

Comments of the Information and Privacy Commissioner of Ontario on Proposed Regulation under *PHIPA* with respect to the Health Data Platform

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Information and Privacy
Commissioner of Ontario

Commissaire à l'information et à la
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INTRODUCTION

The June 20th, 2020 edition of the Ontario Gazette contains a notice by the Minister of Health of a proposed regulation (the Proposed Regulation) under the *Personal Health Information Protection Act, 2004 (PHIPA)*. The Proposed Regulation permits Ontario Health and the Institute for Clinical Evaluative Sciences (ICES) to disclose personal health information to the Minister of Health for the purposes of researching, analyzing, investigating, preventing, responding to or alleviating COVID-19 or its effects.¹ The Information and Privacy Commissioner of Ontario (IPC) understands that the Minister of Health intends to collect the personal health information disclosed under the Proposed Regulation using a health data platform (Health Data Platform).

While the IPC supports the intention of the Minister of Health to assist in responding to COVID-19 or its effects, the IPC makes the following recommendations regarding the Proposed Regulation consistent with Ontario's privacy laws, as well as the principles enunciated in the recently issued Joint Statement of the Federal, Provincial and Territorial Privacy Commissioners on May 7, 2020.²

1. PLACE A TIME LIMIT ON THE PERMITTED DISCLOSURES IN THE PROPOSED REGULATION

The Proposed Regulation does not include a time limit on the permitted disclosures to the Minister of Health for the purposes of researching, analyzing, investigating, preventing, responding to or alleviating COVID-19 or its effects. The Minister of Health's notice in the June 20, 2020 edition of the Ontario Gazette provides that the Proposed Regulation would be in force for 24 months. The IPC recommends therefore that the 24-month time limit be specifically prescribed in the Proposed Regulation.

Limiting the time period under which ICES and Ontario Health are permitted to disclose personal health information to the Minister of Health is an important means of ensuring that this sensitive information is only collected during the timeframe when it is needed to address COVID-19 or its effects. Placing a time limit on the permitted disclosure of personal health information is also consistent with the principles of data minimization under *PHIPA*, which require personal health information only be collected, used, and

¹ Purpose as set out in the posted consultation draft of the Proposed Regulation, *Ontario Regulation to be made under the Personal Health Information Protection Act, 2004, Amending O. Reg. 329/04 (General)*, see *Ontario Gazette* Vol 153-25 pages 1589-92, at page 1590 and also the *Ontario Regulatory Registry* as posted on June 19, 2020.

² See the *Joint Statement by Federal, Provincial and Territorial Privacy Commissioners* dated May 7, 2020.

disclosed where it is necessary for the purpose and that no more personal health information be collected, used, and disclosed than is necessary for the purpose.

The IPC is concerned that if the 24-month time limit is not specifically prescribed in the Proposed Regulation, the disclosure of personal health information may continue beyond the needed timeframe for the purposes of COVID-19. Prescribing a time limit in the Proposed Regulation will help to reassure the public that the disclosure of this sensitive information will only occur during a limited timeframe to address COVID-19 or its effects, as per its stated purpose.

The IPC recommends that section 2 of the Proposed Regulation be amended as follows:

Subsection 18 (11) of the Regulation is revoked on the second anniversary of the day on which subsection 18 (11) comes into force.

In addition, the Minister of Health should ensure that the Proposed Regulation is not extended beyond this time limit unless it is necessary to alleviate COVID-19 or its effects.

2. REQUIRE THAT THE PERSONAL HEALTH INFORMATION COLLECTED BE SECURELY DISPOSED OF OR DE-IDENTIFIED WHEN THE PROPOSED REGULATION EXPIRES

The Proposed Regulation does not place any restrictions on the retention of the personal health information on the Health Data Platform or address whether the Minister of Health will be permitted to continue to use the personal health information to the extent it remains on the Health Data Platform when no longer needed to respond to COVID-19.

The IPC understands that the Minister of Health is considering whether to retain the personal health information on the Health Data Platform for purposes not related to COVID-19 or, alternatively, to dispose of the personal health information at the conclusion of the 24-month time limit. The Proposed Regulation provides that the permitted disclosure to the Minister of Health is for the purposes of researching, analyzing, investigating, preventing, responding to or alleviating COVID-19 or its effects. The people of Ontario should understand whether the personal health information collected under the Proposed Regulation will be securely disposed of at the end of the COVID-19 crisis or will be retained on the Health Data Platform for other purposes unrelated to COVID-19.

The IPC recommends that the information be securely disposed of, de-identified or aggregated in non-identifiable form at the conclusion of the 24-month time limit when the personal health information will no longer be needed for the purposes set out in the Proposed Regulation. This would be consistent with the principles of data minimization under *PHIPA*, referenced above.

The IPC recommends that the Proposed Regulation be amended to prescribe that the personal health information must be securely disposed of, aggregated in non-identifiable form or de-identified in compliance with the requirements under *PHIPA* and O. Reg. 329/04 at the conclusion of the 24-month time limit.

3. UPHOLD PRINCIPLES OF NECESSITY AND PROPORTIONALITY FOR THE BENEFIT OF THE PEOPLE OF ONTARIO

The Proposed Regulation specifies that a disclosure of personal health information by ICES and Ontario Health to the Minister of Health is only permitted where the Minister has determined that the disclosure is necessary for the purposes of researching, analyzing, investigating, preventing, responding to or alleviating COVID-19 or its effects. The Minister of Health must ensure that any disclosures under the Proposed Regulation are only made to the extent necessary and proportionate to the stated purposes in the Proposed Regulation. This is consistent with the data minimization requirements under *PHIPA*.

The IPC recommends that the Minister of Health implement policies and procedures to ensure that ICES and Ontario Health only disclose personal health information to the Minister that is necessary and proportionate for the purposes set out in the Proposed Regulation.

4. PROVIDE THE PEOPLE OF ONTARIO WITH INFORMATION REGARDING THE HEALTH DATA PLATFORM

Transparency is a fundamental pillar of an open government. The people of Ontario may have questions or concerns about the nature of information being collected about them, the purposes for collecting that information, and how that information will be kept secure. The Minister of Health should make available to the public information about the Health Data Platform and the policies and procedures implemented to protect the privacy of individuals and the security of the information.

Specifically, the IPC recommends the Minister of Health make the following information about the Health Data Platform available on a publicly accessible website in plain language:

- a description of the purposes of the Health Data Platform;
- a description of the information collected, used and disclosed;
- a description of the format in which the information is collected, used and disclosed including whether the information is in identifiable, de-identified or aggregated format;
- a description of the process for reviewing and approving research projects that may be permitted access to the Health Data Platform;
- a list of approved research projects, along with a description of the project, the purpose of the research, the persons or organizations conducting the research, and the amount and type of information used;
- a copy of the privacy policies and procedures implemented in respect of the Health Data Platform, including a description of the physical, technical and administrative safeguards implemented to protect the privacy of individuals and the security of the information;
- a statement about whether the information on the Health Data Platform will be securely disposed of at the conclusion of the 24-month time limit or retained thereafter; and
- if retained, a description of the format in which the information will remain on the Health Data Platform after the 24-month time limit and the purpose of the retention.

5. ENSURE APPROPRIATE OVERSIGHT AND ACCOUNTABILITY TO THE PEOPLE OF ONTARIO

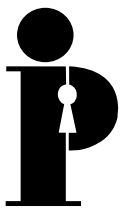
As a big data initiative, the Health Data Platform will contain a substantial amount of highly sensitive personal health information including whether an individual has tested positive for COVID-19. As the health information custodian responsible for the Health Data Platform, the Ministry of Health must ensure there is appropriate oversight and accountability to protect the privacy of Ontarians and the confidentiality of the personal health information contained within the platform.

All service providers who take part in the creation and maintenance of the Health Data Platform and all third parties with access to the data must be required to adhere to the same principles and standards that apply to the Ministry. Further, the Ministry must remain demonstrably accountable for all decisions made respecting the use and disclosure of the data in the Health Data Platform.

6. PRIVACY AND SECURITY OF THE INFORMATION ON THE HEALTH DATA PLATFORM

The Health Data Platform is a novel and unique data research platform that offers the potential to greatly enhance research capabilities and be more agile in the response to COVID-19 or its effects. However, like all other large data repositories or platforms, it also presents inherent challenges and risks to privacy and the security of the personal health information it contains, including the potential for breach or cyber security attacks.

The Ministry of Health must take steps to ensure that it implements and operates a data platform that adheres to legislated privacy and security requirements and the reasonable expectations of the people of Ontario when it comes to effective safeguards and protections of their personal data.



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