GETTING TO ZERO A baseline assessment of policy and program directions to alter the course of the HIV epidemic among Black communities in Toronto and Ontario

An initiative of the Black Toronto to Zero Working Group August 2020

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List of Acronyms

ACB: African, Caribbean, and Black

ACCHO: African and Caribbean Council on HIV/AIDS in Ontario

APAA: Africans in Partnership Against Aids

ASO: AIDS Service Organization

Black CAP: Black Coalition for AIDS Prevention

CAAT: Committee for Accessible AIDS Treatment

CHC: Community Health Centre

CPP: Canada Pension Plan

FTI: Fast Track Initiative

GIPA: Greater Involvement of People with HIV/AIDS

HiFi: High Impact Field-based Interventions

OCASE: Ontario Community-Based AIDS Service and Evaluation

OCHART: Ontario Community HIV/AIDS Reporting Tool

OCS: Ontario health treatment network Cohort Study

ODSP: Ontario Disability Support Program

OHESI: Ontario HIV Epidemiology and Surveillance Initiative

OHTN: Ontario HIV Treatment Network

OSAP: Ontario Student Assistance Program

PEP: Post-Exposure Prophylaxis

PHA: People living with AIDS

PHAC: Public Health Agency of Canada

POC: Point of Care

PrEP: Pre-Exposure Prophylaxis

PWA: People with AIDS

TPH: Toronto Public Health

TTZ: Toronto to Zero

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Maureen Owino Joanne Louis Co-Chair Co-Chair

OVERVIEW

Toronto to Zero (TTZ) is an initiative of the Ontario HIV Treatment Network (OHTN) to reduce HIV transmission to near zero in Toronto. Even though Black communities bear a disproportionate burden of the HIV epidemic in Ontario and across Canada, TTZ was initially conceived and launched with insufficient consideration for the impact of HIV among Black communities. As a result, leading stakeholders in Toronto (program planners, researchers, and community advocates, including Black people who are living with HIV) established the Black Toronto to Zero Working Group (Working Group) in 2019. The Working Group came together to primarily focus on the role of structural determinants associated with anti-Black racism in driving the HIV epidemic among Black communities. The main purpose of the Working Group was to advocate for an approach to TTZ that would substantially change the course of the HIV epidemic among Black communities in Toronto and Ontario.

As part of its work, the Working Group initiated this baseline assessment of critical aspects of the current response to HIV. This assessment captures information from the following sources: deliberations of the Working Group; consultations with the provincial funding and oversight agency, Executive Directors of AIDS organizations service providers, and service users (i.e., people who access HIV services at frontline AIDS organizations); and data from the Ontario Community-Based AIDS Service and Evaluation (OCASE), which is a system for managing the records of people who access services at Ontario's 32 community-based AIDS agencies.

The assessment sought to understand: 1) the main priorities for turning the tide of the HIV epidemic among Black communities based on deliberations among the Working Group; 2) the framework for community-based HIV services and programs available to Black people, including the strengths, challenges and opportunities for improvement associated with current services; 3) and current trends in service use and access.

This report also identifies key recommendations that may strengthen the response to HIV and help change the trajectory of HIV affecting Black communities in Toronto and Ontario.

Structure of the report

This report includes the outcome of discussions and recommendations that emerged from the deliberations among Black stakeholders and consultations with provincial policymakers. The report is structured around these main areas:

- 1. Priority issues and *recommendations* for changing the course of HIV among Black communities in Toronto, based on deliberations among the Black TTZ Working Group.
- 2. An environmental scan of programs and services available to Black communities in Toronto (consultations with leaders in community-based AIDS organizations, service providers, and provincial policy makers), and *recommendations* proposed by ASOs and service users.

- 3. A synthesis of key recommendations from Black stakeholders (i.e., the Black TTZ Working Group, leaders in community-based AIDS organizations, and service users). In addition, we also:
 - 4. Identify various supports and initiatives that policymakers have supported that may provide space for working on the key recommendations.
 - 5. Present a profile of service users and trends in service use over the last five years (2015-2020) (Appendix 1).

It is hoped that the recommendations put forward in this report will strengthen service delivery, highlight opportunities to improve service access and outcomes, initiate a process to systematically track and monitor the epidemic among Black communities, and ultimately strengthen health and wellbeing among Black communities (including those who are living with HIV).

Toronto to Zero

In 2019, the Ontario HIV Treatment Network (OHTN) initiated Toronto to Zero as a program to substantially reduce HIV transmission in Toronto, using the framework of the global Fast Track Initiative (FTI). The FTI is inspired by the Joint United Nations Program on HIV/AIDS (UNAIDS) approach to end HIV transmission, and focuses on cities which account for the vast share of HIV transmission globally.

In 2014, the UNAIDS proposed a cascade of critical steps that will culminate in ending HIV transmission by 2030. Many countries and large cities have adopted the UNAIDS framework and timeline. The cascade of critical steps has set the following goals, often referred to as the 90-90-90 targets, for jurisdictions: 90% of people who are living with HIV are diagnosed; 90% of those diagnosed are retained on treatment; and 90% of those on treatment achieve viral suppression. The result of this cascading scenario is that HIV transmission will be significantly reduced.

The TTZ initiative takes a similar approach to achieve a two-thirds reduction in HIV transmission through a 95-95-97 benchmark process, with the addition of a fourth 90 that represents improving the wellbeing of 90% of people who are living with HIV.¹ The TTZ has selected "champions" comprising agencies and stakeholders who have been at the forefront of responding to HIV among Toronto's diverse population. Among other roles, they are charged with overseeing the initiative's planning, implementation and impact/outcomes, and ensuring its feasibility.²

¹ http://torontotozero.ca

²http://www.ohtn.on.ca/about/ttz-champion-team/

THE BLACK TTZ WORKING GROUP & PRIORITY AREAS FOR CHANGING THE COURSE OF HIV AMONG BLACK COMMUNITIES

Introduction

In 2019, the Ontario HIV Treatment Network (OHTN) supported the formation, leadership, and development of Toronto to Zero (TTZ)³, led by the TTZ Champion team. The Champions comprised agencies and stakeholders who have been involved in the response to HIV in Toronto and Ontario. In response to the TTZ initiative and acknowledging the hugely disproportionate effect of HIV among Black communities in Ontario,⁴ a team of Black champions in Ontario formed the Black TTZ Working Group. The Working Group members understood that Black people are structurally disadvantaged, which means that policies and programs that achieve "zero" for some population groups are unlikely to benefit Black communities to the same degree. Therefore, while Ontario might appear to be ending HIV, the reality might remain different for Black communities.

In August 2019, the Working Group held its first meeting with 50 Black stakeholders from across the response to HIV among Black communities. The meeting provided the foundation for a shared understanding among those involved, gave a general picture of the challenges Black people face and possible remedies, and set the stage for how the Working Group would identify and articulate recommendations for substantively changing the course of the HIV epidemic among Black communities in Toronto and Ontario. The main priority for the Working Group was to propose or support strategies and recommendations that would help change the course of the HIV epidemic. Previously, a group of service providers had expressed concern about whether the current service landscape was robust enough to support TTZ or other initiatives created to address HIV among Black communities. As a result, the Working Group decided to undertake an environmental scan of programs and services in response to the concerns raised by service providers.

Based on the stakeholder meeting from August 2019, the Working group identified five priority areas for strengthening the response to HIV among Black communities (Appendix 2). In March 2020 the Working Group met by videoconference over two days to discuss five priority issues to substantively change the course of the HIV epidemic among Black communities in the next five years. Two members of the Working Group championed each of the five issues, and led the discussion of their respective issue in the meetings. The Working Group designed the process to identify recommendations or courses of action that, together, may substantially reduce HIV transmission among Black communities in Toronto and across Ontario. The Working Group also conducted a scan of available HIV-related services in Toronto to gain more practical insight into access and utilization of HIV programs and services by Black people. Together with the recommendations and actions related to the priorities, these would strengthen health and wellbeing among Black people who are living with HIV.

³ http://torontotozero.ca

⁴http://www.ohesi.ca/documents/OHESI-New-HIV-Diagnoses-preliminary-updates.pdf pg.7

⁵Kataisee, R, (2019): Toronto to Zero African Caribbean and Black Working Group, Meeting Report

Based on the discussions in the stakeholder meeting in 2019, the Working Group also identified two overarching issues to guide or inform understand and possible implementation of the priorities. The overarching issues are as follows:

Anti-Blackness and structural violence

Canadian society is structured to undervalue Black people's health and wellbeing. Enduring inequities in employment, income, wealth, education, access to justice, food security and other areas demonstrate how social arrangements position Black people on the margins of Canadian society. As it relates to HIV, epidemiological data show that Black people carry a disproportionate and growing burden of HIV, while the white population's share of diagnoses has been falling. Moreover, Black people are significantly less likely to benefit from engagement in the care cascade. These trends indicate that the approaches to HIV prevention, care and treatment that work for affected white communities, are unlikely to generate equitable outcomes for Black communities. Moreover, Black stakeholders are often assigned subsidiary roles (or even excluded) in decisions about policy and research, which means that the systems for responding to HIV benefit insufficiently from Black people's knowledge and experience about HIV and their communities. "Getting to zero" calls for a new commitment to Black leadership, and for decision makers to prioritize the actions, recommendations, experiences and enthusiasm of Black communities and stakeholders.

Engaging Black stakeholders to address HIV among Black communities

The effort to substantively change the course of HIV among Black communities requires the attention, support, commitment and contributions of a representative cross-section of interested people and community-based organizations from those communities. This includes people of different nationalities, genders, sexualities and age groups who are affected by HIV; agencies working on the frontlines of the community response; as well as academics, activists, advocates and community organizations with different skills, experiences and expertise that are germane to addressing anti-Black racism, the social determinants of health, policy and program development, and community engagement. Our stakeholders must be willing and able to work collaboratively, and show leadership in our community-based response to HIV.

Priority Areas: discussion and recommendations from the Working group

In this section, we summarize the discussions among the Working Group from March 2020, and outline the recommendations that the Working Group identified.

Priority areas for the Black Engagement for HIV to Zero

- 1. Trends in the epidemic among Black people
- 2. Black people in relation to the HIV cascade
- 3. Innovative approaches to testing that are culturally informed

- 4. Understanding and strengthening the landscape for engagement in care and treatment
- 5. Timely critical evaluation of new technologies for prevention and treatment

HIV testing

Generally, the point of care in Toronto Public Health (TPH) clinics provide most HIV testing services, yet many Black people may not be accessing services at these spaces. Also, race-based data on HIV testing is not available, segments of the Black population are deterred from accessing testing services due to stigma, and the resources for testing may not be sufficient for Black agencies. Some agencies are doing their best to reach a range of people through outreach, but are limited by resource constraints. Besides, research on the effectiveness of testing has not targeted Black people. The most recent initiatives to test the feasibility of self-testing does not include partnerships or high-level engagement with the extensive cross-section of agencies and stakeholders that have a history of serving Black communities. Testing is perhaps the most important 90 of all the established targets, because it is the starting point for the cascade – the other points on the cascade depend on whether HIV testing is effective. Therefore, getting Black people diagnosed and in care by increasing access to testing services, and linking those who test positive to care, will have a substantial impact on the course of HIV among Black communities.

Recommendations for improving testing

- Partner testing services with community-based organizations that serve Black communities.
- Adopt and promote ethically responsible, respectful and innovative testing (e.g., adapting the emergency room testing currently happening in Ottawa to the realities of Black communities).
- Extend point of care testing to areas where vulnerable populations live (e.g., the Black Creek Community Health Centre in north-west Toronto).
- Adopt, promote, facilitate and encourage self-testing based on research and consultation with Black community-based agencies and stakeholders. As soon as a valid self-testing option is available, it will be a good mechanism to promote testing among Black communities. However, getting the best outcomes from self-testing requires the following:
 - Ensuring linkage to the healthcare system for those who test positive
 - Mechanisms for preparing people to test and receive results
 - Information on treatment services, pre- and post-testing, and adherence
 - Addressing self-isolation which often prevents people from seeking treatment
 - Addressing barriers to testing in our communities in a holistic way
 - Addressing structural challenges already faced by Black communities to avoid competition with testing
 - Streamlining service access mechanisms for Black people

- Adequate linkage of the point of care system and the health care system
- Providing people with information on benefits of testing, along with incentives
- Addressing stigma associated with HIV and the ACB communities
- Learning and adopting best practices from communities in other jurisdictions that have successfully implemented self-testing. For example, learning about how they dealt with issues of acceptability by the communities
- Addressing the high estimated costs of the test kit (estimated at \$20) and advocating for free HIV testing for Black communities.
- Ensuring that the self- testing kit is easy to use, with specific information and contact information for Black community-based agencies that can answer questions and provide guidance
- Instituting a national telephone number for people to call for help and answers
- Investigate and develop a testing model that works for Black communities.
- Adopt home testing models that have worked in other countries (e.g., models which promote community engagement).
- Periodically review the trends of HIV testing among Black populations to identify enablers and barriers, and strategies to address them.
- Build and strengthen structures for delivering testing services in Black communities.
- Engage communities and ensure that the messaging on testing is clear, culturallysensitive and beneficially impactful.

The HIV Treatment and Care Cascade

In 2015, the OHTN published data on the cascade for Ontario. There is no publicly available data on the cascade for Black people, although data have been made available to certain members of the Working Group. These data show that Black people are sub-optimally engaged in the cascade, compared to some other group. The essence of achieving 90-90-90 is to have zero new infections across the population. This will not be possible if data from Black populations in Ontario is missed or inadequately captured.

Recommendations to improve cascade outcomes

- Understand and address barriers to recruitment for Black participants in the Ontario Cohort Study (OCS).
- Advocate for disaggregated race-based data from the OCS on Black people in Toronto and Ontario.
- The OCS could consider working with, and collecting data from a wide range of agencies and organizations where Black people access services.
- Work with agencies such as the Black Coalition for AIDS Prevention (Black CAP), Africans in Partnership Against AIDS (APAA), Committee for Accessible AIDS Treatment (CAAT) and Toronto People with AIDS Foundation (PWA) to identify the points at which Black people fall out of the cascade in Toronto (and why they fall out or are not engaged), and adopt a similar strategy in other cities across Ontario.
- Establish how the cascade looks for various segments of the Black population (e.g., gay men, straight men and women etc.).

- Publish routine and timely data.
- Strengthen the capacities of agencies that capture data from/about the Black population.

Data collection and dissemination

Data on trends in diagnoses among Black people are available for Ontario. Moreover, the Public Health Agency of Canada (PHAC) reports that as of 2019, they will no longer publish racially disaggregated data on new HIV cases. It is impossible to determine the trend of the HIV epidemic among the Black population without a range of data. It is also not clear how the data that are available actually benefit Black communities, aside from illustrating how Black communities are disadvantaged. Often, Black communities and stakeholders are the last to know what data are being collected, who is using it, and for what purposes, which raises questions about who benefits from the data on Black people. Given these challenges, it will be extremely difficult for Black people in Toronto and Ontario to demonstrate any success (or failure) in the city's journey towards zero.

Recommendations to strengthen the collection, use and dissemination of appropriate data

- Request a rapid response report from the OHTN on how other jurisdictions such as the USA, Europe, etc. are monitoring the course of the epidemic among Black communities.
- Request clear guidelines from PHAC, OHTN and TPH on the kinds of data being collected, what data would be instrumental to monitoring HIV among Black communities, who is collecting it and the extent to which it is accessible. This process should also identify gaps in data, and actions or strategies to address the gaps.
- Make recommendations to PHAC and TPH about collecting and publishing race-based data. Explore the commitments made on monitoring and surveillance of HIV-related data in the Federal Action Plan and Framework.
- Encourage collection of race-based data on testing services.

Prevention and treatment technology and engagement in the cascade

Black communities and their stakeholders often become sufficiently aware of new and emerging technologies for treatment and prevention only after those technologies are already available to the majority white population that has privileged access to the required information. Besides, Black people are worried about how their confidential information could be used against them when service providers use an integrated care model involving a social worker, a physician, and technology unknown to them. As well, the procedures for successful engagement in the cascade are generally not supportive of Black people, leading to a loss to follow-up, poor adherence support, and low motivational initiatives for those enrolled.

Recommendations to improve access to treatment technology

• Empower Black-serving organizations with knowledge on prevention and treatment technologies to enable them to better serve the Black communities. Information packages could include the range of accredited medications, what these medications do, their side effects and other relevant information. Appended is a summary matrix

highlighting knowledge parameters for implementing new HIV technological and medical interventions, and critical questions for long-acting injectable pre-exposure prophylaxis (Prep), Descovy, post-exposure prophylaxis (Pep) and other new HIV technology interventions (Appendix 3). Also, centralize the source of information for frontline staff to improve their knowledge about new and emerging treatment.

- Review ethical standards and policies which may reduce or eliminate useful interactions between drug companies and communities. This information could be tailored to communities to increase uptake and eliminate myths and misconceptions.
- Initiate a conversation between Black leadership and pharmaceutical companies for information-sharing on drugs. Black agencies should be able to access credible sources of information and data so that they can educate their communities in Toronto and Ontario.
- Share formulations that work for Black people and initiate dissemination of information about the drugs that work. For example, Black people need better access to PrEP at a price they can afford, and with better information to demonstrate its efficacy.
- HIV should be at the centre of the integrated care model by addressing the care cascade beyond HIV, by integrating programs and building them around social determinants of health.
- Support the formation of an organized community of Black people to streamline their service delivery to their community by instituting a hub, while strengthening their internal and external collaborations to create harmonized resource mobilization processes and better services to Black communities.
- Retain Black clients in care and engage them to contribute to care. Engagement helps them find or remain in employment, build their esteem, and feel accepted by the system.
- Provide financial and non-financial incentives, and other forms of motivation to enable retention in care.
- Provide correct information on medications, new HIV technologies, and new medical interventions to Black communities, and address myths and misconceptions. Appended is information/recommendations across medication, patient care, and broad efforts to improve HIV care, and prevention in ACB communities with common themes on medications (Appendix 4).
- Develop a communication strategy to reach out to the community of stakeholders to address racism and other structural determinants and to support the journey towards zero since everyone is affected by HIV. Use provincially recognized days like the Black Mental Health Day in Toronto (1st March each year) to advocate for spaces and initiatives beyond TTZ.

STAKEHOLDER PERSPECTIVES ON HIV SERVICES FOR BLACK COMMUNITIES IN TORONTO - FINDINGS

Our consultations with AIDS Service Organization (ASO) leaders (i.e., executive directors and program managers) and service users, explored the strength, weaknesses, and opportunities in

service provision for Black communities in Toronto. We also explored the standards of service provision available. With funds from the OHTN, and the support of agencies serving Black people in Toronto, the Working Group used the Appreciative Inquiry Model⁶ to design the consultations on available HIV services and programs for Black people.

Methodology and Process

The project team held discussions with the executive directors or program managers from eight organizations whose service users include Black people living with or at increased vulnerability to acquiring HIV. We also interviewed seven service users and held discussions with policymakers from the provincial government who fund and oversee HIV programs in Ontario.

The team reached out to executive directors about the project and requested meetings with them individually. We recruited service users through the agencies that provide support or services. Participating service users had to be at least 18 years old, reside in Toronto, self-identified as Black, and routinely accessed services from one or more of the organizations that provide HIV-related services.

All meetings with ASO leadership and service users took place by telephone. Participants received a consent form, which they reviewed with the project coordinator at the time of their meeting, and gave verbal consent that was part of the meeting's audio-recording. In keeping with the information in the consent form, all meetings were recorded and transcribed. The research team sent an email to all participants individually to prepare them for what they should expect in the telephone meeting. Service users ranged in age from 18-45 years, and included four men and three women, four long-term survivors (i.e., accessing HIV services for at least five years); three who identified as Caribbean and four as African. Each service user received an honorarium for participating.

The project team reached out to the AIDS Bureau at the Ministry of Health and Long-Term Care, with written questions about standardization and oversight of HIV programs, and followed up with a conference call to clarify the information initially provided. The AIDS Bureau is a provincial funding agency.

Findings

ASO leadership's perspective

Summary of main points

Service providers identified the main access barriers to HIV services and programs by Black people in Toronto and Ontario as:

• Disparities in socio-economic wellbeing that affect Black communities. Some Black people cannot (or may not) access HIV services due to the absence of health coverage,

⁶http://appreciativeinquiry.case.edu/

membership to a specific group, and other systemic reasons. Also, there are gaps in programming where the needs of the community are not supported by available funding (or the face of the HIV epidemic is inconsistent with the level of investment in HIV services are care).

- Inadequate resources and information for Black people. ASOs serving Black people are under-resourced, and ASOs usually cannot carry out successful fundraising from the local communities. Also, information on the available HIV and AIDS services for Black people is inadequate.
- Poor coordination of agencies serving Black communities to address cross-cutting issues and access to necessary services by Black people.

ASOs demonstrate several strengths related to their mission. Generally, they:

- Participate in leadership at different levels.
- Offer programs addressing HIV prevention, treatment, care, and support services.
- Have broader health infrastructural capacity.
- Conduct in-house research through evaluations and research on HIV.
- Use peer-based approaches and social media to reach out to their members.
- Have access to advice and support for legal issues that their constituents may face.

Service providers recommended:

- Building an infrastructure that bridges programming, research, and policy as a continuum.
- Making the HIV community model more participatory, empowering people to manage their lives, and advocate for their health needs.
- Providing timely, reliable, accurate information on the HIV and AIDS services available to Black people.
- Improving service and program coordination among ASOs serving Black people.

Detailed service providers' perspectives

Strengths of service providers in delivering services

1. Some ASOs serving Black communities conduct in-house research through evaluations and research on HIV. A respondent noted that:

"Our own ACB researchers in Toronto who are involved in research topics that concern us, they have done a big job really of raising questions, asking questions, and answering questions."

These researchers seek feedback from members utilizing their services through client interviews and surveys to identify program approaches that are working. Also, they gather evidence from external sources by identifying programs with specific outcomes related to the work they do and adapt them to their local reality. ASOs involve their local memberships

to do this research. Through research, ASOs have developed project models, and through partnerships with other agencies, they share knowledge with the research community.

2. Black people participate in leadership at different levels. Some sit on executive boards, as part of the staff or volunteers. Some agencies engage their clients to get information about views on their services through storytelling; and some do client satisfaction surveys on an annual basis as part of funding requirements. Members participate at the community level, by doing research, either as research-participants or as research assistants, as part of different committees, and as peers when collecting data. Others participate in providing healthcare. An interviewee stated the importance of client-led approaches to health care:

"Strengthening community approaches by improving ACB participation helps improve the ACB participation in managing their own health, by engaging them in their own health care. That way, the tendency of thinking that ACB people are not willing to be involved in their own health-care would be dealt with."

During COVID-19, some ASOs engage clients on the phone at least once each month, and others are staying engaged virtually with clients to provide support and services. A service provider highlighted that the ACB community in Toronto is predominantly young, and their participation is paramount:

"...The ACB community in Toronto is a relatively young community; I assume that we have a large cohort of youths, prepared to be engaged, to learn about the importance of managing their own health, the importance of preventing HIV, and the importance of working with other people to improve their own health and wellbeing."

3. Some agencies have extensive HIV programs addressing prevention, treatment, care, and support services. Some agencies place HIV within a broader framework of service delivery such as the primary care model, where HIV service beneficiaries access services through primary health care, which reduces HIV stigma in part. Some of the agencies provide services in community-based settings where Black people congregate, instead of traditional healthcare settings. Other agencies make use of social events like the Toronto Caribana Carnival, Caribana, to provide HIV services to larger groups. They also do service delivery using peer-to-peer approaches. One interviewee said:

"There is a large number of ACB-specific programs in Toronto that I think is a great strength that can be certainly capitalized on."

4. Some ASOs serving Black people have broader health infrastructural capacity to help clients stay linked to services. ASOs are linked to community health centers (CHCs) where clients have access to doctors. Some ASOs also have organizational development capacities to deliver services to Black people such as the agencies which partner with hospitals to provide care and support to pregnant women without health coverage. These partnerships also

mitigate stigma by providing services that are not primarily HIV specific, and provide family doctors and specialists for each of their clients. Two respondents spoke about capacity and organizational development that allow for expanded service delivery:

"We do a whole bunch of testing annually as part of our programming just because we have the capacity to do HIV testing."

"We have the mandate ...our mandate comes from a strategic direction at the board level, straight through to our management and into the delivery of our programs. I can assure you that we need the political will to provide good services to our people."

5. Some ASOs use peer-based approaches and social media to reach their members. By doing this, members remain in touch with each other, communicate with ease even in unprecedented times like the current COVID-19 pandemic. They form a connected community that empowers them to negotiate relationships with other health service providers and hospitals. One participant said:

"Social media is one potential opportunity to spread any message to our members since Black people are frequent users of social media."

- 6. There are also supports for legal issues. The Black Legal Action Centre provides specific service to Black low-income people in Ontario. They handle some of the most common legal issues affecting Black populations such as child protection matters and other issues. These are handled professionally without prejudice by working with HIV-specific and other human rights organizations. A service provider had this to say:
 - "... We work together as a group comprised of the Black Legal Action Centre, Aboriginal Legal Services, Canadian Civil Liberty Association, and HALCO [HIV and AIDS Legal Clinic Ontario], to address issues of HIV and Black people."

Weaknesses/challenges

1. Information on the available HIV and AIDS services for Black people is often inadequate. People are silent about the available HIV services in the same way that the environment is silent about HIV. That is, HIV is often not discussed openly in public. Silence has created a knowledge gap, as these service providers highlighted:

"I think that when new immigrants come into the country, they're not really given information about how to access HIV/AIDS services on prevention, treatment, and care services."

"HIV became a bedroom talk to only the HIV positive people. The public has not been given an opportunity to take part in the HIV interventions in Toronto. I have proof of this on World AIDS Day."

Providing information about HIV to Black communities will address existing knowledge gaps and improve service access. Two service providers had this to say:

"People don't know that PWA [the People with AIDS Foundation] helps people without immigration status, without health coverage to access HIV medication. You can go and pick up medication there, but this information is not readily available."

"People need the right information. I think there's an educational piece that needs to go out to our communities. Black people actually should understand what HIV means. There are a lot of misunderstandings on what that is and what it looks like."

2. There are disparities in accessing HIV services by Black people due to the absence of health coverage, membership to a specific group, and other social systemic reasons. Immigration status determines access to health services in Toronto. One of the service providers observed that:

"[Many] Black people come to Canada as refugees, some get immigration status only for a while, others do not get status at all."

Another added:

"Whether it's through the refugee stream or a different stream in the immigration process, [some] people test positive when they arrive here and find challenges to access HIV services."

Some Black people without status do not access healthcare, do not navigate systems, and do not access information on available services. Many face immigration challenges leading to a lack of, or delayed, legal status that prevents them from accessing social services such as education through the Ontario Student Assistance Program (OSAP) grants and healthcare. A respondent expressed this sentiment saying:

"There are gaps in the immigration system set up, and I have a number of concerns with the medical process that people engage in when they test positive, and I've heard some issues related to linkage to care when a newcomer arrives here."

With growing numbers of Black people of diverse genders and sexualities, from Africa, the Caribbean, and the United States, some of whom are living with HIV, the target populations for most HIV programs has not changed enough. This has reached an extent that one service provider quoted a service user who said:

'Black people are starting to take away our services. They will run out of stock soon. We can't agree to that…"

Anti-Black racism often intersects with other social determinants of health such as sexual orientation, homelessness, and transphobia. Black people have often not felt welcomed at some health facilities, and that has pushed them away from accessing services. That said, some Black people choose not to access HIV services because of low-risk perception. Historically, Black men may not have generally perceived themselves as being vulnerable to HIV. Convincing some men to do an HIV test and seek other HIV services is difficult, as indicated by this respondent:

"Some Black men don't think they need HIV services. They think that HIV is somebody else's issue, they don't understand risk. They say, 'I'm gonna have sex tonight', without conceptualizing that there is a risk of who they are having sex with, and how."

3. There are discrepancies in programming for Black people in Toronto. Sometimes, the needs of the community are not consistent with what is funded and the face of the HIV epidemic doesn't determine HIV investment. Also, racism affects the type and level of services that Black people receive or is available to them. A service provider explained the situation like this:

"I wake up each day feeling [oppressed]. As Black people, that's how it feels. And when I see a fellow Black person being treated differently, it...it really does affect me emotionally...it's very painful, and then, in general, I think there is racism in this country."

Also, some services are not in sync with the needs of Black people, or are not linked to other broader services for a holistic approach to healthcare. Some of the services are fragmented, as if HIV services are provided parallel to the other health services for Black people. A respondent shared their thoughts on this:

"...But how can we incorporate them in some already existing things, where people gather, where people go to get information, you know! There are groups of Ethiopians, groups of South Africans, they gather in different places. How do we infuse and intercept those groups as opposed to have expanded on HIV service to which we expect people to come and access?"

Additionally, some of the services available are designed to meet the needs of specific groups of people living with HIV. In fact, some of the available HIV services still privilege white gay communities as the face of the epidemic.

4. ASOs serving Black people are under-resourced. One respondent had this to say:

"Some funding agencies are not writing cheques for the ACB-specific organizations; no matter how many times the ACB organizations ask for funding, it's less likely that they get the funding because of structural inequities."

ACB organizations are doing community fundraising but this is challenging if they do not have strong grounding in the general Toronto community. A lack of sufficient funding prevents ACB agencies from coordinating the response and being well integrated and appreciated by the Toronto community. A service provider lamented that:

"There's history in this situation of funding where agencies like PWA have successful fundraising programs that have been robust for the last 20 or 30 years. They have fundraising staff, and professionals that work for them, and they have very deep pockets to fund their fundraising in a way that most ACB-specific organizations cannot."

5. Some service providers feel they are not well-coordinated to address cross-cutting issues and aspirations as it relates to Black people's access to HIV services. Many respondents who have been around since the formation of the African and Caribbean Council on HIV and AIDS (ACCHO) said the organization doesn't help them to address their coordination challenges. For example, one of the interviewees said:

"Whereas ACCHO was formed to enhance coordination of ASOs servicing Black people at the province level, it was so helpful at its formation, but not anymore. ACCHO was bringing ASOs together and building collective actions for HIV prevention, treatment, patient care, research, and it was the only viable voice for effective advocacy for Black people on HIV matters."

Another participant said:

"There's a large network, uhm...actually I shouldn't say network cause we're not networked with each other, but there's a large, large number of ACB-specific organizations in Toronto."

ASO executive directors and program managers feel the issue of coordination is very important and say they have invested in the formation and operationalization of ACCHO so much that they want to see it perform better.

6. Some ASOs do not have an anti-oppression policy and/or have one but have not implemented it. Some agencies do activities without an anti-oppressive lens. The tendency of confusing anti-oppression and racism has fueled oppression in some agencies. Black people cannot achieve zero if oppressive tendencies continue to prevail.

Opportunities

1. The Toronto to Zero initiative is an opportunity for Black communities to come together and work collaboratively. Currently, each player is providing services in isolation. Often, one agency is not aware of what is going on at another organization. A member said:

"I think if we put all our eggs together, and see what's missing through this platform of the Black TTZ, it is a chance for us to optimize efforts, and by doing so, we shall get to zero like everybody else."

2. Attending educational institutions in Toronto and Ontario is an opportunity for Black people to further their education, and improve their skills and capacities to deliver better HIV services. They can also change and/or improve their initial careers. OSAP is an option for financing their education. One respondent said:

"...And, I think there's also an opportunity of the formal education around us which we as Black people should make use of."

3. There's an opportunity to create programming that is responsive to the needs of Black people by strengthening the existing agencies serving Black people. This can be achieved by extending their reach, as well as improving the quality of services and programming. Black people can come together and call on interested parties to support this initiative.

<u>Recommendations</u>

- Black people need to build an infrastructure that bridges programming, research, and policy
 as a continuum. Develop evidence-based programming through the continued collection and
 documentation of data as well as review of existing data. Research should guide policy and
 programming, in addition to being used for improved service delivery and to advocate for
 the expansion of HIV services in Toronto and Ontario.
- 2. There is a need to make the HIV community model inclusive of other community-based participatory mechanisms, where it is not just about doctors or hospitals, but also about how people can manage their lives, stay engaged, and advocate for their needs. We could extend the HIV community model to address other chronic conditions for a holistic approach to care. A participant said:

"There is also the piece about working within the community too, so that people are empowered to be able to advocate for themselves, to stand up in a united way, in a united voice to make things happen."

3. Black people need timely, reliable, accurate information on the available HIV and AIDS services, and the situation of the epidemic in Toronto and Ontario. This could help in

improving access to services, better programming, and greater participatory policy formulation. A service user mentioned one newcomer's experience in this regard:

"Oh, I know of this person who is HIV positive, she immigrated to Canada recently and has not been taking her medication for the past six months. When I asked her, she said she didn't have money to buy the medication."

Information gaps could be addressed by partnering with groups like churches, mosques, and other associations that provide services to the Black community. They can also be avenues to reach more Black people. The information gap can also be bridged by disseminating information on available services through social media.

4. Improve coordination of ASOs serving Black people so that they can address relevant cross-cutting HIV and AIDS issues and advocate for improved access to services for Black people in Toronto and Ontario. As well, review and strengthen the functions of the existing coordinating agencies to promote the voices of Black people by giving them a platform to express their views and aspirations. Also, there is a need to rejuvenate other collective voices and/or promote the formation of new ones; voices focusing on Black men, women, and youth could help strengthen the coordination of Black people.

Service user's perspectives

Summary of main points

Service users highlighted the following issues as it relates to access to HIV and AIDS services in Toronto:

- Poor access to treatment by some Black people, which means that some Black people living with HIV cannot get to undetectable because of this disparity.
- There are inadequacies in the referral for HIV and AIDS services for Black people.
- High information gaps with respect to HIV in Toronto communities.
- A reversed relationship between funding and HIV programs (especially awareness).

Service users noted a number of changes in service use that have happened over time including:

- HIV is becoming more professionalized which has compromised participation of communities.
- People living with HIV (PHAs) are no longer being engaged in HIV conversations but rather considered part of statistics.
- Decreased HIV awareness levels.
- Better treatment is available but challenges associated with ageing with HIV is an issue of concern.
- Reduced HIV Stigma in shelters due to some policy changes.

Service users recommended a need to:

- Break the silence, create awareness and reduce stigma through more effective communication
- Take HIV services closer to the people
- Engage youth, public health workers and other stakeholders
- Encourage and facilitate program planning for results

Detailed service users' perspectives on access to HIV services

Issues/challenges

1. Poor access to treatment by some Black people. A substantial number of Black people in Canada do not have access to treatment. These include temporary foreign workers, (e.g., farm workers), people who are employed but do not have insurance (they can't get on Trillium), international students and undocumented residents. One participant said:

"There are refugee people, precarious people who come to work on the farm they don't have access to treatment. And there are some of us like myself and my friends who work but have no insurance and don't have access to treatment. You might be working and have money, but if we can't get paid the Trillium and have enough deductibles, we have no access to treatment. I have a friend who used to work in an ASO and didn't have access to treatment and that is sad."

2. Black people are less likely to reach undetectable because of disparities in access to treatment. Absence of health coverage, membership to a specific group, and other social systemic reasons can prevent Black people from becoming undetectable. Black people sometimes do not feel welcomed at some health facilities. Immigration status determines access to health services in Toronto and Ontario, and being heterosexual can also prevent Black people from accessing HIV services because of stigma. Anti-Black racism often intersects with other dimensions of identity like sexual orientation, homelessness, transphobia. Whereas the Undetectable=Untransmittable (U=U) campaign is a landmark in the progress of combating HIV, it has created a hierarchy, where those who are undetectable are in one class and those who have not become undetectable are in another, resulting in another layer of HIV Stigma.

"U=U is kind of putting people into a certain category, so I'm good enough because I'm undetectable and you are not good enough because you are not. Can everybody become undetectable? No."

3. Lack of adequate supports for young people transitioning to adult care. A participant lamented:

"Some kids have HIV, they are moving to adult healthcare where they are just not

treated fairly, they are not treated nice. Previously, they were accessing medication in a child-friendly healthcare setting and had suppressed their viral load to undetectable. When they moved into adult healthcare, they are now detectable because of drug resistance, they are not taking their medicines, and nobody is following up on them. How do you explain this?"

4. There are inadequacies in the referral for HIV and AIDS services for Black people. Whereas the referral system ensures that the client gets the best services to address their issue(s), it sometimes has information gaps, long waits, inconsistencies, repetitions, and sometimes associated with forced disclosure. One participant shared their experience as a client, noting that they had to explain their situation and circumstances multiple times to different healthcare providers and agencies. Often amidst pain, the client provides the same information to each doctor and some doctors sometimes choose to repeat the whole process without consulting the client's file to understand the history. Other doctors seem not to expect clients living with HIV. Sometimes scheduling an appointment with a new doctor takes a while.

"I got a referral, spent some time to fix an appointment...the doctor and I discussed for like three hours then in the end he was like 'anything else we haven't discussed?' So I was like, 'my HIV status!' He was like 'what? I didn't know about that.' So we lost three hours, [and he] didn't take me on because I didn't qualify, I was sent to another centre."

Another participant shared an experience:

"For instance, I happened to go through emergency because I needed an operation. I had to disclose to about ten people unwillingly but I had no choice because I needed the services."

5. There are significant information gaps about HIV in communities. This is because many ASOs or HIV interest groups do not reach people with messaging about HIV. People who receive information about HIV and AIDS are usually people who visit ASOs and those who can search for information on the Internet.

"There are people that can't go to the HIV agencies, that can't search Google for HIV related information, those are the people to look for as a starting point, and strengthen them, partner with them, and work with them."

Another member added:

"...We are limited to reaching out to newcomers, some of whom come to Canada thinking there is no HIV because of being a first world country; I have heard people say, 'I don't think there is HIV here.' We should put our strength in reaching out to

newcomers including those in shelters and other people out there to talk about HIV prevention, because we haven't done enough in reaching people."

6. The level of funding is not consistent with the nature of the challenge. One participant highlighted that there needs to be greater engagement at the community level by funders, in order to understand the unique needs of the community.

"The more the funding, the less the awareness and vice versa and this could be attributed to the funders somehow. Some funders don't know how the community works, they are not community people."

Ideally, programming should be backed by data on the needs of the target population and not what the funder wants. One participant asked:

"So how are they going to tell us what to do?"

Another participant proposed:

"We need to bring out proposals to them and say, this is how it is going to work. But I have seen over the years that we just want money, we grab it and that's it and it doesn't benefit our communities. It's benefiting our salaries but it's not benefiting our communities and that's sad."

Notable changes in service use

This environmental scan established that several changes have occurred over the years in HIV service delivery and use as highlighted by service users.

1. Professionals have replaced communities. HIV has become so professionalized that the participation of communities in programming and service delivery is compromised. Many participants noted that PHAs used to share their lived experiences in communities, and their messages were very impactful. Today, the lived experiences have been replaced by professional and motivational talks. As one of the participants said:

"It hurts my heart to see the people working in the HIV sector don't give a shit about the people that live with HIV. The turn of the event that happened it's no longer for us and by us, it's that professionals who think they know what's best for us without asking us. They want tokenistic engagement, they say 'oh yeah we had a PHA, but they don't want meaningful engagement' and that's the problem."

2. Conversations about HIV and AIDS have changed to statistics. Discussions about HIV no longer adequately engage PHAs. Instead, PHAs emerge as statistics. Previously, PHAs were part of the conversations about what can lead to an HIV-free generation, but now, PHAs are not

adequately engaged in the discussions.

"We don't speak anymore, we are just counted, and that is what matters today. I think that's the problem because you cannot tell me what is good for me when you don't walk in my shoes. Everything that involved PHAs' participation has been gotten rid of. I am serious ...see what happened to the council at ACCHO."

3. HIV Awareness levels have gone down. There was more awareness in previous years, yet there is more HIV funding today than previously. ASOs used to do a lot more HIV awareness campaigns when they didn't have funding but are now doing less with increased funds.

"I remember the Wednesday when people would put on t-shirts and go stand in the subway [station] at Rexdale, Jane and Finch, and going to barber shops talking about HIV and AIDS. Every barber shop, every salon was recommended to have a conversation about HIV and AIDS. You go to a salon, the women would be having these conversations, these things don't happen anymore."

4. Better treatment is available, but this is leading to challenges as people age with HIV. There is better HIV treatment, and people are living longer than before. Whereas this is a positive thing, it comes with HIV service access challenges because there are no plans for those aging with HIV when they go to nursing homes, or when they become 60 years of age and leave the Ontario Disability Support Program (ODSP) for Canada Pension Plan (CPP), which poses a challenge to HIV treatment and access.

"When people get to CPP we can't wait for them to reach there. So we need to look at those things now before they strike, but we don't do that."

5. HIV stigma in shelters has reduced due to changes in some policies. Previously, PHAs on HIV treatment were required by policies to submit all treatment to the shelter administration desk for custody. This resulted in forced disclosure since shelters have many members of staff working in shifts, and a PHA had to disclose to all of them at different times to access their medication. This has changed, as one of the respondents noted:

"I went to the shelter in 2015 June and according to shelter policies and guidelines, no client in a shelter is supposed to keep personal medication. This has changed by the power of advocacy."

Recommendations

Service users recommended the following:

1. There is a need to create greater awareness of HIV and AIDS in Toronto and Ontario. This can be achieved by sensitizing communities and raising awareness about HIV and AIDS prevention,

treatment, safe behavioural practices, and risk reduction.

"Some people are not aware of HIV. So what they know is that HIV is chronic, dangerous... And it's associated with mostly sex and they link it to immorality, so you end up finding that people find a hard time to discuss about HIV."

There might be a need to reach out to newcomers living in shelters to provide information on HIV and AIDS. Partner with leadership at the shelters to help disseminate information even during the absence of members from HIV agencies. A participant said:

"When I lived in the shelter, they brought people from immigration, and other areas of service providers, but it's rare that they bring people from services like AIDS organizations. I left the shelter, three years now, but I have never seen this happen."

There is also a need to provide translation services for people who can't speak English and/or French.

"For instance, someone coming from Ethiopia and the person doesn't know how to read or understand English. Such people need a one-on-one to help them out."

Regarding HIV in the Black community, there should be increased awareness to reduce stigma, and normalize the situation (similar to the COVID-19 response); mobilize communities and talk to a wider cross-section of people about HIV so that messaging reaches more people than those who are usually engaged.

Breaking the silence about HIV may also be achieved through discussion in public spaces through town hall talks and other dialogue, as a means to find solutions that work for the communities. As well, encourage the conversations on HIV to be as open as it is for other chronic diseases like diabetes and cancer, and for the other viruses like COVID-19.

"... In Canada, not even on International AIDS Day will you ever see something about HIV in the public, not even on national television. I have observed for two years now for a notice on television on World AIDS Day, but there will never be even a message or any statement about HIV or the positive people."

Another respondent shared that the more we talk about HIV, the more people will become familiar and comfortable with it:

"...I believe that some of the success on COVID-19 is because of the level of discussion about it. So that's how HIV should be so that people get familiar with it and they don't make it a big deal. We need to get used to living with HIV, because it has been here, it is here, and it is not going soon."

People who met at an HIV service provider cannot face each other freely while in public due to stigma around HIV. One respondent said:

"HIV is not discussed at lunch tables, on the streets, in malls, anywhere in Toronto.
HIV counsellors can't greet us when they find us on the bus for fear of HIV [stigma]."

Because of stigma, some people choose to access only healthcare but hesitate to join support groups for fear of coming into contact with people from their countries of origin. Stigma compromises participation in HIV events, and limits knowledge transfer when it prevents people from attending. People, including close friends, may stop associating with a friend who is living with HIV once they learn of their status. Some consider HIV to be a death sentence and still have many myths surrounding it. Talking about HIV reduces stigma. A participant said:

"Stigma is still at a high peak I would say everywhere and people still don't want to talk about HIV publicly and it's still a very sensitive issue; even if you raise it somewhere you see people are like getting goose pimples."

Another participant said:

"A friend refused to go to a center providing food bank [services] because of self stigma, yet she had no job."

2. ASOs could consider taking services closer to the people to the communities where people live, rather than forcing people to go to the city looking for HIV services. ASOs need to build expertise to meet people where they are because they may never go out of their way to seek HIV services. Service providers might never know what people lack if they don't reach out to them. For example, service providers shouldn't wait for someone who has tested positive to come for their services. Instead, they should deploy personnel at the testing sites to immediately get in touch with the newly tested client and introduce them to their services.

"We need to look at what has been done in Africa in terms of HIV/AIDS and look at us thinking that in North America we know better, we don't. Because we have seen how people in Africa do things by themselves, they don't need the government to do it. In Africa, they go out to the communities in the rural areas to meet members. They don't expect members to come to the city every day. I am not from Africa but a lot of my friends come from Africa."

"So awareness is not happening because people are not coming to the ASOs. The ASOs need to go out to the people and they are not doing it because they are too professional, they are too good."

Service providers should not disconnect from the service users on the pretext of professionalizing service delivery. They should consider the service users, empower them, and respect their contribution to the HIV fight and change the narrative of what is happening in our community.

"I think some ASOs have become more corporate and are running HIV agencies like corporations and not as a charity organization providing for its people. That's why some community members have disconnected themselves."

Engage people living with HIV and be accountable to them.

"I want to tell you that ACCHO is supposed to stand for the Black community and provide leadership, engage PHAs, coordinate Black people on HIV matters, unfortunately they don't. First of all they had a steering committee that was supposed to be composed of PHAs to keep them accountable, they got rid of it. So that's why they do as they want, they don't have anybody to hold them accountable and that's dangerous when you don't have people to hold you accountable."

3. There is a need to engage or re-engage a range of stakeholders and allies. This will help build strong collaborations to improve access to HIV services for Black people in Toronto and Ontario.

"I have just done my research on Black youth transitioning from paediatric health care to adult care, Black children born with HIV, and I have cried for days when I hear these children's stories. My study revealed that these kids are not connected with us, they don't know about BlackCAP, they don't know about APAA, yet some of them are HIV positive, that's a shame, you know?"

4. Encourage and facilitate programming involve strategic planning, implementation planning, and evaluations of HIV and AIDS programs. For example, the following aspects would be useful in programming for HIV testing: mobilizing communities; informing communities about the benefits of testing; preparing people to receive HIV test results; preparing families to receive the person who has tested; assessing community uptake of the service, and other necessary standards at the facility or in the community. A respondent explained the testing programming process by saying;

"So what we need to do is, before we start the testing, as my grandmother would say 'don't put the husk before the cart' kind of thing, we need to do the groundwork first, and put everything else in order...not everyone has equal access. So, that's another thing you're going to test people, would they be able to get access to treatment? That's another thing we need to look at. These are things we need to put in place before testing begins."

Review programs and establish what worked, and use the lessons to improve access to HIV services for Black people.

5. Consider bridging all communication barriers. This is in relation to accessing HIV services, strengthening referral processes, and creating an enabling environment for effective communication. Ensure proper engagement for the immigration officials to be mindful of Black peoples' privacy, confidentiality and disclosure of HIV status. For example, the microphones at the immigration windows are too loud and the engagement is too open to ensure privacy. Also, address communication barriers such as language and culture by providing translation and interpretation services to those who cannot speak English or French to enable them access to HIV services, and provide culture-friendly services and interpreters in whom people who cannot speak English and/or French can confide. One respondent said:

"When I went for my [Permanent Residence] PR, an immigration officer called my name and said I have to pay extra money, I asked why? My letter indicated the amount of money I was to pay. The officer insisted that I pay an extra \$100. Inside me, I understood that it was because of my HIV status but people around me became inquisitive to know why the extra money. The officer was not polite at all, he shouted at me saying: 'The other problem...you have a condition ... the other problem, you have a condition'."

Policymakers' perspectives

Background

The OHTN evaluated support services provided by AIDS service organizations in Ontario in 2013. The evaluation report identified that AIDS service organizations were doing everything for everybody. The report revealed that, "support workers reported providing a range of services; however, the way they defined and delivered those services varied from agency to agency. Despite this variation, a few services consistently emerged as 'core services' including practical assistance, referrals, case management, intake and assessment, and individual advocacy. However, these services are not being delivered in a consistent way across the province." Also, the universal definitions for support services in the Ontario Community HIV/AIDS Reporting Tool (OCHART) were open to interpretation and there was no clear understanding which services are core across all ASOs. 8

⁷ Everything to Everybody: An Environmental Scan of Support Services Provided by AIDS Service Organizations in Ontario. OHTN, 2012. http://www.ohtn.on.ca/Pages/Knowledge-Exchange/Research-Findings/2013-OHTN-Environmental-Scan-of-ASO-Support-Services.pdf

⁸ Ibid. 4

The evaluation report recommended that the AIDS Bureau, in partnership with the OHTN, should develop comprehensive specific definitions for core support services, and develop a manual defining the scope of services at ASOs for purposes of consistency. It also recommended to review greater involvement of people with HIV/AIDS (GIPA) guidelines for effective implementation of GIPA and recommended an evidence-based practice unit at the OHTN to ensure that data systems are implemented consistently and are useful for ASOs.⁹

These recommendations prompted the evaluation coordinating team to reach out to the AIDS Bureau to ascertain the extent to which these recommendations had been implemented. Besides, the research team had proposed to review the existing topographies and classification systems to determine and adopt an arrangement that accommodates the range of services available and directly applicable to HIV, after it recognized that ASOs offered a wide range of programs and services. The answers from the AIDS Bureau would answer this question. Also, reaching out would help the research team verify the systems in support of service delivery for Black people available at the macro level.

The questions asked of the AIDS Bureau were based on recommendations in the evaluation report, specifically on the standardized delivery of HIV services to Black people in Toronto. The research team followed up with a teleconference to the AIDS Bureau staff to seek clarity on the answers previously given and to ask additional questions. Sample questions include: whether the Bureau had a standardized mechanism for ASOs to deliver core support services to their beneficiaries, and if the GIPA standards were practiced, reviewed, and up-to-date; whether the Bureau had procedures for accessing HIV data, and whether the Bureau had mechanisms for boosting the organizational development of ASOs as a means to strengthening and stabilizing their service delivery mandate in promoting the health and wellbeing of Black people in Toronto and Ontario.

The research team learned from the consultations with the AIDS Bureau staff that the evaluation recommendations prompted the AIDS Bureau to strengthen standards. The purpose of strengthening the standard of service delivery was to improve a continuum of service access, to prioritize the basic HIV supports needed, and to provide a connection to community resources and HIV care. It was also intended to ensure that prevention programs are running, retention in HIV care is achieved, and testing services are accessible. As well, having supportive conversations about HIV with both people living with HIV and those who aren't. The ministry came up with mechanisms for standardizing service delivery as follows:

Mechanisms for improving HIV service delivery

The AIDS Bureau has:

1. Supported the development of the HIV Support Services Resource Guide that provides consistent definitions for services to facilitate standardized report from all ASOs,

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⁹ Ibid. 1

- 2. Funded programs for the African, Caribbean, and Black community as a priority population. This includes funding for: the Black Coalition for AIDS Prevention (Black CAP), Africans in Partnership Against AIDS (APAA), and the HIV program within Women's Health in Women's Hands Community Health Centre as part of its support for Black communities as a priority population; other agencies that serve Black communities (the Centre Francophone de Toronto, Action Positive, Teresa Group, Fife House, Pasan, AIDS Committee of Toronto, PWA, and CAAT); and the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) build capacity for the response to HIV across Ontario.
- 3. Supported the development of the Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities (ACCHO) 2013-2018 (the ACB Strategy), which was extended to 2021.¹⁰
- 4. Supported the development of OCHART and mandated all ministry funded organizations to use that tool for reporting on services.
- 5. Supported capacity building, knowledge exchange, prevention, education, and harm reduction supports to ACB communities.
- 6. Supported events for knowledge sharing and learning every year
- 7. Supported GIPA and the Ontario Accord as core principles and practice for ASOs in Ontario, and encourages ASOs to engage peers in their work. These practices ensure that people who are living with HIV remain central to the efforts to address HIV.
- 8. Set annual priorities for ASOs (e.g., enhanced testing and testing promotion for Ontario's priority populations; increased access to pre-exposure prophylaxis (PrEP) for priority populations (includes ACB communities); activities responding to the needs of Black heterosexual men in the context of HIV; and many others.
- Supported the collection, management, use to enhance HIV program development, policy review and formulation. These include OHTN Cohort Study (OCS) and Ontario's HIV Epidemiology Surveillance Initiative (OHESI); CATIE to summarize and disseminate key HIV research findings for community use.

Issues needing further exploration

We identified the following issues that the Black TTZ Working group may explore with policy makers and funders in order to put Black communities on the path to zero:

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¹⁰http://accho.ca/the-acb-strategy/

- 1. Standardized race-based data is not collected and reported. Although HIV is one of the few diseases for which some race-based data is collected, due to a lack of historical data collection, it is difficult to determine the overall prevalence, a key indicator for programming. Reporting at the local level by Public Health Units is inconsistent and does not include race data collection, which would be quite useful for local programming and service decisions. OHESI and OCS reporting does include data to help monitor some aspect of HIV among Black communities, but the data are still not comprehensive enough or readily available, and delays impact the timeliness in the understanding of trends.
- 2. Appropriate mechanisms do not seem to be in place to strengthen a practice for agencies to report and deliver using the guidelines developed by the AIDS Bureau.
- 3. User-friendly and comprehensive mechanisms for accessing the data on HIV and Black people in Toronto and Ontario (OCS and OHESI) produced with support from the Ministry seem to be lacking. A need to include mechanisms for ensuring that data are accessible by providing the required guidance on where to find the data and how custodians may respond to requests in ways that enhance confidence and collaboration. In other words, mechanism should be in place to ensure that data access is not politicized.

PRIORITIES EMERGING FROM STAKEHOLDER RECOMMENDATIONS

Introduction

This section combines the perspectives of service providers, service users, and the Black TTZ Working Group to identify key priorities and recommendations for substantively changing the course of HIV among Black communities in Toronto and throughout Ontario. Also, we demonstrate the possibilities for change by mapping various initiatives that the Ministry of Health has supported, in relation to the key strategic recommendations.

The Black TTZ Working Group

The Black TTZ Working Group noted that anti-Black racism, and structural violence more generally, has augmented Black people's vulnerability to HIV and limited the type of radical evidence-based response that the situation requires. Consequently, they also noted that policies and programs will not achieve the desired outcomes without incorporating a commitment to anti-Black racism, equity and social justice. The Black TTZ Working Group identified the following five priorities for improving HIV programs and service delivery:

- (i) Need for accessible data to monitor trends in the epidemic among Black people
- (ii) Understanding the situation of Black people in relation to the HIV cascade
- (iii) Innovative approaches to testing that are culturally informed
- (iv) Understanding and strengthening the landscape in HIV treatment and care
- (v) Timely, critical evaluation of new technologies for prevention and treatment

The Black TTZ Working Group believes that the Public Health Agency of Canada (PHAC) and Toronto Public Health (TPH) could consider curating and publishing trends in HIV diagnosis, prevalence and other factors related to the cascade among Black people, and the OCS could consider collecting more data from agencies where Black people access services. In addition, the Working Group proposed that evaluating and implementing innovative approaches in HIV testing services, supporting a well-designed continuum of care for Black communities, and addressing social determinants of health among Black communities could change the trajectory of HIV transmission. Supporting Black communities to build stronger institutions, strengthening partnerships and providing timely information on prevention, treatment and care could improve the delivery of services and programs for Black people.

Collection, use and responsible dissemination of appropriate data

The recommended directions for programs and policy that we have outlined above may be important in and of themselves. However, timely access to data that tracks (a) the epidemic among Black communities, and (b) the outcomes of programs and policy is also a crucial consideration.

Governments and their mandated health authorities and institutions at all levels – federal, provincial and municipal – have been reluctant to collect and share data instrumental to (a) understanding how structural violence and the determinants of health work against Black communities, (b) turning the tide of the HIV epidemic among Black communities, and (c) strengthening Black people's health and wellbeing.

Currently, the OHTN owns the Ontario Cohort Study, which tracks health and wellbeing among people in Ontario who are living with HIV, including Black people. A number of Black people are involved in the various committees that advise the OHTN about the OCS. However, as the owner of the data, the OHTN actively regulates access to the data, such that Black researchers and agencies have only occasional and insecure access to the data. In fact, Black stakeholders whose work address wider of related concerns about health are generally unaware of the OCS or unfamiliar with its procedures and policies. Moreover, despite discussion and advocacy among Black stakeholders over a number of years, the OHTN has been advocating for racebased data without significant input from Black stakeholders who have been articulating the community's interests in race-based data for many years. The result is that Black stakeholders are effectively excluded from opportunities to develop the knowledge base that should inform programs and policy to address HIV and strengthen Black health and wellbeing.

Similarly, Public Health Ontario, along with the OHTN, effectively exclude Black people from any significant role decision-making about epidemiological surveillance of HIV in Ontario, even though Black people are grossly over-exposed to HIV. The result is that Black experts are unable to offer insight into how to get the best from epidemiological surveillance, and are among the last to know current trends in HIV in Ontario.

The OHTN is also the guardian of the OCASE data on utilization of community-based HIV services in Ontario. Though there is an established protocol for accessing these data to examine trends and patterns in service utilization, the data remained under-used by Black stakeholders.

In general, provincial and municipal health authorities in Canada make decisions about HIV surveillance and race-based data without consulting Black communities. If the community wants to exercise leadership in turning the tide of HIV among Black communities, then they must also have ready access to the appropriate data. This also means that Black stakeholders deserve a role in the oversight of data that address Black lives.

Part of the problem is that the OHTN and health authorities at all levels do not communicate effectively with Black stakeholders about the data collection, availability or access. However, communications alone will not resolve the problem of race-based data without a real commitment to engaging Black communities about how to collect, use, disseminate and share data.

To address the issues we have outlined above, we suggest that Black researchers, service providers and community advocates across all domains of health and wellbeing collectively:

- Advocate to the OHTN, health authorities and government-supported health institutions at all levels of government to strengthen and streamline the collection, use and responsible dissemination of race-based data.
- Develop and advocate for mechanisms of governance or oversight that give stakeholders
 a role in how race-based data are collected, used and disseminated.
- Develop and advocate for protocols to access the data on a timely basis.
- Develop strategies for community engagement and communications that apprise Black

Perspectives of the Black TTZ Working Group

Service providers' perspectives

Service users' perspectives

Programming for Results.

Key recommendations: Recurring themes

stakeholders on current issues related to collecting, using and disseminating race-based data, and trends in health and wellbeing among Black communities.

Synthesis of recommendations from stakeholder groups

The coordinating team pooled the various recommendations from service providers (leadership of ASOs), service users and the Black TTZ Working Group to identify four recurring themes or considerations for strengthening ongoing community efforts to address HIV: (i) Knowledge Management, (ii) Communications, (iii) Coordination, and (iv)

Knowledge management

There is an overriding need to strengthen knowledge development, management, and reporting to better inform programs and policy. One way to accomplish this goal may be through the development of a knowledge hub for Black communities in Ontario. The functions may include creating and assessing the knowledge and information pertaining to understanding and addressing HIV among Black communities, sharing knowledge with stakeholders in Toronto and Ontario to inform the HIV agenda, and monitoring the process and outcomes. This approach may improve the performance and creativity of agencies and other stakeholders.

Service providers trust that a knowledge management strategy will support the development of an infrastructure that bridges programming, research, and policy as a continuum. Service providers also believe that proper mechanisms for accessing and using the available information could facilitate information flow that translates into improved service delivery. They also add that identifying and understanding the existing knowledge helps identify current gaps and determine how to address them. This approach would counter redundancy and maximize the use of data to support action.

The Black TTZ Working Group also agreed to the development of the strategy for knowledge development and sharing, which will empower agencies serving Black people with knowledge on HIV prevention, care and treatment to enable them to serve Black communities better. It will also help centralize the information sources for frontline staff providing care services to improve their knowledge about new and emerging approaches to care and treatment. A knowledge management strategy will encourage the collection, use and responsible dissemination of race-based data on HIV testing and other HIV services.

Service users also support the idea of a knowledge management hub, saying that it will lead to the development of models of service delivery that are suited to Black people's circumstances and needs.

Communications

Develop a communication strategy to provide information and raise awareness about HIV amongst agencies providing services to Black communities, and among other stakeholders working in the HIV sector in the province. Increase dialogue on HIV in the public domain and encourage critical dialogue on HIV among communities as a means of normalizing community involvement and ownership of the response.

Members of the Black TTZ Working Group believe that a communication strategy will guide communication plans for reaching out to Black communities to address stigma, racism, and other structural determinants. The strategy will also enhance Black people's access to new, emerging evidence-based perspectives and innovations on prevention, care and treatment.

Service users believe that a communication strategy will enable the design of mechanisms to raise awareness of HIV among communities of Black people in Ontario. Also, it will strengthen the referral processes and improve service delivery.

Service providers believe that through this strategy, Black people will receive timely, reliable, and accurate information on the available HIV and AIDS services.

Coordination

Coordinating the efforts of agencies that provide HIV services to Black communities and bringing about harmony among them is an important theme that emerged from the recommendations of stakeholder groups. This includes integrating and synchronizing the efforts of agencies and individuals to provide unified action in pursuit of achieving zero HIV transmissions in Ontario. A communications strategy may also harmonize relations with stakeholders in the province, and position communities to contribute meaningfully to the provincial HIV agenda.

Service providers believe that improved coordination of ASOs can improve access to HIV services by amplifying the voices of Black people and strengthening evidence-based advocacy to address the existing service delivery gaps. And service users say that coordination will improve referral for services.

Members of the Black TTZ Working Group believe that improved coordination will strengthen the leverage of Black leaders with large institutions (e.g., governments, pharmaceutical companies, etc.), in pursuit of structural priorities, and will improve engagement levels of Black people and other stakeholders.

Programming for results

Adopt results-based programming and management that focuses on performance and achieving results by allowing interventions for Black people in Ontario to be complementary, and avoiding overlap, duplication, and waste in taking these services close to where Black people live. This approach is likely to improve the effectiveness of programs and achieve efficiencies.

Service providers believe that evidence-based programming creates efficiencies and leads to better results. Continuously assessing achievement towards the set targets, and listening to the service users on how they feel about the services they receive, improves service delivery.

Service users believe that promoting results-based management leads to improved access and utilization of services, and will meaningfully engage PHAs in the response to HIV.

And the Black TTZ Working Group considers results-based programming as a mechanism for placing HIV in the centre of the integrated care package by addressing the cascade beyond HIV.

Perspectives of policymakers

As part of our work for this evaluation, the coordinating team also spoke to the HIV funders and policymakers of the AIDS Bureau at the Ontario Ministry of Health and Long-Term Care regarding their support for addressing HIV and AIDS among Black communities. The point of discussion with the AIDS Bureau was not to initiate recommendations but rather, to understand what standards the Ministry has put in place to support service delivery. Below we highlight how what we heard from the AIDS Bureau may support the directions we outlined above.

- Knowledge management: The AIDS Bureau supports the collection, management, use, and application of data in HIV program and policy development. It supports collecting and disseminating data on Ontario's priority populations, through the OHTN Cohort Study (OCS) and Ontario's HIV Epidemiology Surveillance Initiative (OHESI). Also, it supports CATIE to disseminate research findings, and summarize HIV research for community use.
- 2. Communication: The AIDS Bureau supports, promotes, and funds knowledge sharing and learning events for ASOs to communicate achievements, challenges, and lessons learned through conferences and committees. The Bureau also facilitates and encourages participation and engagement with communities in its processes and functions. To support the participation of PHAs, the Bureau reviewed the GIPA framework and facilitated the launch of the Ontario Accord and made it a practice for ASOs
- 3. Coordination: The AIDS Bureau supported the development of the current and previous strategies on HIV for African, Caribbean and Black communities in Ontario, and supports ACCHO to coordinate implementation and monitoring of the Strategy. Also, it provides capacity-building support to the other ACB agencies. The Bureau also supported the OHTN-led Toronto to Zero initiative that aims at reducing HIV in the GTA to zero.
- 4. Programming for results: The AIDS Bureau supported the development of the HIV Support Services Resource Guide that holds the definitions for support services for ministry reporting requirements, and has made reporting through OCHART mandatory for all ASOs. Also, the ministry accredited the ACB communities as one of Ontario's priority populations in addressing HIV and implements this by funding some ACB programs.

These are examples of current and previous initiatives that are consistent with the key recommendations outlined above. Whether, or the extent to which, provincial policy makers and funders will support bold and radical initiatives in the future is uncertain. However, the examples demonstrate the scope for Black stakeholders to negotiate new and innovative approaches to addressing HIV.

APPENDICES

Appendix 1. Profile of service users and trends in service use, 2015-2015

We examined data on service use at ASOs in Toronto to understand patterns and trends in Black people's service use. The Ontario Community-Based AIDS Service and Evaluation (OCASE) unit at the OHTN compiles and manages these data from 32 dedicated AIDS service organizations in Ontario. ¹¹ To access this data, researchers, planners, and other professionals seek permission from the agencies to access the de-identified aggregated data. Once the agencies approve, OHTN staff who manage OCASE make the data available to the entity that requested it.

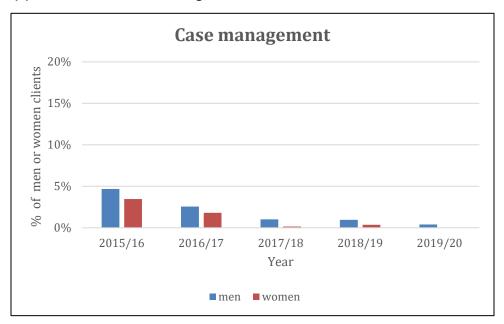
To access the OCASE for the past five years (2015-2016 to 2019-2020), the Black TTZ coordination team met with the OCASE leadership at the OHTN and agreed on the modality of how to access the OCASE de-identified data on Black service users. This included seeking permission from the six ASOs (APAA, Black CAP, ACT, PWA, Fife House, and Teresa Group) that routinely report service utilization by Black people. Five of the agencies agreed (BlackCAP did not respond to the request), after which the OCASE team made the data available to the Black TTZ coordination team.

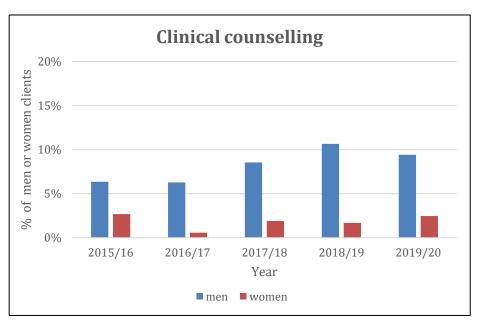
There was a large variation in the data on service use across all the services (i.e., some services were accessed by large proportions of service users, while others were less used). This made it difficult to present the data graphically to compare, contrast and assess the trends and nuances over the 5-year period. Hence, the coordinating team decided to arbitrarily use a 10% cut-off to divide the services into two groups: (a) services that were mostly accessed by less than 10% of male and/or female service users and (b) those that were accessed by mostly 10% or more of service users.

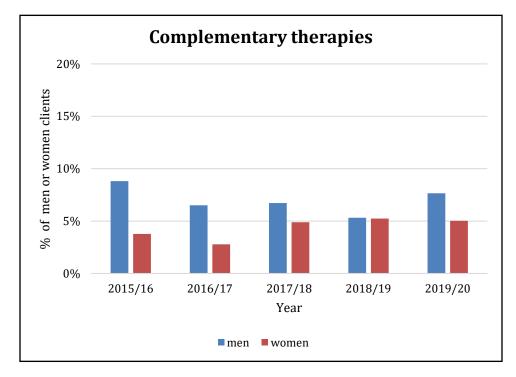
The graphs on service use are followed by a series of graphs to illustrate the sociodemographic profile of service users over the entire period 2015-2020.

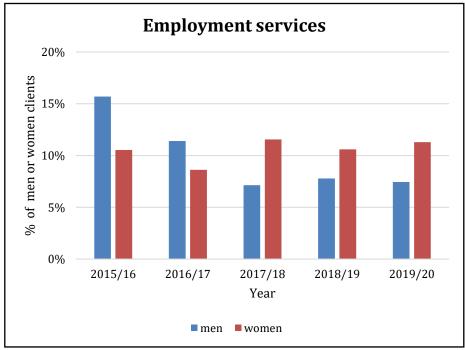
¹¹https://www.ohtn.on.ca/services-for-asos/ocase-ontario-community-based-aids-service-and-evaluation/

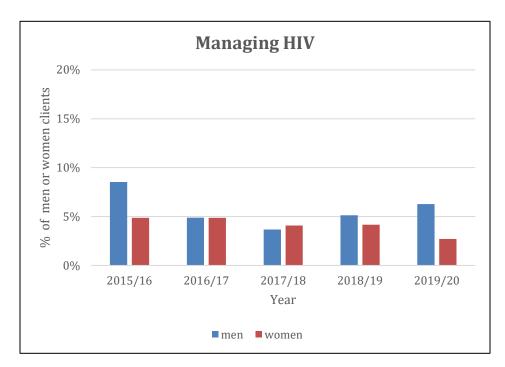
(a) OCASE Data – service categories with < 10% users

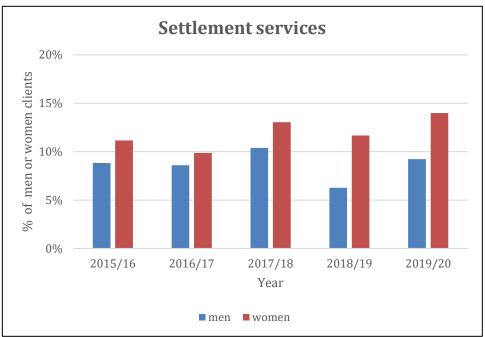


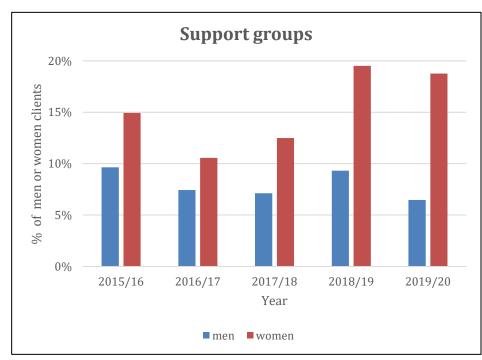


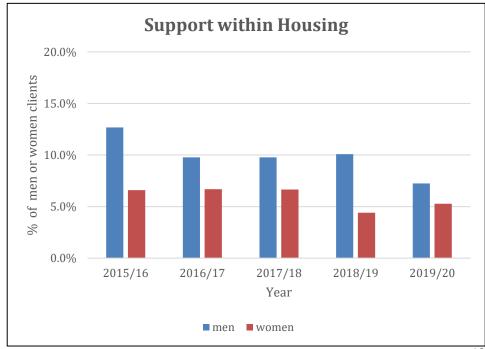




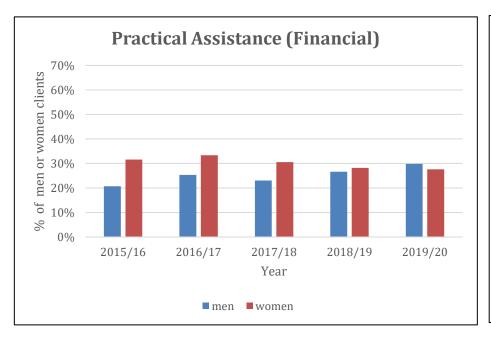


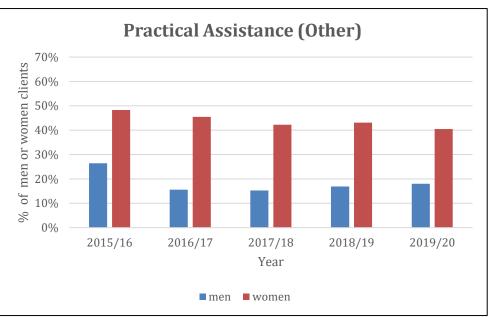


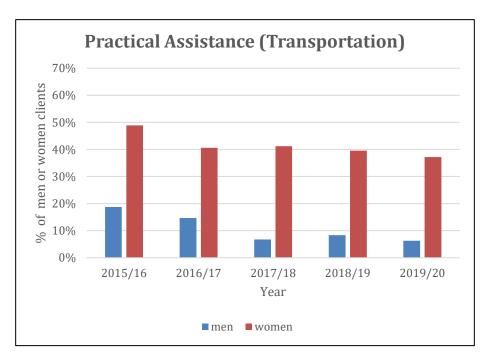


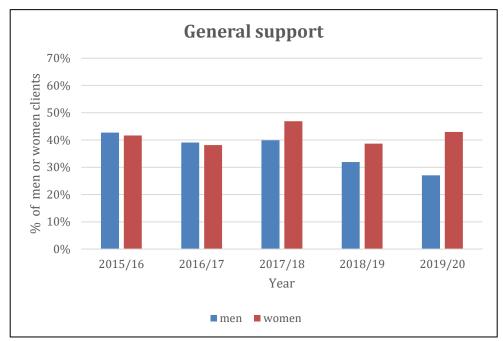


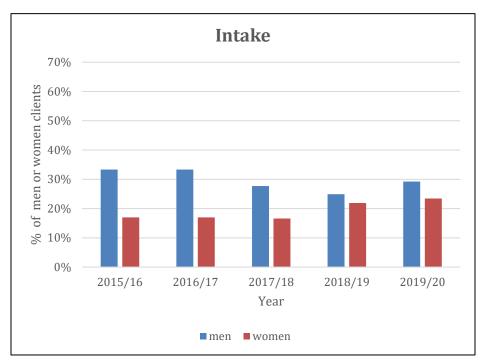
OCASE Data – Service Categories with ≥ 10% of service users

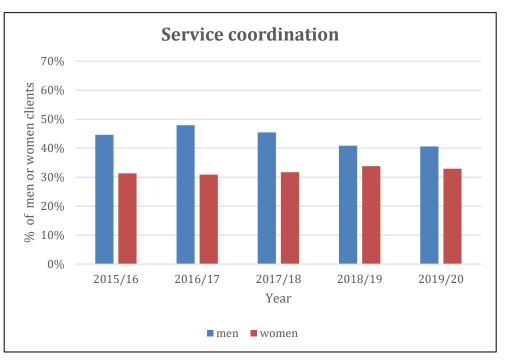


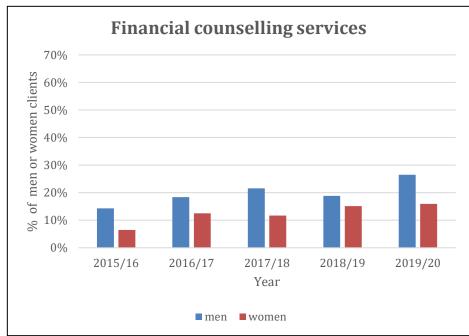


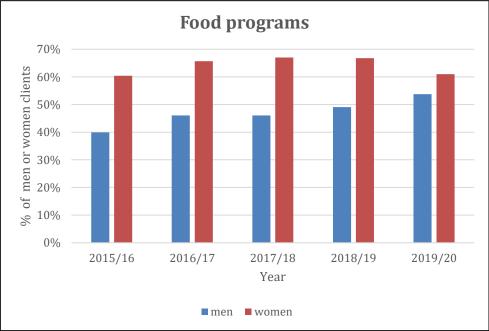












General Observations

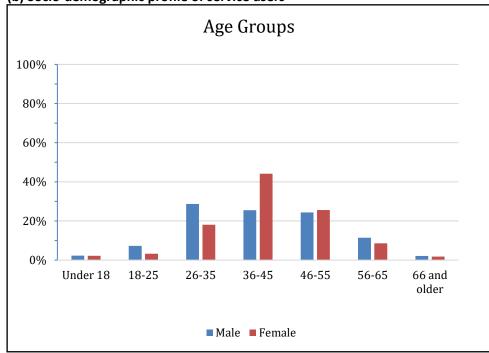
General observation for less than 10% service categories

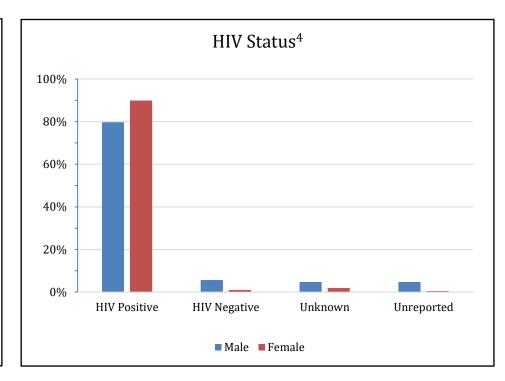
- ✓ The proportion of men using services is higher than that of women except for support groups and settlement support services. It is especially so for clinical counseling. The proportion of women using support groups is much higher than men and this increases towards 2020.
- √ The proportion of male and female clients using case management is low and the proportions decline to almost zero by 2020.
- ✓ Employment services declined for men while for women the trend is more or less stable.

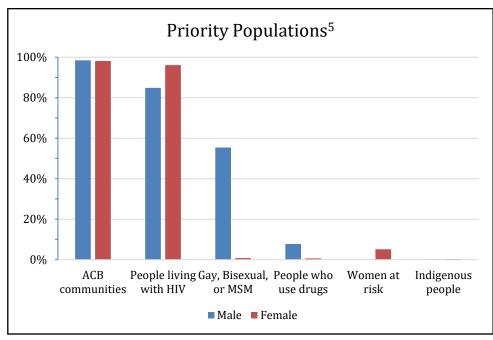
General observation for 10% and greater service categories

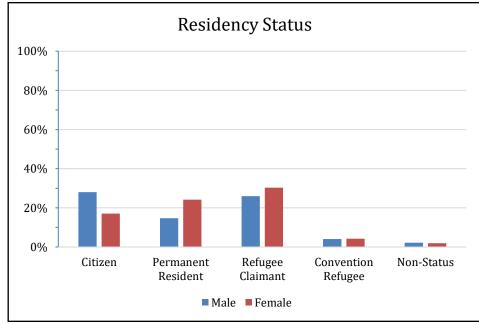
- ✓ Food programs are heavily used by both men and women but especially women.
- ✓ The proportion of women service users for practical assistance is noticeably higher than men except for the financial aspect of practical assistance.
- ✓ For financial counseling services, the proportion of men tends to be very small compared to women; the trend is increasing for both men and women but more quickly among men.
- ✓ There is a declining proportion of men utilizing intake services, while the proportion of women has been increasing.
- ✓ For general support, there is parity between men and women from 2015 to 2017; however, the proportion among women exceeds the proportion among men, and the difference is at its highest from 2019 to 2020.

(b) Socio-demographic profile of service users

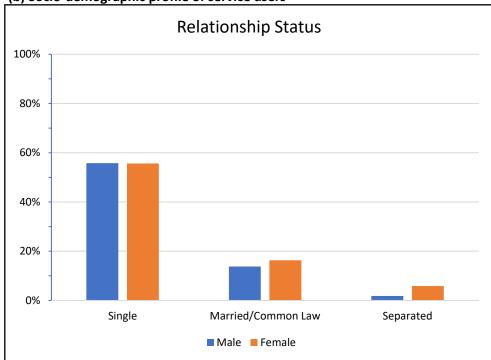


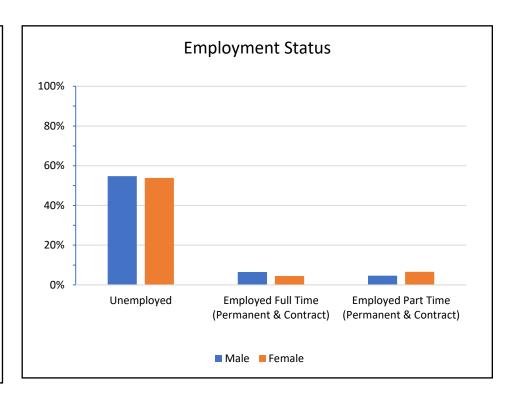


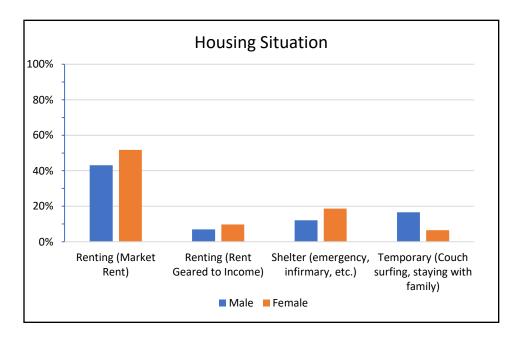


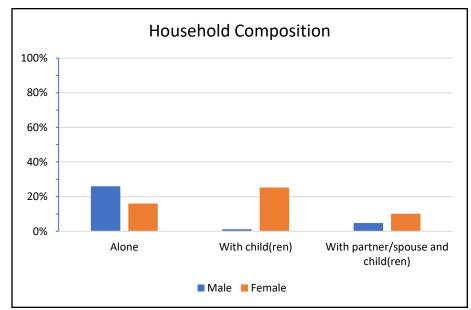


(b) Socio-demographic profile of service users









Socio-demographic profile of Black service users

Available OCASE data on Black service users 2015-2020 show that they are economically marginalized, but also demonstrate important differences between men and women.

Age: Women tend to be older than men. About 70% of women are aged 36 to 55 compared to about half of all the men. On the other hand, 38% of men are less than 36 years old verse slightly less than a quarter of women.

HIV status: More than 80% of Black service users are living with HIV. This includes the proportions shown in the graph, plus the small proportion of service users (not shown) who are co-infected with HIV and another infection (e.g., HIV and HBV co-infection).

Priority populations: Black service users identify with the ACB priority population and other priority populations simultaneously. For example, 55% of Black men also identify as gay, bisexual or MSM.

Residency status: More men identified as Canadian citizens, while more women identify as permanent residents or refugee claimants.

Relationship status: Close to 60% of men and women accessing services identify as single. Less than 20% are married or living in a common-law relationship.

Employment status: Almost 60% of service users are unemployed. Less than 10% are employed full time or part-time.

Housing situation: Most women (52%) and a large proportion of men (43%) are paying market rates for rented accommodation. About one-quarter of men and women are unstably housed (i.e., living in a shelter or temporary accommodation).

Housing composition: Women are much more likely than men to be living with children (i.e., most likely in a single parent household).

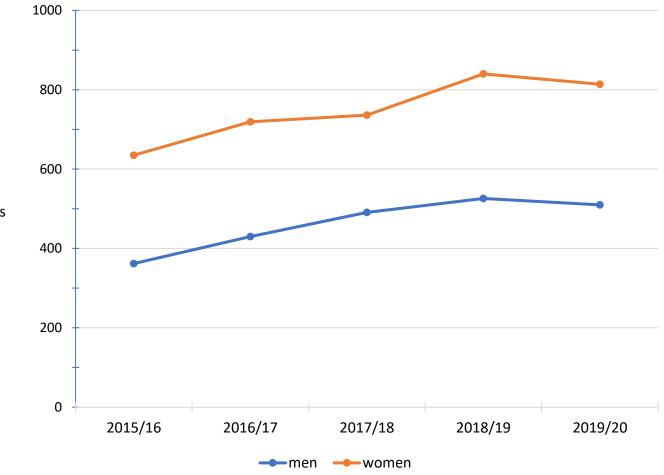
Notes

¹the data are the percentage of men and women service users for each indicator, 2015-2020 ²for all indicators, the vertical axis is the percent of men or women service users (e.g., 44% of women service users were aged 36-45 years)

³for each indicator, the graphs include only selected categories of interest (e.g., the original employment data includes additional categories with very small percentages of men or women) ⁴small percentages of women and men who reported co-infections (e.g., HIV and HCB) are not shown in this diagram

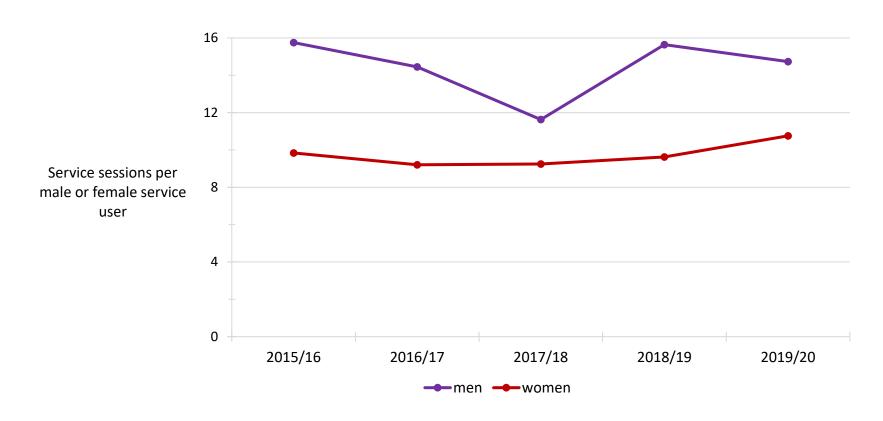
⁵many service users who report as being ACB may also belong to the priority populations (e.g., 55% of male service who identify of ACB also identify as "gay, bisexual or MSM".

(c) Number of Black service users accessing services at 5 ASOs in Toronto



Number of Black men and women service users

(c) Service sessions per Black service user



More Black women accessed services then Black men. For both men and women, the number of service users increased from 2015 to 2018, then decreased slightly. Overall, from 2015 to 2020, Black male service users increased at a faster rate (or more rapidly) than women – 40.9% for men versus 28.2% for women.

Though more Black women accessed services than Black men, on average Black men accesses services more often (or used more services) than Black women. Except for 2017-2018, Black men exceeded 14 service sessions on average, while Black women averaged less than 10 sessions.

Background

The overarching issues and specific priorities (listed below) represent core requirements for decisively changing the course of the HIV epidemic among Black communities in Toronto and throughout Ontario. The issues and priorities emerged from discussions among the Black TTZ Working Group and the Black stakeholder meeting held in August 2019. The list was approved by the Working Group on November 28, 2019.

Overarching issues

1. Anti-Blackness and structural violence

Canadian society is structured to undervalue Black people's health and wellbeing. Enduring inequities in employment, incomes, wealth, education, access to justice, food security and other areas demonstrate how social arrangements position Black people on the margins of Canadian society. Regarding HIV in particular, epidemiologic data show that Black people carry a disproportionate and growing burden of HIV, while the White population's share of diagnoses has been falling. Moreover, Black people are significantly less likely to benefit from engagement in the care cascade. These trends indicate that the approaches to HIV prevention, care and treatment that work for affected white communities, are unlikely to generate equitable outcomes for Black communities. Moreover, Black stakeholders are often assigned subsidiary roles (or even excluded) in decisions about policy and research, which means that the systems for responding to HIV hardly benefit from the Black people's knowledge and experience about HIV and their communities. "Getting to zero" calls for a new commitment to Black leadership, and for the decision-makers to prioritize the actions, recommendations, experiences and enthusiasm of Black communities and stakeholders.

2. Engaging Black stakeholders to address HIV among Black communities

The effort to substantively change the course of HIV among Black communities requires the attention, support, commitment and contributions of a representative cross-section of interested people and community-based organizations from those communities. This includes: people of different nationalities, genders and age groups who are affected by HIV; agencies working on the front lines of the community response; academics, activists, advocates and community organizations with different skills, experiences and expertise that are germane to addressing anti-Black racism, the social determinants of health, policy and program development, and community engagement. Our stakeholders must be willing and able to work collaboratively, and show leadership in our community-based response to HIV.

Priorities

- 1. Trends in the epidemic among Black people where is the epidemic heading
 - trends in diagnoses among gay men, women, straight men, youth
 - data on specific segments of the Black population such transmen and transwomen
 - prevalence

- 2. Black people in relation to the cascade (this includes, where possible, specific segments of the Black community affected by HIV, such as Black transwomen and transmen)
 - how does the cascade look for Black people
 - what are the current areas of concern,
 - what strategies are recommended
- 3. Innovative approaches to testing that are culturally informed and account for structural barriers
 - testing (including self-testing)
 - linkage to care
- 4. Understanding and strengthening the landscape for engagement in care and treatment
 - strengthening our response (ASOs and strategy workers) and the landscape for services
 - mental health
 - substance use
 - stigma
 - justice system/incarceration
- 5. Timely critical evaluation of new technologies for prevention and treatment (e.g., PrEP, U=U) and whether/how they may be accessible to Black communities

From December 2019 to March 2020, the working Group and other stakeholders will constitute five sub-committees (one for each priority) and develop recommendations to change the course of HIV among Black communities. The question that each sub-committee will address for their specific priority, and the Working Group will address overall is: What strategies, actions or plans are required to decisively change the course of HIV infections among Black people in Toronto and Ontario over the next 3 years, and strengthen health and wellbeing among Black people who are living with HIV?

The two overarching issues should inform or guide the work of all the sub-committees and the Working group as a whole. In their deliberations, the sub-committees should consider: (a) how to engage a broader base of stakeholders to address HIV in the context of the systemic and structural issues that undermine Black people's wellbeing; (b) how anti-Blackness and structural violence, and their intersection with gender, sexuality and other factors underlie Black people's vulnerability to HIV; and (c) how the actions, plans and strategies to address HIV should engage, reflect or incorporate those issues.

Appendix 3. Knowledge parameters for implementing new HIV technological and medical interventions

New Interventions	Description	More information	Discussion Points & Critical Questions for Implementation
Medication-relate	ed		
Long-acting injectable PrEP	Aims to reduce issues related to adherence, since adherence to PrEP regimens are crucial to its effectiveness. Longacting PrEP injectable medication may reduce issues seen with adherence to daily PrEP, as these injections would be required once a month or once every three months. No long-acting injectable PrEP medications are currently available; however, several clinical trials are currently in-progress.	Long-Acting Injectable PrEP HPTN 083 HPTN 084 Infographic: Long-Acting Forms of HIV Prevention	 What do we need to know? What would we need to do to implement this? Is the medication reliable? Cost? Dosage? Side effects? Would there be potential stigma surrounding the drug being injectable? How do we make sure that the science behind it is clear; for instance, how do we ensure that patients are aware that this is not like a vaccine since PrEP does not try to elicit a response from the body? Instead, injections would deliver medication that would prevent infection Implementation: Is the drug convenient? How do we ensure that patients come regularly to get their PrEP injection (if it's once a month, once every 3 weeks, etc.)? Do they have to go to a clinic, a community centre, a pharmacy,is it administered at home, etc.? Accessibility: How wouldpatients get to the places where the drug is available? Should avoid barrier of having this medication only available in clinics. Education to healthcare providers (HCP)may need to be provided so that they know how to talk to patients about these medications. Providers can act as gatekeepers if they don't have the time, expertise or

			willingness to explain this to their patients. • Lots of community-level education would be required to help build trust amongst ACB communities about this product.
Descovy (by Gilead)	Aims to avoid common PrEP side effects. Has been proven to be significantly less damaging to kidneys and bone density than regular PrEP (tenofovirdisoproxil fumarate + emcitrabine), which is especially important for members of Black communities already dealing with comorbidities like diabetes and low bone mineral density. Descovy is currently not subsidized by the Canadian health ministries.	Truvada vs Descovy for HIV Prevention Descovy Prescribing Information Descovy Approved In Canada- Key Information	What do we need to know? What do we need to do to implement it? Is itan appropriate first-line drug? Are there physiological parametersthatdictatewhether regular PrEP (Truvada or generics) or Descovy is prescribed? Can there be patient-specific parameters that regulate who we can give normal PrEP to vs Descovy, since Descovy is a more expensive option? For instance, potential bone and kidney effects may not be as problematic to a healthy young adult compared to a teenager whose bones are still developing or an older adult with lower bone density. Will Descovy be covered by provincial drug programs (ODB, Trillium, etc.)? Would patients be able to get a discount card from a physician's office or a pharmacy if there were no generics available? Need to inform patients that different versions of PrEP are available. Patients may be suspicious of regular PrEP because of the side effects; however, at the same time, we don't want patients to be taking a higher-burden drug if they

			were not going to get any additional benefits from it compared to regular PrEP.
PEP (Post- Exposure Prophylaxis)	PEP works to prevent HIV transmission after suspected exposures to the virus.	Post-Exposure Prophylaxis The Efficacy of Post-Exposure Prophylaxis (PEP) for HIV PEP-in-pocket	What do we need to know? What do we need to do to implement it? • How doHCPscurrently respond to patients seeking PEP? Are they less likely to provide it to those they think were willingly engaging in risky behaviours? HCPs' reluctance to prescribing/providing PEP can be a big barrier. HCPs may need training/education on how to administer PEP. • What strategies are available to ensure that ACB people can use PEP with as little barriers as possible? • PEP-In-Pocket: patients can be prescribed this and take it when they think they may have been exposed to the virus. • What is the cost?Is it covered? • Education about it is likely needed- most patients won't know that PEP/ PEP-in-pocket is an option until they need it. There needs to be information campaigns available surrounding what it does, its toxicity, how it's used. These campaigns should also highlight that PEP is not good for longterm use or as a first-line defense • Accessibility: Where do patients get it? Do family doctors provide it or do they need to go somewhere

			specific? How do we ensure that people know where to get PEP and actually get PEP when they arrive? There are some patients who are being told that they do not qualify for PEP although they feel they could have been exposed to infection. Can they have this medication on file so that pharmacies havePEP available should the patient need it? How do we ensure that people know that it can be used as an occupational response to HIV and that all those who have been exposed have been given access to PEP? If a patient comes in and needs PEP, they may not be able to come back 24/48 hours later. Online pharmacy can be involved in innovating delivery and access to PEP and nurse practitioner-based models to improve
bNAbs (Broadly neutralizing antibodies)	Aims to replicate the antibodies of HIV-resistant people in those who are not. The bNAb VRCO1 Ab is currently being studied by Dr. Nelson. bNAbs are hoped to stimulate HIV immunity.	Broadly neutralizing antibodies in HIV-1 treatment and prevention Multiple roles for HIV broadly neutralizing antibodies New antibody therapy controls HIV for months after treatment Antibody Mediated Prevention	efficiency. What do we need to know? What do we need to do to implement it? • Quarterlyinfusion, patients need to sit for 1-1.5 hours • Costs - is it covered by insurance? • How much should it be prioritized over other treatments? • How many people do we want to use bNAbs to get to a convenient level of HIV prevention, like herd immunity? • How would we triage this? How many of these intensive treatments can a clinichandleif they have other responsibilities?

			 Would specialized clinics be needed? Are there ways to think of how we could prioritize this in clinics? Could bNAbs be a preliminary step to a vaccine? Should we push for bNAbs to become a vaccine? Not any of these one interventions would work for all people. More like a toolbox.
Microbicides	Aims to prevent HIV transmission through local protection. These are topical solutions (gels, ointments, lubricants) that protect the site of HIV infection through sexual contact – mucosal membranes. Puts more power in the hands of the receptive partner because it doesn't require the insertive partner to wear a condom/ other protection.	Microbicides Prevention Approaches in Development: Microbicides and Vaccines	 What do we need to know? What do we need to do to implement it? Education on usage, effectiveness, dosage & effects from overdosing, potential Impacts on sensation What can microbicides be paired with to improve prevention? What products used in these areas should microbicides not be paired with? Education from providers How do we ensure that Black patients will use this product/ are open to using it? Cost
MK8591 /MK8591 Pills/Implants	MK8591 is currently being studied as an HIV treatment as well as a preventative medication. In addition, animal studies have shown the effectiveness of an MK8591 implant in providing prophylactic treatment for approximately six months. In humans, the oral version of Islatravir is expected	Merck announces presentation of Phase 2b results for investigational HIV-1 therapy Islatravir (MK-8591) A study of Islatravir (MK-8591) in antiretroviral therapynaive, Human Immunodeficiency Virus-1 infected participants	 • Information on effectiveness, side effects, costs, where would patients go to access it? What do we need to know for implementation? • How do we make sure that patients come back for appointments within an appropriate timeframe? • Education: make sure that patients know that they should keep taking these implants so that they don't experience

	to provide protection for one month (patients will take twelve pills a year). As well, the implantable version of Islatravir is expected to provide protection for twelve months.	Extended-duration MK-8591-eluting implant as a candidate for HIV treatment and prevention Once-weekly oral dosing of MK-8591 protects male rhesus macaques from intrarectal SHIV109CP3	rebounds with other infections, such as Hepatitis B.
Patient Care Rela	ited		
Testing with less engagement	Aims to overpass the robust engagement in counselling before they can get tested. This is to minimize the time commitment for a person to take a test, and subsequently, reduce barriers to testing.	Effect of rapid HIV testing on HIV incidence and services in populations at high risk for HIV exposure Leveraging A Rapid, Round-the- Clock HIV Testing System to Screen for Acute HIV Infection Feasibility and success of HIV point-of-care testing in an emergency department in an urban Canadian setting	 Existing legislation, how would privacy/confidentiality on the matter be handled? What do we need to know for implementation?: Would need concurrent campaigns on stigma. How can we minimize engagement while still having health care professionals checkin to ensure that the patient has a social safety net if results are positive?
Integrative care	Aims to include other services to HIV prevention and treatment such as mental health services and create innovations that are not drugs. Integrative care has the potential to better connect Black	How the delivery of HIV care in Canada aligns with the Chronic Care Model Integrated mental health and HIV care in a majority minority clinic	Concerns about privacy: how do we protect people's data/address concerns about patients' health data being shared amongst different healthcare providers? What do we need to know for implementation?

	patients to several areas in the healthcare system. This is significant as social and medical issues require a multi-pronged approach.		 There is a concern about Black folks' distrust of the healthcare system. There may also be privacy/confidentiality concerns amongst Black folks if different institutions/offices will have access to patients' information. For example, HIV, mental illness and blackness are individually criminalized. Depending on the structuring of these services, Black patients may feel more vulnerable in these spaces. Perhaps social services organizations that ACB patients trust and have previously interacted with can be part of the integrative care network to reduce distrust?
Rapid-HIV testing/Home testing/Without providers	Aims to increase accessibility to HIV testing and reduces fear of HIV discrimination and stigma in healthcare settings. Home testing HIV kits may present a more discreet option for Black people hoping to identify their HIV status. We recognize that there is a high level of distrust among Black patients when it comes to the healthcare system and so this option allows people to access the information that they need without directly contacting a provider. That being said, patients who pursue this option will potentially have	Self-testing, communication and information technology to promote HIV diagnosis among young gay and other men who have sex with men (MSM) Reliability of HIV rapid diagnostic tests for self- testing compared with testing by health-care workers Interventions and approaches to integrating HIV and mental health services	 How would people access these tests? Pharmacy, clinic, etc.? Will these tests be covered by OHIP? Privacy& confidentiality? Legislation? What do we need to know for implementation? How do we ensure that providers of this test kit don't stigmatize their clients for using it? Are there ways to dispose of these tests safely and discreetly, particularly in circumstances where individuals live with other people? Important to include a resource tool (pamphlet, brochure, etc.) with these kits so that individuals who test positive have access to relevant resources.

	to interact with receptionists, cashiers and pharmacists (depending on the site through which these kits are distributed).		
Ontario Health Teams	Aims to increase networks between services by connecting social workers and physicians into one team per area. Ontario Health Teams will streamline access to a counsellor or HIV-care. This should be a 'one-stop shop' for everything.	Ontario Health Teams: Guidance for Health Care Providers and Organizations Ontario Introduces 24 Ontario Health Teams Across the Province to Provide Better Connected Care What you need to know about Ontario's new model for health care	 Do smaller treatment Teams have a voice in decision-making processes? Or are hospitals making the most decisions surrounding what interventions are implemented? How do we make sure that ACB priorities are being listened to/heard/addressed by these Ontario Health Teams? When will all Ontario Health Teams commence operations (24 have already been approved with more in the process)? What ACB organizations have been included in these teams, what barriers are they facing for advocacy in the Team? Who is invited to be a part of these Teams? There are organizations who either directly or tangentially do work pertaining to Black peoples' health that may not be exempt from these clusters of care. What do we need to know for implementation? The organization of these teams may, in themselves, act as barriers to care depending on structure. Assuming the presence of bureaucracy, miscommunication between administrators, providers and clients, problems of efficiency, and the initial adjustment period

			may discourage Black patients from seeking care if direction is not clear. These teams are meant to be locally based. Requiring that individuals seek care within a particular geography creates challenges within specific Black communities in terms of privacy. We may need to clarify whether or not this will interrupt current arrangements between Black patients who are seeking care outside of their communities. These Ontario Health Teams are also supposed to identify target populations to serve (e.g. Elderly, refugees, mental health and addictions patients) within their local community. We need to advocate that ACB populations are identified as a target population to serve especially within health teams in the GTA.
Health promotion	Aims to create supportive environments and eradicate stigma. This can be done through educating populations, awareness campaigns, etc.	The Health Promotion Model in HIV Care Reducing HIV- related stigma and discrimination in healthcare settings #HIV: Alignment of HIV-Related Visual Content on Instagram with Public Health Priorities in the US	 What do we need to know? We need to know to what degree these health promotion models promote principles of social justice and emancipation. How are social determinants accounted for in health promotion models that are taught in medical and nursing schools and that are used in health and social service practice? We need to mitigate the structural factors that might fuel HIV prevalence in urban and suburban marginalized Black communities How do we continue to utilize holistic prevention approaches to

			inform Black communities on newer HIV prevention strategies and HIV management modalities? What must be considered to ensure implementation has beneficial impact? Stigma-reduction activities should be targeted to staff at health care facilities. Health promotion should be viewed as a structural issue that should be reflected in organizational policies and procedures. Education campaigns should also address white privilege, anti-Black racism, homophobia and their contributions to HIV disparities in Black communities. Investments must be made in health promotion that reduces community-level vulnerability to negative outcomes of disasters (human-made or environmental). Stigma campaigns should address Internalized stigma and psychosocial issues such as self-esteem and neurocognitive empowerment among Black communities.
Information dissemination	Aims to use other methods of sharing HIV-related knowledge. This can include peer-based apps and solutions, which can be useful for the Black community. For providers, an example may be the culturally responsive services workshop.	Confronting the challenges of HIV/AIDS information dissemination Self-testing, communication and information technology to promote HIV diagnosis among young gay and other men who have sex with men (MSM) Social Media and HIV: A Systematic Review of Uses of	 What do we need to know? What are acceptable platforms for information dissemination and information exchange for capacity-building? What is the acceptability and feasibility of peer-support solutions in Black communities as tools for stigma-reduction, social support and information sharing. How do we integrate Black peer support services in both traditional health care settings and independent programs in Canada. What must be considered for ensuring equitable implementation?

		Social Media in HIV Communication Uses of information and communication technologies in HIV self-management: A systematic review of global literature	 Black-led organizations should have central roles in design and implementation of information exchange systems. Information dissemination must be able convey evidence-based practices to lay audiences as well as to staff at organizations that provide health and social services to Black communities. Collaboration between organizations must be incentivized and prioritized over strategies that instigate competition. Among Black adolescents, online information-gathering and social support-seeking are especially popular and should be promoted. All HIV literacy campaigns focused on how to encourage Black individuals and families to seek needed services should be culturally adapted.
U=U	Aims to establish that if an HIV+ individual is on consistent ARTs and their viral load becomes undetectable, then they cannot transmit the virus. This international campaign was launched to help lower stigma surrounding HIV, U=U has been criticized for putting additional stigma onto those who have not been able to achieve an undetectable viral load.	U=U taking off in 2017 The science is clear: with HIV, undetectable equals untransmittable Prevention Access Campaign CATIE Summer 2017 U=U Update	 What do we need to know? What is the history of U=U so that Black communities can understand it in a fuller social and political context? What is the evidence that U=U works as a stigma-reduction for Black communities? What must be considered for ensuring equitable implementation? There must be investments in strategies to leverage the science (not necessarily the brand) of U=U in ways that have clear and measurable benefit of Black communities, including observable changes in policies and practices in multiple sectors (e.g., law enforcement, healthcare, public health).

Prevention of	Aims to reduce HIV	New guidance on	What do we need to know?
Mother-to-Child Transmission (PMTCP) Protocols	transmission from a mother to their child by recommending ARV drugs and reducing breast feeding. These often focus on both the health of the pregnant mother and the fetus/newborn.	prevention of mother-to-child transmission of HIV and infant feeding in the context of HIV Prevention of mother-to-child HIV transmission within the continuum of maternal, newborn, and child health services	 What is impact of new biomedical prevention and treatment products on breastfeeding safety to infants? What are the identifiable challenges in scaling-up PMTCP services and protocols in Black communities. How do we develop and use comprehensive communications strategies to promote breastfeeding and ARVs and for HIV-positive Black mothers who want to breastfeed? Can we develop a defaulter tracking mechanism to ensure compliance to HIV treatment among HIV-positive breastfeeding Black mother? What must be considered for ensuring equitable implementation?

Appendix 4. Recommendations across Medication, Patient Care and Broad Scale Efforts to Improve HIV Care and Prevention in ACB Communities

Medication- Related Common Themes:

***The medication-related common themes apply to the following medications: long-acting injectable PrEP (Pre-Exposure Prophylaxis), Descovy (by Gilead), PEP (Post-Exposure Prophylaxis), bNAbs (Broadly neutralizing antibodies), Microbicides and MK8591 /MK8591 Implants

What do we need to know?

- Pharmacology
 - o What are the side/ adverse effects? What is the minimum effective dose?
 - Did the research trials include ACB participants/researchers/stakeholders?
- Accessibility:
 - Where will this medication be available? What is required to access it (ex: a prescription or referral)?
 - How much will it cost? Will this cost be subsidized by ODB or Trillium? Will there be drug cards available if there is no generic available?
 - o How often will patients need to follow-up with a healthcare provider?
 - Which medications can be administered at home by the patient? Which medications require a healthcare professional?
- Prioritization of Intervention:
 - o Is this a first-line intervention? If not, how will we decide which of these interventions should be first-line and which should be second-line?
 - How many of these intensive treatments can a clinic handle if they have other responsibilities? Would specialized clinics be needed? How would these treatments be triaged?
- Route of Administration:
 - How will patients take the medication (e.g. injection, topical, pill, etc.)?
 - o Is the medication invasive?
 - o Can they take it with other drugs/ interventions?

What do we need to know for implementation?

- Patient Relations:
 - How will information be disseminated for ACB peoples? What health education resources will be available? Lots of community-level education would be required to help build trust amongst ACB communities about this product
 - How will patients be able to decide which medications are appropriate for their needs? This must be determined to have fully informed consent from patients.
- Provider Relations:
 - o How will we educate providers on the usage of the medication?
 - How will they communicate to ACB patients about the medication? Providers can act as gatekeepers if they don't have the time, expertise or willingness to explain this to their patients.
 - Are they less likely to provide it to those they think were willingly engaging in risky behaviours?

- Will providers be obligated to discuss or explore all HIV-prevention medications with their patients? Should all patients be informed of all options?
- Socio-environmental Factors:

What barriers are there to adherence?

- o How would HIV-related stigma or fears affect medication initiation and adherence?
- Do patients have a social support network available? How will contact or follow-up communications be conducted?
- What resources are available for patients who do not have access to a physician?
 - Could these therapies be provided at community health centres (e.g. the 519) or clinics?
 - Do patients have these clinics in their communities?
- Which medications/interventions are appropriate for those who require discretion? Which are appropriate for patients experiencing domestic violence?
- How do we integrate existing community-based organisations/ shelters that work with marginalized communities in disseminating information about these interventions? How do we integrate these organisations in dispensing these medications/ interventions?

Patient Care-Related Common Themes:

These patient care-related common themes apply to the following: testing with less engagement, integrative care, rapid HIV testing/home testing, Ontario Health Teams

What do we need to know?

- Privacy/Confidentiality
 - How would privacy/confidentiality be handled?
 - What privacy concerns exist regarding patients' health data being shared amongst different healthcare providers?
- Accessibility
 - o How would patients access self-testing kits? Will OHIP cover the test kits?
- Community Engagement
 - When will Ontario Health Teams commence operations (24 have already been approved with more in the process)?
 - What ACB organizations have been included in these Teams? What barriers related to advocacy are they facing in the Team?
 - Who is invited to be a part of these Teams? There are organizations who either directly or tangentially do work pertaining to ACB peoples' health that may not be exempt from these clusters of care.

What do we need to know for implementation?

- Privacy
 - How could ACB folks' concerns and distrust of the healthcare system, especially with respect to the criminalization of HIV, mental illness and Blackness be addressed?
 - o How could privacy, or lack thereof, further impact these issues?

• Are there ways to dispose of these tests safely and discreetly, particularly in circumstances where individuals live with other people?

Accessibility

- How will we educate pharmacists/healthcare professionals on how to communicate with ACB patients on purchasing Home Testing kits?
- o How could the organization of Ontario Health Teams lead to barriers in care?
 - How do we ensure that ACB patients receive adequate care despite issues such as miscommunication between administrators, providers and clients and the initial adjustment period? How do we ensure that ACB patients aren't discouraged by changes to the healthcare system?
 - How do we connect a client's preferred health care service/providers that are outside the community with their local Ontario Health Team?

Community Engagement

- How can we ensure that ACB populations are identified as a target population to serve especially within health teams in the GTA?
- How can we ensure education and participation among the ACB community in terms of Home Testing?
- Will community centres, pharmacies, clinics, etc. provide resource tools (pamphlet, brochure, etc.) with these kits so that individuals who test positive have access to relevant resources?
- Can social services organizations that ACB patients trust and have previously interacted with be part of the integrative care network to reduce distrust?

Broadscale Efforts-Related Themes:

The following common themes were found across the categories of health promotion, information dissemination, U=U and protocols for the prevention of mother-to-child transmission.

What do we need to know?

• Social Determinant factors:

- To what degree do these health promotion models promote principles of social justice and emancipation? Are they taught in professional schools or used in health and social service practices?
- How do we mitigate the structural factors that might fuel HIV prevalence in urban and suburban marginalized ACB communities?
- What is the history of U=U so that ACB communities can understand it in a fuller social and political context?
 - What is the evidence that U=U is a successful stigma-reduction campaign for ACB communities?
- How does stigma affect ACB women? There are unique manifestations of stigma against
 ACB women in these settings
 - How do these systems treat ACB women in terms of their fertility when living with HIV?
- What are the identifiable challenges in scaling-up PMTCT services and protocols in ACB communities?
- How do we integrate ACB peer support services in both traditional health care settings and independent programs in Canada?

Accessibility of Information

- How do we utilize holistic prevention approaches to inform ACB communities on newer HIV prevention strategies and HIV management modalities?
- What are acceptable platforms for information dissemination and information exchange for capacity-building?
- What is the acceptability and feasibility of peer-support solutions in ACB communities as tools for stigma-reduction, social support and information sharing?

• Development of Research

- What is the impact of new biomedical prevention and treatment products on breastfeeding safety for infants?
- How do we develop and use comprehensive communications strategies to promote breastfeeding and ARVs for HIV-positive ACB mothers who want to breastfeed?
- Can we develop a defaulter tracking mechanism to ensure compliance to HIV treatment among HIV-positive breastfeeding ACB mothers?

What do we need to know for implementation?

• Social Determinant Factors:

- o How can stigma-reduction activities be targeted towards staff at health care facilities?
- How will organizational policies and procedures reflect the necessary changes needed for appropriate health promotion?
- How will topics such as white privilege, anti-Black racism and homophobia be addressed in educational campaigns given their relevance to the HIV disparities in ACB communities?
- How will funding be allocated to ensure strong health promoting measures that reduce community-level vulnerability to negative outcomes of disasters (human-made or environmental)?
- How will stigma campaigns address internalized stigma and psychosocial issues such as selfesteem and neurocognitive empowerment in ACB communities?

Accessibility of Information

- How can we ensure Black-led organizations have central roles in the design and implementation of information exchange systems?
- How will information be disseminated to audiences who are unfamiliar to social justice frameworks? This includes people in ACB communities and staff at organizations that serve them.
- How will we ensure that collaborative relationships between organizations be prioritized and incentivized over strategies that instigate competition?
- How will ACB adolescents be engaged? How can we use online information-gathering and social support-seeking for this population?
- How will we integrate and ensure cultural sensitivity in HIV literacy campaigns focused on how to encourage ACB individuals and families to seek needed services?

• Development of Research

How can we use the science of U=U to benefit ACB communities (i.e. change policies and practices in law enforcement, healthcare, public health)?

Appendix 5. Maps of Toronto's Ethnic Distribution of Black Canadians by Neighborhood Overlayed with Location of CHCs and ASOs

