Collective Action Community Change

A Local Report of Community Consultations

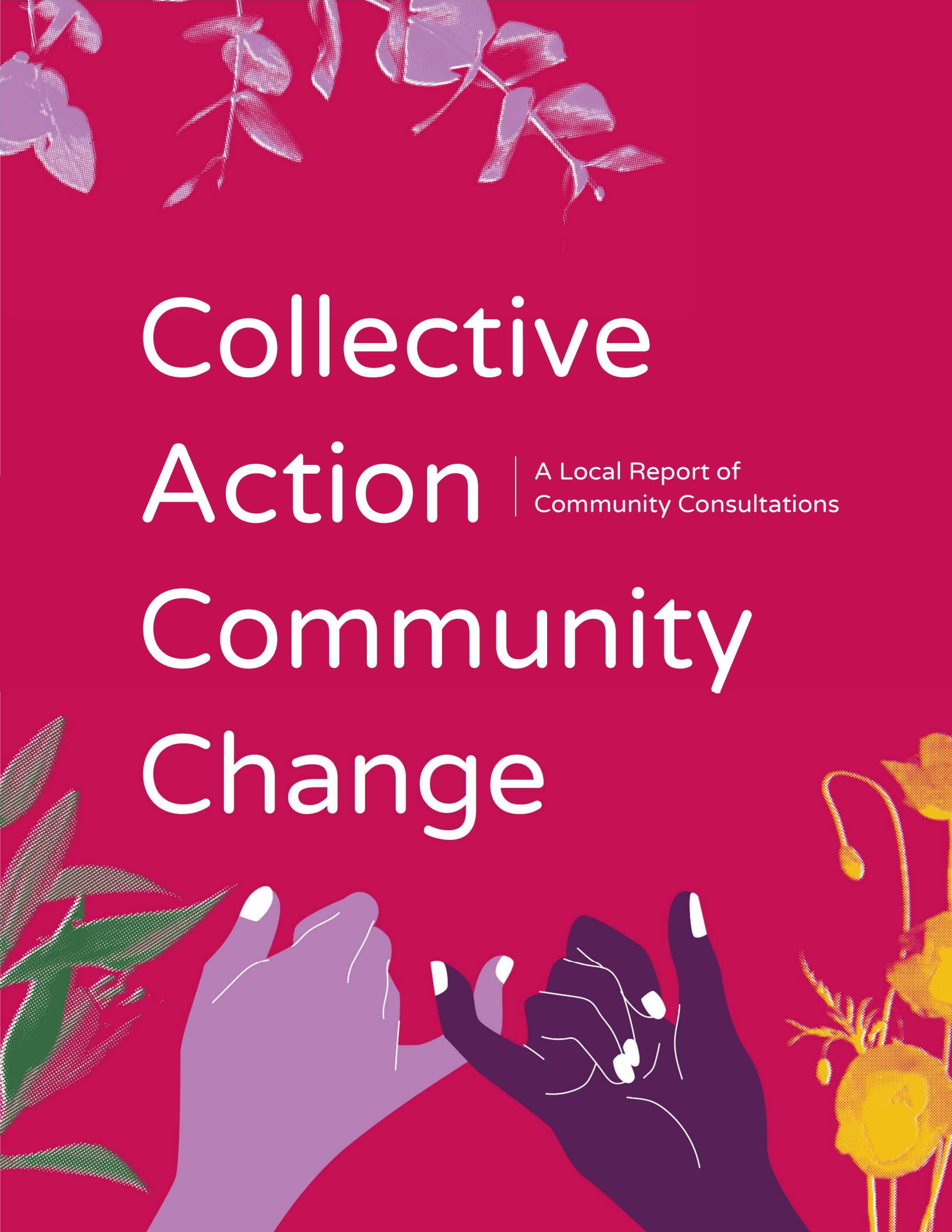
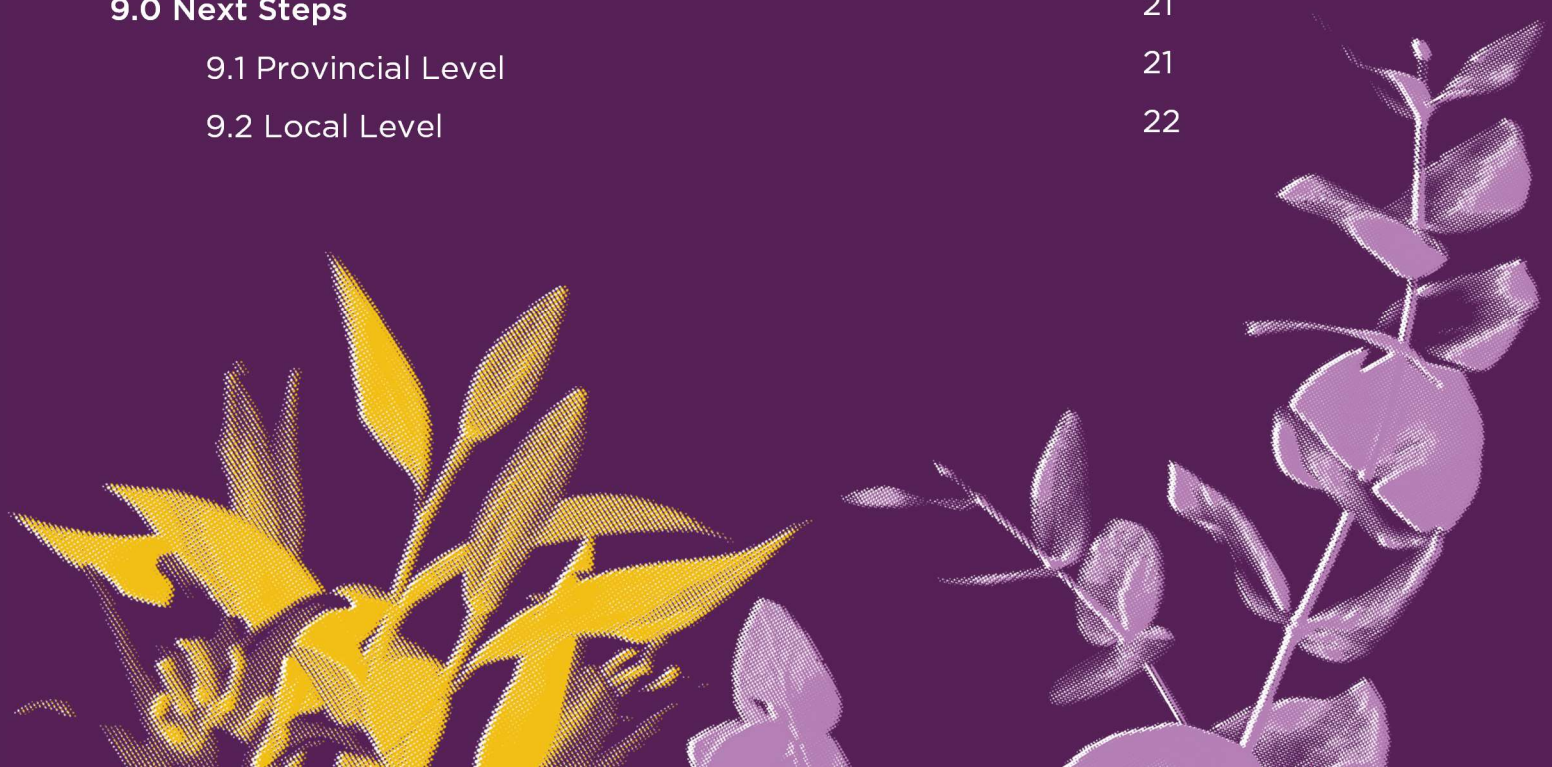


Table of Contents



1.0

Introduction

Pozitive Pathways is a registered charity that provides client advocacy, support, harm reduction, health promotion, education and outreach services for people living with, affected by, or at-risk of HIV and Hepatitis C in Windsor-Essex and Chatham-Kent.

As part of the Education & Outreach team, Pozitive Pathways' regional WHAI Coordinator:

- Engages women and service providers at local community organizations to increase their HIV knowledge, reduce stigma, and help women better advocate for their sexual health needs.
- Creates opportunities for women to have a safe space to have sexual health discussions and connect to their communities.
- Outreaches to women across the counties by providing access to one-on-one sexual health discussions and supplies.

In 2021 as part of a provincial initiative, the WHAI Coordinator began conducting community consultations with women and community partners to gather knowledge regarding barriers to sexual health and related supports.

Consultations were carried out using a WHAI one-on-one discussion tool with women in the community with a total of 25 women sharing their voices. The insights provided by these women were then brought to community partners where their own input was added and considered. Following these consultations, the knowledge gathered was compared and analyzed to identify key barriers and six Priority Areas for Collaboration that will drive the future of the WHAI Coordinator's work in the community.

This local report is created with the intention of sharing the voices of women in our community and identifying ways in which we as a community can increase our capacity to respond to structural barriers to their sexual health and well-being. The hope is that as you move through the report you gain an understanding of WHAI's purpose, the consultation process and its results, how each of the six Priority Areas for Collaboration is experienced in our community, and how this will guide our work for the next 3-5 years.

2.0

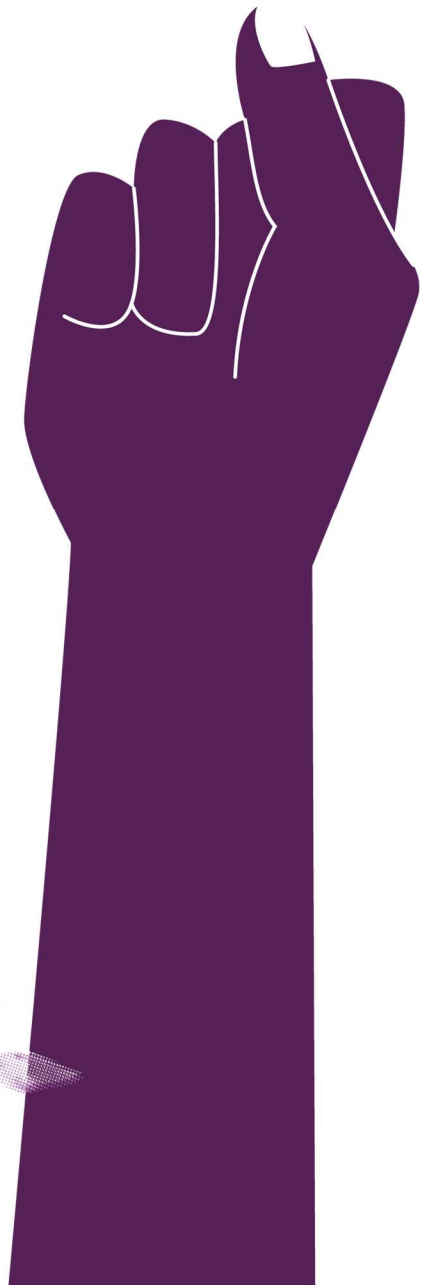
Acknowledgements

Pozitive Pathways and WHAI would like to thank the numerous women who participated in the consultations. We thank them for their time, knowledge, and willingness to share their experiences which were fundamental in identifying and developing WHAI's Priority Areas for Collaboration.

We would also like to thank our community partners for sharing their own stories and ideas for collaboration to work towards a collective goal of increasing our capacity to respond to women's health and well-being. Additionally, we would like to thank everyone who contributed to the development of this report at its different stages, including the previous WHAI Coordinator who conducted the consultations with WHAI's priority populations and another consultant who conducted the consultations with community partners.

We sincerely thank these women for their invaluable contributions to the future direction of WHAI and our own local development:

Haley, Dara, Minerva, Tannis Lemmon, Tweets, Brandy Boyle, Linda, Sarah Hickmott, Susan, Care Bear, Brandy Jackson, Melanie, Melina Hayik, Joanne Schingh, Alek, Leau Druer, Lindsey, and all of those who are not named but who we are also appreciative of.



3.0

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 for Collaboration

4.0

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:

Reduce risk for women disproportionately affected by HIV and AIDS

Enhance local community capacity to address HIV and AIDS

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.

[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.

5.0

Who we Work with & What we Mean by "Women"

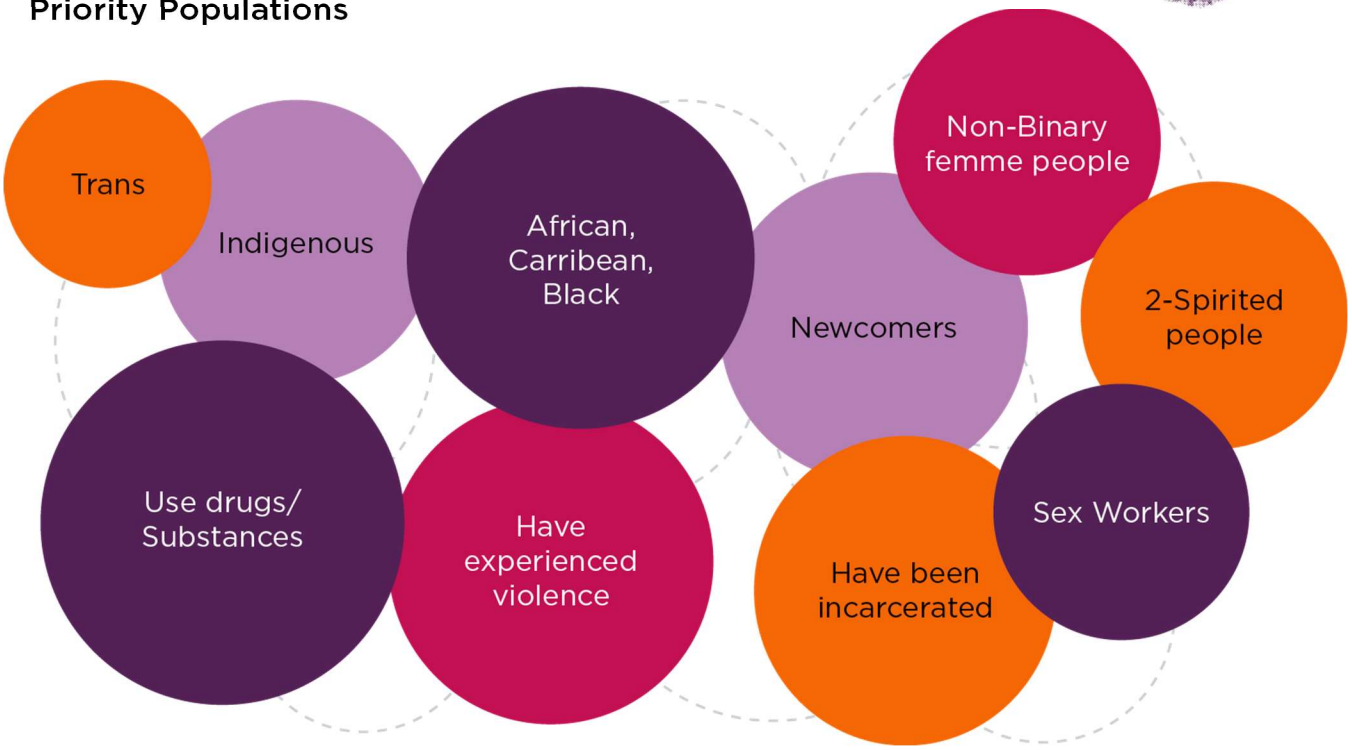
WHAI seeks to be informed by, and amplify, the experiences of those who face structural discrimination and exclusion, impacting HIV risk and the health outcomes of those living with HIV. Our work focuses on engagement with cis and Trans women, 2-Spirited and Non-Binary Femme people who are living with 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.

6.0

What we Did and Who we Spoke to

Priority Populations



6.1 Consultations with WHAI's Priority Populations

Consultations were held among three local organizations in Windsor-Essex: Pozitive Pathways, The Downtown Mission of Windsor, and the Welcome Centre for Women and Families. In total, 25 women participated in the consultation process and were interviewed in person using the "1-on-1 Discussion Tool."[1] Participants of the consultations were engaged through community partners and an honorarium was provided to each participant in the form of a monetary payment of $50.

[1]Learn more about the tools used in the Provincial Report here https://whai.ca/resource/collective-action-community-change-a-report-amplifying-community-voices/

Generally, a majority of WHAI's priority populations were represented in the participant pool.

40%
of women had previously experienced violence

28%
of women identified as Indigenous

20%
of women used substances

8%
of women identified as ACB

4%
of women identified that they were living with HIV

One priority population that was not represented in the consultations are Trans women. The WHAI Coordinator during the consultation process was able to make an initial connection with an organization that targeted Trans populations to engage women through them. However, during the process, communications stalled on the organizations end and the coordinator was unable to follow through with the consultations.

Additionally, the area of Chatham-Kent was not included in the consultations with women due to community partners in this region being unresponsive to communication. Difficulty connecting to community partners was a common issue since the beginning of the pandemic.

Fortunately, the women who were able to participate in the consultations were still able to provide valuable perspectives on challenges they have identified in their community.

6.2 Consultations with WHAI's Priority Populations

Due to coordinator turnover and challenges with communication, the consultation with community partners process was delayed resulting in limited participation. Therefore, feedback from community stakeholders is limited. However, collaborators were able to come together to engage community partners and consultations were still conducted with valuable information emerging.

Across 4 consultations, 4 individual participants from 3 organizations across Windsor-Essex and Chatham-Kent participated in the consultation process.

The sectors that were involved in this process were two shelters/transitional housing and an AIDS Service Organization. Organizations were initially approached by the WHAI Coordinator via email requesting their participation and were later contacted for one-on-one interviews over the phone by a consultant in the coordinator's absence. These specific organizations were approached due to their engagement with women who have experienced violence, women who use substances, women who are living with HIV, and other women who are considered a priority population.

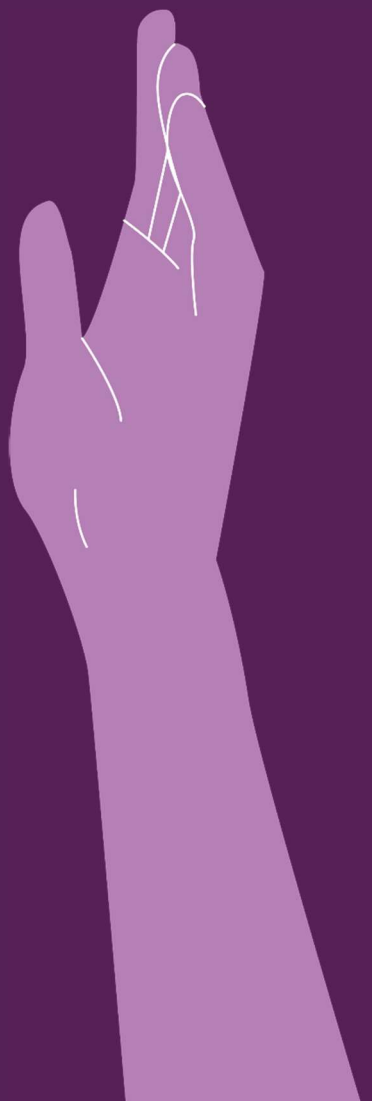
7.0

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 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.

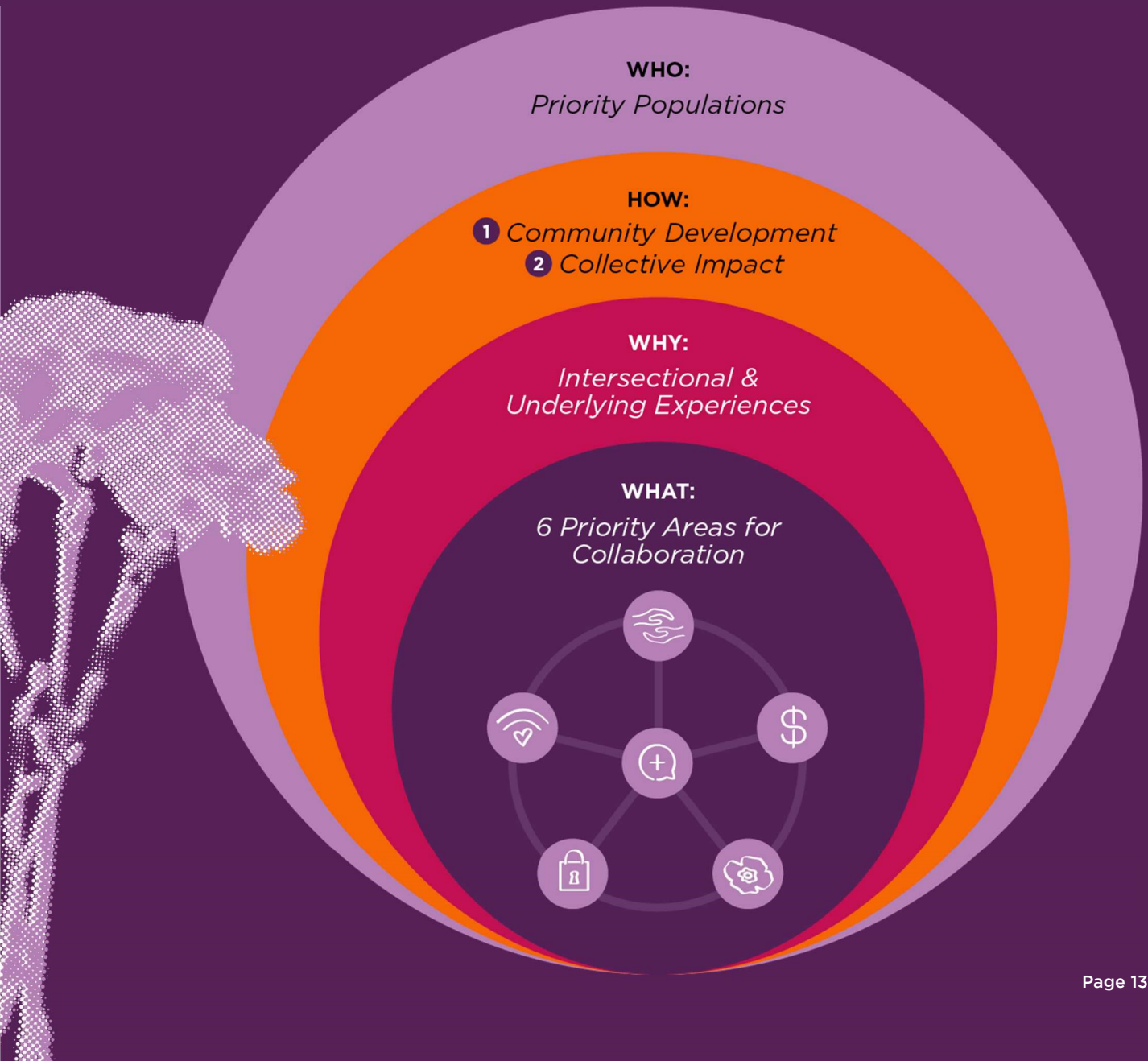


This process of collective analysis and sense-making led to a categorization of women's experiences into three key areas:

1. Intersectional and underlying factors that impact women's health outcomes,

2. Priority Areas for Collaboration, and

3. Community actions for change that can be undertaken both at the provincial and local level, rooted in community development and collective impact frameworks



8.0

Understanding WHAI's Priority Areas for Collaboration

The following sections will illustrate how each of WHAI's six Priority Areas for Collaboration are experienced by women and community partners in the Windsor-Essex and Chatham-Kent regions.

8.1

HIV Education, Prevention, Care & Support

Provincially, one of the most widely acknowledged needs identified through the consultation process was HIV education, prevention, care, and support, and thus is a guiding theme in future work.

Locally, many women feel adequately supported when it comes to their sexual health. When asked if they have been able to support their sexual health in the past year, a majority of women said yes. Additionally, most knew where to access an HIV test if they needed one, that they had received a test recently and had no issues accessing it and could list several places where they could access a test.

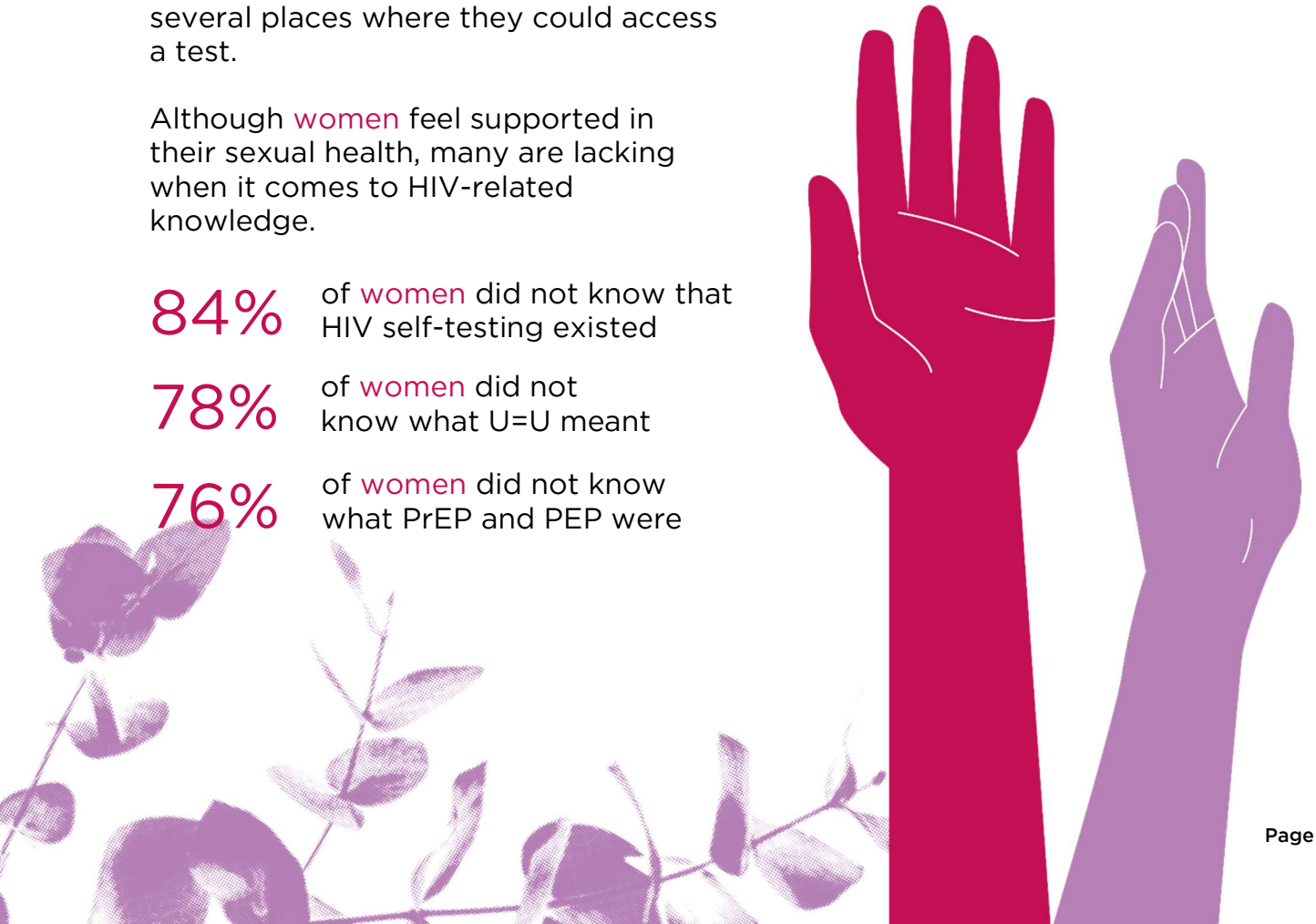
Although women feel supported in their sexual health, many are lacking when it comes to HIV-related knowledge.

84% of women did not know that HIV self-testing existed

78% of women did not know what U=U meant

76% of women did not know what PrEP and PEP were

Lack of HIV knowledge is echoed by community partners, who throughout the consultation process emphasized the need for HIV education and for creative ways to deliver it. Stakeholders themselves experienced a lack of knowledge of supports and were not aware of many supportive services outside of their immediate networks. They expressed an interest in learning more about access to resources and educational pieces surrounding HIV care and support.



8.2

Community Connection

Connecting to other people who have similar interests or challenges to you, who can provide support, or just to decrease isolation is a major area of interest for people and what many consider a necessity to their well-being.

Most women expressed a need for some sort of remedy for their feelings of isolation from their community around them and shared different ideas surrounding the need for safe, supportive communities and programs. Some women thought it would be helpful to have supportive programs that connect people who are facing similar challenges, such as mental health issues or struggling with grief. Others expressed just wanting a space for women to be together to connect, talk, support each other, and do activities together. A few talked about the need for improved versions of programs that already existed in the community.

Stakeholders identified a lack of community connection as a prevailing issue. Community partners themselves lacked knowledge of supportive services outside of their own immediate networks and considered the culture around building a community to be "siloed." This was attributed competitiveness due to funding and awareness, which can create a divide among organizations.

"I need a community and people to talk to – a place to express myself through art."

- Community Voice

8.3

Economic Autonomy

Poverty and financial insecurity were identified in the provincial report as critical barriers to women's health and HIV prevention. This is reflected locally as well.

When asked if they had been able to meet the practical needs of themselves and their families in the past year:

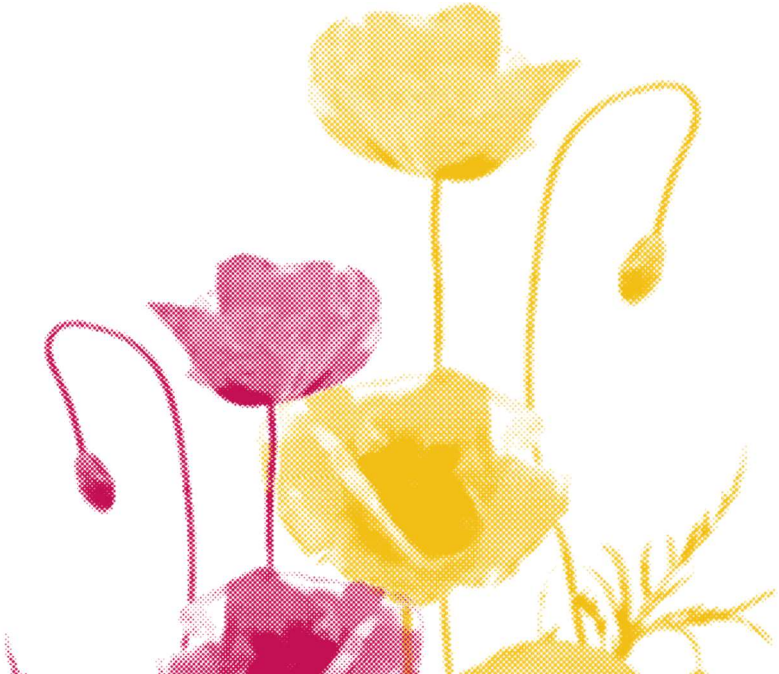
41% of women said no

27% of women said somewhat

Practical needs were indicated to be crucial to women's overall wellness and lacking in this area created barriers for other aspects of their lives. The most common practical need that women were unable to meet was housing. As identified by women in the community, housing is scarce, unaffordable, and many had difficulties scheduling viewings. The intersecting identities of participants as well as stigma they face create an additional barrier to finding housing; some women expressed that landlords were looking for tenants of a specific gender, race, religion, or that they felt that they were being denied renting opportunities due to being homeless.

The importance of economic autonomy was heard widely from Indigenous women, with 5 out of 8 Indigenous participants identifying this as an important area of well-being as well as an area where they felt they needed more support.

Community partners also identified economic autonomy as a key component in women's well-being. There was consistent discussion around a lack of housing and the repercussions of it. With a lack of housing opportunities available to them, many women were forced to remain in housing shelters, leading to longer wait times for others who also required these services and created a backup.



8.4

Women-Centred Harm Reduction

Overdose prevention was recognized as an important component of physical wellness by some women in the consultations; although they didn't consider it necessarily important for themselves, they recognized it as a need for their communities.

Some women brought up that trying to reduce their substance use was a major priority for them, but most simultaneously admitted that trying to reduce their use is difficult. The stigma surrounding substance use can make it difficult for women to access certain resources out of fear of being discriminated against. They also noted that stigma surrounding their substance use impacted other areas of their lives, such as housing opportunities. Some women identified their substance use as a reason that they were denied housing from landlords, and others said that the stigma they experienced was generalized to their everyday life and opportunities.

Stakeholders identified access to supplies as a common issue. They acknowledged that many women did not have access to the tools they required, including syringes, pipes, condoms, and other paraphernalia. They noted that supplies needed to be more accessible for women to reach, and spaces needed to feel safer for women to want to access.

"With the addiction and the homelessness, I experience a lot of stigma."

- Community Voice

Safety

Provincially, it was found that safety intersects with all of the other themes and was conceptualized in a lot of different ways. Safety from interpersonal violence and systemic violence alike were described as essential to the health and well-being of women.

In our community, when asked if they have experienced violence in the past year:

53% of women said yes

9% of women said somewhat

The ways in which women experienced violence reflects the provincial need for safety from both interpersonal and systemic violence.

- Some of the women had experienced violence in the context of an intimate relationship
- Some women mentioned that they experience violence due to racism
- Other women said they experience it more sporadically, such as a robbery or random acts of violence due to being homeless

Some women expressed that although they didn't experience physical violence, they experienced emotional abuse in intimate relationships. They asserted that this form of violence was even more damaging than physical violence.

"Verbal abuse is worse than physical... you have to retrain your mind."

- Community Voice

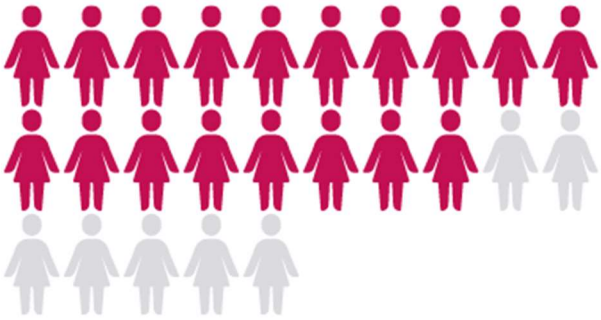
Community partners noted that safety was an issue for some women trying to access certain services. Aside from physical violence, they acknowledged the need for women to receive services from providers who created a safe, welcoming, and non-judgemental environment. Additionally, community partners recognize racism occurring in their organizations but are unsure what to do about it. While racism is prevalent among individuals in shelters, organizations feel ill-equipped to address it.

"A little while ago I was randomly beaten up... just because I am First Nations."

- Community Voice

Wholistic Care

Wholistic care involves several intersecting elements of well-being that impact women's health and happiness including physical, mental, emotional, spiritual, and community factors. Throughout the consultations, participants frequently mentioned that their mental and emotional health were barriers for their wellness as a whole.



18 out of 25 of women disclosed challenges they experienced relating to grief, struggles with mental illness, unresolved trauma, and isolation due to COVID-19.

The women who disclosed these challenges mentioned that if these areas of their mental and emotional health weren't addressed, other areas of their lives struggled because of it. Wholistic care, defined as encompassing several areas of a person's life and well-being, is influenced by other areas of collaboration identified in this report.

Economic autonomy plays a part in wholistic care, as many women confided how their physical wellness was important to them and expressed a need for quality sleep and the desire to have freedom from physical pain.

Women and community partners both discussed the need for an increased number of mental health services in Windsor-Essex. Community partners acknowledged their limited abilities due to the high demand of services and desired more services in the community to be able to direct women to. However, they also acknowledged the competitiveness this creates among organizations with similar services who are vying for the same funding.

"That's what people don't understand, our problem is the trauma."

- Community Voice

9.0

Next Steps

9.1 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.

9.2 Local Level

Locally, the regional WHAI Coordinator will use the findings from the consultations and the foundations of the Priority Areas for Collaboration to guide their planning for local development.

By using frameworks of collective impact and community development, the WHAI Coordinator will continue to work with community partners as well as the provincial network of WHAI Coordinators to share ideas, strategies, and resources to create change in our community. This development is and will continue to be informed and driven by the voices and lived experiences of women in the community to respond to the needs they've identified.

HIV Education, Prevention, Care and Support will be the main focus and driving theme of work to come. Additionally, other areas will be chosen based on community need. As of current, Economic Security, Community Connection, and Wholistic Care were widely identified by both women and community partners as a primary area of concern. These areas will be a focus in upcoming work plans for the community; however, the WHAI Coordinator will continue to engage with and listen to women in the community to keep pace with their changing needs and Priority Areas for Collaboration may shift over the years to respond accordingly.