OFFICE OF THE INFORMATION
AND PRIVACY COMMISSIONER
NEWFOUNDLAND AND LABRADOR

Supplementary Submission of the Office of the Information and Privacy Commissioner to the *Personal Health Information Act* Review Committee

March 8, 2017

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Dr. David Morgan
Chair
PHIA Review Committee

Dear Dr. Morgan:

I am pleased to provide you and the Committee with a supplementary submission from the Office of the Information and Privacy Commissioner in response to the Round 3 process of the statutory review of the *Personal Health Information Act*. As with our initial submission, it was drafted by Sean Murray with input from other staff in the Office. Once again, please do not hesitate to reach out to Mr. Murray should you or the Committee members require clarification on any items discussed in this submission or if you would like us to consider and provide further comments on any aspect of *PHIA*.

Yours truly,

Donovan Molloy, Q.C.
Information and Privacy Commissioner

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Introduction

According to the guidelines on the web site of the *PHIA* Review Committee, this opportunity to provide a supplementary submission allows stakeholders to respond to submissions made by others in the first round of the process. We will therefore proceed to list all of the submissions which were made in the first round and provide any comments we have in response to these submissions.

Workplace NL

We agree with the points brought forward in the Workplace NL submission.

College of Massage Therapists (CMT)

The CMT provided a brief submission, raising three points. The first is that "the definition of custodian does not specify if an RMT is self-employed who is the designated custodian." In our view, *PHIA* is clear on this point. A self-employed Registered Massage Therapist (RMT) is a custodian by virtue of section 4(1)(e) combined with the definition of "health care professional" in section 2(1)(j)(viii).

The second point raised by CMT is more complex, and a practical one. It refers to the lack of clarity regarding custodianship in a multi-disciplinary practice involving multiple health professions. CMT states that *PHIA* provides no clear direction as to custodianship in such situations. This can become a particularly vexing question where patients are seeing more than one professional in the practice. In our initial submission to the *PHIA* Review Committee we referenced the fact that *PHIA* does not address group practices. We realize that it is possible for health professionals to determine the roles and relationships among health professionals regarding *PHIA* through agreements when setting up a practice. In our experience, this does not always occur, and the issue only comes to a head when accountability for information needs to be determined due to a breach or when one of the professionals wishes to leave the practice. At that point, when these issues were never considered in the past, it can be very difficult to sort things out. One perspective would be that it is up to custodians to understand and apply the law, and leave it at that. The problem, however, is that interpreting and applying *PHIA* can be difficult, and unless custodians are given clearer legislative provisions to follow, ultimately it may be patients who suffer when there is a failure to establish clear accountability. It would be helpful if the Committee could consider a better approach to defining custodianship which considers the different ways that health professionals set up their practices.

The third point raised by CMT is also worthy of consideration. There are circumstances in which the owner of a business which either employs health care professionals or rents space and provides facilities and amenities for health care professionals has asserted control over health records. *PHIA* does not allow a business owner who is not providing health care to patients to be the custodian. Rather it is the health professional who is the custodian, unless the operation falls within the unnecessarily vague and often misunderstood category in section 4(1)(g)(iv).

It is not always clear to CMT whether records of personal health information must stay with the business when an RMT departs, to potentially be passed onto another RMT who may come in as a replacement, or whether the RMT may take the information when he or she leaves, and thus

continue to be the custodian. Furthermore, the records involved might also be records relied upon by other custodians in the same location, such as chiropractors, physiotherapists, etc. As with the second question raised by CMT, if sufficient effort is put into establishing appropriate agreements up front, these questions can be managed within *PHIA* as it now stands, however this solution does not often reflect the practical realities encountered by CMT, and again it would be helpful if the Committee would consider whether an amendment to provide greater clarity might be feasible. Such an amendment might perhaps consider whether the definition of "custodian" should include "a person who operates a group practice of health care professionals". Any such amendment should be undertaken bearing in mind the different operational arrangements in common use, ranging from situations where a health care professional is simply renting space in a building with other health care professionals, to situations where a business owner has hired health care professionals to work as employees, as well as other contractual arrangements. The outcome should be such that health care professionals and business owners enjoy greater clarity and encounter fewer difficulties determining who is intended by *PHIA* to serve as custodian.

Eastern Health (EH)

Eastern Health covered many topics in its submission, including the oath or affirmation. While we recognize the difficulties associated with an oath or affirmation for certain contractors, further consideration of this subject by the Committee may determine the most appropriate solution, or if any change is warranted at all. Further to EH's comments, we are also of the view that the contents of the oath should be specified by regulation, and that the elements of the oath should reflect the language in the offence provision. Whether through policy or legislation, we would add the proposal that a new oath be required at specific intervals (perhaps every three years) and whenever an employee changes position.

In part C.3.1 of EH's submission, there is a request for greater clarity as to the custodianship of information held in Meditech which was placed there by a physician who is also a custodian in his or her own right. It would seem that the physician should be considered the custodian, but of course it is EH which maintains the security of the system, and it is not possible for the physician to change it. Is EH then an information manager for the physician? These are important considerations when faced with questions as to whether EH or the physician has the right to make or is responsible for disclosures to researchers and others as permitted or required by *PHIA*. It is unclear whether this matter can be or should be resolved through written agreement between EH and physicians at the time access to Meditech is granted, or whether a legislative amendment is required. Further consideration of this issue by the Committee is warranted.

In part C.3.2 EH says that the definition of custodian must include those faculties and schools of post-secondary institutions which are involved in health research. This not only supports our position on the matter of ensuring that the parts of Memorial University which are currently custodians remain so, but opens the door for broadening the definition as well.

In part C.3.3, EH proposes that a separate category of custodianship which contains fewer disclosure provisions but many of the responsibilities of full custodianship be considered for private companies that are involved in the collection, use or disclosure of personal health information. Fundamentally this is the same issue that the OIPC and others have identified in terms of the problems associated with custodians disclosing personal health information to non-custodians,

usually in a research context, although there may be other contexts in the experience of EH. We don't explicitly endorse the proposed solution, but we recognize the concern. We have proposed a particular approach as have others, but the important thing is that the Committee is aware of this concern and that it make recommendations to remedy it.

In part C.6 EH expresses a need for a more prescriptive approach to fees. The recently revised, current policy regarding fees adopted by all RHAs seems fair and reasonable. It is not clear, however, whether this same policy is a good fit for all custodians. The OIPC released Report AH-2012-001 on the subject in 2012. One newer issue which has emerged, however, relates to individual custodians who retire or cease to practice who contract with an out-of-province storage company to retain all the custodian's health records. We understand that the fees charged to patients for access by these companies can be excessive. Furthermore, if the practitioner remains a registered health professional in this province, the arrangement with the storage company would be an information manager arrangement. However, once the individual ceases to practice, or moves to another province or country, it is unclear whether the status of custodian still applies, and therefore whether there is any longer a valid information manager agreement, which requires a custodian to maintain such an agreement. We are hearing more and more of custodians utilizing the services of such companies, and it would be of great benefit to the public if *PHIA* would address this situation and ensure reasonable, affordable access to health records.

In part C.7 EH says that the 14 day time period for a custodian to produce a record to the Commissioner can be too restrictive. Section 24 of *ATIPPA, 2015* allows the Commissioner to consider extraordinary circumstances and to vary a time period under the *Act*. Perhaps a provision such as this may assist. A further point made by EH is that *PHIA* does not specify business versus calendar days. Central Health also raises this point. We have not seen this as a significant concern, however we do not oppose inclusion of a definition of "day" in *PHIA* as calendar days. Use of the "business day" approach can be confusing when the the definition of "holiday" in section 27(1)(l) of the *Interpretation Act* compares to the actual days when a custodian may be closed due to a recognized holiday. Furthermore, some custodians may routinely be open when a holiday as defined in the *Interpretation Act* occurs. This is compounded by the fact that some custodians operate in the private sector while others operate in the public sector, with variability between the recognized holidays. Again, we do not recommend a move to "business days" for *PHIA*, however if it would be helpful to custodians experiencing uncertainty, the term "day" in *PHIA* can be defined as calendar days.

In part C.8 EH recommends that there be a change in procedure specified in *PHIA*. Currently the custodian is required to notify the complainant of the custodian's decision in response to a recommendation in a Commissioner's Report. EH says that the complaint has been made to the Commissioner rather than the custodian, so the Commissioner should forward the custodian's response to the complainant. We have not heard of this being a significant issue in the past. It should be noted that the original complaint, which typically includes the complainant's address and other contact information, is required to be provided to the custodian by the Commissioner in accordance with section 66(5). If a circumstance were encountered by a custodian where there were difficulties in providing a response to a complainant, the Commissioner would be willing to assist where possible. We do not believe an amendment is warranted, and furthermore, any such amendment would be a break from the long established practice under *ATIPPA, 2015* which is common in other privacy statutes in Canada.

Labrador-Grenfell Health (LG)

LG proposes a definition of the term "spouse". We agree that this would be helpful. LG also proposes that Regional Health Authorities (RHAs) be explicitly listed in section 24(2) for clarity. LG says that they believe RHAs are included because a health authority is a "person" in section 4(g) who operates a health care facility, however LG says that section 24(2) should be made explicitly clear to avoid confusion. The OIPC supports this recommendation, as it is important that *PHIA* be made as user-friendly as possible.

LG proposes greater clarity around the terms material breach, students, and deceased individuals, all of which we have addressed elsewhere. LG has also proposed that the terms "representative" and "personal representative" be clarified, which we support.

LG also requests clarification of the term "minor", found in section 7(d). Central Health also makes a similar proposal. The current provision involves an assessment by the custodian as to whether the minor understands the nature of the right or power granted to him or her under *PHIA* and the consequences of exercising that right. LG proposes that a strict definition of the term "minor" be adopted, similar to the *Advance Health Care Directives Act*, in which a directive is presumed not valid if it is made by a person under the age of 16 and is presumed valid if the person is over 16. LG also references the *Children and Youth Care and Protection Act*, which defines a youth as a person between the ages of 16 and 18 and child as a person actually or apparently under the age of 16.

With no specific definition of "minor" in *PHIA*, the *Age of Majority Act* applies, which says that persons under the age of 19 are minors. For those patients, the custodian is required to make a determination as to what rights and powers of *PHIA* are available to the minor based on the circumstances, including the particular information and the capacity of the patient to understand it and the consequences of a decision he or she might make. The problem with the approach offered by LG is that it does not account for the ability of the individual or the context. Certain information may be able to be shared with a young patient, but other information may not because of its complexity and the capacity of the young person.

One of the issues which has been considered and discussed in significant depth at the Canada Health Infoway Privacy Forum is the age at which minors should be given access to their own personal health information through emerging technology often referred to as a patient portal. Significant research has been conducted on this subject, and it is important that we attempt to adopt an approach that considers new advances in the ways that patients interact with their own personal health information, such as patient portals, which could provide significant clinical value to all patients, including minors, depending on the circumstances. This may prove to be a valuable consideration in a Province with a large rural population and service delivery challenges.

Given the time available to prepare this submission, rather than repeat or try to summarize all of the research that has been conducted, several links are provided below to research papers, presentations and reports available on the Canada Health Infoway web site. These reports are quite recent and should be considered with some confidence to be among the latest work done on the subject in Canada. Canada Health Infoway provided permission for me to include links to these resources found on its web site, but has asked that the documents themselves not be republished on another web site or in other formats. We thank LG for raising this issue, and propose to the Committee that it be the subject of greater in-depth study.

https://www.infoway-inforoute.ca/en/what-we-do/blog/consumer-health/7233-what-canadians-think-about-adolescents-accessing-their-electronic-personal-health-information

https://www.infoway-inforoute.ca/en/what-we-do/blog/consumer-health/7195-adolescent-access-to-digital-health-records-results-of-an-environmental-scan

https://www.infoway-inforoute.ca/en/component/edocman/webinars-en/3130-webinar-pandora-s-box-is-open-mature-minors-access-to-their-health-information?Itemid=101

https://www.infoway-inforoute.ca/en/component/edocman/resources/reports/3118-pandora-s-box-adolescent-access-to-digital-health-records-research-summary?Itemid=101

https://www.infoway-inforoute.ca/en/component/edocman/resources/3088-adolescent-e-access-research-final-report?Itemid=101
https://www.infoway-inforoute.ca/en/component/edocman/resources/3087-provisions-relating-to-minors-in-provincial-and-territorial-health-information-privacy-and-health-care-consent-statutes?Itemid=101

https://www.infoway-inforoute.ca/en/component/edocman/resources/3085-environmental-scan-statutory-provisions-relating-to-rights-of-minors-summary-table?Itemid=101

https://www.infoway-inforoute.ca/en/component/edocman/resources/3083-environmental-scan-statutory-provisions-relating-to-rights-of-minors?Itemid=101

https://www.infoway-inforoute.ca/en/component/edocman/resources/3081-environmental-scan-processes-to-enable-adolescent-access-to-personal-health-records?Itemid=101

Newfoundland and Labrador Association of Social Workers (NLASW)

NLASW filed a brief submission which identifies several topics of interest, some of which we have addressed elsewhere. One of the recommendations of NLASW is that "ongoing education pertaining to *PHIA* through the privacy office is recommended." It is unclear if this is meant to refer to the Commissioner or the privacy office at the Department of Health and Community Services. Speaking for the Commissioner's Office, we are ready at the invitation of any professional body, custodian or group of custodians to address any particular topic, or to work with them to assist in the delivery of education on a broad array of topics related to *PHIA*.

It must be observed, however, that section 14(2) places this onus on custodians to a large degree. While the Commissioner has a specific duty to inform the public about the *Act* in accordance with section 79, and it is agreed that this is something we need to pursue with greater vigor, there is a reason why custodians must take on their own education role as required by *PHIA*. Essentially, *PHIA* relies to a significant degree on the requirement that custodians develop their own policies and procedures in compliance with *PHIA*, and the rationale for this is that each custodian operates in his or her own field of professional expertise (or multiple fields), and ways of doing things may vary across specialties and be dependent on the size of the custodian organization. The training/education component then must be partly based on *PHIA* itself and partly based on the particular policies and procedures of each custodian. The OIPC is certainly available as a resource to

discuss the essential elements of such policies and procedures, to review drafts and provide input, etc, but *PHIA* rests on the assumption that this work, and subsequent education about *PHIA* and the policies and procedures, is the responsibility of the custodian.

NLASW proposes some additional points of clarification which are worthy of consideration, such as incorporating electronic communication (texts, e-mails, etc) within the definition of the types of records which can contain personal health information. NLASW also proposes that the term "guardian" be defined, which we support for the benefit of greater clarity and understanding.

Central Health (CH)

Central Health provided a number of suggestions, recommendations and comments. First among them is the recommendation that the term "agent" be better clarified through a revised definition. This has come up elsewhere and we support this recommendation.

CH also proposed that home support agencies should be included as custodians under *PHIA*. We believe that home support agencies are *already* custodians in accordance with 4(1)(g)(iv) as a "person" who operates a program or service for community health, the primary purpose of which is the provision of health care by a health care provider. The terms "person", "health care provider" and "health care" are defined in *PHIA*. The definition of health care includes "care … [for the] promotion of health." That being said, we accept that there should be greater clarity and that home support agencies should be included explicitly as custodians in order to make *PHIA* more user-friendly. Generally speaking, it should not require an in-depth legislative interpretation to determine whether home support agencies, which play a significant role in health care, are custodians or not, and this can be resolved through the amendment proposed by CH.

CH discusses the issue of the rights of minors, however we have addressed that issue elsewhere in this document with respect to the submission of Labrador-Grenfell.

CH discusses section 6(2)(c) which states that even where a custodian is permitted to disclose personal health information without the consent of the individual, there is no prohibition against seeking the consent of the individual before disclosing. CH asserts that this provision may result in an interpretation in the minds of some health professionals who have a statutory obligation to report, such as under the *Children and Youth Care and Protection Act*, that there may be a resultant risk of harm if they seek consent first. The important distinction here is between the terms "permits" and "requires". This provision refers to situations where a disclosure is permitted rather than required. Section 6(2)(c) would not apply to any disclosures without consent that are required rather than permitted. In other words, any disclosure that is mandatory (rather than merely permitted) is not subject to section 6(2)(c).

CH also raises an interesting issue with respect to section 41(2)(a) in which a custodian "may disclose personal health information for the purpose of a proceeding or contemplated proceeding in which the custodian is or is expected to be a party or a witness where the information relates to or is a matter in issue in the proceeding or contemplated proceeding." CH questions whether there is authority in this provision to disclose to a disciplinary body of a health care profession in certain circumstances. This point deserves investigation and further consideration.

CH also discusses section 42 – disclosure for enforcement purposes, and raises a number of interesting points. CH refers to differences in the analogous provision in Ontario's *Personal Health Information Protection Act* (*PHIPA*). Although the OIPC's initial submission to the *PHIA* Review Committee recommended some changes to this provision, the points made by CH also deserve further consideration.

CH offers some useful commentary on section 7 with respect to the person who can act in the place of a deceased person. While the term "personal representative" is a term with broad application in law and is understood as having a specific meaning, there is value in defining it in *PHIA* in order to make the *Act* more user-friendly. The primary issue brought to light by CH though is the fact that the term spouse as found in the *Advance Health Care Directives Act* does not include a non-married but cohabiting partner. CH points out other provincial legislation which does include this broader definition, but also points out that custodians are currently limited by section 7(e) to only considering the nearest relative as determined by the *Advance Health Care Directives Act*. This has been problematic on a practical level, and should be addressed through amendment.

Health Research Ethics Board (HREB)

Both HREB and the Newfoundland and Labrador Centre for Health Information (NLCHI) have proposed reviewing the differences in the definition of research in *PHIA* as compared to *HREA* and potentially amending one of them to make them consistent. As with our comments on NLCHI's recommendation, the OIPC is of the view that these *Acts* have different purposes, and it is not clear that a change is warranted to *PHIA*. However, if any amendment is contemplated to *PHIA*, we believe there should be a more in-depth discussion and investigation of the potential impacts.

That being said, HREB has noted that there are research activities that are exempt from Research Ethics Board (REB) review, and that the *PHIA* review committee may wish to "evaluate the current governance environment of research activities that are exempt from REB review that rely on the use or disclosure of personal health information." We support this recommendation.

HREB also proposes that certain other non-research activities which are exempt from REB review, including quality assurance and quality improvement studies, program evaluation activities and performance reviews, be subject to scrutiny by the Committee given the potential ethical considerations associated with these activities. We support this recommendation. If the Committee intends to investigate this area, they may wish to review Bill 70, currently before the House of Assembly, which introduces a new *Patient Safety Act*.

HREB also proposes that the treatment of non-health research that uses personal health information should also be examined by the Committee. We support this recommendation.

HREB also proposes that the Committee examine whether additional clarity is needed in circumstances where custodians receive a request to disclose data but there is some difficulty in determining who the receiving custodian will be, and thus who is accountable for data after it is disclosed. This may arise in situations where it is unclear whether the individual making the request or the organization associated with the individual will ultimately be the custodian under *PHIA*. Clearly, it is essential that custodians in receipt of a request to disclose data must establish whether

the intended recipient is also a custodian under *PHIA* in order to establish what can be expected of the receiving party and where accountability for the information lies. Whether this is something that must be addressed through legislation or policy is an open question.

HREB also raises the question of ongoing governance of personal health information after it has been disclosed to a non-custodian for research purposes and questions whether *PHIA* is currently adequate to clearly address this. In our view this question is tied to the issue we raised regarding disclosure of information for research purposes to non-custodians, which has been echoed in other submissions. We believe this is a very important question to be resolved in this Review.

HREB goes on to discuss in detail issues associated with the application of section 44, generally concluding that this provision is not adequate to handle issues around the disclosure of personal health information for research purposes. Included among the points raised by HREB is that REB approval does not absolve custodians of their responsibility to consider whether disclosure should or should not occur, and that *PHIA* should address the responsibilities of custodians in that regard. HREB has raised a number salient points which deserve careful consideration and we support the comments and recommendations presented by HREB.

Western Health

Western Health provides useful commentary and recommendations on the terms "student", "spouse", "minor", "material breach" and on the subjects of deceased individuals and the status of Regional Health Authorities under section 24. We have addressed all of these issues either in our initial submission or in this document in response to similar comments and recommendations made by other stakeholders.

Newfoundland & Labrador Centre for Health Information (NLCHI)

NLCHI covered a wide range of topics in its submission. The first one raised was the suggestion that the term "information network" be clarified and that the process for designation be spelled out in the regulations. We have no objection to this suggestion. Later in its submission on page 5, NLCHI provides further support for its position with reference to the regime for designating an information network which is specified by law in Alberta and Ontario. NLCHI advocates that such a provision be created here in order to facilitate greater transparency and public awareness. We support this proposal.

NLCHI proposes that the term "research" in *PHIA* should align with the one found in *HREA* for consistency. The differences in the definition were also noted by the HREB. It is not clear whether the *HREA* definition would be the one to change or the one in *PHIA*. Adjusting the definition in *PHIA* could have significant impacts, perhaps unintended ones, and we would not recommend it unless there were an opportunity for a much more fulsome discussion on the implications.

We agree with the suggestion by NLCHI that additional clarification would be helpful regarding the term "evaluation."

NLCHI has proposed that the term "person" be defined. We believe the term is appropriately defined in section 2(1)(o).

NLCHI proposes that "genetic information" should be explicitly included in the definition of personal health information. We support this recommendation.

NLCHI's comments with regard to registries created under section 39(4)(d) are consistent with those raised in the OIPC submission. NLCHI proposes that a process for designating a registry be spelled out in *PHIA* or in the Regulations. This Office, along with the Department of Health and Community Services, has invested a significant amount of time in working towards a viable process for doing so, and we would be pleased to see it reflected in the regulations.

It must be observed that, currently, any registries operating in the Province are operating in non-compliance with *PHIA* and thus are in violation of the law, because none have been formally designated by regulation. It was expected after initial proclamation of *PHIA* that all registries would be appropriately designated within a reasonable period of time, however this did not occur. This state of affairs regarding registries cannot be allowed to continue. The current process must be formalized, and registries must be designated.

Of crucial importance is that there must be a process for either the Minister or the Commissioner (as is the case in Ontario) to review, at defined intervals, the operation of each registry, to ensure that it continues to operate as intended, and that if there is to be any expansion of the mission or function of a registry, that any such proposed new mandate be subject to appropriate scrutiny from a privacy perspective. The fact that registries amass a huge amount of personal health information on a mandatory basis without consent must not be forgotten in the course of moving forward with the laudable public health goals facilitated by registries.

NLCHI makes a number of important points in relation to disclosure for research purposes in accordance with section 44. NLCHI would like to see this provision expanded to include specific parameters. Other submissions, including the initial OIPC submission, have proposed something similar, although not identical. There seems to be consensus among many stakeholders that clear parameters and criteria are appropriate and would add significant value to the process.

As we note elsewhere in this submission with regard to the recommendation of Memorial University that its schools/faculties be de-listed as custodians under *PHIA*, NLCHI also underscores the potential negative impact on researchers and their ability to acquire data necessary to proceed with their projects if such custodians were de-listed.

NLCHI notes that organizations which de-identify personal health information yet retain the code which could be used to re-identify it are considered to hold identifiable information. We would agree. The Centre notes that it considers all record-level data to be identifiable due to the small population size in this Province, and the fact that de-identified information could in many cases be re-identified. NLCHI is of the view that de-identification and re-identification are not understood and applied consistently across custodians, and therefore advocates that *PHIA* be amended to resolve this. NLCHI further supports inclusion of a definition of "aggregate" information as found in Alberta's HIA. We support these positions.

NLCHI proposes additional clarity regarding how privacy should be handled for the aboriginal community. No specific concerns were referenced by NLCHI but we would support further consideration of this issue.

Comments by NLCHI about the role of information manager in *PHIA* are consistent with those presented by this Office, however consideration should also be given to situations where NLCHI is in a role which would appear to be that of information manager but NLCHI is managing information of a non-custodian. Unless subject to an amendment, it is not possible for NLCHI to assume the role of information manager in such a situation, and by default it would have to be acting as a custodian.

Sequence Bio

It is important to recognize at the outset that Sequence Bio will very likely not be the only company to come forward within this Province to propose genetic research as a business undertaking. The approach taken by the *PHIA* Review Committee and ultimately the Government of Newfoundland and Labrador to determine what if any legislative changes will be made to *PHIA* will likely determine whether such undertakings can be accomplished in a way that provides sufficient value to the citizens of the province to justify any social or economic costs or risks. The process of determining the potential value and the costs or risks is one that should be subject to significant research and analysis. Is the value real – does it live up to the hype? Can we even predict the potential value at this point? What are the costs and risks – how well are they understood? Are they exaggerated? Are there too many "unknown unknowns" at this point? Beyond Sequence Bio, there remain larger questions about how we apply basic privacy principles to genetic research, for example, how can one individual consent to participate in a research study which necessarily involves the personal health information of family members? If such consent is granted, what are the rights of those family members?

Among those risks which the Committee and the Government must grapple with is the risk to privacy. As we noted in our initial submission, there have been experiences in places such as Iceland where personal health information derived from genetic testing has been removed from the jurisdiction and from the regulatory control of that government. When we contemplate large scale private sector research involving the collection of genetic information about citizens of this Province, it is crucially important that we try to anticipate any circumstances in which that personal health information might escape provincial oversight, through such events as a sale of assets, a sale of the company, a bankruptcy, a move by the company to another jurisdiction, etc. It is also important that we do not craft a provision tailored to Sequence Bio that wouldn't address a company based elsewhere in Canada or the world wishing to pursue similar projects in this Province.

In our initial submission, the OIPC attempted to explain this concern and propose one possible legislative approach to mitigate it. That concern was also highlighted by other stakeholders, who proposed similar measures. In its submission, Sequence Bio recognizes that some degree of regulation and oversight of its activities will in fact facilitate progress towards their goals and objectives. Sequence Bio proposes a means of addressing the issue by recommending that some of Sequence Bio's activities be subject to *PHIA*. The approaches suggested by the different stakeholders are not entirely dissimilar.

We do not wish to say that the recommendation put forward by the OIPC is the best or sole solution to all of these challenges, however the important thing to emphasize at this point is that there seems to be some degree of consensus on the essential issue to be addressed. The ultimate solution, if there is one, must be a legislative amendment which ensures that the personal health information of citizens of this Province will not be misused or removed from the regulatory oversight of this jurisdiction.

Newfoundland and Labrador Medical Association (NLMA)

The submission of the NLMA covered several topics. Three recommendations were made regarding "circle of care". The first was that the definition should be included in section 2 of *PHIA*. In our view, "circle of care" is already defined in section 24, however if it was determined that there is value in including it within the definition section of *PHIA*, a provision similar to 2(1)(f) would suffice, in which the definition of the term would be "as described in section 24."

The second recommendation, that family physicians automatically be considered to be in the circle of care unless a patient expresses otherwise is probably redundant. It is agreed that on face value, the family physician is generally responsible for coordinating care by other professionals and providers, and would in most cases fall within the circle of care anyway. We appreciate that care can be disjointed and that silos may exist between disciplines and programs, but this is a matter of improving standards of professional practice. It is not clear from the information provided that a misunderstanding or misapplication of the term "circle of care" is the cause of this situation, nor would the proposed amendment necessarily be the solution even assuming there is a problem.

The NLMA's third recommendation on circle of care is "a consistent interpretation and use of the circle of care and communication on this definition to all custodians and their employees." As noted, section 24 contains a clear definition of the term at issue. Resources are available on the Department of Health and Community Services web site which discuss the concept in more detail. If there has been inconsistent interpretation of the term, this Office is willing to discuss the matter and help sort out differing approaches. Ultimately, however, section 13 of *PHIA* requires each custodian to develop policies and procedures regarding collection, use and disclosure of personal health information. The OIPC is available as a resource to review draft policies and procedures to help ensure that they remain consistent with the language in *PHIA*.

The NLMA also discussed the term "agent" in its submission, indicating that the term is not well understood or consistently applied. We agree. The Canadian Nurses Protective Society, according to how it uses the term in its submission, appears to be operating with a very expansive view of the term which seems to include all nurses. There may be an opportunity to better define this term in *PHIA*, or at least to provide examples of its correct use. We are willing to work with the Department, RHAs and other custodians to further refine it either in legislation or in policy.

We support the NLMA recommendation that all custodians be involved in further discussion about the use of consent directives in information systems. It is clear that there are many shortcomings in how this process currently operates, leaving patients with less control over their personal health information than is intended by *PHIA*.

Finally, the NLMA provided some commentary about reforming the health care system. Among the comments was a statement that "physicians are concerned that the interpretation and implementation of section 15 must not place information protections that make it impossible to modernize the health system." The NLMA then discusses various advances in the use of technology that may improve the health care system, and the concern is expressed that section 15, which is the security provision of *PHIA*, may hinder such progress. It should be noted that section 15 requires "steps that are reasonable in the circumstances," and it is this standard that the OIPC will apply. That being said, we believe that the adoption of new technologies in the collection, use and disclosure of personal health information requires appropriate scrutiny. This is typically accomplished through a Privacy Impact Assessment (PIA), which has been recognized across Canada and around the world as a reasonable step to take prior to implementing such a new program or service. The OIPC stands ready to consult at any stage in the PIA process and to assist custodians in moving new programs and services towards implementation. The OIPC discussed and provided recommendations regarding PIAs in its initial submission.

Memorial University

Although Memorial has productively engaged with this Office on many issues over the years, and in fact has played a positive role in the promotion of access to information and protection of privacy, there have been occasions where we have been critical of Memorial's position on certain matters, and there have also been areas of profound disagreement. The following issue is fairly placed in the latter category.

A number of points were raised by Memorial in its submission which require a response. Memorial argues that the four schools/faculties that are currently designated as custodians subject to *PHIA* should no longer be custodians and therefore no longer subject to the *Act*. It is already clear from the comments in our initial submission that we take the opposing view. Our initial submission briefly summarized our position on this issue, in which we took the view that the *Health Research Ethics Authority Act* (*HREA*) and *PHIA* are intended to operate *inter*dependently, and we note that *HREA* lacks a complaint investigation mechanism available to the general public to protect the privacy rights of individuals whose information may be used in research approved by a Research Ethics Board. There are, however, additional points that can be made in favour of retaining these schools/faculties as custodians subject to *PHIA*.

Memorial has in the past opposed our jurisdiction to carry out our privacy and access to information oversight role in several contexts (see our Report P-2011-002 for example). Report P-2011-002 investigated a privacy breach involving researchers employed by Memorial University. Among other things, Memorial refused to provide the Commissioner with documentation detailing the information which researchers were approved to collect by the Human Investigations Committee. If a new complaint of that nature arrived today, under *PHIA*, that information would be essential in order to determine compliance with section 44 of *PHIA*, ie, whether a disclosure which has occurred accords with the approval granted by a research ethics board. It should be noted that the events covered in the Report occurred prior to the proclamation of either *HREA* or *PHIA*, and that the version of *ATIPPA* referenced in the Report has also been superseded by the *ATIPPA, 2015*, so much of the discussion hinging on legislative interpretation is moot. However, paragraphs 85 through 88 remain relevant considerations in assessing the relationship of faculty members to Memorial University in the conduct of their research.

An aspect of the jurisdictional issue expressed by Memorial from time to time over the years is the assertion that many of the activities of its academic employees are not within the scope of their employment duties at Memorial and therefore many of the records associated with those activities are not within the control or custody of Memorial. For example, Memorial has argued that the research data researchers obtain in the course of discharging their contractual obligation to conduct research as per the MUNFA agreement is in fact in the individual custody and control of each researcher, and not in the control or custody of Memorial. This is despite the fact that research funding applications are made by these researchers under the auspices of Memorial University, funding for the research is processed and administered through Memorial's Office of Research, faculty members are required to engage in research under their collective agreement, and researchers seeking approval through a Research Ethics Board present themselves as having all of the institutional support of Memorial behind them. This often includes elements such as data storage and security, and policies and procedures to protect the data from unauthorized access, use, disclosure, loss, theft, and to ensure its secure destruction under terms required by the REB.

It is well-known that graduate and post-graduate students as well as faculty move to other universities throughout the course of their career. It is unclear whether Memorial expects that such research data could be taken with these researchers personally to their new appointments. Alternately, it is unclear whether Memorial intends to undertake, either through an agreement with all researchers, or by default, to maintain the security of such data after the departure of researchers. If these schools/faculties remain as custodians, some form of accountability will be maintained for such research data. If not, accountability becomes very elusive, and risks to privacy become much more significant.

On November 27, 2014 a government news release announced the TPM Initiative. This is a significant new venture which will no doubt bring many benefits to the public. Having *PHIA* continue to apply to the current custodians at Memorial has not, to our knowledge, interfered with the laudable goals outlined in the news release. Rather, the interconnected statutory regime of *PHIA* and *HREA* ensures that there are standards in place which establish clear lines of accountability. The following links provide information about this initiative:

http://today.mun.ca/news.php?id=9279

http://www.med.mun.ca/Medicine/Faculty/Staff/Faculty-Handbook/Research/Research-Support/Patient-Oriented-Research.aspx

It is clear through the example of such initiatives as TPMI that the Faculty of Medicine is currently a custodian of a large amount of personal information. It is important to note that even if personal information has been de-identified, if the data can be re-identified then it still requires protection. Furthermore, there are other risks associated with small sample sizes and our rural population which means that personal information that has been nominally de-identified may in fact be readily re-identifiable.

Another point which is not fundamentally a privacy issue, but more of a practical concern, is perhaps the unintended consequence of de-listing these custodians at Memorial. Amending *PHIA* as proposed by Memorial may in fact affect the willingness of custodians such as Eastern Health, NLCHI, or any other custodian of personal health information to disclose data to researchers.

In its submission to *PHIA* Review, NLCHI has clearly advised that it has concerns about this proposed amendment. As a custodian of personal health information, NLCHI must decide when and under what conditions to disclose personal health information at the request of a researcher. Approval by the REB is simply a pre-requisite – NLCHI must also satisfy itself that the disclosure is appropriate and any risks can be mitigated. After all, the REB process, while having elements of data security and ethics, is not explicitly a privacy review.

NLCHI therefore operates on a trust model, and it is our understanding that this is not an uncommon approach. NLCHI advises in its submission that this is a two-tier model. Currently, researchers from Memorial applying for data from NLCHI are accorded a higher degree of trust than independent researchers because the schools/faculties with which they are affiliated are custodians subject to *PHIA*. NLCHI advises that the change in status proposed by Memorial "would impact the disclosure of data to researchers affiliated with that organization."

Eastern Health also commented in its submission on the application of *PHIA* to personal health information used in research. Contrary to Memorial's view, Eastern Health has recommended expanding the coverage of *PHIA* to include all post-secondary institutions whose employees are conducting research involving personal health information, as well as expansion of *PHIA* coverage at Memorial University beyond the four schools/faculties currently listed. It should be noted that Eastern Health, like NLCHI, is also a custodian which frequently receives requests from researchers at Memorial for personal health information. Clearly, Eastern Health is more comfortable disclosing personal health information to a researcher affiliated with an institution that is designated as a custodian under *PHIA* and would prefer to operate under that model in its relationship with the research community.

In its submission, Memorial repeatedly emphasizes that the REB process is in place, and it is proposed that any requirements on researchers flowing from that process are sufficient. The submission of the HREB takes the opposite view. HREB makes the point that the REB process is not intended to serve as a *PHIA* lens on the proposed research process. HREB emphasizes that custodians should conduct their own reviews of research requests in addition to the REB process. Based on the submissions provided, Eastern Health and NLCHI take the approach recommended by HREB, and one of the factors considered by those custodians which supports the decision to disclose is whether the receiving party is also a custodian or employee of a custodian. This is simply part of the risk analysis that it is incumbent upon Eastern Health and NLCHI to apply when receiving requests for personal health information from researchers, and it is supported by HREB. In fact, HREB would like to see language in section 44 of *PHIA* strengthened to emphasize this responsibility on the part of custodians who receive requests for information from researchers. Simply put, the status of custodian is a significant factor which plays into the decision to disclose data to researchers, because it provides a level of assurance that the information will remain secure, and that there is accountability for maintaining that security.

The submissions of NLCHI, Eastern Health and *HREA*, in our view, clearly demonstrate that the statutory regime that exists currently is not a barrier to research, but instead is an asset which supports research by providing the assurance of clear legislated accountability. We would therefore recommend that further consideration be given to the recommendations of Eastern Health and *HREA* that section 44 be clarified and that coverage of *PHIA* be broadened to include other educational institutions which are carrying out research involving personal health information.

Memorial's submission asserts that, among other reasons, the schools/faculties should not be included as custodians because "the delivery of health care services does not fall within Memorial's mandate." This statement is not a relevant consideration, when one refers to section 3 of *PHIA*, where six separate purposes for the *Act* are outlined, including "to establish rules for the collection, use and disclosure of personal health information that protect the confidentiality of that information and the privacy of individuals with respect to that information." Nowhere in section 3 or anywhere else in *PHIA* is it indicated that the *Act* is only intended to cover personal health information which resides with a body that is directly engaged in the delivery of health care services.

On page 3 Memorial states *PHIA* "potentially creates various impediments to research and the development of intellectual property and undermines existing practices in academia around research data custody and control." These various potential impediments are not listed in the submission. Furthermore, even if it is accepted at face value that *PHIA* has any impact on "existing practices in academia" it is not at all clear that such impacts are substantial or even negative. In fact, as noted above, the argument put forward by NLCHI and Eastern Health is that being subject to *PHIA* has assisted researchers in accessing data by providing a level of trust and assurance associated with the application of *PHIA* to the schools/faculties which would not be possible if researchers' data requests were to be evaluated independent of such an affiliation.

Memorial quotes at length the Tri-Council Policy Statement regarding the importance of academic freedom. It is not clear how *PHIA* undermines this. This Statement says that researchers have an obligation to maintain ethical standards that protect and respect the participants. Certainly if Memorial University became aware of an unethical practice on the part of one of its researchers, it would not sit idly by and do nothing. By being subject to *PHIA*, the schools/faculties simply facilitate and ensure that a law is followed that protects and respects research participants. If there is an example of how the application of *PHIA* has negatively impacted the conduct of research by researchers at Memorial in the nearly 6 years it has been in force, it is presumed that such information would have been laid before the *PHIA* Review Committee.

On page 4 of its submission Memorial refers to the importance of protecting the trust relationship between a researcher and his or her research subject. Such a relationship would more than likely involve direct collection with consent. Of course, it should be noted that section 44 of *PHIA* facilitates disclosure of personal health information to a researcher *without* consent, which means that there is no trust relationship with the research subject, only between the disclosing custodian and the receiving party. Our argument is simply that the receiving party must be subject to *PHIA* in order to better ensure the protection of the research subject, who is unaware that this disclosure has occurred.

The concern is also expressed by Memorial that research data may "potentially" create an obstacle to academic freedom because under *PHIA* the Commissioner could "potentially" access the information during an investigation. Section 71 of *PHIA* ensures that this power is used sparingly by the Commissioner. It should be noted that, although issues have arisen under *ATIPPA* on a couple of occasions, there have been no demands by the OIPC for research information from Memorial University under *PHIA* to date. Furthermore, the purpose of any such investigation, should one occur in the future, is to protect the interests of the research subjects. This might occur, for example, as a result of a complaint from a person who has been a research subject. Even if it were to occur, the investigation would be limited to issues which arise under *PHIA*, and there would be no hindrance of academic freedom. In this sense, having *PHIA* applicable, even if it has so far not been

used in an investigation in a research context, is in fact an asset allowing researchers to demonstrate that potential research participants and disclosing custodians can have confidence in the research endeavor, because there is oversight and recourse in the case of a complaint.

Further along on page 4 of its submission, Memorial says once again that "subjecting research data to *PHIA* also ***potentially*** creates impediments to research generally by imposing obligations on researchers at Memorial that are not imposed on researchers in private industry … or on other institutions…"[emphasis mine]. Again, we have no evidence of these alleged impediments. It is acknowledged that proper administration of *PHIA* by the named custodians at Memorial should entail some administrative responsibility, however this is actually in service of the researchers because it allows the researchers to rely on the policies and procedures and security arrangements of a large institution, which carries a great deal of value at an REB or for a custodian considering whether or not to disclose personal health information.

I note the concern expressed that Memorial is not being treated fairly because other parties may not have to comply with *PHIA*. Interestingly, we see in the submission of Sequence Bio, a private sector entity, that they wish to come under the *PHIA* umbrella because of the value it provides. Furthermore, we see Eastern Health suggesting that *PHIA* be expanded to cover other entities engaged in research. What Memorial is attempting to evade is actually considered to be an asset elsewhere. Further to Memorial's comment about the advantages of private sector researchers, a private sector researcher would likely be subject to *PIPEDA*, which would likely subject such a company to the access and correction provisions of that statute.

Again, further along on page 4 of its submission, Memorial talks about "potentially" slowing research, and it expresses concern that "applying *PHIA* to research data could also threaten the commercial viability and value of intellectual property" generated from research. Unfortunately, we are not provided with any evidence that this is the case. However, assuming for the moment that there is evidence or that this is a real cause for concern, it would be a much more productive exercise to look at the specific provisions within *PHIA*, whether it is access, correction, or mandatory disclosure, which are the root of the concern, and see if there is an amendment necessary to deal with a real problem.

Memorial also notes that the *Personal Health Information Protection Act* (*PHIPA*) in Ontario does not name universities or academic units as custodians. It should be noted that *PHIPA* provides for a completely different regime for the protection of privacy in the course of research, and furthermore Ontario does not have an equivalent to *HREA*, so the comparison is not "apples to apples".

In a legislative review process, it is important to not only look back at how the law has functioned, but also to look ahead to the demands and expectations of the coming years. The Organization for Economic Cooperation and Development (OECD) in January 2017 published a recommendation containing 12 principles on health data governance:

http://www.oecd.org/health/health-systems/Recommendation-of-OECD-Council-on-Health-Data-Governance-Booklet.pdf

This recommendation is intended to apply to all 35 member countries, including Canada, and it is intended to advance and facilitate access to data for research purposes. The process to develop this recommendation was advised by an Expert Group, including well-known Canadians, former Privacy

Commissioner of Canada Jennifer Stoddart and leading health research ethicist, Professor Bartha Knoppers. Among the 12 principles are the following:

> *10. Establishment of appropriate training and skills development in privacy and security measures for those processing personal health data, that are in line with prevailing standards and data processing techniques.*
>
> *11. Implementation of controls and safeguards. These should:*
>
> > *i. Provide clear and robust lines of accountability for personal health data processing, accompanied by appropriate mechanisms for audit.*
> >
> > *ii. Establish requirements that personal health data can only be processed by, or be the responsibility of, organisations with appropriate data privacy and security training for all staff members, commensurate with their roles and responsibilities in relation to processing personal health data and consistent with any applicable professional codes of conduct.*
> >
> > *iii. Encourage organisations processing personal health data to designate an employee or employees to coordinate and be accountable for the organisation's information security programme, including informing the organisation and its employees of their legal obligations to protect privacy and data security.*
> >
> > *iv. Include formal risk management processes, updated periodically that assess and treat risks, including unwanted data erasure, re-identification, breaches or other misuses, in particular when establishing new programmes or introducing novel practices.*
> >
> > *v. Include technological, physical and organisational measures designed to protect privacy and security while maintaining, as far as practicable, the utility of personal health data for health-related public interest purposes. Such measures should include:*
> >
> > > *a. Mechanisms that limit the identification of individuals, including through the de-identification of their personal health data, and take into account the proposed use of the data, while also allowing re-identification where approved. Re-identification may be approved to conduct future data analysis for health system management, research, statistics, or for other health related public interest purposes; or to inform an individual of a specific condition or research outcome, where appropriate.*
> > >
> > > *b. Agreements, when sharing personal health data with third parties for processing that help to maximise the benefits and manage the risks while maintaining the utility of personal health data. Such agreements should specify arrangements for the secure transfer of data and include appropriate means to effectively sanction non-compliance.*
> > >
> > > *c. Where practicable and appropriate, considering alternatives to data transfer to third parties, such as secure data access centres and remote data access facilities.*
> > >
> > > *d. Robust identity verification and authentication of individuals accessing personal health data.*
>
> *12. Require organisations processing personal health data to demonstrate that they meet national expectations for health data governance. This may include establishment of certification or accreditation of organisations processing personal health data, in so far as these certifications or accreditations help to implement standards for the processing of personal health data or demonstrate capacity to meet recognised governance standards.*

It is apparent in reviewing this document that it would be impractical to place such burdens on individual researchers. The clear intention is that health data governance accountability is best placed at an institutional level in an organization that has the capacity to deliver on these requirements (such as, in this jurisdiction, Memorial University or designated schools or faculties therein). Any organization that is prepared to comply with the mandate outlined above should have no trouble complying with *PHIA*. *PHIA* compliance would then provide the assurance to the public and to custodians who are asked to disclose personal health information that appropriate oversight is in place. Given that this standard has been "welcomed by Health Ministers" representing OECD membership, it appears to represent a consensus on the way forward for health data governance in the 21st century.

If *PHIA* were to be out of the picture for personal health information at Memorial, there would be no legislated requirement for information security policies and procedures; no complaint mechanism for the public if someone believes their information has been collected, used or disclosed improperly in the course of research activities; and no real oversight of the privacy rights of citizens whose information is used in research activities.

There are no provisions for a complaint from the general public through *HREA* and no investigative processes available to the public through *HREA*. *PHIA* is currently the only recourse for members of the public who believe their information has been misused in a research context by one of these custodians. It is worth noting that there have been rare and isolated cases in other jurisdictions where custodians or their employees have illicitly sold personal health information for profit, or engaged in other gross misconduct. Again, the regime in place under *PHIA* would allow for appropriate accountability actions to take place in such an extreme circumstance, including the prosecution of such acts as an offence under *PHIA*.

Memorial has asserted throughout its submission that *PHIA* is somehow a barrier to research. With respect, Memorial has offered no evidence to support that claim. *PHIA* is no more an impediment to academic freedom than *HREA*. Contrary to the assertion by Memorial that the protection of privacy through *PHIA* is an impediment, other participants in this Review, on whom researchers depend for access to data, have clearly stated that the privacy standards associated with *PHIA* are in fact making access to data smoother and easier for Memorial researchers, and that removing the schools/faculties as custodians is likely to create a barrier to data access which does not currently exist.

Canadian Nurses Protective Society (CNPS)

CNPS raises a number of issues in its submission. With all due respect, the OIPC disagrees with most of the recommendations and suggestions proposed by CNPS. The following comments will address the most noteworthy of these.

The first significant issue is related to the observation that the policies and procedures of custodians required by *PHIA* under section 13 are intended to be legal obligations in accordance with 14(2)(b) of *PHIA*. CNPS objects to this as being burdensome for custodians "who are required to anticipate any and every situation in which every employee may have to make decisions with respect to the collection, use and disclosure of PHI." On the one hand, it is our experience that smaller custodians

seem to have had great difficulty coming to terms with the requirement to have policies and procedures, and this is an issue which the *PHIA* Review Committee may wish to address. On the other hand, the description that such policies and procedures must "anticipate any and every situation" vastly overstates the requirement. An interesting point made by CNPS however is its observation at the top of page 4 of its submission that there is no process to review or ensure that the content or application of policies and procedures adopted by a custodian is in accordance with *PHIA* (or other statutes). As we have stated elsewhere, the OIPC stands ready to review and comment on any draft policies and procedures prepared by a custodian with the goal of helping to ensure that they are compliant with *PHIA*, however in practice this has rarely occurred. Furthermore, it is expected that policy and procedure documents of the RHAs would be publicly available, and if CNPS wishes to review same and provide comments to the RHAs, that is also an option.

CNPS also states that nurses as health care professionals have certain legal and professional obligations. CNPS proposes that *PHIA* expressly authorize regulated health care professionals to collect, use, and disclose personal health information to meet their professional obligations. CNPS says on page 5 of its submission that *PHIA* does not contain "express authorization" for certain disclosures, however *PHIA*, like other health information statutes in Canada, does not contain a provision for every circumstance. It is our view that *PHIA* as it stands is designed to allow for the appropriate collection, use and disclosure of personal health information by health professionals, whether they are employees of a custodian, agents of a custodian, or acting as a custodian in their own right.

CNPS expresses concern that certain disclosures which registered health professionals are obligated to make might be contrary to *PHIA*. That does not reflect our reading of *PHIA*, although the process for making such a disclosure should be addressed through a custodian's policies and procedures. It would be useful to know whether there have been any cases in this Province where a nurse believed that *PHIA* interfered with a professional obligation to report (disclose personal health information) under *the Children and Youth Care and Protection Act*, the *Highway Traffic Act*, or the *Adult Protection Act* listed as examples by the CNPS. The vast majority of nurses in this Province are employed by one of the four Regional Health Authorities (RHAs). If this issue is a concern for CNPS, it is suggested that CNPS may wish to review and provide comment to the RHAs about any perceived gaps in the policies and procedures of the RHAs.

It is noted that CNPS, throughout its submission (the middle paragraph on page 7 for example) refers to nurses as "agents". Other submissions to the *PHIA* Review Committee have expressed some uncertainty regarding the definition of agent. In our view, nurses employed by Regional Health Authorities are not agents, but are simply employees. While there is no definition of "employee" provided in *PHIA*, provisions like 13(2)(b) and 14(2) demonstrate that employees and agents are intended to be separate categories because they are listed separately. The principles of statutory interpretation tell us that the decision to use different terms in a statutory provision means that they are intended to have different meanings. There may be other nurses who are in fact agents who occupy other roles, but this would be very much the minority.

We disagree with the suggestion at the top of page 8 that the requirement to comply with a custodian's policies and procedures is "superfluous". Removing the requirement for policies and procedures would undermine the entire structure of *PHIA*, which we do not see as productive. Later, on page 8, CNPS says that "*PHIA* does not stipulate whether the employer's authorization to

collect, use or disclose PHI can be implicit or if it must be an express authorization." We are of the view that sections 24 and 25 adequately address this issue, and that RHAs are covered by section 24(2). CNPS says that "… it has been our experience that some employers have concluded that employees inappropriately accessed PHI when this was done without express authorization." If there are grievance awards, court decisions or other documents available which might demonstrate this, we would be interested in seeing them. In our interactions with RHAs, we have not encountered such a circumstance. We have, however, seen this conclusion drawn when the patient was not in the circle of care of the nurse in question.

On page 9 CNPS discusses issues relating to procedural fairness, and notes that *PHIA* does not contain any specific provisions which ensure that procedural fairness must be followed by an employer when attempting to determine whether personal health information has been inappropriately accessed. It is our understanding that such provisions are not common in personal health information statutes, but would be expected in human resources processes such as grievances and investigations by employers. This is an area that is well understood within the field of labour law, and it is not something we anticipate would find a home in *PHIA*. Any disciplinary finding or measure imposed by an employer based on its policies or procedures, whether or not they are *PHIA* policies or procedures, is a matter between the employee and employer, unless the matter comes before the Commissioner and it is determined that an offence under section 88 of *PHIA* may have been committed. In such a case, the assessment of any issues relating to procedural fairness is a matter for the courts.

On page 14 CNPS asserts that the circle of care provision is inadequate. In our view, the language in section 24 is sufficiently broad to capture all of those persons and activities appropriately considered to be in the circle of care. CNPS says that "… the concept of 'circle of care', as it applies to agents of custodians nonetheless is often given a very restrictive interpretation." CNPS does not say who has provided this restrictive interpretation and what effects it may have had. Through our regular discussions with RHAs we have not been advised of these types of difficulties and we do not support the recommendation of CNPS.