



Submission to the Ministry of Government and Consumer Services: Public Consultation – Reforming Privacy in Ontario’s Private Sector

October 16, 2020

1 INTRODUCTION AND SUMMARY OF SUBMISSIONS

The HIV & AIDS Legal Clinic Ontario (HALCO) makes this submission in response to the Ministry of Government and Consumer Services' (the "Ministry") consultation to strengthen privacy protections of personal data.

As is described in further detail in this submission, HIV-related stigma remains shockingly pervasive in Ontario and across Canada. For people living with HIV, the consequences of this ongoing and persistent stigma can be devastating. People living with HIV continue to face discrimination, social exclusion, and even violence across all aspects of their lives. It is therefore vital that Ontarians living with HIV have access to robust and meaningful privacy protections to prevent privacy breaches in relation to their HIV status, and access to adequate and responsive remedies when privacy breaches do occur.

Added to HIV-related stigma, the rapid proliferation of personal information online means that sensitive personal information, including personal health information, is more easily accessible than ever before. Once available online, such information is often accessible indefinitely. As a result, employers, housing providers, service providers, and family members, friends, and acquaintances can and often do search an individual's name through online search engines, and can therefore easily find and disseminate any personal information available online. Within this new reality, the need for meaningful privacy protections and remedies becomes even more acute.

HALCO strongly encourages the Province to adopt each of the eight privacy protecting measures set out in the Ministry's Discussion Paper for this consultation.¹ In this submission, HALCO will address the three proposed measures most relevant to our client communities and our mandate as a legal clinic that serves people living with HIV:

- (i) **Introducing a "right to be forgotten"**: As we describe in further detail below, people living with HIV who experience privacy breaches in relation to their HIV status often cannot access adequate remedies to minimize the potentially devastating consequences of such privacy breaches. This remedial gap typically manifests because of online disclosure of the person's HIV status (through online media coverage and/or search engine results). The generally available avenues of recourse when discrimination occurs against people living with HIV, such as courts and human rights tribunals, are almost always unable to address the online disclosure of HIV status (since the media organizations and search engine companies are typically not parties to the litigation, which is usually brought against an employer, housing provider, or other service provider that has engaged in discriminatory conduct). As a result, even if the person living with HIV is successful in litigation flowing from the discriminatory conduct they have faced, their HIV status remains easily accessible online, which means they

¹ Ontario Private Sector Privacy Reform, "[Improving private sector privacy for Ontarians in a digital age](#)", Discussion Paper at pp 3-4.

continue to be extremely vulnerable to future acts of discrimination, social exclusion, and even violence. The recognition of a right to be forgotten is therefore vital to fill this significant remedial gap. As described further below, HALCO recommends the adoption of the mechanisms of “**source takedown**” (meaning requiring the publisher to remove the material) and “**de-indexing**” (meaning requiring online search engines to no longer show results related to certain information in some circumstances) to implement a right to be forgotten. HALCO also recommends that the Province set out a clear process for entities to follow in response to source takedown or de-indexing requests, and that an independent review or appeal process be implemented for denials of such requests.

- (ii) **Increase enforcement powers for the Information and Privacy Commissioner (the “IPC”) to ensure businesses comply with the law, including the ability to impose penalties:** The most effective response to privacy breaches is to implement measures that prevent privacy breaches from occurring in the first place. Granting the IPC increased enforcement powers, including the ability to impose penalties, is much more likely to create a deterrent effect, which could motivate private and public entities to take proactive steps to prevent privacy breaches from occurring. The IPC’s enforcement powers and the scope and quantum of penalties available must be significant and robust, in order for such a deterrent effect to manifest. In addition, the IPC should be granted the authority to order compensatory remedies in response to privacy breaches, so that affected individuals are not forced to go through court or tribunal processes to be made whole (so far as a monetary remedy can do).
- (iii) **Expanding the scope of the law to include commercial and non-commercial organizations:** Ontario’s present legislative privacy regime applies only to public institutions and health information custodians. Commercial and non-commercial entities also, however, frequently commit privacy breaches. HALCO submits that Ontario’s privacy laws must be expanded to apply to such entities, so that Ontarians have access to meaningful recourse, without having to resort to costly, complex, and/or time-intensive court and tribunal proceedings.

2 THE HIV & AIDS LEGAL CLINIC ONTARIO

HALCO, founded in 1995, is a community legal clinic serving the legal needs of low-income people in Ontario who are living with HIV. It is the only such organization in Canada. The clinic is governed by a board of directors, the majority of whom must be living with HIV. In addition to providing direct legal services, HALCO staff engage in public legal education, law reform and community development initiatives. Among other activities, clinic staff have (i) handled over 65,000 legal issues, including those related to human rights, privacy, housing, income maintenance, HIV non-disclosure and the criminal law, health, immigration, insurance, and employment; (ii) conducted hundreds

of public legal education workshops; (iii) produced numerous public legal education materials; (iv) provided submissions in relation to various government consultations; and (v) intervened in proceedings affecting people living with HIV before various courts and tribunals, including on numerous occasions before the Supreme Court of Canada and the Court of Appeal for Ontario.

In HALCO's experience working directly with clients, it has been apparent that people living with HIV are very often justifiably concerned about the privacy of their HIV status and other medical conditions. Since 2001, HALCO has responded to more than 1,600 enquiries about privacy-related issues and more than 2,300 human rights issues. Privacy and human rights issues permeate all aspects of HALCO's work, whether in relation to:

- (i) direct client services, such as privacy complaints, privacy torts, and human rights complaints;
- (ii) public legal education; or
- (iii) law reform activities, such as interventions in *Sherman Estate v Donovan*² before the Supreme Court of Canada, about the test to be applied to obtain a confidentiality order in proceedings before courts and tribunals, and *Toronto Star v. Attorney General of Ontario*³, about the application of Ontario's *Freedom of Information and Protection of Privacy Act* to administrative tribunals; submissions to the Human Rights Tribunal of Ontario about access and privacy issues; and submissions to the Ministry of Health and Long-Term Care about rights of access and correction of health records under the *Personal Health Information Protection Act, 2004*.

3 STIGMA AND DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV

People living with HIV hold a vital privacy interest in relation to their personal health information. This is in part because they often experience discrimination of varying degrees of severity, as a result of the unauthorized disclosure of their HIV status. Information about a person's HIV status is extremely sensitive because it remains highly stigmatized in Canada and internationally.⁴ HALCO observes, on a far too frequent basis, how the invasions of privacy that occur when others become aware of a person's HIV-positive status create serious and concrete harms due to ongoing stigma and discrimination against people living with HIV.

² Supreme Court of Canada file number 38695, heard on October 6, 2020, decision pending.

³ [2017 ONSC 7525](#).

⁴ Canadian HIV/AIDS Legal Network, Canadian Public Health Association, "[Reducing Stigma and Discrimination Through the Protection of Privacy and Confidentiality](#)" (2017).

HIV-related stigma arises mostly from fear and ignorance about HIV and/or hostility and existing prejudices about the groups most affected by it (for example, men who have sex with men, people who inject drugs, Indigenous communities, and racialized communities). HIV-related discrimination is the unfair treatment of people on the basis of their actual or suspected HIV status. Discrimination against people living with HIV also extends to those populations at risk of HIV (for example, people who use drugs and men who have sex with men).⁵

The discrimination that people living with HIV face far too often is, unfortunately, not surprising. HIV stigma and accompanying discrimination remain pervasive in Canada. The two most recent attitudinal studies commissioned by the Public Health Agency of Canada revealed that:

- (i) 15% of Canadians feel afraid of people living with HIV;
- (ii) 24% of Canadians feel uncomfortable wearing a sweater once worn by a person living with HIV;
- (iii) 51% of Canadians would be uncomfortable if a close family member or friend dates someone living with HIV;
- (iv) 22% of Canadians feel uncomfortable shopping at a small neighbourhood grocery store owned by someone living with HIV;
- (v) 40% of Canadians would not use the services of a dentist or doctor living with HIV and 24% of Canadians would not use the services of a hairstylist or barber living with HIV;
- (vi) 66% of Canadians hold low discriminatory beliefs towards people living with HIV, 19% hold medium-level discriminatory beliefs, and 15% hold high-level discriminatory beliefs; and
- (vii) 88% of Canadians believe that people living with HIV can experience difficulty getting housing, health care, and employment because of HIV-related stigma.⁶

These survey results suggest that much of the fear surrounding the emerging HIV epidemic in the 1980s persists today.⁷ The resulting stigma and discrimination manifest in a number of ways. HALCO routinely receives inquiries for legal services related to HIV discrimination and harassment in employment, housing, education, other services, and in the context of personal and familial relationships, which result in denials of

⁵ CATIE, "[HIV in Canada: A primer for service providers](#)" (2017).

⁶ EKOS for the Public Health Agency of Canada, "[2012 HIV/AIDS Attitudinal Tracking Survey](#)" (October 2012), pp 45-58, 66-72; EKOS for the Public Health Agency of Canada, "[Canadians' Awareness, Knowledge and Attitudes Related to Sexually Transmitted and Blood-Borne Infections, 2018 Findings Report](#)" (August 2018), pp 41-45.

⁷ Avert, "[HIV Stigma and Discrimination](#)" (2018) [Avert HIV Stigma].

opportunities, social exclusion, and even violence. Discrimination and other human rights violations also occur in health care settings, barring people living with HIV from accessing health services that are essential for their well-being and survival or enjoying quality health care.⁸ Some people living with HIV and other key affected populations are shunned by family, peers, and the wider community, while others face poor treatment in educational and work settings, erosion of their rights, and psychological damage.⁹

In light of the ongoing stigma associated with HIV, it is vital for people living with HIV to have control over if and when they disclose their HIV status to others. Given the unavoidable nature and reality of online engagement, and the widespread use of online search engines, the spectre of online disclosure is tremendously broad (potentially to all who access the internet) and everlasting. HIV-related information can be discovered by those who seek out or stumble upon information, particularly through the use of search engines.

4 THE IMPORTANCE OF RECOGNIZING A RIGHT TO BE FORGOTTEN

The recognition of a right to be forgotten in Ontario is necessary to ensure that people living with HIV, and other Ontarians, have access to remedies that adequately respond to privacy breaches and discriminatory conduct. There is also a strong legal basis for recognizing a right to be forgotten in relation to sensitive personal health information.

As the Office of the Privacy Commissioner of Canada (the “OPC”) has stated, “[p]roviding an individual with some measure of control on personal information disseminated on the internet (especially where it creates a risk of harm [...]) is connected to fundamental values such as privacy, dignity and autonomy.”¹⁰ The OPC has therefore stated that it seeks to “create an environment where individuals may use the Internet to explore their interests and develop as persons without fear that their digital trace will lead to unfair treatment.”¹¹ The creation of such an online environment is incredibly important for people living with HIV.

4.1 The Basis for a Right to be Forgotten

HIV is a disability as contemplated by human rights laws across Canada. Unfortunately, however, in the vast majority of discrimination claims, people living with HIV are unlikely to achieve a “right to be forgotten” through a human rights forum. Typically, human

⁸ UNAIDS, “[Agenda for zero discrimination in health-care settings](#)” (2017).

⁹ Avert HIV Stigma, *supra* note 7.

¹⁰ Office of the Privacy Commissioner of Canada, “[Draft OPC Position on Online Reputation](#)”, at page 7. [Draft OPC Position].

¹¹ *Ibid.* at page 1.

rights cases are brought against the party that engaged in discriminatory conduct, such as an employer, landlord, or service provider. In circumstances where the discriminatory conduct has led to online disclosure of the person's HIV status (for example, through online media coverage), the human rights body typically won't have jurisdiction to order source takedown or de-indexing, since the publishers and search engines are not parties to the human rights litigation.

In addition to the need to recognize a right to be forgotten to ensure that adequate remedies exist for breaches of privacy related to HIV status, there is also a strong legal basis for recognizing such a right.

Canada and Ontario have explicitly recognized HIV as a disability in their jurisprudence and legislation. The *Canadian Charter of Rights and Freedoms* ("Charter") guarantees "the right of equal protection and equal benefit of law ... without discrimination based on ... physical disability."¹² Courts and tribunals have interpreted "disability" in the context of the Charter to include HIV.¹³ HIV is also considered a disability under all human rights legislation in Canada.¹⁴ In Ontario, HIV is recognized as a disability under the *Ontario Human Rights Code* (the "Code"), which provides that all people who have or are perceived to have HIV-related medical conditions are entitled to protection against discrimination in employment, services, housing, contracts, and membership in trade unions.¹⁵

Given that search engines use information for the creation of a "profile of the most relevant information' about [a] person that is available online,"¹⁶ it is uncontroversial to recognize that current and prospective employers, landlords, other service providers, and family members, friends, and acquaintances can and routinely do make use of search engines to execute searches to evaluate the suitability of an individual as an employee, tenant, or service user, or out of curiosity. If information in that profile includes information about a person's HIV status, however, the result can be discriminatory exclusion from employment, housing, or services, social alienation, and/or the threat of violence. Such a result would be inconsistent with the spirit underlying human rights legislation in Canada and Ontario.

Within this analysis, it is vital to note that employers, housing providers, and other service providers are almost always **not** entitled to know a person's HIV status (there are extremely limited circumstances in which such access is justifiable and/or legally permissible). Such entities often mistakenly believe they are entitled to know a person's

¹² *Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982*, being Schedule B to the *Canada Act (1982)* U.K., 1982, c. 11, s. 15.

¹³ *Brown v British Columbia (Minister of Health)* (1990), 66 DLR (4th) 444 (BCSC); *Wakeford v Canada* (1998), 166 DLR (4th) 131 (Ont Gen Div).

¹⁴ R. Elliott and J. Gold, "[Protection against Discrimination Based on HIV/AIDS Status in Canada: The Legal Framework](#)", *HIV/AIDS Policy & Law Review* 10,1 (2005): 20–31.

¹⁵ Ontario Human Rights Commission, "[Policy on HIV/AIDS-related Discrimination](#)" (November 27, 1996) at page 4-5 [OHRC Policy].

¹⁶ Draft OPC Position, *supra* note 10 at page 10; see also pages 8, 9, 16.

HIV status, but this misconception is typically based on unfounded and erroneous fears about the risk of HIV transmission (HIV is in fact difficult to transmit). The Ontario Human Rights Commission has stated that there are no permissible questions about disability on employment application forms,¹⁷ and acknowledges that HIV is transmitted in very limited circumstances. The Commission also states that “[i]n most work settings, it is unlikely that testing for HIV infection or other protective measures would be necessary or justifiable.”¹⁸ There is therefore no public interest in having information about a person’s HIV status readily available online, and the recognition of a right to be forgotten in relation to HIV status would be consistent with existing laws and privacy principles.

In the context of the Province determining how to strengthen privacy protection laws, we note that “[p]rivacy legislation is not mere consumer protection legislation, it is human rights legislation; our statutory framework and its enforcement mechanisms needs to reflect this.”¹⁹ Given the broad reach of online data and the quasi-constitutional status of human rights legislation, the development of law, policies, and practices in relation to privacy protection ought to reflect human rights principles, including fostering the realization of substantive equality for people living with disabilities.

4.2 Source Takedown and De-indexing as the Mechanisms to Achieve a Right to be Forgotten

Given the significant harms that can arise to people living with HIV when their private health information is made readily accessible through a search engine, HALCO submits that Ontarians ought to have a right to request source takedown and/or de-indexing of online search engine results.

One manner in which information relating to an individual’s HIV status arrives online, and where source takedown and de-indexing may reduce the impact of the resulting harms, is via accounts of HIV non-disclosure allegations. By way of illustration, we offer a scenario where a person’s HIV status is discovered online and discuss the role of source takedown and de-indexing:

A person living with HIV has been on medication for several years, and therefore has a “suppressed HIV viral load” (meaning 200 copies or less of the HIV virus per millilitre of their blood). In such circumstances, they are not able to transmit HIV through sex, regardless of whether or not a condom is used. They have sex with someone they met online, who later learns that the person is living with HIV. The sexual partner goes to the police, and the police lay charges against the person living with HIV, even though there was no risk of HIV transmission (note

¹⁷ Ontario Human Rights Commission, “[Human Rights at Work](#)” (2008, 3rd ed.) at section IV.4.

¹⁸ OHRC Policy, *supra* note 15 at page 8.

¹⁹ L. M. Austin, “[Protecting the public interest when ‘Your user agreement sucks’](#)”, Toronto Star April 18, 2018, p. A11.

that, as a result of recent changes to the law, police would not currently lay charges in such a scenario absent exceptional circumstances, but did lay such charges for decades – this scenario takes place before the recent changes to the law). As part of the police and criminal law processes, the police issue a press release that includes the person's name, HIV status, and picture, and invite other sexual partners to come forward (even though, again, there would be no risk of HIV transmission to other sexual partners). Several online media outlets publish the press release and/or articles covering its contents.

Within a few months of the charges being laid, the Crown prosecutor decides to withdraw the charges, because it is clear there was no risk of HIV transmission based on the person's suppressed HIV viral load. Long after charges have been withdrawn, however, the online articles referring to the press release (and including the person's name, HIV status, and picture) are still online and are included in search engine results when the person's name is searched. The articles state that the person was charged with an offence related to HIV non-disclosure and do not mention that the charges were withdrawn (and, even if they were updated to refer to the withdrawal of charges, they would still disclose the person's HIV status). There is no reason for the person to share the information about the withdrawn charges or their HIV status in their employment setting, but the information is discovered during a Google search of that person's name by a co-worker. The colleague, surprised and alarmed by the information, approaches the person's employer demanding to be protected from HIV. The information spreads quickly around the office. The person is terminated without explanation.

In this scenario, the person living with HIV can seek some recourse against their employer by initiating a human rights application. Even if they are successful (and there is no guarantee of success), the most fulsome remedy they could possibly achieve would be reinstatement to their employment and monetary damages to account for the wrong done to them (notably, however, reinstatement is rarely granted). In these circumstances, however, the person living with HIV must return to a workplace in which their HIV status is widely known, and they remain extremely vulnerable to future HIV-related discrimination in all areas of their life, because their HIV status can still easily be accessed online. Importantly, as previously mentioned, the human rights tribunal would not have jurisdiction to order removal of the online articles in question or de-indexing of the search engine results relating to the person's HIV status, because neither the publishers of the online articles nor the search engine companies would be proper parties before the human rights body. In these circumstances, access to a right to be forgotten in the form of source takedown and/or search engine de-indexing would be the only way to achieve a complete remedy for the person living with HIV.

We must also note that the above scenario is not far fetched. Several people living with HIV in Ontario and across Canada have been charged (prior to the aforementioned changes to the law) with HIV non-disclosure-related offences in circumstances where the sexual act in question posed little to no risk of HIV transmission, such that the charges were ultimately stayed or withdrawn or an acquittal was entered at trial. While

the law has now changed such that these people would not be charged for the same conduct today, online articles and press releases disclosing their HIV status remain online and easily accessible.

Measures such as source takedown and de-indexing can protect individuals from unwanted disclosure of information by reducing the risk that sensitive, stigmatized information such as one's HIV status will be discovered. As illustrated above, such measures can mitigate the risk of future human rights violations.

4.3 Necessary Features of the Implementation of Source Takedown and De-indexing

Source takedown and de-indexing mechanisms must be implemented in a manner that makes them available and meaningful remedies. In particular, the responsibility to determine source takedown or de-indexing requests should not rest solely with commercial entities (i.e., media organizations and search engine companies), given that such entities are likely to prioritize their own interests, which are unlikely to align with the interests of the affected individual.

If the Province determines that requests for source takedown or de-indexing must first be made to the organization collecting and using the information, therefore, we submit that the Province should put into place well-crafted legislation or policy that provides clear guidance on the obligations of organizations when considering such requests, both in regards to process and the substantive privacy rights of individuals.

In addition, we submit that it is imperative that the Province also implement an appeal or review process for source takedown or de-indexing requests that are denied. We recommend that any such appeal or review process be housed at the IPC. We also submit that the appeal or review process should be set out in sufficient detail in either legislation or policy, and should allow for timely resolution of complaints and remedies, including monetary damages, in appropriate cases. The appeal or review process should also provide for requests that the information at issue be temporarily suspended from public use/access during the appeal or review process, where certain factors are met (for example, where there is a risk of harm to the individual in the interim period, where the affected person is a minor). Finally, as part of deciding such appeals or reviews, the IPC (or other body tasked with such determinations), ought to have jurisdiction to decide questions of fact and law, including human rights and/or *Charter* issues. As seen from recent U.K. High Court decisions,²⁰ in appeals of de-indexing denials by Google, the task of balancing privacy and expression interests are driven by a sometimes deeply complex consideration of public values, such that the ability to consider *Charter* and human rights issues is of significant importance.

²⁰ [NT1 & NT2 v Google LLC](#), [2018] EWHC 799 (QB).

5 INCREASING ENFORCEMENT POWERS FOR THE INFORMATION AND PRIVACY COMMISSIONER

HALCO strongly encourage the Province to increase enforcement powers for the IPC, to ensure that businesses comply with the law, including giving the commissioner the ability to impose meaningful penalties and remedies where breaches are made out.

As has been described above, the consequences of privacy breaches for people living with HIV can be severe. As the law currently stands, the IPC has limited enforcement powers and does not have jurisdiction to award compensatory remedies to affected individuals. As a result, even where the IPC determines that a privacy breach has taken place, an affected individual must still apply to the Superior Court of Justice to obtain a compensatory remedy. This two-stage process imposes additional burdens on individuals who already face a power imbalance where a privacy breach has taken place, and who may not have the resources to commence a court proceeding. The IPC should therefore be granted the authority to order compensatory remedies, in order to meaningfully advance access to justice in Ontario in relation to privacy breaches.

While the IPC has authority to order administrative penalties for breaches governed by the *Personal Health Information Protection Act* (which penalties were significantly broadened and increased in March 2020), the IPC does not have comparable authority to order administrative penalties for breaches of obligations under the *Freedom of Information and Protection of Privacy Act* (“*FIPPA*”) or the *Municipal Freedom of Information and Protection of Privacy Act* (“*MFIPPA*”). HALCO submits that the IPC should be granted authority to order both administrative penalties and compensatory remedies for breaches of *FIPPA* or *MFIPPA*. While providing for meaningful remedies following privacy breaches is appropriate and necessary, the optimal approach to personal privacy is discouraging privacy breaches in the first place. Putting into place robust penalty and remedy schemes can provide the necessary incentive for government entities and other organizations to take proactive steps to prevent privacy breaches from occurring.

6 EXPANDING THE SCOPE OF THE LAW TO INCLUDE COMMERCIAL AND NON-COMMERCIAL ORGANIZATIONS

Ontario’s present privacy regime, which operates under *PHIPA*, *FIPPA*, and *MFIPPA* applies only to health information custodians (through *PHIPA*) and public institutions (through *FIPPA* and *MFIPPA*).

Both commercial and non-commercial entities can and do, however, commit privacy breaches. When such breaches take place, individuals ought to be able to easily and meaningfully seek recourse through the IPC, without having to resort to costly and/or complex court and tribunal processes. HALCO therefore submits that Ontario’s privacy laws ought to be expanded to apply to commercial and non-commercial entities, and

that the IPC be granted authority to order administrative penalties and compensatory remedies where privacy breaches are made out against such entities.