Collective Action Community Change Report

WHAI at PARN 2023

WHAI Women & HIV/AIDS Initiative

PARN
COMMUNITY-BASED HIV/STBBI PROGRAMS
SUPPORT. PREVENTION. EDUCATION.

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Acknowledgements

While this report was consolidated by current WHAI Coordinator, Brooke Dewhurst, the initial research with women was gathered by Lora Keitel, the 2021-2022 WHAI Coordinator at PARN, with assistance from 4th year Social Work Student's at Trent University Victoria Kitamura and Heather Vance. In their new roles, the research with stakeholders was gathered by Heather Vance, the WHAI coordinator at PARN in 2022, with support from the Manager of Education, Lora Keitel.

First and foremost, we would like to express our deep appreciation to the community consultation participants and various women with lived/living experience sharing their knowledge and experience with researchers. A special thanks Ash O'Brian, Penelope, R. Reid, Tibs, Kathleen, Cathy O'Reilly, Binti, Marisa, Michele Cilcus, Brittany Cameron, Pheonix and Mkwa Giizhis and all others who participated. Without their generosity and vulnerability, this report would be impossible.

As a group we would like to express our gratitude to Women HIV/AIDs Initiative (WHAI) provincial team, PARN - Your Community HIV/AIDS Network, the HARM REDUCTION WORKS @ PARN team, and THRIVE Northumberland.

The WHAI, Ontario provided extensive trainings and resources to support the consultation process. They will be providing the provincial findings based on community consultations across Ontario in 2022. THRIVE, Northumberland provided $500 to be offered to women for the completion of surveys. Using these funds we were able to interview 25 and offer them $25 for participation.

We would like to acknowledge that, the community consultations took place in what is currently known as Peterborough, which occupys Traditional Michi Saagiig Nishnaabeg Territory. This land is associated with the Williams Treaty of 1923 and Rice Lake Treaty #20 of 1818. We are grateful that the Indigenous peoples of this territory, and Turtle Island as a whole, have been caretakers and inhabitants of the land since time immemorial.

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. As such, our work focuses on engagement with cis and Trans women, 2-Spirited and Non-Binary Femme people who are living with HIV, African, Caribbean and Black (ACB), 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 people, and to support the amplification of identities outside gender-binary constructions.

Introduction:

From November 2021 to December of 2021, the Women and HIV/AIDs Initiative (WHAI) Coordinator at PARN - Your Community AIDS Resource Network, consulted with 92 women with lived experience in Peterborough (PTBO), Northumberland, Haliburton, and City of Kawartha Lakes (CKL). The aim of this was to listen to their experience of wellness, its facilitators, barriers, and areas for improvement. Using this information and information gathered by 17 other WHAI Coordinators across Ontario the provincial WHAI network reviewed the data to draft updated Areas of Collaboration. 6 news Areas of Collaboration were suggested to be wholistic care; safety; HIV education, care, and support; women centred harm reduction; economic empowerment; and community connection.

Beginning in June of 2022 through August 2022, WHAI at PARN consulted with 14 local stakeholders who provide support and services to women living with and/or who face systemic risk of acquiring HIV. The intent behind this was to review the drafted Areas of Collaboration and receive recommendations and alternative local perspectives. This would and will determine future work done by the WHAI across the province and locally in Peterborough and the Four Counties.

Background

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.

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:

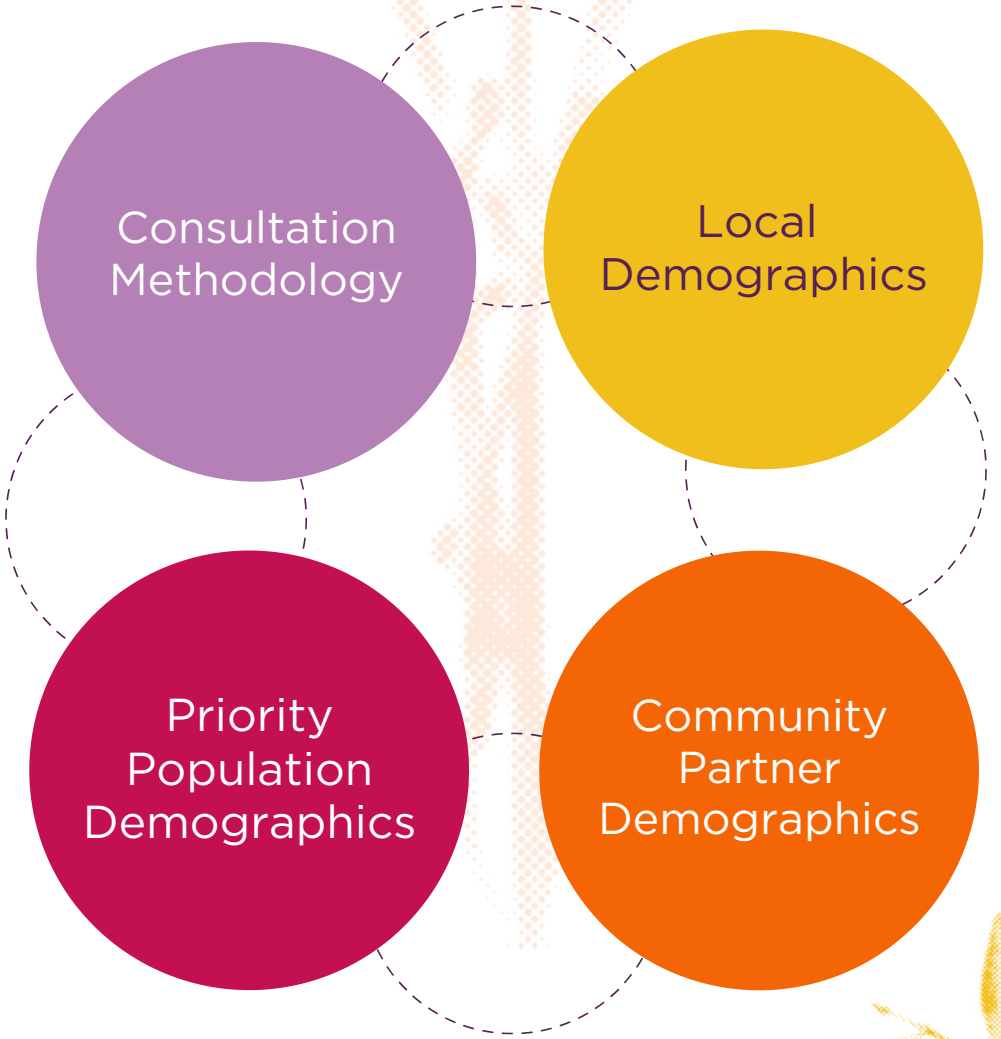
1. Reduce HIV risk for women disproportionately affected by HIV and AIDS;
2. Enhance local community capacity to address HIV and AIDS; and
3. Build safe environments to support women's HIV- and AIDS-related needs.

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.

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. 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.

What We Did and Who We Spoke To

The following section looks at the populations reached in our consultations and the tools that we used throughout the process



Consultation Methodology

Use of surveys and 1:1 discussion were the main tools used throughout the community consultations

While provincial WHAI developed four community consultation tools to support knowledge gathering, we focused in on one-on-one discussion, often employing the Dove and Ant tool.

In November to December of 2021 WHAI at PARN consulted with women who live with and/or face increased systemic risk for HIV in Peterborough, Northumberland, Haliburton, and the City of Kawartha Lakes (CKL). The aim of this was to listen to their experiences of wellness, its facilitators, barriers, and areas for improvement to identify themes resulting in Areas of Collaboration which would guide future work.

In total 92 women returned surveys within the Four Counties. Surveys took place in various locations, typically community agencies.

Individuals were compensated for their time depending on how long it was expected to take: brief interviews ($20), engagement in the ant and dove activity ($40), and participation in the Dove and Ant 1 on 1 interviews ($100).

Beginning in June of 2022 through August 2022, WHAI at PARN consulted with 14 local stakeholders who provide support and services to women living with and/or who face systemic risk of acquiring HIV through a series of surveys.

12 of these 14 surveys (85%) occurred via individuals completing surveys online following receiving an email correspondence from the local WHAI coordinator. The remainder were completed in one-on-one meetings both online and in person.

The Ant & Dove, Aesop's Fable

A Dove saw an Ant fall into a brook. The Ant struggled in vain to reach the bank, and in pity, the Dove dropped a blade of straw close beside it. Clinging to the straw like a shipwrecked sailor to a broken spar, the Ant floated safely to shore.

Soon after, the Ant saw a man getting ready to kill the Dove with a stone. But just as he cast the stone, the Ant stung him in the heel, so that the pain made him miss his aim, and the startled Dove flew to safety in a distant wood.

Kindness is never wasted.

The next few pages provide an overview of local, priority population and stakeholder demographics reached during community consultations

Local Demographics

According to the Central East LHIN (2019), Haliburton County and the City of Kawartha Lakes (CKL) combined have a population of 93,485 people. The largest percentage of this population is individuals aged 65 to 74, and a small group of individuals aged 0 to 19 (11%).

Key Information about Haliburton and CKL:

- Unemployment rate (14.66%).
- Low income (13.56%).
- Indigenous population (2.72%).
- Visible Minorities (1.89%).

Furthermore, the Central East LHIN (2019) explained Northumberland County has a population of 73,754 people. Within Northumberland, Cobourg had a small percentage of people aged 20-64 (51.13%) and high population of people aged 75+ (11.34%). Similarly, in Trent Hills there was a large percentage of people aged 65 - 74 years (16.43%).

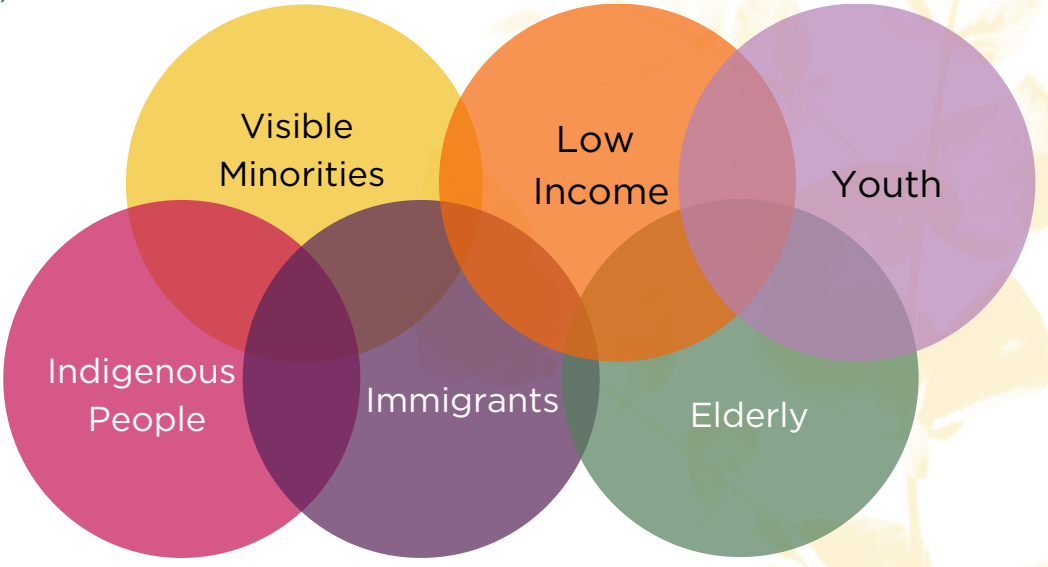
Key Information about Northumberland:

- Low Income Population (11.34%).
- Visible Minorities (3.46%).
- Indigenous Population (2.69%).

Lastly, the Central East LHIN (2019) explained that Peterborough City and County has a population of 138,236 people - making it the largest population within the four counties. Peterborough had a small Immigrant population (8.21%) with the county of Otonabee-South Monaghan having the one of the smallest percentage of people who identified as having immigrated to Canada (6.21%).

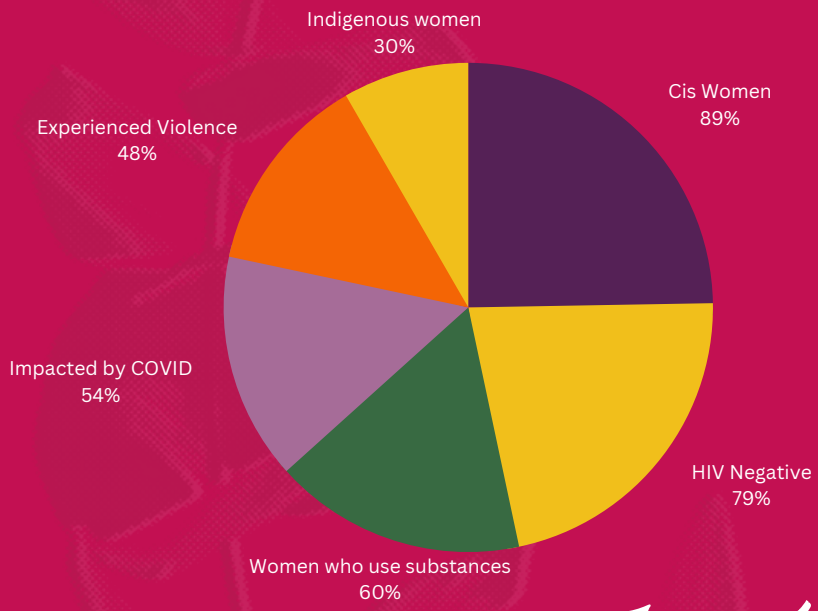
Key Information about Peterborough:

- Low Income population (14.58%).
- Visible Minority population (4.29%).
- Post-acute Inpatient Mental Health Hospitalizations (4.62 per 1,000).



Priority Population Demographics

WHAI conducted interviews with 92 women-identifying people during the community consultations

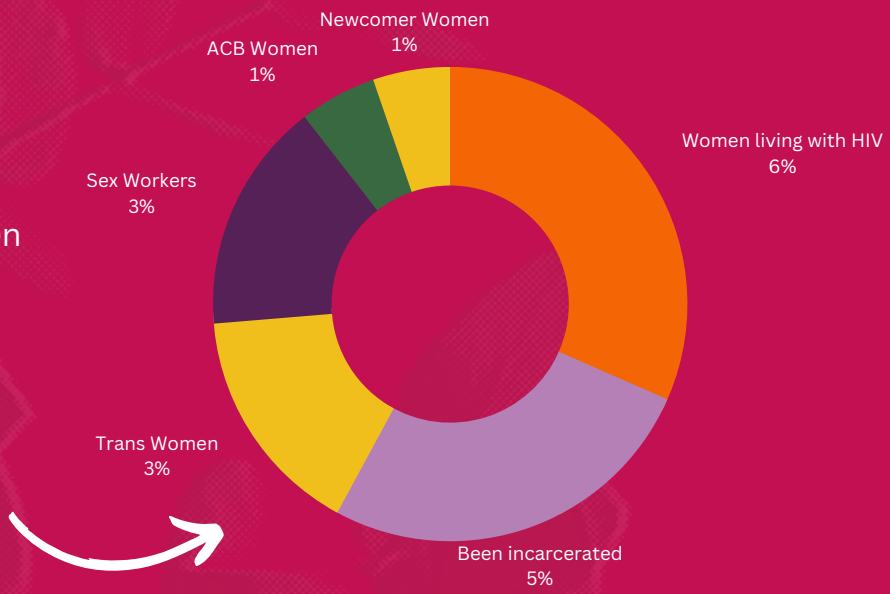


Among the women surveyed, many of them belonged to WHAI's priority population group of women who use substances, many were of women were disproportionately impacted by COVID-19, and of women who have experienced violence. Other well represented groups were cis women, Indigenous women, and HIV Negative women.

This graphic depicts the percentage of women belonging to each well-represented population in the study.

Groups that were under represented within our study were ACB women, newcomer women, trans women, sex workers, women who have been incarcerated, and women with HIV.

This graphic depicts the percentage of women from underrepresented priority populations reached.



Folks underrepresented in our study has to do with both demographic realitites and lack of access to folks from these priority populations. WHAI at PARN will conduct outreach and programming specifically for these populations in reponse to these findings.

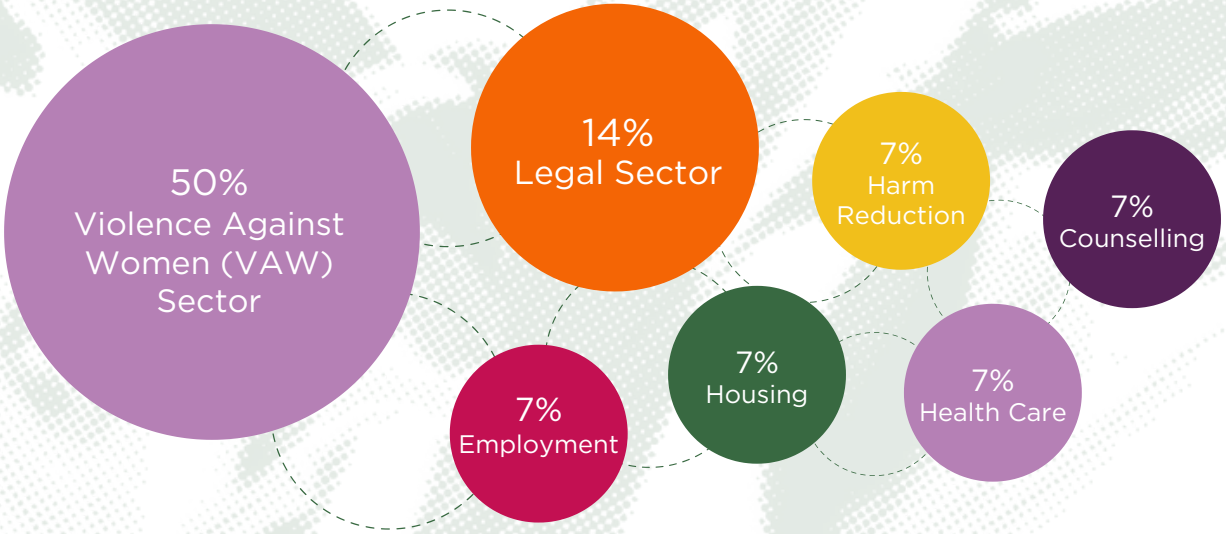
Another gap in this research is the lack of participation in Haliburton. Only one individual in Haliburton completed the short survey, with no one completing the secondary survey. This may mean the needs of women in this country specifically are not adequately represented. Overall. WHAI was able to reach a wide range of women.

Community Partner Demographics

WHAI consulted with 14 stakeholders

Engagement in Consultations from Various Sectors:

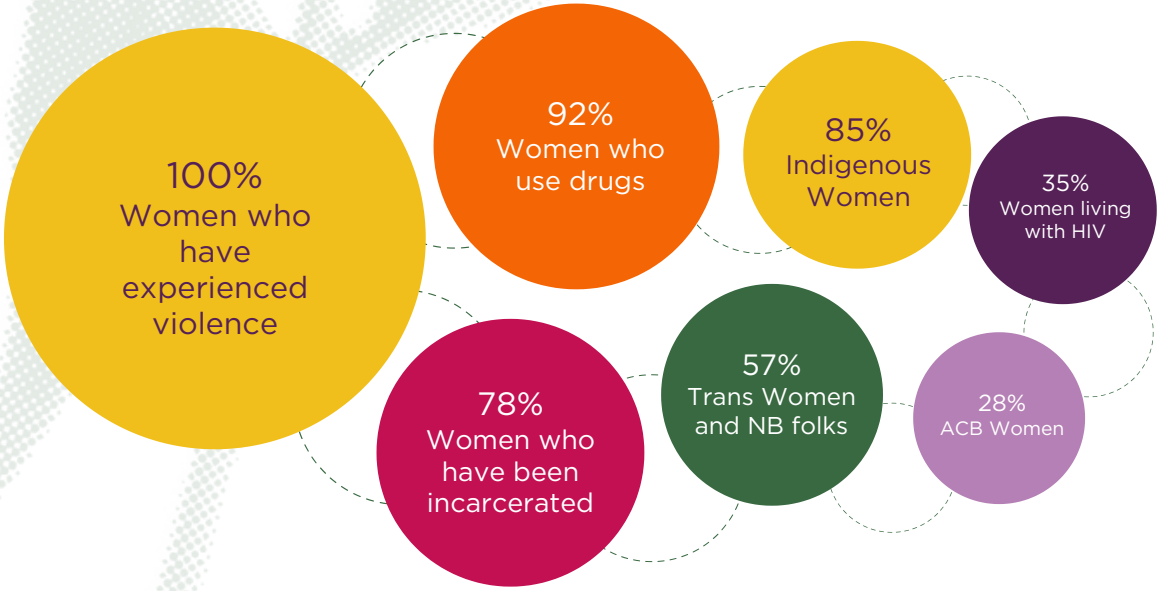
The graphic below depicts the percentage of stakeholders working in each sector that was covered throughout consultations.



This survey had low engagement from stakeholders that work with African, Caribbean, and Black women, however PARN is working on building partnerships with organizations that support ACB women.

Stakeholder Engagement with Priority Populations:

The graphic below depicts the percentage of stakeholders that have worked with each listed priority population.

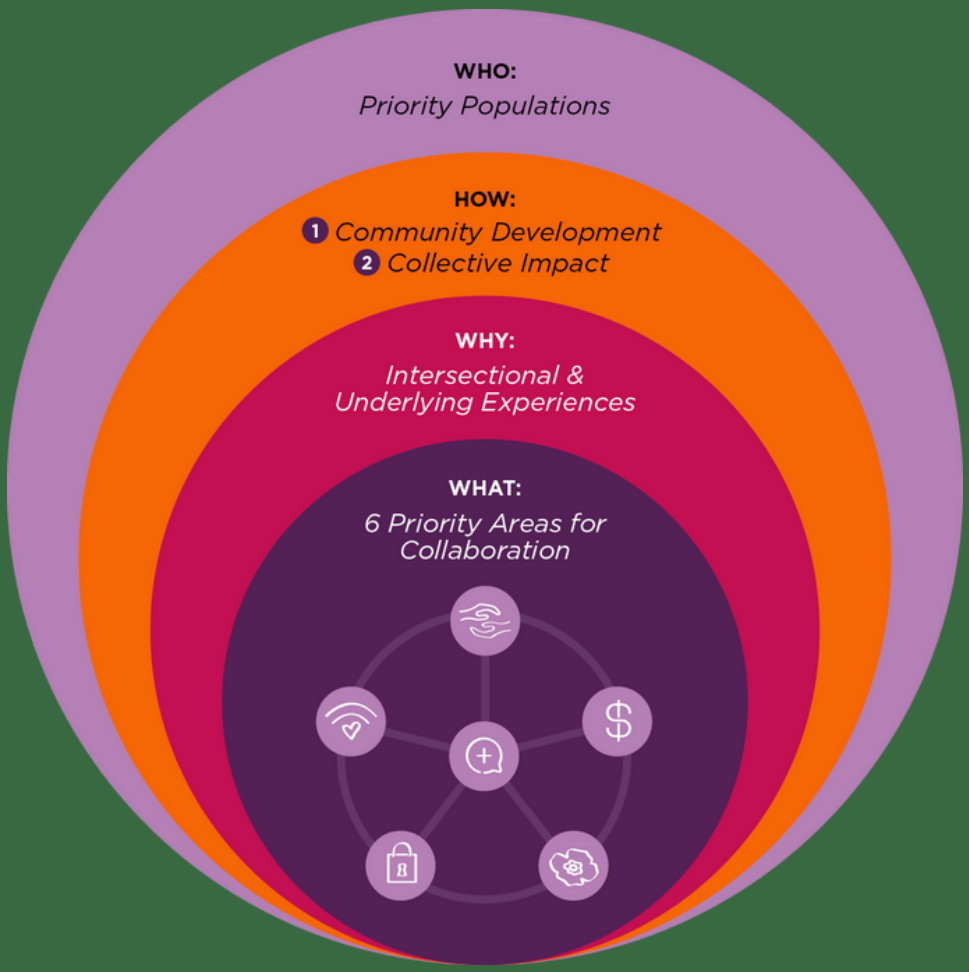


Understanding Women's Voices & Community Feedback

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



WHAI Priority Areas for Collaboration

Following a comprehensive process of theme identification, six (6) Priority Areas for Collaboration were identified to guide WHAI's work forward which are illustrated below. These Priority Areas for Collaboration resonated across the communities where WHAI works, with each community having local experiences, expertise, and wisdom, creating a foundation for provincial collaboration and locally implemented strategies over the coming years. Overall, they will serve as a foundational community-based roadmap to further WHAI's goals and align with Ontario's response to HIV.

The following section provides an overview of how both WHAI's priority populations and the community partners experience each theme within the Peterborough surrounding area.

Wholistic Care

14% Wholistic care was only reflected in the work by 14% of the community partners involved in the study

70% of the priority populations explained that emotional and mental health are important to their overall wellbeing

Community Partners

Stakeholder survey participants didn't directly speak about the notion of wholistic care, aside from one participant stating health care should be women centered. However, various individuals referenced this idea indirectly, for example, one participant said we could work together to build community capacity by "creating safe spaces not only in agencies but within the community. Whether it's posters, or events. Maybe even if there is a way to implement knowledge of HIV into education to prevent stigma. The physical effects of STDs are discussed in schools, but never the emotional/financial/social impacts it could have." While another participant said, "supporting woman experiencing DV and living with HIV."

"Connections between issues or areas of wellbeing underlies all our work" Community Partner

Priority Populations

Within community consultations 'a wholistic view of wellness' was defined by women naming 3 or more categories on the wellness wheel. Out of the individuals who answered this question 81% selected 3 or more areas from the wellness wheel. With this, physical wellness was a theme within the 4 counties.

57% stated that physical wellness was an important aspect of their overall wellbeing. In connection, survey participants highlighted the connection between physical and mental health; 70% explained that emotional and mental health are important to their overall wellbeing. Others also highlighted how individuals and their communities impacted their wellness as well.

Safety

47% of the women consulted had experienced violence at some point in their lives

57% of the community partner organizations reported safety is reflected in their work

Priority Populations

Among all four counties, nearly half (47%) had experienced violence at some point in their lives. Specifically looking at Northumberland, 64% of women interviewed had experienced violence at some point in their lives - a much higher rate than the average in the four counties.

47% had accessed support

36% had not accessed support

When discussing the type of gender based violence, 26% specifically named family violence, 42% specifically named IPV,42% specifically named SA, and 1 person specifically named human trafficking.

Cornerstone, Police, Family Court, CAS, Victim Services, Doctor, NHH Mental Health, FourCAST were all mentioned as places folks sought out support.

"Having community is super important to feeling safe and stigma free." Priority Population Participant

Community Partners

Community partners indicated that women's safety is connected to these main themes

- 42% of survey participants observed women's safety being impacted by economic empowerment or lack thereof
- 42% of survey participants indicated that affordable housing was a barrier to their clients
- 35% of survey participants indicated a connection between women's safety and women centred harm reduction services

HIV Education, Care, & Support

14% Only 14% reflected in the work by community partners involved in the study

50% of community partners indicated a need for increased knowledge surrounding this

Priority Populations

The most common area of focus identified by women was Healthcare Centered on Women's Needs and Lived Experiences by 51 out of 92 individuals (55%).

Women who were surveyed identified a need for anti-stigma education at systemic and social levels. Participants highlighted a need for this to occur within healthcare and social services. 11 of the 32 respondents spoke about the need for anti-stigma education needed in the community, within services agencies and in medical settings (34%).

This is especially important because stigma has a significant impact on the health outcomes of people living with HIV.

"Doctors listening to women's needs"

"Less stigma about HIV & STBBIs"

"No more violence"

"Less stigma around folks in shelters"

"Anti-oppression training for service providers"

"(We) need more compassionate, empathetic, non-judgemental services and resources in order create meaningful engagement." Priority Population Participant

Community Partners

Overall there was a lack of knowledge amongst service providers and the broader community about HIV Education, Care, and Support.
50% of individuals surveyed indicated a need for increased knowledge for both service providers and community members about: HIV and STBBI testing, including HIV self-testing, PEP & PrEP, U=U. In relation to this, addressing stigma related to HIV and AIDS were mentioned by 28% of individuals.

A clear takeaway from this is that there is a need for increased education and supports for service providers in the area surrounding HIV care and support.

Women Centred Harm Reduction

57% of the community partner organizations reported this theme is reflected in their work

80% of the women consulted identified that this priority area is important to them

Community Partners

Women centered harm reduction was a commonly discussed Area of Collaboration. 8/14 survey participants said women centered harm reduction* (57%) was reflected and resonated within their local work as a stakeholder. Participants frequently spoke about how access, or lack thereof, to women centered harm reduction impacted women's safety, which was discussed previously.

"We practice harm reduction, client-centered services to provide safe spaces for women experiencing violence. These women often present with complex needs - substance use, abuse, mental health concerns. Important to expand our client base to women of indigenous backgrounds and LGBTQ2S+."

Community Partner

Priority Populations

42 out of 52 individuals that completed the secondary survey identified that Women Centered Harm Reduction was important to them (80%). This shows the importance of accessible harm reduction services being provided to women. It was explained by women that there were difficulties accessing various support services, including healthcare, housing supports and women centred harm reduction.

52% in Northumberland

7% in Peterborough

Urban vs. Rural Access to Services

It can be implied that areas with a larger population have a larger availability of accessible services. In Northumberland, 52% of survey participants named **inaccessible programming as a barrier**, compared to 7% from Peterborough.

Stigma

Stigma around addiction, mental health and homelessness were also identified as barriers to wellness by a high number of women who were surveyed in Peterborough, with 48% identifying that stigma and discrimination were experienced.

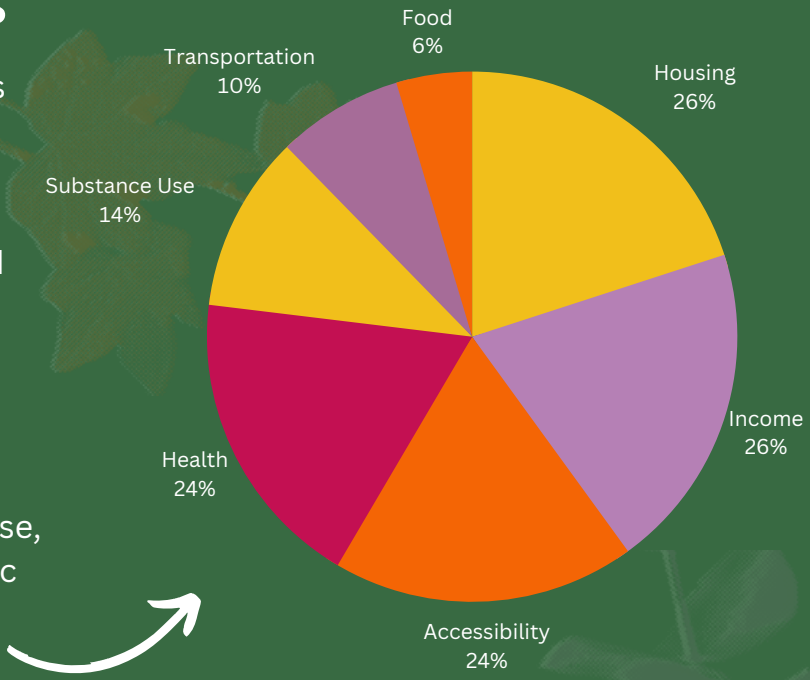
Economic Empowerment

57% of the community partners reported this is reflected in their work

50% of the women consulted had unmet practical needs

Priority Populations

During the community consultations with women it was identified that many had unmet practical needs, creating barriers to their wellness. Across the 50 women who answered the barriers question 25 of them identified at least 1 or more unmet practical need (50%). Individuals mentioned unmet needs such as housing, income, accessibility, mental/physical health, substance use, transportation and food. This graphic depicts the percentage of folks who identified each as an unmet need.



These are all aspects of wellness that require economic empowerment as part of the solution. Folks without access to safe, stable and adequate income are unable to meet their needs.

"Economic empowerment is huge source of stress for so many of my clients. They are living in poverty, struggling to make ends meet, forced into sex work and exploitative/unsafe jobs to make ends meet, and unable to leave abusive/unhealthy relationships due to lack of affordable housing. They have limited/no access to healthcare, are met with judgement from many staff/agencies clients alike, and feel such huge shame in accessing services."

Community Partner

Community Partners

Similarly, the community partners consulted identified safe an affordable housing as a barrier to accessing local work. Many commented on the rising cost of living amidst wages remaining stagnant as well as the intersecting issues folks deal with as a result of economic insecurity. As noted in the quote above, there are many aspects of life that contribute to or take away from one's wellbeing. More will need to be done to make economic empowerment a reality for women in the four counties.

Community Connection

14% only 14% reflected in the work by community partners involved in the study

42% of women consulted reported this as an important aspect to their wellness

Priority Populations

Connections to a community were observed as a theme in Peterborough and Northumberland. Two major overarching themes were developed from the responses: feeling connected and being connected to individual(s) or a part of a larger community. 21% of individuals who answered this question identified that individuals had been facilitators of their wellness and 15% identified that a sense of community was an important facilitator of their wellness. Important individuals/groups mentioned were the following.

Safe Spaces

In addition, the importance of having physical spaces to gather and connect was highlighted. Increased safe spaces for women and marginalized communities to connect & learn was a theme identified by women in the community consultation. 66% of participants spoke to a need for safe spaces for women and folks of marginalized communities to connect and learn.

"I feel best when I know I have a community that supports me" Priority Population Participant

Community Partners

Safe spaces for individuals were identified as a need by 28% of the community partners consulted. Many individuals emphasized the importance of safe spaces/ways for individuals to gather as a method of increasing community connection. Some individuals spoke about the best ways they believed safe spaces could operate.

Overall, we know that community connections are made when people feel safe and feeling part of a community promotes overall individual wellness.

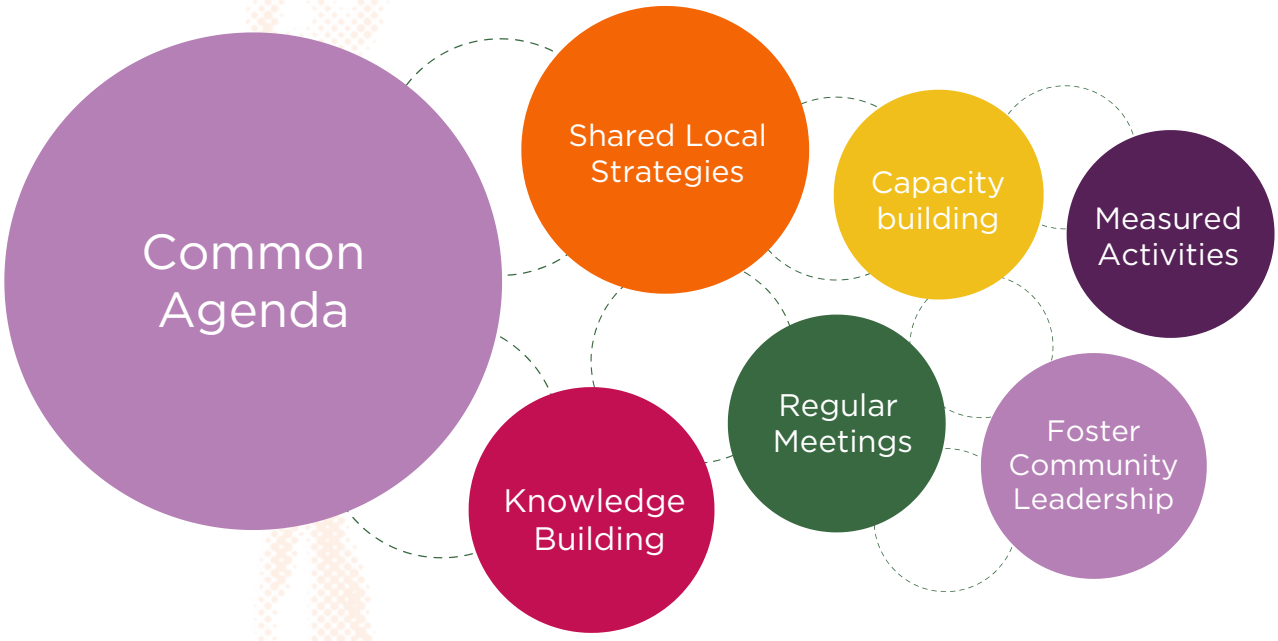
Next Steps: Provincially

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

Drawing upon the Priority Areas for Collaboration, provincial WHAI continues to determine overarching goals and provide leadership for women specific harm reduction across Ontario



Next Steps: Locally

57% of the community partner organizations are interested in further WHAI educational programming

66% of the women consulted identified a need for improvement in Addictions, Mental Health & Housing services

Community Partners

Overall, the community partners who were consulted showed an interest in further education, inter-agency education sessions and increased collaboration. Other ideas for fostering collaboration included offering HIV 101 training to agencies, hosting workshops or sharing further educational opportunities, sharing pamphlets/resources with other agency staff, and hosting virtual meetings.

Barriers identified in increasing community capacity were the "silo'd" nature of social service providers, stigma, lack of funding, high turnover and burnout. Lack of communication between agencies limits access to services and makes it harder for women in the community to thrive.

Increased partnerships between agencies to support priority populations is something that WHAI at PARN is interested in continuing to pursue moving forward. Our educational programming will reflect these consultations by reaching out to community partners involved and creating agency-specific trainings to spread knowledge and increase awareness.

Priority Populations

Based on the consultations with priority populations, it is clear that further work to reach out, support, educate, connect, and build relationships with women in our community."The Need for Adaption to Existing Services Related to Addictions, Mental Health & Housing" was indicated by 66% of participants. Further conversations about adaptations needed were conversations around accessibility to programming, not understanding what agencies had to offer, a need for an easier way to understand services as well as addressing wait times to services (such as mental health services).

Further, the impact of stigma in our community and service organizations continues to act as a barrier for women to access support. Women consulted suggested there was a need for less stigma about HIV & STBBIs, acceptance, no more violence, less stigma for folks in shelter, anti-oppression training for service providers, and doctors listening to women's needs.

These suggestions and reflections will be taken into account and inform WHAI at PARN's work with service providers as well as in the community. More women's specific harm reduction projects will be incorporated into our yearly planning, as well as community-level educational programming and accessible events.

Conclusion

Beyond the main focus of HIV Education, Prevention, Care & Support, WHAI at PARN will be specifically focusing on Women Centred Harm Reduction, Commmunity Connection and Wholistic Care

We have begun this work by continuing to expand our educational programming, developing a WHAI advisory board, initiating monthly HIV+ women's-only spaces, restarting a monthly low-barrier meal, increasing access to menstrual products and incorporating artistic projects into our community outreach. We are going to continue to expand our programming based on these consultations and are grateful for all those who participated in this. Our work in the community is better for it.

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