent of comments that recommended promotional activities indicated that the promotion of patient rights information should be done at the point of care, where health care practitioners would provide information to patients as a routine part of the delivery of health care.

Approximately 9 percent of comments suggested that education should be provided to help ensure that Nova Scotians are aware of their patient rights under the Act.

Of the 127 responses, three indicated that enough is done in the current state to ensure Nova Scotian's area aware of their patient rights under PHIA.

5.2 Themes and Findings

5.2.1 Themes Emerging from Qualitative Responses

The final section of the survey invited respondents to share any additional feedback or concerns relating to PHIA and/or the management of their personal health information. 64 responses were received, covering a wide range of topics and concerns relating to PHIA and to personal health information. In addition to this, many of the responses received on the open-ended survey questions provided additional comments and questions about PHIA well beyond the specific question topic. As such, the qualitative sections of the PHIA three-year review survey provided a rich source of commentary on the Act within and beyond the topics that the survey specifically addressed.

Online access to personal health information

One theme that emerged from the qualitative responses on accessing one's own personal health information is the desire on the part of Nova Scotians to be able to access their personal health information in an online format. This interest was noted across multiple questions, noting that this format could improve the speed and efficiency of requests for personal health information.

Variation in fees for personal health information requests

Comments about the fees associated with requesting one's own personal health information were also raised across multiple questions within the survey. When taken together, a theme that stands out about these comments is the variation in fees that respondents noted having paid to receive their personal health information, such as:

- *"It cost $50 and was only in black and white."*
- *"He charged me $1.00 per page!"*
- *"$65.00"*
- *"Pay family doctor $2.00 per page of report photocopied."*
- *"There was a $50 fee."*
- *"$20 for a one page printout."*

Alternative access practices

One respondent shared their experience of an alternative method for obtaining a copy of their personal health information to avoid paying the fee. In this case, the individual went to the Emergency Department and obtained copies of their personal health information in a report as part of being seen and treated at the Emergency Department. In addition to this, a small number of survey comments did make note of viewing and/or accessing their personal health information during a formal visit with their health care provider. It was unclear if these visits functioned as a "workaround" to avoid paying a fee for requesting one's own personal health information, and although there is nothing inherently problematic in patients receiving reports or other personal health information from their providers within the context of an office visit, the Department felt it important to note that there may be cases where the means taken to avoid a fee are costlier to the system than waiving a fee.

Lack of Awareness of Patient Rights

The survey results reported that 45% of respondents were unaware of their patient rights under the Act. This data was supported by several comments provided on the open-ended questions that reiterated a lack of awareness of their patient rights under PHIA, and, in some cases, of PHIA itself. One commenter stated:

> *I didn't even know this existed until I saw a request to do this survey.*

Similarly, another respondent shared:

> *I had no idea until I read the question above that I have the right to correct my medical records. How is this done? I didn't even know there was a Privacy Review Officer! A bit of advertising of these services would be lovely.*

5.2.2 Summary Observations

Summary observations based on survey responses:

- In general, survey responses indicate satisfaction with the process for accessing / requesting their personal health information;
- Nova Scotians are interested in accessing their personal health information, particularly with online/electronic options;
- Many Nova Scotians are not aware of their patient rights under PHIA, and some are not aware of the PHIA legislation;

- In general, survey responses indicated willingness to share personal health information with researchers inside and outside Nova Scotia providing the proper privacy and security measures are taken; and
- It is not clear whether the fee schedule within the PHIA regulations is being consistently followed by custodians across the province.

5.2.3 Findings

The findings support a promotional campaign to raise awareness of individual rights under PHIA. This could be part of a number of awareness-building activities undertaken to assist the public and custodians in understanding their rights and responsibilities under PHIA. Other activities could include updating the PHIA toolkit, and communicating about the toolkit and other available resources to promote custodians' understanding of the rules for protecting and managing personal health information.

Part 6
Summary of Findings

This part of the Report summarizes the findings made throughout the document. The findings are grouped according to each of the four types of findings – legislative amendment, further investigation and consultation, awareness building, and no change.

6.1 Legislative Amendment

Topic Area and Sections of Act	Findings
Substitute Decision-Makers Sections 21-23	The findings support amending PHIA to: 1. deem persons who are authorized by law to make treatment decisions to be substitute decision-makers under PHIA, if the collection, use and disclosure is related to the care decision. This would clarify that custodians are permitted to disclose personal health information to a substitute decision-maker authorized by law for the purpose of making a treatment decision. 2. clarify that when an individual is deceased, it is the executor or administrator of the individual's estate who would determine the collection, use or disclosure of the deceased individual's personal health information; and 3. permit substitute decision-makers to exercise any right or power conferred on an individual in circumstances where the substitute decision-maker is authorized to act.
Privacy Breach Reporting Sections 69, 70	The findings support: 4. amendment of PHIA regarding the notification of breaches to (a) include the Commissioner when individuals are notified of breaches with a real risk of significant harm and (b) bring the Act into alignment with requirements in similar legislation across Canada.
Powers of the Privacy Commissioner to disclose personal health information to another Commissioner in the case of investigating or coordinating privacy breaches involving Nova Scotia and at least one other jurisdiction	The findings support: 5. that PHIA be amended to add a provision in section 91(2) to permit the Commissioner to collect and use personal health information needed to participate in a privacy breach investigation that involves Nova Scotia and at least one other jurisdiction.
Recurring Review of PHIA Section 109	The findings support: 6. an amendment to PHIA to require full or partial review of PHIA every five years following the first review, given the anticipated changes in health system information technology to be implemented within the next decade and the unknown impacts this will have on the collection, use, disclosure, storage and retention of personal health information.
Housekeeping items	The findings support: 7. amending section 45, which references a non-existent section 9(2); and 8. amending section 101(1), which refers to itself.

6.2 Further Investigation & Consultation

Topic Area and Sections of Act	Findings
Additional Custodians	The findings support: 9. further investigation and consultation with the Dalhousie Dental School on whether the School should be included as a custodian under PHIA.
Multiple Custodians & Electronic Health Records Sections 3(f), 35(1)(ha), 38(1)(u)	The findings support: 10. establishing a Digital Health Privacy Working Group, chaired by the Department of Health and Wellness, to further investigate this topic, engage in additional stakeholder consultation and develop an approach tailored for Nova Scotia. This approach may result in a range of outcomes, from amending PHIA, to developing a framework, policy and guidelines and/or implementing information sharing agreements, as appropriate.
Prescribed Entity Sections 3(t), 38(2-6)	The findings support: 11. the Digital Health Privacy Working Group assess and clarify the roles of custodians, agents and prescribed entities, in the context of the current approach of supporting digital health privacy through the application of PHIA's privacy and access requirements for custodians and their agents and contractual measures.
Mature Minors and Disclosure without consent for administration of a payment	The findings support: 12. further investigation and consultation on how to (1) determine whether the disclosure is reasonably necessary, and (2) ensure only the minimum necessary personal health information is included in billing information. Custodians and the public would benefit from further guidance on how to apply PHIA's provisions in order to continue to achieve the right balance between the privacy of a mature minor and the disclosure of personal health information for the administration of payment.
Disclosure without consent Section 38	The findings support: 13. further investigation and consultation on circumstances for disclosure without consent that could be appropriately included in PHIA, given that a number of stakeholder suggestions and provisions from other jurisdictions merit further consideration. For any new additions to the disclosures without consent, the privacy implications of permitting disclosure of an individual's personal health information without the individual's consent will need to be considered and addressed in order to achieve the right balance between the individual's privacy and the need to disclose this information in the context of health care.
Disposition of health records	The findings support: 14. the Digital Health Privacy Working Group conduct further investigation and consultation on the disposition of personal health information in health records and outsourcing storage of health records (including storage outside Nova Scotia) and recommend an appropriate approach for Nova Scotia. It will be important to consult with the regulatory bodies of health care professionals as these bodies may have discretionary power to appoint a person to hold, protect and provide access to patient records.
Record of User Activity & Additional Safeguards for Electronic Health Records PHIA Regulations, sections 10-11	The findings support: 15. that the Digital Health Privacy Working Group investigate and conduct further consultation on the record of user activity and additional safeguards for the Electronic Health Record, given the Province's vision and progress toward using electronic health records to improve the delivery of health care to Nova Scotians, the potential gaps in PHIA safeguards and the diverse feedback from stakeholders on these issues.

Topic Area and Sections of Act	Findings
Fees & Exceptions for Access PHIA Regulations, sections 12,16	The findings support: 16. that the Digital Health Privacy Working Group (or a sub-group) be tasked with conducting further investigation and consultation on the topic of fees to determine whether amendment of the regulations as they relate to the exception in section 12(f), record transfers and direct costs in section 16 is appropriate.
One Person One Record)	The findings support: 17. that the Electronic Health Record Working further investigate and consult with stakeholders regarding the privacy and access implications of implementing One Person One Record in Nova Scotia. This work will assist the Department in determining the appropriate approach required to protect the privacy of personal health information in this future system and ensure it is appropriately managed.
Data linking & matching for research and planning & management within government	The findings support: 18. that the Digital Health Privacy Working Group conduct further investigation and consultation and provide findings for addressing stakeholder concerns regarding the appropriate collection, use and disclosure of personal health information in data matching and linking for research, and planning and management purposes.
Genetic information	The findings support: 19. further investigation and consultation to determine if (a) PHIA should be amended to include genetic information in the definition of personal health information and/or add more safeguards, or (b) the existing provisions of PHIA are sufficient. The consultation should include representatives from the practice of medical genetics to ensure the unique requirements of these providers and their patients are considered.

6.3 Awareness Building

Topic Area and Sections of Act	Findings supporting the Health Privacy Awareness-Building Working Group
Additional Custodians Section 3(f)	The findings support: 20. building awareness with the public and custodians about the roles and responsibilities of custodians and agents under PHIA to address misunderstandings about these terms.
Knowledgeable Implied Consent Sections 12-15	The findings support: 21. that the topic of knowledgeable implied consent be addressed through awareness building measures, such as updating the PHIA Toolkit to include additional information and scenarios, and communication with custodians about the use of this information in any guidelines or educational materials that custodians may have previously developed for their agents.
Disclosure outside Nova Scotia Section 44	The findings support: 22. that there be further awareness building for custodians on the topic of disclosure of personal health information outside Nova Scotia for the purpose of providing health care. Further information and illustrative examples could be added to the PHIA Toolkit to assist in clarifying the form of consent required and what would constitute a reasonably necessary disclosure for this purpose.

Topic Area and Sections of Act	Findings supporting the Health Privacy Awareness-Building Working Group
Correction of a record of personal health information Sections 85-89	The findings support: 23. that awareness building activities would be appropriate to address concerns with how to apply the provisions for correction in certain circumstances.
Research Ethics Boards & Research Sections 52(d) and (e), 55-57	The findings support: 24. that the PHIA Toolkit be augmented to provide additional clarity and direction on the above questions and concerns about research ethics boards and PHIA that were raised by stakeholders.
Survey Results	The findings support: 25. a promotional campaign be undertaken to raise awareness of individual rights under PHIA. This could be part of a number of awareness-building activities to assist the public and custodians in understanding their rights and responsibilities under PHIA. Other activities could include updating the PHIA toolkit, and communicating about the toolkit and other available resources to promote the public's and custodians' understanding of the rules for protecting and managing personal health information.

6.4 No Change

Topic Area and Sections of Act	Findings
Purpose, objectives & functioning of the Act Section 2	The findings support: 26. leaving the purpose and objectives of PHIA unchanged and continuing to support these objectives and the effective and appropriate functioning of the Act and regulations, given the broad consensus among stakeholders who provided responses on this topic area.
Limited or Revoked Consent Section 17	The findings support: 27. that there be no change to the notification of limited or revoked consent in PHIA as there is general consensus that these provisions strike the right balance between protecting privacy and providing, managing and supporting health care.
Express consent required for use of personal health information for fund-raising and marketing Section 34	The findings support: 28. that there be no change to section 34 of PHIA, as it strikes the right balance between protecting the privacy of an individual's contact information in their health care record and a custodian's wishes to use this information for fund-raising activities, market research or marketing services for a commercial purpose.
Educating Agents Section 33(c)	The findings support: 29. that section 33(c) of PHIA permitting custodians to use personal health information for educating agents to provide health care should remain unchanged to ensure that custodians are able to provide the appropriate education to their agents to provide health care, while following the privacy protections required by the Act.

Topic Area and Sections of Act	Findings
Disclosure of name and contact information for research requires consent & other research requirements Sections 56, 57	The findings support: 30. that no change to PHIA or sections 56 and 57 is required in relation to disclosure of name and contact information of individuals for research (i.e., this disclosure requires consent) and the PHIA requirements for disclosure of personal health information for research.
Powers of the Commissioner to compel records; use & disclosure provisions for the Office of the Commissioner; immunity for the Commissioner and staff	The findings support: 31. no change to PHIA to add these provisions for these additional powers for the Commissioner. The authority to augment the power of the Commissioner falls under the jurisdiction of the Minister of Justice, who administers the majority of the privacy legislation for Nova Scotia, including the Privacy Review Officer Act, the Freedom of Information and Protection of Privacy Act, and the Personal Information International Disclosure Protection Act. Amending PHIA alone to add these powers for the Commissioner would lead to a misalignment of the powers of the Commissioner between PHIA and the privacy legislation under the administration of the Minister of Justice.
Definition of planning & management of the health system Section 3(s)	The findings support: 32. no changes to the definition of planning and management of the health system at this time.
Definition of record Section 3(v)	The findings support: 33. no change to the definition of record, noting it can be inferred that the existing definition incorporates video, given that it states that the record can be in "any form or in any medium" and includes records in electronic form. Although video is not explicitly listed as one of the mediums, the current definition is flexible enough to allow for video as a form of a record of personal health information.
Multi-jurisdictional Electronic Health Records and information-sharing agreements	The findings support: 34. no change to the provisions of PHIA, in order to preserve the flexibility of custodians to choose the most appropriate approach to protect and manage personal health information in the context of multi-jurisdictional electronic health records. Custodians undertaking the implementation of inter-jurisdictional electronic health records are encouraged to consider information sharing agreements as a best practice, where this approach would be appropriate.
Cloud-computing services & new technologies	The findings support: 35. No change to the provisions of PHIA to add additional safeguards for cloud-based services. PHIA has sufficient safeguards in place to protect personal health information in relation to cloud services or other changing technologies and recommends no change to PHIA or its regulations at this time. As a best practice and to meet the existing requirements for safeguards in PHIA, custodians should include privacy and security clauses in contracts with cloud service providers.

Appendix A
Acknowledgements

The Department of Health and Wellness would like to acknowledge and thank the following individuals for invaluable input into this Report & Findings:

Advisory Committee Members

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Appendix B
List of Stakeholder Groups

The Department sent the Discussion Paper to over 400 stakeholder groups inviting their feedback for the three-year review of PHIA. The following stakeholder groups responded, either in writing or through verbal feedback in meetings or teleconferences:

- Association of Psychologists of Nova Scotia
- Canadian Blood Services
- Canadian Institute of Health Information
- Canadian Medical Protective Association
- Canadian Nurses Protective Society
- Cape Breton County Homemaker Agency and Antigonish Homemaker Service
- College of Licensed Practical Nurses of Nova Scotia and the College of Registered Nurses of Nova Scotia
- Cornerstone Psychological Services
- Doctors Nova Scotia (provided written feedback in addition to their initial submission)
- Family 1st Medical Equipment Supplier
- First Nations
- Guysborough County Home Support Agency
- Health Data Nova Scotia
- IWK (provided written feedback in addition to their initial submission)
- IWK Medical Genetics
- Northwood
- Nova Scotia Department of Education and Early Childhood Development
- Nova Scotia Department of Internal Services Information Access & Privacy Office
- Nova Scotia Department of Justice
- Nova Scotia Health Authority (provided written feedback in addition to their initial submission)
- Office of the Information and Privacy Commissioner of Nova Scotia (provided written feedback in addition to their initial submission)
- Provincial Dental Board of Nova Scotia
- Provincial Programs (including the Nova Scotia Breast Screening Program, Reproductive Care Program of Nova Scotia, Cardiovascular Health Nova Scotia, Diabetes Care Program of Nova Scotia, Nova Scotia Provincial Blood Coordinating Program, Nova Scotia Renal Program, Program of Care for Cancer)
- Shannex Home Healthcare Service

Appendix C
Survey Questions

Access to Your Own Information

1. The Personal Health Information Act gives patients the right to see and have copies of their personal health information such as test results, specialist reports, and hospital and health care professionals' office records (for example, records held by your doctor, dentist, physiotherapist, psychologist or other health care professional).

   a. Since June 2013, when the Personal Health Information Act came into effect, have you had to access or request copies of your own personal health information?

   Yes / No

   If yes, please describe your experience. If no, please go to question #2.

   b. Were you satisfied with the process?

   Yes / No

   If yes, please explain. If no, please explain why not.

   c. Did you get all the information you requested?

   Yes / No

   If no, what reason did your provider give you?

   d. Doctors can charge an administrative fee to provide this information. The maximum fee they can charge is covered under the Personal Health Information Act. Were you charged a fee for this information?

   Yes / No

   If no, please go to question #2.

   e. Did you understand why you were charged a fee for this information?

   Yes / No

   f. Were you provided with a breakdown of the fee?

   Yes / No

Substitute Decision Makers

2. The Personal Health Information Act describes how Substitute Decision Makers can make decisions about your personal health information. A Substitute Decision Maker is used when you are not able to make decisions about your health care and/or information. For example, Mary has dementia and doesn't understand and remember information to make decisions about her health care. Mary's husband Joe, as her substitute decision maker, can bring her to medical appointments and discuss Mary's health care with her doctor.

   a. Are you, or have you been, a Substitute Decision Maker for someone and needed personal health information about that person?

   Yes / No

   If yes, please describe your experiences. If no, please go to question #3.

   b. As a substitute decision maker who needed to access personal health information about a person under your care, was your experience satisfactory?

   Yes / No

   If yes, please explain. If no, please explain why not.

Research

3. The Personal Health Information Act has rules in place about how personal health information can be used for research purposes in Nova Scotia. However, the Act doesn't cover how, or if, personal health information can be used by researchers in other provinces. a. If the proper privacy and security measures are in place, do you think the personal health information of Nova Scotians should be shared with researchers who are located out of the province (or in the province)?

   Yes / No

   If yes, please explain? If no, explain why not?

Patient Rights

4. The Personal Health Information Act (novascotia.ca/dhw/phia/ PHIA-legislation.asp) sets out the rights of patients with respect to:

   - accessing their own records
   - controlling who may collect, use and disclose their records
   - making correction to their own records
   - asking the Privacy Review Officer to review a complaint about privacy, access and correction

   a. Are you aware of your patient rights under the Personal Health Information Act?

   Yes / No

   If yes, go to question 5.

   b. What do you think can be done to make sure you, and other Nova Scotians, know about their patient rights under the Act?

Additional Information

5. Do you have additional feedback that you would like to share? We ask that you do **not** provide us with any of your detailed medical or personal health information in your response.

Demographic Information

These final questions will help us analyze the survey results. As with all answers you have provided, your responses will be kept strictly confidential.

Please tell us your gender:

- Male
- Female
- Prefer not to say

Which category best describes your age?

- 17 or under
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older
- Prefer not to say

Which of the following categories best represents the highest level of education you have completed?

- Less than high school
- Graduated high school
- Some trade/technical college/university
- Graduated trade/technical college/university
- Prefer not to say

Appendix D
Definitions from PHIA

Term	Definitions from PHIA
Agent	In relation to a custodian, means a person who, 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 and includes, but is not limited to, an employee of a custodian or a volunteer who deals with personal health information, a custodian's insurer, a lawyer retained by the custodian's insurer or a liability protection provider.:
Custodian	Means an individual or organization described below who has custody or control of personal health information as a result of or in connection with performing the person's or organization's powers or duties: • A regulated health professional or a person who operates a group practice of regulated health professionals, • The Minister of Health and Wellness; • A district health authority under the Health Authorities Act; • The IWK Health Centre; • The Review Board under the Involuntary Psychiatric Treatment Act, • A pharmacy licensed under the Pharmacy Act; • A continuing care facility licensed by the Minister under the Homes for Special Care Act or a continuing care facility approved by the Minister; • Canadian Blood Services; • Any other individual or organization or class of individual or class of organizations as prescribed by regulation as a custodian. Note: this now include the Nova Scotia Hearing and Speech Centres, home care agencies approved by the Department and that have a service agreements with a district health authority or the IWK, and home oxygen agencies approved by the Department that have a service agreement with the Department.
Personal health information	Identifying information about an individual, whether living or deceased (in both recorded and unrecorded forms), if the information: • relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family; • relates to the application, assessment, eligibility and provision of health to the individual, including the identification of a person as a provider of health care to the individual; • relates to payments or eligibility for health care in respect of the individual; • relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance; • is the individual's registration information, including the individual's health-card number; or identifies an individual's substitute decision-maker.
Planning and management of the health system	The analysis of information with respect to: • the management, evaluation or monitoring of • the allocation of resources to, or • planning for all or part of the health system, including the delivery of services.

Term	Definition
Regulated health professional	A health professional who is licensed or registered to provide health care under an Act of the Province specific to his or her profession and who provides health care or who is a member of a class of persona prescribed as regulated health professionals.
Prescribed entity	This term is not defined in PHIA. According to the PHIA toolkit developed by the Department of Health and Wellness and available on their website, a prescribed entity may be an organization that is not a custodian but participates in the planning and management of the health system, working with and supplementing the work of the Department of Health and Wellness.

Appendix E

Links to Supporting Materials

PHIA legislation and regulations: **http://novascotia.ca/dhw/phia/PHIA-legislation.asp**

PHIA Toolkit: **http://novascotia.ca/dhw/phia/custodians.asp**

PHIA information for the public: **http://novascotia.ca/dhw/phia/public.asp**


NOVA SCOTIA