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# Comments of the Information and Privacy Commissioner of Ontario on Bill 138

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# COMMENTS OF THE INFORMATION AND PRIVACY COMMISSIONER OF ONTARIO ON BILL 138

## SCHEDULE 30: *PERSONAL HEALTH INFORMATION PROTECTION ACT, 2004*

Schedule 30 to Bill 138, *Plan to Build Ontario Together Act, 2019* (Bill 138) introduces discrete yet significant amendments to the *Personal Health Information Protection Act, 2004* (*PHIPA*). The Office of the Information and Privacy Commissioner of Ontario (the IPC) has reviewed these changes and has the following comments.

## 1. OVERARCHING COMMENTS

The Ontario government is in the process of transitioning the delivery of publicly funded health care to Ontario Health Teams and of amalgamating various provincial health agencies into a super-agency — Ontario Health. Schedule 30 to Bill 138 would create several regulation-making powers governing how Ontario Health and Ontario Health Teams can collect, use and disclose personal health information. Given the potential for these changes to transform how health information is shared in Ontario, the IPC believes the legal authorities for Ontario Health Teams and Ontario Health should be made directly into *PHIPA*, and not be left to regulation. This will help ensure that these changes are transparent to the public, and that these authorities can be the subject of deliberation in the legislature.

Lastly, the IPC is concerned that the breadth of the proposed regulation-making power could potentially authorize the making of regulations permitting the commercialization of Ontarian's health information. This issue will be addressed later in this submission.

## 2. ENSURE ACCOUNTABILITY FOR ONTARIO HEALTH TEAMS

The transition to Ontario Health Teams raises significant challenges, particularly relating to how personal health information will be collected, used and disclosed by persons or entities participating in Ontario Health Teams.

By way of background, *PHIPA* governs regulated entities called "health information custodians" (custodians), which include hospitals, doctor's offices, long-term care

homes, etc. Custodians are subject to various obligations, including restrictions on the collection, use and disclosure of personal health information, the obligation to provide patients with access to their health records subject to limited exceptions, the requirement to be transparent about their information practices, and the obligation to notify patients of privacy breaches. Custodians are also subject to oversight by the IPC.

The transition to Ontario Health Teams has the potential to undermine the protection of personal health information in the custody or control of custodians — because an Ontario Health Team is not, in and of itself, a custodian. And, as currently worded, Schedule 30 would permit non-custodians to participate in Ontario Health Teams and have the authority to collect, use and disclose patient information. As non-custodians, they may not be subject to the rules established by *PHIPA* nor to oversight by the IPC.

The IPC is therefore significantly concerned with the possibility that non-custodians be able to participate in Ontario Health Teams and not be subject to the same privacy obligations as custodians under *PHIPA*. Going forward, the government must ensure that only custodians are permitted to collect, use and disclose personal health information as part of Ontario Health Teams, unless there is a comprehensive privacy framework that applies equivalent obligations on non-custodian participants in the teams. These non-custodian participants must also be subject to IPC oversight. Until such a framework is in place, the ability to collect, use and disclose personal health information should be limited to custodians.

The following proposed amendment would clarify that only custodians can collect, use and disclose personal health information under *PHIPA* as participants in Ontario Health Teams.

Amend clause (n.3) to section 73(1) of *PHIPA* (in section 8 of schedule 30) to read:

(n.3) prescribing,

i) under what circumstances a health information custodian who is, or is a part of, a person or entity or group of persons or entities designated under subsection 29 (l) of the *Connecting Care Act, 2019* may collect, use and disclose personal health information,

ii) conditions and requirements that apply to the collection, use and disclosure of personal health information ~~by a person, entity, or group~~ mentioned in subclause (i), and

iii) disclosures of personal health information that may be made by a health information custodian or other person to a health information custodian ~~person, entity or group~~ mentioned in subclause (i);

# 3. CLARIFY THE PROHIBITION ON RE-IDENTIFICATION

Section 3 of Schedule 30 to Bill 138 would amend *PHIPA* to prohibit a person from using or attempting to use de-identified information to identify an individual. The IPC supports this prohibition. However, the wording currently proposed is overly broad.

Section 11.2(2) sets out the exception to the prohibition on re-identifying an individual established in section 11.2(1). The IPC believes that subsection (2) lists the appropriate individuals and organizations who may use de-identified information to identify an individual. However, by adding the words, "unless this Act or another Act permits the information to be used to identify the individual" to subsection (1), the ability to re-identify individuals would likely in fact apply to organizations beyond those set out in subsection (2). The IPC therefore recommends that this limiting language be removed from section 11.2(1) and placed in section 11.2(2). This amendment would also ensure that organizations who are able to re-identify an individual may only do so where permitted by *PHIPA* or another act.

This section would therefore be amended as follows:

> 11.2 (1) Subject to subsection (2) and to any other exceptions that may be prescribed, no person shall use or attempt to use information that has been de-identified to identify an individual, either alone or with other information, unless this Act or another Act permits the information to be used to identify the individual.
>
> (2) The limitation in subsection (1) does not prevent any of the following from using information that they de-identified, either alone or with other information, to identify an individual if the identification of the individual is a use of the information that is permitted by this Act or another Act:
>
> 1. A health information custodian.
> 2. A prescribed entity mentioned in subsection 45 (1).
> 3. A prescribed person who compiles or maintains a registry of personal health information.
> 4. Any other prescribed person.

Lastly, going forward, the proposed prohibition on re-identification should be brought into force as part of a comprehensive series of amendments that address de-identification, including the purposes for which personal health information can be de-identified and regulating recipients of de-identified information. This is particularly important given the IPC's broader concern about the commercialization of Ontarians'

health information, and the potential for this to occur with de-identified information. This is discussed in more detail in the below section.

The IPC should also note that there are other amendments in Schedule 30 to Bill 138 that the IPC supports (and even recommended), such as the amendment to the IPC's order-making power under clause 61(1)(e) of *PHIPA*.

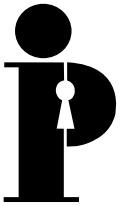
## 4. A NOTE OF CAUTION ABOUT COMMERCIALIZATION

The commercialization of personal data by government is an increasing concern to the public. This concern remains even if attempts to de-identify the data are made prior to the government's sale of the data to private corporations.

This issue is exacerbated when the discussion turns to personal health information. In the course of seeking health care, Ontarians provide this information to their health care providers. Even if de-identified, the government or health care provider does not "own" this data. Ultimately, it remains the information of the patient. The sale of health information by the government, without complete transparency and public consultation and support, is unacceptable.

As a result, the IPC is concerned that the breadth of the proposed regulation-making powers in schedule 30 could potentially authorize regulations permitting the commercialization or monetization of Ontarian's health information. While the IPC understands that this is not the stated purpose for these powers, any move towards the commercialization of Ontarian's health information, without proper public discussion and support, would be opposed by this office.

While health information, properly de-identified, might be of great value in improving the health care system, it should not be viewed by government as a source of revenue. Similarly, while it might be acceptable for Ontario Health to collect, use and disclose personal health information for health care and planning purposes by way of regulation, it is quite a different matter to enable the commercialization of individuals' health information by this method. If the government is considering giving Ontario Health the ability to sell health data to private interests, this must be done transparently and with specific amendments to *PHIPA* itself. This will allow for the required public debate on this controversial issue to take place.



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