Canadian HIV/AIDS Legal Network
Réseau juridique canadien VIH/sida

HALCO
HIV & AIDS Legal Clinic Ontario

Submission to the Office of the Privacy Commissioner of Canada Regarding its Draft Position on Online Reputation

April 27, 2018

INTRODUCTION

This submission is made jointly by the HIV & AIDS Legal Clinic Ontario (HALCO) and the Canadian HIV/AIDS Legal Network ("Legal Network") in response to the call for comments from the Office of the Privacy Commissioner of Canada (OPC) on its Draft Position on Online Reputation ("Position Paper").[1]

The rapid proliferation of personal information online, driven by the monetization of information and information flow, has allowed commercial interests to shape a new social landscape whereby individuals are readily judged on the basis of available online information. The information disclosed by a search engine in response to a search of an individual's name is commonly sought out or stumbled upon by would-be employers, landlords, colleagues and friends, among others. As noted in the Position Paper, "information, once posted online, gains characteristics that affect reputation—it can easily be distorted, is persistent and can be extremely difficult to remove."[2]

This submission examines the privacy compliance duties under the *Personal Information Protection and Electronic Documents Act*, 2000 (PIPEDA) as they relate to the unique impact of the disclosure of sensitive personal information about people living with HIV.[3] After providing an overview of our organizations, we examine the pervasive stigma and accompanying discrimination faced by people living with HIV. Next, we discuss the applicability of PIPEDA to search engines and illustrate how the rights to request source takedown of information and search engine de-indexing of web pages relate to the circumstances faced by many people living with HIV. Finally, we examine the need for recourse for those individuals whose source takedown or de-indexing requests are denied, as well as the role of Parliament in this regard.

OUR ORGANIZATIONS

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 almost 60,000 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 at various courts including the Court of Appeal for Ontario and the Supreme Court of Canada.

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 1,500 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 direct client services (e.g., privacy complaints and torts, human rights complaints), public legal education or law reform (e.g., intervention in *Toronto Star v. Attorney General of Ontario*[4] 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).

The Legal Network is a non-governmental organization that promotes the human rights of people living with, at risk of or affected by HIV or AIDS, in Canada and internationally, through research and analysis, litigation and other advocacy, public education and community mobilization. It is the only national organization working exclusively on HIV-related legal issues in Canada and is one of the world's leading organizations in the field, with an extensive body of human rights–based research and analysis on a range of legal and policy issues related to HIV. Founded in 1992, the organization holds Special Consultative Status with the Economic and Social Council of the United Nations.

The Legal Network aims to contribute to the informed development of Canadian laws and policies that support the right to privacy and the confidentiality of health information of people living with HIV. It recognizes that people living with HIV often experience discrimination as a result of the unauthorized disclosure of their HIV status and that, as a result, may lose their jobs and/or housing and see their personal relationships with family and friends compromised.

STIGMA AND DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV

People living with HIV or AIDS 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 unfairly stigmatized in Canada and internationally.[5] Our organizations observe, on a daily 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.

HIV-related stigma arises mostly from fear and ignorance about the disease and/or hostility and existing prejudices about the groups most affected by it (e.g., gay men, people who inject drugs, Indigenous communities, migrant 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 (e.g., people who use drugs and men who have sex with men, among others).[6]

Canadians' attitudes and opinions toward people living with HIV were most recently assessed in a national study in 2012.[7] Many Canadians still report feeling uncomfortable having contact with a person with HIV or AIDS.[8] Twenty-four percent would be somewhat or very uncomfortable wearing a sweater previously worn by someone with HIV. Forty-nine percent say that they would feel uncomfortable using a restaurant drinking glass once used by a person living with HIV. Fifty-one percent say they would be uncomfortable if a close family member or friend dated someone with the illness.[9]

In addition, 69 percent of respondents felt that people may be unwilling to disclose their HIV status because of the stigma associated with HIV. Furthermore, 55 percent felt that people with HIV may experience difficulty with activities such as finding housing, healthcare or employment because of the stigma.

These survey results suggest that much of the fear surrounding the emerging HIV epidemic in the 1980s persists today.[10] The resulting stigma and discrimination are manifest in a number of ways. HALCO routinely receives enquiries for legal services related to HIV discrimination and harassment in employment, housing, education and other services, which result in denials of opportunities, social exclusion and even violence. Discrimination and other human rights violations also occur in health care settings, barring people from accessing health services or enjoying quality health care.[11] 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.[12]

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 (i.e., potentially to all who access the internet) and everlasting. HIV information can be discovered by those who seek out or stumble upon information, particularly through the use of search engines.

ADDRESSING HARMS TO PEOPLE LIVING WITH HIV STEMMING FROM UNWANTED DISCLOSURE OF INFORMATION

Our organizations agree with the OPC statement that "[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,"[13] and support the OPC's goal of "[helping] 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."[14]

PIPEDA applies to search engines

Our organizations support the OPC's Position that PIPEDA applies to search engines.

There can be no question that activities of search engines, particularly the collection and disclosure of information, fall under the scope of PIPEDA.[15] As such, information trafficked by search engines is subject to s. 5(3) of PIPEDA which provides that "[a]n organization may collect, use or disclose personal information only for purposes that a reasonable person would consider are appropriate in the circumstances." Further, PIPEDA Principle 4.6 requires that "personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used." More specifically, PIPEDA Principle 4.6.1 states the following:

> The extent to which personal information shall be accurate, complete, and up-to-date will depend upon the use of the information, taking into account the interests of the individual. Information shall be sufficiently accurate, complete, and up-to-date <u>to minimize the possibility that inappropriate information may be used to make a decision about the individual.</u> [emphasis added]

We submit that the risk that a digital trace concerning sensitive information related to a highly stigmatized condition (e.g. HIV status) will lead to *discriminatory* treatment requires special attention. The application of PIPEDA ought to implement human rights principles given the (i) quasi-constitutional nature (i.e., fundamental and paramount) of human rights legislation; and (ii) importance of privacy as an element of human rights. Where the risk of harm is more than trivial because of the stigma associated with a ground protected under human rights law, de-indexing or in some cases source takedown is warranted.

Canada has explicitly recognized HIV as a disability in its 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."[16] Courts and tribunals have interpreted "disability" in the context of the Charter and other legislation to apply to HIV and AIDS.[17] HIV and AIDS are also considered disabilities under all human rights legislation in Canada.[18] In Ontario, for example, HIV is recognized as a disability under the *Ontario Human Rights Code* ("Code") which provides that all people who have or are perceived to have AIDS or HIV-related medical conditions are entitled to protection against discrimination in employment, services, housing, contracts and membership in trade unions.[19]

Given that search engines use information for the creation of a "'profile of the most relevant information' about that person that is available online,"[20] it is uncontroversial to recognize that current and prospective employers, landlords and other service providers 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. However, if information in that profile includes information about a person's HIV status, the result can be loss of opportunity as well as the threat of violence in a manner that violates the Charter and/or human rights legislation.

In addition, due to widespread ignorance and fear about the risk of HIV transmission, some sectors of the population have a sense of entitlement to the knowledge of others' HIV status. In fact, there are extremely limited circumstances in which such access is justifiable. The Ontario Human Rights Commission has stated that there are no permissible questions about disability on employment application forms,[21] 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."[22] Any argument supporting a public interest in having information about a person's HIV status readily available online must be examined with deep skepticism to guard against HIV stigma and phobia cloaking "mere curiosity or prurient interest."[23]

We recognize that PIPEDA is not intended to address the needs of people with disabilities. However, "[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."[24] Given the broad reach of online data and the quasi-constitutional status of human rights legislation, the development of law, policies and practices ought to foster the realization of substantive equality for people living with disabilities.

Source takedown and de-indexing under PIPEDA

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, our organizations support the OPC's Position that individuals have a right under PIPEDA to request source takedown, and that individuals have a right under PIPEDA to request de-indexing.

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:

> Long after charges have been withdrawn, an online news article still indicates that a person has been charged with an offence related to HIV non-disclosure. There is no reason for the person to share this information 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 the scenario above, reinstatement may not be a meaningful remedy as the law cannot grant "unknowing" and the person may not want to return to a workplace where their HIV status is broadly known. Further, in a wrongful dismissal or human rights application, a court or human rights tribunal would not have jurisdiction to order removal or de-indexing of the online information. However, source takedown and/or de-indexing under PIPEDA provides the person a chance to keep their HIV status private going forward in their search for new employment.

A successful request for source takedown of the actual news article under PIPEDA s. 5(3) and Principles 4.6 and 4.6.1 in the above scenario may eliminate further unwanted disclosure. Our organizations also support the OPC's Position that de-indexing provides an alternative to takedown by simply removing its association with a search of a person's name. Such a measure can reduce the risk of further unwanted disclosure of their HIV status to others.

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 further human rights violations.

REVIEW OF DENIALS AND ACCESS TO JUSTICE

Individuals whose source takedown or de-indexing requests are denied should have access to recourse so that they may assert their right to privacy, protect their reputation and human rights, and reduce the risk of harm arising from ready access to information through a search engine. In particular, while our organizations support the OPC Position that there is authority under PIPEDA to order source takedown and de-indexing, we also agree that Parliament has a role to play in certain circumstances.

The ability of an individual to assert privacy and human rights protections is an issue of access to justice. If a request for source takedown or de-indexing must first be made to the organization collecting and using the information, we have serious concerns about imputing this public function to a self-interested commercial entity such as a search engine. For this reason, well-crafted legislation or policy should provide clear guidance on the obligations of organizations, both in regards to process and the substantive privacy rights of individuals. The federal government should study the issues, taking into account, *inter alia*, the Charter and human rights legislation, and find the most precise way of balancing the competing interests at play. The federal government has a further obligation to clearly articulate the scope of these privacy rights and to engage in comprehensive education about those rights in order to ensure they are understood and upheld.

It is also imperative that oversight of such decisions be readily accessible to individuals seeking to assert their rights. We recommend that the OPC be provided with the resources to deal with complaints in a timely manner. In addition, given the imbalance of power between individuals and entities in the data sector, we believe that the federal government must support auditing of source-takedown and de-indexing denials.

Moreover, it is crucial that bodies overseeing complaints and applications have jurisdiction to decide fact and law, including human rights and/or Charter issues. The task of balancing underlying societal values including human rights requires a proper grasp of relevant legal principles. As seen from recent U.K. High Court decisions[25] 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.

Applications for orders and damages should be uncomplicated, expeditious and accessible. There should be an avenue for information to be suspended from use and distribution while requests, complaints, applications or appeals are underway where there is *prima facie* evidence of risk of significant harm. Penalties for breach should be swift and compensation meaningful.

While PIPEDA includes the ability to apply to civil court for enforcement and compensation, we have concerns that court proceedings can be prohibitively lengthy, overly formal and costly. Legislators should consider creating a more streamlined process, including expanding OPC powers to include the authority to make orders or creating a dedicated tribunal.

CONCLUSION

Our organizations support the OPC Position Paper. In particular, we urge the OPC to include the following positions in its final paper and subsequent Action Plan:

- **PIPEDA applies to search engines;**
- **individuals have a right under PIPEDA to request source takedown;**
- **individuals have a right under PIPEDA to request de-indexing;**
- **the OPC has authority under PIPEDA to decide complaints about and audit activity regarding source takedown or de-indexing requests; and**
- **Parliament should clarify, strengthen and/or increase accessibility to mechanisms available to individuals to assert their right to privacy, protect their reputation and human rights, and reduce risk of harm arising from the ready access to information through a search engine.**

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[1] Draft Position on Online Reputation (Office of the Privacy Commissioner of Canada, January 26, 2018) (“Position Paper”).

[2] Position Paper, at page 2.

[3] *Personal Information Protection and Electronic Documents Act*, SC 2000, c. 5.

[4] 2017 ONSC 7525.

[5] Canadian HIV/AIDS Legal Network, Canadian Public Health Association, “Reducing Stigma and Discrimination Through the Protection of Privacy and Confidentiality” (2017). Available at www.aidslaw.ca/site/reducing-stigma-and-discrimination-through-the-protection-of-privacy-and-confidentiality/?lang=en.

[6] CATIE, “HIV in Canada: A primer for service providers” (2017). Available at www.catie.ca/en/hiv-canada/4/4-1/4-1-1.

[7] EKOS Research Associates, “2012 HIV/AIDS Attitudinal Tracking Survey: Final Report (October 2012). Available at www.catie.ca/sites/default/files/2012-HIV-AIDS-attitudinal-tracking-survey-final-report.pdf.

[8] Ibid.

[9] Ibid.

[10] Avert, “HIV Stigma and Discrimination” (2018). Available at www.avert.org/professionals/hiv-social-issues/stigma-discrimination.

[11] UNAIDS, “Agenda for zero discrimination in health-care settings” (2017). Available at www.unaids.org/sites/default/files/media_asset/2017ZeroDiscriminationHealthCare.pdf.

[12] Avert, “HIV Stigma and Discrimination” (2018). Available at www.avert.org/professionals/hiv-social-issues/stigma-discrimination.

[13] Position Paper, at page 7.

[14] Position Paper, at page 1 “Executive Summary.”

[15] See *A.T. v. Globe24h.com*, 2017 FC 114; *Google Inc. v. Equustek Solutions Inc.*, 2017 SCC 34.

[16] *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.

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

[18] Human Rights, Citizenship and Multiculturalism Act, RSA 2000, c. H-14 [Alberta]; Human Rights Code RSBC 1996, c. 210 [British Columbia]; Human Rights Code, CCSM 1987, c. H175 [Manitoba]; Human Rights Act, RSNB 1973, c. H-11 [New Brunswick]; Human Rights Code, RSNL 1990, c. H-14 [Newfoundland & Labrador]; Human Rights Act, SNWT 2002, c. 18 [Northwest Territories]; Human Rights Act, RSNS 1989, c. 214 [Nova Scotia]; Human Rights Act, SNu 2003, c. 12 [Nunavut]; Human Rights Code, RSO 1990, c. H.19 [Ontario]; Human Rights Act, RSPEI 1988, c. H-12 [Prince Edward Island]; Québec Charter of Human Rights and Freedoms RSQ 1975, c. C-12 [Québec]; Saskatchewan Human Rights Code, SS 1979, c. S-24.1 [Saskatchewan]; Human Rights Act, RSY 2002, c. 116 [Yukon]. As compiled in 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. Available at www.aidslaw.ca/site/protection-against-discrimination-based-on-hivaids-status-in-canada-the-legal-framework-hivaids-policy-law-review-101.

[19] *Policy on HIV/AIDS-related Discrimination* (Ontario Human Rights Commission, November 27,1996) at page 4-5. Available at www.ohrc.on.ca/sites/default/files/policy%20on%20hiv%20aids%20related%20discrimination.pdf.

[20] Position Paper, at page 10 and also at pages 8, 9, 16.

[21] *Human Rights at Work* (Ontario Human Rights Commission, 2008) at section IV.4. Available at www.ohrc.on.ca/en/iv-human-rights-issues-all-stages-employment/4-designing-application-forms.

[22] *Supra* note 19, at page 8.

[23] Position Paper, at page 6.

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[24] L. M. Austin, “Protecting the public interest when ‘Your user agreement sucks’,” Toronto Star April 18, 2018, p. A11. Available at www.thestar.com/opinion/contributors/2018/04/17/protecting-the-public-interest-when-your-user-agreement-sucks.html.

[25] *NT1 & NT2 v Google LLC* [2018] EWHC 799 (QB). Available at www.judiciary.gov.uk/wp-content/uploads/2018/04/nt1-Nnt2-v-google-2018-Eewhc-799-QB.pdf.