



Information and Privacy
Commissioner of Ontario

Commissaire à l'information et à la
protection de la vie privée de l'Ontario

VIA ELECTRONIC MAIL & ONLINE SUBMISSION

May 17, 2023

Goldie Ghamari
Chair of the Standing Committee on Justice Policy
Legislative Assembly of Ontario
99 Wellesley Street West
Room 1405, Whitney Block
Queen's Park
Toronto, ON M7A 1A2

Dear Chair Ghamari:

**RE: Written Submission to the Standing Committee on Justice Policy for the
Legislative Assembly of Ontario: Schedule 2 of Bill 102, *Strengthening
Safety and Modernizing Justice Act, 2023***

As an Officer of the Legislature with a mandate to protect the access and privacy rights of Ontarians, I am writing with reference to Schedule 2 of Bill 102, *Strengthening Safety and Modernizing Justice Act, 2023*, recently introduced in the Ontario Legislature.

If Bill 102 is passed, Schedule 2 will amend the *Coroners Act* to expand regulation-making authority by repealing and substituting section 56 (1)(g) to include "collection" authority for tissue samples, implanted devices and body fluids obtained from a body that is the subject of a *post mortem* examination or other examination or analysis under section 28. In addition, Schedule 2 stipulates that the regulation-making authority in section 56 (1)(g) may be used to permit examinations and analyses for an open-ended and unspecified range of purposes and techniques, including but not limited to, examinations and analyses for the purpose of enabling genetic analysis.

Background

The Office of the Information and Privacy Commissioner of Ontario's (IPC) powers and authorities to oversee the collection, use and disclosure of personal information by provincial public institutions are set out in the *Freedom of Information and Protection of Privacy Act (FIPPA)*. The Office of the Chief Coroner of Ontario is subject to *FIPPA*, as it is part of the Ministry of the Solicitor General (the Ministry).

Under *FIPPA*'s provisions, a deceased individual's information only ceases to be personal information after they have been dead for more than 30 years. Before then, the collection of tissue samples, implanted devices and bodily fluids (tissues, devices and fluids), as well as the analysis of those materials, can have significant impact on the human dignity and personal privacy of deceased individuals. Because of its unique and sensitive nature,



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genetic information can also have significant implications for their families as well. Rapid advances in genomic technologies may allow for broader insights to be derived from genetic information, as seen through the recent use of investigative genetic genealogy (IGG) by police, for example. The potential for prejudicial impacts on families and broader communities has yet to be fully understood and the appropriate guardrails have yet to be put in place to ensure ethical and responsible use of these new technologies.

Based on information provided by the Ministry and the Chief Coroner and our analysis of Bill 102, it is our understanding that:

- The regulation-making powers proposed under Schedule 2 would enable the Ministry to allow the coroner to collect, retain and store tissues, devices and fluids for purposes beyond the immediate needs of a death investigation;
- The intended scope of activity to be authorized under a Schedule 2 regulation is the identification of hereditary diseases and the identification of unknown deceased persons; and
- Tissues, devices and fluids obtained from the body may be retained for future testing purposes by the coroner for the identification of hereditary diseases and the identification of unknown deceased persons.

I recognize the Ministry's laudable objective to amend the *Coroners Act* to improve public health, provide human dignity to the deceased and bring emotional closure for their family. However, the intended constraints around the intended application of Schedule 2 are not mirrored in its proposed language. If clear purpose limitations are not enshrined in the legislative language, Schedule 2 may facilitate additional and unknown future activity around genetic analysis, creating significant privacy risks.

IPC Comments and Recommendations on Schedule 2

The IPC's main concerns and recommendations with respect to Schedule 2 are set out below for your consideration.

1. Purpose Limitation

Schedule 2's draft language is not clear on its intended purpose for genetic analysis, namely the identification of hereditary diseases and the identification of unknown deceased persons. We recommend that Schedule 2 be clarified as follows:

- i) Specify that the regulations made under section 56 (1)(g) are restricted to the duties of the coroner consistent with the *Coroners Act*, and
- ii) Create a purpose limitation for collection, retention, use, and disclosure of tissues, devices and fluids obtained from a body, and related analysis, including genetic analysis, that restricts future activity to the identification of hereditary diseases and the identification of unknown deceased persons.

Use of tissues, devices and fluids beyond the identification of hereditary diseases and the identification of unknown deceased persons, such as criminal investigations by police, raise significant privacy and human rights concerns, particularly in light of rapidly-evolving technologies that are making possible today things that were never before even imagined.¹ Such uses **should only** be pursued when appropriate statutory guardrails have been put in place to protect individuals, families and communities.

2. Post Collection Safeguards

Given the highly sensitive nature of the information at issue, there must be reasonable safeguards in place for practices and procedures after tissues, devices and fluids have been collected from a body. On that basis, we recommend that Schedule 2 be further amended to specify the following:

- i) The tissues, devices and fluids retained under the Office of the Chief Coroner's custody or control, including within information management systems and local databases, cannot be used as an index or search record system that includes, or is linked, to any biometric information for purposes other than identifying hereditary diseases and identifying unknown deceased persons, and
- ii) The disclosure of records or tissues, devices and fluids to police, or other third parties, must only be permitted through specified legal processes, such as a judicial warrant or production order.

3. Public Consultation

There is significant public interest around genetic testing and its future insights, particularly when combined with other investigative techniques and technologies that are not necessarily infallible. Ontarians should be informed of future regulations that may impact their privacy and consulted prior to their adoption. On that basis, we recommend that Schedule 2 be amended to specify a requirement for public consultations, consistent with the approach required under section 74 of the *Personal Health Information and Protection Act*, before making regulations that would enable biometric analysis, including genetic analysis.

It may interest Committee members to know that my office will be holding a strategic foresight event in September 2023, where we intend to engage multiple interested parties in a deliberative dialogue to anticipate and address the future risks and implications of genetic genealogy in the context of law enforcement. We intend to publish the results of this event to help support informed public debate of what an appropriate and effective governance framework might look like.

¹ Elizabeth Anne Brown, "[Your DNA Can Now Be Pulled From Thin Air. Privacy Experts Are Worried](#)", *New York Times*, May 15, 2023

Thank you for receiving my recommendations on Schedule 2. I would be pleased to answer any questions Committee members may have. In addition, I encourage the Ministry to consult with my office on these matters.

In the spirit of openness and transparency, I am providing a copy of this letter to the Minister, Deputy Minister, as well as the Chief Coroner, and will be posting this submission on my office's website.

Sincerely,

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

Patricia Kosseim
Commissioner

Cc: Hon. Michael Kerzner, Solicitor General
Mario Di Tommaso, Deputy Solicitor General, Community Safety
Karen Ellis, Deputy Solicitor General, Correctional Services
Dr. Dirk Huyer, Chief Coroner, Solicitor General
Thushitha Kobikrishna, Committee Clerk, Standing Committee on Justice Policy