

Collective Action Community Change



A Report Amplifying Local Experiences
and Voices





Table of Contents

Acknowledgments	... 3-5
Introduction	...6
Background	... 7-8
What is WHAI?	... 9-10
What We Did and Who We Spoke To	... 11-14
Understanding Priority Areas for Collaboration	... 15-16
Next Steps	...20-21





Acknowledgments

We would like to express our deepest gratitude and thank you to the **women** who shared their knowledge and experiences. Your shared voice has helped to illuminate the experiences of women in the Region of Waterloo.

Thank you to the following organizations for being a part of this consultation process:

The AIDS Committee of Cambridge, Kitchener, Waterloo, and Area (ACCKWA)

HIV/AIDS Resources and Community Health Clinic (ARCH)

YW Emergency Shelter

The Healing of the Seven Generations

SPECTRUM

Sexual Assault Support Center (SASC)

Sexual Health Options Resource Education (SHORE)

OK2BME

Land Acknowledgement

We acknowledge that this work has been conducted on the unceded, occupied Haldimand Tract. This land is within the territory of the Neutral, Anishinaabe, and Haudenosaunee peoples. We honor and respect the First People on this land in the work that we do, and acknowledge that their sovereignty over the land has never been truly returned. We stand in solidarity with Indigenous communities in movements for justice, decolonization, and self-determination.



Ancestral Acknowledgement

We acknowledge African, Black, and Caribbean (ACB) people in Canada that have come before us. Those who have contributed to the fabric of this nation, without compensation, acknowledgement, or recognition. We further acknowledge ACB people who fought for their own and descendants' freedom, rights, safety, economic autonomy, culture and so much more. As we continue to fight and stand up for injustice against ACB people in this nation we are supported by their years of resistance. Lastly, we honour the work that has been and is currently being completed to actively liberate, empower and strengthen African, Black and Caribbean communities.



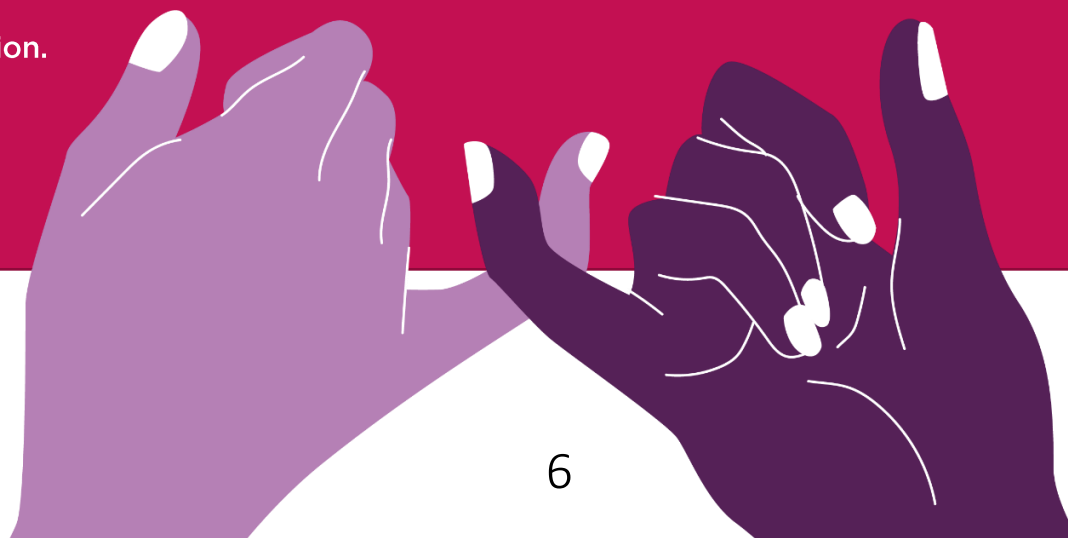
Introduction



The AIDS Committee of Cambridge, Kitchener, Waterloo, and Area (ACCKWA) is an HIV service organization located in the Region of Waterloo. ACCKWA's work is focused on supporting people in the Waterloo Region who are living with or at risk of acquiring HIV, hepatitis C, and sexually or blood-borne infections.

The Region of Waterloo contains three cities; Kitchener, Waterloo, and Cambridge. There are three major hospitals in the region and many smaller clinics. Access to PrEP is mainly facilitated by two local organizations, ACCKWA and Sanguen, who connect community members to healthcare providers for PrEP prescriptions. ACCKWA also offers a unique HIV self-test program, which allows community members to take a self-test with the facilitation and support of an ACCKWA staff member. These self-tests are regularly brought to spaces where **women** in some of WHAI's priority populations reside to offer better access to them.

The goal of this report is to consolidate the input gathered from community consultations with **women** living with HIV or at systemic risk of acquiring HIV, and people who work to support them, on needs surrounding the **women's** wellness, support, and HIV prevention. This report specifically compiles the feedback given by **women** in WHAI priority populations and community partners in the Waterloo Region.



Background

In 2021, the Women and HIV/AIDS Initiative (WHAI) began the process of province-wide consultations with cis and Trans women, 2-Spirit, and Non-Binary Femme people to focus its work to reduce HIV transmission; to enhance community capacity to address HIV; and to create environments that support **women** in their HIV related experiences. In keeping with the principles of collective action for community change, the consultation process was thoughtfully designed to be participatory, inclusive, and creative, amplifying the wisdom and leadership of **women** who face intersecting and structural barriers to sexual health. The focus of this process was specifically on **women** living with HIV who identify as African, Caribbean, and Black (ACB), as Indigenous, as newcomers, who use drugs or substances, who have experienced violence and/or incarceration, and/ or who engage in sex work.



The consultation process was planned in collaboration with the WHAI Network community partners, and knowledge holders within a decolonial, anti-racist, participatory, and trauma-informed lens. A set of four (4) knowledge-gathering tools was developed in consultation with community knowledge holders that included a one-on-one discussion guide, a brief interaction tool, a storytelling tool, and a focus group/talking circle discussion guide. All tools could be adapted amidst COVID-19-related public health restrictions and catered to a range of facilitation and engagement styles, ensuring **women** had meaningful, accessible options for participation. WHAI Coordinators implemented these tools to consult with **women** in their local communities.



501 Women



317 partners



161 Organizations

The stories they gathered were carefully reviewed to inform a second phase of consultations with community organizations and networks. This included coordinators sharing what was learned from **women** and gathering stories and experiences from community partners. An additional discussion guide was developed to support coordinators to facilitate these consultations. A total of 501 **women** from WHAI's priority populations participated, along with 317 partners from 161 community organizations and networks across Ontario, in this intentional process to ensure that community voices directed the themes that emerged.

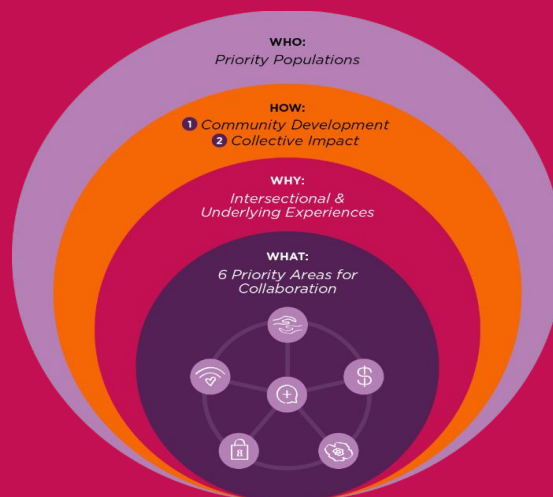
The collective knowledge gathered from **women** and community partners was collaboratively synthesized, reviewed, and analyzed along with relevant research and epidemiological reports. Reviews were conducted collaboratively by the provincial WHAI team, WHAI network membership, and a provincial review team of community knowledge holders to ensure a plurality of perspectives. Subsequently, a mapping of key barriers to HIV care and wellness, as well as strategies for enhancing care was developed.

What is WHAI?

The Women and HIV/AIDS Initiative (WHAI) is a community-based response to HIV and AIDS among cis and Trans **women**, 2-Spirit, and Non-Binary Femme people in Ontario. Through a network of 17 WHAI Coordinators located in 16 AIDS Service Organizations (ASOs) throughout Ontario, WHAI aims to:

- Reduce HIV risk for **women** disproportionately affected by HIV and AIDS;
- Enhance local community capacity to address HIV and AIDS; and
- Build safe environments to support **women's** HIV- and AIDS-related needs.

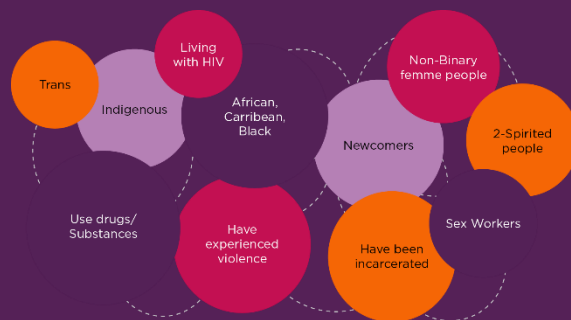
WHAI's work across Ontario is rooted in the principles of community development and collective impact. Community development values the ability of community members to affect change in their lives, in ways that are most relevant to them. Instead of organizations identifying the issues of focus, the voices of community members are centered in determining priorities. Community development is an ongoing, iterative process that guides WHAI. Coordinators work as liaisons between community groups and organizations in order to collectively develop relevant strategies to further **women's** HIV-related care.



Who We Work With & What We Mean By “Women”

WHA! seeks to be informed by, and amplify, the experiences of those who face structural discrimination and exclusion, impacting HIV risk and the health outcomes of those living with HIV. Our work focuses on engagement with cis and Trans **women**, 2-Spirited and Non-Binary Femme people who are living with HIV, are African, Caribbean, Black, Indigenous, or newcomers, who use drugs or substances, have experiences with violence and/ or have been/ are incarcerated. Within these communities, our work includes those who are pregnant or parenting, living with different abilities, and span from young adults to seniors.

Throughout this document, the term ‘**women**’ is written in colour to remind us of the importance of prioritizing and centering communities of **women** who face disproportionate structural risk factors related to HIV, as well as being a reminder that gender is not binary, and the importance of thoughtfulness towards inclusivity for Trans, 2-Spirited, and Non-Binary femme people in WHAI work. Identities are capitalized throughout, except “cis”. This is to remind us of the privilege and space afforded cis gender people, and to support the amplification of identities outside gender-binary constructions.



For More Information

(1) whai.ca/ourwork

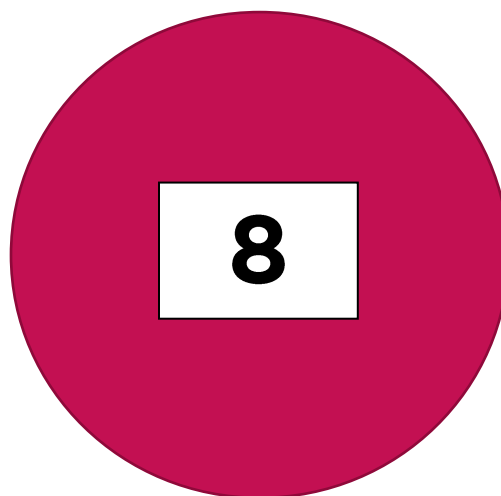
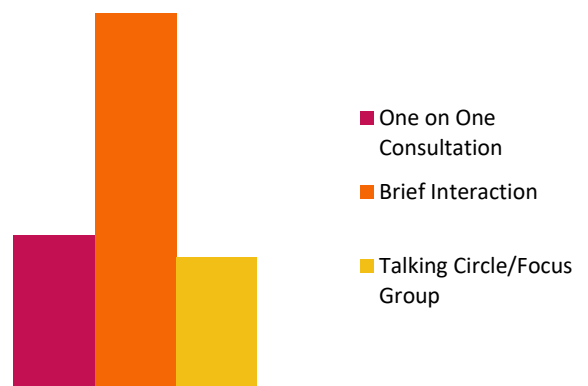
(2) Women and HIV / AIDS Initiative Program Guidelines, AIDS Bureau Ministry of Health and Long-Term Care, April 2012. (3) Learn more about the Collective Impact model here <https://www.tamarackcommunity.ca/collective-impact>.

What We Did & Who We Spoke To



30 Participants

Response Tool

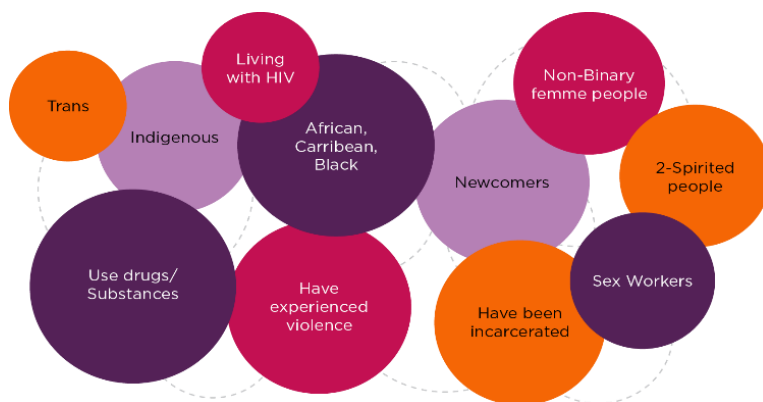


Organizations

Consultations with WHAI

Priority Populations

The consultations were conducted by three different WHAI coordinators from 2021 to 2023. Two fact-checking rounds of consultations were conducted following the initial consultations in 2021 to ensure that the voices of community members were well represented.



During the community consultations, 30 **women** from WHAI priority populations in the Waterloo Region were engaged. Consultations took place at five different locations in the community, most of which were regular gathering spaces for the **women**. Community partners assisted WHAI coordinators with recruiting **women** to complete the consultations, and some consultations were carried out by a female-identifying frontline worker at ACCKWA. Conducting the consultations in familiar spaces was intended to create an environment of safety and easy accessibility for the **women** interviewed.

Three different tools were used to complete the consultations; a 1-on-1 discussion tool, a brief interactions tool, and talking circles. These consultation tools were created by the WHAI Provincial Network and were designed to provide a variety of contexts for **women** to share feedback. Each tool used a different approach for collecting feedback. The 1-on-1 discussion tool involved a longer conversation between the WHAI coordinator and community members. The brief interactions tool allowed for shorter consultations with **women**, and the talking circles created a group setting for **women** to give feedback.

The consultations aimed to get feedback from **women** in each of the WHAI priority populations. However, due to the self-selecting nature of the consultations, WHAI coordinators were unable to get feedback from **women** in Waterloo Region in all of the priority populations. The voices of Trans **women**, Indigenous **women**, **women** who use drugs or substances, **women** who have experiences with violence, **women** who have been or are incarcerated, and Sex Workers were included in the Waterloo Region consultations. Although they are not represented in the specific feedback from the consultations, the voices of newcomer **women** and African, Caribbean, or Black **women** are incredibly important and are always valued in the ongoing work surrounding HIV prevention for **women** in Waterloo Region. Demographics from the consultations were self-reported by the **women** who participated. Twenty participants did not know their HIV status, one participant preferred not to disclose their status and eight participants were not living with HIV.





Consultations with Community Partners

The community partners who participated in consultations work with organizations that support **women** from WHAI priority populations. They gave informed feedback on the observed needs and barriers of the **women** they support. WHAI coordinators engaged with community partners via in-person meetings, phone calls, emails, and other online platforms.

Partners from 8 different organizations in Waterloo Region participated in consultations. WHAI coordinators reached out to community partners who support a range of needs. Partners were involved in the homelessness and housing sector, 2SLGBTQIA+ community support, Indigenous community support, sexual health education, support for **women** who experienced gender-based violence, and HIV prevention and support. They were able to speak to **women's** needs and barriers from a variety of angles.

Understanding Women's Stories and Community Partner Feedback

Much like the community development and collective impact approaches used throughout the consultation process, the analysis, interpretation, and review of what was shared also followed these principles. The use of community-led approaches helped to ensure time and space to understand the experiences and wisdom shared by communities across Ontario through the use of multiple tools and approaches.



Facilitated by the provincial team, WHAI Coordinators utilized a mix of templates, online whiteboards for visual collaboration, individual reflections and collective discussion tools, capacity-building sessions on coding, and thematic analysis to support a thorough review process. In parallel, a team of community knowledge holders reviewed what WHAI Coordinators had gathered to provide varying perspectives, systemic insights, and analysis to deepen and enhance the thematic review. This group reviewed with an eye to the experiences of Black **women**, Indigenous **women**, Trans, 2-Spirit, and Non-Binary Femme people, and other groups who often face structural exclusion, to ensure their voices were captured and amplified. Overall, this uniquely collaborative approach to theming enabled a rich plurality of perspectives to deepen understanding and elevate **women's** voices in framing WHAI's Priority Areas for Collaboration.

This process of collective analysis and sense-making led to a categorization of **women's** experiences into three key areas:

- Intersectional and underlying factors that impact **women's** health outcomes;
- Priority areas for collaboration; and
- Community actions for change that can be undertaken both at the provincial and local level, rooted in community development and collective impact frameworks



HIV Education, Care, and Support

There is a need for ongoing HIV education for **women** in the Waterloo Region. Knowledge of HIV testing was high among the **women** who gave feedback during consultations; 83% of **women** were aware of HIV self-testing and 96% of **women** said they knew where to go to get an HIV test. However, knowledge of pre-exposure prophylaxis (PrEP) and post-exposure prophylaxis (PEP) was low. Out of the women who were specifically consulted on PrEP and PEP awareness, only 46% of participants were aware of PrEP and only 14% knew of PEP. The **women** were also not aware of U=U, which is new research showing that people living with HIV who have an undetectable viral load cannot pass HIV along to a sexual partner. All of the **women** who were asked where they would prefer to receive an HIV test locally shared a preference for receiving a test at a community organization or sexual health clinic, rather than more a traditional medical setting like a family doctor, health clinic, or public health unit.



Holistic Care

During the consultations, **women** responded to questions surrounding wellness and what it means to them. They highlighted a variety of factors that meet their physical, emotional, social, and psychological needs, and contribute to their experience of wellness. Some women spoke about their connection to their family and community; some highlighted their physical needs and access to health care; while other women spoke about the importance of housing and support for addictions. The variety of perspectives on what contributes to wellness demonstrates the need for care that addresses a range of health factors.



Safety

Women in WHAI's priority populations face a higher risk of acquiring HIV due to systemic inequalities. These inequalities also create higher vulnerability to various forms of violence. Some of the **women** who participated in the consultations spoke about experiences of violence and shared barriers to their safety and well-being. Some of the barriers that **women** spoke about were sex work discrimination, unsafe living spaces, police harassment fueled by a lack of sensitivity training, and intimate partner violence. Other responses to questions surrounding wellness also had a relationship to safety. For example, **women** spoke about ongoing trauma resulting from previous acts of violence. The responses highlight that safety needs should be addressed at various levels including systemic, social, interpersonal, and psychological.



Community Connection

Connection to others was brought up often by **women** as an important factor in overall wellness. Community connections, familial connections, and positive connections with organizations and support workers were all mentioned as promoters of wellness. Some **women** also shared that disconnection from the community, and isolation were barriers to their wellness. Connection often acts as a facilitator for meeting other needs such as safety and economic empowerment, and can be important for emotional wellness and access to information that is shared within communities.



Economic Empowerment

Empowering **women** economically can have widespread impacts on their wellness. Quality of healthcare, access to mental health support, and safety from intimate partner violence are some areas that can be impacted by economic independence. Some **women** highlighted economic empowerment as one of the most important focus areas for WHAI initiatives. **Women** talked about food insecurity and lack of access to housing being barriers to their overall wellness. These highly important basic needs are heavily impacted by **women's** economic security.

Women-Centered Harm Reduction

66% of the **women** whose voices were included in the consultations were **women** who use substances. Women-centered harm reduction acknowledges that getting services can be particularly difficult for **women** and that predominantly male harm-reduction spaces may not be suitable for **women** who have faced specific traumas, like intimate partner violence. **Women** who use substances who participated in the consultations spoke about facing discrimination surrounding their substance use. They also shared other forms of violence that they face, including intimate partner violence and sex worker discrimination. The unique needs of **women** who use substances lead to a need for harm reduction that is specific to them.

Next Steps

At The Provincial Level

Implementation of this work will be rooted in the principles of collective impact and guided by community development frameworks. Provincially, the WHAI network will select Priority Areas for Collaboration to focus on annually, thereby strengthening our work both provincially and regionally. Each year, HIV Education, Prevention, Care, and Support will be our main area of work. In addition, 2 or 3 of the other Priority Areas for Collaboration will be selected collectively as a provincial network to foster collaboration across regional sites, and within local communities, through mutually reinforcing activities. More broadly, a common agenda and shared local strategies with measurable activities and goals for the work will be collectively set based on the Priority Areas for Collaboration. Regular Network meetings will serve as a core space for communication and coordinated efforts to achieve set goals alongside communities across Ontario. WHAI will focus efforts on continuing to facilitate space where communities work together to determine strategies that address identified needs including capacity building and knowledge building, and draw on tools and resources that foster community leadership and amplify voices.



At The Local Level

Work in the Waterloo Region will continue to focus on supporting women in each of the WHAI priority populations through connections with the women themselves and the organizations that support them. Through collaboration with community partners, the aim is to continue offering events, educational support, and other forms of connection to meet needs surrounding HIV prevention for women in WHAI priority populations. A focus on the Priority Areas of Collaboration set by WHAI, based on the expressed needs of women in the community, will also continue at the local level.

