Collective Action Community Change

A Report Amplifying Community Voices

by the Women and HIV/AIDS Initiative (WHAI)
and Positive Living Niagara

WHAI Women & HIV/AIDS Initiative

Positive Living NIAGARA

Introduction

Positive Living Niagara is an HIV Service Organization located in St. Catharines providing people in the Niagara Region with HIV support and prevention services and Harm Reduction services for people who use drugs.

The Niagara Region spans the area between Grimsby, Ontario and the New York State boarder and is heavily reliant on tourism and agriculture. The nearest HIV specialist is the Special Immunology Clinic (SIS) at the McMaster Hospital in Hamilton. People living with HIV in Niagara, must travel to Hamilton or Toronto for their HIV related care, including pre and post-natal care and childbirth.

HIV Prevention in the form of PrEP in Niagara has become more accessible with the opening of Niagara's PrEP Clinic in 2020. The PrEP clinic operates as a partnership between Positive Living Niagara and three local Community Health Centres in St. Catharines, Niagara Falls and Ft. Erie.

The following report is a summary of community consultations conducted with women in Niagara living with HIV or experiencing systemic risk factors for HIV, during the fall of 2021 and consultations with community partners during the spring and summer of 2022. This report includes:

- The background for the community consultations
- Details of how the information was gathered
- A snapshot of who took part in the consultation process and who is missing
- Summaries of what was said during the consultations
- Next steps-how this information will be used

The intention is that through this report, readers will come to have a better understanding of priorities defined by women affected by HIV; and will be inspired to build community responses centred on the voices of women living with HIV or experiencing systemic risk factors for HIV that create opportunities for all women to reach their full potential.

Acknowledgements

Many women in Niagara and local organizations contributed to the community consultation process.

It is with immense gratitude that we thank to the women who shared their knowledge and experiences. Through adding your voice, you helped to amplify the voices of women affected by HIV in Niagara and across Ontario.

Thank you to the following organizations for your support:
ARID Recovery Homes-Wish House Women's Support Home
De dwa da dehs nye s Aboriginal Health Centre
Gillian's Place
Niagara Council of Native Women (NCNW)
Niagara Falls Community Health Centre
Niagara Sexual Assault Centre
Niagara Sexual Health Centre
Positive Living Niagara
Silver Spire United Church
TOES Niagara (Tools of Empowerment for Success)
Westview at Night

SUMMARY

In 2021, the Women and HIV/AIDS Initiative (WHAI) began the process of province-wide consultations with cis and Trans women, 2-Spirited and Non-Binary Femme people to focus its work to reduce HIV transmission; enhance community capacity to address HIV; and 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, women living with HIV, who identify as African, Caribbean, 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 de-colonial, anti-racist, participatory and trauma-informed lens. A set of four (4) knowledge gathering tools were 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. 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.

6 Priority Areas

WHAT IS WHAI?

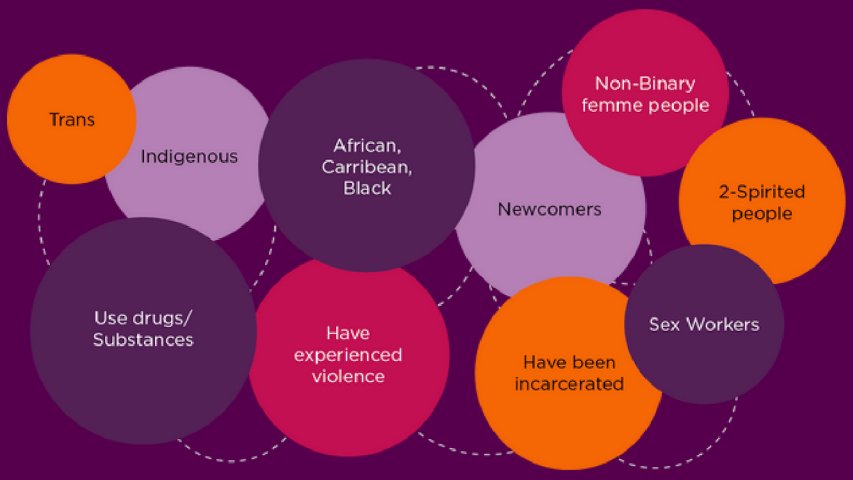
The Women and HIV/AIDS Initiative (WHAI) is a community-based response to HIV and AIDS among cis and Trans Women, 2-Spirited and Non-Binary Femme people in Ontario. Through a network of 17 WHAI Coordinators located in 16 AIDS Service Organizations (ASOs) throughout Ontario, WHAI aims to:
1.Reduce HIV risk for women disproportionately affected by HIV and AIDS;
2.Enhance local community capacity to address HIV and AIDS; and
3.Build safe environments to support women's HIV- and AIDS-related needs. (1)

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 centred 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. (2)

Collective impact refers to intentional ways of working together and sharing information for the purpose of solving a complex problem resulting in impactful change. Informed by the Collective Impact model shared by the Tamarack Institute, this work is typically determined by a common agenda, shared measurements of progress, mutually reinforcing activities, continuous communication, and strong collaborative supports (3). Collective impact is furthered by values of deepening community leadership, inclusivity, community conversations, collaboration, adopting strengths-based approaches, developing relationships, and investing in long-term change.

WHO WE WORK WITH & WHAT WE MEAN BY "WOMEN"

WHAI 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.



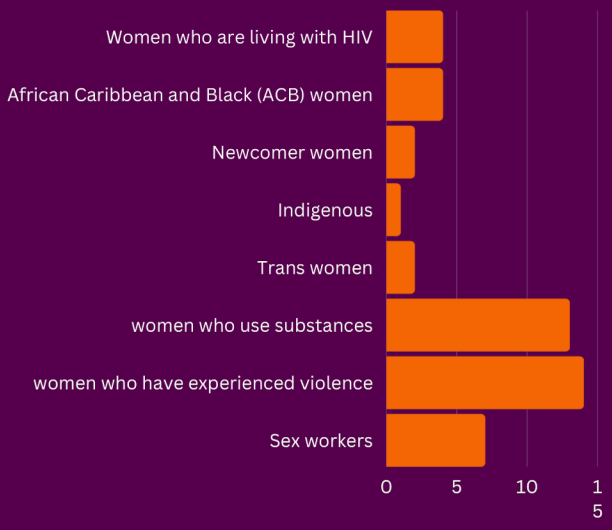
Throughout this document the term 'women' is written in colour to remind us of the importance of prioritizing and centring communities of women who face disproportionate structural risk factors related to HIV, as well as being a reminder that gender is not binary, and the importance of thoughtfulness 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.

(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.

Consultations with WHAI's Priority Populations

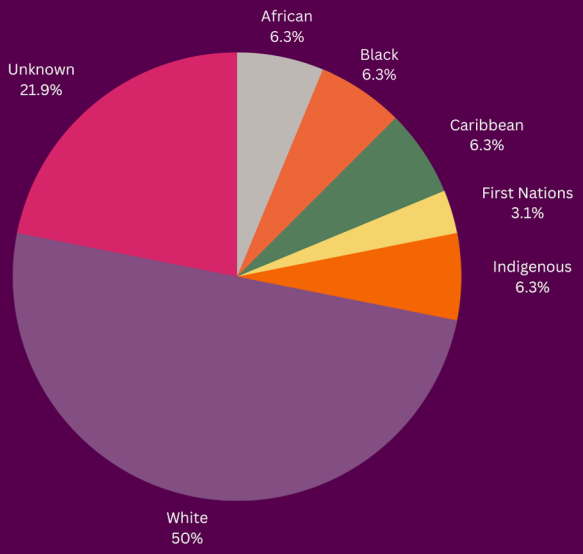
The community consultations engaged 29 women from WHAI's priority populations from across the Niagara Region. Women were recruited primarily through existing partnerships with organizations that provide services for priority populations and incorporating the consultation into their programs. Hosting the consultations in spaces where women gather helped to foster a sense of familiarity, comfort and safety for the participants. It also meant that staff were available for women who may have felt triggered during the consultation process and who needed additional support, referrals and resources.

Recruitment posters were also created and circulated through community partners and peers and shared on social media.



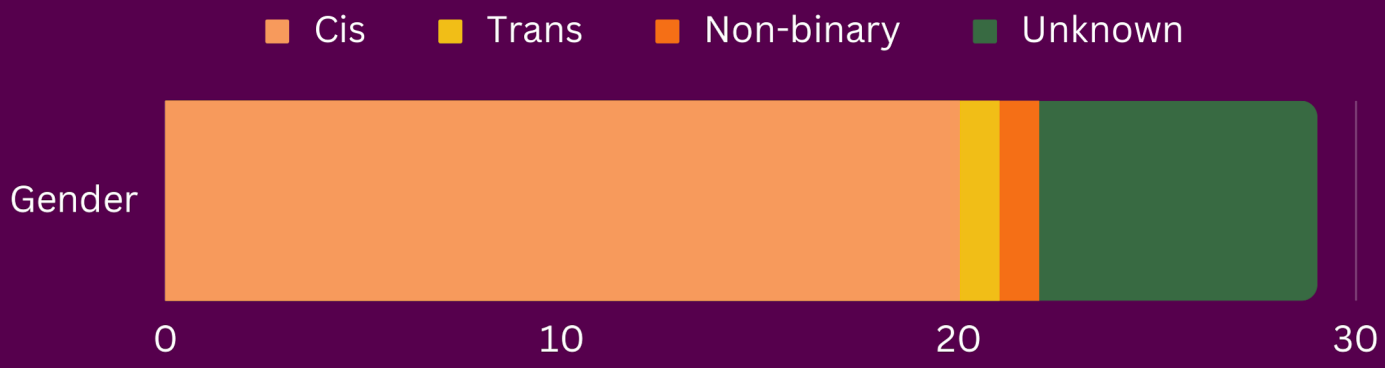
The goal of the recruitment strategy was to engage a representative number of women impacted by HIV in the Niagara Region. The COVID pandemic created challenges in achieving this goal. Many social service programs for women were put on hold or limited due to restrictions on gatherings. Other pandemic related challenges included the fact that many organizations were working from home and mandatory vaccination policies in some organizations meant those women who couldn't provide proof of vaccination were unable to enter some public gathering spaces. As a consequence of some of these challenges, the voices of people who identify as African, Caribbean and Black (ACB), Indigenous or Trans women are underrepresented in the final consultation results.

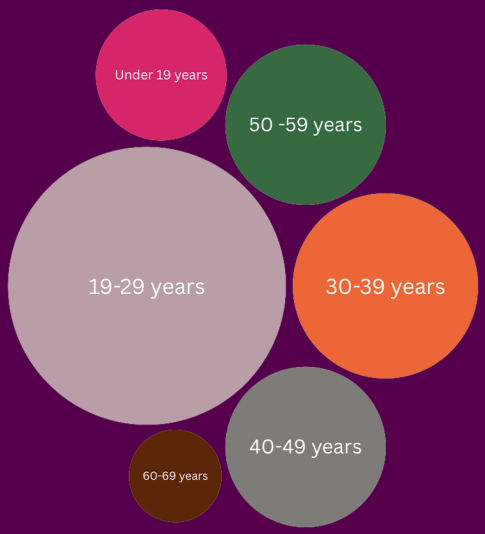
Demographic information was collected from each participant using a survey tool. Participants were able to self-select which responses best reflected their identities and could choose not to respond to questions. “Unknown” reflects questions that did not receive a response.



People could self-identify in more than one category for priority populations, race and ethnicity. Participants included women who self-identified as; living with HIV, African Caribbean and Black (ACB), newcomer women, Indigenous, Trans women, 2-Spirited and Non-Binary people, women who use substances, women who have experienced violence and Sex workers. Just over half (55%) identified as white.

The majority of participants (20 individuals or 69%) identified as cis-gender. The gender identity of seven (24%) of the participants is unknown.

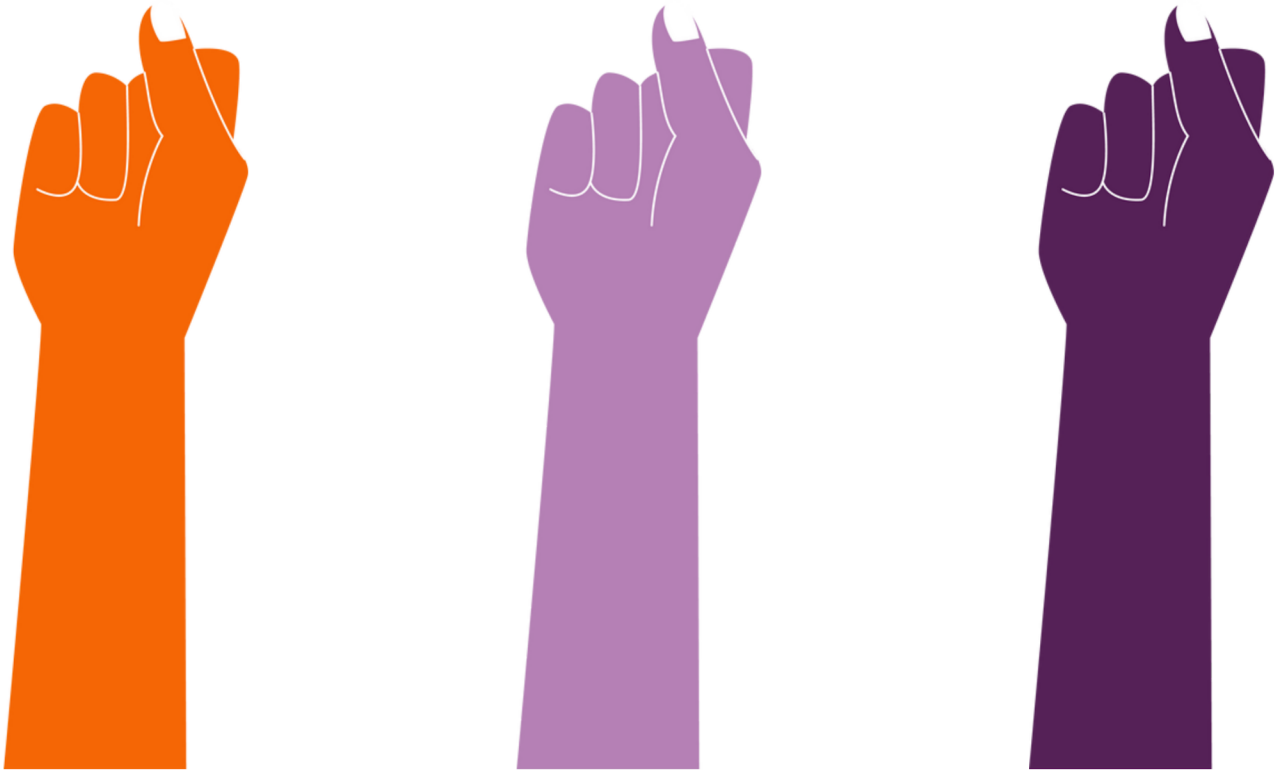




The ages of the participants range from under 19 to 69 years old with the largest age group from 19 to 29.

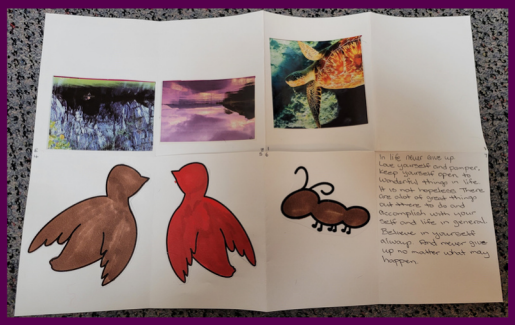
Various tools were used to conduct consultations with community members, including; the brief interaction tool, the Dove and Ant Fable tool, 1:1 consultations and a Talking circle. (Please see the WHAI provincial report for a more detailed description of the tools). Everyone taking part in the community consultations received a $30 honorarium, regardless of how they chose to participate.

The brief interaction tool was used to engage women at a drop-in space for women who participate in survival sex work. The drop-in is located in an area of Niagara with high rates of poverty, high rates of drug poisonings and an area where outdoor survival sex work occurs. Many of the women who access the drop-in experience poverty, are homeless or under housed, may engage in some form of outdoor survival sex work and identify as women who use drugs. The brief interaction tool was used due to the unstructured nature of the program. The consultation was conducted using five poster boards, each with one consultation question, post-it notes and stickers. Participants were instructed to write their responses to the consultation questions on the post-it notes and place them onto the corresponding board. Participants also added stickers to the boards to indicate answers given by others that resonated with them.



The Dove and Ant Fable tool was used for six of the consultations and was used in conjunction with an art-based activity. Participants had the option to create a personal zine to respond to the question "what do you need to be well?"

These tools were used for both in-person consultations with individuals and groups. Participants were recruited through women serving organizations, including an HIV organization, a shelter for women who experience violence and a recovery residence for women who use drugs. The group consultations were incorporated into existing structured programs for women. Three of the consultations were conducted using the 1:1 consultation tool. This method was used with people who preferred to participate using zoom or by phone interview. Participants in the 1:1 consultations all identified as African, Caribbean and/or Black and were recruited through peers.



The Talking circle used to engage with Indigenous community.

Thirty-two people from ten different organizations were engaged in the consultation process. These organizations were invited to participate in the community consultations because they provide services for women from priority populations and/or provide HIV specific services. Two of the organizations involved serve women who use substances, experience poverty or engage in sex work, two Indigenous organizations, one organization that serves ACB women, one organization that serves women living with HIV, one clinic that serves trans and non-binary people and is one of the community partners for Niagara PrEP Clininc, one sexual health centre that provides HIV testing.

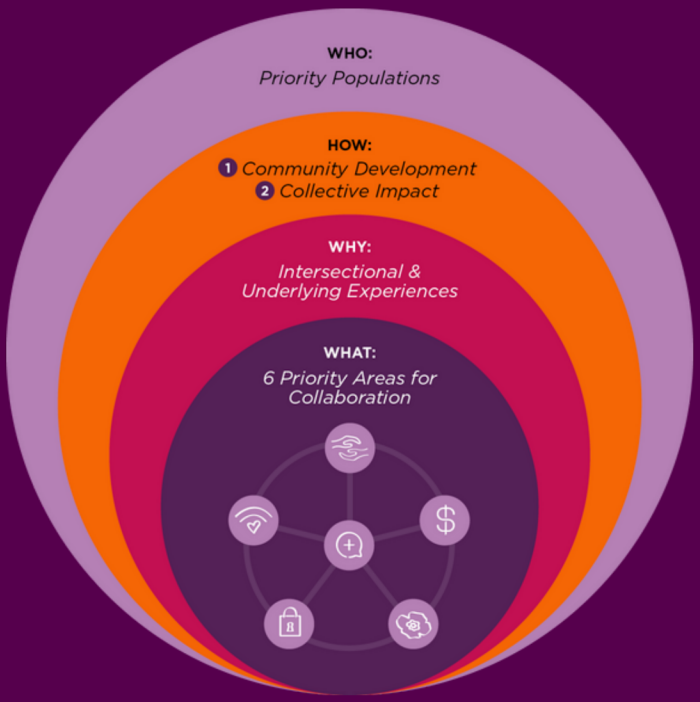
UNDERSTANDING WOMEN'S STORIES AND COMMUNITY PARNTER FEEDBACK

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 a 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-Spirited 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: Prevention, Care & Support

Many women described difficulties navigating health care systems. Participants talked about not knowing what services are available or how to access them. Rigid policies were also a barrier for several women including time limits (providers only addressing one issue at a time), prescription limits and fees to transfer files between providers. Also, a barrier, were policies requiring patients/clients to communicate directly with the provider in order to receive services (identifying a need for workers to communicate for them when experiencing a crisis). Women also identified the need for support to complete necessary paperwork.

The pandemic created challenges for women needing to access health care and supports. Service delivery became limited and some closed their doors to the public. Women talked about long wait lists to receive services. Many services have only been available by phone. Women who have other people in their home are not able to discuss private health such as sexual health or mental health. Some women described feeling less connected to their regular service providers.

Results from the community consultations indicate that education about HIV prevention and HIV testing options are needed for women at risk, as well as the staff of women serving organizations.

- 38% (11) of participants indicated that they did not know their HIV status.
- Of the participants who responded to the question, "Are you familiar with PrEP?" (21 responses), 52% (11) participants responded "No" and 19% (4) responded somewhat.
- Service providers indicated that they were not familiar with U=U and HIV self-tests and had limited knowledge about PrEP.

Service providers pointed out that many of the people they serve do not have a family physician and rely on walk-in clinics, where there is no opportunity to build relationship. Service providers also suggested that some doctors may inadvertently project their personal views onto the patient. Ensuring that walk-in clinic staff receive up-to-date education and have resources about HIV to share with patients may mitigate some of these challenges.

Service providers indicated a desire for information and support on how to engage service users in discussions around HIV prevention, testing and supporting those with HIV. An example of this could be providing assistance with reviewing existing organizational tools, with the aim of incorporating questions and facilitating discussions about sexual health and harm reduction (ex. Safety planning, follow-up after intake, goal setting exercises)

Community Connection

Forming supportive relationships with people who make women feel they are understood and valued was identified by all consultation participants as a necessary facilitator of wellness.

Many women described helpful personal relationships as relationships with people who accept them, who understood them and their needs and who supported them unconditionally and without ulterior motives. Personal relationships that were identified included family (partner, parents, children- one women identified that spending time with the children of others helps because she cannot be with her own children), friends, romantic relationships and employer relationships.

Significant connections that were discussed during the consultations were those with community, especially with other women. Staff at a women's shelter who talked about how residents would work together and support one another echoed this.

Pets were also considered important to supporting mental and emotional wellness. These relationships became even more significant during the pandemic when people had to isolate and were cut off from other support systems. In recognition of the important role pets play in providing emotional support, one of the women's shelters has plans to add space for residents to board their animals.

Several women talked about the importance of having a loving relationship with yourself in order to give love and receive it. Some talked about the benefits of mutually supportive relationships and how giving to and helping others supports their own wellness.

According to participants, the COVID pandemic has negatively impacted their mental wellness. Lockdowns and restrictions limited connections with other people and consultation participants described feelings of loneliness. Some women described a feeling of uncertainty. Women are forced to put mental wellness on the backburner to take care of day to day needs.

Economic Autonomy

Poverty was often brought up as a barrier to health and wellness. There are several contributing factors limiting the control women have over their own economic security.

Women talked about limited opportunities to make an adequate income. Single parents talked about the difficulty of balancing supporting their children financially on their own while also having limited opportunities to work when you they have young children.

Health also has an impact on a person's ability to earn an income. Women experiencing health challenges may not be able to work a 9-5 job and employer expectations "don't support wellness". One woman living with HIV also talked about the challenges of re-entering the workforce after being absent for a long period of time. Having no access or limited access to health benefits was also mentioned as a barrier to economic security.

Most women also brought up homelessness or lack of access to housing. The cost of housing continues to rise while opportunities to increase income have not, especially for women receiving ODSP or OW. There are long waitlists for subsidized housing. Having to rent housing can be unstable/insecure. Women do not have control over their housing situation. Landlord bias was also brought up by several participants and examples included not wanting to rent to single mothers, landlords only wanting to rent to students and credit scores impacting ability to be housed.

Women-Centred Harm Reduction

45% (13) of the community consultation participants identified as women who use substances. Some women identified substance use as a coping method. People with mental illness and substance use face stigma for both. Women talked about loss of relationships due to their substance use because others do not understand harm reduction or the spectrum of substance use.

> "There is a hierarchy of mental health and stigma associated with certain mental health issues."
>
> - Consultation participant who uses drugs

Safety

Wellness was often defined as feeling safe and having security. For many it meant being in control of oneself ("physically, emotionally and mentally" or "mind, body and soul") and ones' life. To foster a sense of safety and security, women identified the importance of having their practical needs met such as having a safe place to live, the ability to buy groceries and getting enough sleep.

Women described various threats to their sense of safety including HIV stigma, racism, transphobia and gender-based violence. Women living with HIV described some challenges to getting support because of HIV stigma. Some expressed concerns about being in spaces with others, especially shelters, because others may find out about their HIV status. There is also concern about the impact on loved ones if they are public about living with HIV. One woman who used to give educational presentations about HIV stopped because of their concerns around the impact of doing so, on their child.

Other factors identified as having an impact on the mental health of women included experiencing violence. Gender based violence has lasting effects and women described having low self-worth, and personal insecurities and ongoing difficulty coping with past trauma.

Racialized women also talked about the trauma and lasting impact of ongoing systemic racism including PTSD. Racism was described by ACB women as something that is part of their daily lives "It's just something I have to deal with every day". Some examples given were being treated differently from other staff by an employer (assigned tasks not assigned to others), inappropriate comments from classmates at school, trying to find housing, accessing health care (ex. fear of being labelled a "crazy black woman"), witnessing racism, fear for others (ex. racist perceptions of black men and fearing for safety of male family member).

Transphobia impacts the ability to find healthy relationships and access adequate health care. One Transwoman described the difficulty with trying to find a romantic relationship. Transwomen are often fetishized and she experienced harassment on dating sites. When seeking care, some providers have old information or do not understand the transition process. The focus is on the transition/body parts instead on whole person.

An Indigenous community partner highlighted the need for service providers to receive Cultural Safety training. Colonialism meant that the "sense of belong has been ripped out from underneath Indigenous people". Along with training, organizations should provide visible indicators for example, staff wearing a unity or 2 row wampum button and having a list of Indigenous organizations available for referrals.

"It is the role of service providers to hold space for women until they feel balanced enough to go on their own"

Indigenous Service Provider

Wholistic Care

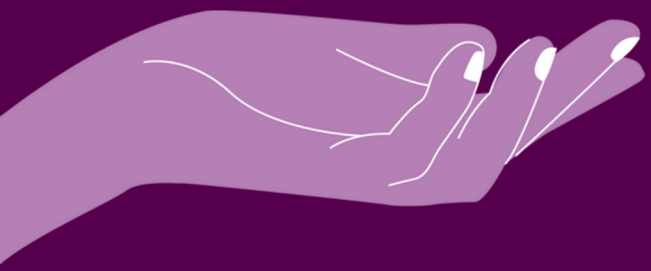
Consultation participants expressed the need for culturally relevant services and more women specific health care. Women also expressed the need to have health care providers that take the time to listen and learn from their patients and value their experiences.

Women expressed the importance of hiring more female and BIPOC health care and service providers. Many participants talked about having a greater level of comfort with providers that reflect their own experiences. One person pointed out that providers with backgrounds different from their patients may interpret situations differently than their patient.

Another participant suggested that combining traditional knowledge and new knowledge would help to bridge the gaps in services. Spirituality and Traditional ways of knowing helps support wellness for many women. Some participants connected with their personal spirituality through attending church and "the power of prayer". One person described this connection as having a "relationship with a higher power". Some participants spoke of traditional medicines and teachings. Examples of this include connecting with nature, showers as a form of medicine (water), having fires in the back yard and exploring new ways of healing. One woman spoke of the teachings she received from her grandmother in Jamaica which continue to guide her even after the death of her grandmother.

The relationships women have with their providers is integral to their health. Most women shared what they need from organizations and individual providers. They described "good" health care and support services/ providers as those that foster self-determination, provide women specific services, provide holistic care and are non-judgmental.

Several community partners talked about service providers being territorial and "gatekeeping" behaviour such as not sharing information or making referrals to other organizations. All community partners interviewed agreed that women should be able to access services where they choose and that a coordinated response best serves the needs of women.



"You can't do wholistic care on your own"

- Newcomer Service Provider

NEXT STEPS: 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 spaces 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.

This report focusses on the local experiences shared, linking them to our Provincial Areas for Collaboration. Please see the WHAI website at whai.ca/resources for our provincial Collective Action Community Change Report.

Next Steps at the Local Level

The results from the community consultations are a snapshot in time. This report is meant to be a living document and will serve as a tool to continue the conversations with women and community partners and add to the stories that we have already heard. These conversations with our local community will help to identify community priorities, identify new trends, and foster a collective community response to existing and emerging issues. Priority will be placed on engaging with women who identify as African, Caribbean and Black (ACB), Indigenous and Transgender, 2-Spirited and Non-Binary. These populations are underrepresented in the initial consultation process.

Ongoing partnerships to build capacity around HIV prevention and care with organizations that serve women, 2-Spirited and Non-Binary people living with HIV or experiencing systemic risk factors for HIV remains vital to creating greater access to wholistic care, reducing HIV related stigma and preventing new case of HIV.

The practice of bringing the information from the report back to the community on a continual basis will be important to ensuring that the information remains relevant to the lives of women affected by HIV and that community action is centered on their voices and experiences.