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Digital Health Program Branch
Digital and Analytics Strategy Division
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Proposal Number: 24-HLTC020

To Whom it May Concern:

The purpose of this correspondence is to formally respond to the call for feedback on the proposed changes to the Personal Health Information Protection Act, (PHIPA) 2004-Proposal Number 24-HLTC020.

Background

Home Care Service Providers (SPOs) and Community Support Services Health Service Providers (HSPs) take their role and responsibilities seriously regarding their ultimate accountability to ensure privacy, security and safe keeping of patient personal health information within digital resources and ensure that their organizational practices are aligned with provincial and federal legislation.

Optimal operations of all digital resources should include operational functioning such as open and secure Application Programming Interface (APIs), bi-directional information exchange, standardized terminologies, minimum data sets and interoperability. These operational functions are fundamental to the PHIPA regulation.

In collaboration with government, Home Care Service Provider Organizations (SPOs) and Community Support Services Health Service Providers (HSPs) are committed to navigating the implications of legislative change as outlined below.

These implications include:

- Administrative Burden & Compliance Costs: The potential exists for an increase in future compliance costs and administrative burden to meet new cyber security and Artificial Intelligence (AI) requirements.
- Data Breach Implications: There must be robust measures across systems to prevent data breaches and manage notification requirements.
- Interfacing with Public Sector: Clarity is required regarding how provider systems will interface with public sector entities' enhanced security and AI frameworks.
- Operational Challenges: There are potential challenges in aligning SPOs and HSPs existing systems with new public sector requirements.

Home Care Ontario and Ontario Community Support Association are pleased to be able to share the following specifics on the proposed legislative changes for consideration:

Validation, Verification and Authentication Service Regulation

Home Care Ontario and Ontario Community Support Association support the vision for patient access and management of their own health records.

It is recommended that the proposed legislative changes include further guidance regarding how the vision for patient-managed digital resources will be accomplished.

The definition of Health Information Custodian (HIC) should also be clarified and be inclusive of all Home Care Service Provider Organizations (SPOs) as outlined in the PHIPA changes of January 2020.

This critical and continued omission (since the 2020 PHIPA regulatory changes), has long been a serious issue impacting access to digital health information by some SPOs and their staff.

It is recommended that the current proposed changes include the clarification and recognize the key role as HICs that all Home Care SPOs have in overall collection, use, disclosure and retention of patient health information.

EHR Access Regulation

From proposed legislative change "Where OH is not required to consider the exceptions from the right to access listed in s. 52(1) but would establish a notification process with HICs that have provided or intend to provide records to the EHR."

Home Care Ontario and OCSA support the intention that safeguards should be put in place to ensure that records will not be released without the proper authority and that strict governance will be required to ensure compliance and public transparency of compliance should be included as part of the proposed changes.

From proposed legislative change "Where OH is enabled to deactivate access through the digital means of access to all of the affected individual's records if a Contributing HIC has notified OH about a s. 52(1) exception applying to record(s) that the HIC has provided or intends to provide to the EHR."

From a patient perspective, this approach could be distressing to an individual, especially if there is a delay in re-directing the individual to the HIC or if there is a delayed response from the HIC.

It is recommended that the legislation include a prescribed time for response. This would facilitate management of expectations from all parties.

Deactivating access through digital means of access to all of an individual's records when an exception is applied seems extreme and unnecessary.

It is recommended that an alternative of "severing the record" as per current legislation (*PHIPA* 51(2)) be considered instead.

Currently the legislative changes are silent on Ontario Health (OH) responsibilities for notification of a HIC when a request for correction is received.

It is recommended that management of record corrections should also be articulated in the proposed legislative change.

In addition, the proposed changes exempt OH as outlined below:

From the proposed legislative changes:

- Exempt OH from the requirement in s. 52(1.1) to provide the records through the digital means of access in the electronic formats specified in that subsection;
- Exempt OH from the requirements under s. 52(4) to (7) relating to provisions for HICs at the point of care;
- Exempt OH from the requirement under s. 55 to correct EHR Records; and
- For the Audit Records (i.e., the records described in paragraph 2 of s. 51(5)), permit OH to only provide summaries of such records; provide OH with an initial period of 90 days to provide such summaries; and enable OH to only prepare summaries for the 12-month period preceding the request. These summaries would be provided via the digital means of access for individuals specified by OH who have an OHA or an alternative process for individuals who are unwilling or unable to use the digital means of access.

It is recommended that greater clarity on the rationale for these exemptions be provided as part of the documentation for the proposed legislative changes.

Additional Considerations

Improved security and privacy are essential to supporting patient trust in digital systems. Both Home Care Ontario and the Ontario Community Support Association know that secure, complete electronic medical records that can be among providers improves patient care however the details regarding 'how' that information can be transferred has not been articulated in the legislative changes.

Artificial Intelligence (AI) in Digital Resources

Expansion of the use of Artificial Intelligence (AI) as part of digital resources requires independent testing standards for validity and reliability. The proposed regulatory change is silent on the use of AI as part of the digital resources and should be articulated in terms of the current expectations. There are large resource costs in energy required to use AI. There needs to be active mitigation around the large energy use of AI and its potential to impact critical health digital infrastructure integrity and security, as well as the large environmental footprint that AI has already developed. It is our understanding that AI requires one to three years of reliable information, as well as robust staff training in developing and using AI queries. This impact should also be considered.

As the work on digital resources and provincial EHR evolve, existing implementation structures, such as the Home Care Ontario and Ontario Community Support Associations' Joint Digital Health Work Group, should be leveraged as a key input into governance structures to ensure ongoing alignment to the privacy and security work of OH.

In addition, engagement of Home Care Ontario and Ontario Community Support Association members in defining minimum business and clinical use cases and requirements for integration with provincial digital health assets is critical.

As mentioned earlier, key principles of open and secure Application Programming Interface (APIs), bi-directional information exchange, standardized terminologies, minimum data sets and interoperability are fundamental to the PHIPA legislation and should be clearly articulated in the proposed changes.

While this legislative change has the significant potential to improve trust in digital solutions, the lack of independent standards, which are not addressed in the proposed changes, may impact that trust in immediate future.

This legislative change will increase transparency concerning Ontario Health (OH) accountabilities for digital resources, increase ease of access to digital health resources and clarify the legislative obligations between the HIC and OH.

If these changes are refined and implemented in a thoughtful, inclusive way that can enable future digital resources, including AI and data streaming, it will lead to enhanced trust in digital solutions and data protection for SPOs and HSPs and their patients. If clear, independent standards are developed to support an increased use of AI and other emerging digital tools, it will improve reliability and accuracy of patient records and improve patient care.

Thank you sincerely for the opportunity to provide input into the proposed legislative changes to PHIPA.

Respectfully submitted,

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