NEWFOUNDLAND AND LABRADOR
MEDICAL ASSOCIATION

April 25, 2023 **by e-mail**

Ms. Angela Power
Chair
Personal Health Information Act Review Committee
c/o INQ Consulting
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Dear Ms. Power,

The Newfoundland and Labrador Medical Association (NLMA) thanks the Personal Health Information Act (PHIA) Review Committee for the opportunity to comment on PHIA through this submission and the in-person consultation on March 30, 2023.

The NLMA is the voice of organized medicine in Newfoundland and Labrador, Canada and represents more than 1300 practicing physicians, including 700 fee-for-service physicians, which is the single largest group designated as custodians under PHIA. Membership also includes approximately 600 salaried and alternatively funded physicians, and students and residents enrolled at Memorial University. As a group, physicians play a lead role in the collection, use, disclosure and protection of the personal health information of the residents of Newfoundland and Labrador.

PHIA has a significant influence on the daily activities of all physicians in the Province. It is important that any changes, or decisions to keep the status quo, consider the implications on physicians and the different settings in which they practice.

There are two discussion points, in particular, that could have a significant effect on physicians, including changes to the custodianship model and the patient's role in information governance.

Custodianship Models

Custodianship models in Canada were designed when records were in paper or in health information systems in hospitals, where it was clear who was responsible for the records. Health information was not easily shared digitally between custodians, and custodians did not have a shared interest in the accountability for the personal health information. In the last 15 years the landscape has changed significantly.

In a few years, all patient records in Newfoundland and Labrador Health Services (PHA) will reside in a single health information system which will facilitate their access by authorized users across the province. The majority of community physicians will continue to record and manage their patients' information in the provincially approved Electronic Medical Record (EMR).

There are many contexts in which the custodian role overlaps and should be shared: physicians who have privileges with the health authority and use the authority's records system but who

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continue to have obligations to the College regarding how they maintain their records; physicians who have records in the health authority but who also maintain an EMR in a community-based practice; physicians in a community-based practice who share the same EMR instance; and physicians in a community-based practice who opt-into the health authority's EMR instance. It is unclear who is accountable under PHIA for the protection of the personal health information when there is more than one custodian involved.

During the consultation meeting on March 30th, there was discussion about changing the custodian responsibilities and possibly introducing another accountability role, such as steward, with responsibilities for only part of the life cycle of the personal health information. Another suggestion was that accountabilities could be based on the information and not on the role. The NLMA considers these both significant changes to physicians' responsibilities and suggests that further discussions with many stakeholders is required before these changes can be included in legislation. NLMA members are concerned about ensuring that any changes do not interfere with their workflow and their access to information to care for their patients by themselves or other health providers.

Patient-Centric Information Governance

The Canadian Medical Association (CMA), Canada Health Infoway and others have begun discussions on updating the health information governance models. Infoway recommends "a balanced and proportionate duty to protect and share information according to the patient's choices … with the patient at the centre of health data sharing and anyone providing health care as managing the data on behalf of the patient[1]." The CMA recommends a framework where "The design of the health information governance framework is centred on the needs and perspectives of individuals, not exclusively on the needs of health system services."[2]

These are very lofting statements by the CMA and Infoway that would benefit from a thorough discussion among stakeholders. Attention must be paid to how the objective of better and effective engagement of patients in the governance of their personal health information can be operational.

> **Recommendation**: The Government of Newfoundland and Labrador hold further discussions with stakeholders on significant changes to the custodianship model in PHIA and information governance before including them in legislation.

OTHER TOPICS

The Federal **Bill C-27** *An Act to enact the Consumer Privacy Protection Act, the Personal Information and Data Protection Tribunal Act and the Artificial Intelligence and Data Act and to make consequential and related amendments to other Acts* introduces several new requirements and standards for organizations, including physicians who are currently organizations under PIPEDA. PIPEDA does allow for provinces to enact "substantially similar" privacy legislation which would allow provincial organizations to follow the provincial legislation. In NL, physicians are subject to PHIA and not PIPEDA, as PHIA has been deemed substantially similar to PIPEDA.

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[1] Data-sharing White Paper, Canada Health Infoway, undated

[2] CMA Statement on the Governance of Health Information A patient-partnered health information governance framework , Canadian Medical Association, June 2022

> **Recommendation**: Ensure that PHIA remains or is updated to retain the "substantially similar" status.

Joint Custodianship: If the Committee is not making substantial changes to the custodianship model of PHIA at this time, the NLMA requests that greater clarity on **t**he use of shared EMRs between custodians, particularly between the salaried PHA and fee-for-service physicians, be included in PHIA. The current custodianship model has led to several questions about where the accountabilities of one custodian stops and the other starts. Currently PHIA does not allow for joint custodianship, rather there is simultaneous custodianship where each custodian has accountabilities for the same personal health information at various times in the information's lifecycle. This raises particular challenges on determining access, disclosures, secondary uses, retention and destruction, managing records when moving to a new EMRs, and other issues.

This is a significant issue for private physicians using an EMR operated by the PHA. With the introduction of Blended Capitation teams more private physicians will be considering sharing an EMR. Therefore, clarification is needed on the issue of the joint custodianship of personal health information in a single EMR instance.

The NLMA considers that personal health information will be better managed and protected if the custodians share jointly in the accountability for the personal health information in the EMR, not separately or in a hierarchical structure as may happen in a simultaneous relationship.

> **Recommendation:** PHIA be updated to reflect the need for different custodian models in the digital health environment.

Information Manager: Under PHIA an Information Manager "processes, retrieves, stores or disposes of personal health information for a custodian, or provides information management or information technology services to a custodian"**.** PHIA does not currently allow for a custodian to also be an Information Manager. Within the provincial eDOCSNL EMR program, physicians are custodians who have contractual arrangements with eDOCSNL. eDOCSNL provides information technology services and program administration to physicians, similar to the relationship between the vendor (Telus) and integration services. The PHA does not take custody or control of the EMR data during the patient care phase of the information life cycle. This occurs only when EMR data is disclosed to the provincial data warehouse.

Physicians are required to enter into custodian to custodian agreements with eDOCSNL rather than Telus, the information manager for the EMR. The physician has no contractual arrangement with Telus, the EMR vendor and IT service provider. The interpretation of PHIA establishes the PHA as the custodian who enters into the information management contract with Telus and not the true custodian of the personal health information.

PHIA recognizes that custodians can take on two or more roles. A physician who is a custodian in a community clinic could be an employee or agent of the PHA in another setting, or even a researcher at MUN. Each role requires the physician to understand their accountabilities under PHIA.

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With the integration of the Newfoundland and Labrador Centre for Health Information into the PHA, private physicians are concerned about their ability to manage the personal health information in, and associated with, their EMR in the same co-operative manner they established with NLCHI.

> **Recommendation:** clarify in PHIA that a custodian may act as an information manager for another custodian.
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> **Recommendation:** The provincial EMR program be recognized as an information manager within the PHA to allow for policies and operations that recognize the independence of private physicians.

Penalties for Vendors and Information Managers: PHIA requires custodians to take steps to ensure IT vendors and information managers adhere to PHIA. Despite best efforts by the custodian, the IT vendor or information manager may cause a breach, or in some manner fail to meet the requirements of PHIA. These organizations should be subject to penalties and fines under PHIA, in addition to any action the custodian may take against the IT vendor or information manager.

> **Recommendations**: PHIA should be updated to allow for complaints to, and investigations by the Commissioner, to include those related to IT vendors and information mangers, and that third parties also be subject to penalties under PHIA.

Retention: As the Newfoundland and Labrador health system moves into more shared electronic health records it becomes increasingly difficult for physicians to destroy records of personal health information for which they are the custodians. The College of Physicians and Surgeons of Newfoundland and Labrador recommends records of personal health information be destroyed ten years after last seeing the patient. If physicians cannot destroy their records they will remain a custodian of them long past a reasonable time for this responsibility. Further, IT vendors frequently retain records long after the physician ceases to be a custodian as part of their business continuity process. Who is the custodian of these records? If the records continue to exist, how is access granted to the patient?

> **Recommendation**: PHIA should provide more direction on responsibility for records when the custodian ceases to be a custodian and the records cannot be destroyed.

Age of Access to a person's own PHI: PHIA does not establish an age at which someone can access their own record. The RHAs are using the age of 16 as this is the age of consent for treatment. This means a parent or guardian controls the access to the record and a youth cannot access their information without parental consent, nor can they restrict or deny the parent or guardian's access. The PHA does have a process by which a youth can request control over their own record.

Many young people take, or are given, responsibility for their own health care around the age of 14 with the support of their physicians. Many children in care are responsible for their own health care by 14, as are others of that age who may not have contact with a parent or guardian. In other Canadian jurisdiction the age of controlling access is 12 or 14.

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> **Recommendation**: Include in PHIA an age of access and control of a person's own information, preferably 14 years of age. Consideration should be given to allow a physician to restrict the young person's ability to access or control their own personal health information if deemed appropriate.

Circle of Care: This may not require any legislative changes but rather a better awareness of the appropriateness of sharing personal health information for patient care within the circle of care. Family physicians are not being included in the circle of care by the PHA programs, as these programs are relying on collecting express patient consent instead of relying on PHIA s. 24. The programs should either share reports through HEALTHeNL or send them directly to family physicians or others in the circle of care.

A clear understanding of the circle of care is essential for strong coordination of services to patients. Section 24 of PHIA allows for the use of implied consent within the circle of care when providing health care or assisting in the provision of health care. Subsection 3 defines the expression "circle of care". This definition should be included in Section 2 of PHIA. Circle of care has come to be one of the foundations of the Act to allow for the sharing of personal health information among health care professionals and providers.

> **Recommendation:** The definition of circle of care should be included in section 2 of PHIA. Clarify the language in PHIA s. 24 to create a consistent interpretation of the use of the circle of care and improve education to all custodians and their employees about their meaning of the circle of care.
> The definition of circle of care should be amended to include the family physician as a permanent member of the circle of care unless the patient expresses otherwise.

Secondary Use of Personal Health Information: Personal health information is used for secondary purposes, although frequently it is de-identified or anonymized before it is used. The NLMA supports the use of health information for secondary purposes but is concerned about the growing use of personal health information or health information that a knowledgeable person has a reasonable ability to re-identify the information. There is a growing number of people in this province with expertise in data analytics that have the skills to remove the anonymity of health information, thereby risking patient privacy.

> **Recommendation**: Establish in PHIA oversight of all secondary uses of personal health information and health information that is potentially re-identifiable and not just oversight of secondary use of personal health information for research.

Agent: "Agent" is another term that has caused some problems for physicians. Physicians in community settings often have residents or students work with them. There is not a clear understanding that while the resident or student is using personal health information at a physician's practice, the physician is accountable and the student is an agent of the physician and must adhere to the physician's policies and procedures. This is in addition to any policies and procedures the Medical School requires the resident or student to adhere to. This interpretation of agent has not been clearly and consistently communicated from the Department of Health and Community Services (HCS) or the Medical School to the physician, resident or student.

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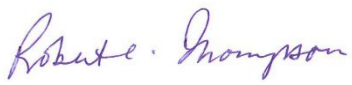
Additionally, it should be clarified that the sharing of an EMR or personal health information in an EMR does not, in and of itself, make the physician an agent of another custodian.

> **Recommendation**: A consistent interpretation and use of "agent" and communication on this definition to all custodians.

NLMA thanks the Committee for this opportunity to comment. Physicians in both the community and institutional settings make extensive use of personal health information. They also share personal health information with others providing care. Physicians want to ensure that they are not in contravention of PHIA, or breaking the rules, when they are collecting, using or disclosing personal health information. This can best be achieved through consistent provincial interpretation and application of PHIA and related best practices.

Best regards



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