

**Privacy Concerns, HIV Care Provider Trust, and Clinical Care  
Engagement among Women Living with HIV in Response to the  
Criminalization of HIV non-disclosure in Canada**

by

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## **Ethics Statement**

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## **Abstract**

In 2012, the Supreme Court of Canada ruled that people with HIV have a legal obligation to disclose their serostatus to partners prior to sex that poses a “realistic possibility” of HIV transmission. This study used Wave 2 survey data from 1422 women living with HIV (WLWH) enrolled in the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study to examine (1) the proportion and socio-demographic characteristics of WLWH who perceived privacy concerns due to the law; (2) the association between WLWH’s privacy concerns and trust of HIV care providers; and (3) the association between WLWH’s privacy concerns and HIV clinical care engagement. Results showed that a majority of participants reported privacy concerns, and that the socio-economically vulnerable women had significantly higher odds of privacy concerns. WLWH with lower provider trust had higher odds of privacy concerns. There was no significant association between privacy concerns and HIV care engagement.

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## **Chapter 1 Background, Literature Review, and Objectives**

### **1.1 Background**

#### **1.1.1 Criminalization of HIV non-disclosure in Canada**

The early 1980s saw the onset of the AIDS epidemic.<sup>(1)</sup> Since 1987, when HIV-specific criminal statutes were first enacted in the United States, many jurisdictions around the world have applied existing criminal laws and/or created HIV-specific criminal statutes to prosecute people living with HIV (PLWH) who have, or are believed to have, put others at risk of acquiring HIV.<sup>(2)</sup> In 1989, Canada became one of such countries.<sup>(3)</sup> Because its Criminal Code lacks HIV-specific laws, Canadian courts have followed legal precedents set by the Supreme Court of Canada (SCC) in applying existing criminal laws to cases of HIV non-disclosure.<sup>(4-8)</sup> In most cases, courts have applied sexual assault law on the rationale that non-disclosure of HIV status by people living with HIV (PLWH) constitutes fraud and thereby vitiates consent by their HIV-negative partners to the sexual encounters.<sup>(8, 9)</sup> Aggravated sexual assault, defined as a sexual assault that “wounds, maims, disfigures or endangers the life of the complainant,” and can lead to a maximum sentence of life imprisonment and registration as a sex offender, has been most frequently applied.<sup>(8, 10, 11)</sup> Canada is believed to be the first country where a person living with HIV’s non-disclosure of their HIV status led to a murder conviction in its 2009 ruling of *R. v. Aziga*.<sup>1(12, 13)</sup>

Throughout the 1990s, there was an increase in the use of criminal law against PLWH in Canada.<sup>(8, 14)</sup> In 1998, the SCC held in *R. v. Cuerrier* that PLWH who fail to disclose to partners

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<sup>1</sup> Aziga was the first Canadian to be criminally convicted on charges for having unprotected sex with 11 women without disclosing his HIV status to his victims, two of whom later died of AIDS-related cancer. He was found guilty of two counts of murder in the first degree, 10 counts of aggravated sexual assault, and one count of attempted aggravated sexual assault at the Hamilton Superior Court, Ontario. He was sentenced to life imprisonment with no possibility of parole for 25 years. On August 2, 2011, the same court granted a request by Crown Prosecutors to have him jailed indefinitely under the Dangerous Offender act on the ground that he was believed to be at a high risk to re-offend.

before sex that represents a “significant risk” of HIV transmission could face criminal charges.(4) After *Cuerrier*, the number of criminal charges, as well as their severity, continued to rise due to uncertainty in how the law should be applied.(8, 15)

In 2012, the SCC set a new legal precedent for criminalizing HIV non-disclosure in Canada through its landmark ruling on two major cases, *R. v. Mabior* and *R. v. D.C.*(6, 7) In *Mabior*, the SCC determined that PLWH could face a conviction for aggravated sexual assault if they did not disclose their HIV status before sex that posed a “realistic possibility” of “significant bodily harm,” i.e. HIV transmission. It suggested that PLWH have no legal obligation to disclose if they engage in condom-protected vaginal sex and have a “low” HIV RNA plasma viral load (defined by the SCC as <1500 copies/mL).(6) *D.C.* concerned a woman who was charged with sexual assault and aggravated assault for engaging in vaginal intercourse with her sexual partner without disclosing her HIV-positive status to him when her viral load was undetectable.(7) The SCC affirmed the ruling in *Mabior* by opining that condom use—in addition to a low viral load—are required to preclude a “realistic possibility” of HIV transmission.(7) By suggesting that both condom use and a low viral load by PLWH would be required to avert the legal obligation of disclosure, the SCC increased the scope of criminal liability for HIV non-disclosure established in its *Cuerrier* decision. Although the *Cuerrier* Court did not provide a clear interpretation of the circumstances that would constitute a “significant risk” of HIV transmission, several lower courts interpreted this ruling to determine that condom use alone would avert the legal duty to disclose.(16) In addition, the legal test established in *Mabior* failed to incorporate clear scientific evidence of the negligible risk of HIV transmission associated with consistent use of ART produced since the *Cuerrier* decision.(17)

Since *Mabior*, evidence that having an undetectable viral load means that HIV is untransmissible has also grown substantially, leading the World Health Organization and Centre for Disease Control to release statements declaring that the science is clear regarding

“effectively” zero risk of HIV transmission when a PLWH is virally undetectable.(18, 19) A consensus statement by the 2017 Prevention Access Campaign states that “[p]eople living with HIV on ART with an undetectable viral load in their blood have a negligible risk of sexual transmission of HIV.”(20) A 2018 expert consensus statement on the science of HIV in the context of criminal law states for vaginal-penile sexual intercourse, “there is no possibility of HIV transmission when a person has an undetectable viral load.”(21) Hence, laws criminalizing HIV non-disclosure are out of line with science and the reality of living with HIV today. The Canadian legal approach towards HIV non-disclosure therefore does not reflect the scientific evidence of HIV transmission and contradicts both national and international consensus statements and recommendations against criminalizing HIV non-disclosure.(18-21) Currently, Canada has among the strictest laws for the criminal prosecution of HIV non-disclosure, and is only second to the U.S. for the absolute number of convictions among individuals charged.(22)

### **1.1.2 Women and the Criminalization of HIV non-disclosure**

HIV criminalization law has been supported, in part, on the expectation that it would protect women from HIV infection,(23, 24) by promoting HIV disclosure and improving sexual health practices (such as condom use) and thereby reducing HIV incidence.(25) However, there is no evidence demonstrating that such laws actually do prevent HIV transmission.(26, 27) Moreover, such laws largely ignore the gendered barriers and challenges encountered by women living with HIV in disclosing their HIV status and negotiating condom use given risks of gender-based violence and power inequities between men and women.(8, 28, 29) Where women living with HIV (WLWH) are in abusive relationships, or are financially or otherwise vulnerable, disclosing HIV status presents serious risks of violence, abandonment, and/or rejection.(30)

Another rationale for criminalizing HIV non-disclosure was that it would serve to protect the sexual autonomy of women, on the ground that non-disclosure by PLWH vitiates sexual consent of the HIV-negative partner and transforms otherwise wanted sex into a

violation akin to sexual assault, thus imposing grievous physical, dignitary and psychological harm that warrants prosecution.(30) Indeed, promoting affirmative definitions of consent for sexual activity have constituted critical progress in Canada's sexual assault laws.(22) However, this argument relies on the unfounded assumption that non-disclosing HIV-positive partners are men, whereas the uninformed HIV-negative partners are women.(30) In *Cuerrier*, the SCC took for granted that HIV deception was typically a heterosexual act, "assum[ing] that it will more often be the man who lies," and that the deceived partner would be a woman.(4, 30) This invokes a "scenario of male deception and female vulnerability," hence the need to protect women against infection by men.(30) Often, however, those living with HIV are women, as in the case of *D.C.* In such cases, the argument that such laws protect women's sexual autonomy does not work.

For WLWH, laws criminalizing HIV non-disclosure may increase the risks of intimate partner violence after disclosure.(31, 32) These laws may also be used as a tool for abusive partners to propagate further violence against WLWH. One good example is found in *D.C.*, where the SCC overturned an initial charge of domestic violence by a WLWH against her male partner after the latter charged the former for HIV non-disclosure, which related to only one alleged—and contested—episode of condomless sex without HIV serostatus disclosure at the beginning of their four year-long mutually disclosed relationship during which no HIV transmission occurred.(7)

Criminalizing HIV non-disclosure has also led to WLWH being criminally charged by their sexual partners and in several cases, their incarceration, among whom WLWH experiencing social and economic insecurity or of racial/ethnic minority groups are over-represented.(8, 33) Whereas WLWH were more often accusers than accused in HIV non-disclosure cases in Canada,(8) the first documented case of a WLWH being charged with aggravated sexual assault happened in 1991 in British Columbia.(34) Since then, at least 18

WLWH faced charges in an estimated 22 criminal cases of HIV non-disclosure.(8) Of 18 cases where the outcome of the charge is known, there were 13 (72%) convictions or guilty pleas, and some convicted of aggravated sexual assault were registered as sex offenders, sentenced to two years' house arrests and three years' probation, or three years in jail.(8, 23) Among cases where there was a conviction, and for which information on HIV transmission to the accuser is available (n=12), alleged or proven HIV transmission to the accuser occurred in 6 cases (50%).(8) Of the 18 women accused in these cases, six were Indigenous and at least two were immigrant women.(8, 35, 36) Among them, there were at least three single mothers, four women with histories of sex work, and four women with histories of substance use.(8, 37) In addition, at least five WLWH in these cases were survivors of sexual or physical violence.(8, 38)

Finally, criminalizing HIV non-disclosure may create an additional barrier to the engagement in HIV medical care. Research, both in Canada(22, 39-41) and globally(42-44), indicates that stigma and discrimination may increase barriers to engagement in HIV clinical care among PLWH more generally, by inhibiting access to HIV testing (22, 39, 42, 43) and by discouraging PLWH's sharing of personal information such as their sexual practices with care providers which would be useful to their proper care.(22, 40, 41, 44) Increased stigma and discrimination from care providers due to these laws may also disrupt PLWH's access to and retention in HIV clinical care.(22, 40, 41) For WLWH in Canada, recent research indicates that HIV-related stigma is associated with reduced likelihood of ART initiation and current ART use, and suboptimal ART adherence.(45) The increasing barrier to linkage and retention in HIV care, especially in terms of ART use and adherence, is concerning, as UNAIDS has defined the prevention of HIV transmission as the most important public health objective, and adherence to ART can effectively prevent HIV transmission. The Swiss Federal AIDS Commission, for example, released a landmark statement in 2008 stating that "an HIV-infected person on antiretroviral therapy with completely suppressed viraemia ("effective ART") is not sexually infectious and cannot transmit HIV through sexual contact."(46) PLWH who have adhered to

ART for six months, with an undetectable viral load (<40 copies/mL) and no concurrent sexually transmitted infections, could not transmit HIV through sexual contact.(47-50) This position was endorsed in the 2017 U=U (Undetectable=Untransmittable) Consensus Statement and the 2018 expert consensus statement on the science of HIV in the context of criminal law.(20, 21)

Although a proposed pathway to poorer retention in HIV care is through WLWH's concerns about the confidentiality of their medical records and stigma from their healthcare providers, to date there have been very few studies that empirically assess this pathway concerning privacy concerns due to laws criminalizing HIV non-disclosure and healthcare engagement, particularly since the 2012 ruling.

## **1.2 Literature Review**

### **1.2.1 Privacy Intrusion and Engagement in HIV Clinical Care**

The SCC described the importance of the privacy of information, stating that “retention of information about oneself is extremely important” in modern society and “all information about a person is in a fundamental way his own, for him to communicate or retain for himself as he sees fit.”(51) Based on this definition alone, there are two ways in which the 2012 ruling implicates PLWH's right to privacy. First, it intrudes upon PLWH's right to keep their HIV status private. Second, it threatens PLWH's right to keep their personal information (such as their condom use and number of sexual partners) private in a health care setting and not to have it shared with outside authorities. This thesis focuses on the second way in which PLWH's/WLWH's sense of privacy is threatened.

In a healthcare setting, the sharing of personal information by PLWH such as their sexual practices and number of sexual partners during consultations with their providers is

useful to their proper care.(22, 40, 41, 44). In Canada, public health authorities may provide PLWH's health records to law enforcement on potential HIV non-disclosure cases when a warrant or subpoena for information has been served or in circumstances involving a high risk of transmission to others.(52, 53) It not easy to determine in what circumstances, under the law, confidentiality may or should be set aside in cases where there is concern that someone is at specific risk of HIV.(54)<sup>2</sup> Research in Canada shows that laws criminalizing HIV non-disclosure have reoriented HIV prevention as a public health issue towards a criminal law concern and fostered close ties between public health and the police in the minds of PLWH.(55) Hence, PLWH's uncertainty about the limits of confidentiality of their personal information and their fears that their privacy of information could be breached and such information would be subpoenaed by the police for use in criminal trials has discouraged the sharing of personal information that would be important for effective healthcare consultations with their providers.(55-57)

In addition, WLWH may be reluctant to share their personal information with healthcare providers because they fear increased stigma and discrimination from them.(58) WLWH in Canada in general are more poorly engaged in healthcare relative to their male counterparts, including receiving poorer quality of initial HIV care(59), delayed engagement into care(17, 60), increased likelihood of unstructured treatment interruptions(61), sub-optimal ART adherence(50), delays in achieving viral suppression(62), and lower life expectancy.(8, 63) This is possibly because WLWH, who have specific healthcare requirements due to their sexual, reproductive and maternal health needs, generally experience gendered barriers to healthcare engagement, including HIV-related stigma and concerns relating to HIV serostatus

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<sup>2</sup> In a 1999 ruling called *Smith v. Jones*, the SCC decided that there is discretion to disclose confidential information about a client in order to prevent harm to another person where these three conditions are satisfied: 1. there is a clear risk of harm to an identifiable person or group of persons; 2. there is a risk of serious bodily harm or death, and 3. the danger is imminent. Here, the SCC was deciding whether and when a lawyer's duty of confidentiality to his or her client could be waived. The principles set out in this case apply to every service provider who works with and counsels people living with HIV, whether they are regulated professionals or not.



disclosure.(8, 64) In semi-structured interviews with 15 HIV/ AIDS service providers in Toronto, providers expressed the belief that the SCC's 2012 ruling further increased stigma directed towards PLWH—particularly women, sex workers and those living with addiction—and this may compromise healthcare engagement.(22, 65) In another set of semi-structured interviews with African/Black men living with HIV and WLWH in the Greater Toronto Area, participants reported experiencing increased stigma and discrimination from healthcare providers themselves due to HIV criminalization.(58) These participants also questioned the privacy of healthcare information that they shared with healthcare providers.(58) Recent research indicates that HIV-related stigma among WLWH is associated with reduced likelihood of ART initiation and current ART use and suboptimal ART adherence.(45) The pathway between WLWH's privacy concerns over their personal health information they share with healthcare provider and their engagement in HIV clinical care needs to be further assessed.

### **1.2.2 Trust in HIV Care Providers and Its Potential to Alleviate Perception of Privacy Intrusion**

Trust in healthcare providers plays a significant role in clinical settings for PLWH, despite the HIV-related stigma and discrimination that they experience. In a healthcare context, trust refers to “a firm belief in the reliability, truth, or ability of someone or something,”(66) or “an expectation that the other person will behave in a way that is beneficial, or at least not harmful, and allows for risks to be taken based on this expectation,” so that it provides “a basis for taking the risk of sharing personal information.”(67)

A 2012 study, based upon in-depth interviews with 122 PLWH in Ontario, reveals that participants with longstanding relationships with healthcare providers did not report difficulty trusting them despite the Canadian law criminalizing HIV non-disclosure, one reason being their belief that the care providers would not disclose their information to third parties and that being honest with their care providers would be beneficial to them.(25) Moreover, studies,

conducted both before and after the 2012 ruling, indicate that WLWH in Canada generally trust their healthcare providers, but this patient-provider trust may be compromised due to concerns over the exposure of confidential medical information.(40, 55) Although these studies do not define precisely what “trust” means, they describe trust in care providers as willingness to engage in open dialogues and share information with care providers.(25, 55)

Research indicates that PLWH’s trust in HIV care providers in particular is associated with better engagement in HIV clinical care and better health outcomes.(68-70) These studies describe trust as a belief in the competence of care providers who give them the right information(70) and who want to give them the best care possible,(69) and a willingness to confide in care providers who accept them.(68) A long-term and trusting relationship with HIV care providers (including nurses, physicians and physician assistants) is an essential part of HIV treatment over the continuum of HIV care, from initial diagnosis, to entering treatment for HIV, adhering to medication regimens, and staying in medical care.(68, 70) Trust in HIV care providers is also associated with improved reported physical and mental health, whereas distrust in them may be a barrier to service use and therefore to optimal health.(69) While these studies confirm the positive impact of their trust in HIV care providers on HIV care engagement, there is a lack of research directly addressing the association between WLWH’s (or PLWH’s) trust in HIV care providers and their perception of privacy intrusion in terms of sharing personal information with healthcare providers more generally.

### **1.3 Knowledge Gap**

Although there is research showing that criminalizing non-disclosure threatens PLWH’s information privacy by discouraging them from disclosing their health information to their HIV care providers due to their concerns about the confidentiality of the information, this body of research is restricted and primarily qualitative.(55, 57, 58) The qualitative studies, which

conducted in-depth interviewing, relied on purposeful sampling methods and did not focus exclusively on WLWH.(55, 57, 58) One study involved interviews with 28 service providers and 26 PLWH, some of whom revealed that PLWH had become less willing to share information (such as sexual practices) with service providers in the climate of HIV non-disclosure criminalization.(55) One study interviewed 27 men who have sex with men (12 HIV-positive, 15 HIV-negative), some stating that they were reluctant to use public health services due to their beliefs that local public health departments openly share their information with the police.(57) Still another qualitative study focused exclusively on African/black women and men with HIV in Greater Toronto area who revealed privacy concerns due to the laws criminalizing HIV non-disclosure.(58) The only quantitative study focuses exclusively on Ottawa-based gay men.(56) There is thus a lack of nationwide, quantitative research examining whether the 2012 decision impacted the perceptions of privacy concerns of WLWH more broadly. In addition, although WLWH marginalized by precarious socio-economic situations, insecure immigration status, and/or members of ethno-racial minorities report more HIV-related stigma and discrimination than middle-class white women(1, 32), there have been no studies on whether the law has had a differential impact on the willingness to disclose personal information at healthcare consultations among WLWH of different demographic groups and backgrounds. A study drawing upon a broad sample of WLWH of different demographic backgrounds would serve such a purpose.

Second, although the role of trust and its impact on healthcare engagement is fairly well-documented in the context of HIV clinical care, there is no research directly addressing whether and to what extent that WLWH's trust of their HIV care providers may be associated with their concerns about privacy in terms of willingness to share personal information with healthcare providers due to the 2012 ruling. Moreover, there is a dearth of studies on how the differential impact that trust may play among WLWH of different social and economic demographic groups on their perception of privacy intrusion.

Finally, the extent to which the 2012 ruling has shaped the healthcare engagement of WLWH across Canada also remains underexplored.(8) While research indicates a pathway between HIV-related stigma and the likelihood of ART initiation and current ART use and suboptimal ART adherence,(45) it is uncertain whether WLWH's perception of privacy intrusion due to the law may have negatively impacted their engagement in HIV clinical care, and how social and economic marginalization factor into the possible pathway between perception of privacy intrusion and engagement in HIV clinical care.

#### **1.4 Study Objectives**

This thesis aims to study the impact of the law on HIV non-disclosure in Canada on WLWH's sense of privacy and engagement in HIV clinical care within a critical feminist framework. Under this aim, three research objectives were identified as follows:

**1) To measure the proportion and characteristics of WLWH who report that HIV non-disclosure laws might affect the type of information that WLWH would be willing to share with their healthcare providers, such as information about sexual activities and HIV disclosure.** In fulfilling this objective, I sought to assess the proportion who perceive that HIV non-disclosure laws might affect the type of information that WLWH would be willing to share with their healthcare providers. Additionally, I sought to assess differences in perceptions across diverse identities and social positions of WLWH in Canada. I hypothesized that WLWH who are socially vulnerable, experience other forms of social and legal surveillance, or are marginalized from care would be more likely to perceive that the HIV non-disclosure laws might impact the type of information women would be willing to share with their healthcare providers.

**2) To assess the association between WLWH's trust of HIV care providers and their perception that HIV non-disclosure laws might affect the type of information WLWH would be willing to share with their healthcare providers.** In fulfilling this objective, I sought to examine whether WLWH who report high levels of trust of their HIV care providers alleviate their privacy concerns due to non-disclosure law. Because research indicates that patients who trust their HIV care providers are more willing to share their personal information in medical contexts, I hypothesized that WLWH's trust of their HIV care providers is negatively associated with expressing the belief that HIV non-disclosure laws might affect the type of information women would be willing to share with healthcare providers.

**3) To assess the association between expressing the belief that HIV non-disclosure laws might affect the type of information WLWH would be willing to share with healthcare providers and poorer engagement in HIV clinical care, as measured by ART adherence.** In fulfilling this objective, I sought to examine whether WLWH's perception of privacy intrusion due to the law is associated with engagement in HIV clinical care. Because past studies indicate that criminalizing HIV non-disclosure generally correlates with poorer engagement in HIV care, I hypothesized that expressing the belief that HIV non-disclosure laws might affect the type of information women would be willing to share with providers is associated with poorer HIV care engagement.

## **1.5 Theoretical Framework**

This thesis adopts a critical feminist framework to study the impact of the 2012 ruling on the privacy concerns of WLWH, its potential impact on their engagement in HIV clinical care, and the possible role played by WLWH's trust in their care providers in alleviating their privacy concerns. A feminist framework is highly relevant to the study of privacy issues among WLWH caused by the law. The relevance of privacy to women was recognized by feminist scholars such

as Catherine MacKinnon and Anita Allen. While the former argues that although privacy can harm women as it can be exploited to cover up their abuses in the domestic sphere, the latter contends that privacy can protect women from unreasonable surveillance and intervention by the state, and so they can and ought to embrace opportunities for privacy.(71, 72) The law on HIV non-disclosure, which puts WLWH at risk of privacy intrusion as well as HIV-related stigma, is an example of state intervention and may threaten WLWH's sense of privacy by making them less willing to disclose their information to their care providers.

However, it is a critical feminist perspective that is especially relevant to the study of the law's impact on different communities of WLWH, as it asserts that multiple social identities, including gender, race, sexual orientation, and socio-economic status, intersect at individual and structural levels to create the social inequalities and oppression experienced by women.(8, 73-75) In fact, intersectionality frameworks, which assert these numerous factors are always at play in determining health outcomes, and which encourage a contextual analysis of a range of axes of differences to better understand any situation of disadvantage, have been advocated for use in HIV research.(76) Given that WLWH experiencing social and economic insecurity or of racial/ethnic minority groups are over-represented among those facing charges for HIV non-disclosure in Canada, the critical feminist perspective has aptly been identified as a priority for scholarship in the field of HIV criminalization.(40)

In this thesis, a critical feminist framework helps illuminate the differential impact of the non-disclosure law on the perception of privacy intrusion among WLWH, many of whom are socially or structurally marginalized and feel more vulnerable to stigma and discrimination caused by the law than those who are not marginalized. It helps to explore the differential impact of privacy intrusion on WLWH's healthcare engagement and the role of trust in alleviating any privacy intrusion, and in doing so, better inform policy and legal changes.

## **1.6 Data Sources**

### **1.6.1 CHIWOS and Its Relevance to this Study**

According to the Public Health Agency of Canada, there were approximately 16,880 WLWH in Canada in 2016, the majority of whom residing in British Columbia (BC) (8.4%), Ontario (54.4%) and Quebec (26.9%).(77, 78) This study thus draws upon cross-sectional survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based longitudinal cohort study of WLWH from BC, Ontario and Quebec. The CHIWOS team began this study in 2011 to better understand women-centred HIV care for WLWH across Canada, and to explore the mental, sexual and reproductive health benefits of as well as the limits to this healthcare approach. Based upon the principles of critical feminist theory and community-based research (CBR), CHIWOS involved WLWH and allied clinicians, researchers, and community members as core partners throughout all stages of the research in all three provinces. Of particular significance is the involvement of Peer Research Associates (PRAs; i.e., WLWH who received research training), who provided research leadership at all levels of the study, including contributing to the development of data collection tools, leading participant outreach and recruitment efforts, administering questionnaires to participants, engaging in data analysis and interpretation, disseminating research findings at community and academic events, and co-authoring peer-reviewed manuscripts.(79-81) These efforts produced a large nationwide sample of subjects of different demographic backgrounds in all three provinces.

WLWH eligible to participate in CHIWOS met three criteria: they were 16 years old or above, self-identified as a woman living with HIV (trans-inclusive), and residents in one of the three study provinces. Given the overrepresentation of socio-economically marginalized women among WLWH, the team made special efforts to recruit WLWH from marginalized and

vulnerable populations disproportionately affected by HIV in Canada or underserved by health services, including sex workers, trans-women, immigrant women, Indigenous women, women who use injection drugs, and ethno-racial populations. Such a community-based approach to include underserved women living with HIV aimed to capture the diversity of WLWH's health concerns and experiences, consistent with this study's critical feminist approach to investigating the law's impact on the healthcare engagement of WLWH.

The baseline (Wave 1) CHIWOS survey took place from August 2013 to May 2015, during which time 1422 participants were enrolled. Participants completed a PRA-administered survey, which asked questions concerning their reproductive, sexual, mental and women's health outcomes, and their use of HIV services. This baseline survey was conducted in English or French using Fluidsurveys, an online survey instrument (supported by White Label FluidSurveysTM software), at collaborating HIV clinics, community-based AIDS Service Organizations (ASOs), or other community organizations. For participants located in rural or remote regions, the survey was conducted via telephone or over Skype. From September 2015 to January 2017, participants were invited to complete an 18-month follow-up (Wave 2) survey (retention rate= 88%; n=1252), also administered by PRAs, which incorporated longitudinal evaluation of baseline study variables and examined novel priority research topics identified through community consultation. From February 2017 through September 2018, a 36-month follow-up (Wave 3) survey was carried out (retention rate=64%, n=1155). Additional details of CHIWOS could be found in a number of published peer-reviewed articles.(80-83)

This study made use of data collected in the Wave 2 survey, for which PRAs and the CHIWOS Community Advisory Board independently identified the criminalization of HIV non-disclosure as a key concern for Canadian WLWH and a critical research priority for the CHIWOS team. For this purpose, novel and structured research questions assessing awareness and understanding of the 2012 ruling and its perceived healthcare impacts among WLWH were



included in the CHIWOS wave 2 data collection instrument (many of which, including questions concerning WLWH's awareness and understanding of laws criminalizing HIV non-disclosure, were retained in the Wave 3 survey, and some in modified versions, including the question concerning WLWH's willingness to share information with healthcare providers because of laws criminalizing HIV non-disclosure.)

Both to ensure that priority questions for WLWH in the wider community were addressed and that they would not threaten the health, rights or safety of participants, the data collection instrument employed in the Wave 2 survey was comprehensively reviewed prior to survey administration. Considering that the privacy and confidentiality of individuals participating in health research has been called into question by the Canadian Criminal Justice System in the past, and researchers might be subpoenaed to provide evidence, including research transcripts and data, it was of utmost importance that the instrument would not threaten the health, rights or safety of participants.(8, 84, 85) One important example relevant to this study (as the subsequent chapters will further explain) is the CHIWOS team's consideration that direct questions inquiring whether participants may change their disclosure practices due to the 2012 ruling may put their privacy and safety at risk. Due to this privacy and safety consideration, the Wave 2 survey contains an indirect question to achieve this purpose, one which asks whether participants agree that "HIV disclosure laws might affect the type of information that women living with HIV would be willing to share with their healthcare providers." This safety and privacy of participants was further facilitated by specialized training undergone by CHIWOS PRAs on the criminalization of HIV non-disclosure in Canada. This helped PRAs to acquire a thorough understanding of the SCC's 2012 decision and reinforced the importance of protecting the privacy of participants as they conducted the survey on this sensitive topic. In addition, the team provided information on the law as well as referral services to participants who raised questions or concerns during the survey administration.

### **1.6.2 Ethical approval for this study**

Ethical approval for the study procedures of CHIWOS was granted by the Research Ethics Boards of Simon Fraser University, University of British Columbia/Providence Health, Women's College Hospital, and McGill University Health Centre. Participants in CHIWOS provided voluntary written informed consent to participate at study enrolment (or voluntary verbal informed consent in the presence of a witness from the CHIWOS study team for surveys completed over the telephone or Skype). Each participant was provided with a \$50 honorarium for completing each baseline or follow-up survey.

## **1.7 Overview of Thesis**

This is a manuscript-style thesis containing two manuscripts intended to be submitted to peer-reviewed journals for publication.

Chapter Two, the first of these manuscripts, employs descriptive statistics and both bivariate and multivariable logistic regressions to measure CHIWOS participants' privacy concerns, measures in terms of their perception of WLWH's willingness to disclose their personal information with their healthcare providers, and identify associations with their trust in their HIV care providers.

Chapter Three, the second of these manuscripts, employs both bivariate and multivariate logistic regressions to examine the association between CHIWOS participants' privacy concerns and their HIV clinical care engagement, primary in terms of their ART adherence and secondarily in terms of their retention in HIV care, ART use, and virological suppression.

Chapter Four summarizes the objectives, results, and findings in Chapters Two and Three. It also provides suggestions for future research on this topic as well as programming and

policy implications of the study findings. Finally, it summarizes recent developments to the law on HIV non-disclosure in Canada.

## **Chapter 2 Perceptions of Privacy Concerns and HIV Care Provider Trust among Women Living with HIV in Response to the Criminalization of HIV non-disclosure in Canada**

### **Abstract**

**Background:** In 2012, the Supreme Court of Canada ruled that people living with HIV have a legal obligation to disclose their serostatus to sexual partners prior to having sex that poses a “realistic possibility” of HIV transmission. The ruling’s impact on the privacy concerns of women living with HIV and its association with care provider trust remain unexplored. The objectives of this analysis were (1) to measure the proportion and socio-demographic characteristics of women living HIV (WLWH) who reported that HIV non-disclosure laws might affect the type of information (e.g., regarding sexual activity and HIV disclosure practices) that WLWH would be willing to share with healthcare providers; and (2) to assess the association between WLWH’s perception that HIV non-disclosure laws might affect the type of information WLWH would be willing to share with their healthcare providers and WLWH’s trust of their HIV care providers.

**Methods:** This study drew upon cross-sectional Wave 2 survey data from the community-based Canadian HIV Women’s Sexual and Reproductive Health Cohort Study. The primary outcome was WLWH’s perception of privacy concerns due to the law defined as “Strongly Agreeing” or “Agreeing” that HIV disclosure laws might affect the type of information that WLWH would be willing to share with their healthcare providers. The primary explanatory variable was women’s overall trust in care providers at their HIV clinics, defined as reporting being “Extremely satisfied” or “Strongly satisfied” vs. “Satisfied/Somewhat satisfied/Not at all satisfied.” Two multivariable logistic regression models assessed (1) socio-demographic and

clinical variables associated with privacy concerns; and (2) the association between privacy concerns and care provider trust.

**Results:** Overall, 1252 participants completed the Wave 2 survey, of whom 1182 (of 1,422 enrolled at baseline; 83.1% of the total cohort) were included in the analysis on the law's impact on the willingness to share information. The median age was 44 years [IQR: 37-52]. 21.6% identified as Indigenous, 29.9% African, Caribbean, or Black (ACB), 41.6% white, and 6.9% other ethnicities. 810 (68.5%) of participants reported perceiving privacy concerns. Women who were older, identified as ACB, employed, and unstably housed had significantly higher adjusted odds of reporting such concerns. In addition, 494 (45.3%) of 1091 participants reported trusting their HIV care providers. Both bivariate and multivariable logistic regressions showed that women who reported lower trust in HIV care providers had higher odds of privacy concerns (OR: 1.42; CI: 1.10-1.84; aOR: 1.27; 95% CI: 0.95-1.69), although the 95% confidence interval for the adjusted OR included the null.

**Discussion:** Over two-thirds of WLWH enrolled in the CHIWOS study perceived privacy concerns in the healthcare setting due to HIV non-disclosure laws, and social inequities and racial identities played an important role shaping women's perceptions of privacy concerns. That WLWH who reported having less trust in their HIV care providers had higher odds of perceiving privacy concerns indicated that fostering strong overall trust in HIV care providers among WLWH may help to alleviate healthcare-related privacy concerns in the climate of HIV criminalization.

## **2.1 Introduction**

In 1989, Canada became one of the many jurisdictions around the world to prosecute people living with HIV (PLWH) who have, or are believed to have, put others at risk of acquiring

HIV.(2, 3) It followed precedents set by the Supreme Court of Canada (SCC) in applying existing criminal laws (in most cases sexual assault law) to cases of HIV non-disclosure).(4-8) In 1998, the SCC held in *R. v. Cuerrier* that PLWH failing to disclose to partners prior to sex that represents a “significant risk” of HIV transmission could face criminal charges.(4) In 2012, the SCC further established a new legal precedent through its landmark ruling on two major cases, *R. v. Mabior* and *R. v. D.C.*(6, 7) In *Mabior*, the SCC determined that PLWH could face a conviction for aggravated sexual assault if they did not disclose their HIV status before sex that posed a “realistic possibility” of “significant bodily harm,” i.e. HIV transmission. PLWH who engage in condom-protected vaginal sex and have a “low” HIV RNA plasma viral load (defined by the SCC as <1500 copies/mL) have no obligation to disclose.(6) In *D.C.*, the SCC affirmed the ruling in *Mabior* by opining that both condom use and a low viral load are required to preclude a “realistic possibility” of HIV transmission.(7) By suggesting that both conditions are required to avert the disclosure obligation, the SCC broadened the scope of criminal liability for HIV non-disclosure established in *Cuerrier*.

Laws criminalizing HIV disclosure have been criticized by health scientists for failing to consider the issue through a gendered lens. Women living with HIV (WLWH) experience barriers to HIV disclosure and condom negotiation due to gender-based power inequities (8, 22, 28, 29, 65). Those in abusive relationships, experiencing violence, who are financially or otherwise dependent on their partners, are imprisoned, are undocumented, or otherwise vulnerable may be challenged to disclose their HIV status without risking violence, stigma, or discrimination.(30) Moreover, the laws criminalization of HIV non-disclosure negatively impact how WLWH engage in HIV-related healthcare contributing to poorer HIV outcomes among women along the HIV care cascade (22, 65). A suggested pathway for poorer healthcare engagement includes women’s concerns about privacy of their personal information.(58)

In *R. v. Spencer*, the SCC stated that “retention of information about oneself is extremely important” in modern society and “all information about a person is in a fundamental way his own, for him to communicate or retain for himself as he sees fit.”<sup>(51)</sup> There are at least two ways in which the 2012 ruling implicates PLWH’s right to privacy. First, it intrudes upon PLWH’s right to keep their HIV status private. Second, it threatens PLWH’s right to keep their personal information (such as their sexual behaviours and disclosure practices) private in a health care setting and not to have it shared with outside authorities. The latter scenario is the focus of this study.

In an HIV care setting, sharing information about sexual and disclosure practices during clinical consultations is important to guide comprehensive care.<sup>(22, 40, 41, 44, 86)</sup> In Canada, public health authorities may provide PLWH’s health records to law enforcement in HIV non-disclosure cases when a warrant or subpoena for information has been served or in circumstances involving a high risk of HIV transmission to others.<sup>(52, 53)</sup> In *Smith v. Jones* (1999), the SCC decided that there is discretion to disclose confidential information about a client in order to prevent harm to another person where these three conditions are satisfied: first, there is a clear risk of harm to an identifiable person or group of persons; second, there is a risk of serious bodily harm or death, and third, the danger is imminent.<sup>(87)</sup> Although the SCC was deciding whether and when a lawyer’s duty of confidentiality to his or her client could be waived, the principles set out in this case apply to every service provider caring for and counseling people living with HIV, whether they are regulated professionals or not.<sup>(87)</sup> However, determining the specific circumstances in which confidentiality may or should be set aside is not straightforward.<sup>(54)</sup> For instance, uncertainty about the limits of confidentiality of medical records in the current legal climate has, in some cases, led HIV care providers to change their notetaking practices.<sup>(86)</sup>

Research in Canada shows that laws criminalizing HIV non-disclosure risk re-orienting HIV prevention efforts from a public health priority towards a criminal law concern, implying close ties between public health and the police in the minds of PLWH.(55) Hence, PLWH's uncertainty about the limits of confidentiality of their personal information in healthcare settings may discourage them from sharing information important for effective consultations with HIV providers.(55-57) Research also indicates that WLWH may be reluctant to share their sexual behaviors and disclosure practices with healthcare providers for fear of experiencing stigma and discrimination, especially WLWH experiencing challenging socio-economic circumstances, insecure immigration status, or members of ethno-racial minorities disproportionately burdened with HIV-related stigma and discrimination.(1, 32) Emerging research among racialized communities suggests that HIV-related stigma and discrimination and privacy concerns in the healthcare setting have increased due to the threat of HIV criminalization.(58)

Trust in healthcare providers plays a significant role in clinical settings for PLWH. In a healthcare context, trust refers to “a firm belief in the reliability, truth, or ability of someone or something,”(66) or “an expectation that the other person will behave in a way that is beneficial, or at least not harmful, and allows for risks to be taken based on this expectation,” so that it provides “a basis for taking the risk of sharing personal information.”(67) A 2012 Ontario-based study found that participants with longstanding relationships with healthcare providers did not report difficulty trusting them despite laws criminalizing HIV non-disclosure, although they reported concerns about interacting with new healthcare providers.(25) This was explained by their belief that long-time healthcare providers would not disclose their information to third parties and that being honest with their healthcare providers would be beneficial to them.(25) Moreover, studies, conducted both before and after the 2012 ruling, indicated that WLWH in Canada generally trust their HIV care providers, but this patient-provider trust may be compromised due to WLWH's concerns over the sharing of their confidential medical



information with law authorities.(25, 55) Although none of these studies specifically defined “trust,” trust in care providers is broadly represented as willingness to engage in open dialogues and share information with care providers.(25, 55)

Importantly, research also indicates that PLWH’s trust in HIV care providers in particular is associated with better engagement in HIV clinical care and better health outcomes.(68-70) These studies describe trust as a belief in the competence of care providers who give them the right information(70) and the best care possible,(69) and a willingness to confide in care providers who accept them.(68) A long-term and trusting relationship with HIV care providers (including nurses, physicians and physician assistants) is an essential part of HIV treatment throughout the continuum of HIV care.(68, 70) Trust in HIV care providers is associated with improved self-reported physical and mental health, whereas distrust in them may be a barrier to service use and therefore to optimal health.(69)

Very recently, research has drawn upon data from the Canadian HIV Women’s Sexual and Reproductive Health Cohort Study (CHIWOS) to study the awareness and understanding of HIV non-disclosure case law among WLWH in Canada and its association with their HIV care engagement.(8, 88) To date, however, there is no large-scale, quantitative study using nationwide data to examine such laws through a privacy lens and whether the 2012 decision has impacted WLWH’s privacy concerns, in terms of willingness to disclose personal information to their healthcare providers, and the socio-demographic characteristics of WLWH who report perceived privacy concerns. In addition, although the relationship between provider trust and healthcare engagement is well-documented in the context of HIV clinical care, there is no research directly addressing whether and to what extent that WLWH’s trust of their HIV care providers is associated with concerns about privacy of their personal health information in the wake of the 2012 ruling.

The objectives of this study were (1) to measure the prevalence and socio-demographic characteristics of WLWH who reported that HIV non-disclosure laws might affect the type of information (e.g., sexual activity and HIV disclosure practices) that WLWH would be willing to share with healthcare providers (i.e., privacy concerns); and (2) to assess the association between WLWH's trust of their HIV care providers and privacy concerns. Its two hypotheses are: (1) WLWH who are socially or economically vulnerable have higher odds of reporting that HIV non-disclosure laws might affect the type of information (e.g., sexual activity and HIV disclosure practices) that WLWH would be willing to share with healthcare providers (i.e., privacy concerns); and (2) WLWH's trust in their HIV care providers is negatively associated with their privacy concerns.

## **2.2 Methods**

### **2.2.1 Setting**

The Public Health Agency of Canada's record shows that there were approximately 16,880 WLWH in Canada in 2016.<sup>(77)</sup> Most (81%) WLWH in Canada reside in the three provinces of British Columbia (BC) (8.4%) Ontario (54.4%), and Quebec (26.9%).<sup>(78)</sup>

### **2.2.2 Study Design**

This study employed cross-sectional survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based longitudinal cohort study of WLWH from BC, Ontario and Quebec to examine access to and impacts of women-centred HIV care.<sup>(81)</sup> Based upon the principles of critical feminist theory and community-based research (CBR), CHIWOS involved WLWH and allied clinicians, researchers, and community members as core partners throughout all stages of its research. Peer Research Associates (PRAs; i.e., WLWH who received research training)<sup>(79)</sup> provided research leadership at all levels of the study, including contributing to the development of data collection tools, leading participant outreach and recruitment efforts, administering questionnaires to

participants, engaging in data analysis and interpretation, disseminating research findings at community and academic events, and co-authoring peer-reviewed manuscripts.(89)

WLWH eligible to participate in CHIWOS met three criteria: they were 16 years old or older, self-identified as a woman living with HIV (trans-inclusive), and were residents in one of the three study provinces. The CHIWOS team made special efforts to recruit WLWH from marginalized populations disproportionately affected by HIV or underserved by health services, including women engaged in sex work, trans-women, immigrant women, Indigenous women, women who use injection drugs, and members of ethno-racial minority groups (those of African, Caribbean and Black origins). These efforts, aimed to capture the diversity of WLWH's health concerns and experiences, are in line with CHIWOS's critical feminist approach to investigating the law's impact on the healthcare engagement of WLWH.(90)

The baseline (Wave 1) CHIWOS survey took place from August 2013 to May 2015. The 1422 participants completed a PRA-administered survey, which asked questions concerning their reproductive, sexual, mental and women's health outcomes and their use of HIV services. This survey was conducted in English or French using Fluidsurveys, an online survey instrument (supported by White Label FluidSurveys™ software), at collaborating HIV clinics, community-based AIDS Service Organizations (ASOs), or other community organizations. For participants located in rural or remote regions, the survey was conducted via telephone or over Skype. From June 2015 to January 2017, the same participants were invited to complete an 18-month follow-up (Wave 2) survey (retention rate= 88%; n=1252), again administered by PRAs, which included longitudinal evaluation of baseline study variables and examined new priority research topics identified through community consultation. From February 2017 through September 2018, a 36-month follow-up (Wave 3) survey was carried out.

This study employed data collected in the Wave 2 survey. In this survey, PRAs and the CHIWOS Community Advisory Board independently identified the criminalization of HIV non-

disclosure as a major concern for Canadian WLWH and a critical research priority for the CHIWOS team. A multidisciplinary team of experts, including academic researchers, frontline research staff, WLWH and a legal representative, took part in the development of new survey questions assessing WLWH's awareness and understanding of the 2012 ruling and its perceived healthcare impacts among WLWH.

The data collection instrument in the Wave 2 survey was thoroughly reviewed prior to survey administration to ensure that priority questions for WLWH in the wider community were addressed and that these questions would not threaten the health, rights or safety of participants.(8) Proposed questions were piloted with the CHIWOS PRAs to identify problems with validity, clarity, and inclusiveness of their response options.(8) CHIWOS PRAs also underwent training on laws criminalizing HIV non-disclosure in Canada to understand the SCC's 2012 decision and learn how to protect the privacy of participants during the survey administration.(8) The PRA team further provided information on the law as well as referral services to participants who raised questions or concerns during the survey administration.(91-94)

### **2.2.3 Theoretical Framework**

This study adopts a critical feminist framework to study the impact of the 2012 ruling on WLWH's perception of privacy concerns and its association with their trust of their HIV care providers. A critical feminist perspective asserts that multiple social identities, including gender, race, sexual orientation, and socio-economic status, intersect at individual and structural levels to create the social inequalities and oppression experienced by women.(8, 40, 73-76). This study applies an intersectional framework both to the acknowledge the diverse identities and experiences of WLWH and to contextualize and better understand the individual, social and structural factors contributing to their perception of privacy concerns and its potential association with their HIV care provider trust.

#### **2.2.4 Ethical Approval**

Ethical approval for the study procedures of CHIWOS was granted by the Research Ethics Boards of Simon Fraser University, University of British Columbia/Providence Health, Women's College Hospital, and McGill University Health Centre. In addition, participants in CHIWOS provided voluntary written informed consent to participate at enrolment (or voluntary verbal informed consent in the presence of a witness from the CHIWOS study team for surveys completed over the telephone or Skype). Each participant was also provided with a \$50 honorarium for completing each baseline or follow-up survey.

#### **2.2.5 Inclusion and Exclusion Criteria**

This study on WLWH's perception of privacy concerns and its association with HIV care provider trust was restricted to CHIWOS participants who completed the Wave 2 survey (n=1,252) and who also had non-missing responses to the outcome variable on privacy concerns (i.e., survey question S5-118 concerning whether WLWH believe that the 212 ruling might affect the type of information that WLWH would be willing to share their personal information with health providers). Those who reported "Don't know," "Prefer not to answer," "Other," or provided no answer were excluded. For the second objective, participants also had to have non-missing responses to S3-28(j), which asks them to report the level of satisfaction about the care received the HIV clinic during the last 12 months. Those who responded "Don't know," "Prefer not to answer," or had missing data were excluded. The exclusion of "Don't know" and "Prefer not to answer" in both cases was to ensure that only affirmative responses were included in the measurement. If very few chose these options, they are unlikely to bias the results. Missing responses can be random or systematic.<sup>(95)</sup> Because the options of "Don't know" and "Prefer not to answer" were provided to the participants as options, any data further missing in the answers are likely to be random rather than due to systematic reasons and so their exclusion would less likely lead to biased results.<sup>(95)</sup>

## **2.3 Measures**

### **2.3.1 Outcome Variable**

The primary outcome of interest was WLWH's perception of WLWH's willingness to share personal information with their healthcare providers, referred to as "privacy concerns." Because questions inquiring participants' own disclosure practices may put their privacy and safety at risk, this variable was measured by responses to this indirectly phrased 5-point Likert scale survey question S5-118: *"Please indicate to what degree you agree or disagree with the following statement: "HIV disclosure laws might affect the type of information that women living with HIV would be willing to share with their healthcare providers, such as information about sexual activities and HIV disclosure."* To ensure that only participants who affirmatively perceived privacy concerns would be counted, responses were dichotomized into "Strongly Agree" or "Agree" vs. "Neutral" or "Disagree" or "Strongly Disagree" to distinguish participants who perceived concerns over the sharing personal information from WLWH who did not.

### **2.3.2 Explanatory Variable**

The primary explanatory variable was WLWH's overall trust in their care providers at their current HIV clinic. This was measured by the level of satisfaction reported in response to S3-28(j): *"... My overall trust in the health professionals here"* (at the HIV clinic). Because the literature shows that WLWH in general are trustful of their HIV care providers, a more stringent definition of "trust" was chosen and responses were dichotomized into "Extremely Satisfied" or "Strongly Satisfied" vs. "Satisfied" or "Somewhat Satisfied" or "Not at all satisfied." In this way, participants who reported strong satisfaction in their overall trust (i.e., higher trust) in HIV care providers were distinguished from those who did not (i.e., lower trust).

### **2.3.3 Covariates**

Correlates of women's perception of privacy concerns were identified by the literature review set out in this study's introduction as well as its theoretical framework section shaped by

a critical feminist and intersectional approach. Sociodemographic variables included province of interview (BC vs. Ontario vs. Quebec), age at interview (continuous variable), ethnicity (Indigenous vs. African/Caribbean/Black vs. white vs. Other ethnicities), born in Canada (No vs. Yes), legal status in Canada (Canadian citizen vs. landed immigrant/Permanent resident vs. Other legal status), formal education (high school or less vs. more than high school), current employment (No vs. Yes), stable housing (stable housing (Strongly agree/Somewhat agree) vs. unstable housing (Neutral/Somewhat disagree/Strongly disagree)), and self-reported participation in HIV work in the community (No vs. Yes) since the last CHIWOS interview, in the form of paid or volunteer work such as providing peer support, community outreach, delivering HIV education, conducting research and helping with funding raising. HIV stigma score was included as both a continuous variable and a dichotomized variable (low (<median score=58) vs. high (>=median score=58)) and was measured using a 10-item HIV Stigma Scale (HSS).<sup>3</sup> Scores for the HSS ranged from 0 to 100, with higher scores indicating higher stigma.(96)

HIV clinical variables included years living with HIV (continuous variable) and years receiving HIV care from their current HIV medical clinic (less than 3 years vs. 3 to 5 years vs. 5 to 10 years vs. 10+ years vs. did not receive HIV care since last interview).

## 2.4 Statistical Analysis

Descriptive statistics (median and interquartile range [IQR] for continuous variables, numbers [n] and percentages [%] for categorical variables) were used to measure the prevalence

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<sup>3</sup> The stigma scale was based on question S6-01 in CHIWOS Wave 2 survey: "For each of the following items, please indicate whether you: Strongly Agree, Agree, Neither Agree nor Disagree, Disagree, or Strongly Disagree Note to PRAs: These questions can refer to the participant's entire life. Select one per line. a. I have been hurt by how people reacted to learning I have HIV. b. I have stopped socializing with some people because of their reactions of my having HIV. c. I have lost friends by telling them I have HIV. d. I am very careful who I tell that I have HIV. e. I worry that people who know I have HIV will tell others. f. I feel that I am not as good a person as others because I have HIV. g. Having HIV makes me feel unclean. h. Having HIV makes me feel that I'm a bad person. i. Most people think that a person with HIV is disgusting. j. Most people with HIV are rejected when others find out."

of WLWH who reported that they agree (vs. disagree) that HIV disclosure laws might affect the type of information that WLWH would be willing to share with their healthcare providers as well as socio-demographic and HIV clinical characteristics. Differences between groups were assessed using Pearson's X-squared test (Fisher's exact test when count <5) for categorical variables, and the Wilcoxon rank sum test for continuous variables. Bivariable logistic regression was used to compute unadjusted odds ratios and 95% confidence intervals of the association between socio-demographic and clinical variables and participants' perception of WLWH's willingness to share information.

For objective one, multivariable logistic regression in an exploratory model was used to identify independent covariates of participants' perception of willingness to share information and produce adjusted odds ratios with 95% confidence intervals. For objective two, multivariable logistic regression in a confounding model was used to assess the independent association between participants' HIV care provider trust and perception of willingness to share information, while controlling for known and potential confounders. For both objectives, the final models were selected through a backwards selection process and guided by minimizing the Akaike Information Criterion and maintaining Type III p-values. Variables demonstrating a significance level of  $p < 0.2$  in multivariable analysis were selected in the multivariable model. P-values were two-sided and considered statistically significant at  $< 0.05$ .

## **2.5 Results**

Of 1422 participants who enrolled in CHIWOS, 1,252 completed the Wave 2 survey (88%) and 1182 (83.1%) had non-missing responses to the primary outcome variable. The analytic sample represented the socio-demographic diversity of Canadian women with HIV (Table 2.1). The median age of participants was 44 years (IQR: 37-52), among whom 255 (21.6%) identified as Indigenous, 354 (29.9%) as ACB, 492 (41.6%) as White and 81 (6.9%) as



other ethnicities. The majority were born in Canada (753, 63.7%) and were Canadian citizens (1005, 85%). 559 (47.3%) reported to have received a formal education beyond high school level. At the time of the survey, 412 (34.9%) were employed, and 993 (84%) were stably housed. 352 (29.0%) participated in HIV work in their communities. On average, they had been living with HIV for 13 years (IQR: 8-19) (see Table 2.1).

### **2.5.1 WLWH's Willingness to Share Information with Healthcare Providers**

Overall, 810 (68.5%) agreed that non-disclosure laws might affect the type of information that WLWH would be willing to share their information with their healthcare providers, while 372 (31.5%) disagreed (Table 2.1). Several socio-demographic and HIV-related variables were shown to be associated with WLWH's willingness to share information.

The first hypothesis that WLWH who are socially or economically vulnerable have higher odds of reporting that HIV non-disclosure laws might affect the type of information (e.g., sexual activity and HIV disclosure practices) that WLWH would be willing to share with healthcare providers (i.e., privacy concerns) was not rejected by both adjusted and unadjusted results. Unadjusted results (Table 2.2) indicate that ACB women (OR: 1.96, CI: 1.44, 2.67), WLWH who were older (OR: 1.02 per year, CI: 1.01, 1.04), who had landed immigrant/permanent resident status (OR: 1.91, CI: 1.23, 2.97), and who were unstably housed (1.65, 1.15, 2.38) had significantly higher odds of reporting privacy concerns. Those who participated in HIV work in the community (1.64, CI: 1.24, 2.18) also had significantly higher odds of reporting privacy concerns. However, WLWH born in Canada (OR: 0.60, CI: 0.46, 0.78), living in Ontario (OR: 0.72, CI: 0.53, 0.99) (as opposed to Quebec and British Columbia), and with high stigma scores (both dichotomized and continuous) had significantly lower odds of reporting privacy concerns due to such laws (OR: 0.77, CI: 0.60, 0.99; OR: 0.99, CI: 0.99, 1.00 respectively).

Adjusted results (Table 2.2) indicate that women of ACB descent (AOR: 1.58, CI: 1.11, 2.24), who were unstably housed (AOR: 2.03, CI: 1.31, 3.14), who were older (AOR: 1.03 per

year, CI: 1.02, 1.04), and who were employed (AOR: 1.38, CI: 1.02, 1.86) all had significantly higher adjusted odds of reporting privacy concerns. All other covariates that showed significant associations in the unadjusted results (immigrant status, born in Canada, province, stigma scores, and participation in HIV community work) were not selected in the adjusted model.

### **2.5.2 Perception of Privacy Concerns and Trust in HIV Care Providers**

Among the 1091 (76.7% of 1422 or those who completed Wave 2 survey) participants who answered the questions both regarding privacy concerns and regarding their overall trust in HIV care providers, 494 (45.3%) reported high levels of trust in the providers at their HIV clinic, compared with 597 (54.7%) who reported lower levels of trust.

The second hypothesis that WLWH's trust in their HIV care providers is negatively associated with their privacy concerns was also not rejected. Trust was associated with expressing privacy concerns (Table 2.3) (perceived unwillingness of WLWH to share personal information with healthcare providers in the wake of the SCC ruling). In the unadjusted logistic regression analysis, women who reported having low trust had significantly increased odds of reporting privacy concerns (OR: 1.42, CI: 1.10, 1.84). In the confounding model, women with low trust had 1.27 higher adjusted odds of perceiving privacy concerns. However, the 95% CI included the null and the true estimate fell within the range of 0.95 to 1.69.

## **2.6 Discussion**

Over two-thirds (68.5%) of WLWH in this study perceived privacy concerns in the wake of the 2012 ruling on HIV non-disclosure, measured in terms of their perceived impact of the law on WLWH's willingness to share their information with their healthcare providers, while one-third (31.5%) did not. This majority who perceived privacy concerns supports prior research indicating that PLWH's uncertainty about the limits of confidentiality of their personal

information in the healthcare setting has discouraged them from sharing information that would be important for effective healthcare consultations.(55-57). These findings are also consistent with a previous CHIWOS analysis and precursor to this work that examined awareness and understand of the 2012 ruling.(8, 88)<sup>4</sup>

Among prior studies on privacy and the sharing of information, one study is qualitative and looks at PLWH.(55) Two other studies focus on gay, bisexual, and other men who have sex with men living with HIV. One of these two is qualitative, in which a subgroup of 27 men who have sex with men (12 HIV-positive, 15 HIV-negative) believed that the local public health department openly shares information about people living with HIV with the police; some, perceiving an association between the public health department and police services, were therefore were unwilling to access public health department services.(57) The other study is quantitative, according to which 13.8% of participants with HIV indicated that nondisclosure prosecutions made them afraid to talk to nurses and physicians about their sexual practices.(56) A more recent study, based not on CHIWOS but a different sample, further shows that slightly more WLWH (58%) than MLWH (52%) perceived less willingness to share information with healthcare providers due to the 2012 ruling.(8) This study, without comparing WLWH to their male counterparts, furthers the knowledge on this topic by showing that a large majority of WLWH experienced privacy concerns in the wake of the 2012 ruling, by their perceived unwillingness to share information with healthcare providers.

Considering the role of social inequities in shaping WLWH's experiences, it is perhaps not surprising that women who are ACB, older, with landed immigrant/permanent resident

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<sup>4</sup> "[A]most two-thirds of participants believed that HIV non-disclosure case law might affect the type of information that women with HIV would share with their healthcare providers, a belief more commonly held among those aware of the ruling [prior to survey completion] (67% vs. 60%,  $p=0.037$ )."<sup>88</sup> Patterson S, Nicholson V, Milloy M-J, et al. Awareness and understanding of HIV non-disclosure case law and the role of healthcare providers in discussions about the criminalization of HIV non-disclosure among women living with HIV in Canada. *AIDS & Behavior*. 2019.

status (non-citizens), and unstably housed—all socially or economically vulnerable—had higher adjusted odds of perceiving privacy concerns. WLWH experiencing challenging socio-economic situations, insecure immigration status, and/or members of ethno-racial minorities report more HIV-related stigma and discrimination than middle-class white WLWH (1, 32, 97) This study shows that these factors made WLWH not only more prone to stigma and discrimination, but also more likely to perceive privacy concerns in the wake of the 2012 ruling. This analysis also supports prior research indicating greater privacy concerns among racial and ethnic minorities regarding their personal information in the healthcare setting more generally.(98, 99)

In the adjusted analysis, participants employed at the time of the survey had higher odds of perceiving privacy concerns may seem unexpected in light of prior research about the impact of economic inequities on WLWH's experiences.(1, 32, 97) One possible reason might be that participation in the work force, like the participation in HIV community work, enabled WLWH to connect with the HIV community and to become more concerned about risks of sharing of personal information in a healthcare setting. Another reason might be that employment status is correlated with higher education and greater awareness of the ruling.(88)

Almost half of participants (45.3%) reported trusting care providers at their HIV clinics. This result agreed with prior research indicating the generally high level of trust among WLWH in their HIV care providers.(25) Previous CHIWOS research has similarly pointed to women's trust in their HIV care providers and identified HIV care providers as the preferred source of information about the law (8). The present analysis showed that women with lower HIV provider trust had higher odds of perceiving privacy concerns in both unadjusted (OR: 1.42, CI: 1.10, 1.84) and adjusted results (OR: 1.27, CI: 0.95, 1.69). This both confirms prior research on the importance of trust in healthcare settings and in HIV care, and indicates that fostering strong trust in HIV care providers among WLWH may help to alleviate privacy concerns and promote willingness to share information with healthcare providers which is essential to

effective care provision. According to patients' reports in prior research, WLWH tend to trust HIV care providers who respect them by engaging in conversations about their health and healthcare, and who acknowledge and validate their experience, knowledge and expertise regarding their own bodies and illnesses.(70) In other words, provider trust is promoted by strong patient-provider relationships and rapport within a care environment that prioritizes patient autonomy and respect. The lack of a statistically significant association (at  $p < 0.05$ ) between trust and privacy concerns in the confounding model might be explained by confounding effects of ethnicity and housing situation. The significance of these two covariates indicate that fostering trust in HIV care providers may be particularly important to alleviate privacy concerns among WLWH who are of ACB descent or who are unstably housed. This is consistent with findings that stigma and discrimination continue to disproportionately affect WLWH who are members of ethno-racial minorities.(1, 32) Providing greater access to ethno-racially diverse and/or culturally competent healthcare providers may be an important step toward increasing trust in these providers.(100)

Recent developments in HIV non-disclosure law in Canada may impact privacy concerns of WLWH over the sharing of personal information in healthcare settings. On December 1, 2017, or the World AIDS Day, Ontario's provincial government announced that its crown attorneys would no longer criminally prosecute HIV-positive people who do not disclose their status to sexual partners if there is no realistic possibility of transmission.(101) On December 1, 2018, the Minister of Health of Canada officially endorsed the Undetectable = Untransmittable (U=U) campaign that promotes new scientific evidence indicating that an individual who is being treated for HIV and who maintains a suppressed viral load poses essentially no risk of sexual transmission.(102) On the same day, the Minister of Justice and Attorney General of Canada also issued a new directive on the prosecution of HIV non-disclosure stating that there should not be criminal prosecution of HIV non-disclosure where: (1) the person living with HIV has maintained a suppressed viral load (i.e. under 200 copies of the virus per millilitre of blood)

because there is no realistic possibility of transmission; (2) the person has not maintained a suppressed viral load, but used condoms or engaged only in oral sex or was taking treatment as prescribed, unless other risk factors are present; (3) reclassifying cases of HIV non-disclosure as non-sexual criminal offences would be more appropriate than sexual offences.(103) The criminal law will continue to apply if PLWH do not disclose, or misrepresent, their HIV status before sexual activity that poses a realistic possibility of HIV transmission.(103)

Recent developments in HIV non-disclosure law in Canada may further shape privacy concerns of WLWH over the sharing of personal information in healthcare settings. On December 1, 2017, on the World AIDS Day, Ontario's provincial government announced that its crown attorneys would no longer criminally prosecute people living with HIV who do not disclose their status to sexual partners if there is no realistic possibility of transmission.(101) On December 1, 2018, the Minister of Health of Canada officially endorsed the Undetectable = Untransmittable (U=U) campaign that promotes new scientific evidence indicating that an individual who is being treated for HIV and who maintains a suppressed viral load poses essentially no risk of sexual transmission.(102) On the same day, the Minister of Justice and Attorney General of Canada issued a new directive on the prosecution of HIV non-disclosure stating that there should not be criminal prosecution of HIV non-disclosure where: (1) the person living with HIV has maintained a suppressed viral load (i.e. under 200 copies of the virus per millilitre of blood) because there is no realistic possibility of transmission; (2) the person has not maintained a suppressed viral load, but used condoms or engaged only in oral sex or was taking treatment as prescribed, unless other risk factors are present; (3) reclassifying cases of HIV non-disclosure as non-sexual criminal offences would be more appropriate than sexual offences.(103) The criminal law will continue to apply if PLWH do not disclose, or misrepresent, their HIV status before sexual activity that poses a realistic possibility of HIV transmission.(103)

On April 16, 2019, the BC Crown Counsel issued a policy manual on the prosecution of HIV non-disclosure indicating how people living with HIV in BC may be charged in cases of non-disclosure.(104) This “Sex 2” manual lays out steps that the Crown needs to complete before pressing charges, including case assessment by more than one Crown Counsel lawyer and determination that public interests weigh in favor of the charges.(104)

It is still uncertain as to what impact the Ontario government’s decision and the Federal government’s new directive may have on WLWH. Because these new measures would make prosecution in non-disclosure cases more unlikely than before, knowledge of such may help to loosen the perceived ties between public health and law enforcement authorities and make the efforts of HIV prevention more a public health than a criminal law concern. Likewise, BC’s Sex 2 policy manual makes it more difficult for the Crown to lay criminal charges against WLWH who did not disclose their HIV statuses to their partners. However, it is premature to suggest that these new directive and prosecution guidelines would serve to alleviate privacy concerns among WLWH in terms of their willingness to share their personal information with healthcare providers.

On June 17,2019, the Standing Committee on Justice and Human Rights, at its 42nd Parliamentary meeting, issued a report on the criminalization of non-disclosure of HIV status. The report recommended, among other things, “that the Government of Canada create a specific offence in its Criminal Code related to the non-disclosure of an infectious disease (including HIV) when there is actual transmission, and that prosecutions related to such transmission only be dealt under that offence.”(105) The government should draft the contemplated legislation “in consultation with all relevant stakeholders, including the HIV/AIDS community,” to circumscribe such use of criminal law and “make sure HIV is treated as a public health issue like any other infectious disease.”(105) The Committee also recommended that the Minister of Justice and Attorney General of Canada “immediately establish a federal-provincial working

group to develop a common prosecutorial directive to be in effect across Canada to end criminal prosecutions of HIV non-disclosure, except in cases where there is actual transmission of the virus, to ensure that the factors to be respected for criminal prosecutions of HIV non-disclosure reflect the most recent medical science regarding HIV and its modes of transmission and only applies when there is actual transmission having regard to the realistic possibility of transmission.”(105) In addition, the Committee recommended immediate establishment by the Minister of Justice and Attorney General of Canada of a mechanism to review all cases of individuals who have been convicted or prosecuted for not disclosing their HIV status and who would not have been prosecuted or convicted under the new standards set out in the recommendations of the Committee.(105)

Unlike the measures by the Ontario and the Federal governments, the recommendation that a directive be developed to end criminal prosecutions of HIV non-disclosure, if followed, may contribute to alleviating WLWH’s privacy concerns. Should the directive be in place, WLWH’s personal information would not be used for prosecution purposes, except “where there is actual transmission of the virus.”(105)

## **2.7 Limitations**

The CHIWOS project, with its expert-designed and reviewed questions and skilfully administered surveys, facilitates the study of WLWH’s privacy concerns and their engagement in HIV clinical care. However, because WLWH engaged in the community and its health services were likely more willing to have participated in the surveys, this might have led to a representation bias.(88) This representation bias might have become more severe considering that WLWH sufficiently engaged with the CHIWOS community were more likely to have participated in the Wave 2 survey.(88)



Another representation bias exists in the possible overrepresentation of WLWH who have been living with HIV for several years. The median number of years that participants have been living with HIV was 13 years (Q1-3: 8-19). Hence, it is not surprising that a sizeable percentage of participants have been receiving HIV care at the current HIV clinic for 10 or more years (374%, 32%), and most for a period from 3 to 10 years was (488, 41%), and a smaller percentage for less than 3 years (224, 19%). Research indicates that PWLW with longstanding relationship with HIV care providers generally trust them in that they would be willing to share their personal information with these providers and believed that the providers would not disclose their confidential information to third parties(25). These figures indicate that there may be an overrepresentation of participants with high care provider trust. Although the study already adopted a stringent definition of trust, this overrepresentation of participants living with HIV for several years may have inflated our estimates of provider trust.

The data drawn from the Wave 2 survey in this analysis might also have been influenced by social desirability biases because all the relevant variables were self-reported. Any such biases might have led to overestimated or underestimated WLWH's privacy concerns as well as their levels of trust, and therefore did not accurately measure the role of trust in alleviating privacy concerns. The extensive training undergone by PRAs in methods of survey delivery, described earlier, should have served to reduce some of these biases.(88) However, these biases in this instance may have been reduced by the indirect nature of the question, which asked not whether participants would be willing to share their personal information but whether they believe WLWH in general would be less willing to share such information in the wake of the 2012 ruling.

The inclusion/exclusion criteria may have produced another bias. For the question measuring WLWH's privacy concerns, no participants answered "Don't know" or "Prefer not to answer." However, only 1182 of 1152 (94.4%) answered this question (i.e., there were 70 missing

responses). Missing responses may indicate participants who were uncomfortable answering the question, and thus may have been more likely to perceive that the law may affect the willingness of WLWH to share information with healthcare providers. Thus, the exclusion of participants with missing data likely underestimated the estimate of participants who perceived privacy concerns due to the law.

For the questioning measuring their HIV care provider trust, 16 reported “Don’t know” or “prefer not to answer” or had missing responses (while 75 responded “not applicable” because they had not received medical care since the last interview). Given the small proportion of missing responses (16/1177; 1.4%) any biases due to missing data are minimal. Similarly, the number of participants answering “Don’t Know” “Prefer not to answer,” or had missing responses to covariates were small in comparison to the sample size. Thus, the exclusion of missing responses would not have affected the findings regarding the relationship between privacy concerns and trust.

This study, based upon the SCC’s 2012 ruling, was nonetheless conducted with a view to improve the health of WLWH globally. It remains unclear whether the results of this study may have direct applicability to other countries. Yet they hopefully should make a convincing case about the privacy concerns raised by criminalizing HIV non-disclosure, and the role of provider trust in alleviating these concerns. As such, the study should contribute to the emerging literature showing the detrimental impacts of similar laws to the health and rights of WLWH and measures that could be taken to alleviate such impacts (88)

## **2.8 Conclusion**

This chapter is the first quantitative study of WLWH’s perception of privacy concerns in the wake of the SCC’s 2012 ruling criminalizing HIV non-disclosure in Canada and the role of

HIV provider trust in alleviating these concerns. By drawing upon Wave 2 survey data of CHIWOS, this study showed that over two-thirds of WLWH who had prior understanding of the ruling perceived privacy concerns, defined in terms of their perception that such laws might affect the type of information that WLWH would be willing to share with their healthcare providers. Results also supported prior research by showing that WLWH who were socio-economically marginalized tended to have significantly higher adjusted odds of reporting privacy concerns.

Findings suggested that WLWH with low HIV care provider trust had significantly higher odds of perceived privacy concerns, indicating that high provider trust among WLWH can potentially alleviate privacy concerns due to laws criminalizing HIV non-disclosure.

CHIWOS is a community-based longitudinal cohort study of WLWH from BC, Ontario and Quebec implemented to better understand women-centred HIV care for WLWH across Canada. The current analysis, by drawing CHIWOS survey data to examine WLWH's privacy concerns in response to the SCC's 2012 ruling and the role of trust in alleviating such concerns, both calls for the repeal of laws criminalizing HIV non-disclosure and the cultivation of trusting provider-patient relationships to better safeguard WLWH's health and well-being.

**Table 2.1: Social-demographic and clinical characteristics of women living with HIV enrolled in the CHIWOS study at Wave 2 overall and stratified by privacy concerns in the healthcare setting due to HIV non-disclosure law (n=1,182)**

Variable	Total N	Overall (total=1182) n (%)	Privacy concerns*		P-value
			Agree to privacy concerns (n=810) n(%)	Disagree to privacy concerns (n=372) n(%)	
<b>Province of interview</b>	1182				0.009
British Columbia		284(24.0)	203(25.1)	81(21.8)	
Ontario		597(50.5)	385(47.5)	212(57.0)	

Quebec		301(25.5)	222(27.4)	79(21.2)	
<b>Ethnicity</b>	1182				<0.001
Indigenous		255(21.6)	169(20.9)	86(23.1)	
African/Caribbean/Black		354(29.9)	273(33.7)	81(21.8)	
White		492(41.6)	311(38.4)	181 (48.7)	
Other ethnicity		81(6.9)	57(7.0)	24(6.5)	
<b>Born in Canada</b>	1182				<0.001
No		427(36.1)	322(39.8)	105(28.2)	
Yes		753(63.7)	487(60.1)	266(71.5)	
DK/PNTA/Missing**		2(0.2)	1(0.1)	1(0.3)	
<b>Legal status in Canada</b>	1182				0.014
Canadian Citizen		1005(85.0)	672(83.0)	333(89.5)	
Landed Immigrant/Permanent Resident		131(11.1)	104(12.8)	27(7.3)	
Other		44(3.7)	32(4.0)	12(3.2)	
DK/PNTA**		2(0.2)	2(0.2)		
<b>Formal education</b>	1182				0.197
Completed High school or less		618(52.3)	414(51.1)	204(54.8)	
More than high school		559(47.3)	394(48.6)	165(44.4)	
DK/PNTA/Missing**		5(0.4)	2(0.2)	3(0.8)	
<b>Currently employed</b>	1182				0.134
No		763(64.6)	512(63.2)	251(67.5)	
Yes		412(34.9)	294(36.3)	118(31.7)	
DK/PNTA/Missing**		7(0.6)	4(0.5)	3(0.8)	
<b>Stable housing situation</b>	1182				0.007
Stable housing		993(84.0)	665(82.1)	328(88.2)	
Unstable housing		187(15.8)	144(17.8)	43(11.6)	
DK/PNTA/Missing**		2(0.2)	1(0.1)	1(0.3)	
<b>Participate in HIV work in the community</b>	1182				0.001
No		821(69.5)	536(66.2)	285(76.6)	
Yes		352(29.8)	266(32.8)	86(23.1)	
DK/PNTA**		9(0.8)	8(1.0)	1(0.3)	
<b>How long receiving HIV care from current HIV clinic</b>	1182				0.407
< 3 years		224(19)	154(19)	70(19)	
Between 3 to 10 years		488(41)	334(41)	154(41)	
10 or more years		374(32)	271(33)	103(28)	
Did not receive HIV medical care since last interview		75(6)	41(5)	34(9)	
DK/PNTA/Missing**		21(2)	10(1)	11(3)	
<b>HIV Stigma Score (dichotomized)</b>	1182				0.037
Low (<median=58)		572(48)	408(50)	164(44)	
High (>=median=58)		597(51)	392(48)	205(55)	
PNTA**		13(1)	10(1)	3(1)	
<b>Continuous Variable</b>	<b>Total N</b>	<b>Median(Q1-Q3)</b>	<b>Median(Q1-Q3)</b>	<b>Median(Q1-Q3)</b>	<b>P-value</b>

<b>Age at Interview</b>	1181	44(37-52)	45(38-53)	41(35-50)	<0.001
<b>Years living with HIV</b>	1146	13(8-19)	13(8-19)	12(7-18)	0.149
<b>HIV Stigma Score</b>	1169	58(45-70)	55 (45-69)	60(45-73)	0.069

Note: \* Privacy concerns, defined by their perception of how the HIV non-disclosure laws might affect WLWH's willingness to share information with their healthcare providers

\*\*excluded from calculation of the p-value

DK/PNTA Don't know/prefer not to answer

Percentage totals may exceed 100% due to rounding

**Table 2.2: Crude and adjusted odds ratios for correlates for participants' perception of privacy concerns\* due to the HIV laws on non-disclosure (n=1182)**

Variable	Unadjusted OR (95% CI) Agree vs. Disagree to privacy concerns		Adjusted OR (95%CI) Agree vs. Disagree to privacy concerns	
	OR	95% CI	OR	95% CI
<b>Province of interview</b>			Not selected	
British Columbia				
Ontario	0.72	0.53, 0.99		
Quebec	1.12	0.78, 1.61		
<b>Ethnicity reported at Wave 1</b>				
Indigenous	1.14	0.83, 1.57	1.28	0.89, 1.86
African/Caribbean/Black	1.96	1.44, 2.67	1.58	1.11, 2.24
Caucasian				
Other	1.38	0.83, 2.30	1.17	0.68, 2.01
<b>Born in Canada</b>			Not selected	
No				
Yes	0.600	0.46, 0.78		
DK/PNTA/Missing**				
<b>Legal status in Canada</b>			Not selected	
Canadian Citizen				
Landed Immigrant/Permanent Resident	1.91	1.23, 2.97		
Other	1.32	0.67, 2.60		
DK/PNTA**				
<b>Formal education</b>			Not selected	
High school or less				
More than high school	1.18	0.92, 1.51		
DK/PNTA/Missing**				
<b>Current employment</b>				
No				
Yes	1.22	0.94, 1.59	1.38	1.02, 1.86
DK/PNTA/Missing**				

<b>Stable housing situation</b> Yes No DK/PNTA/Missing**	1.65	1.15, 2.38	2.03	1.31, 3.14
<b>Participate in HIV work in the community</b> No Yes DK/PNTA**	1.64	1.24, 2.18	Not selected	
<b>How long receiving HIV care from this clinic</b> Less than 3 years Between 3 to 10 years 10 or more years Did not receive HIV medical care since last interview DK/PNTA/Missing**	0.99 1.20	0.70, 1.39 0.83, 1.72	Not selected	
<b>HIV Stigma Score (dichotomized)</b> Low (<median=58) High (>=median=58) PNTA**	0.77	0.60, 0.99	Not selected	
<b>Continuous Variable</b>	<b>OR</b>	<b>95% CI</b>	<b>Adjusted OR</b>	<b>95% CI</b>
<b>Age at Interview</b>	1.02	1.01, 1.04	1.03	1.02, 1.04
<b>Years living with HIV</b>	1.01	1.00, 1.03	Not selected	
<b>HIV Stigma Score</b>	0.99	0.99, 1.00	Not selected	

Note: \* Privacy concerns, defined by their perception of how the HIV non-disclosure laws might affect WLWH's willingness to share information with their healthcare providers

\*\*excluded from calculation of the p-value

DK/PNTA Don't know/prefer not to answer

OR odds ratio

**Table 2.3: Crude and adjusted odds ratios for WLWH's trust in their HIV care providers and other correlates and their association with WLWH's privacy concerns (n=1091).**

Variable	Unadjusted OR (95% CI) Agree vs. disagree to privacy concerns		Adjusted OR (95%CI) Agree vs. disagree to privacy concerns	
	OR	95% CI	OR	95% CI
<b>Overall trust in health professionals</b> High Trust				

Low trust	1.42	1.10, 1.84	1.27	0.95, 1.69
<b>Province of interview</b>				
British Columbia				
Ontario	0.75	0.55, 1.04	0.71	0.50, 1.00
Quebec	1.13	0.78, 1.63	1.04	0.68, 1.58
<b>Ethnicity reported at Wave 1</b>				
Indigenous	1.18	0.84, 1.67	1.13	0.78, 1.66
African/Caribbean/Black	1.82	1.33, 2.50	1.58	1.12, 2.24
Caucasian				
Other	1.29	0.77, 2.16	1.17	0.69, 2.01
<b>Born in Canada</b>			Not selected	
No				
Yes	0.65	0.50, 0.86		
DK/PNTA/Missing (not included in odds ratio)				
<b>Legal status in Canada</b>			Not selected	
Canadian Citizen				
Landed Immigrant/Permanent Resident	1.74	1.11, 2.73		
Other	1.25	0.64, 2.47		
DK/PNTA*				
<b>Formal education V2</b>			Not selected	
High school or less				
More than high school	1.15	0.89, 1.49		
DK/PNTA/Missing*				
<b>Current employment</b>			Not selected	
No				
Yes	1.29	0.98, 1.69		
DK/PNTA/Missing*				
<b>Stable housing situation</b>				
Stable housing				
Unstable housing	1.82	1.23, 2.70	1.92	1.24, 2.96
DK/PNTA/Missing*				
<b>Participate in HIV work in the community</b>			Not selected	
No				
Yes	1.55	1.16, 2.08		
DK/PNTA*				
<b>How long receiving HIV care from this clinic</b>			Not selected	
Less than 3 years				
Between 3 and 5 years	1.01	0.72, 1.42		
Between 5 and 10 years	1.20	0.84, 1.73		
10 or more years				
Did not receive HIV medical care since last interview				
DK/PNTA/Missing*				

<b>Age at Interview (per year)</b>	1.02	1.01, 1.04	Not selected
<b>Years living with HIV (per year)</b>	1.01	0.99, 1.03	Not selected
<b>HIV Stigma Score (per increase score)</b>	1.00	0.99, 1.00	Not selected

Note: \*not included in odds ratio

DK/PNTA Don't know/prefer not to answer

OR odds ratio



# **Chapter 3 Perceptions of Privacy Concerns and HIV Clinical Care Engagement among Women Living with HIV in Response to the Criminalization of HIV non-disclosure in Canada**

## **Abstract**

### **Background:**

The Supreme Court of Canada (SCC) in 2012 held that people living with HIV must disclose their serostatus to partners before sex that poses a “realistic possibility” of HIV transmission, while condom-protected vaginal sex with a low viral load (<1500 copies/mL) incurs no disclosure obligation. Pathways for the ruling’s impact on women living with HIV’s (WLWH) engagement in HIV healthcare through their privacy concerns remain unexplored. Among women who were aware of and understood the law, the objective of this analysis was to examine the association between WLWH’s privacy concerns and their HIV clinical care engagement.

### **Methods:**

Drawing upon Wave 2 survey data from the Canadian HIV Women’s Sexual and Reproductive Health cohort study, this study focused on participants who were aware of and understood the law, were currently on ART, and responded to questions about ART adherence. The primary outcome of interest was WLWH’s HIV clinical care engagement in terms of their adherence to antiretroviral therapy (ART), measured using the Walsh scale indicating their reported percentage ART adherence in the preceding month of the survey and dichotomized into optimal ( $\geq 95\%$ ) and suboptimal ( $< 95\%$ ) adherences. The secondary outcomes of interest included WLWH’s retention in HIV medical care (“yes” or “no” to engagement in HIV care since last CHIWOS interview), current use of ART (“yes” or “no” to current use of ART), and virological suppression (“yes” or “no” to undetectable viral load), all measured via self-report. The primary explanatory variable was WLWH’s perception of privacy concerns. Women who “Strongly

Agreed” or “Agreed” that HIV disclosure laws might affect the type of information that WLWH would be willing to share with their healthcare providers were assessed as perceiving privacy concerns. Multivariable logistic regression models were used to assess the independent effect of participants’ perception of privacy concerns on their reported ART adherence, retention in HIV medical care, current ART use, and viral load.

## **Results:**

Of 1422 women enrolled in CHIWOS, 1252 completed Wave 2, of whom 401 (31.8%) were aware of and understood the law, were currently on ART, and responded to questions about ART adherence. 318 (79.3%) of women reported optimal ART adherence and 285 (71.1%) reported privacy concerns. Both unadjusted (OR: 0.75; 95%CI: 0.45, 1.26) and adjusted results (aOR: 0.83; 95%CI: 0.47, 1.47) revealed no significant association between privacy concerns and optimal ART adherence. WLWH receiving formal education beyond high school had higher adjusted odds of optimal adherence (aOR: 2.08; CI: 1.20, 3.62). Those incarcerated since the last interview had lower adjusted odds of optimal adherence (aOR: 0.30; CI: 0.11, 0.80). Unadjusted results indicated no significant association between privacy concerns and retention in HIV medical care (OR: 0.67; CI: 0.25, 1.75), current ART use (OR: 0.65; CI: 0.35, 1.19), and suppressed viral load (OR: 0.67; CI: 0.34; 1.32).

## **Conclusion:**

The lack of statistically significant association between WLWH’s privacy concerns and retention in HIV medical care, ART adherence and current use, and viral load may be explained by the study’s focus on WLWH who understood the law. The results did not show the effect of privacy concerns on HIV care engagement among WLWH who misunderstood the law. However, this lack of association may also be explained by the indirect method that measured WLWH’s

privacy concerns. Future work should study WLWH who misunderstood the law and use more direct methods to measure participants' privacy concerns and its impact on their healthcare engagement.

### **3.1 Introduction**

UNAIDS has defined the prevention of HIV transmission as the most important public health objective in combating the global HIV epidemic and identified adherence to antiretroviral therapy as the most effective measure to prevent HIV transmission.(106, 107) As early as 2008, the Swiss Federal AIDS Commission released a landmark statement that “an HIV-infected person on antiretroviral therapy with completely suppressed viraemia (“effective ART”) is not sexually infectious and cannot transmit HIV through sexual contact.”(46) Over the last decade, a number of studies (including HPTN 052 and the Partners studies) showed that PLWH who have adhered to ART for six months, with an undetectable viral load (<40 copies/mL) and no concurrent sexually transmitted infections, could not transmit HIV through sexual contact.(17, 19, 47-50, 62) The importance of ART adherence in HIV prevention was also confirmed in the 2017 U=U (Undetectable=Untransmittable) Consensus Statement as well as the 2018 expert consensus statement on the science of HIV in the context of criminal law.(20, 21)

Hence, successfully engaging all people living with HIV in HIV care is important for their own health and survival as well as for HIV prevention goals. However, in Canada, several HIV care inequities persist. Women living with HIV (WLWH) experience gendered barriers to HIV care and have worse HIV-related outcomes relative to their male counterparts.(8, 59-61) For instance, WLWH experience poorer initial HIV care(8, 59), delayed HIV treatment(8, 17, 60), increased likelihood of unstructured treatment interruptions(8, 61), more instances of sub-optimal ART adherence(8, 50), delayed viral suppression(8, 62), and lower life expectancy.(8, 63) HIV-related stigma, a major contributing factor to poor HIV care engagement, is associated

with reduced likelihood of ART initiation, current ART use, and suboptimal ART adherence among WLWH in Canada.(45)

Criminal law may present a further barrier to HIV care engagement. In 1989, Canada became one of the jurisdictions around the world to prosecute people living with HIV (PLWH) who have, or are believed to have, put their sexual partners at risk of acquiring HIV by failing to disclose their HIV status prior to having sex with their partners.(2, 3) Following precedents set by the Supreme Court of Canada (SCC), it applied existing criminal laws—in most cases sexual assault law—to cases of HIV non-disclosure.(4-8) In 1998, the SCC further held in *R. v. Cuerrier* that PLWH who fail to disclose to partners before sex that represents a “significant risk” of HIV transmission could face criminal charges.(4) In 2012, the SCC set a new precedent through its landmark ruling on two major cases, *R. v. Mabior* and *R. v. D.C.*(6, 7) In *Mabior*, it ruled that PLWH could be charged if they failed to disclose their HIV status before sex that posed a “realistic possibility” of “significant bodily harm,” i.e. HIV transmission. PLWH have no legal obligation to disclose only if they engaged in condom-protected vaginal sex and have a “low” HIV RNA plasma viral load (defined by the SCC as <1500 copies/mL).(6) In *D.C.*, the SCC affirmed the ruling in *Mabior* by opining that condom use—in addition to a low viral load—are required to preclude a “realistic possibility” of HIV transmission.(7) By suggesting that both condom use and a low viral load by PLWH are required to avert the legal obligation of disclosure, the SCC thus broadened the scope of criminal liability for HIV non-disclosure established in *Cuerrier*.

The new law may have raised WLWH’s privacy concerns. The SCC stated in a different decision that “retention of information about oneself is extremely important” in modern society and “all information about a person is in a fundamental way his own, for him to communicate or retain for himself as he sees fit.”(51) There are two ways in which the 2012 ruling affects PLWH’s right to privacy. First, it intrudes upon PLWH’s right to keep their HIV status private. Second, it

threatens PLWH's right to keep their personal information (such as their sexual behaviors and disclosure practices) private in a health care setting and not to have it shared with outside authorities.

In an HIV care setting, the sharing of information about a patient's life, including their sexual and disclosure practices, during consultations with providers is often important for the patient's comprehensive care.(22, 40, 41, 44, 108) However, public health authorities in Canada may provide PLWH's health records to law enforcement on potential HIV non-disclosure cases where a warrant or subpoena for information is served or in circumstances that involve a high risk of transmission to others.(52, 53) Owing to legal uncertainty, deciding in what circumstances confidentiality may or should be set aside is not straightforward.(54)<sup>5</sup> Research shows that laws criminalizing HIV non-disclosure have reoriented HIV prevention as a public health issue towards a criminal law concern and fostered close ties between public health and the police in PLWH's minds.(55) PLWH's uncertainty about the limits of confidentiality of their personal information and their fears that such information would be subpoenaed by the police for use in criminal trials has discouraged them from sharing personal information that would be important for effective healthcare consultations with their providers.(55-57)

PLWH, especially the socio-economically disadvantaged, those with insecure immigration status, and members of ethno-racial minority groups who disproportionately face other forms of criminalization, may feel particularly reluctant to share their sexual behaviors and disclosure practices with healthcare providers due to stigma and discrimination.(1, 32, 58) Emerging research among racialized communities further suggests that HIV-related stigma and

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<sup>5</sup> In *Smith v. Jones* (1999), the SCC determined that there is discretion to disclose confidential information about a client in order to prevent harm to another person where these three conditions are satisfied: (1) there is a clear risk of harm to an identifiable person or group of persons; (2) there is a risk of serious bodily harm or death; and (3) the danger is imminent. Here, the SCC was deciding whether and when a lawyer's duty of confidentiality to his or her client could be waived. The principles set out in this case nonetheless apply to every service provider who works with and counsels people living with HIV, whether they are regulated professionals or not.

discrimination and privacy concerns in the healthcare setting have increased due to the threat of HIV criminalization.(58)

PLWH's privacy concerns due to the 2012 ruling may have negative impacts on their HIV care engagement. In semi-structured interviews, HIV/AIDS service providers in Toronto expressed the belief that the SCC's 2012 ruling increased stigma among PLWH—particularly women, sex workers and those living with addiction—and this may compromise their healthcare engagement.(22, 65) In different semi-structured interviews, African/Black MLWH and WLWH in Greater Toronto, themselves reporting increased stigma and discrimination from healthcare providers due to HIV criminalization, questioned the privacy of healthcare information they shared with providers.(58)

Research indicates that a pathway to poorer retention in HIV care is through WLWH's privacy concerns about their health information and their stigma and discrimination, including discrimination by their healthcare providers.(8, 22, 45, 64, 65) Recent research drew upon data in the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) to conduct preliminary assessment of the awareness and understanding of HIV non-disclosure case law among WLWH in Canada and their HIV care engagement.(8, 88) It found that the understanding of the case law was low among WLWH, although their awareness of the law made them perceive that HIV disclosure laws might affect the type of information that WLWH would be willing to share with healthcare providers.(8, 88)

To date, few studies have empirically assessed the association between privacy concerns and its impact on HIV care engagement, especially since the 2012 ruling. The objective of this analysis was to measure the association between WLWH's privacy concerns, measured in terms of their perception that HIV non-disclosure laws might affect the type of information WLWH would be willing to share with their healthcare providers, and their HIV clinical care engagement, primarily measured in terms of their ART adherence. For a more comprehensive

analysis of this association, this study also aimed to measure the association between WLWH's privacy concerns and other stages of the HIV cascade of care, a widely used model to describe the various stages of HIV clinical care at a population level—including HIV diagnosis, linkage to and retention in HIV care, ART initiation, use and adherence, and viral suppression—which helps to measure and reduce/prevent attrition from HIV care.(109) Because WLWH's linkage to HIV medical care after diagnosis and their initiation in ART may have occurred before the 2012 ruling and any privacy concerns among WLWH caused by the law, this analysis focused on three other stages of the care cascade, namely, retention in HIV medical care, current ART use, and viral suppression. The hypothesis of this study is: WLWH's privacy concerns are negatively associated with their HIV clinical care engagement, primarily measured in terms of their ART adherence, and secondarily measured in terms of their retention in HIV care, ART use, and viral suppression.

## **3.2 Methods**

### **3.2.1 Setting**

According to the Public Health Agency of Canada, there were approximately 16,880 WLWH in Canada in 2016.(77) Most resided in British Columbia (BC) (8.4%), Ontario (54.4%), and Quebec (26.9%).(77, 78) Socio-economically marginalized women and members of ethno-racial minority groups are disproportionately affected by HIV nationally.(1, 32) Hence, the intersection of social inequities, such as poverty and violence, with personal identities, including race and gender identity, has influenced WLWH's experiences of stigma and discrimination and reinforced obstacles to their HIV clinical care engagement.(59, 97)

### **3.2.2 Study Design**

This study draws upon cross-sectional survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based longitudinal cohort study of WLWH from BC, Ontario and Quebec initiated to better understand women-centred HIV care for WLWH across Canada, and to explore the mental, sexual and reproductive health benefits of this healthcare approach as well as its limits.<sup>(81)</sup> Based upon the principles of critical feminist theory and community-based research (CBR), CHIWOS involved WLWH and allied clinicians, researchers, and community members as core partners throughout all stages of its research. Peer Research Associates (PRAs; i.e., WLWH who received research training) played a particular significant role, as they provided research leadership at all levels of the study, including contributing to the development of data collection tools, leading participant outreach and recruitment efforts, administering questionnaires to participants, engaging in data analysis and interpretation, disseminating research findings at community and academic events, and co-authoring peer-reviewed manuscripts.<sup>(89)</sup>

Eligible participants in CHIWOS met three criteria: 16 years of age or above, self-identification as a woman living with HIV (trans-inclusive), and residency in one of the three study provinces. Special efforts were made to recruit WLWH from marginalized and vulnerable populations disproportionately affected by HIV in Canada or underserved by health services, including workers in the sex industry, trans-women, immigrant women, Indigenous women, women who use injection drugs, and ethno-racial populations. The inclusion of underserved WLWH served to capture the diversity of WLWH's health concerns and experiences, in line with CHIWOS's critical feminist approach to investigating the law's impact on WLWH's healthcare engagement.<sup>(90)</sup>

The baseline (Wave 1) CHIWOS survey took place from August 2013 to May 2015, with the enrolment of 1422 participants. These participants completed a PRA-administered survey



containing questions about their reproductive, sexual, mental and women's health outcomes as well as their use of HIV services. The survey was conducted in English or French using Fluidsurveys, an online survey instrument (supported by White Label FluidSurveys<sup>TM</sup> software), at collaborating HIV clinics, community-based AIDS Service Organizations (ASOs), or other community organizations. The survey was also conducted via telephone or over Skype to better serve participants located in rural or remote regions. From June 2015 to January 2017, participants were invited to complete a PRA-administered 18-month follow-up (Wave 2) survey (retention rate= 88%; n=1252), which contained longitudinal evaluation of baseline study variables and examined new research topics identified through community consultation. From February 2017 through September 2018, a 36-month follow-up (Wave 3) survey was carried out.

This study employed data collected in the Wave 2 survey, for which PRAs and the CHIWOS Community Advisory Board independently identified the criminalization of HIV non-disclosure as a key concern for Canadian WLWH and a critical research priority for the CHIWOS team. A team of experts, including academic researchers, frontline research staff, WLWH and a legal representative, developed structured research questions aimed at assessing WLWH's awareness and understanding of the 2012 ruling and its perceived healthcare impacts among WLWH in the CHIWOS wave 2 survey.

The questions in Wave 2 survey were comprehensively reviewed prior to survey administration to ensure that all priority questions were addressed and that they would not threaten the health, rights or safety of participants.(8, 84, 85) CHIWOS PRAs also underwent special training on the criminalization of HIV non-disclosure in Canada, which enabled them to thoroughly understand the SCC's 2012 decision and equipped them to protect the privacy of participants as they conducted the survey on this sensitive topic. The CHIWOS team also provided information on the law as well as referral services to participants who raised questions or concerns during the survey administration.(69, 91-94)

### **3.2.3 Theoretical Framework**

This study employs a critical feminist framework to study the impact of the 2012 ruling on WLWH's perception of privacy concerns and its association with their HIV care engagement. Through a critical feminist perspective, multiple social identities, including gender, race, sexual orientation, and socio-economic status, intersect at individual and structural levels to create the social inequalities and oppression experienced by women.(8, 40, 73-76). A critical framework is relevant to this study as it both acknowledges the diverse identities and experiences of WLWH and serves to understand the individual, social and structural factors contributing to their perception of privacy concerns and its potential association with their HIV clinical care engagement.

### **3.2.4 Ethical Approval**

Ethical approval for the study procedures of CHIWOS was granted by the Research Ethics Boards of Simon Fraser University, University of British Columbia/Providence Health, Women's College Hospital, and McGill University Health Centre. In addition, participants in CHIWOS provided voluntary written informed consent to participate at study enrolment (or voluntary verbal informed consent in the presence of a witness from the CHIWOS study team for surveys completed over the telephone or Skype). Each participant was also provided with a \$50 honorarium for completing each baseline or follow-up survey.

### **3.2.5 Inclusion and Exclusion Criteria**

This analysis on privacy concerns and engagement across the HIV care cascade was restricted to CHIWOS participants who completed the Wave 2 survey (n=1,252). In addition, because this study aimed to identify the potential impact of the 2012 ruling on WLWH's engagement in HIV clinical care, eligible participants must have reported "yes" to S5Q113 ("In 2012, the Supreme Court of Canada made a new ruling regarding the conditions under which a person living with HIV has to disclose his or her HIV status to a sexual partner. Are you aware of

this new ruling?”), which indicated that they were aware of the 2012 ruling, and “the same” or “mostly the same” to S5Q114 (“How similar is this definition to what you thought you understood about HIV disclosure and the law in Canada?”), which indicated that they understood the law. These criteria were set to more specifically assess the association between privacy concerns and healthcare care engagement among those women who understood the disclosure expectations of the law. Participants also had to have non-missing responses to the survey question S5-118 concerning whether WLWH believe that the 212 ruling might affect the type of information that WLWH would be willing to share their personal information with health providers. Hence, those who reported “Don’t know,” “Prefer not to answer,” “Other,” or provided no answer were excluded. For ART adherence, participants must also have reported “yes” to S2Q2a (“Have you ever taken Antiretroviral Medication (ARVs) for your own health?”) and completed S2Q9b (“Visual analog scale of ART adherence”). For retention in HIV medical care, participants had to have completed S3-Q7 (“Have you received any HIV medical care since the last CHIWOS interview?”). For current ART use, participants had to have completed S2-Q02d (“Are you currently taking ARVs?”) For viral load, participants must have completed S2-Q11a (“What is your most recent viral load, undetectable or detectable?”) For these questions concerning healthcare engagement, those who reported “Prefer not to answer,” “Don’t know,” or provided no answer were excluded. “Prefer not to answer,” “Don’t know,” or provided no answer were excluded to ensure that only affirmative responses were included in the measurements. If very few chose these options, they are unlikely to bias the results. Missing responses can be random or systematic and the exclusion of the former would less likely lead to biased results.(95)

### **3.3 Measures**

#### **3.3.1 Outcome Variables**

The primary outcome of interest was WLWH's engagement in HIV clinical care, primarily measured in terms of their adherence to ART. Among women on ART, ART adherence was measured using the Walsh scale, whereby participants are asked to self-report their "percentage adherence," or proportion of doses of ARV they had taken in the preceding month(110), which ranged from 1% to 10% on a 5%-interval scale in this study. This self-reported single-item visual analogue rating scale is a non-invasive, inexpensive, valid, highly sensitive and reproducible way of assessing medical adherence,(111-113) and has been used in many studies worldwide.(45, 114-117) Because the  $\geq 95\%$  adherence level is well regarded to be most effective for most people in producing full and durable viral suppression,(118, 119) responses were dichotomized in this study into optimal ( $\geq 95\%$ ) and sub-optimal adherences ( $< 95\%$ ).

The secondary outcome variables are retention in HIV medical care, current ART use, and viral load. WLWH's retention in HIV medical care was measured by their answers ("yes" vs. "no") to S3-Q7 ("Have you received any HIV medical care since the last CHIWOS interview?"). Current ART use was measured by answers ("yes" vs. "no") to S2-Q02d ("Are you currently taking ARVs?"). Viral load was measured by answers ("yes" vs. "no") to S2-Q11a ("What is your most recent viral load, undetectable or detectable?"). On the survey undetectable was considered as having a viral load  $< 50$  copies/ml.

#### **3.3.2 Explanatory Variables**

The primary explanatory variable of interest was WLWH's perception of privacy concerns, defined in terms of their perception of the 2012 SCC ruling on WLWH's willingness to share personal information with their healthcare providers. Because questions inquiring participants' own disclosure practices may put their privacy and safety at risk, this variable was

measured by response to this indirectly phrased survey question S5-118: “Please indicate to what degree you agree or disagree with the following statement: “HIV disclosure laws might affect the type of information that women living with HIV would be willing to share with their healthcare providers, such as information about sexual activities and HIV disclosure.”” Responses were dichotomized (“Strongly Agree” or “Agree” vs. “Neutral” or “Disagree” or “Strongly Disagree”) to distinguish participants who perceive concerns over the willingness to share personal information from WLWH who do not.

### **3.3.3 Covariates**

The correlates to WLWH’s HIV clinical care engagement were identified by the comprehensive literature review set out in this study’s introduction as well as its theoretical framework section emphasizing the need for a critical feminist and intersectional approach to the law’s impact on WLWH’s healthcare experiences and engagement. Sociodemographic variables included province (BC vs. Ontario vs. Quebec), age at interview (continuous variable), ethnicity (Indigenous vs. African/Caribbean/Black vs. White vs. Other), formal education (graduated high school or less vs. more than high school), residence where currently live (Apartment/condo/house vs. other (Hotel room / SRO (single room occupancy) Hotel/Shelter/ Recovery house/ Transition House / Halfway House / Safe House/Living outdoors, street, parks, car, parkades/Couch surfing)), and incarceration since last interview (no vs. yes).

The behavioural variable included was injection drug use in last 6 months (no vs. yes). Socio-structural variables included history of violence as an adult (never vs. previously vs. currently (last 3 months)) and HIV stigma score, which was measured using a 10-item HIV Stigma Scale with scores ranging from 1 to 100, and converted into a dichotomized variable (low (<median=58) vs. high (>=median=58)) in this study.(45)

### **3.4 Statistical Analysis**

Descriptive statistics were used to measure the number and percentages of participants whose adherence was optimal ( $\geq 95\%$ ) and whose adherence was suboptimal ( $< 95\%$ ). In addition, socio-demographic, behavioural, and socio-structural variables were compared between the two groups of participants. For continuous variables, median and interquartile range [IQR] were computed; for categorical variables, numbers [n] and percentages [%] were computed. Pearson's Chi-squared test (Fisher's exact test when count  $< 5$ ) was used for categorical variables, and the Wilcoxon rank sum test was used for continuous variables.

Bivariable logistic regression assessed the association between privacy concerns and ART adherence. Multivariable logistic regression provided adjusted results by identifying socio-demographic, behavioral, and clinical correlates of this association between privacy concerns and ART adherence. Variables demonstrating a significance level of  $p < 0.2$  in bivariable analysis were considered for inclusion in the multivariable model. The final model was selected through a backwards selection process and guided by minimizing the Akaike Information Criterion (AIC) and maintaining Type III p-values. P-values were two-sided and considered statistically significant at  $< 0.05$ .

In addition, bivariable logistic regression was used to assess the associations between privacy concerns and (1) retention in HIV medical care, (2) current ART use, and (3) viral load. All analyses were conducted using SAS 9.4 software (SAS Institute Inc., Cary, NC).

### **3.5 Results**

Of 1422 participants who enrolled in CHIWOS, 1,252 completed the Wave 2 survey (88%), 756 (53.2%) reported that they were aware of the 2012 ruling and 453 (31.9%) reported they were both aware of and understood the law, 452 (31.8%) reported they were currently taking ART, and 401 (28.2%) completed the visual analog scale of ART adherence. The final

analytical sample for the analysis of privacy concerns and ART adherence—this study’s primary outcome variable—was 401 (28.2%) of the 1422 women enrolled in CHIWOS.

The analytic sample of these participants reflected the socio-demographic diversity of women living with HIV in Canada (Table 3.1). Median age was 47 years (Q1-Q3: 38-54), among whom 76 (19%) identified as Indigenous, 118 (29.4%) as African, Caribbean and Black, 175 (43.6%) as white, and 32 (8%) as other ethnicities. 185 (46.1%) received a formal education beyond high school level, 377 (94%) were stably housed, 24 (6%) had been incarcerated since the last CHIWOS interview, and 27 (6.7%) used injection drugs in the last six months.

Among these 401 participants, 318 (79.3%) reported optimally adherent to ART, while 83 (20.7%) reported sub-optimal ART adherence. 285 (71.1%) perceived privacy concerns and agreed that HIV disclosure laws might impact WLWH’s willingness to share their information with healthcare providers, while 116 (28.9%) disagreed. 230 (72.3%) of those who were optimally adherent perceived privacy concerns, while 55 (66.3%) of the sub-optimally adherent perceived privacy concerns ( $p=0.278$ ) (Table 3.1).

Unadjusted results (Table 3.2) showed no statistically significant association between privacy concerns and ART adherence (OR: 0.75, CI: 0.45, 1.26). Adjusted results (Table 3.2) also indicated no significant association between privacy concerns and ART adherence (aOR: 0.83; CI: 0.47, 1.47). Among the covariates, however, WLWH who received a formal education beyond high school level had higher adjusted odds of optimal ART adherence (aOR: 2.08; CI: 1.198, 3.62). Those who were incarcerated since the last CHIWOS interview had lower adjusted odds of optimal ART adherence (aOR: 0.30; CI: 0.11, 0.80). Those who reported high HIV-related stigma also had lower adjusted odds of ART adherence, although the 95% CI included the null (aOR: 0.64; CI: 0.37, 1.09).

In secondary analyses, we assessed the association between WLWH’s privacy concerns and other stages of the HIV care cascade. Of 453 participants who completed the Wave 2 survey

and reported that they were aware of the 2012 ruling and understood the law, 452 completed the question concerning whether they received HIV medical care since the last CHIWOS interview. Of these 452 participants, 434 (96.0%) reported having received HIV medical care since the last interview, while 18 (4.0%) reported not having received it. Among those who reported having received medical care since the last interview, 305 (70.3%) reported perceiving privacy concerns compared with 11 (61.1%) who reported not receiving medical care ( $p$ -value=0.41). Results of the bivariable logistic regression indicated no significant association between privacy concerns and receipt of HIV medical care (OR: 0.67; CI: 0.25, 1.75) (Table 3.3).

Of 453 participants who completed the Wave 2 survey and reported that they were aware of the 2012 ruling and understood the law, 452 completed the question concerning whether they were currently using ART. Out of these 452 participants, 403 (89.2%) reported currently using ART, while 49 (10.8%) reported not currently using ART. Among those currently using ART, 286 (71%) reported perceiving privacy concerns compared with 30 (61.2%) among those not using ART ( $p$ -value=0.16). Results indicated no significant association between participants' privacy concerns and current ART use (OR: 0.65; CI: 0.35, 1.19) (Table 3.4).

Of 453 participants who completed the Wave 2 survey and reported that they were aware of the 2012 ruling and understood the law, 440 completed the question concerning whether they had an undetectable viral load. Out of these 440 participants, 401 (91.1%) reported having an undetectable viral load, while 39 (8.9%) reported a detectable viral load. Among those who reported having an undetectable viral load, 283 (70.6%) reported perceiving privacy concerns compared with 24 (61.5%) among those with a detectable viral load ( $p$ -value =0.24). Results indicated no significant association between participants' privacy concerns and their self-reported viral load (OR: 0.67; CI: 0.34, 1.32) (Table 3.5).



Hence, the hypothesis that WLWH's privacy concerns are negatively associated with their HIV clinical care engagement, in terms of their retention in HIV medical care, ART use and adherence, and virological suppression, was rejected.

### **3.6 Discussion**

In this study of WLWH in Canada who were aware of and understood the law criminalizing HIV non-disclosure, and were on ART, 318 (79.3%) were optimally adherent to ART and 285 (71.1%) perceived privacy concerns related to the law. Adjusted analysis showed no statistically significant association between privacy concerns and ART adherence (aOR: 0.83; CI: 0.47, 1.47). Similarly, in unadjusted analyses, we found that privacy concerns were not significantly associated with HIV treatment outcomes including retention in HIV medical care (OR: 0.67; CI: 0.25, 1.75), current ART use (OR: 0.65; CI: 0.35, 1.19), and viral load (OR: 0.67; CI: 0.34; 1.32).

A large majority of WLWH (71.1%) perceived privacy concerns among WLWH due to the law on HIV non-disclosure, measured in terms of their perception of the law's impact on WLWH's willingness to share their information with their healthcare providers. This result concerning privacy concerns agrees with prior research showing that PLWH's uncertainty about the limits of confidentiality of their personal information in the healthcare setting has discouraged them from sharing personal information that would be important for effective healthcare consultations with their providers.(8, 55-57)

Research indicates that the 2012 ruling increased stigma experienced by PLWH—particularly women, sex workers and those living with addiction—which may compromise healthcare engagement,(22, 58, 65) and that HIV-related stigma among WLWH is associated with reduced likelihood of ART initiation and current ART use and with suboptimal ART adherence.(45) However, the adjusted analysis showed no statistically significant association

between privacy concerns and ART adherence (aOR: 0.83; CI: 0.47, 1.47), and unadjusted analyses showed no statistically significant association between privacy concerns and HIV treatment outcomes including retention in HIV medical care (OR: 0.67; CI: 0.25, 1.75), current ART use (OR: 0.65; CI: 0.35, 1.19), and viral load (OR: 0.67; CI: 0.34; 1.32). All these therefore seemed to contradict prior research. However, this study focused only on the sample of participants (401, 28.2% of the CHIWOS cohort) who were aware of and understand the law, among whom almost 80% reported optimal ART adherence (318, 79.3% of 401), which is higher than the percentage reporting optimal ART adherence for the entire CHIWOS cohort (68%)(109) and substantially higher than the North American average for PLWH, which, according to some studies, is estimated to be around 60%.(120-122)<sup>6</sup> The awareness of the importance of ART adherence among this group of participants may have enabled them to overcome privacy concerns. Continued use and adherence to ART to—or beyond—the optimal level accordingly led to an undetectable viral load. This study did not include all participants in the Wave 2 survey who as a group reported a lower percentage of optimal ART adherence (68%), or participants who were aware of but did not understand the case law on HIV non-disclosure. Particularly for participants who were knew but lacked understanding of the case law, their privacy concerns may negatively impact their ART adherence. In addition, the lack of a significant association between privacy concerns and retention in HIV medical care may be explained by the high degree of trust among WLWH in their HIV care providers whom they had been consulting.(25, 55) This high degree of trust, which is critical to high retention in medical care,(68, 69, 123) may have offset any potential impact of WLWH's privacy concerns on their retention in medical care.

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<sup>6</sup> A meta-analysis of patients in North America ( $n = 17\ 573$ ) conducted in 2006 estimated that only 55% of people living with HIV achieved over 80% adherence. A meta-analysis on 84 observational studies conducted in 2011 estimated that roughly 62% achieved an adherence rate of 90%.

Nonetheless, the lack of a significant association between participants' privacy concerns and HIV clinical care engagement could also have been due to the method used to measure privacy concerns and the way this privacy variable was defined. This study measured participants' privacy concerns by inquiring whether they perceive the ruling may have an impact on WLWH's willingness to share personal information with healthcare providers. This question, phrased indirectly to protect participants' safety and privacy, may not have sufficiently reflected the law's impact on participants' own willingness to share information with healthcare providers. As a result, the law's impact on privacy concerns as well as the association between privacy concerns and their HIV clinical care engagement may have been underestimated. Future research should examine the association between privacy concerns and HIV care engagement by asking women directly about their own privacy concerns. Given the quantitative nature of this study, interviews may also be conducted with participants to identify the reasons for why privacy concerns may or may not impact their HIV care engagement.

Additionally, to ensure that only participants who affirmatively reported privacy concerns would be counted as expressing such concerns, responses to the question about concerns over the willingness to share personal information were dichotomized ("Strongly Agree" or "Agree" vs. "Neutral" or "Disagree" or "Strongly Disagree"), while those who answered "Don't know" or "Prefer not to answer" were excluded. Although no participants answered "DK" or "PNTA" for any of these explanatory variables, it was possible that women responding that they were "Neutral" may have had privacy concerns, but did not feel comfortable telling the interviewer, leading to a form of reporting bias. The figures who responded "Neutral" were 68 of 401 (17.0%) for ART adherence, 81 (17.9%) of 452 for retention in HIV medical care, 81 (17.9%) of 452 for current ART use, 80 (18.2%) of 440 for virological suppression. Hence, classifying these women who reported that they were "Neutral" may have underestimated the proportion of women with privacy concerns as well as distorted the results regarding the impact of privacy concerns on HIV care engagement.

Finally, that participants who had above-high school level education had higher odds of reporting optimal ART adherence indicates that education may increase awareness of the importance of HIV care and therefore help WLWH sustain optimal adherence.(124-126) That those incarcerated since the last CHIWOS interview had lower odds of reporting optimal ART adherence supported research indicating the disruptive impact of incarceration on PLWH's HIV care engagement, including ART adherence.(26, 27, 127-129)

### **3.7 Limitations**

The CHIWOS project, with its expert-designed and reviewed questions, as well as skilfully administered surveys, facilitates the study of WLWH's privacy concerns and their HIV clinical care engagement. Nonetheless, a representation bias might exist because WLWH engaged in the community and its health services were likely more willing to have participated in the surveys.(88) Moreover, those sufficiently engaged with the CHIWOS community were more likely to have participated in the Wave 2 survey.(88)

The data drawn from the Wave 2 survey in this analysis might also have been influenced by social desirability biases due to the fact that all the relevant variables were self-reported. Any such biases might have led to overestimated reports concerning WLWH's privacy concerns due to the law and reported levels of HIV care engagement. The extensive training undergone by PRAs in methods of survey delivery, described in the earlier part of this study, is thought to reduce some of these biases.(88) Nonetheless, another form of bias might be caused by the indirect question posed to participants to measure WLWH's privacy concerns, which, as discussed in the previous section, may not have sufficiently reflected the law's impact on participants' own concerns. As a result, the law's impact on their privacy concerns as well as the association between privacy concerns and their HIV clinical engagement care may have been underestimated. A question directly inquiring participants' willingness to share their personal

information with their healthcare providers due to the law would have served as a more reliable method of measuring their privacy concerns and enabled its association with their HIV care engagement to be tested more accurately.

The inclusion/exclusion criteria may have produced some bias. No participants answered “Don’t know” or “Prefer not to answer” to the question regarding privacy concerns and the questions concerning ART adherence and use, retention in medical care, and viral load. However, among 453 who reported that they were aware of and understood the law, 452 reported they were currently taking ART, and 401 completed the visual analog scale of ART adherence. The 52 missing responses may have been given by participants who did not feel comfortable about reporting their ART adherence. Thus, the exclusion of missing data may have overestimated the ART adherence rate and underestimated the impact of privacy concerns on ART adherence.

Otherwise, the inclusion/exclusion criteria likely would have produced negligible impact on the measurements. Participants answering “DK”, “PNTA” or did not answer questions measuring covariates were very small in number (current housing: 1; Injection use in the last 6 months: 2; Reported experienced violence as an adult: 22; HIV Stigma score: 4) in comparison to the sample size of 401 for ART adherence, and so these responses would likely have produced negligible differences in estimations of the significance of these covariates in the relationship between privacy concerns and ART adherence.

Among the 453 participants who were aware of and understood the law, and 452 completed questions on retention in medical care and ART use, meaning the missing responses to each question was 1. In addition, 440 completed the question on viral load, meaning that the missing data for the questions was 13. The small number of missing responses is unlikely to have biased the estimates.

### 3.8 Conclusion

This chapter is the first quantitative study of WLWH's perception of privacy concerns in response to the SCC's 2012 landmark ruling criminalizing HIV non-disclosure in Canada and the association between their privacy concerns and HIV clinical care engagement. By drawing upon Wave 2 survey data of CHIWOS, this study showed that nearly three-quarters of WLWH who had prior understanding of the ruling expressed privacy concerns, defined in terms of their perception that such laws might affect the type of information that WLWH would be willing to share with their healthcare providers. There was, however, no significant association between WLWH's perception of privacy concerns and their ART adherence, retention in HIV care, current ART use, and viral load.

CHIWOS is a community-based longitudinal cohort study of WLWH from BC, Ontario and Quebec implemented to better understand women-centred HIV care for WLWH across Canada. The current analysis, by drawing CHIWOS survey data to examine WLWH's privacy concerns in response to the SCC's 2012 ruling and its impact on HIV clinical care engagement, both calls for the education of WLWH about the case law and the repeal of such laws.

**Table 3.1 Social-demographic, behavioural and clinical characteristics of women living with HIV, stratified by self-reported adherence to antiretroviral therapy (n=401)**

Categorical Variables	Total N	Overall (n=401) n (%)	Self-reported ART adherence (%)		
			95 or more (n=318) N(%)	Less than 95 (n=83) N(%)	P-value
<b>Self-reported ART adherence (%)</b>	401				
95 or more		318 (79.3)			
Less than 95		83 (20.7)			

<b>Privacy concerns: HIV disclosure laws impact sharing of information with healthcare providers</b>	401			0.278
Agree		285 (71.1)	230 (72.3)	55 (66.3)
Disagree		116 (28.9)	88 (27.7)	28 (33.7)
<b>Province of interview</b>	401			0.016
British Columbia		119 (29.7)	92 (28.9)	27 (32.5)
Ontario		159 (39.7)	118 (37.1)	41 (49.4)
Quebec		123 (30.7)	108 (34.0)	15 (18.1)
<b>Ethnicity reported at Wave 1</b>	401			0.173
Indigenous		76 (19.0)	58 (18.2)	72 (86.7)
African/Caribbean/Black		118 (29.4)	96 (30.2)	22 (26.5)
White		175 (43.6)	143 (45.0)	32 (38.6)
Other ethnicity		32 (8.0)	21 (6.6)	11 (13.3)
<b>Formal education</b>	401			0.008
Graduated high school or less		185 (46.1)	136 (42.8)	49 (59.0)
More than high school		216 (53.9)	182 (57.2)	34 (41.0)
<b>Current housing</b>	401			0.034
Apartment/condo/house		377 (94.0)	303 (95.3)	74 (89.2)
Other		23 (5.7)	14 (4.4)	9 (10.8)
(Apartment/condo/house vs. other (Hotel room / SRO (single room occupancy)				
Hotel/Shelter/ Recovery house/ Transition				
House/Halfway				
House/Safe House/Living outdoors, street, parks, car, parkades/Couch surfing)				
DK/PNTA/Missing		1 (0.2)	1 (0.3)	
<b>Incarceration since last interview</b>	401			0.004
No		377 (94.0)	305 (95.9)	72 (86.7)
Yes		24 (6.0)	13 (4.1)	11 (13.3)
<b>Injection drug use in last 6 months</b>	401			0.097
No		372 (92.8)	298 (83.7)	74 (89.2)
Yes		27 (6.7)	18 (5.7)	9 (10.8)
DK/PNTA		2 (0.5)	2 (0.6)	

<b>Reported experienced violence as an adult</b>	401				0.002
Never		246 (61.3)	204 (64.2)	42 (50.6)	
Previously		42 (10.5)	36 (11.3)	6 (7.2)	
Currently (last 3 months)		91 (22.7)	60 (18.9)	31 (37.3)	
DK/PNTA		22 (5.5)	18 (5.7)	4 (4.8)	
<b>HIV Stigma Score (dichotomized)</b>	401				0.023
Low stigma (<median)		228 (57.0)	190 (60)	38 (46)	
High stigma (>=median)		169 (42.0)	125 (39)	44 (53)	
PNTA		4 (1.0)	3 (1)	1 (1)	
<b>Continuous Variable</b>	<b>Total N</b>	<b>Median (Q1-Q3)</b>	<b>Median (Q1-3)</b>	<b>Median (Q1-3)</b>	<b>P-value</b>
<b>Age at interview</b>	401	47 (38-54)	47 (38-55)	46 (37-53)	0.358

Note: DK/PNTA responses were not included in p-values calculations

**Table 3.2 Crude and adjusted odds ratios for correlates for WLWH's self-reported ART adherence levels (n=401)**

Variable	Unadjusted OR (95% CI) 95 or more Vs. less than 95 OR 95% CI		Adjusted OR (95%CI) 95 or more vs. less than 95 OR 95% CI	
<b>HIV disclosure laws impact sharing of information with healthcare providers</b>				
Agree				
Disagree	0.75	0.45, 1.26	0.83	0.47, 1.47
<b>Province of interview</b>				
British Columbia				
Ontario	0.84	0.48, 1.47	0.72	0.38, 1.40
Quebec	2.11	1.06, 4.21	1.90	0.83, 4.32
<b>Ethnicity reported at Wave 1</b>				
Indigenous	0.72	0.38, 1.39	1.15	0.53, 2.52
African/Caribbean/Black	0.98	0.54, 1.78	1.06	0.54, 2.08
White				
Other ethnicities	0.43	0.19, 0.97	0.41	0.17, 1.02
<b>Formal education</b>				
Graduated high school or less				
More than high school	1.93	1.18, 3.15	2.08	1.20, 3.62
<b>Residence where currently live</b>			Not selected	
Apartment/condo/house				
Other	0.38	0.16, 0.91		
(Apartment/condo/house vs. other (Hotel room/SRO (single room occupancy) Hotel/Shelter/				



Recovery house/Transition House / Halfway House/Safe House/Living outdoors, street, parks, car, parkades/Couch surfing)		
<b>Incarceration since last interview</b> No Yes	0.28      0.12, 0.65	0.30      0.11, 0.80
<b>Injection drug use in last 6 months</b> No Yes	0.50      0.21, 1.15	Not selected
<b>Experienced violence as an adult</b> Never Previously Currently (last 3 months)	Reference 1.24      0.49, 3.12 0.40      0.23, 0.69	Not selected
<b>HIV Stigma Score (dichotomized)</b> Low (<median) High (>=median)	0.57      0.35, 0.93	0.64      0.37, 1.09
<b>Continuous Variable</b>	<b>OR</b> <b>95%CI</b>	<b>OR</b> <b>95%CI</b>
<b>Age at interview</b>	1.01      0.99, 1.04	1.00      0.98, 1.03

**Table 3.3 p-values and crude odds ratios for WLWH's self-reported retainment in HIV medical care**

<b>HIV medical care since last interview (retention in HIV medical care)</b>	<b>Overall (N=452)</b>	<b>HIV medical care since last interview</b>	<b>Bivariate Logistic HIV medical care since last interview</b>
		No      Yes (N=18) (N=434)	Yes vs. No
	N (%)	N(%)      N(%)      p-value	OR      95% CI      p-value
No Yes	18 (4.0) 434 (96.0)		
<b>HIV disclosure laws impact sharing of information with healthcare providers</b>			
Agree Disagree	316 (69.9) 136 (30.1)	11 (61.1) 305 (70.3) 7 (38.9) 129 (29.7)	0.67      0.25, 1.75      0.41

**Table 3.4 p-values and crude odds ratios for WLWH's self-reported current ART use**

Current Use of ARVs	Overall (N=452)  N (%)	Current Use of ARVs			Bivariate Logistic Current Use of ARVs  Yes vs. No		
		No (N=49) N(%)	Yes (N=403) N(%)	p-value	OR	95% CI	p-value
No Yes	49 (10.8) 403 (89.2)						
<b>HIV disclosure laws impact sharing of information with healthcare providers</b>				0.16			
Agree	316 (69.9)	30 (61.2)	286 (71.0)				
Disagree	136 (30.1)	19 (38.8)	117 (29.0)		0.65	0.35, 1.19	0.16

**Table 3.5 p-values and crude odds ratios for WLWH's self-reported viral load**

Current Use of ARVs	Overall (N=440)  N (%)	Current Use of ARVs			Bivariate Logistic Current Use of ARVs  Yes vs. No		
		No (N=39) N(%)	Yes (N=401) N(%)	p-value	OR	95% CI	p-value
No Yes	39 (8.9) 401 (91.1)						
<b>HIV disclosure laws impact sharing of information with healthcare providers</b>				0.24			
Agree	307 (69.8)	24 (61.5)	283 (70.6)				
Disagree	133 (30.2)	15 (38.5)	118 (29.4)		0.67	0.34, 1.32	0.24

## **Chapter 4 Conclusion**

### **4.1 Summary of Thesis Objectives and Purpose**

The SCC in 2012 held that people living with HIV must disclose their serostatus to sexual partners before sex posing a “realistic possibility” of HIV transmission, but that condom-protected vaginal sex with a low viral load (<1500 copies/mL) incurs no disclosure obligation. Studies suggest that laws criminalizing HIV non-disclosure raised WLWH’s privacy concerns in the healthcare setting. Studies also suggest that such laws had a negative impact on WLWH’s engagement in HIV healthcare. However, previously limited research had quantitatively examined the 2012 ruling’s impact on WLWH’s privacy concerns, the association between privacy concerns and HIV care provider trust, and the pathway for the ruling’s impact on HIV care engagement through women’s privacy concerns. Thus, the objectives of this thesis were (1) to measure the proportion and socio-demographic characteristics of WLWH’s privacy concerns, defined in terms of their perception that HIV non-disclosure laws might affect the type of information that WLWH would be willing to share with healthcare providers; (2) to assess the association between WLWH’s privacy concerns and their HIV care provider trust; and (3) to examine the association between WLWH’s privacy concerns and their engagement in HIV clinical care, as measured by their ART adherence, as well as their retention in HIV medical care, current ART use, and viral load.

### **4.2 Summary of Findings**

This study adopted a critical feminist framework. Feminist scholar Catherine McKinnon contends that privacy is important for women as it can protect them from unreasonable surveillance and intervention by the state.(71, 72) Results of this study indicated a high prevalence of privacy concerns among WLWH due to the law on non-disclosure, which is an

instrument of the state. Among 1182 (83.1% of 1422, the total CHIWOS cohort) who were included in the analysis, 810 (68.5%) perceived that the law might have an impact on WLWH's willingness to share their personal information with their healthcare providers.

Critical feminism asserts that women's experiences are not the same, as multiple social identities, including gender, race, sexual orientation, and socio-economic status, intersect at individual and structural levels to create the social inequalities and oppression that they experience.(8, 73-75) Intersectionality frameworks, which assert these numerous factors are always at play in determining health outcomes and which have been advocated for use in HIV research(76), illuminate the differential impact of the law on women of different backgrounds. Results indicated that WLWH of ACB descent (AOR: 1.58, CI: 1.11, 2.24), who were unstably housed (AOR: 2.03, CI: 1.31, 3.14), who were older (AOR: 1.03 per year, CI: 1.02, 1.04), and who were employed (AOR: 1.38, CI: 1.02, 1.86) all had significantly higher adjusted odds of reporting privacy concerns. These results confirmed the important role of social inequities and racial identities in shaping women's perceptions of privacy concerns due to the 2012 ruling.

494 (45.3%) of 1091 participants (76.7% of 1422 of the total cohort) reported trusting their HIV care providers, and those reporting lower trust in HIV care providers had higher odds of privacy concerns (OR: 1.42; CI: 1.10-1.84; aOR: 1.27; 95% CI: 0.95-1.69). Fostering strong overall trust in HIV care providers among WLWH may help to alleviate healthcare-related privacy concerns in the climate of HIV criminalization. The critical feminist framework also illuminates the differential impact that WLWH's care provider trust may have on their privacy concerns, as results indicated that fostering trust may be even more important in alleviating privacy concerns among WLWH who are of ACB descent and who are unstably housed.

Finally, of 401 (28.2% of the 1422 women or the total cohort) who were aware of and understood the law, were currently on ART, and responded to questions about ART adherence, 318 (79.3%) of participants reported optimal ART adherence and 285 (71.1%) reported privacy

concerns. Both unadjusted (OR: 0.75; 95%CI: 0.45, 1.26) and adjusted results (aOR: 0.83; 95%CI: 0.47, 1.47) revealed no significant association between WLWH's privacy concerns and optimal ART adherence. Here, results also indicated the differential impact that WLWH's privacy concerns may have on clinical care engagement, as WLWH who reported to have received a formal education beyond high school level had higher odds of reporting optimal ART adherence levels (aOR: 2.08; CI: 1.198, 3.62), while those who were incarcerated since the last CHIWOS interview had lower odds of reporting optimal ART adherence levels (aOR: 0.30; CI: 0.11, 0.80). Unadjusted results also indicated no significant association between privacy concerns and HIV medical care since the last CHIWOS interview (OR: 0.67; CI: 0.25, 1.75), current ART use (OR: 0.65; CI: 0.35, 1.19), and viral load (OR: 0.67; CI: 0.34; 1.32). The lack of association between WLWH's privacy concerns and HIV care engagement may due to the indirect method used to measure privacy concerns, which asked for their perception of WLWH's willingness to share information rather than their own willingness to share such information. The lack of association may also indicate that privacy concerns do not have a significant impact on HIV care engagement among WLWH who are well informed about the law, although such concerns may have an impact on the care engagement of WLWH who are misinformed about the law. That participants with higher levels of formal education showed higher odds of reporting optimal ART adherence indicates that education may boost awareness of the importance of HIV care and help WLWH sustain optimal adherence. That those incarcerated since the last CHIWOS interview had lower odds of reporting optimal ART adherence supported research indicating the disruptive impact of incarceration on PLWH's engagement in HIV care.

### **4.3 Limitations**

Despite its expert-designed and reviewed questions and skilfully administered surveys, the CHIWOS project does have some limitations. Because WLWH engaged in the community

and its health services were likely more willing to have participated in the surveys, this might have led to a representation bias.(88) This representation bias might have become more severe considering that WLWH sufficiently engaged with the CHIWOS community were more likely to have participated in the Wave 2 survey.(88)

The critical feminist framework used in this study illuminated how WLWH's social identities, including gender, race, sexual orientation, and socio-economic status, intersect to impact their privacy concerns, trust, and clinical care engagement. Accordingly, the framework can inform policy and practice reforms (as described in section 4.6). While WLWH's social identities have played a role in shaping their experiences, their experiences—clinical care engagement in particular—are also informed by other factors that are not at all covered by the framework in this study but can be illuminated by different models or frameworks. The Health Belief Model, for example, can be used to examine how WLWH's beliefs about their health problems, perceived benefits of their health-related practices, and perceived barriers to their clinical care engagement, impact their levels of engagement in clinical care.(130) Additional models can provide a more holistic picture of their health-related behavior and inform more policy and practice reforms.

The data drawn from the Wave 2 survey in this analysis might also have been influenced by social desirability biases because all the relevant variables were self-reported. Any such biases might have resulted in the overestimation or underestimation of WLWH's privacy concerns, their levels of trust, and HIV clinical care engagement, and either way, less than accurate measurements of the role of trust in alleviating privacy concerns and the impact of privacy concerns on the engagement in HIV clinical care. The extensive training undergone by PRAs in methods of survey delivery should have served to reduce some of these biases.(88)

The inclusion/exclusion criteria may have been another source of bias. Because 1182 (out of 1252 participants who completed Wave 2 survey) answered the question measuring privacy,

there were 70 missing responses. These missing data may have come from participants who were uncomfortable answering the question due to the sensitivity of the information, and who would have reported that the law may affect the willingness of WLWH to share information with healthcare providers. Thus, their exclusion likely underestimated the participants who reported privacy concerns due to the law. In addition, regarding ART adherence, among 453 participants who reported that they were aware of and understood the law, 452 reported they were currently taking ART and 401 completed the visual analog scale of ART adherence. The 52 missing responses may have been given by those who did not feel comfortable about reporting their ART adherence, and whose exclusion thus overestimated the ART adherence rate and underestimated the impact of privacy concerns on ART adherence. Otherwise, due to the small number of participants who chose “DK” and “PNTA” or had missing answers for other explanatory and outcome variables and covariates, excluding them likely did not bias the results.

#### **4.4 Recommendations and Future Research**

As discussed in Chapter 3, the lack of a significant association between participants’ privacy concerns and their engagement in HIV clinical care could have been due to the indirect method of measuring privacy concerns. Question S5-118 of Wave 2 survey, which this study used to measure WLWH’s privacy concerns and which asks for participants’ perception of the law’s impact on WLWH’s willingness to share personal information with healthcare providers, might not accurately reflect their own privacy concerns in the wake of the 2012 ruling. Further research should be carried out by using data from CHIWOS Wave 3 survey conducted from March 2017 to September 2018. Question S5-34(a) of Wave 3 survey addressing the law’s impact on WLWH’s willingness to share personal information with healthcare providers is posed directly, by requiring participants to indicate to what extent they agree or disagree with this statement: “*HIV disclosure laws affect (or would affect) the type of information that I share*

*with my healthcare provider(s).*” Answers to this question should reflect participants’ own privacy concerns more accurately than the corresponding Wave 2 question. Hence, the data should be used to re-examine WLWH’s privacy concerns and the impact of privacy concerns on their engagement in HIV clinical care.

In addition, this study focused on the smaller sample of participants who heard about and understood the law on HIV non-disclosure and answered questions about their engagement in HIV clinical care at the time of the survey. The lack of a significant association between privacy concerns and HIV care engagement, as explained, might also have been due to the generally high percentage of ART adherence among this group of participants. Future research can therefore look at the sample of participants who had heard about the law but reported “mostly different” and “completely different” to the question addressing their understanding of the law, to examine whether their lack of understanding or misinformation about the law had an impact on their HIV care engagement, especially ART adherence.

Furthermore, this study defined overall provider trust as “Extremely satisfied” or “strongly satisfied” (vs. “Satisfied/Somewhat satisfied/Not at all satisfied”) in the level of satisfaction in the health professionals here at the HIV clinic. Results based upon this stringent definition of trust showed that HIV care provider trust may alleviate privacy concerns. In fact, a less stringent definition of HIV care provider trust was used in the initial stage of this research, by counting also participants who reported “satisfied” as harboring trust in their care providers, to test whether care provider trust is associated with privacy concerns based upon this new definition, and higher HIV care provider trust was found to be not significantly associated with lower odds of privacy concerns among WLWH. Hence, results indicated that only very strong care provider trust may alleviate privacy concerns among WLWH, as shown in this study. In future studies, interviews with WLWH should be conducted to examine the best ways of fostering strong care provider trust among them.



Finally, whereas this study's approach towards privacy concerns was primarily descriptive, future research can take a more legally-oriented approach by examining the meaning and significance of privacy in Canadian law, and whether WLWH's right to privacy trumps those of their sexual partners. The SCC viewed privacy as a human right, a *Charter* protected value, under its Section 7 (the right to life, liberty and the security of the person)(131, 132) and Section 8 (the right to be secure against unreasonable search or seizure).(133, 134) While the legal concept of privacy has been largely developed from within the context of criminal prosecutions in which accused persons assert their section 8 Charter right to be free from unreasonable search and seizure by the state, Canadian courts also linked privacy to an individual's Section 7 liberty interests, by conceptualizing privacy as the right to make personal and private decisions free from state interference and as essential to an individual's liberty, security, integrity, and dignity.(131, 133, 135) In *R. v. Dyment* (1988), Supreme Court Justice la Forest cited Alan F. Westin's *Privacy and Freedom* (1970) to emphasize that privacy is "[g]rounded in man's physical and moral autonomy," "essential for the well-being of the individual," and "at the heart of liberty in a modern state." (133)<sup>7</sup> The *Dyment* Court's emphasis on the importance of privacy of information was then followed by the *Spencer* Court's decision mentioned in this study.(51) Further, the SCC in *R. v. O'Connor* (1995) stated that where a breach of information privacy occurred, the invasion is not with respect to a particular document or record that was disclosed, but "an invasion of the dignity and self-worth of the individual, who enjoys the right to privacy as an essential aspect of his or her liberty in a free and democratic society." (136)

In *Mabior*, the SCC did not consider the privacy interests of PLWH that may be violated by criminalizing HIV non-disclosure. However, it did indicate that the privacy interests of

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<sup>7</sup> While the *Dyment* Court did not define "autonomy," the SCC defined in *R. v. Dagg* (1997) "physical and moral autonomy" as "the freedom to engage in one's own thoughts, actions, decisions."

people who had sex with PLWH may be harmed where non-disclosure vitiates their consent to sexual relations (“[t]he Charter values of equality, autonomy, liberty, privacy and human dignity are particularly relevant to the interpretation of fraud vitiating consent to sexual relations.”)(6) Future research therefore should further examine whether WLWH’s right to privacy is being intruded upon by the 2012 ruling and whether their privacy right trumps competing interests, especially the privacy of their sexual partners. By weighing these different rights and interests, future research can deepen future discussion about legal reform.

#### **4.5 Recent Legal Developments**

Recent developments in HIV non-disclosure law in Canada may impact privacy concerns of WLWH over the sharing of personal information in healthcare settings. On December 1, 2017, or the World AIDS Day, Ontario’s provincial government announced that its crown attorneys would no longer criminally prosecute HIV-positive people who do not disclose their status to sexual partners if there is no realistic possibility of transmission.(101) On December 1, 2018, the Minister of Health of Canada officially endorsed the Undetectable = Untransmittable (U=U) campaign that promotes new scientific evidence indicating that an individual who is being treated for HIV and who maintains a suppressed viral load poses essentially no risk of sexual transmission.(102) On the same day, the Minister of Justice and Attorney General of Canada also issued a new directive on the prosecution of HIV non-disclosure stating that there should not be criminal prosecution of HIV non-disclosure where: (1) the person living with HIV has maintained a suppressed viral load (i.e. under 200 copies of the virus per millilitre of blood) because there is no realistic possibility of transmission; (2) the person has not maintained a suppressed viral load, but used condoms or engaged only in oral sex or was taking treatment as prescribed, unless other risk factors are present; (3) reclassifying cases of HIV non-disclosure as

non-sexual criminal offences would be more appropriate than sexual offences.(103) The criminal law will continue to apply if PLWH do not disclose, or misrepresent, their HIV status before sexual activity that poses a realistic possibility of HIV transmission.(103)

On April 16, 2019, the BC Crown Counsel issued a policy manual on the prosecution of HIV non-disclosure indicating how people living with HIV in BC may be charged in cases of non-disclosure.(104) This “Sex 2” manual lays out steps that the Crown needs to complete before pressing charges, including case assessment by more than one Crown Counsel lawyer and determination that public interests weigh in favor of the charges.(104)

It is uncertain what exact impact the Ontario government’s decision and the Federal government’s new directive may have on WLWH. Because these new measures would make prosecution in non-disclosure cases more unlikely than before, knowledge of such may help to loosen the perceived ties between public health and law enforcement authorities and make the efforts of HIV prevention more a public health than a criminal law concern. Likewise, BC’s Sex 2 policy manual makes it more difficult for the Crown to lay criminal charges against WLWH who did not disclose their HIV statuses to their partners. Although WLWH’s personal information, disclosed to health practitioners, would less likely be used for prosecution purposes, it might be premature to suggest that these new directive and prosecution guidelines would serve to alleviate privacy concerns among WLWH in terms of their willingness to share their personal information with healthcare providers.

On June 17,2019, the Standing Committee on Justice and Human Rights, at its 42nd Parliamentary meeting, issued a report on the criminalization of non-disclosure of HIV status. The report recommended, among other things, “that the Government of Canada create a specific offence in its Criminal Code related to the non-disclosure of an infectious disease (including HIV) when there is actual transmission, and that prosecutions related to such transmission only be dealt under that offence.”(105) The government should draft the contemplated legislation “in

consultation with all relevant stakeholders, including the HIV/AIDS community,” to circumscribe such use of criminal law and “make sure HIV is treated as a public health issue like any other infectious disease.”(105) The Committee also recommended that the Minister of Justice and Attorney General of Canada “immediately establish a federal-provincial working group to develop a common prosecutorial directive to be in effect across Canada to end criminal prosecutions of HIV non-disclosure, except in cases where there is actual transmission of the virus, to ensure that the factors to be respected for criminal prosecutions of HIV non-disclosure reflect the most recent medical science regarding HIV and its modes of transmission and only applies when there is actual transmission having regard to the realistic possibility of transmission.”(105) In addition, the Committee recommended immediate establishment by the Minister of Justice and Attorney General of Canada of a mechanism to review all cases of individuals who have been convicted or prosecuted for not disclosing their HIV status and who would not have been prosecuted or convicted under the new standards set out in the recommendations of the Committee.(105)

Unlike the measures by the Ontario and the Federal governments, the recommendation that a directive be developed to end criminal prosecutions of HIV non-disclosure, if followed, may alleviate WLWH’s privacy concerns. Should the directive be in place, WLWH’s personal information will not be used for prosecution purposes, except where a real transmission has taken place.

#### **4.6 Implications for Practice and Policy**

Whether or not the recommendations by the Justice Committee will be adopted, health practitioners must get educated about the current law on non-disclosure and be informed that a majority of WLWH have privacy concerns in the healthcare setting due to such laws. These

concerns not only negatively impact the general well-being of WLWH, but also make them less willing to share information with their healthcare providers which may be crucial to their effective care, especially WLWH of ACB descent, who were unstably housed, and who were older. Recent research indicates that care providers are beginning to get educated on the law, while discussions about HIV disclosure and the law are still lacking in healthcare settings, despite WLWH expressing a willingness and desire to engage in discussions of this nature with providers.(8, 137) As HIV care providers continue to get educated on the law on HIV non-disclosure, they can provide correct knowledge to WLWH—as this thesis has shown, full understanding of the law by WLWH may help to reduce the impact that privacy concerns may have on their clinical care engagement.

Fostering trust among WLWH in their HIV care providers is important to alleviate privacy concerns that will continue to arise in HIV care due to the overly broad criminalization of HIV non-disclosure. One important way to foster provider trust among WLWH is to build rapport, acknowledge their experience and expertise, and value their safety and autonomy.(70) One study, though not conducted within the HIV care setting, indicates that providing greater access to care providers of the same racial/ethnic group may also be an important step toward increasing trust in care providers and the services they provide.(100)

The new measures by the Federal and Ontario governments and the BC government's Sex 2 policy are all good signs that these governments took the interests of PLWH and the public health implications of overly broad criminalization of HIV non-disclosure seriously. The Federal directive also set the bar for what provincial attorneys general should do when they decide to adopt it or similar measures in individual provinces, something for which HIV/AIDS activists should lobby.

## **4.7 Conclusion**

On December 1, 2018, Canada became the first national government to sign on to the U=U campaign in its plan to improve the lives of PWLH by reducing stigma.(138, 139) This is the first study that drew upon nation-wide quantitative data to show that laws criminalizing HIV non-disclosure had impacted privacy concerns among WLWH and that HIV provider trust may alleviate these concerns, and to examine the association between privacy concerns and HIV care engagement. Hopefully, this study will add to the growing body of literature that calls for repealing overly broad criminalization of HIV non-disclosure in Canada and improving the health and well-being of WLWH worldwide.

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