Information and Privacy
Commissioner of Ontario
Commissaire à l'information et à la
protection de la vie privée de l'Ontario

December 12, 2024 ***VIA ELECTRONIC MAIL & ONLINE SUBMISSION***

Christine Hogarth, Chair
Standing Committee on Social Policy
Legislative Assembly of Ontario
Whitney Block, Room 1405
99 Wellesley Street West
Toronto, ON M7A 1A2

To Ms. Hogarth:

Re: Schedule 6 to Bill 231, *More Convenient Care Act, 2024* amending the *Personal Health Information Protection Act, 2004*

I am writing regarding Bill 231, *More Convenient Care Act, 2024*, specifically Schedule 6 amending the *Personal Health Information Protection Act, 2004* (PHIPA or the Act). As Ontario's Information and Privacy Commissioner, I am an independent Officer of the Legislature mandated to protect individuals' privacy and access to information rights. As part of that mandate, I offer advice on the privacy and access to information implications of proposed legislative schemes such as Schedule 6.

INTRODUCTION

According to the government, Schedule 6 will make it easier for Ontarians to access their health care records.[1] It involves significant changes to the province's health privacy statute, PHIPA, including the introduction of a digital health identifier tool or Digital Health ID. The intent is for Ontarians to use Digital Health IDs as a key to a digital doorway. The doorway is intended to open access to health records contained in the centralized health record data repository known as the provincial Electronic Health Record (EHR)[2] and other undefined services as may be prescribed.

The government first put forward its plan for Digital Health IDs tied to EHR access last summer in a pair of proposed regulations. In my public comments on that proposal, my office concluded that despite laudable intentions to give Ontarians easy and meaningful access to their health information, the proposed regulations were "rushed, problematic and incomplete".[3] I recommended that the government not move forward with the regulations and instead complete the necessary operational, design, and policy development work first. Unfortunately, much of the

[1] Comments of Hon. Syliva Jones, Minister of Health on first reading of Bill 231 (accessed on December 3, 2024, available here).
[2] Part V.1 of PHIPA.
[3] Information and Privacy Commissioner of Ontario, Public comment re: Proposed regulations impacting individual access to electronic health records, establishing a digital identity ecosystem and other new digital health-related tools. Published September 4, 2024. Access December 3, 2024, available here.

content of the regulations has simply been repackaged into Schedule 6 of Bill 231. As a result, the Schedule suffers from many of the same defects as the previous regulatory proposals.

SUMMARY OF IPC CONCERNS AND RECOMMENDATION

Schedule 6 of Bill 231 depends on the persistent collection, use, and disclosure of large quantities of Ontarians' sensitive personal health information. It repeals rights that were meant to be enabled and tests the principles of transparency and accountability rather than fostering them. It also further confuses the many roles of Ontario Health and challenges my office's ability to oversee and enforce the law.

Rather than fostering trust, the sum of all these factors invites mistrust in the very digital health system that the government seeks to build. If Ontarians do not trust (or understand) what the government, its agencies and subcontractors are doing with their personal health information, they will not opt in to the use of digital IDs. The right of access to one's EHR will be hampered, as will widespread adoption of digital health tools. Unfortunately, the related benefits to people's health outcomes and the health care system as a whole may not be realized.

For these reasons, which I explain further in this submission, **I urge the legislature to strike Schedule 6 from Bill 231** until such time as these critical issues can be properly addressed and reintroduced in an improved legislative proposal.

CONCERNS WITH SCHEDULE 6

1. Rather than confer individuals access rights to their health records in the EHR, Schedule 6 actually diminishes those rights.

Schedule 6 actually repeals Ontarians' already-established right of access to their records in the EHR. Since 2016, PHIPA has contained provisions guaranteeing individuals' right to access their personal health information contained in the EHR.[4] Enabling individuals easy, meaningful access to all of their health records in one centralized place supports people's efforts to better understand and control their own health care. The government had yet to proclaim these provisions, which include access to one's health care records[5] and a set of activity logs related to who else has had access to them.[6] The government passed related regulations in 2022 in anticipation of proclaiming these PHIPA provisions into force,[7] but for operational reasons, the latter never happened, and these access rights have remained dormant ever since.

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[4] Section 1(10) to the *Health Information Protection Act, 2016*.
[5] See PHIPA, Sec. 51(5) para. 1.
[6] See PHIPA, Sec. 51(5) para. 2. These logs include those that track when a health record is viewed, handled, or otherwise dealt with (para. 4 to Sec. 55.3 of the Act); when a person limits who else may access their record(s) (known as a "consent directive", para. 5 to Sec. 55.3 of the Act); and, when that "direction" is overridden for one reason or another (known as a "consent override", para. 6 to Sec. 55.3 of the Act.). Note there is a similar requirement for custodians to track this information on their end of the data flow (Sec. 51(6) of the Act). It is not proclaimed.
[7] See O. Reg 329/04, Secs. 18.1.1 and 18.1.2.

If Bill 231 were to receive Royal Assent, Schedule 6 would repeal these access rights altogether (Sec. 14). Schedule 6 contemplates reintroducing EHR access rights; however, those changes would only come into force on a later date to be proclaimed by the Lieutenant Governor of Ontario (Sec. 15(5)). While Schedule 6 of Bill 231 may reintroduce access rights to the EHR, it would authorize the government to narrow these rights through rule-making authority by excluding classes of records from the application of the EHR access provisions, excluding classes of persons from access to those records, or by blocking access altogether (Sec. 13(2), m.2 and m.6). This language plainly diminishes Ontarians' right to access all of their health records.

Moreover, the current proposal on its face sets up a two-tiered access system: one for those who can use Digital Health IDs to gain digital access (to their records) and one for those who cannot use it. For example, minors, individuals who lack the capacity to consent to the collection, use and disclosure of their personal health information, those without a health card with picture ID, and those who lack access to devices would not be eligible to use a Digital Health ID and therefore digitally access the EHR.[8] Many of these individuals will likely be among our most vulnerable and marginalized.

2. The Digital Health ID scheme relies on open-ended authority and leaves out why and how it will be used, and by whom

Schedule 6 introduces Digital Health IDs through a new Part V.2 in PHIPA but leaves out why and how this new tool will be used and by whom. Digital Health IDs, and the digital health identifier activities on which they depend, involve the persistent collection, use, and disclosure of Ontarians' sensitive personal health information. This includes their health card number and all the information it contains, as well as their photo. The "verification and validation services" authorized under Part V.2 involve comparing an Ontarian's face through a "selfie" to their health card picture. This information will be stored in a new database to which unnamed, undetermined actors will have access.[9] Yet the Schedule does not set out any limits on how and when Digital Health IDs may be used, the purposes to which they may be directed, and the parties who may rely on or use it. Without such limits, Digital Health IDs can potentially be used for anything — and by anyone. In fact, the Schedule explicitly removes the purpose of the prescribed organization (Ontario Health, in this case) from the confines of Part V.1 of PHIPA in respect of developing and maintaining the EHR and contemplates defining its purpose instead through future rulemaking (Secs. 1(2) and 13(1)(d.1)). This approach raises serious transparency and accountability concerns, to say nothing of the privacy risks.

Further, there is no requirement to log any collection, use or disclosure of "Digital Health Identifier Records" under Part V.2 in activity logs that would demonstrate who is collecting, using, and disclosing those records.[10] Nor is there any right of access to those logs to facilitate individuals' ability to know who is doing what with their personal health information. A requirement to keep

[8] See supra note 3 at pgs. 4-5 (where our submission on the summer proposal highlights the exclusionary design of the digital health ID scheme, which requires limiting eligibility for operational reasons).
[9] See supra note 3 at pg. 7 (where our submission on the summer proposal details, among other privacy risks, the scheme's reliance on third parties to perform the Digital Health Identifier Activities).
[10] Note the only reference to logging or auditing requirements is through optional ministerial directives. See Sec. 8,55.26(1)(c).

such logs with respect to Digital Health ID records, and Ontarians' right to access them, are necessary transparency and accountability requirements for any large-scale data repository. PHIPA already has requirements to keep activity logs and provide access to such logs in respect of the EHR, and such requirements are just as necessary for Digital Health IDs.

3. Schedule 6 potentially unravels established rights and requirements under PHIPA by way of future rule making

Schedule 6 authorizes major reworking of the application of PHIPA through rulemaking to modify or exclude the application of several key parts of the Act without any justification or purpose. For example, Schedule 6 would require "express consent" for the collection, use and disclosure of personal health information for the purpose of conducting digital health identifier activities (Sec 8, 55.17), yet simultaneously authorizes modification or exclusion of Part III which governs consent. Most notably, Schedule 6 explicitly authorizes excluding the Act's consent requirement for "specified activities" to be named in future rulemaking (Sec. 8, 55.27(h)). This authority to limit the consent requirements exists in two additional places of the Schedule (Secs. 8, 55.18 and Sec. 13(1)(d.7). While there are consent exceptions in PHIPA currently, and potentially others may be justified over time, such fundamental policy choices should be circumscribed by a clear and justifiable purpose in the law itself, not left open to be determined through future regulations.

The Schedule contains other expansive and vague permissions to modify PHIPA's carefully constructed, privacy-protective framework through future rulemaking. For example, it authorizes other persons to be prescribed to collect, use or disclose personal health information related to Digital Health IDs (Sec.8, 55.27(m)). Rulemaking may also prescribe further disclosures of personal health information by health information custodians or other persons to the prescribed organization overseeing the Digital Health IDs (Sec.8, 55.27(c)).

The use of Ministerial Directives to make important policy choices (Sec. 8, 55.26) is also problematic. Although the Schedule includes public consultation and engagement for their development, Ministerial Directives do not seem appropriate for the purposes for which they are being proposed. Directives are appropriate for guiding the implementation of legal requirements, not for establishing the very legal requirements to be implemented. Yet the government seeks to use Ministerial Directives to create requirements with respect to key topics such as "the eligibility of individuals or groups of individuals to receive digital health identifier activities" (subsection a) and "audit log and auditing requirements" (subsection c). Substantive requirements such as these should be set out directly in the Act and its regulations.

4. Ontario Health's discrete and separate data roles are being conflated and converged

Schedule 6 conflates and converges Ontario Health's many discrete, separate authorities especially in its capacity as the prescribed organization. Its role in respect of Digital Health IDs under the proposed new Part V.2 (Sec. 8) is a separate function from that of its existing role maintaining the EHR (under Part V.1). However, the distinction between these roles is not clearly delineated in the Schedule, and owing to several unfortunate drafting errors or oversights, Schedule 6 is difficult and confusing to understand. Practically speaking, this will make implementing and operationalizing the initiative that much more complicated as well. Note too that the impact goes

beyond merely Ontario Health. The Digital Health ID scheme requires a complex set of moving parts and involves unnamed third parties as agents that may be used to facilitate the technology. The complexity of all of this cannot be overstated.

In addition, Schedule 6 authorizes Ontario Health broad latitude to step into the shoes of a health information custodian, with all the flexibility reserved for health care providers that maintain a direct relationship with a person (Secs. 8 and 13(1)(d.5)). Yet, Ontario Health would not be providing direct health care to individuals as part of a digital identity scheme. This authorization to function "as if it were a custodian" also invites the government to further expand the authorities of Ontario Health to collect, use, and disclose personal health information in yet undefined ways. Ontario Health already holds multiple *other* functions under PHIPA, including but not limited to "prescribed organization" for purposes of the EHR, "prescribed entity"[11] and "prescribed person".[12] Affording Ontario Health with additional authorities as if it were a custodian will further confuse and confound its roles and responsibilities under PHIPA. For example, as drafted, Schedule 6 may authorize through rulemaking the exchange of Ontario's personal health information between Ontarian Health's many functions for unspecified purposes. If the government wishes to expand the authorities of Ontario Health, it must be clear and transparent in how it intends to expand them and for which purposes. This should be part of a more coherent and workable scheme, rather than expanding the organization's many roles through vague and incremental rule making. Clarity and coherence would enable Ontarians to better understand who is doing what and for what purposes so they could exercise their right of privacy vis a vis Ontario Health and its agents more meaningfully.

5. Schedule 6 hampers enforcement and oversight with incomplete and inconsistent powers

Clarity and coherence of the many roles of Ontario Health would also assist my office's oversight and enforcement role. As it is, my office is charged with reviewing Ontario Health every three years with respect to its many prescribed statuses under PHIPA. Taking the time to carefully rationalize and simplify the many interrelated functions of the agency writ large, including the new functions being proposed, as part of a more coherent scheme would greatly facilitate and streamline the three-year review process not only for my office, but for the prescribed organization and its agents as well.

Schedule 6 is inconsistent and incomplete in its approach to my office's oversight and enforcement authority. As drafted, Schedule 6 leaves several clear gaps in oversight of the prescribed organization. Schedule 6 does not clearly address oversight and enforcement with respect to Ontario Health's functions under Part V.1, Part V.2 and Part V. For example, it only directly addresses oversight of Ontario Health that is related to individual access to records rather than the full suite of powers and duties the agency is being given as prescribed organization (Sec. 9). The order-making powers should go beyond Ontario Health's obligation to enable individual access to records (Sec. 10). Yet the current language of Schedule 6 fails to include all order-making powers needed to address Ontario Health's many roles and ensure that it has and follows adequate

[11] PHIPA, Sec. 45(1).
[12] PHIPA, Sec. 39(1)(c).

practices and procedures to protect the privacy of individuals and maintain the confidentiality of their personal health information.

CONCLUSION

Like the government's proposal last summer, Schedule 6 appears unduly rushed and awkwardly tacked onto PHIPA. Similar to my comments on the regulatory proposals of last summer, my view of Schedule 6 remains the same. The result of the drafting choices is a complex and confusing set of provisions that will be very difficult to interpret, implement and enforce in practice.[13]

To be clear, the objective underlying Schedule 6 is something I fully support — enabling easy, meaningful access to one's health records is a core mandate of my office. I agree with the government that EHR access can help Ontarians better manage their health, and in turn, help create efficiencies in the health care system. Unfortunately, Schedule 6 as currently conceived is not drafted to achieve this objective and is not set up to support the policy goals behind them.

I therefore recommend that the Legislature strike Schedule 6 from Bill 231, to allow time for government to properly address and resolve the issues identified above. As always, my office stands by ready to assist and support in any way we can.

In the spirit of openness and transparency, I will be posting this letter on my office's website.

Sincerely,

Patricia Kosseim
Commissioner

c. Hon. Sylvia Jones, Minister of Health
Deborah Richardson, Deputy Minister of Health
Matthew Anderson, Chief Executive Officer, Ontario Health

[13] See supra note 3 at pg 2.