



VIA ELECTRONIC MAIL

December 1, 2021

Mr. Evan Mills
Director, Digital Health Program Branch
Digital Health Division
Ministry of Health
1075 Bay Street, 12th Floor
Toronto, ON M5S 2B1

Dear Mr. Mills:

RE: Proposed Amendment to O. Reg. 329/04 under the *Personal Health Information Protection Act, 2004 (PHIPA)* on the right to access records in electronic format

The Ontario Gazette, published on October 16, 2021, contains a notice by the Minister of Health of a proposed regulation under the *Personal Health Information Protection Act, 2004 (PHIPA)* relating to the right of access to records of personal health information in electronic format (the Proposed Regulation).¹ As Information and Privacy Commissioner of Ontario (IPC) who oversees the province's access and privacy laws, including *PHIPA*, I have reviewed the Proposed Regulation. In keeping with my statutory authority to offer comment on the privacy protection implications of proposed legislative schemes or government programs, I would like to offer the following observations and recommendations.

I. Background

Section 52 of *PHIPA* affords individuals with the right to access their records of personal health information, subject to limited exclusions and exceptions. In March 2020, in a broader context that recognizes the need to build an integrated health care system centered on the needs of patients, accelerate the digitization of health records, and empower individuals by facilitating access to their own personal health information, a new subsection (1.1) was added to section 52.² This subsection provides:

Format of records

(1.1) The right to access a record of personal health information includes the right to access the record in an electronic format that meets the prescribed requirements, subject to any restrictions, additional requirements or exceptions that may be prescribed.

¹ See [Ontario Gazette Vol. 154-42](#), pages 3741-3743. The notice of the Proposed Regulation was also posted in the Ontario Regulatory Registry, which also includes the proposed text of the regulation ([Proposal number 21-HLTC024](#)).

² See [Bill 188, Economic and Fiscal Update Act, 2020](#), S.O. 2020, c. 5, Sched. 6, s. 9.



The Proposed Regulation provides:

18.0.1 (1) For the purposes of subsection 52 (1.1) of the Act, the right of an individual to access a record of personal health information about the individual that is in the custody or under the control of a health information custodian includes the right to have the health information custodian provide the record to the individual in a PDF file.

(2) A health information custodian is exempt from the requirement described in subsection (1) to provide a record in a PDF file if doing so would result in undue hardship to the health information custodian, having regard to the nature of the health information custodian's records, the capacity of the health information custodian to utilize technology and the financial costs of complying with the requirement.

II. General comments

In our respectful view, the Proposed Regulation will soon become outdated, is attempting to solve a problem that may not exist, and risks reversing -- rather than enhancing -- Ontarians' digital privacy and access rights.

Subsection 18.0.1 (1) of the Proposed Regulation

The practice of providing records in electronic format in response to requests for access under *PHIPA* is not new. *PHIPA* defines "record" to mean "a record of information in any form or in any medium, whether in written, printed, photographic or electronic form or otherwise."³

There is already a mechanism in *PHIPA* for addressing the time and expense to a health information custodian (custodian) of responding to an access request. Subsections 54 (10) and (11) of *PHIPA* state:

Fee for access

(10) A health information custodian that makes a record of personal health information or a part of it available to an individual under this Part or provides a copy of it to an individual under clause (1) (a) may charge the individual a fee for that purpose if the custodian first gives the individual an estimate of the fee.

Amount of fee

(11) The amount of the fee shall not exceed the prescribed amount or the amount of reasonable cost recovery, if no amount is prescribed.

Fifteen years ago, the Ministry of Health and Long-Term Care acknowledged that custodians could provide electronic records in response to access requests when it proposed a regulation setting out a fee scheme for access (the "2006 Framework").⁴ The 2006 Framework refers to actions such as "[p]reparation of the record for photocopying, printing or *electronic* transmission" [emphasis

³ See *PHIPA* section 2, which goes on to state that "record" does not include a computer program or other mechanism that can produce a record.

⁴ See [Ontario Gazette Vol 139-10](#), pages 374-381. The 2006 Framework was not adopted as a regulation.

added] and “electronically transmitting a copy of the electronic record instead of printing a copy of the record and shipping or faxing the printed copy.” The 2006 Framework proposed a fee schedule with a maximum base fee of \$30 that could be charged to an individual for providing access to personal health information records, and provided for additional fees in specific circumstances. For example, when “making and providing a floppy disk or a compact disk containing a copy of a record stored in electronic form”, an additional \$10 could be charged to recover the fees of purchasing the portable storage device.

Although the 2006 Framework was never adopted into regulation, the IPC adopted and developed the fee framework as a way of recognizing the vital interest that individuals have in their health records, while also allowing custodians to recover some of the costs associated with providing access.⁵ There have been a number of *PHIPA* Decisions issued by the IPC assessing the concept of “reasonable cost recovery” in instances where custodians were requested to provide records to individuals in electronic format, including by scanning documents into PDF and making them available to the individual on a portable storage device such as CDs or USB flash drives.⁶

By specifying that an individual’s right to access their personal health information records in electronic format includes the right to obtain the records in PDF upon request, the Proposed Regulation does little more than make explicit a limited baseline requirement that is already reflected in jurisprudence.

More relevant, we believe, would be to go further than PDF and specify through regulation a number of alternative electronic formats that allow individuals to take control over their personal health information records so as to transfer them to other health providers or port them on to other communication media, patient portals or health apps of their choosing. For example, in addition to PDFs, other modern means of digitization that may qualify as prescribed electronic formats include:

- text file formats which may include plaintext data structured in such a way to allow interpretation and display by other software programs or apps; and
- formats such as JPG or MPG or DICOM (Digital Imaging and Communications in Medicine) that capture medical scans, digital images or videos.

Alternatively, the prescribed requirements specifying which electronic formats would qualify under the right to access one’s personal health information records under *PHIPA* might better speak to principles or general characteristics of accessibility, rather than specific file formats that are likely to become outdated by rapidly-evolving technologies. For example, in certain circumstances the European Union’s General Data Protection Regulation requires controllers to make data available in a structured, commonly used, machine-readable and interoperable format that allows the individual to transfer the data to another controller.⁷

⁵ See Orders [HO-009](#), [HO-014](#) and [PHIPA Decision 17](#). See also *PHIPA* Decisions [137](#), [142](#), and [143](#).

⁶ See, e.g., *PHIPA* Decisions [111](#) and [143](#).

⁷ See EU General Data Protection Regulation, [Article 20](#) (Right to data portability), paragraph 1: “The data subject shall have the right to receive the personal data concerning him or her, which he or she has provided to a controller, in a structured, commonly used and machine-readable format and have the right to transmit those data to another

Such a principled approach would be, in our view, a much more effective way of advancing the legislative intent of facilitating access to one's personal health information records in electronic format in a modern digital context that is invariably moving towards the permanent delivery of virtual health services, even post-pandemic.

Subsection 18.0.1 (2) of the Proposed Regulation

In our view, the second subsection of the Proposed Regulation is attempting to solve a problem that may not exist. The suggestion that providing a record in a PDF file could result in undue hardship to a custodian in this day and age seems unlikely. Providing a record in PDF is not generally any more expensive or technologically more difficult than photocopying the records, and may in fact be less expensive than printing on paper. Even where records are retained in paper format, most modern day photocopy machines used by large and small custodians have scanning functions built right into the machine, allowing the owner to create PDF files.

Moreover, portable devices on which to store the PDF records are very reasonably priced or have been replaced by more expedient methods of document transmission or electronic communications such as encrypted email or patient portals.

Given that PDF is a very low-tech solution for providing records in electronic format, all custodians should realistically have the technological capacity to be able to produce PDF files if the individual requests access to records in that format. Creating a PDF is simple and does not require sophisticated technology or a high level of technological expertise on the part of the custodian or its agents. We would expect that all custodians would have the technological capacity to comply with this minimal requirement.

In our respectful view, subsection 18.0.1(2) of the Proposed Regulation, if adopted, would be a significant step backwards for individuals' digital access and privacy rights in Ontario. It might also inadvertently create a new problem by undermining the government's larger ambition of becoming a world-leading digital jurisdiction. If custodians are provided the option of claiming undue hardship when asked to provide personal health information records in PDF, as proposed in subsection 18.0.1(2), individuals will revert to requesting the same records in paper format instead which will be even more expensive for both individuals and custodians, and in the case of voluminous paper records, will quickly become very unwieldy and much less practical. This result seems directly opposed to the apparent intention of subsection 52(1.1) of *PHIPA*, which is to enhance the ability of individuals to access their records of personal health information in electronic format, and further the government's objectives of moving towards an integrated system of patient-centred care where individuals can feel more empowered as they journey through the health system and become more active and informed participants in their own care.

controller without hindrance from the controller to which the personal data have been provided, where: ...". The UK Information Commissioner's Office provides clarifying advice and commentary on what "structured", "commonly used", and "machine-readable" mean when providing personal data (see <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/right-to-data-portability/#ib10>).

III. Recommendations

In light of the above observations, we would recommend that subsection 18.0.1(1) be expanded to include a range of other modern electronic formats in which personal health information must be provided beyond PDF records, or better still, be amended to refer to principles or characteristics of accessibility.

We would also strongly recommend deleting subsection (2) of the Proposed Regulation altogether for the reasons described above. While subsection (1) of the Proposed Regulation is a small step forward, subsection (2) would be a larger step back.

If the government intends to proceed with the policy direction of having PDF be the only format specified in the Proposed Regulation, we have included an Appendix setting out our recommended changes (indicated by an underline for new text and a strikethrough for deleted text).

IV. Conclusion

In closing, we would like to note that the amendment to section 52 creating subsection (1.1) was only one of several important amendments made in recent years to modernize *PHIPA*.⁸ Some of the new provisions of *PHIPA* (for example, those concerning administrative penalties, electronic audit logs, and consumer electronic service providers) are unproclaimed and/or still awaiting regulations before they can become operational. We urge the government to prioritize these other legislative and regulatory amendments and deliver on the will of the legislature to enhance protections of personal health information in an increasingly digitized health care system. In that regard, the Proposed Regulation should be viewed as a first step, with many other steps more urgently required to fully realize the promise of digital health for the benefit of Ontarians.

We appreciate the opportunity to make this submission. Please let us know if you have any questions.

In the interest of transparency to the people of Ontario, we will be making this submission available on our website.

Sincerely,

A handwritten signature in black ink, appearing to read 'Kosseim', with a horizontal line underneath.

Patricia Kosseim
Commissioner

⁸ See the IPC's [Digital Health under PHIPA: Selected Overview](#).

Appendix: the Proposed Regulation with IPC recommended changes

Right to access record in electronic format

18.0.1 ~~(1)~~ The following is prescribed as a requirement for For the purposes of subsection 52 (1.1) of the Act, ~~the right of an individual to access a record of personal health information about the individual that is in the custody or under the control of a health information custodian includes the right to have the health information custodian provide the record to the individual in a PDF file.~~ with respect to the electronic format in which an individual has a right to access a record of personal health information:

1. The copy of the record provided by the health information custodian must be a PDF file, if the individual requests access in that format.

~~(2) A health information custodian is exempt from the requirement described in subsection (1) to provide a record in a PDF file if doing so would result in undue hardship to the health information custodian, having regard to the nature of the health information custodian's records, the capacity of the health information custodian to utilize technology and the financial costs of complying with the requirement.~~