




# 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

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## Abstract

In 2012, the Supreme Court of Canada ruled that people with HIV are legally obligated to disclose their serostatus before sex with a “realistic possibility” of HIV transmission, suggesting a legal obligation to disclose unless they use condoms and have a low HIV viral load (< 1500 copies/mL). We measured prevalence and correlates of ruling awareness among 1230 women with HIV enrolled in a community-based cohort study (2015–2017). While 899 (73%) participants had ruling awareness, only 37% were both aware of and understood ruling components. Among 899 aware participants, 34% had never discussed disclosure and the law with healthcare providers, despite only 5% being unwilling to do this. Detectable/unknown HIV viral load, lack of awareness of prevention benefits of antiretroviral therapy, education ≤ high-school and high HIV-related stigma were negatively associated with ruling awareness. Discussions around disclosure and the law in community and healthcare settings are warranted to support women with HIV.

**Keywords** HIV · Women · Criminalization of HIV non-disclosure · Canada · CHIWOS · Community based research

## Resumen

En 2012, la Corte Suprema de Canadá dictaminó que las personas con VIH están legalmente obligadas a revelar su estado serológico antes de tener relaciones sexuales con una “posibilidad realista” de transmisión del VIH, lo que sugiere una obligación legal de divulgar a menos que usen condones y tengan una carga viral baja (< 1500 copias/mL). Medimos la prevalencia y los correlatos de la conciencia dominante entre 1230 mujeres con VIH inscritas en un estudio de cohorte basado en la comunidad (2015–2017). Si bien 899 (73%) de los participantes tenían conciencia sobre el gobierno, solo el 37% conocía y entendía los componentes dominantes. Entre los 899 participantes conscientes, el 34% nunca había discutido la divulgación y la ley con los proveedores de atención médica, a pesar de que solo el 5% no estaba dispuesto a hacerlo. La carga viral del VIH detectable/desconocida, la falta de conciencia de los beneficios de prevención de la terapia antirretrovírica, la educación en la escuela secundaria y el alto estigma relacionado con el VIH se asociaron negativamente con la conciencia dominante. Las discusiones sobre la divulgación y la ley en entornos comunitarios y de atención médica están justificadas para apoyar a las mujeres con VIH.

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## Introduction

Use of antiretroviral therapy (ART) has transformed the clinical outcomes and sexual and reproductive health opportunities available to women with HIV [1–5]. However, pervasive HIV-related stigma and discrimination, rooted in misconceptions about HIV, remain considerable barriers to

women's health and wellbeing [6–11]. The growing use of criminal law against people with HIV is both a symptom of and contributor to continued HIV-related stigma [12, 13]. At least 49 countries have prosecuted people with HIV for HIV non-disclosure, exposure or transmission [14].

Use of criminal prosecutions against people with HIV is typically justified as a structural attempt to curb HIV incidence. However, more than 20 years of research findings fail to support the use of punitive laws as an effective HIV prevention strategy [15, 16]. Rather, evidence shows that the use of criminal laws against people with HIV creates barriers to engagement with HIV testing, treatment, and care services, driven by concerns about the exposure of confidential medical information and the exacerbation of HIV-related stigma [15–18]. There is strong evidence that engagement with such services reduces HIV incidence [19].

Applying a critical feminist lens to discussions around the criminalization of HIV non-disclosure is vital to appreciate intersecting systems of oppression experienced by women with HIV, and to recognise the role of social identities and inequities in shaping women's health and lives in the current legal climate [11, 20, 21].

Women experience gendered barriers to, and consequences of, HIV disclosure to sexual partners, including higher rates of violence, dissolution of partnerships, stigma, and social isolation [22–25]. Marginalized and vulnerable women with HIV are disproportionately burdened by challenges to safe HIV disclosure, particularly those who engage in survival sex work, or use illicit drugs [22, 24, 26]. Women with HIV may be uniquely affected by navigating healthcare engagement in an environment shaped by the criminalization of HIV non-disclosure [16, 27, 28], due to sexual, reproductive and maternal health needs [29–33], and gendered barriers to healthcare engagement [34–36]. Previous work has identified gender inequalities across the cascade of HIV care [37–44], particularly among Indigenous, Black, and other women of colour, and women with low economic power, resulting in poorer clinical outcomes among women compared to men [2, 45–47]. A recent review and similar work have suggested that the use of criminal prosecutions against women with HIV may augment barriers to engagement with HIV care, perpetuate gendered inequalities in health outcomes, and further isolate the most marginalized and vulnerable women with HIV from healthcare services [16, 48].

Canada has the second largest absolute number of HIV-related convictions of people with HIV [49]. At the time of writing, 181 people with HIV have faced criminal charges for HIV non-disclosure [15], including 17 women. As no HIV-specific laws exist within the Canadian Criminal Code, the Canadian criminal justice system applies existing criminal laws to prosecute HIV non-disclosure cases, guided by legal precedents set by the Supreme Court of Canada (SCC). In most cases of HIV non-disclosure, prosecutors apply laws

intended for sexual assault cases, based on the interpretation that HIV non-disclosure represents fraud that vitiates consent that was given to a sexual encounter [50]. A conviction for aggravated sexual assault can result in a maximum life sentence and mandatory registration as a sex offender. The application of sexual assault law for cases of HIV non-disclosure has been criticized by feminist legal scholars, who argue that this legal approach misuses consent law that was the result of a radical human rights movement from within the feminist community to protect women's sexual autonomy, and undermines the gravity of sexual assault charges [24, 51].

In October 2012, the SCC established a new legal test for Canadian HIV non-disclosure prosecutions after ruling that people with HIV who engage in sex with, in their words, a *realistic possibility* of HIV transmission without disclosing their HIV status can face criminal charges. In clarifying that condom-protected vaginal sex in the presence of a low HIV viral load (VL) (< 1500 copies/mL) would avert the legal obligation to disclose, the SCC increased the reach of criminal liability for HIV non-disclosure past that which was previously established by a 1998 SCC ruling. This ruling failed to incorporate modern evidence-based science showing no risk of HIV transmission among people living with HIV on sustained ART with a suppressed VL (findings forming the scientific basis of the Undetectable = Untransmittable (#U=U) campaign) [5, 52–54]. Although there has been some variation in the interpretation of this legal test within the lower courts [55], it is critical for women with HIV to assume the strictest interpretation in order to protect themselves from prosecution.

Legal scholars have cautioned that the revised legal test for Canadian HIV non-disclosure prosecutions may disproportionately impact women with HIV, due to gendered barriers to condom use negotiation and inequalities in health outcomes [56]. This concern has since been reinforced by empirical evidence among a community-recruited cohort of people with HIV who use illicit drugs in Vancouver, showing that women are less likely than men to meet the legal criteria for HIV non-disclosure [57].

Despite the threat of charges for, and legal consequences of, HIV non-disclosure, awareness and understanding of the legal obligation to disclose remains uncharacterised empirically across the diverse identities and social circumstances of women with HIV in Canada in the wake of the 2012 SCC ruling. Clinicians, public health experts, human rights activists and community leaders have expressed substantial concern about the negative impacts of HIV non-disclosure on the health and rights of women with HIV [58–67], however the voices of women with HIV remain notable in their absence from this conversation.

Using survey data from a community-based cohort study developed by, with, and for women with HIV in three

Canadian provinces, we measured prevalence and correlates of awareness and understanding of the 2012 SCC ruling on HIV non-disclosure, to ascertain whether women with HIV are equipped with fundamental information to avoid prosecution. We also sought to determine the existing and preferred role of healthcare providers in conversations around HIV disclosure and the law, to inform future efforts to support women with HIV in the current legal climate. Finally, we considered the perceived impact of HIV non-disclosure case law on the healthcare engagement of women with HIV.

## Methods

### Study Setting

The Public Health Agency of Canada estimates that there were 16,880 women living with HIV in Canada in 2016 [68], with the majority (81%) residing in the provinces of British Columbia (BC), Ontario and Quebec [69]. Regional HIV epidemics in Ontario and Quebec comprise a large prevalence of immigrant, refugee and African, Caribbean and Black (ACB) women, whereas in BC, Indigenous women and women who have used injection drugs are overrepresented [69]. Despite these regional differences, what is consistently observed is that socio-economically marginalized women are disproportionately affected by HIV nationally, with women often experiencing intersecting social inequities (e.g., poverty, structural violence), in addition to their own personal identities (e.g., gender, ethnicity) that shape experiences of stigma and barriers to healthcare engagement [21, 69, 70].

### Data Source

We used cross-sectional survey data from the Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS), a community-based longitudinal cohort study of women with HIV from BC, Ontario and Quebec, described in detail within the CHIWOS cohort profile [71]. CHIWOS was initiated in 2011 to evaluate the prevalence of, barriers to, and facilitators of accessing women-centred HIV care for women across Canada, and to explore overall, HIV, women's, mental, sexual and reproductive health benefits of this healthcare approach.

Grounded in the principles of Critical Feminist theory [20] and Community-Based Research [72], CHIWOS involves women with HIV and allied clinicians, researchers, and community partners as core partners throughout the research process. Peer Research Associates (PRAs; women with HIV who receive research training) [73] are involved in the development of surveys, participant recruitment, and online survey administration and scientific co-authorship

and dissemination. Between August 27, 2013 and May 1, 2015, women with HIV older than 16 years, self-identifying as a woman with HIV (trans-inclusive), and resident in BC, Ontario or Quebec, were recruited into CHIWOS. Efforts were made to recruit women from marginalized and vulnerable populations disproportionately affected by HIV or underserved by health services by utilising PRA networks [74].

Participants completed a PRA-administered survey, which collected information on reproductive, sexual, mental and women's health outcomes, and use of HIV services. The survey was administered in English or French using Fluid-surveys (an online survey instrument) at HIV clinics, community-based AIDS Service Organizations (ASOs), other community organizations, or at women's homes. For rural/remote participants, the survey was administered via telephone/online videoconferencing. Participants were invited to complete a follow-up (wave 2) survey approximately 18 months after baseline interview (June 2015–January 2017) and again at 36-months (wave 3, February 2017–September 2018).

### Data Collection on the Criminalization of HIV Non-disclosure

Following administration of the baseline survey, participants, PRAs and the CHIWOS Community Advisory Boards identified the criminalization of HIV non-disclosure as a key concern for women with HIV and a critical research priority. Accordingly, novel research questions were designed for integration into the wave 2 survey focused on assessing the awareness, understanding, existing and preferred sources of information, and perceived healthcare impacts of HIV non-disclosure case law among women living with HIV. Further details on this process have been previously published [75]. A multidisciplinary team of experts contributed to the development of the survey questions, including academic researchers, frontline research staff, women with HIV, and a legal representative. Question development was informed by a comprehensive literature review [16] and community consultation, to ensure that questions reflected priority concerns of women with HIV in Canada, and contributed evidence to gaps in the literature.

Based on community consultation, in some instances structured questions were posed hypothetically to encourage honest responses from participants, to minimize concern about compromising participant safety or comfort, and to enable participants who had no prior awareness of the law to answer questions relating to potential impacts. Questions were reviewed and piloted to ensure that they would not threaten the health, rights or safety of participants. After comprehensive pilot testing, the questions about HIV non-disclosure case law were included in the CHIWOS wave

2 survey (available at <http://www.chiwos.ca/chiwos-study/chiwos-documents>).

In conducting this research, considerable effort was made to increase awareness of HIV disclosure and the law among participants and PRAs. CHIWOS PRAs underwent training on the criminalization of HIV non-disclosure in Canada to support their own understanding. A concise description of the legal obligation to disclose, based on the 2012 SCC ruling, was discussed with all participants after assessing awareness of the ruling in the survey and before assessing perceived impacts (Appendix A). Referral services and information on HIV disclosure and the law were also available for participants who raised questions or concerns about the case law during administration of the survey [50, 76–78].

### Theoretical Framework

Marginalized and vulnerable women who experience intersecting axes of inequality and stigma, including those who are Indigenous and racialized, are over-represented among women who have faced charges for HIV non-disclosure in Canada [79]. Given this reality, a Critical Feminist framework was applied to this work. This framework considers gender as the dominant focus of the analysis [20]. Furthermore, it acknowledges that varied and numerous social identities of women intersect to create inequality and oppression, pulling from Intersectional Feminist theory [80]. Applying this framework within our methodology, analysis and interpretation, we sought to acknowledge the diverse identities and experiences of women living with HIV in the current legal climate, and to contextualise individual, social and structural barriers to awareness and understanding of HIV non-disclosure case law.

### Ethical Considerations

Ethical approval was granted by the Research Ethics Boards of Simon Fraser University, University of BC/Providence Health Care, Women's College Hospital, and McGill University Health Centre. Participants provided voluntary written informed consent (or verbal consent in the presence of a witness from the study team for surveys completed over the telephone/videoconferencing). Participants were provided with a \$50 honorarium for survey completion.

### Inclusion Criteria

We included CHIWOS participants who completed the wave 2 survey and answered questions pertaining to the criminalization of HIV non-disclosure.

## Measures

### Primary Outcome

The primary outcome of interest was self-reported awareness of the 2012 SCC ruling on HIV non-disclosure, measured by response to the question “*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?*” Participants responding “Yes” were considered to be aware.

Correlates of awareness of the 2012 SCC ruling were identified based on a comprehensive literature review [16]. Socio-demographic variables included age, province of interview, ethnicity, years living in Canada; sexual orientation; education; unstable housing at interview (defined as living outside/in a car/couch surfing, living in a transition house/halfway house/shelter/single room occupancy hotel) (yes vs. no); incarceration history; and history of injection drug use. HIV-related stigma was measured using the 10-item HIV Stigma Scale (HSS) [81, 82], with scores ranging from 0 to 100. Scores equaling or exceeding the median were categorized as high vs. low HIV-related stigma. Violence experienced as an adult was defined as reporting verbal, physical, controlling and/or sexual abuse. Engagement with the HIV community was measured by self-reported participation in HIV community work since the last interview.

HIV clinical variables included years living with HIV; self-reported undetectable VL (< 50 copies/mL) at interview (previously shown to have a high positive predictive value when compared with gold-standard laboratory confirmed VL [83]); awareness of the prevention benefits of ART (self-reported belief that ART makes the risk of HIV transmission a lot lower); and receipt of HIV medical care since last interview. Sexual health variables included sexual activity in the 6 months before interview (defined as no consensual sex vs. consensual sex with 100% condom use vs. consensual sex with < 100% condom use); relationship status; serostatus of sexual partners; number of consensual sexual partners in the 6 months before interview (0 vs. 1 vs. > 1); sex work in the 6 months before interview (i.e., exchanged sex for money, drugs, clothing, or other possessions), and having been tested for sexually transmitted infections (STIs: chlamydia, gonorrhea or syphilis) in the year before interview.

### Understanding of the Legal Obligation to Disclose

After assessing awareness of the 2012 SCC ruling, a concise definition of the conditions under which people with HIV would face no legal obligation to disclose was reviewed with all participants (Appendix A). Among those aware of the ruling, we determined consistency of participant understanding

of the legal obligation to disclose with the definition of the case law provided, based on responses to the question “*How similar is this definition to what you had previously understood about the laws relating to HIV disclosure?*” Responses were dichotomized as “the same” vs. “mostly the same/mostly different/completely different”. Participants responding that the definition provided was the same as what they had previously understood were considered to understand the case law. Whilst indirect, based on community consultation we determined that this method of aided recall would assist participants in remembering the detailed specifics of the case law under pressure, which might otherwise be challenging within an interview setting.

### Sources of Information Around HIV Disclosure and the Law

Among participants self-reporting awareness of the 2012 SCC ruling, we identified sources from which individuals learned about HIV disclosure and the law (healthcare providers; service providers at ASOs or other community-based organizations; newspapers/media; friends; PRAs; Canadian HIV/AIDS Legal Network; other). Participants could select more than one response option. For each source of information reported, we determined the proportion of participants who demonstrated a complete understanding of the legal obligation to disclose, as a basic indicator of the quality of information received. Participants were also asked to specify which healthcare providers (e.g., HIV physician, general practitioner (GP), nursing staff, counsellor, social worker, peer worker, other), if any, had talked to them about HIV disclosure and the law. Participants could report more than one provider. The perceived degree of importance of HIV healthcare provider-led discussions around HIV disclosure and the law was assessed across three levels: very important, a little important or not important. Finally, participants were asked to identify one or more types of healthcare provider(s) with whom they would feel comfortable talking to about HIV disclosure and the law.

### Disclosure in the Climate of HIV Non-disclosure Criminalization

Barriers to and challenges of HIV disclosure in the current legal context were assessed among participants. Specifically, we measured HIV disclosure worries by responses to the statement “*I have been afraid to tell other people I have HIV*”. Fear of losing access to health services following disclosure of HIV status was measured by response to the statement “*I have been worried that I’ll lose access to health services or care if people find out I have HIV*”. Additionally, we assessed satisfaction with HIV disclosure support services using a five-point Likert scale measuring agreement with the statement “*I am satisfied with the support services*

*currently available in my community to help women with HIV navigate HIV disclosure to sexual partners*”. In each case, responses were dichotomized as strongly agree/agree versus neither agree or disagree/disagree/strongly disagree.

### Healthcare Engagement in the Climate of HIV Non-disclosure Criminalization

To characterize patient-provider relationships in the current legal climate, we asked participants whether they trusted healthcare professionals at the HIV clinic they attended in the previous year, and whether they perceived their HIV clinic to be a place where their information is kept confidential. Responses were dichotomised as strongly agree/agree versus neither agree or disagree/disagree/strongly disagree. We assessed the perceived importance of HIV healthcare provider-led discussions to promote understanding of individual rights to confidentiality, respect and quality care. Responses were assessed across three levels: very important, a little important, not important. Finally, we assessed the perceived impact of HIV non-disclosure case law on consultations with healthcare providers by measuring agreement with the statement: “*HIV disclosure laws might affect the type of information that women with HIV would be willing to share with their healthcare provider, such as information about sexual activities and HIV disclosure*”. Responses were dichotomised as strongly agree/agree versus neither agree or disagree/disagree/strongly disagree.

### Statistical Analysis

Variable distributions were characterized using descriptive statistics (median and interquartile range [IQR] for continuous variables and n [%] for categorical variables). Wave 2 socio-demographic, sexual health, and HIV clinical characteristics were compared between participants who self-reported awareness of the 2012 SCC ruling and those who did not, using Pearson’s  $\chi$ -squared test (Fisher’s exact test when count < 5) for categorical variables, and the Wilcoxon rank sum test for continuous variables.

Multivariable logistic regression identified independent correlates of awareness of the ruling. Variables demonstrating a significance level of  $p < 0.2$  in bivariable analysis, or variables considered to influence awareness of the ruling following a priori literature review were candidates for model inclusion. During the model selection process, missing responses were imputed based on information captured within the wave 1 survey to preserve statistical power. If this strategy was not possible, participants were excluded from model selection unless the proportion of missing data for a variable was > 5% (in which case missing was included in the model as a response option). After assessing collinearity, the final model was selected using a backwards selection

process, guided by minimizing the Akaike Information Criterion, and maintaining Type III P-values. P-values were two-sided and considered statistically significant at  $\alpha < 0.05$ . All analyses were conducted using SAS 9.4 software (SAS Institute Inc., Cary, NC).

### Sensitivity Analysis

Simply being aware of the law may be insufficient if an individual does not understand its specifics. As such, we conducted a sensitivity analysis with the outcome of understanding the law (i.e., aware of the case law and reporting that their understanding of the legal obligation to disclose was “the same” as the provided definition).

### Results

Of 1424 participants enrolled in CHIWOS, 1230 (85%) participants completed the wave 2 survey by February 2017 and answered questions on the criminalization of HIV non-disclosure. Four participants completing the wave 2 survey who deliberately chose not to answer questions on the criminalization of HIV non-disclosure were excluded. Our analytic sample showed the socio-demographic diversity of Canadian women with HIV (Table 1). The median age was 44 years (IQR: 37–52), with 145 (12%) participants identifying as lesbian, gay, bisexual, transgender, Two-Spirit or queer. Overall, 1053 (86%) participants were receiving ART, and 1039 (84%) participants self-reported an undetectable VL. Among 533 (43%) participants who reported consensual sex in the six months before the interview, 490 (92%) practiced consistent condom use *or* had an undetectable VL, but only 185 (35%) reported both consistent condom use *and* an undetectable VL (i.e., the legal criteria for non-disclosure).

### Awareness and Understanding of the 2012 SCC Ruling

While 899 (73%) women reported being aware of the 2012 SCC ruling, only half of those aware (457, 51%) understood the legal obligation to disclose. Overall, 37% of women had both awareness and understanding of the law. In adjusted analyses, participation in HIV work in the community (Adjusted Odds Ratio [AOR]: 1.96, 95% confidence interval [CI] 1.41–2.71) was positively associated with awareness of the 2012 SCC ruling. Having a detectable or unknown VL (AOR: 0.61, 95% CI 0.43–0.86), lack of awareness of HIV prevention benefits of ART (AOR: 0.66, 95% CI 0.49–0.88), education  $\leq$  high school (AOR: 0.70, 95% CI 0.53–0.92), and high HIV-related stigma (AOR: 0.75, 95% CI 0.57–0.98) were negatively associated with awareness of the ruling (Table 2).

### Sources from Which Participants Learned About HIV Disclosure and the Law

Among participants aware of the 2012 SCC ruling ( $n = 899$ ), the most common sources for learning about HIV disclosure and the law were ASOs (53%), newspapers/media (35%), healthcare providers (30%) and friends/peers (30%) (Table 3), with some variation by province (Fig. 1). Participants who understood the ruling were significantly more likely to report learning about HIV disclosure and the law from healthcare providers (36% vs. 25%,  $p < 0.001$ ) or the Canadian HIV/AIDS Legal Network (23% vs. 17%,  $p = 0.026$ ). Participants with an incomplete understanding were significantly more likely to have learned about the law from friends/peers (23% vs. 37%,  $p < 0.001$ ) (Table 3).

### Healthcare Providers to Whom Women Talked About HIV Disclosure and the Law

Among those aware of the ruling, 65% reported that they had talked to at least one type of healthcare provider about HIV disclosure and the law. HIV physicians (39%), community workers (18%), social workers (13%) and GPs (12%) were the most commonly identified types of providers with whom women had discussed disclosure and the law.

Among all participants ( $n = 1230$ ), a large majority ( $n = 971$ , 79%) believed that it was very important for HIV physicians to discuss issues around the criminalization of HIV non-disclosure in the healthcare setting, a belief that did not vary significantly by ruling awareness (80% vs. 77%,  $p = 0.05$ ) (Table 4). A regular HIV physician was identified by 59% of women as the type of healthcare provider they would prefer to approach with concerns around HIV disclosure and the law. Only 5% of participants reported that they would not feel comfortable discussing issues around disclosure and the law with any healthcare provider (Fig. 2).

### HIV Disclosure in the Climate of HIV Non-disclosure Criminalization

A significantly larger proportion of participants who had been afraid to disclose their HIV status to others were represented among those who were unaware versus aware of the ruling (84% vs. 74%,  $p < 0.001$ ) (Table 4). A minority (515, 42%) of participants expressed satisfaction with current community support services available to help women navigate HIV disclosure to sexual partners, with a higher prevalence of satisfaction among those who were aware vs. unaware of the ruling (45% vs. 32%,  $p = 0.001$ ). Additionally, 258 (21%) women were afraid of losing access to health services if people found out that they were living with HIV. This response varied significantly by ruling awareness (19% vs. 26%,  $p = 0.007$ ). Generally speaking, women who

**Table 1** Socio-demographic, behavioural and clinical characteristics of women with HIV, stratified by self-reported awareness of 2012 SCC ruling on HIV non-disclosure (n = 1230)

Variable	All participants (n = 1230, 100%)		Participants aware of the ruling (n = 899, 73%)	Participants not aware of the ruling (n = 331, 27%)	P value
	Median [IQR] or n (%)	Total			
<i>Socio-demographic variables</i>					
Age at interview	44 [37, 52]	1230	45 [37, 53]	42 [36, 52]	0.033
Province of interview		1230			0.410
British Columbia	296 (24)		225 (25)	71 (21)	
Ontario	613 (50)		444 (49)	169 (51)	
Quebec	321 (26)		230 (26)	91 (27)	
Ethnicity		1230			0.015
Indigenous	271 (22)		179 (20)	92 (28)	
African/Caribbean/Black	366 (30)		267 (30)	99 (30)	
White	507 (41)		390 (43)	117 (35)	
Other ethnicity	86 (7)		63 (7)	23 (7)	
Years living in Canada		1224			0.847
Born in Canada (years)	788 (64)		573 (64)	215 (65)	
< 10	230 (19)		167 (19)	63 (19)	
≥ 10	206 (17)		154 (17)	52 (16)	
Sexual orientation		1225			0.692
Heterosexual	1080 (88)		786 (87)	294 (89)	
LGBTQ	145 (12)		108 (12)	37 (11)	
Education completed		1217			< 0.001
> High school	609 (50)		479 (53)	130 (39)	
≤ High school	608 (49)		409 (45)	199 (60)	
Unstable housing <sup>a</sup>		1229			0.083
No	1091 (89)		807 (90)	284 (86)	
Yes	138 (11)		92 (10)	46 (14)	
Personal annual income		1211			0.945
< \$20,000	813 (67)		594 (67)	219 (67)	
≥ \$20,000	398 (33)		292 (33)	106 (33)	
Participated in HIV work in community since last interview		1230			< 0.001
Yes	367 (30)		306 (34)	61 (18)	
No/don't know/PNTA	863 (70)		593 (66)	270 (82)	
Incarcerated ever		1228			0.637
Yes	426 (35)		308 (34)	118 (36)	
No	802 (65)		590 (66)	212 (64)	
Injection drug use L6 M		1217			0.030
Yes	108 (9)		69 (8)	39 (12)	
No	1109 (91)		821 (92)	288 (88)	
Injection drug use ever		1203			0.723
Yes	361 (30)		261 (30)	100 (31)	
No	842 (70)		618 (70)	224 (69)	
Experienced violence as adult ever		1170			0.560
Yes	955 (82)		692 (81)	263 (83)	
No	215 (18)		160 (19)	55 (17)	
HIV-related stigma		1230			< 0.001
Low stigma (score ≤ median)	599 (49)		467 (52)	132 (40)	
High stigma (score > median)	631 (51)		432 (48)	199 (60)	
<i>HIV clinical variables</i>					
Years living with HIV		1194			0.429
> 6	300 (25)		216 (25)	84 (27)	
6–14	475 (40)		346 (39)	129 (41)	

**Table 1** (continued)

Variable	All participants (n = 1230, 100%)		Participants aware of the ruling (n = 899, 73%)	Participants not aware of the ruling (n = 331, 27%)	P value
	Median [IQR] or n (%)	Total			
> 14	419 (35)		318 (36)	101 (32)	
ART experience		1230			0.004
On ART	1053 (86)		788 (88)	265 (81)	
Previously on ART	102 (8)		67 (7)	35 (11)	
Never on ART	68 (6)		40 (4)	28 (9)	
Self-reported VL at interview		1230			< 0.001
Undetectable	1039 (84)		785 (88)	254 (77)	
Detectable//DK/PNTA/never received VL results	191 (16)		114 (13)	77 (23)	
Aware of ART prevention benefits <sup>b</sup>		1225			< 0.001
Yes (a lot lower)	883 (72)		678 (76)	205 (63)	
No/DK	342 (28)		219 (24)	123 (37)	
Received HIV medical care since last interview		1230			0.001
Yes	1150 (93)		853 (95)	297 (90)	
No/DK/PNTA	80 (7)		46 (5)	34 (10)	
Months receiving care from HIV doctor <sup>c</sup>	71 [36,132]	1071	72 [36,132]	60 [30,120]	0.098
<i>Sexual health variables</i>					
In a relationship		1230			0.583
Yes	400 (33)		288 (32)	112 (34)	
No	830 (67)		611 (68)	219 (66)	
Consensual sex in L6 M		1230			0.691
No consensual sex	626 (51)		459 (51)	167 (50)	
Condom protected sex	227 (18)		173 (19)	54 (16)	
Condomless sex	306 (25)		225 (25)	81 (24)	
Skipped section/DK/PNTA	71 (6)		42 (5)	29 (9)	
Number of consensual sex partners in L6 M		1229			0.440
0	626 (51)		459 (51)	167 (50)	
1	427 (35)		314 (35)	113 (34)	
> 1	76 (6)		61 (7)	15 (5)	
Skipped section/DK/PNTA	100 (8)		64 (7)	36 (11)	
Serodiscordant partners in L6 M		1230			0.484
No sexual partner	626 (51)		459 (51)	167 (50)	
All HIV + partners	126 (10)		91 (10)	35 (11)	
≥ 1 HIV negative or unknown status partner	378 (30)		285 (31)	93 (27)	
Skipped section/DK/PNTA	104 (8)		64 (7)	36 (12)	
Sex work L6 M		1230			0.891
Yes	73 (6)		55 (6)	18 (5)	
No	1089 (89)		805 (90)	284 (86)	
Skipped section/DK/PNTA	68 (5)		39 (4)	29 (9)	
Tested for STI in past year		1230			0.989
Yes (tested for any)	398 (32)		291 (32)	107 (32)	
No (tested for none)/DK	832 (68)		608 (68)	224 (68)	

Percentage totals may exceed 100% due to rounding

*DK/PNTA* Don't know/prefer not to answer, *L6M* last 6 months before interview, *STI* sexually transmitted infection (chlamydia, gonorrhoea or syphilis), *ART* antiretroviral therapy, *LGBTQ* lesbian, gay, bisexual, transgender, Two-Spirit and queer, *VL* viral load

<sup>a</sup>Defined as living outside/in a car/couch surfing, living in a transition house/halfway house/shelter/single room occupancy hotel

<sup>b</sup>Self-reported belief that ART makes the risk of HIV transmission a lot lower

<sup>c</sup>Participants who had received HIV medical care since last interview and were willing to answer questions about HIV doctor were included



**Table 2** Crude and adjusted odds ratios for correlates of awareness of the 2012 SCC ruling on HIV non-disclosure among women with HIV (n = 1155)

Variable	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age at interview (years)	1.01 (1.00, 1.03)	Not selected
Ethnicity		Not selected
White	1.00 (–)	
Indigenous	0.61 (0.44, 0.85)	
African/Caribbean/Black	0.75 (0.55, 1.03)	
Other	0.87 (0.51, 1.47)	
Education		
> High school	1.00 (–)	1.00 (–)
≤ High school	0.58 (0.45, 0.76)	0.70 (0.53, 0.92)
Unstable housing at interview <sup>a</sup>		Not selected
No	1.00 (–)	
Yes	0.67 (0.45, 1)	
Participate in HIV work in community since last interview		
No/DK	1.00 (–)	1.00 (–)
Yes	2.27 (1.65, 3.13)	1.96 (1.41, 2.71)
Injection drug use in past 6 months		Not selected
No	1.00 (–)	
Yes	0.64 (0.41, 0.98)	
Self-reported VL		
Undetectable	1.00 (–)	1.00 (–)
Detectable/DK/PNTA/never received VL results	0.46 (0.33, 0.64)	0.61 (0.43, 0.86)
Received HIV medical care since last interview		Not selected
Yes	1.00 (–)	
No/DK/PNTA	0.47 (0.29, 0.77)	
Aware of prevention benefits of ART <sup>b</sup>		
Yes (a lot lower)	1.00 (–)	1.00 (–)
No/DK	0.54 (0.41, 0.71)	0.66 (0.49, 0.88)
Personalized stigma		
Low stigma (score ≤ median)	1.00 (–)	1.00 (–)
High stigma (score > median)	0.63 (0.49, 0.82)	0.75 (0.57, 0.98)

75 participants with missing data excluded from the model

VL viral load, DK/PNTA Don't know/prefer not to answer, OR odds ratio, STI sexually transmitted infection (gonorrhea, chlamydia or syphilis), ART antiretroviral therapy

<sup>a</sup>Defined as living outside/in a car/couch surfing, living in a transition house/halfway house/shelter/single room occupancy hotel

<sup>b</sup>Self-reported belief that ART makes the risk of HIV transmission a lot lower

were not aware of the ruling were more likely to be afraid to disclose, to fear losing access to health services if they disclosed, and to be dissatisfied with HIV disclosure support services.

### Healthcare Engagement in the Climate of HIV Non-disclosure Criminalization

Of 1150 participants who received HIV care in the year before the interview, 929 (81%) trusted the healthcare providers at their HIV clinic and 1043 (91%) believed their

information was kept confidential (Table 4). Among all 1230 participants, 1099 (89%) women believed that HIV provider-led discussions promoting women's understanding of their rights to confidentiality, respect and quality care in the healthcare setting were very important.

Despite high levels of trust in healthcare providers, 799 (65%) participants believed that HIV disclosure laws might affect the type of information that women with HIV would be willing to share with healthcare providers. This belief was more commonly held among participants who were aware of the ruling (67% vs. 60%,  $p = 0.037$ ) (Table 4).

**Table 3** Sources of information about HIV disclosure and the law among participants self-reporting awareness of the 2012 SCC ruling, stratified by completeness of understanding of the legal obligation to disclose (n = 899)

Variable	Total N	Overall (n = 899) N (%)	Participants aware with understanding of the ruling N = 457 (51%) N (%)	Participants aware without understanding of the ruling N = 442 (49%) N (%)	P-value
Source from which participants learned about HIV disclosure and the law <sup>a</sup>	899				
AIDS service organizations		472 (53)	228 (50)	244 (55)	0.111
Newspapers/media outlets		311 (35)	157 (34)	154 (35)	0.878
Health care providers		274 (30)	163 (36)	111 (25)	< 0.001
Friends/peers/PRA's		269 (30)	107 (23)	162 (37)	< 0.001
Canadian HIV/AIDS legal network		184 (20)	107 (23)	77 (17)	0.026
Service providers not part of an AIDS service organization		52 (6)	31 (7)	21 (5)	0.192
Other		49 (5)	32 (7)	17 (4)	0.037
Type of healthcare providers participants talked to about HIV disclosure and the law <sup>a</sup>	899				
HIV physician		354 (39)	215 (47)	139 (31)	< 0.001
No healthcare providers have talked to me		308 (34)	128 (28)	180 (41)	< 0.001
Community worker		158 (18)	92 (20)	66 (15)	0.041
Social worker		118 (13)	62 (14)	56 (13)	0.691
General practitioner/family doctor		110 (12)	55 (12)	55 (12)	0.852
Nursing staff		95 (11)	67 (15)	28 (6)	< 0.001
Peer worker		90 (10)	51 (11)	39 (9)	0.243
Counsellor		63 (7)	38 (8)	25 (6)	0.118
Case manager		34 (4)	12 (3)	22 (5)	0.065
Other		10 (1)	3 (1)	7 (2)	0.185
DK/PNTA		10 (1)	4 (1)	6 (1)	0.491

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

<sup>a</sup>Not mutually exclusive, as such percentage totals may exceed 100%

## Sensitivity Analysis

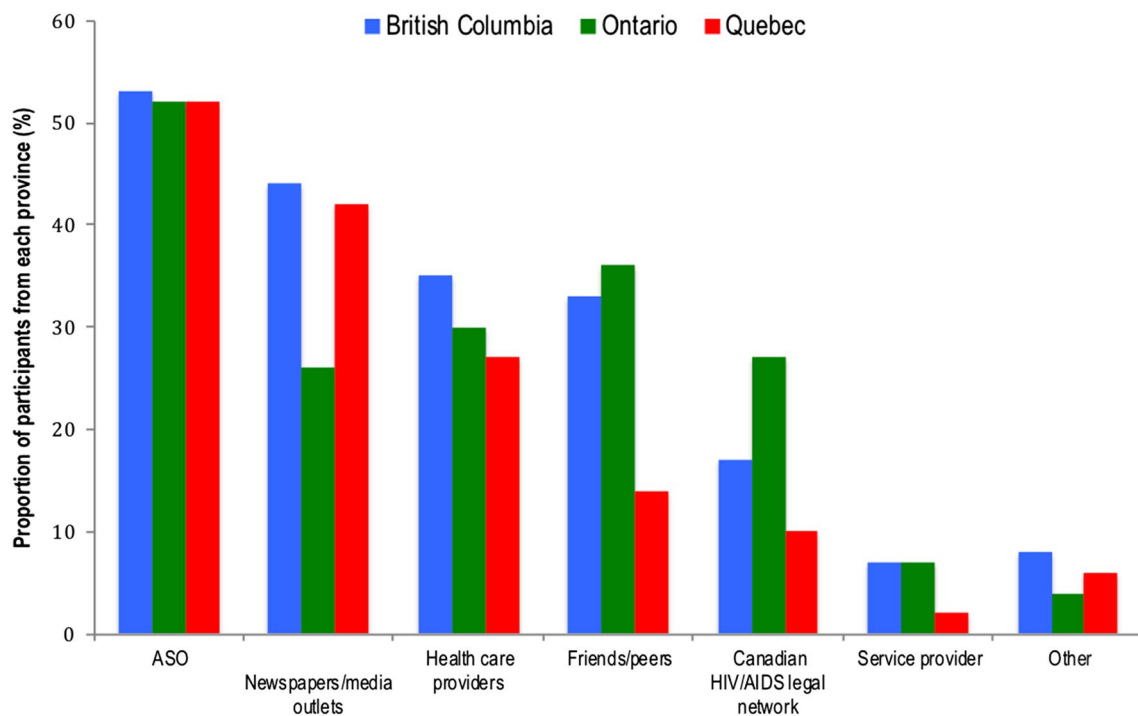
In the sensitivity analysis examining prevalence and correlates of reporting both awareness and understanding of the legal obligation to disclose, the model showed the exact same covariates as those which were associated with awareness of the case law in the original analysis, and consistent effect size estimates (Supplementary Table 5Si).

## Discussion

This is the first study to assess awareness, understanding and perceived healthcare impacts of the criminalization of HIV non-disclosure among the diversity of Canadian women with HIV since the 2012 SCC ruling. Awareness of the ruling was

relatively high within this cohort (73%), however, only 37% of participants were both aware of the ruling *and* understood the legal obligation to disclose to sexual partners. Notably, awareness and understanding of the ruling in this cohort was higher than that observed among a cohort of people with HIV who had used illicit drugs in BC, where only 45% were aware and 18% had an understanding of the law [84].

These findings echo previous work showing poor understanding of the legal obligation to disclose among women with HIV before [27, 85, 86], and after [84, 87] the 2012 SCC ruling on HIV non-disclosure. Qualitative work in Canada similarly shows that women who are aware of the ruling express confusion and disbelief about specific details and expectations of the case law [87]. This analysis validates concerns that women with HIV lack understanding of the legal obligation to disclose in the wake of the 2012 SCC



**Fig. 1** Sources from which participants who were aware of the 2012 SCC ruling on HIV non-disclosure learned about the ruling, stratified by province of interview (n = 899)

ruling [88], compromising their ability to practice informed sexual decision-making to protect their health and rights and avoid prosecution.

In adjusted analyses, women reporting identities or characteristics shown to contribute to marginalization from healthcare and community services were among those less likely to be aware of the 2012 SCC ruling. Specifically, women with high HIV-related stigma were less likely to be aware of the ruling, consistent with previous work in this field [89]. Women who experience a higher burden of stigma face barriers to engagement with healthcare services and the HIV community, with reduced access to information about the law [89, 90]. Moreover, women experiencing stigma face challenges to safe HIV serostatus disclosure [6, 10, 90]. Given that laws criminalizing HIV non-disclosure further fuel HIV-related stigma [13], education and support around disclosure and the law targeted to women experiencing high levels of HIV-related stigma in the current legal climate is indicated. These measures should be combined with wider initiatives to reduce HIV-related stigma at a societal level.

Our finding that women with a detectable/unknown HIV VL were less likely to be aware of the SCC ruling is a concern, given that these participants risk prosecution if they do not disclose to sexual partners. Relatedly, women unaware of the HIV prevention benefits of ART were more likely to be unaware of the SCC ruling. Participants who understand the importance of maintaining an undetectable

VL to prevent onward HIV transmission, and those who demonstrate an undetectable VL, likely represent women engaged with healthcare services who may benefit from opportunities to discuss HIV disclosure and the law in the healthcare setting. While current messaging about ART-driven HIV prevention is built upon empirical evidence that there is no risk of sexual HIV transmission with a sustained undetectable VL through adherence to ART [5, 54, 91], criminal justice and public health systems follow distinct interpretations of HIV transmission risk [92]. Critically, 17% of participants reported awareness of the HIV prevention benefits of ART without being aware of the 2012 SCC ruling. In the current legal climate, awareness and adherence to #UequalsU principles is insufficient to protect women from prosecution.

Recent participation in HIV community work was positively associated with ruling awareness. While not all women desire to participate in HIV community work or have the privilege to be out in their community, this finding emphasizes the benefit of community engagement to facilitate access to information about disclosure and the law. Women actively engaged with the HIV community are well positioned to learn about disclosure and the law through ASOs and trained peer-driven mechanisms. Finally, reporting a high school level education or less was negatively associated with ruling awareness, likely mediated through lower health literacy [93].

**Table 4** Experience of HIV disclosure and healthcare engagement in the climate of HIV non-disclosure criminalization, stratified by self-reported awareness of the 2012 SCC ruling on HIV non-disclosure (n = 1230)

Variable	All participants (n = 1230, 100%)		Participants aware of the ruling (n = 899, 73%)	Participants not aware of the ruling (n = 331, 27%)	P-value
	Median [IQR] or n (%)	Total			
<i>Disclosure in the climate of HIV non-disclosure criminalization</i>					
Afraid to disclose HIV status to others		1230			< 0.001
Yes	942 (77)		665 (74)	277 (84)	
No/DK/PNTA	288 (23)		234 (26)	54 (16)	
Afraid of losing access to health care services if disclose HIV status		1230			0.007
Yes	258 (21)		171 (19)	87 (26)	
No/DK/PNTA	972 (79)		728 (81)	244 (74)	
Satisfied with HIV disclosure support services		1230			< 0.001
Yes	515 (42)		408 (45)	107 (32)	
No/DK/PNTA	715 (58)		491 (55)	224 (68)	
<i>Healthcare engagement in the climate of HIV non-disclosure criminalization</i>					
Believe information is kept confidential at HIV clinic <sup>a</sup>		1150			0.163
Yes	1043 (91)		780 (91)	263 (89)	
No/DK/PNTA	107 (9)		73 (9)	34 (11)	
Trust in health professional at HIV clinic <sup>a</sup>		1150			0.733
Yes	929 (81)		691 (81)	238 (80)	
No/DK/PNTA	221 (19)		162 (19)	59 (20)	
Importance of provider discussing HIV disclosure		1230			0.050
Very important	971 (79)		716 (80)	255 (77)	
A little important	129 (10)		83 (9)	46 (14)	
Not important/DK/PNTA	130 (11)		100 (11)	30 (9)	
Importance of provider ensuring women's understanding of right to confidentiality, respect and quality care		1230			0.011
Very important	1099 (89)		809 (90)	290 (88)	
A little important	95 (8)		59 (7)	36 (11)	
Not important/DK/PNTA	36 (3)		31 (3)	5 (2)	
HIV disclosure laws might affect type of information shared with providers		1230			0.037
Yes	799 (65)		600 (67)	199 (60)	
No/DK/PNTA	431 (35)		299 (33)	132 (40)	

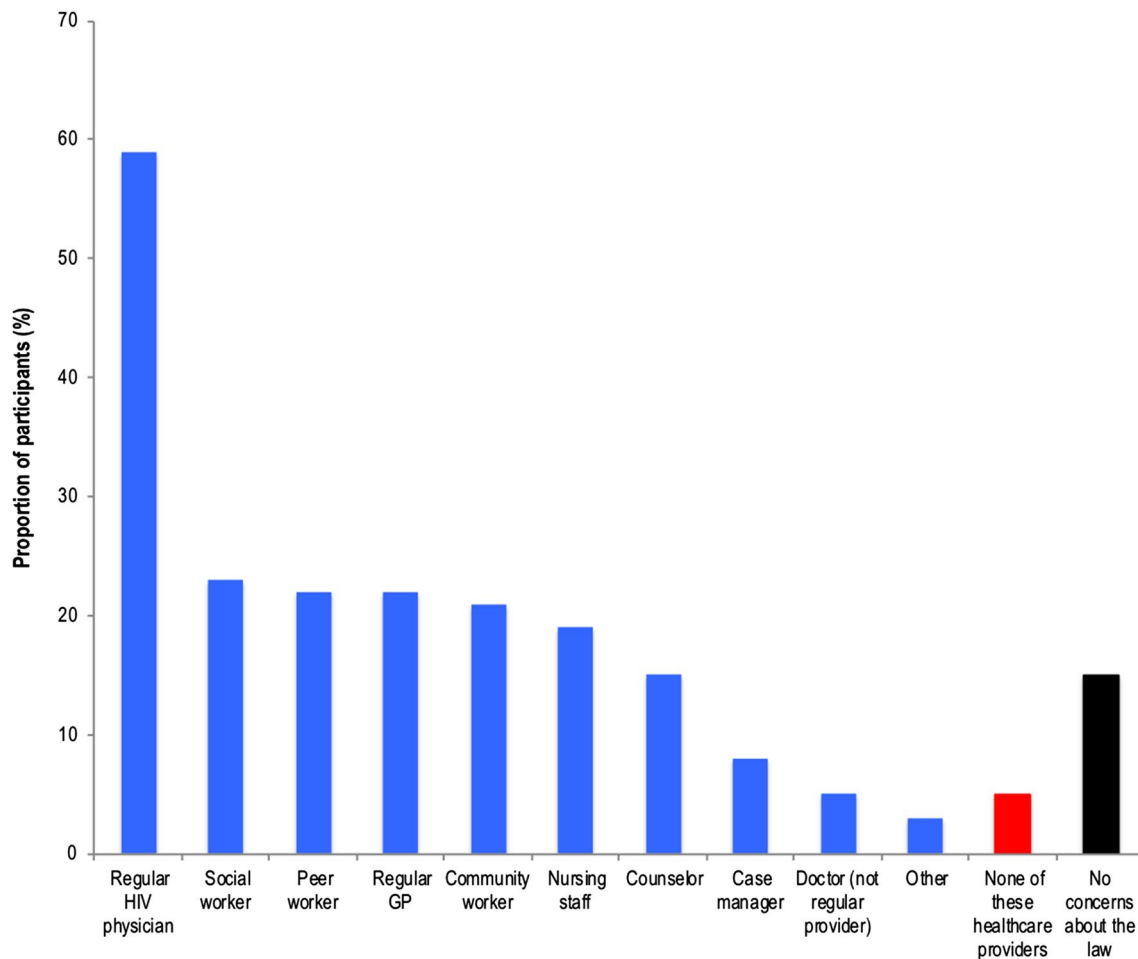
*DK/PNTA* don't know/prefer not to answer

<sup>a</sup>Excluding n = 80 participants who had not received HIV care since last CHIWOS interview

When we conducted a sensitivity analysis evaluating correlates of reporting awareness of the ruling and understanding the legal obligation to disclose, outcomes were largely consistent with our primary analysis, adding further weight to our findings.

ASOs and peer networks emerged as a common existing and preferred mechanisms for communications about HIV disclosure and the law, consistent with findings from recent qualitative work [27]. However, accessing information from these sources requires women to be engaged with the HIV community [94]. Women who are not openly disclosed may

be unable to take advantage of these support services due to concerns of secondary HIV disclosure [95], which may further isolate them from community support. ASOs have attempted to provide clear and concise information about disclosure and the law [76–78, 96]. However, women-specific organizations have identified challenges in communicating information of this nature, including legal complexities, language and literacy issues, HIV-related stigma and the emotionally charged nature of this topic [85]. While previous work has shown the value of peer support that is shaped by lived experiences [97], CHIWOS participants who learned



**Fig. 2** Type of healthcare providers participants would feel comfortable talking to about questions or concerns about HIV disclosure and the law (not mutually exclusive) (n = 1230)

about the ruling from peers were less likely to correctly understand the legal obligation to disclose. This highlights the need for further knowledge translation efforts around HIV disclosure and the law within community and peer networks, tailored to specific community needs.

While the vast majority of participants had recently received HIV medical care and expressed a willingness to receive information about HIV disclosure and the law from healthcare providers, they were not the primary source from which participants learned about the 2012 SCC ruling. This is unfortunate, since women learning about the law through this mechanism were more likely to correctly understand the legal obligation to disclose. The suboptimal prevalence of provider-led discussions about disclosure and the law may reflect competing priorities within the limited time available for consultations, particularly when providing care to women with acutely pressing healthcare needs, owing to multiple comorbidities, poor healthcare engagement or challenging social/structural circumstances. Previous work suggests that Canadian health

and social care providers themselves lack awareness and understanding of the legal obligation to disclose [17, 88, 98], which may affect their inclination to provide legal information to their patients.

Counselling patients on HIV disclosure and the law may present complex challenges for healthcare providers, extending beyond their area of expertise and comfort. Tensions between clinical and legal responsibilities and expectations are likely to influence discussions of this nature in a health-care setting. This highlights an urgent need to clarify the role of healthcare providers in discussions around HIV disclosure and the law. Despite some guidance being available from Canadian legal agencies, and community and professional organisations [99–104], no official best-practice recommendations are available to guide ethical conduct and professional responsibilities for health and social care providers caring for women with HIV in the current legal climate. Establishing strong connections between providers caring for people with HIV and licensed legal professionals with expertise in this field is of paramount importance.

We observed a high level of provider trust and confidence in the confidentiality of healthcare encounters among women navigating healthcare engagement under the threat of HIV non-disclosure prosecutions. This is encouraging, given that previous work has identified provider trust as a key determinant of healthcare engagement [105, 106]. However, almost 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. This finding echoes previous work conducted in Canada and internationally [17, 107–109]. While CHIWOS participants identified HIV healthcare provider-led discussions about the right to confidentiality as a highly important aspect of holistic healthcare, previous work has shown that the risk of subpoena of medical documentation for use in HIV non-disclosure trials may influence discussions around the limits of confidentiality in the healthcare setting to preserve therapeutic relationships [110].

The use of criminal law against people with HIV has been framed as a means to protect women from HIV acquisition within abusive or power-imbalanced partnerships and promote sexual autonomy [111, 112]. However, the identities and experiences of women within this cohort undermine the logic of this strategy, and advance arguments that the use of criminal law against women with HIV compromises health and rights [113]. More than three quarters of this cohort had been afraid to disclose their HIV serostatus, and almost a quarter feared that disclosing their HIV status might compromise their access to health care services. Notably, those who were more fearful of HIV disclosure were significantly less likely to be aware of the SCC ruling. Strict legal frameworks regulating HIV disclosure do little to improve the safety and remove barriers to HIV disclosure for marginalized and vulnerable women [85].

## Limitations

CHIWOS is the largest Canadian cohort of women with HIV, thus facilitates robust evaluation of the awareness and perceived impacts of HIV non-disclosure case law across the diverse and intersecting identities of Canadian women with HIV. However, women who are connected with community and health services are likely overrepresented within our sample. By using wave 2 survey data, we additionally selected women who remained sufficiently engaged with the CHIWOS community to re-present for interview.

Many variables captured in this analysis are self-reported, including our primary outcome variable, meaning these data may be influenced by social desirability bias. This bias would overestimate reports of SCC awareness, meaning the need to better inform women could be more important than

reported. However, PRAs received extensive training in methods of survey delivery to reduce biases.

Understanding of the legal obligation to disclose was assessed in an indirect manner, which may introduce error in the form of social desirability bias and overestimate understanding of the legal obligation to disclose within this cohort. We considered women to have an understanding of the legal obligation to disclose if they believed that their understanding of the law was “the same” as the definition provided. Whilst reporting an understanding that was “mostly the same” as the definition provided could arguably be described as having an understanding of the legal obligation to disclose, we applied a narrower definition on the basis that it is critical for women to understand the ruling in the most detail possible to avoid legal risk.

As previously discussed, perceived impacts rather than direct personal impacts of the HIV non-disclosure case law on healthcare engagement were assessed in this analysis, which may limit the weight of these findings to inform policy change.

Although these findings may not be generalizable beyond Canada due to the specificity of the case law, they add to the growing body of international literature showing that the overly broad use of the criminal law against people with HIV in many global settings is detrimental to the health and rights of women with HIV [112, 114].

## Conclusions

In a community-based, multi-site cohort of Canadian women with HIV, we observed suboptimal awareness and understanding of the current legal obligation to disclose HIV serostatus to sexual partners. Our findings suggest that women with HIV who are inadequately engaged with healthcare services and community support lack fundamental information to avoid prosecution and optimise their health and rights in the current legal climate.

Healthcare providers represented a preferred and accurate source of information about HIV disclosure and the law within this cohort, but discussions of this nature were not commonplace. Clarifying the professional role and ethical conduct of health and social care providers caring for women with HIV in the current legal climate through best-practice guidelines is indicated to maintain patient-provider trust, and to reduce harms incurred by navigating healthcare engagement under the threat of HIV non-disclosure prosecutions.

This research was conducted in response to a call for action from CHIWOS peer researchers and participants, and this topic remains a considerable concern for many women with HIV, both in Canada and internationally. Meaningful involvement of women with HIV is a crucial part of the research, to ensure women’s experiences are accurately and

sensitively represented. The advancement of community organisation and peer network involvement in dialogues around HIV disclosure and the law is key to empower community leadership in this field.

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## Appendix A

Brief definition of 2012 SCC ruling discussed with all participants answering CHIWOS survey questions on the criminalization of HIV non-disclosure.

*“In Canada, people living with HIV can face criminal charges for not telling their sexual partners what their HIV status is, even if they do not intend to transmit HIV, and even if no HIV transmission actually occurs. In 2012, the Supreme Court of Canada ruled that people living with HIV must disclose their HIV status to a sexual partner before having sex unless they use condoms AND have a viral load of 1500 copies/mL or less. People who do not meet these criteria can face a criminal charge of aggravated sexual assault if they do not tell their sexual partners they have HIV. To summarize, people living with HIV are legally required to disclose their HIV status to sex partners UNLESS they use a condom AND have a viral load less than 1500 copies/mL.”*

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