



# LIT REVIEW: TESTING TO CARE

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## Introduction

The Canadian Treatment Action Council was funded by the Public Health Agency of Canada in 2017 to explore issues affecting the engagement of people living with HIV in healthcare. Our study seeks to identify policy issues that impact upon treatment access for people living with HIV, and to explore opportunities to make the healthcare system more accessible for people living with HIV.

The first part of this project consisted of two comprehensive literature reviews of the research relating to the HIV Treatment Cascade in Canada with particular focus on two portions of the HIV Care Cascade: 1) HIV testing/linkage to care and 2) retention in care leading to viral suppression of HIV. These reviews identified issues facing people living with HIV generally and specific issues for various communities disproportionately impacted by HIV. Where our literature reviews have uncovered possible policy barriers for people living with HIV, CTAC has completed supplementary research on relevant federal and provincial policies that may be implicated.

The second part of this project consisted of a series of qualitative interviews with service providers and people living with HIV in the Province of Ontario. Interviews with 20 service providers focused on the scope of their work with people living with HIV, their role supporting people living with HIV to access healthcare and stay on treatment, and barriers they see impacting access to health care. People living with HIV were engaged in focus groups of 10 participants on average; with questions exploring their experiences with health care in their city/region, how living with HIV has changed their experience with health care, challenges with engaging in health care across the cascade, and specific challenges that have negatively impacted their accessing health services.

In order to have a sample that is representative of the epidemic in Ontario, CTAC recruited people living with HIV from each of Ontario's priority populations (gay, bi and other MSM; African, Caribbean and Black people; Indigenous People; People who use injection drugs). We also worked with community partners to gather a geographically diverse sample including hosting 11 focus groups in total (5 in Toronto, 4 in suburban and rural communities in the GTA, 1 in northern Ontario, and 1 in Ottawa).

Partnerships with the community in terms of recruitment and review of project outputs were key to making this project a success, as well as relevant. From this project, we have gained valuable insight into the challenges in the treatment cascade for frontline service providers and policy makers, as well as revealing opportunities for community-based agencies to organize and promote policy change that will broaden access to treatment. The next steps for this project will include dissemination of the valuable insights and knowledge gathered throughout the course of this project in order to help service providers more effectively advocate for the needs of their clients and the identification of further areas of work for policy with communities most affected by HIV and HIV/Hep C co-infection. Although this project was focused on access to services within Ontario, the literature reviews drew on literature and evidence from around the world. Also, many of the treatment access issues that were brought to light during this project can be found across Canada.

## Statistics:

“The total number of people with diagnosed HIV living in Ontario has increased steadily over time and almost doubled from 2000 to 2015. A combination of factors has likely contributed to this increase, including ongoing new HIV diagnoses each year and improved life expectancy of people living with HIV due to successful treatment regimens.”<sup>i</sup>

“Of new HIV diagnoses in Ontario, about: 60% are gay men and men who have sex with men; 25% are people from African, Caribbean and Black communities; 13% are people who inject drugs; 1 in 5 people newly diagnosed are female; 1 in 3 are age 45 or older; of these, 82% are men and most report sex with men as a risk factor.”<sup>ii</sup>

## Infection Rates:

“...rates of HIV infection are increasing in nonurban centers, particularly in areas previously considered to have low prevalence rates such as the Southern United States and the Canadian Prairies.”<sup>iii</sup>

“HIV is not a generalized epidemic in Ontario. It is concentrated in a small number of marginalized populations that have high rates of HIV including: ...gay, bisexual and other men who have sex with men, including trans men; African, Caribbean and Black communities – including men and women from parts of Africa and the Caribbean where HIV is endemic; Indigenous peoples; people (men and women) who inject drugs (PWID); at-risk women (women who are sexual partners or drug-using partners of people with HIV), including trans women.”<sup>iv</sup>

## Key populations:

### Women:

“With respect to women living with HIV, a comprehensive body of literature has described various barriers impeding access to regular HIV-related care, including lack of transportation, depression, and history of physical or sexual abuse...women living with HIV are more likely to delay initiating cART and less likely to begin treatment. Several reasons have been postulated to account for these sex-based discrepancies in treatment uptake, including concern about disclosure of HIV status to children, socio-economic circumstances and family commitments, which often include assuming the role of primary caregiver to other family members living with HIV. Furthermore, several toxic effects of antiretroviral drugs are noted to occur at greater frequency among women relative to men, including severe hypersensitivity reactions and lipodystrophy. As a result, women may be more likely than men to discontinue cART. Although individuals living in low-income neighbourhoods undoubtedly share some of the obstacles to care faced by women, other structurally mediated inequities are important determinants of health among these patients. Specifically, instability with respect to housing status and food security have both been documented to undermine adherence with antiretroviral therapy and to contribute to poor outcomes among people with HIV. Furthermore, despite the availability of various programs intended to mitigate the expense of cART for Ontario residents with HIV who lack alternative sources of drug coverage, individuals who do not qualify for provincially funded social assistance must assume a share of the cost of their treatment, in the form of a copayment, which may be prohibitive when evaluated against competing demands for food and housing.”<sup>v</sup>

“...women’s focus on coping with immediate risks may place concerns surrounding HIV as a secondary priority, while simultaneously increasing their vulnerability to infection.”<sup>vi</sup>

“Women living with HIV described interdependent and mutually constitutive relationships between social identities and structural inequities such as HIV-related stigma, racism, sexism and gender discrimination, homophobia and transphobia. Our findings suggest that multiple forms of stigma such as symbolic, internalized, and enacted, are associated with marginalized identities: HIV-positive serostatus, female gender, sex worker, sexual minority, transgender, and ethnic minorities. These forms of stigma operate across micro, meso, and macro levels – as do the coping strategies implemented by HIV-positive women.”<sup>vii</sup>

### First Nations population:

“...the Aboriginal population in Canada is almost four times more likely to be infected with HIV as compared to others.”<sup>viii</sup>

“In Canada, Indigenous peoples (First Nations, Inuit, and Metis peoples), who typically live in predominantly nonurban locations, are overrepresented in the HIV incidence and AIDS prevalence. Although they represent approximately 4.3% of the Canadian population, Indigenous peoples represented 16% of new HIV cases in 2014.”<sup>ix</sup>

“In Saskatchewan and Manitoba, Indigenous people accounted for 12% and 15% of the population, respectively, but accounted for 79% and 37% of new HIV infections in those provinces in 2009. Not only is this group disproportionately affected by HIV, but most Indigenous peoples in both Manitoba (54%) and Saskatchewan (53%) live on First Nations reserves...In Saskatchewan, many PLWH reside in reserve communities. Within Saskatchewan’s on-reserve population, the overall HIV incidence is 67.6 cases per 100,000 population and is as high as 95 cases per 100,000 population in the Indigenous reserves in the South-Central part of the province. Even more alarming is the prevalence of HIV among individuals’ Indigenous communities, reaching as high as 3.5%. A major barrier to care in these communities is the lack of provincial and federal health care coordination.”<sup>x</sup>

“The prevalence of HIV is 0.43% in Indigenous people in Ontario or 1.7 times that of the non-Indigenous population. We also know that about one of every three Indigenous people with HIV is co-infected with hepatitis C. Among Indigenous people in Ontario diagnosed with HIV from 2009 to 2011, the most commonly reported risk factors were sexual exposure (64%) and injection drug use (45%). (OHTN #’s).”<sup>xi</sup>

“Several of the studies described Aboriginal women’s experiences of a disconnect between their traditional or cultural understanding of illness and health and the Western biomedical approach to HIV espoused by most mainstream Canadian health care services...a lack of focus on holistic health (body, mind, spirit and emotion)...lack of Aboriginal health practitioners and a lack of focus on Aboriginal-specific issues...the expressed Aboriginal belief that a diseases must exhibit physical symptoms of illness before treatment is sought may contribute to Aboriginal women being diagnosed later and having poorer HIV treatment outcomes. HIV prevention stratifies, especially the promotion of HIV testing, must consider this and its interaction with the dominant biomedical approach in an effort to address HIV prevention for Aboriginal women through education for individuals, communities, and health practitioners.”<sup>xii</sup>

### Transgender:

“The term transgender (trans) is an umbrella term used that encompasses those whose gender identities do not match their birth-assigned sex. Trans persons may hold a broad spectrum of gender identities...in Canada, each of the 13 provinces and territories is individually responsible for providing essential medical services via a universal, publicly funded, health insurance program. However, despite this, previous research in Canada on the health of trans individuals has revealed this population to be medically underserved in both primary and specialist care settings: barriers included lack of providers knowledgeable about trans issues, denial of health care altogether and/or refusal to approve hormone therapy and/or gender-affirming surgeries. Consequently, health care avoidance remains high amongst trans persons: an estimated 21% of trans Ontarians have avoided going to the emergency department when emergency care was needed, explicitly because of concerns related to accessing emergency department services as a trans individual. Of those who had accessed the emergency department while expressing a gender different from their birth-assigned sex, 52% had experienced negative treatment due to being trans, ranging from insulting or demeaning language to outright refusal of care...moreover, while 83.1% of trans Ontarians had a regular family doctor, approximately half indicated they were not comfortable discussing trans issues with their regular health care provider.”<sup>xiii</sup>

“Consistent with existing literature on health and health services in trans communities, a large proportion of trans individuals reported having needed healthcare in the past year that they did not receive. This proportion was significantly higher than would be expected for cisgender Ontarians, with one-third of trans Ontarians reporting a past-year unmet health need in excess of expectations. Trans individuals were more likely to rate the quality of health care in their community as poor, despite having a positive assessment of health care availability in Ontario. Hence, it appears that equal recognition of the availability of health care in their province (though not always in their community) does not translate into equal access...research certainly supports the existence of barriers to healthcare for trans persons, including an absence of formal education of health care providers on trans issues (an issue identified by both physicians and trans community members), and high frequencies of harassment and discriminatory practices experienced by trans individuals in health care settings...while trans men perceive better health care availability than trans women, they also suffer from greater levels of unmet health care need compared to cisgender Ontarians, possibly stemming from feelings of poorer healthcare quality. Previous studies have shown transphobia and discrimination are more pronounced in the workplace for trans men – it’s possible that this trend also extends to health care...there were no statistically significant differences between trans men and women in health and perceptions of health care.”<sup>xiv</sup>

“...limited visibility of trans health issues and institutional (e.g. Medical record) systems...physicians have identified numerous barriers to competent care of trans patients, nothing that because of limited clinical experience and a lack of trans-specific medical education, trans patients must often provide trans health care education to their physicians...in the Ontario context, access to EDs {emerg. depts.} by trans people is likely shaped by the availability of publicly funded primary and emergency care, and perhaps by greater social and legal recognition of trans persons relative to other jurisdictions, both in Canada and internationally. Such recognition includes an array of trans-specific social and medical services, particularly in Ontario’s urban regions, and municipal and provincial human rights protections. ED avoidance or negative experiences may be more common among trans persons in regions where they have less social and legal recognition than in Ontario.”<sup>xv</sup>

“...trans people constitute a hidden population, and it is not known to what extent trans demographics actually mirror population demographics...violence against trans people and suicide, in particular, have been recently raised as serious health and equity concerns...existing trans-specific or trans-friendly services, while limited, are concentrated in Toronto. That two-thirds of trans people did not live in metropolitan Toronto illustrates the need for development of trans-friendly services in smaller Ontario cities and towns.”<sup>xvi</sup>

### People who inject drugs (PWID):

“...substance users, particularly those who inject drugs and often have visible signs of use (track marks, scarring, and the like), commonly face marked discrimination in both communities and health care settings. They are often deemed unworthy of care. Among all key populations living with HIV infection, PWID generally experience the lowest levels of ART coverage. Sub-groups of these populations may face compounded stigma...pejorative public discourse, including derogatory levels for MSM, female sex workers (FSW), PWID, and transgender populations, limit the effectiveness of health communication programs intended to support these populations.”<sup>xvii</sup>

“Other important epidemiologic characteristics of the HIV epidemics in the Canadian Prairies (Alberta, Saskatchewan, and Manitoba) are the higher proportion of infections in women and the strong association with drug use. In Saskatchewan, 40% of the prevalent HIV cases are in women compared with 23% nationally. The main mode of transmission in Manitoba is heterosexual transmission compared with IDU in Saskatchewan.”<sup>xviii</sup>

## Cascade of Care:

“The HIV care cascade, also called the care continuum, has been increasingly used to document engagement in care among people living with HIV (PLWH). The care cascade documents losses from each “step” between HIV status awareness, linkage to care, engagement and retention in care, initiation of antiretroviral therapy (ART), and viral suppression. While the care cascade has become of increasing importance in understanding the HIV response, this tool has been less rigorously applied to document the health disparities of key populations.”<sup>xix</sup>

“Successful treatment can sustain viral suppression and lead to immunological improvement among those that are HIV-infected, but requires that individuals engage and remain in the HIV care cascade. This cascade involves a series of actions, starting with HIV screening/testing, and followed by linkage to HIV care after HIV diagnosis, retention in pre-ART care prior to ART initiation, initiation of ART once eligible for treatment, retention on treatment once ART is started, and then maintenance of good ART adherence in order to achieve viral suppression and immunological improvement. However, evidence indicates that many individuals are lost at each stage of the cascade, and many individuals are diagnosed late, only initiating ART at the onset of symptoms.”<sup>xx</sup>

“The HIV continuum of care has become a standard framework for understanding the HIV epidemic and developing interventions. It underlies the UNAIDS 90-90-90 targets, which call for 90% of persons with HIV to be aware of their HIV infection, 90% of all diagnosed will be on ART, and 90% of people on ART will have an undetectable HIV viral load. The continuum of care facilitates consideration of the challenges and potential solutions surrounding HIV in nonurban areas. Barriers that contribute to this continued epidemic are many, and include lack of access to primary care, lack of prevention and harm reduction services, limited affordable transportation, and lack of culturally congruent services.”<sup>xxi</sup>

“Effective and safe delivery of medical care for HIV requires a sequence of diagnostic tests, assessments, treatment delivery, support and monitoring. This care continuum has been termed the ‘HIV treatment cascade’. The cascade can be used to illustrate and measure the effectiveness of a country’s ART programme. Cascades report various stages, including total; HIV positive people diagnosed, linked to care, retained in care, treatment eligibility, on ART, adherence to treatment, retention post ART initiation and viral suppression...several key factors affect coverage of the various steps of HIV cascades; individual, societal and structural. Initially, community education and uptake of testing is required at a population level, widespread among generalized epidemics and targeted testing within focused epidemics. Second, linkage to care, retention in care and support following diagnosis is required for all HIV positive individuals prior to starting treatment. Sustainable procurement and provision of ART is imperative. Finally, individual understanding and motivation is required to maintain treatment adherence and post-ART retention combined with HIV viral load testing for monitoring. Until recently, there has been an absence of standardized reporting methodologies, stage definitions and agreed structures to unify cascade data making comparison of HIV treatment cascades difficult.”<sup>xxii</sup>

## Risk Determinants:

“Community-level risk determinants reflect inequities in social, economic, organizational, and political power and contextualize proximal risk factors for HIV infection, such as unprotected intercourse with serodiscordant viremic partners, sharing of injection equipment, and lack of treatment uptake during antenatal services for women living with HIV. Community-level determinants generally act by limiting

or facilitating access to HIV prevention, treatment, and care services or commodities, including education, condoms, condom-compatible lubricants, antiretroviral therapy (ART), safe working spaces, safe injection devices, and protection and acceptability by the general community of such harm-reduction interventions for specific populations. Moreover, stigma and discrimination in health care settings can present significant barriers to HIV prevention, treatment, care, and support...community determinants are especially important among key populations, including men who have sex with men (MSM), people who inject drugs (PWID), sex workers of all genders, and transgender women. Community-level determinants have had more impact, arguably, on these populations than on others affected by HIV because they generally face multiple stigmas and social opprobrium: They share social harms based on HIV burdens, but they also face the additional stigmas related to their identities (e.g. Sexuality or gender nonconformity), practices (such as substance use), or occupations (such as sex work). Because many of these identities, occupations, and practices are criminalized and stigmatized, these persons often face legal, police, and policy barriers to services that add to the community-level harms they face. This stigma and its manifestations can markedly increase risks for HIV acquisition and lack of access to services. Conversely, there is a growing literature base of both empirical studies and mathematical modeling approaches supporting the value of community empowerment as a means of decreasing risks among key populations.”<sup>xxiii</sup>

## Testing:

“HIV testing is the first stage of engagement within the cascade of HIV care, when people with HIV are diagnosed and subsequently linked with health services. In Canada, an estimated 25% of PLWH are unaware of their HIV serostatus. Increasing HIV testing among individuals who suspect that they may be HIV-positive but do not wish to know their status and those truly unaware of their status is a rate limiting step in the cascade of HIV care, compromising the ability to identify and link to care those most at risk of onward HIV transmission.”<sup>xxiv</sup>

“However, HIV testing circumstances may influence decisions to disclose and engage with health services. Women accessing HIV testing in traditional risk-based, client-initiated voluntary counselling and testing settings make a considered, risk-based decision to present for HIV testing, often after discussion with their partner. However, women who are offered routine HIV testing in a prenatal clinic appointment may not have previously considered accessing testing, and may face additional barriers to accepting their positive diagnosis, engaging with treatment services or disclosing to partners.”<sup>xxv</sup>

“International focus on reducing onward HIV transmission emphasizes the need for routine HIV testing and early uptake of antiretroviral treatment (ART)... strategic targets have been set for 2020 to achieve 90% of infected people diagnosed, 90% of diagnosed people on treatment, and 90% of those on treatment virally suppressed (90-90-90) (UNAIDS, 2014), and research is underway to evaluate future universal testing and treatment (PopART trial) (HAYES, 2014).”<sup>xxvi</sup>

“It was estimated that in 2008, 2300 to 4300 new infections occurred in Canada, yet 26% of Canadians living with HIV are unaware of their status...there is increasing evidence that the longer antiretroviral therapy is delayed the poorer the patient outcomes will be, with a decreased likelihood of immune recovery and life expectancy...in addition to these individual consequences of late presentation and delayed access to care, there are public health and health system implications as a result of the increased cost associated with late presentation...it is of tremendous significance that all the individuals who tested positive in our study were linked to timely care. Many argue that HIV screening alone is insufficient and that linkage to care should be considered as a more relevant marker...growing recognition of the need to increase testing and facilitate earlier diagnosis and linkage to care, given the challenges associated with late presentation...the longer patients were unaware...the more opportunities there are for transmission...late presentation is known to increase the risk of HIV-related complications and reduce life expectancy. Life expectancy is strongly correlated with CD4 count at the start of therapy.”<sup>xxvii</sup>

“Although primary care physicians order most HIV tests in Ontario, the positivity rate is much higher among tests done through anonymous and rapid point-of-care test sites. This trend may be related to HIV stigma: many people at risk, including gay men and members of racialized communities, may not feel comfortable talking with their doctor about their sexual risk or drug use practices. According to a BC study, only 20% of gay men are “out” to their doctor- mainly because they fear their doctor would “disapprove”. However, not being able to be open with their physicians means they may not be offered testing or other care that could enhance their health... many people at risk of HIV are also at risk of other STIs and HCV. Ontario’s HIV testing guidelines recommend that anyone who comes for an HIV test should be offered HCV and STI testing, and vice versa. However, in practice, the combined testing does not occur consistently. Ontario’s HIV testing guidelines also recommend that people at high risk of HIV be tested at least once a year – more often if they have had a high-risk exposure. However, if people at risk do not feel comfortable talking about their sexual health or practices with their care providers, it is unlikely they will be offered regular testing unless they ask for it... a recent pilot of anonymous testing found that prisoners were willing to be tested when testing was done by public health nurses... barriers to testing still exist. In many cases, health care providers do not perceive women as being at risk – even women from populations with higher HIV prevalence, such as African, Caribbean and Black communities – and do not offer them HIV testing.”<sup>xxviii</sup>

“Timely HIV testing is only the first step. Early access to treatment is also critically important. Once someone is diagnosed with HIV, it is essential that they receive support to cope with the diagnosis and become engaged in care. People need to know the importance of early treatment, so they can make informed decisions about their health. Right now, there are few processes in place to actively engage someone who tests positive in care. If the person’s physician ordered the test, then the physician will likely follow up with the patient. However, in the province’s anonymous testing sites or sexual health clinics, there are few consistent mechanisms to ensure that people who test positive receive the support they may need to access care. If people are asymptomatic (as is often the case after someone experiences the initial symptoms of infection, known as seroconversion illness), many months may go by before they see a care provider.”<sup>xxix</sup>

## Diagnosis to treatment initiation:

### Diagnosis:

“Epidemiologists at the Public Health Agency of Canada estimate, based on modelling, that about 19% (range 14% to 21%) of Ontarians who have HIV do not know they are infected. People who are not diagnosed and treated – particularly those who are newly infected – are likely to have high viral loads and be at high risk of transmitting the virus. Knowing their HIV status is critical for their own health. It can also help prevent new HIV infections because when people with HIV are diagnosed, they are more likely to take steps to reduce the risk of HIV transmission.”<sup>xxx</sup>

### Linkage to Care:

“Co-location and integration of services, such as STI screening, TB screening or opioid substitution (OST) as part of HIV care, have been shown to improve HIV care cascade outcomes.”<sup>xxxi</sup>

“Unsuccessful linkage was mostly attributable to a geographic barrier (i.e., living outside of Montreal) ...Some characteristics of successfully linked and retained positive testers may act paradoxically as both HIV-infection risk factors and facilitators of retention in care after diagnosis. Greater proportions of them tested often, had unprotected sex with a known HIV-positive partner, and knew about PrEP. Engagement in care prior to HIV diagnosis through routine screening...along with good relationships with care providers (possibly suggested by regular testing) and low stigma related to HIV (potentially indicated by unprotected sex with HIV-positive partners) ...are general characteristics of PLHIV successfully linked and retained, and also characteristics of PrEP candidates.”<sup>xxxii</sup>

### Barriers:

“Low perception of the need for treatment (i.e., not experiencing HIV-related illness) was reported as a barrier to both starting and staying on treatment...Considering the lifelong strict regimen required for effective viral suppression, some PLHIV may delay the initiation of ART until they feel ready or capable to commit to the lifelong adherence...This includes a social and psychological readiness to commit to the behaviour change required for effective adherence...mental health issues...and poor coping skills...have been reported as barrier to starting and continuing treatment. For instance, Canadian Aboriginal youth have reported delaying initiating treatment (sometimes by a few years following diagnosis) because of fear and suicidal thoughts...having inadequate information about treatments and care also acts as a barrier to treatment initiation.”<sup>xxxiii</sup>

“...common barriers to HIV-related services and other formal health care services described in these studies included: a lack of culturally-appropriate available services; fear of HIV testing and a lack of knowledge regarding testing and treatment options; non-existent or inconsistent HIV-related services in rural or remote locations; past negative experiences interacting with health practitioners; a lack of confidentiality when accessing health services in small communities or if the service was Aboriginal-specific or HIV-specific there was a fear associated with people in their community knowing that they were accessing HIV-related services; and lastly, many women found that services were not always open to family members, which was especially problematic for women with children...need consideration of on-reserve and off-reserve issues and the unique barriers experienced by people living in rural or remote communities.”<sup>xxxiv</sup>

### Barriers-Homelessness/Housing:

“An array of health problems has been associated with being homeless, including mental illness, physical violence, and substance abuse...many homeless persons are confronted with environmental conditions that may further exacerbate drug and sexual practices, placing them at higher risk for HIV infection...evidence suggests that homeless persons experience numerous barriers to accessing health care and harm reduction services.”<sup>xxxv</sup>

“Homeless people are at a disproportionate risk for negative health consequences. For instance, they typically have more chronic diseases and more physical and mental health problems than do the general population, and they are at greater risk for infectious diseases. Homelessness is often coincident with poverty, mental illness, and alcohol and drug use, compounding the other health problems experienced by these individuals. Homeless people are also more likely than other groups to engage in behaviours that place them at risk for HIV infection, including risky sexual practices, injection drug use and needle sharing, and performing sexual acts in exchange for money, drugs, or a place to stay. It may be difficult for homeless people, who are often faced with immediate subsistence needs (e.g., finding adequate food and shelter), to obtain medical care and adhere to treatment regimens. As a result, homeless individuals are less likely than are the general population to have stable sources of care, and they often rely on emergency departments or ambulatory care settings for their healthcare needs. Delayed medical care or lack of care has negative effects such as delayed HIV diagnoses and higher rate of serious opportunistic infections.”<sup>xxxvi</sup>

### Barriers-Stigma:

“...fear of stigma keeps people from accessing services, such as testing, that could enhance their health. It also keeps them from disclosing their HIV status, receiving social support and being able to negotiate safer sex. Community, societal and policy level interventions – such as providing welcoming services – can reduce HIV stigma as well as the discrimination associated with race, gender, and sexual identity.”<sup>xxxvii</sup>

“...the influence of HIV and substance use-related stigma and social exclusion on HAART access and adherence is not well understood. Substance use remains deeply moralized in many societies and those violating existing norms face stigmatization, and social exclusion. The individually focused conceptualization of substance use and HIV infection, as the result of moral deviance and repeated bad choices, amplifies the social exclusion and disadvantage of IDU...drug addiction received among the highest ratings of social disapproval cross-culturally and was in most settings more negatively viewed than having a criminal record for burglary or not caring properly for one’s children. The effects of stigma and social exclusion are often exacerbated for female IDU or for IDU belonging to ethnic minority groups. This likely contributes to the greater drug-related harms women and members of ethnic minority groups face such as elevated risk for HIV and hepatitis C. One way in which the social exclusion of IDU is directly relevant to the care they receive, is reflected in public opinion concerning the setting of health care priorities...despite the recommendations of the World Health Organization, many clinicians, remain reluctant to prescribe HAART to IDU, ignoring evidence which highlights the effectiveness of HAART among this population.”<sup>xxxviii</sup>

## Importance of the Patient/Provider Relationship for Treatment Initiation:

“Lack of a doctor’s recommendation to initiate treatment at the time of HIV diagnosis has been associated with delays in accessing care...Patients may be less likely to start and/or continue treatment if they feel coerced...or feel that the provider has a narrow medical focus...”<sup>xxxix</sup>

“...trans men faced more barriers accessing testing for STIs other than HIV because these tests generally necessitate disclosure of trans status and discussion of genital status (particularly for those who might otherwise be perceived as cisgender men). Moreover, in requesting STI tests, trans men uncovered “cisnormative”...assumptions among testing providers...at the institutional level, services that were gender-segregated- even if nominally trans-inclusive- posed unique barriers, particularly for STI testing. Some trans men were uncomfortable with the binary division of services and therefore avoided such services. Yet even when trans men felt that a men’s-only environment was suitable and decided to attend, they sometimes encountered clinics that were unready to provide culturally and clinically competent care.”<sup>xl</sup>

## Extrapersonal barriers to starting treatment:

“Lack of universal access to ART and related costs of treatment, unstable housing, and distance and cost of travelling to health services are among modifiable extrapersonal barrier to treatment initiation and adherence...Stress associated with unstable housing may exacerbate health issues and interfere with disease management and self-care...The underlying inequalities driven by social determinants of health exacerbate the lived experiences of extrapersonal barriers to ART for certain PLHIV groups.”<sup>xli</sup>

## Shortage of Physicians/Specialists:

“At the current time, Ontario has a shortage of primary care physicians with the knowledge and skills to care for people with HIV. There is also a shortage of other specialists – including cardiologists, oncologists and gerontologists – with expertise in managing the

complexities of treating people with heart disease or cancer who also have HIV. At the time of writing this strategy, there was not a single gerontologist in Ontario who specialized in HIV.”<sup>xlii</sup>

## Geographical barriers to testing and entering care:

“Since 1995, HIV incidence rates have dropped notably, in all regions, except Manitoba and Saskatchewan, areas with significant nonurban populations. The highest incidence rate in Canada since 2006 is in Saskatchewan (14.4 per 100,000 population in 2009) followed by Manitoba (8.1 per 100,00 in 2015). Saskatchewan is a province with few urban centers, and a predominantly nonurban distribution of population. The HIV cases in Saskatchewan have mirrored this nonurban distribution and represent an incident rate which is 2.5 times that of the national average.”<sup>xliii</sup>

“While for the sake of privacy (particularly in small, rural communities) PLHIV may prefer accessing non-local HIV health services, and individuals living with complex comorbidities may need to travel further to access specialist care...financial constraints will prevent some from accessing care....Financial stress associated with HIV care has been an underreported phenomenon in high-income countries...and most pronounced for females...individuals with low income and no health card...those who are ineligible for subsidies...pensioners...and those living in rural and remote areas...”<sup>xliiv</sup>

“Travel to urban centres for treatment places a considerable burden on PHAs and the friends and family members who support them. Little public transportation is available in the areas studied and PHAs who are in ill-health or lack financial resources may not be able to drive or afford to operate a car.”<sup>xliv</sup>

“Similarly, in comparing 3 nonurban Canadian communities with matched urban regions, respondents living in nonurban regions were less knowledgeable about HIV/AIDS and were less likely to have spoken with others about the disease. In addition, in these conservative nonurban communities roll out of the necessary harm reduction programs including needle distribution are systematically missing. Members of the nonurban HIV care community (e.g., providers, patients, and advocates) perceive a lack of visible governmental acknowledgement or action to address the root causes of the non-urban HIV epidemic including poverty, racism, and other forms of stigma, historical and multigenerational trauma, poor pain management, and addictions. Furthermore, until recently, data on HIV did not encompass nonurban settings. Barriers against the Continuum of Care in Nonurban settings: shortage of health care providers and limited HIV expertise; Scarcity of funding for widespread testing and treatment programs in nonurban areas of the United States and Canada; lack of systematic harm reduction programs and programs to address the root causes of HIV acquisition (e.g., opioid addiction, trauma, poverty); increased geographic distance to providers and lack of transportation options; insufficient HIV awareness and knowledge at the community level; high rates of poverty, low educational attainment, substandard housing and food insecurity; stigma, isolation, and heightened fear of discrimination; socially conservative climate, racism, anti-immigrant sentiment; limited community leadership and political support.”<sup>xlvi</sup>

“In the short term, migrants may be at risk for delays in HIV diagnosis and entry into HIV care because of lack of medical insurance, language barriers, and fear of deportation if undocumented...as multiple studies link delays in initiation of HIV care and treatment to increased mortality, mobile populations’ delay in HIV diagnosis and care-seeking could impact their overall survival.”<sup>xlvii</sup>

### HIV and incarceration:

“The rates of HIV infection among prisoners in many countries are significantly higher than those in the general population. Coincident with the HIV/AIDS epidemic, many countries have been experiencing a significant increase in the incarcerated population, often as a result of an intensification of the enforcement of drug laws in an effort to limit the supply and use of illegal drugs. Each of the two “epidemics” – HIV and incarceration – has affected the other...HIV surveillance has been the most common form of HIV research in prison, although this has largely been restricted to high-income countries...even within high-income countries, the precise number of prisoners living with HIV is difficult to estimate. Rates of HIV infection reported from studies undertaken in a single prison or region may not accurately reflect HIV prevalence in prisons across the country...everywhere, the prison population consists of individuals with greater risk factors for contracting HIV (and HCV and TB) compared with the general population outside of prisons...more recent reports show that HIV prevalence rates remain high in prisons in North America and western Europe, although they have decreased in countries like Spain that have introduced comprehensive HIV interventions in prisons, including needle and syringe programmes and methadone maintenance treatment...the HIV epidemic in prisons is not occurring alone: prevalence rates of viral hepatitis in prisons are even higher than HIV rates.”<sup>xlviii</sup>

“There are also structural barriers to testing. For example, testing is not always easily available to people in prisons or, if it is, prisoners are reluctant to be tested by prison staff. A recent pilot of anonymous testing found that prisoners were willing to be tested when the testing was done by public health nurses instead of by health staff within the correctional institution.”<sup>xlix</sup>

## Incarceration and PWID:

“For people who inject drugs, imprisonment is a common event, with studies from a large number of countries reporting that between 56% and 90% of people who inject drugs had been imprisoned at some stage. Multiple prison sentences are more common for prisoners who inject drugs than for other prisoners.”<sup>1</sup>

## Barriers to access for Trans:

“One emergent concept characterized the trans community as a “hidden population”—a group underestimated in size and therefore underrepresented in social spaces. Several participants correlated the lack of knowledge in trans healthcare with the relative obscurity of trans identities within the general population...the assumption that most physicians will never encounter a trans patient contributes to informational erasure, whereby the need for healthcare training, research, and policies inclusive of trans people is systematically unrecognized...other participants described the “hidden population” phenomenon differently, suggesting that clinical encounters with trans patients are more common than generally acknowledged, but for various reasons, trans patients may be unwilling to disclose their transition history to physicians.”<sup>ii</sup>

“Physicians commonly identified barriers to care provision in the context of not knowing the available resources or care strategies appropriate for the trans patient population...a major barrier to healthcare provision was the identification, availability, and quality of referral networks and information sources regarding trans medical care.”<sup>iii</sup>

“The complexity of a physician’s referral strategy appeared to be related to their level of experience in managing the care of trans patients. Those with more familiarity in trans healthcare referred patients to specific colleagues with whom they had developed a working relationship. Overwhelmingly, participants cited deficiencies in informative sources regarding trans care management as a substantial barrier to care. Most participants specified the need for readily accessible information from efficient media, such as the internet...the lack of advance exposure to trans patients prevented physicians from acquiring clinical proficiency in trans healthcare needs.”<sup>iiii</sup>

“Participants acknowledged that even where specific policies discriminating against trans patients are not in place, the general attitude of an institution contributed largely to care delivery at that site. Inadequate cultural competence and restrictive policies—whether official or not—were seen to contribute to systematic discrimination and transphobia that manifest as barriers to care provision at the institutional level.”<sup>liv</sup>

## Barriers to testing for Trans:

“Trans MSM may be affected by general and MSM-specific barriers to testing such as low risk perception, HIV-related and anti-gay stigmas, and concerns regarding confidentiality, and general facilitators including shorter wait times, less invasive testing methods, and normalization as part of routine care...Further, trans-specific barriers to healthcare may limit accessibility of HIV and other sexually transmitted infections (STI) testing. Trans people have traditionally been invisible in healthcare education and policy...and therefore, healthcare providers often feel ill-prepared to provide care...trans people frequently report negative experiences in healthcare settings, ranging from insensitive language to refusal of care...as a result, they may avoid both preventative and urgent care...”<sup>lv</sup>

“Both trans-specific and general barriers (e.g., hours of operation) to sexual health services were described...how moving to another city - with fewer trans-friendly health resources – led to an interruption in his history of regular HIV and STI testing...a few trans men indicated that they largely avoided preventative care altogether due to medical mistrust...reluctance or refusal to provide sexual health services to trans men may be related to misperceptions that they are at low HIV and STI risk...”<sup>lvi</sup>

“Participants explained that sex-specific eligibility criteria for certain procedures, screening tests, or therapies could prevent adequate healthcare for trans patients...Rather, health system level barriers exist when it is impossible or difficult to order a test or therapy for a patient who is considered ineligible based on their gender...limited care options remain a significant barrier. In the context of medically transitioning sex, these barriers stem from having few practitioners available to initiate and monitor therapy, and from restricted management options for transitioning.”<sup>lvii</sup>

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