Information
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Speaking Notes for a Presentation to the Standing Committee on General Government:

Bill 31: *Health Information Protection Act*

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Good morning members of the Committee, ladies and gentlemen. I am very pleased to have this opportunity to address the Committee today.

Since I have not yet had the pleasure to meet some of the members of the Committee, I wanted to take a minute to introduce my office. I am joined today by my Assistant Commissioner of Privacy, Ken Anderson.

My office was created in 1988 to oversee Ontario's public sector access and privacy legislation, the *Freedom of Information and Protection of Privacy Act* and three years later, its municipal equivalent, the *Municipal Freedom of Information and Protection of Privacy Act*.

I have been with the IPC since it was created in 1987, and was appointed Information and Privacy Commissioner in 1997.

Now let me start by saying how pleased I am that the new government has moved forward so quickly with the introduction of this much-needed health information privacy legislation.

My office has been advocating the need for health information privacy legislation since our office was first created in 1988.

But we are not alone in this regard – members of the public, health care providers and other stakeholders have been waiting for the introduction of this legislation since Justice Horace Krever's Report of the Royal Commission on the Confidentiality of Health Information in 1980 – 24 years ago.

There have been numerous attempts over the years to get a bill introduced and passed, but for one reason or another, they have never succeeded. This is largely due to the unique characteristics of personal health information and the enormity of the task of balancing all of the competing interests.

On the one hand, you have the need to protect the privacy of individuals with respect to their most sensitive personal information. On the other hand, you have the legitimate needs of the health sector to collect, use and disclose this information for a wide range of purposes that not only benefit the individual, but the public as a whole.

Personal health information is not only used to provide health care to the individual, but is also used to help manage and plan our publicly-funded health care system, to improve the quality of health care and for medical research purposes – uses that benefit us all.

In my view, this is the first piece of proposed health sector legislation that strikes an appropriate balance between these competing interests. I want to acknowledge the efforts of the Ministry of Health and Long-Term Care for listening carefully to stakeholder concerns and developing what I see as a very workable framework.

Positive Features of Bill 31

I would like to take a few minutes to highlight some of the improvements in this bill over previously-proposed health sector legislation.

All previously-proposed legislation has relied heavily on the use of broad regulation-making power to specify operational details – Bill 31 is no different in this respect.

But what is different about this bill is that it incorporates an open and transparent regulation-making process. While the bill includes the ability to alter the established rules through regulations, my office and the public in general will have an opportunity to comment before any regulation is adopted. This is a significant breakthrough.

Another significant improvement is the establishment of a health data institute to receive and de-identify personal health information that the government needs for analysis of the health system.

You may recall from hearings on previous legislation that there was strong opposition to the government giving itself the authority to direct any health information custodian to submit any personal health information that it needed for this purpose.

Under Bill 31, these directed disclosures of identifiable data to the government, without any oversight by my office, are a thing of the past.

We are also pleased that Bill 31 will apply to all types of personal health information – there are no carve outs for certain types of information such as mental health records.

Another positive feature of the legislation is the use of an "implied consent model" for the collection, use and disclosure of personal health information for the purpose of providing health care. In my view, this model more accurately reflects existing patient–provider interactions than the previous "no consent model" and should not in any way hinder that relationship.

This implied consent model comes with the so-called "lock box" – which allows individuals to instruct their health care providers not to disclose their personal health information to other health care providers.

I know there may be some opposition to the "lock box," particularly from health care providers, but it is important to note that an instruction not to disclose does not preclude disclosure – it just means you have to obtain express consent before the disclosure can be made.

Also, in the event that an individual does exercise the right to have certain personal health information withheld from disclosure, there are safeguards built into the legislation to ensure that health care providers inform any recipients that not all of the personal health information that they may require has been disclosed.

This will ensure that recipients know that they should be approaching the individual regarding withheld personal health information to explore obtaining consent for that information.

These are all significant improvements over previous drafts of health information privacy legislation.

IPC Concerns about Bill 31

While this legislation is significantly better than anything we have seen to date, I still have one major area of concern – my office's powers, or lack thereof, in conducting reviews.

I am particularly concerned about my inability to demand production or inquire into records of personal information without consent, unless I apply for a warrant, and a justice of the peace agrees to this. Such a limitation on a privacy oversight body is unheard of. No other jurisdiction in Canada – no other Commissioner – is subject to this limitation.

Since the conditions under which a warrant may be issued are very limited and do not include circumstances in which I merely need access to personal health information, conducting effective reviews will be virtually impossible in many cases. How can I conduct a review without access to the very information that is the subject of that review?

And it is important to point out that this type of restriction on access to personal health information does not apply across the board, but only to the oversight body.

The legislation permits the use and disclosure of personal health information without consent and without a warrant for a wide range of other purposes – to an individual conducting an audit, to the Chief Medical Officer of Health, a health professional regulatory College, the Board of Regents under the *Drugless Practitioners Act*, the Ontario College of Social Workers, the Public Guardian and Trustee, the Children's Lawyer and a children's aid society, among others.

We cannot understand why there would be greater restrictions on access to personal health information for the oversight body administering and enforcing the *Health Information Protection Act* than there are for other individuals and organizations administering and enforcing other legislation.

In addition, the proposed *Act* permits a health information custodian to disclose personal health information for the purpose of a proceeding, without consent or a warrant.

What justification is there for requiring consent or a warrant before personal health information can be disclosed for a proceeding before the Commissioner?

It is also important to note that, unlike other potential recipients of personal health information, my office would be bound by strict confidentiality provisions set out in section 66 of the *Health Information Protection Act* – so we could never use the information for any other purpose, nor could we disclose it to anyone – nor would we.

In virtually all jurisdictions with privacy legislation, including jurisdictions with legislation specifically governing the health sector, the Commissioner is permitted to access any necessary information, including personal health information.

This legislation needs to be amended to ensure that my office has access to whatever information is necessary to conduct an effective review. Only then will we be able to assure the public that health information custodians are indeed living up to their obligations under the legislation.

I am also concerned about the Commissioner's inability to compel testimony, in the absence of a warrant.

You may recall an investigation that my office conducted into the disclosure of personal information by the Province of Ontario Savings Office (POSO). In that case we were unable to conduct a thorough investigation into the disclosure of sensitive financial data, primarily because a number of key individuals refused to be interviewed. The result was a report that could not satisfy the public's right to know the full details of a public institution's non-compliance and unauthorized use of personal information.

In virtually every other jurisdiction with similar legislation, including Canada (federal), British Columbia, Alberta, Saskatchewan, Manitoba, Quebec, Australia and New Zealand, the privacy oversight bodies have the power to require testimony without a warrant. I see no reason why Ontario should fall short in this critical area.

It is also important to note that, without this power, the proposed legislation may run a serious risk of not being considered substantially similar to the federal *Personal Information Protection and Electronic Documents Act*. This would be a most unfortunate and unnecessary outcome.

Privacy oversight bodies operate primarily as privacy advocates, advisors and educators – ensuring compliance with legislation through establishing co-operative relationships with the trusted keepers.

When an issue of non-compliance arises, the vast majority of cases can be resolved through mediation, education and persuasion, as opposed to imposing penalties and sanctions. For example, under the existing public sector legislation in Ontario, over 80 per cent of privacy-related complaints and appeals are resolved informally through mediation and other alternative dispute resolution methods – rarely do we have to resort to issuing a formal investigation report or ordering an institution to take some remedial action to ensure compliance.

In the proposed legislation, the powers of the Commissioner to compel testimony and to demand the production of records only exist within the context of an inspection with a warrant. This would force the Commissioner to resort to obtaining a warrant on a frequent basis, instead of pursuing the more desirable informal route of mediation.

Since a search warrant is almost always associated with criminal or quasi-criminal activity and issued to force individuals to take some action that they would not otherwise take, it is our view that conducting inspections with a warrant would be embarrassing and humiliating to health information custodians, who are generally viewed as the trusted keepers of personal health information by the public. They are often extremely willing to co-operate in resolving any issues of non-compliance.

Routine use of warranted powers would be counterproductive, as it will change the nature of the relationship between the oversight body and the health information custodian – from a co-operative to an adversarial relationship.

It would also make the entire complaint resolution process more costly, formal and adversarial and as a result, less accessible to the general public.

The requirement to obtain a warrant in a substantial number of reviews would also place an undue burden on an oversight body, such as ours, which is a small agency with limited resources.

For all of these reasons, we strongly urge the deletion of sections 57, 58 and 59 of the proposed legislation and a complete redrafting of the provisions relating to the powers of the Commissioner in conducting a review. Please refer to our submission for specific proposed language for these powers. In summary, our recommendations would eliminate the concept of investigations with warrants and they would provide the Commissioner with the powers necessary to compel testimony and to access personal health information during a review.

Before concluding, I would like to touch on one other important change that I believe would enhance this bill. As currently drafted, health care institutions, such as hospitals, will require express consent in order to use personal health information for fundraising purposes. Although at first blush this may appear to be desirable from a privacy perspective, this does not reflect the existing realities facing health care organizations. These organizations are heavily dependent on fundraising to meet their goals and serve the public. Requiring express consent for fundraising purposes will adversely impact their ability to raise funds.

To assist organizations, and yet still provide privacy protection for patient information, we prefer an opt-out requirement for fundraising. This would allow a health care organization, or its related foundation, to make a single, initial patient contact for fundraising purposes. At that point, the patient must be given the clear opportunity to opt-out of any future fundraising solicitations. Patients must also be offered an opt-out opportunity each time their name and address is used for fundraising purposes. Of course, we support keeping the express consent requirement when patient information is used for other purposes such as marketing.

In our written submission, you will find additional recommended amendments to enhance the privacy protections provided by this legislation, to promote harmonization with legislation in other jurisdictions, particularly the federal *Personal Information Protection and Electronic Documents Act*; and to facilitate implementation of the legislation.

I invite you to read our submission for details on all of our recommendations.

Thank you for your kind attention. Please feel free to call upon me and my office to assist in any way we can as this bill progresses through the legislative process.