

Collective Action Community Change

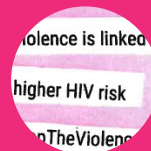
A Provincial Situational Analysis
Report by the Women &
HIV/AIDS Initiative

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Each community that took part in the situational analysis created an art piece demonstrating resilience. These pieces are represented throughout this report.



Summary

Collective Action Community Change is a collective representation of 16 situational analyses that were completed by Women and HIV/AIDS Initiative (WHAI) Coordinators across Ontario.

Each situational analysis explored the strengths, needs, and experiences of women* living with HIV and facing systemic risk factors for acquiring HIV as well as the capacity of communities to address women's HIV-related needs.

The situational analysis process marks the first stage of a coordinated collective impact initiative (CCII) that will guide the work of WHAI for the next three

years. Using collective impact as the foundation for truly collaborative, women-centred, and cross-sectoral work, WHAI is embarking on a new chapter.

The intent and objective of the situational analysis is to identify key issues affecting the capacity of communities to support women living with and facing systemic risk factors for HIV. In particular, the situational analysis was designed to:

- 1 Explore the structural context of the community including; the strengths, needs and priorities;
- 2 Understand the lived experiences of women living with HIV and facing systemic risk factors for acquiring HIV;
- 3 Explore the realities of the service landscape;
- 4 Investigate the relationships and connections between relevant stakeholders including community members, HIV service organizations, women-serving organizations, and HIV clinics and other medical service providers;
- 5 Build a foundation for collaborative provincial change.

*Throughout this report, the term "women" is used as an umbrella term, meant to be inclusive of all women, including cis and trans women, women with trans experience, as well as folks on the transfeminine spectrum.

Across Ontario, over 800 people were engaged in local situational analyses. Findings illustrated that there is a great deal of commonality in the issues communities are facing throughout the province. This report details how local findings were then analyzed to create 7

overarching key issues titled "Provincial Areas of Focus." It also summarizes and provides a collective analysis of the 16 local situational analyses and presents a roadmap for provincial change work that WHAI will work toward in the coming years.

7 PROVINCIAL AREAS OF FOCUS:



HIV Disclosure



Stigma, Discrimination and Institutional Violence



Gender-Based Violence



Women And Harm Reduction



Community And Emotional Wellness



Economic Insecurity



Health Care Centred On Women's Needs And Lived Experiences

What is WHAI?

WHAI is a community response to HIV and AIDS among women in Ontario with a focus on the structural and societal factors that increase women's risk factors for HIV. The goals of WHAI are to:



Reduce HIV transmission among women.



Enhance local community capacity to address HIV and AIDS.



Create environments to support women and their HIV and AIDS-related experiences.

WHAI's objective is to strengthen the capacity of communities to support women living with and/or affected by HIV and AIDS through the implementation of strong community development practices. At WHAI, community development refers to collective efforts by communities which are directed towards increasing community control over the social determinants of health, thereby improving health. WHAI works with women living with and facing systemic risks for HIV, as well various community partners, to collectively identify and address their shared health concerns.

A key principle separating community development from other health promotion approaches is that the needs, problems, or issues around which a community is organized must be identified by community members themselves. As such, WHAI focuses on collaborative problem-solving, raising awareness of structural forces, and getting people to view their problems as collective social issues instead of solely individual problems.

WHAI Coordinators work out of 16 HIV service organizations across Ontario.



To find a WHAI Coordinator near you, go to whai.ca for contact information.

Women & HIV in Ontario*

*Statistics sourced from: Women & HIV in Ontario: An Introductory Toolkit (WHA!, 2016).

HOW MANY WOMEN ARE LIVING WITH HIV IN ONTARIO?

8,000

The approximate number of women living with HIV in Ontario.



Women represent about 1 out of every 6 new HIV diagnoses each year.



Over the past five years, the number of new HIV diagnoses has started to decline slightly.

NEW HIV CASES & WOMEN IN ONTARIO

Anyone can contract HIV; however, social determinants of health significantly impact the lives of individuals and communities, making some women more likely to contract HIV. In Ontario research shows that of all new HIV diagnoses amongst women:

INDIGENOUS WOMEN

Approximately 50% of new HIV infections among Indigenous people are women.



are from countries where HIV is endemic.



contracted HIV through heterosexual sex.



contracted HIV through injection drug use.

TRANS WOMEN & HIV

Because of the way in which statistics are collected, there is not a lot of information available about the prevalence of HIV among trans women. What is known, however, is that trans women, particularly racialized trans women, trans women living with disabilities, those in poverty, or those who are street involved, are often disproportionately affected by systemic factors that increase the likelihood of HIV acquisition. For example:

20% of trans people report being physically or sexually assaulted.

APPROX. 50% of trans women earn incomes that fall below the poverty line.

What is a Situaitonal Analysis?

WHAI's situational analysis was derived from community-driven research that was carried out to support collaborative community and provincial change.

The overarching intent and objective of each local situational analysis was to identify key issues affecting the capacity of communities across Ontario in their work to support women living with and facing systemic risk factors for HIV. More specifically, the situational analysis was designed to explore the structural context of communities; the strengths, needs, priorities, and lived experiences of women living with HIV and facing systemic risk factors for contracting HIV; the assets and gaps of the service landscape; and investigate the relationships and connections between relevant stakeholders including community members, HIV service organizations, women-serving organizations, and HIV clinics and other medical service providers.

WHAI's situational analysis was also designed to make concrete connections between the network's aims and the *HIV/AIDS Strategy to 2026: Focusing Our Efforts - Changing the Course of the Prevention, Engagement and Care Cascade in Ontario*. The situational analysis is aligned with the goals of this strategy by examining issues related to improving the health and well-being of populations most affected by HIV, promoting sexual health and prevention of new HIV, STI and hepatitis C infections, diagnosing HIV infections early and engaging people in timely care, improving the health, longevity and quality of life for people living with HIV, and ensuring the quality, consistency and effectiveness of all provincially funded HIV programs and services. Finally, the situational analysis was designed to build a foundation for collaborative change work across Ontario.



To read the HIV/AIDS Strategy for Ontario go to:

http://www.health.gov.on.ca/en/pro/programs/hiv aids/docs/oach_strategy_2026.pdf

Situational Analysis in a Local Context

To allow local WHAI Coordinators the flexibility to create adaptive research strategies that met the needs of their community, there was no provincially standardized situational analysis methodology.

WHAI Coordinators developed their local methodologies independently but with input from the network. Beginning in late 2015, WHAI Coordinators began to develop local tools including research questions, facilitation guides, recruitment plans, and more.

There was a set of guiding principles that governed the aims and main investigative areas of the situational analysis work. Named the Priority Areas of Inquiry, WHAI Coordinators were expected to engage women with lived experience in order to develop knowledge about:

- 1 The environmental and structural context of its community;
- 2 The needs, priorities, and lived experiences of women living with and facing systemic risk for HIV;
- 3 The service landscape;
- 4 The relationships and connections between WHAI stakeholders (e.g., women living with HIV, women-serving organizations, HIV service organizations and HIV-specific programs, including clinical care).

It is from this shared bedrock that each WHAI Coordinator developed their local situational analysis, working to ensure that the voices and experiences of women with lived experience were centred, valued, and celebrated.

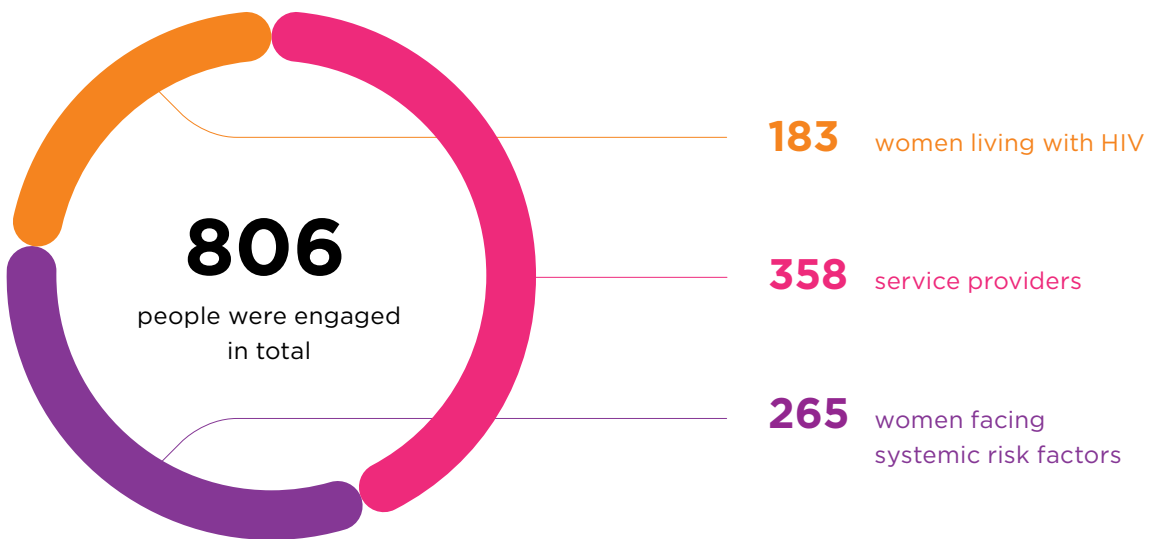


To learn more about local situational analysis processes and results, connect with your local WHAI Coordinator. Find them at whai.ca

Snapshots from Ontario

Following a year of work on local situational analyses, here is an overview of what happened across Ontario.

WHO WAS ENGAGED IN THE PROCESS?



KEY STATISTICS

IN NIAGARA

80%

(n=8) of women living with HIV responded that they wanted more education for themselves regarding HIV disclosure.

IN TORONTO

95%

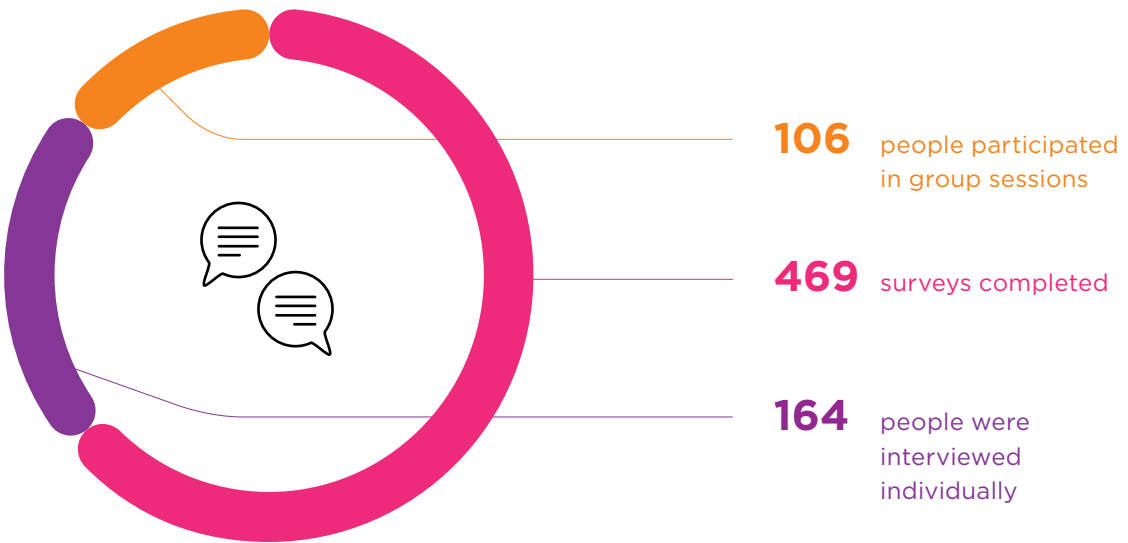
(n=22) of women facing systemic risk were not aware of post-exposure prophylaxis (PEP) & pre-exposure prophylaxis (PrEP).

COMMUNITY PERSPECTIVES

“You need to do more of these talks. Women need this and we don’t have any spaces where we can connect and talk about the issues that impact us.”

- Woman facing systemic risk, Windsor

HOW WERE PEOPLE ENGAGED?



IN OSHAWA

42%

(n=6) of women living with HIV reported having to travel outside of Durham for HIV-related care.

IN NORTH BAY

43%

(n=6) of service providers working with Indigenous women indicated that trauma, current and historical, is a top concern for the women they work with.

Coordinating Provincial Change



METHODOLOGY FOR THE PROVINCIAL REPORT

With 16 completed, diverse, and locally specific situational analysis reports, the path to coordinating provincial change-making work was complex. To gain an understanding of what trends emerged across the province, each local report was treated as a piece of data that was part of a collective provincial data set. Like pieces of a larger puzzle, the results from each local community were analyzed together to aid in categorization and theme creation. Three members of the provincial WHAI team then met regularly to discuss the emerging trends across the reports, finally arriving at a list of 7 key themes that reflect what communities across Ontario expressed. These 7 themes were then named the Provincial Areas of Focus.



PROVINCIAL AREAS OF FOCUS

To better focus WHAI work and foster collective change work across Ontario, the following 7 areas of focus have been identified as priority issues for WHAI work for the next 3 years. By clearly defining these areas of focus, and their interconnections, this will act as the foundation that will be used to foster WHAI goals and objectives and alignment with the HIV/AIDS Strategy for Ontario.



HIV DISCLOSURE



STIGMA, DISCRIMINATION AND INSTITUTIONAL VIOLENCE



GENDER-BASED VIOLENCE



WOMEN AND HARM REDUCTION



COMMUNITY AND EMOTIONAL WELLNESS



ECONOMIC INSECURITY



HEALTH CARE CENTRED ON WOMEN'S NEEDS AND LIVED EXPERIENCES

The following sections describe findings across Ontario in the 7 areas, drawing on examples, quotes, and statistics to illustrate the findings.



HIV

Disclosure



HIV Disclosure refers to how, when, and why a woman's HIV status is disclosed.

Having the autonomy to make informed choices about HIV disclosure plays a key role in creating a sense of safety and dignity, and strongly influences how women feel about accessing programs and services, which in turn, impacts their health outcomes. However, control over how, when, and to whom one's HIV status is shared was identified as a consistent challenge across Ontario. Many women had their HIV status exposed by service providers including nurses and pharmacists. Fear of having one's status exposed prevented some women from accessing HIV-specific services or led them to travel outside of their community to access HIV clinical care.

Concerns related to the criminalization of HIV non-disclosure was often cited as keeping women living with HIV from seeking romantic or sexual relationships. Women identified disclosure as an important area of learning for themselves, other community members, and care providers (i.e. health care providers, community workers, etc.)

COMMUNITY PERSPECTIVES



"With these laws, I gave up on dating. I don't want to go to jail."

- Woman living with HIV, Ottawa

IN NIAGARA

70%

(n=7) of women responded that they had a fear of disclosing their HIV status because of the potential for emotional harm.

Stigma, Discrimination and Institutional Violence



Inclusive, non-judgmental communities reduce HIV risk and facilitate positive health outcomes; however, experiences of stigma and discrimination emerged as a unifying theme for women living with and at systemic risk for HIV across Ontario.

Particularly highlighted in the context of institutions such as health care, prisons, and community agencies, women described experiences of discrimination related to their HIV status, drug use, mental health needs, socioeconomic status, and race/ethnicity. Institutional stigma and discrimination were often cited as reasons for not accessing health care or community supports. For example, women with children were often fearful that accessing particular services, like harm reduction, would lead to involvement with child protection services.

Many women living with HIV described insensitive and discriminatory treatment from health care providers once their HIV status was known. These experiences of institutional violence were described as expected and everyday occurrences that generated anxiety, low self-esteem, self-isolation, grief and trauma, ultimately creating worse health outcomes.

COMMUNITY PERSPECTIVES



“at my doctor’s office, I saw the computer screen when my file was up that said ‘substance abuser, on methadone, injection drug user’. Doctors reinforce that you’re no good, you’re just a junkie.”

– Woman facing systemic risk,
Peterborough

IN THUNDER BAY

100%

(n=10) of the women interviewed stated that they experienced stigma/discrimination from a doctor/nurse or front line staff surrounding their care and treatment once their status was known.

Gender-Based Violence



Gender-based violence emerged as an integral part of conversations about women and HIV.

Physical, sexual and emotional safety play a critical role in preventing HIV and encourage better health outcomes for those living with HIV; however, both women living with and at systemic risk for HIV across the province shared experiences of gender-based violence and trauma, including intimate partner violence, sexual assault, and street harassment. For some, violence experienced as children or years ago, or in their country of birth, continue to disrupt their lives, impacting their ability to trust and connect to others. Often, violence was normalized or described as an everyday occurrence or something that was expected. The WHAI situational analyses contributed to an understanding of the relationship between gender-based violence and HIV as complicated, often cyclical, and all too common across Ontario.

Despite this being an area of concern across Ontario, women demonstrated great strength and resilience in their ability to move forward from experiences of violence.

COMMUNITY PERSPECTIVES



“I can’t report the violence or go anywhere else; I am economically dependent on my husband”

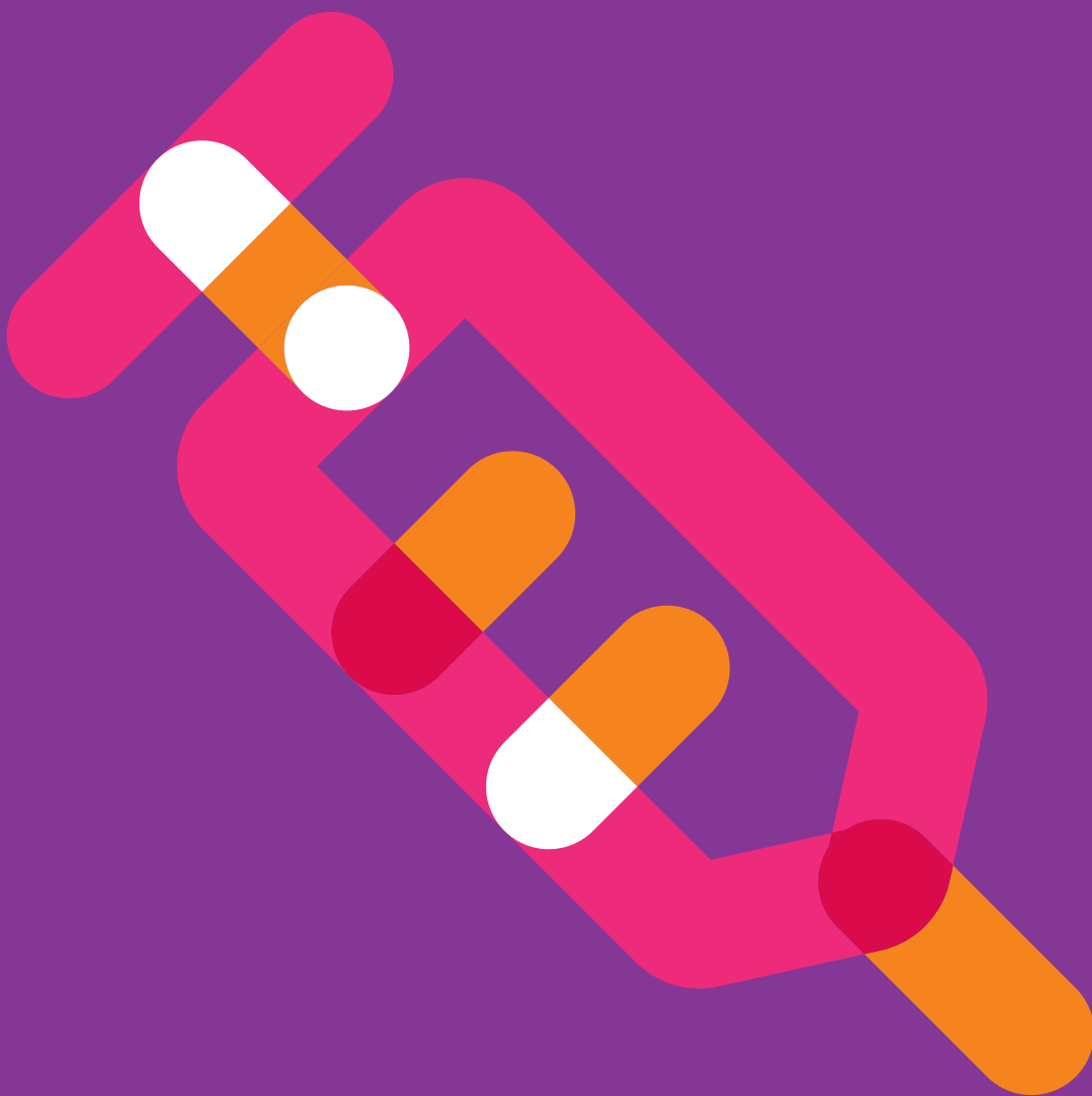
- Woman facing systemic risk,
Brampton

IN HAMILTON

46%

(n=16) of women surveyed have experienced sexual violence; 9% of these women (n=3) attribute this violence to becoming HIV-positive.

Women and Harm Reduction



Issues surrounding the realities of women who use drugs were identified in many WHAI communities.

Often, participating women reported using drugs to cope with their current reality. At the same time, women across Ontario identified judgement about drug use as a factor that contributes to diminished health outcomes.

Women who use drugs experienced an extreme degree of stigma and discrimination when accessing health and social services. Women described experiences of judgmental and insensitive treatment from health care professionals, including judgement about their drug use as well as being denied services. Women described limitations in terms of the range of harm reduction services available to them and expressed serious concerns that by accessing these services, they could expect continued discrimination from health and social service professionals. For example, women with children often decided not to access needed harm reduction services out of concerns that child welfare services would apprehend their children. Additionally, women who were accessing drug treatment services often found the number of service providers involved in their care complex and overwhelming. For example, a woman could have a drug counselor, a case manager, a methadone clinic doctor, an HIV-specialist, a hepatitis C-specific care provider, and a family physician.

In sum, all the challenges identified by women who use drugs represent tremendous barriers to needed health and social services, and manifested as discrimination and institutional violence.

COMMUNITY PERSPECTIVES



“...they know I have addiction issues so they tell me not to use the public washroom for too long”

- Woman living with HIV,
Guelph

IN PEEL

90%

(n=20) of respondents indicated a need for greater access to harm reduction supplies.

Community and Emotional Wellness



Across the province, the resilience of women, and the need for resilient communities was identified.

Community and emotional wellness generate strength and resiliency where women have less likelihood of acquiring HIV and those living with HIV have increased positive health outcomes. Conversely, isolation was a common theme across WHAI sites, identified as both a cause and consequence of other provincially identified priority issues. Women's experiences of violence and trauma, stigma and discrimination, HIV disclosure, and economic insecurity were described as generating a great deal of emotional pain and isolation. Depression, hopelessness, increased drug use and loneliness were identified as outcomes of this isolation that heightened women's vulnerability to economic insecurity, and sometimes made it difficult for women to prioritize their physical health needs. Many women sought harm reduction and mental health supports; however, timely, free, non-judgmental, and responsive programs were described as extremely limited in many regions.

Women across Ontario expressed a desire to meaningfully connect with other women to both receive and provide support to others; however, without organizational change or support, women often felt unable to facilitate these social connections.

COMMUNITY PERSPECTIVES



“It makes me manage my health better. I am always looking to eat healthy, which I wouldn't have done if I wasn't positive.”

- Woman living with HIV,
St. Catharines

Economic Insecurity



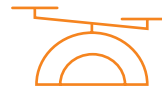
Economic security is a foundation for women’s wellness and resilience

Economic security affects not only women but also their families and communities; however, economic insecurity was a common issue for women living with and at systemic risk for HIV, making it more difficult for them to care for themselves and their families and increasing risk for behaviours related to HIV acquisition.

Challenges related to housing, transportation, employment, and food security were identified as issues throughout Ontario. For example, many women living with HIV described feeling forced to access ODSP rather than employment because of the high cost of HIV medication (which may not be covered by an employee drug plan), the need for a flexible schedule to make their various health care appointments, and concerns that their HIV status would be disclosed at their workplace due to accessing health coverage and/or frequent time off work to attend appointments. Social assistance was described as insufficient to cover basic needs. The cost of eye, dental, and mental health care often meant these services could not be accessed, regardless of need. Sex work was identified as a realistic option to assist with the inadequate income on social assistance for some women living with HIV and those facing systemic risk factors for HIV acquisition; however, condom negotiation was a complicating factor due to increased income for condomless sex as well as risks related to HIV criminalization. Lack of safe and affordable housing heightened women’s vulnerability to harms, including violence and involvement with child protective services.

Continued economic insecurity was described as isolating and negatively impacting women’s emotional/mental health, and ultimately leading to increased risk for HIV transmission and reduced health outcomes for women living with HIV.

COMMUNITY PERSPECTIVES



“If I am offered a full-time job, how will I attend appointments without losing my job? It is challenging to balance working and HIV.”

- Woman living with HIV,
Guelph

IN OTTAWA

100%

of trans women interviewed reported that they would like better job opportunities in line with their skill set and consideration for their civil status.

Health Centred on Women's Needs and Lived Experience



Health care that acknowledges and is based on women’s experiences helps to facilitate strong engagement in care and positive health outcomes; however, culturally appropriate, HIV-informed and holistic women-specific care emerged as an identified need.

Women living with and at systemic risk for HIV described challenges with insensitive, judgmental, not culturally competent and/or uninformed service providers, programs and service gaps, poor coordination between organizations, and cold, unwelcoming environments. Many women living with HIV expressed a desire to have their HIV clinical care integrated within an organization that offers other health and social services to women. Many women at systemic risk for HIV described having few spaces where they felt comfortable to connect with other women. In some cases, women reported gaps in services for women who use drugs or the requirement to use their methadone doctor as their primary care provider. In many regions, women and service providers described limited access to family physicians, and some service providers expressed feeling as though the only thing they could offer women were referrals.

COMMUNITY PERSPECTIVES



“We need services that are specific to women and family. As women, we are not individual, we have family. Some have a husband/partner some have children. I would like to see my children get involved [in issues or care related to living with HIV]”

- Woman living with HIV,
Oshawa

From Areas of Focus to Collective Impact & Provincial Action

COMMUNITY ACTIONS



In York Region, partnerships with local women-serving organizations will be fostered and trauma-informed care frameworks will be implemented.



In Windsor, a community process will explore the need for a mobile sexual health unit that address the specific needs of women.



Peterborough will see the development of a women's speaker bureau that will foster community engagement, peer support, and community development and capacity building workshops.

COMMUNITY ACTIONS

These 7 areas of focus mean nothing without clear, concerted, and collaborative action that includes both provincial and local change work.

Over the next three years, WHAI will be engaging in CCII work, selecting 2 to 3 of the 7 areas of focus for provincially coordinated action each year. The selection and operationalization of the yearly provincial areas of focus will include a network-wide process that results in tangible, measurable outcomes. This process will be inclusive of all WHAI sites, responsive to emerging provincial trends, require network collaboration, and will include the creation of goal statements and collective actions that each WHAI Coordinator can commit to. Together, WHAI will work toward ongoing evaluation to measure the effect of local and provincial work.

In addition to provincial work, each local situational analysis included the creation of an action plan that is directly informed by local results and, in many cases, created in collaboration with community partners. These local actions, when mapped on to the provincial areas of focus, illustrate the many ways individual communities are working toward similar goals. The areas of focus provide a framework for local work to have provincial impact, and provincial work to have a local impact.

This report, and the local situational analysis reports that informed it, will continue to serve as foundational documents to guide WHAI work. As a network, WHAI commits to these areas of focus and to creating collaborative and collective provincial change that actively integrates women's experiences and expertise.



In London, a discreet resource for women who are street involved will be collaboratively developed and include harm reduction strategies and community resources.



Kingston will see partnerships between WHAI and local support services result in monthly talking circles where women living with or facing systemic risks for HIV will discuss community issues as well as participate in community development work.



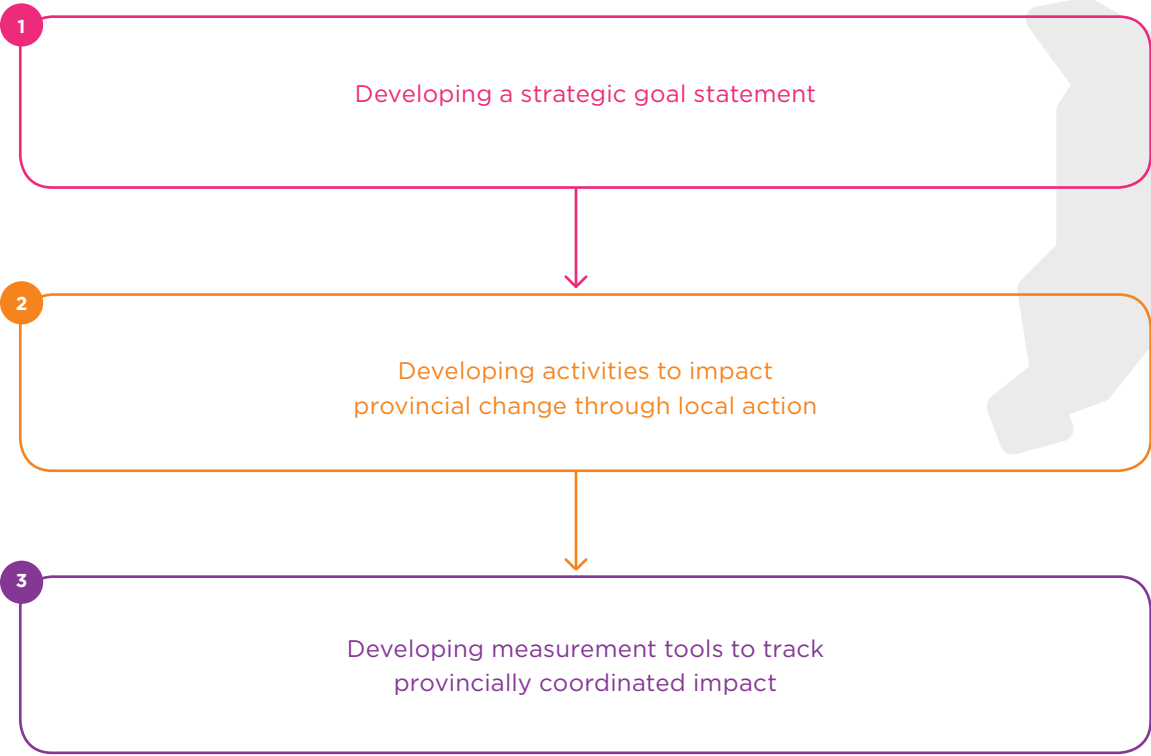
In Kitchener, partnerships with the local women's federal prison will be redeveloped to better address HIV-related issues for women who are incarcerated.



A Sudbury-based women's advisory group for women living with and facing systemic risks for HIV will be developed to ensure ongoing community engagement in change-making work for incarcerated.

Planning for Provincial Action

The process for addressing each provincial area of focus will involve a three-step, network-wide process including:



Conclusions and Implications

This report has echoed the voices of women living with and facing systemic risk for HIV, community partners, and service providers across Ontario.

In many ways, this report highlights how much work still needs to be done. Across 16 communities, seven areas of focus were identified. These areas are big, complex, and they vary across urban, suburban, and rural communities. But what this process has also shown is the enduring strength and resilience of women across this province. In the face of intersecting challenges, women living with and facing systemic risk for HIV have continued to speak up, act as leaders, provide and receive support, and create stronger communities.

From these accounts, WHAI has committed to a new way forward; one that places the need to do community-led change work at the centre. WHAI will continue to work from a place of engagement and partnership building and from a place that sees strengths before needs. Over the next three years, connect with local WHAI Coordinators, ask questions, and check in about how this work is happening. This work, and this process, belongs to communities and communities are stronger when people engage together. their expertise as leaders of this work.

