

# Local & Provincial WHAH Consultations: Final Report

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# A Summary

**CAYR Community Connections was originally founded as the AIDS Committee of York Region in 1993 and formally incorporated as a registered charitable organization in 1996. Our mission and vision are to create safe, confidential, and inclusive spaces and services in York Region where people can access dignified support and meaningfully engage in self-determined pathways to well-being. We envision an informed, healthy, stigma-free, and compassionate community.**

Additionally, we offer specialized and combined programs for: people living with HIV/AIDS, people affected by or at risk of HIV and HEP C, people who use drugs, people who identify as 2SLGBTQ+, and people supporting vulnerable and marginalized community members.

CAYR has a longstanding relationship with the Women & HIV/AIDS Initiative (WHAI). WHAI is a community-based response to HIV and AIDS among Cis and Trans women in Ontario (WHAI, Our Work, 2020). The initiative is located in 16 AIDS Service Organizations (ASOs) throughout Ontario, of which CAYR is one. This report was completed through the directive of WHAI and based on a series of consultations with women and community stakeholders in York Region.

In 2021, WHAI began the process of province-wide consultations with women 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. CAYR participated in these consultations locally, however it is important to note that due to staff transition and the ever-changing nature of the pandemic some of our collected data was lost.

Of the remaining data, CAYR was able to engage 13 women across York region and 9 community partners. The details of these consultations will be explored in further detail throughout this report.

Additionally, the following report will discuss in more detail the background of this consultation process, specifically WHAI's Collective Impact approach, and an overview of what we hoped to learn. As well, we will be providing insight into the methods, participation, analysis, and interpretation of these consultations. Finally, this report will situate WHAI's priority areas for collaboration in the context of York Region while discussing what's coming next from CAYR's WHAI program.

Overall, it is CAYR's hope that this report will inform those in York region on the lived realities of women living with and at risk of contracting HIV. We also would like this report to serve as a thank you and summary of the invaluable information share from the women in our community and the community partners also conducting meaningful and important work.

*CAYR engaged 13 women across York region and 9 community partners in the consultations*

# Acknowledgements

I would like to express my profound gratitude to every individual that participated in the community consultation process. Your insights and stories are invaluable to the work we do and will shape future programming and supports for **women** in York Region and across Ontario.

Thank you to past and present staff who drive this work forward and continue to support the York Region community.

I would like to express special thanks to our **Women's** Peer Advisory Committee for their time and efforts informing our work and supporting **women**.

Additionally, CAYR Community Connections recognizes and acknowledges the lands originally used and occupied by the First Peoples of The Williams Treaties First Nations and other Indigenous Peoples, on behalf of our agency, we would like to thank them for sharing this land. We would also like to acknowledge the Chippewas of Georgina Island First Nation community and recognize the unique relationship the Chippewas have with the land and waters of this territory. They are the water protectors and environmental stewards of these lands, and we join them in these responsibilities.

# Background

## 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.ca/ourwork](http://whai.ca/ourwork)).

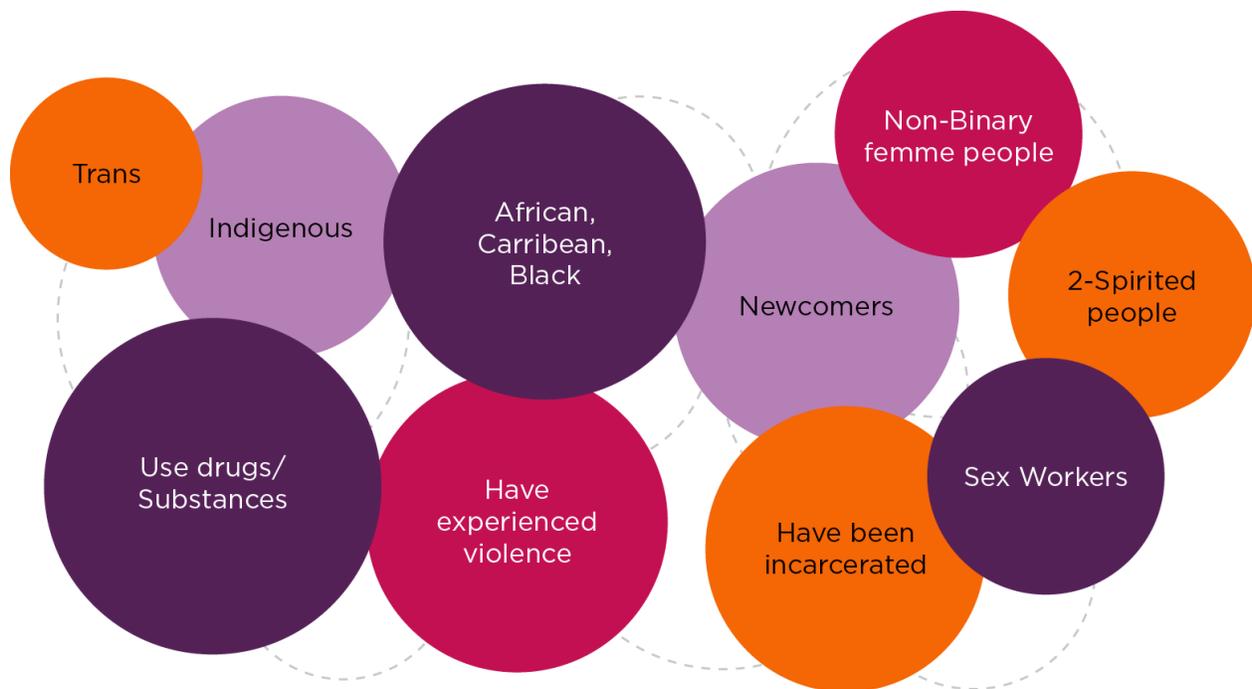
WHAI's work across Ontario is rooted in the principles of community development and collective impact. Community development values the ability of community members to affect change in their lives, in ways that are most relevant to them. Instead of organizations identifying the issues of focus, the voices 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 (Women and HIV/AIDS Initiative Program Guidelines, AIDS Bureau Ministry of Health and Long-Term Care, April 2012).

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 (<https://www.tamarackcommunity.ca/collective-impact>). 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.

## Consultations

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 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.

# Methods and Participation

## Consultations with WHAI's Priority Populations

As mentioned above, CAYR Community Connections underwent staff/structural transition throughout the pandemic. Despite these changes and turnover staff have done their best alongside those at pWHAI to integrate the valuable data collected during the consultations into this report.

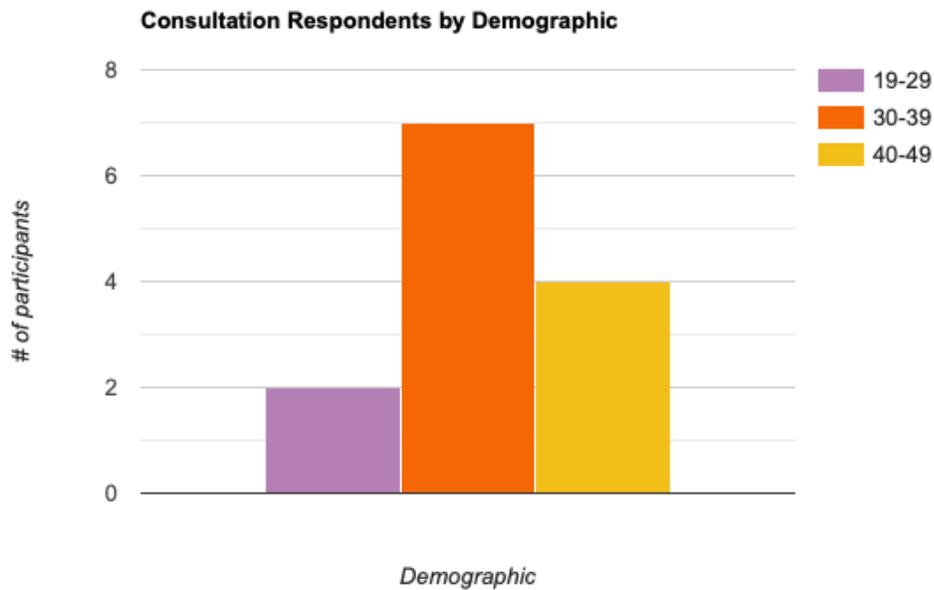
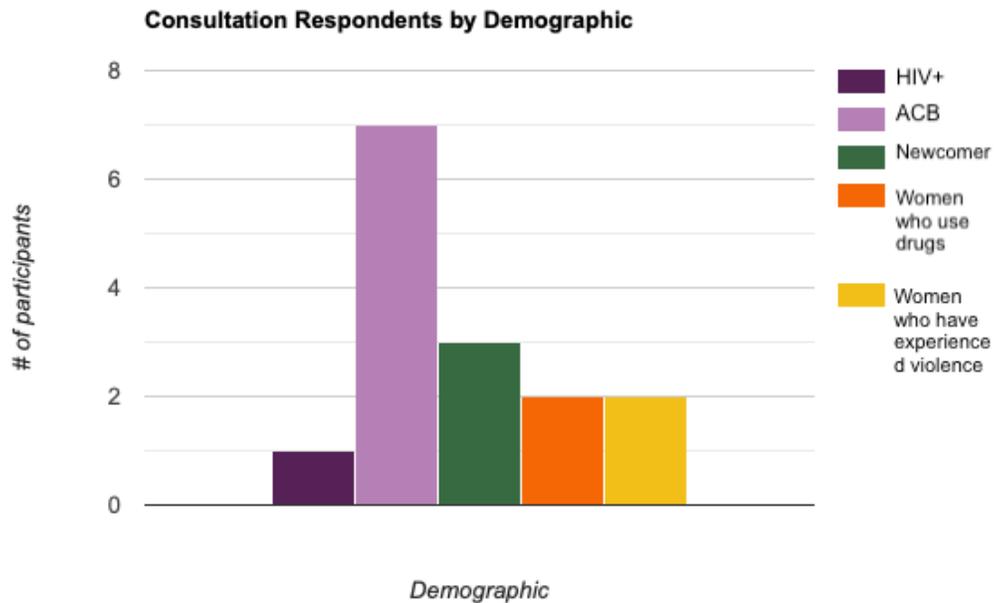
For example, from November 2021 to January 2022 staff at CAYR spoke with 13 **women** regarding HIV, community supports, general wellness and relationships. Some **women** were approached/engaged organically in community spaces, while others were consulted in a focus group setting with a staff and a peer facilitator.

For these consultations staff utilized both the 1-on-1 discussion guide which included demographic questions and possible conversation points to facilitate discussion with **women**. They also used the Dove & Ant Fable tool in a focus group setting. This involved sharing a fable about relationships/wellness with **women** and facilitating a subsequent discussion through prompted conversation topics. For example, *"Think about the leaf the Dove brought that helped the Ant climb to safety. What helps you be well? What has helped to address the barriers you experience to wellness?"* The responses from these tools were collected by WHAI staff and Community Peers and submitted to WHAI on behalf of CAYR. Further detail on how the consultation tools were developed and who

participated in the consultations province wide can be found in the provincial WHAI report.

### Fig. 1 Demographics of Respondents

*To note: Women were able to identify with more than one demographic category while some may not have. The results are a basic summary but may not be fully exhaustive of all demographics represented. For women living with or at risk of HIV, some of the following categories may be harder for some to report than others.*



Reflecting on our programming outside of this project, it has been difficult to receive the same turn out to events, workshops, and community initiatives that we experienced prior to COVID-19. The staff at CAYR have shown their flexibility and innovation when adapting to the new realities of the pandemic. While we cannot report fully on the populations we

had hoped to reach and overall experienced difficulty in this section of the consultations we are grateful for the insights and guidance that can be summarized from the [women](#) in York region. For readers interested in further detail on what [women](#) in Ontario report in relation to wellness and HIV we urge you to consult the provincial WHAI report that summarizes the responses of 501 [women](#) province wide.

## Consultations with Community Partners

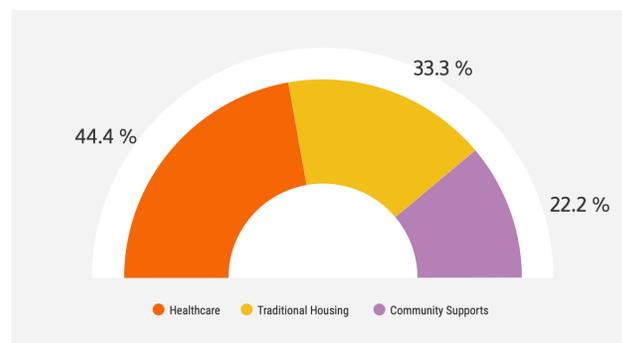
As mentioned, in addition to the consultations with WHAI's priority populations this project also involved consultations with community partners. It was important to the project that we sought out feedback from organizations in York Region doing support work with the priority populations identified. We were interested in their perspectives on; the provincial themes and how they connect to the work being conducted, knowledge on HIV education/care & support, anti-racism work, and community capacity. Similar to the first consultations, staff at CAYR utilized the "WHAI Consultations with Community Stakeholders Note Taking Template" to guide the discussions.

CAYR staff conducted 9 consultations in total, with 7 different organizations, and engaged approximately 21 to 25 participants. The organizations involved represented three key sectors: transitional housing, healthcare and community supports. More specifically the focus of the organizations we connected with ranged from, [women](#) centred community supports, to shelters, public health and paramedic services, legal supports, harm reduction and youth community supports.

The organizations were identified through existing CAYR partnerships and have long-standing relationships to communities in York Region. While those consulted by no means represent the entirety of the partners CAYR works with, we are happy to have included a variety of sectors in this project.

### Fig. 2 Visual Overview of Community Partner Consultations

*Some organizations may offer services from each category. We have identified them in this chart by their primary service offering.*



Again, we urge readers to consult the provincial WHAI report for further detail into the community partners consulted province wide. While not specific to York Region, the WHAI report will paint a better picture of those doing work in neighbouring regions.

# Analysis and Interpretation

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:

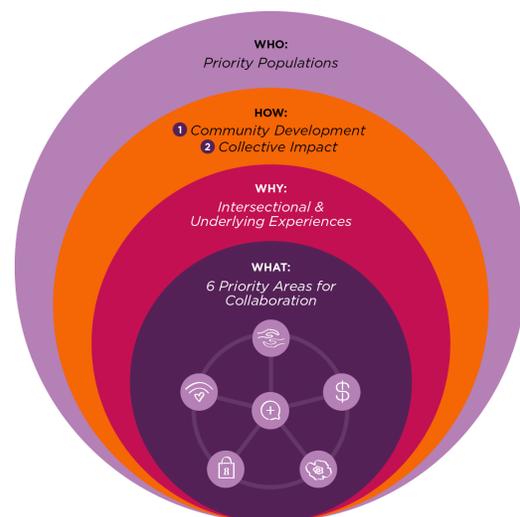
1. **Intersectional and underlying factors that impact women's health outcomes,**
2. **Priority Areas for Collaboration, and**
3. **Community actions for change that can be undertaken both at the provincial and local level, rooted in community development and collective impact frameworks**

**Fig 3. Priority Areas for Collaboration**

## 3.1 - Theme Overview



## 3.2 - Circular Work Model



# WHA1 Priority Areas for Collaboration: Regional Realities

When thinking about the work we conduct and the provincial Priority Areas for Collaboration it is clear that while we can look at these themes as separate, they are overlapping and intersectional for the **women** experiencing them. Figure 3.2 visually outlines the way that these themes and underlying factors influence and layer on top of each other. In this section of the report, we will aim to discuss the context of these themes in York Region through summarizing the gaps identified in the consultations, the experiences of **women** and organizational partners and observations made over the last year of this work from CAYR staff.

## HIV Education, Prevention, Care & Support

As seen in figure 3.2 this theme is at the core of the work we conduct. In York Region specifically there have been clearly identified gaps in basic knowledge surrounding HIV and STBBI's. We know that through covid many organizations in the health and community support sector have experienced turnover and an influx of new staff. This in conjunction with existing societal wide knowledge gaps surrounding PrEP, PEP, PIP and U=U have shown that more education and intentional resource sharing is necessary. When discussing resource sharing, it is also clear that many **women** in the region are struggling to access culturally relevant and diverse resources. Directing **women** and those in the community to HIV related supports is made increasingly difficult by limited resources in a variety of languages, especially for newcomers. Overall highlighting an intersectional concern, **women** who are new to Canada are exposed to so much information, oftentimes not in their native language, that there is reported issues with knowing which resources are the most useful, knowing individual laws/rights, and who to contact for support or even knowing that support exists.

Beyond resources and HIV basics information, there was also an identified concern around stigma and associated misinformation. Those in the community highlighted that many **women** hold on to personal stigma related to HIV and diagnosis that inhibit their access to services. Additionally, organizations and providers in the region have room to grow in relation to updated understandings of HIV. For example, U=U or Undetectable = Untransmittable; the medical understanding that HIV+ individuals “who take ART and who achieve and maintain an undetectable viral load have effectively no risk of transmitting HIV” (Canada, 2020). Without this updated knowledge of HIV many individuals are misinformed and still harbour unbased beliefs that being around people with HIV is inherently dangerous, that it's a disease associated only with gay men, or that being HIV+ is something to feel shame about. Not only does this stigma impact the care that can be provided from supports in York Region, **women** in York region also experience adverse effects to their overall wellness due to fear of how they will be treated when connecting with their community or accessing services. Understandably this stigma is layered with other forms of discrimination and stigma for racialized **women**.

## Women Centred Harm Reduction

Further, this limited education and stigma around **women's** experiences with HIV and STBBI's also translates into limited knowledge around **women** and harm reduction. For example, if HIV risk is viewed as a gay men's only issue than those in the community will have misinformed education around risk for **women**, specifically **women** who use drugs. Understanding risk and taking preventative measures is essential for populations at risk for contracting HIV. In addition, gaps were identified for more resources in non-harm reduction community spaces on substance use and supporting individuals who use substances. For example, staff at CAYR have noticed a need for regional naloxone and harm reduction basics training for community members and organizations.

Additionally, we know that the COVID-19 pandemic forced individuals into isolation. From a harm reduction lens this means less individuals were able to seek out meaningful community supports. For example, resources, social connection, and harm reduction supplies. CAYR staff also highlighted increased concern around individuals being forced to use drugs alone with less safety

## Safety

When thinking of safety, it's important to include conversation around physical, social, and economic security as well as increased risk. Conversations around stigma, misinformation and isolation cannot be had without considering the overall impact on individual safety. **Women** in York Region are at increased risk for poor mental health outcomes as a result of these concerns, in addition to increased risk of general health concerns due to not accessing services. For example, organizations in York Region have noted that **women** are less likely to seek out social supports or healthcare due to fear of familial judgement or social or stigma. These concerns are intensified for **women** experiencing additional barriers due to racism, ableism, homophobia, transphobia and more. Additionally, when discussing difficulty navigating available supports/resources or increased community isolation for **women** we also know this impact's individual ability to leave domestically violent situations or learn that help is available.



# Wholistic Care, Community Connection and Economic Autonomy

As mentioned, the 6 key themes identified as Priority Areas for Collaboration are interconnected by the **women** who experience them. Through our consultations we found a variety of gaps and concerns experienced by **women** that would fit under multiple theme topics. Specifically, the increased pressure placed on **women** who wear multiple hats of responsibility. For example, mothers, homemakers, working professionals etc. For **women**, these additional life pressures can impact their ability to participate in community, financially sustain themselves and their loved ones, and seek out care.

As well, the stigma and isolation mentioned prior directly impacts **women's** ability to take initiative on their health and wellness needs.

Organizations in York Region, including CAYR, have struggled to get attendance to events, workshops, social gatherings, and resources from **women** in the community. Conversations have been generated around how organizations in the region can be more interconnected when thinking of referrals, information sharing, and cultural competency. From the perspective of the individual, workers have found that the burden of having to access multiple agencies and continually be vulnerable about their story & needs is exhaustive and an added barrier to accessing support.

Suggestions have been made around improved methods of sharing resources amongst agencies, educational opportunities for workers in the region and new ways to reach **women** experiencing isolation. With both organizations and community members highlighting shared concerns around safety, mental health, violence, and discrimination.

Overall, the consultations and the collected information have allowed us to more accurately understand the picture of HIV related care and support in York Region. Through the provincial report shared by WHAI readers can see in further detail how these themes and the examples shared here are universally impacting **women** across the province.

## Next Steps

### At the provincial level

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

continuing to facilitate 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.

## At the Local Level

CAYR is committed to the continued goal of creating safe, confidential, and inclusive spaces and services in York Region. Our values are rooted in the principles of anti-racism/anti-oppression, harm reduction and the greater and meaningful involvement and engagement of people with lived experience of; HIV/AIDS, drug and substance use, as well as 2SLGBTQ+ identified community members.

The information collected from these consultations will help to inform future programming and educational initiatives. For example, from resource perspective, looking into increasing our catalogue of culturally competent/language diverse resources and considering innovative ways to engage **women** with information on HIV through discreet resources. Additionally, as the lead access point for HIV-Self Testing kits in York Region we are continuously working to increase community access to this valuable resource. As well, our team is continuously developing and delivering our portfolio of workshops and available trainings for individuals and organizations in the region. Beyond the information collected through the consultations, the additional tools developed by WHAI to increase capacity building in the community will be valuable assets to incorporate into continued programming and support work.

Finally, we want to again thank the valuable contributions made by all those who participated in the consultation process and who make this work possible. This report focusses on the local experiences shared, linking them to WHAI's Provincial Areas for Collaboration. Please see the WHAI website at [whai.ca/resources](http://whai.ca/resources) for our provincial Collective Action Community Change Report.

**For further information on the consultations province-wide we recommend reading the provincial WHAI report. This can be found on WHAI.ca under the resources tab, titled "Collective Action Community Change: A Report Amplifying Community Voices"**

## References

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