



# A/C STUDY



# Community Report

**HIV among African, Caribbean,  
and Black People in Ontario**

**December 2020**



# **A/C STUDY COMMUNITY REPORT: HIV AMONG AFRICAN, CARIBBEAN, AND BLACK PEOPLE IN ONTARIO**

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The Public Health Agency of Canada has also contributed to, and learned from, this study through the purchase of items such as 'lessons learned' to inform potential future similar surveys.

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# Executive Summary

## A/C Study Community Report: HIV among African, Caribbean, and Black People in Ontario

### Background:

African, Caribbean, and Black (ACB) communities in Ontario are significantly impacted by HIV. ACB people comprise only 5% of Ontario's population yet routinely account for 25% of new HIV diagnoses. The aim of this community report is to present major findings and key actions from the A/C Study—a study that was conducted to understand factors that influence HIV among ACB people in Ontario. The information in this report can be used to help mobilize community actions, policy, programming, and further research to help reduce the impact of HIV in ACB communities.

### Research Approach:

The A/C Study was developed by a team of mostly ACB researchers and service providers in Toronto and Ottawa. The A/C Study was a community-based research project, and people from ACB communities played leading roles in all aspects of the project. Phase One collected data from 1,380 individuals who represented a broad cross-section of ACB communities. Data collection in this phase included a survey, a collection of a blood sample that was used to screen for HIV, linkage to health administrative data, and a point-of-care HIV test for participants who wanted to know their HIV status. Phase Two consisted of a two-day online workshop where information about the A/C Study was shared with the public for discussion. Twelve focus group discussions were held during the event to gather information regarding the public's reaction to the findings of the A/C Study.

### Key Findings:

The study's key findings, categorized by topic area, are as follows:

#### HIV Infection

Our study found that participants who experience greater social disadvantage were more likely to test positive for HIV. Various social determinants such as education, immigration experience, employment status, and gender identity were used to assess HIV vulnerability. Our findings also showed that participants aged 50-59 years old were more likely to test positive for HIV than younger participants. While people recruited from AIDS service organizations (ASOs) were more likely to test positive for HIV, only 13% of participants recruited from ASOs tested positive, thus demonstrating that ACB people access ASOs for a variety of reasons.

#### Sexual Practices and Sexual Health

The exchange of sex for drugs, money, goods, or services does not appear to be a main factor for HIV transmission in ACB communities in Ontario. However, factors that affect HIV risk among A/C Study participants included having multiple sex partners (both regular and casual) and low levels of condom use. Thus, sexual practices were found to be a relevant factor influencing HIV risk among ACB people. Substances, mainly alcohol and marijuana, were commonly used during sex, which can undermine prevention practices such as condom use.

#### HIV Testing and Counselling

Most survey participants (69%) had tested for HIV at least once, and the vast majority were not living with HIV (89%; also referred to as

“HIV-negative”). Barriers to getting an HIV test included stigma, fear of being deported if found to be living with HIV, lack of information about HIV, lack of connection to health care, and poor relationships with health care providers. Providing more HIV testing options, like home-based self-testing, might help ACB people avoid some of the social and structural barriers to HIV testing.

### **Knowledge about HIV Transmission and Acquisition**

Level of education, language, and employment status significantly impacted participants' knowledge about HIV transmission and acquisition. Those with fewer years of formal education, those who were under-/unemployed, and French-speaking people had lower levels of knowledge. Our findings also indicated that most survey participants had accurate knowledge about HIV, although a substantial proportion had inaccurate information or no knowledge at all. ACB community members also expressed concern about decreasing levels of knowledge in their communities.

### **HIV Care and Treatment**

About 87% of participants who are people living with HIV (PLWHs) were under the care of a health professional. Most (88%) survey participants who are PLWHs were taking prescribed medication for HIV infection, so the vast majority of ACB PLWHs were accessing HIV treatment. About 7% of survey participants who are PLWHs were diagnosed within the last year.

### **Access and Use of Health and Social Services**

Overall, this study established that ACB people faced many barriers to accessing health and social services. Further, those who completed the survey in French were less likely to have a primary care provider than those who completed it in English, but they were more likely to access medical specialists. Hence, Francophone ACB people were generally disadvantaged in ways that may have compromised access to health and social services.

### **Anti-Black Racism and Other Forms of Oppression**

Survey participants reported that racism, sexism, and xenophobia (based on immigrant status) were the top three reasons for experiencing unfair treatment. These three factors result in systemic oppression that sidelines ACB communities, making them vulnerable to ill health and poor social and economic outcomes. Many focus group participants described experiences of systemic racism in the health care system and in Canadian society as a whole. Information about human rights was seen as a way to combat systemic anti-Black racism in the health sector.

### **Immigration Experience**

ACB immigrants who lived in Canada longer were more likely to have post-secondary education, be employed full-time, have a primary care provider, and have no difficulty meeting basic needs with their household income. However, participants who had lived in Canada for 5-9 years were more likely to have less HIV-related knowledge compared to other immigrants and those born in Canada. We also found that, as time spent in Canada increased, so did the likelihood of encountering unfair treatment and attributing this treatment to racism rather than immigration status.

### **Community Social Support**

Many survey participants (30% to 49% in each city) agreed with statements that indicate there was social support in their communities, but a sizable proportion (8% to 28% in each city) disagreed with these statements. Levels of social support also differed depending on the city (i.e., Toronto or Ottawa), as participants from Toronto were more likely to report lower levels of social support in ACB communities compared to those from Ottawa. Participants identified community organizations, peers, and role models as important resources for addressing HIV in ACB communities.

## Key Actions:

Key actions identified based on the A/C Study's findings are presented below, and they have been categorized by level within a modified social-ecological framework. Recognizing some of these actions necessitate complex changes that require collaboration among multiple stakeholders, neither the actions nor their levels within the framework identify a party responsible for making the changes.

### ACB Leadership:

ACB leadership is necessary for addressing HIV, anti-Black racism, and social and health issues affecting ACB communities.

- Create an ACB-led governance structure to help guide collection, access, analysis, interpretation, and dissemination of systematically collected disaggregated race and other equity-related data in the health and social services sectors.
- Leverage community assets, including political and religious leadership, in efforts to address anti-Black racism, social, and health issues affecting ACB communities.
- Engage faith-based and grassroots organizations in the response to HIV in ACB communities.
- Increase the sense of community and connectedness among ACB people.

### Structural/ Policy Actions:

Policy change is needed to resolve structural factors that negatively affect ACB communities.

- Develop interventions that address structural disadvantages that make ACB people more vulnerable to HIV infection.
- Develop interventions that protect the social and economic wellbeing of ACB people living with HIV.
- Advocate for widespread dissemination of HIV self-tests in Canada.

- Include HIV counselling and testing as part of routine health check-ups.
- Remove socio-economic barriers to accessing pre-exposure prophylaxis (PrEP)/ post-exposure prophylaxis (PEP).
- Guarantee access to HIV care and treatment regardless of residency status or other factors.
- Address racism, sexism, and xenophobia against ACB people in all interventions aimed at reducing structural disadvantages affecting ACB communities.
- Develop structural interventions to ensure recognition of professional experience and training of ACB immigrants.

### Research-Related Actions:

Research remains an important tool for knowledge generation, intervention development, and advocacy.

- Estimate the prevalence and incidence of HIV in ACB communities.
- Estimate the level of viral suppression among ACB people living with HIV.
- Collect or synthesize existing data to assess how ACB communities are doing along the 90-90-90 cascade.
- Conduct more research on the clinical effectiveness and social impacts of PrEP/ PEP on ACB communities, particularly ACB women.
- Collect data to assess the extent to which inequities in access to HIV-related information and health and social services exist for ACB people in general, and French-speaking ACB people in particular.
- Collect data to assess the extent to which discrimination in the job market exists for ACB people in general, and ACB immigrants in particular.

**Service Provision-Related Actions:**

- Access to health and social services, as well as the experience one has when using those services are both important.
- Provide anti-oppression, anti-discrimination, and unconscious bias training to health and social services providers.
- Develop and evaluate interventions to enhance health and social services providers' knowledge and skills for ethno-racially responsive services for ACB people.
- Address anti-Black racism, xenophobia, and protectionism in all interventions aimed at helping immigrants to settle and integrate into Canadian society.
- Identify optimal models for providing health, social, and HIV services to ACB communities.
- Create a structure to ensure that ACB stakeholders can make the best possible use of data for program development and policy advocacy.

**Community-Level Actions:** There is a need for community-level actions when addressing HIV, health, and social issues in ACB communities.

- Increase the availability and accessibility of HIV-related information for ACB communities.
- Address HIV stigma in ACB communities, which serves as a barrier to accepting and sharing information about HIV.
- Promote PrEP/ PEP as an HIV prevention tool for ACB people.
- Strengthen access to information about civic and health consumer rights for ACB people.

**Individual-Level Actions:**

While individual-level factors are insufficient for addressing HIV on their own, these still play an important role in HIV risk.

- Provide education about HIV risk when alcohol and marijuana are used during sex.
- Provide continuous education about HIV and available resources to all ACB people, not just new immigrants.
- Increase HIV knowledge among young ACB people and those born in Canada.
- Include information about the time gap between HIV exposure and a positive test result in health/ HIV education curricula.
- Promote the benefits of early detection (early treatment, life expectancy, and reduction in HIV transmission).
- Raise awareness about HIV prevalence and incidence in Canada, and in ACB communities in particular.

# Chapter 1: Background



# Chapter 1: Background

## Are Black communities disproportionately affected by HIV in Ontario?

African, Caribbean, and Black (ACB)<sup>1</sup> communities, which includes people from Caribbean and sub-Saharan African countries, is one of six population groups in Ontario that are most affected by HIV and have therefore been prioritized for HIV prevention, care, treatment, and support (Ontario HIV Treatment Network, n.d.-a). These populations have greater vulnerability to HIV due to social determinants of health<sup>2</sup> and structural factors<sup>3</sup> that threaten health and wellbeing (Ontario HIV Treatment Network, n.d.-b). Even though Black people constitute only about 5% of Ontario's population (Government of Canada, 2017), in 2017 they accounted for about 29.3% of all new diagnoses (Ontario HIV Epidemiology and Surveillance Initiative, n.d.).

## What does existing disease surveillance data tell us about HIV in Ontario's Black communities?

"Existing provincial HIV surveillance data does not always have information on race or ethnicity, and therefore many ACB people with HIV may be missed" (Mbuagbaw et al., 2020, pg. 1). These ACB people living with HIV "include Ontario residents who test positive, and people living with HIV who migrate to Ontario from other [Canadian] provinces [or other] countries and test positive in Ontario for the first time" (Mbuagbaw et al., 2020, pg. 1). Partly due to the lack of consistent information about race or ethnicity, data and estimates about the prevalence of HIV in ACB communities have been unavailable to researchers and other stakeholders. Consequently, it is difficult to

<sup>1</sup> The term "African, Caribbean, and Black (ACB) people" is used for those who self-identify as Black, which is a racial category, but it includes ethnicity as well, thereby recognizing the ethnic diversity in Ontario's Black population and the two regions from which the majority of the Black population originates. Despite the ethnic diversity in this population, however, its members are bound by race due to a sense of shared history and experience of social exclusion resulting from xenophobia, anti-Black racism, and exploitation due to colonialism and slavery. Furthermore, Black people in Ontario organize themselves by both race and ethnicity—there are community organizations focused on collective Black issues as well as organizations specific to regions or ethnic groups. Hence, the term ACB acknowledges the various ways in which Ontario's Black population organizes itself.

<sup>2</sup> Social determinants of health are social and economic factors that influence the health of individuals and populations. These can impact health directly or indirectly (i.e., through other factors), and they help shape the context of people's lives and lifestyles. Examples of social determinants of health include income level, education and literacy, gender, race and ethnicity, and social support networks.

<sup>3</sup> Structural factors are those that operate system-wide and are responsible for inequities between groups. These often operate through social determinants of health to influence health outcomes. Social and economic structural factors that have been shown to impact individual and population health include: anti-Black racism, homophobia, other forms of discrimination and social exclusion, income distribution, income security, food insecurity, and distribution of health services.

quantify the extent to which HIV affects Ontario's ACB communities. "Furthermore, provincial surveillance does not always capture detailed information on factors associated with HIV acquisition and transmission (such as sexual risk behaviours and substance use) or the broader determinants of health that may increase vulnerability to HIV among ACB people. In 2016 and 2017, data on race/ ethnicity and exposure category were available for only 47.4% and 49.3% of cases, respectively" (Mbuagbaw et al., 2020, pg. 1).

## Why are surveillance and research data important?

Data from health surveillance and research provide foundational evidence to inform the provision of responsive interventions that are comprehensive and culturally appropriate;<sup>4</sup> these comprise a key strategy for improving health and wellbeing among ACB people in Ontario (Mbuagbaw et al., 2020). "Understanding lived experiences and determinants of health of ACB people—including access to health services—is essential for tackling the root causes of HIV vulnerability and providing effective and specific HIV services" (Mbuagbaw et al., 2020, pg. 2). For ACB people living with HIV, it is especially important to collect data on multiple forms of discrimination and oppression simultaneously, because the intersection of HIV stigma and discrimination with other systems of oppression build on the known barriers to achieving health and wellbeing (Kerr et al., 2018; Ontario HIV Treatment Network, n.d.-a).

## Why conduct the A/C Study?

The purpose of the A/C Study was to: improve understanding of underlying factors that increase HIV risk and vulnerability in ACB communities; and to inform policy and practice in Ontario with regards to HIV prevention, care, and support for ACB people.

<sup>4</sup>Cultural appropriateness takes sensitivity and awareness of cultural differences and puts these into action by tailoring health interventions to meet the needs of different cultural groups. Examples of approaches for enhancing cultural appropriateness include: designing communication materials (e.g., pamphlets, flyers, posters, videos, etc.) in ways that will likely appeal to a given cultural group; providing information/ evidence that is specific to a given cultural group; providing services and/ or materials in a target group's dominant or native language; hiring staff or training peers from the target group; and recognizing the group's cultural values, beliefs, and behaviours, and reinforcing and building on these to develop programs and services for the group (Kreuter et al., 2003).

# Chapter 2: About the A/C Study

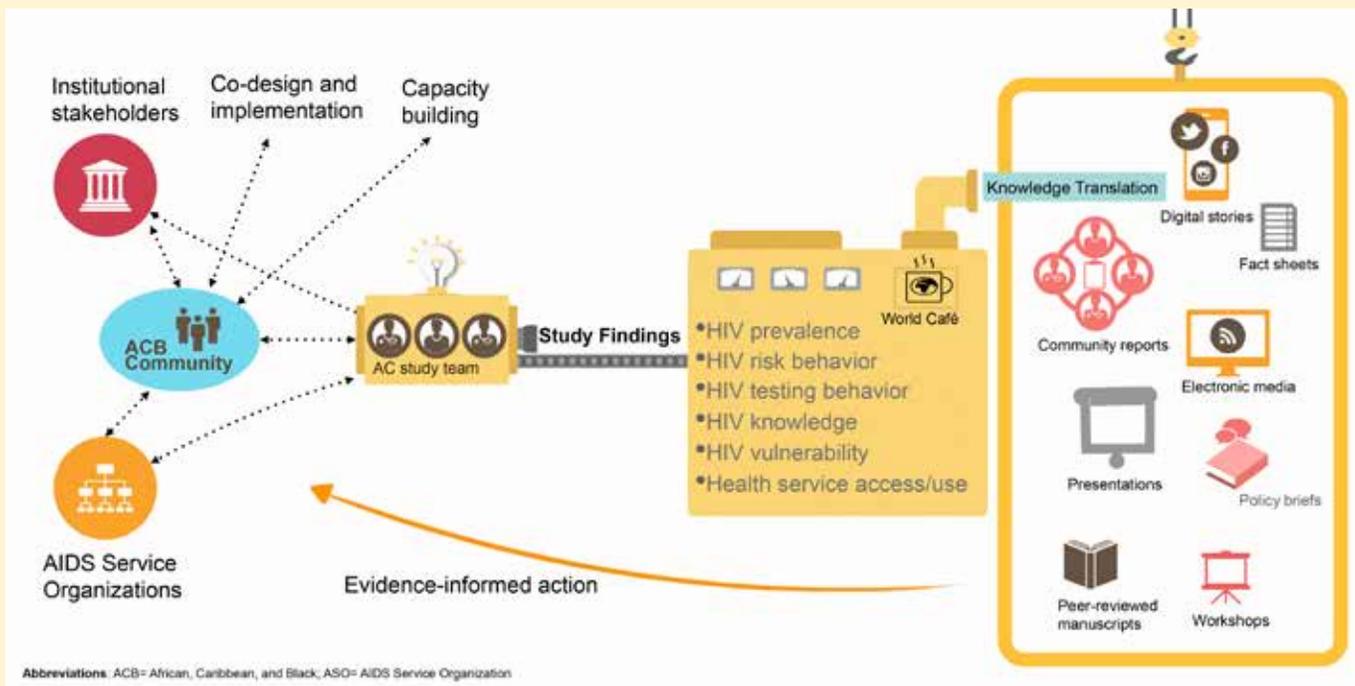


# Chapter 2: About the A/C Study

A team primarily comprised of African, Caribbean, and Black (ACB) researchers and service providers developed the A/C Study in Toronto and Ottawa. The A/C Study was a community-based research (CBR) project, and ACB stakeholders played leading roles in all aspects of the project. The study aimed to estimate the prevalence of HIV and determine the main factors that influence HIV risk and vulnerability among ACB communities in both cities. Results will be used to promote

understanding and support action in responding to HIV among ACB communities, such as informing policies and programs that may prevent HIV transmission and promote health. Figure 2-1 provides an overview of the A/C Study's structure, values, and key knowledge outputs. The study's research methods are described in Appendix A.

**Figure 2- 1: Diagram of the A/C Study**



## What were the objectives of the A/C Study?

As shown in Figure 2-1, the primary objectives of the A/C Study were to describe: (1) prevalence of HIV, (2) behaviours associated with transmission of HIV, (3) HIV testing behaviours, (4) core knowledge related to HIV transmission and acquisition, (5) key individual and structural factors that affect vulnerability to HIV, and (6) care and treatment history for HIV as well as access to and use of health services (Mbuagbaw et al., 2020).

## Why implement the A/C Study at this time?

Although HIV is not a problem in Canada to the same extent as in other parts of the world, certain population groups in Canada are more affected than others. Mounting evidence collected over the past two decades have shown ACB communities to be disproportionately negatively affected by HIV. Despite the evidence amassed to date, however, there is still a lot of uncertainty about how ACB people are affected by HIV. For example, in five out of every 10 HIV cases in Ontario, there is no information on the ethnic or racial background of those who are diagnosed (Mbuagbaw et al., 2020). This means there is some uncertainty about how widespread HIV is among ACB people in Ontario. More comprehensive information is needed about the livelihood, challenges, and experiences of ACB people living with HIV in Ontario. Furthermore, more research is needed to elucidate factors associated with HIV exposure in ACB communities, as existing information about why and how ACB people in Ontario become exposed to HIV is not adequate. Without better knowledge, we are unable to develop more effective programs and policies to address HIV-related disparities in ACB communities. In addition, ACB people need better information

to help inform advocacy, activism, education, and community mobilization related to health and wellbeing.

## What was the team's composition?

The leadership of the A/C Study and most of the research team consisted of experienced ACB institution- and community-based researchers and service providers. The A/C Study team included a broad range of stakeholders with demonstrated expertise and experience in health care, research, program and policy development, and advocacy with ACB communities in Ontario. Many members of the research team were located in AIDS service organizations. See Appendix B for details about the research team.

## What values guided the A/C Study?

- **Community stewardship:** ACB community members, researchers, and service providers were actively engaged in all phases and processes of the A/C Study.
- **Diversity:** "ACB communities share commonalities, but they are not homogenous" (Mbuagbaw et al., 2020, pg. 2). The A/C Study captured and reflected this diversity, including challenges and strengths it confers, "to make the project and its aftermath successful" (Mbuagbaw et al., 2020, pg. 2).
- **Capacity building:** "ACB communities possess resources (specifically knowledge and abilities) that can inform the work of researchers and [policy makers]. The A/C Study [aspired] to empower [ACB communities] and to increase the ability of service providers working with these communities to address HIV-related issues" (Mbuagbaw et al., 2020, pg. 2).

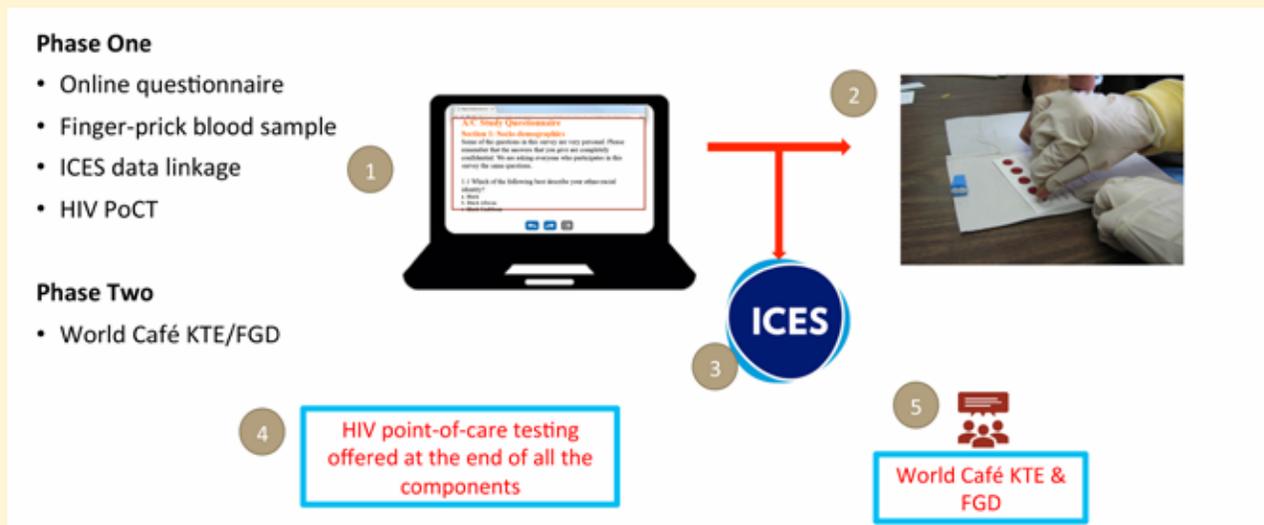
- Integrating knowledge and action: “The A/C Study team brought together researchers and knowledge users ([i.e.,] service providers, people living with HIV, etc.) to collaboratively develop, share, and use the knowledge generated by [the] study... The knowledge generated... will be disseminated to meet the needs of diverse stakeholders, while upholding and respecting the dignity of ACB people” (Mbuagbaw et al., 2020, pgs. 2-3).
- Respect: The A/C Study demonstrated respect for all participants, and generally for ACB communities in Toronto and Ottawa. This includes responding honestly and timely to questions about the research, ensuring the confidentiality of all participants, reporting on the study in a timely manner to facilitate greater understanding, and conducting the research in the interest of promoting community wellbeing.
- Ethics: The A/C Study was conducted with the highest ethical standards, and the study was approved by Research Ethics Boards at five institutions: Toronto Public Health, Ottawa Public Health, Laurentian University, University of Ottawa, and University of Toronto.
- Scientific rigour: The A/C Study drew on the expertise of experienced researchers and methodologists to ensure this scientific research was conducted to the highest methodological standards.
- Co-design and implementation: The A/C Study team (including researchers and knowledge users) worked collaboratively to make decisions about the study, while recognizing that the Co-Principal Investigators were ultimately responsible for managing the budget and reporting to funders.

## What were the components of the A/C Study?

The A/C Study consisted of two phases, which are shown in Figure 2-2. Phase One collected data from 1,380 individuals and included:

- an online survey that covered socio-demographic characteristics (i.e., age, education, etc.), HIV-related sexual and substance use practices, HIV-related knowledge, HIV testing, HIV care and treatment, blood donation, experiences with HIV stigma and discrimination, experiences with racism and other forms of discrimination, access to and use of health systems and services, and community social support;
- a finger prick to collect a blood sample that was used for dried blood spot testing to determine HIV status;
- linkage to health administrative data held by ICES; and
- point-of-care HIV testing for participants who wanted to receive their HIV test results.

Figure 2-2: Components of the A/C Study



Phase Two consisted of a world café event, a virtual two-day workshop that supported knowledge sharing. Twelve focus group discussions (FGDs) held during the event were used to gather additional qualitative data to augment the survey data. Fifty individuals participated in the FGDs on the first day, and 57 participated on the second day. The FGDs covered the following topics: health research with ACB communities, HIV testing and counselling, experiences with addressing basic needs, HIV vulnerability and risk, service access, and HIV-related knowledge.

### Why did the research team link A/C Study participants to administrative health data?

The purpose of this component of the A/C Study was to gain a better understanding of how ACB people living in Toronto and Ottawa access and use health services. The information will be used to determine the health services that ACB people in Toronto and Ottawa use, how they use these services, and how it affects their health. Individuals cannot be identified from the linkage.

### What are the anticipated outcomes of the A/C Study?

A/C Study will provide the first comprehensive picture of how HIV affects ACB communities in Ontario. We expect that the research will:

- increase core knowledge related to HIV transmission and acquisition among ACB communities;
- identify key individual and structural factors that may influence ACB people's possible exposure (or not) to HIV;
- shed light on the extent to which the health care system may be helping or hindering the fight against HIV; and
- demonstrate the extent to which connections to Black communities and experiences of HIV stigma and discrimination, anti-Black racism, and other forms of oppression may help to spread or stop HIV.

The team will share the results with ACB researchers and community-based agencies that focus on improving health and wellbeing among ACB communities. The results will lead to evidence-informed actions by: strengthening programs and services to promote health among ACB people, helping to strengthen advocacy and activism related to health and wellbeing among ACB communities, and helping ACB communities exercise power and control over their access to health services. The data generated from the A/C Study will be “owned” by the research team. The research team will establish a community-based working group to ensure that the data are accessible to community stakeholders to support program development, advocacy, community engagement, and further research.

## **What knowledge translation products are expected to come out of the A/C Study?**

In addition to this community report and the fact sheets embedded within it, the A/C Study team is committed to generating knowledge products for researchers and service providers, which are summarized in Figure 2-1. For example, there will be peer-reviewed academic journal articles targeted to researchers. Additionally, the research team will create policy briefs for service providers. For multiple audiences, the research team will produce digital stories, and deliver presentations and workshops.

# Chapter 3: About this Report



# Chapter 3:

## About this Report

### Who is the target audience?

The target audience for this report are African, Caribbean, and Black (ACB) community members, service providers (particularly in the health and social services sectors) who work with ACB people, and AIDS service organizations (ASOs). We recognize that a broader audience would be interested in this report, so it is written to also appeal to policy makers, researchers, and funders of programs, services, and research.

### Why did we choose the ACB community as our target audience?

It is imperative to empower ACB community members to lead efforts to address HIV and other health and social issues affecting ACB communities. Community leadership has been essential in the fight against HIV to date, as it is community leadership that has brought us to this juncture where: ACB communities are recognized as a priority population for HIV prevention, support, and care; race-based data is collected for new HIV diagnoses in order to help us estimate the burden of HIV in ACB communities; specific funding has been allocated to ASOs, programs, and services focused on HIV among ACB people; and HIV research focused on ACB people is successfully attracting funding. One value that has guided the A/C Study is the integration of knowledge and action. Empowering ACB people with knowledge from this research can help them

to take ownership of issues affecting their communities, drive actions to address these issues, and advocate for ACB communities.

### How is this report organized?

This report is organized into 14 chapters that align with the chapters in a traditional research report. The first two chapters provide contextual information related to this research and an overview of the research process, respectively. This chapter provides an overview of the report and aims to orient readers to the document. The next 10 chapters provide results from the A/C Study. Each of these chapters is about three pages long and is designed to function as a stand-alone fact sheet, so readers can choose to read the whole report or the parts most relevant or interesting to them. The results chapters are followed by a conclusions and recommendations chapter that integrates the discussions from the implications section of the results chapters. This chapter is intended to be academic in nature, so it cites research and other evidence to support assertions made in the results chapters. This chapter applies a social-ecological lens to interpreting the findings from the A/C Study. The final chapter is followed by a technical appendix that gives an account of the research methods used in the A/C Study; it draws largely on the study's published, peer-reviewed protocol. In addition, this report is accompanied by an extensive executive summary that repeats key findings and key actions from each results chapter.

## Why are the chapters structured like fact sheets?

Since the target audience for the report is community members, service providers, and ASOs, it was important to write the report in a more accessible manner. This meant keeping the writing brief and simple, organizing the information into specific topics, distilling the information into meaningful yet understandable portions, and identifying actions to address issues. From experience, we believed chapters written in bullet form and organized using a set template would be more appropriate than traditional chapters.

## What are the sections of the chapters?

In general, the chapters are divided into the following sections:

- Key Findings: a summary of the main results from the study as they relate to the topic being presented;
- Key Actions: statements identifying actions for addressing issues raised in the chapter;
- What We Found:
  - Quantitative results from the survey are presented in the “Supporting Facts” sub-section, and text and charts are used to provide summary statistics, and
  - Qualitative results (when available) from the focus group discussions are presented in the “In Their Own Words” sub-section using text to summarize responses and illustrative quotes; and
- Implications for Policy and Practice: a discussion of the implications of the results, which draws on broader evidence and applies a social-ecological lens that

considers social determinants of health and structural determinants of inequities when contextualizing and interpreting the findings from the A/C Study.

## How should you use this report?

Some or all of the chapters in this report may be of interest to you. Since the chapters are designed to stand alone, you can go directly to the chapters that you want to read or you can read the entire report. As you read through this report, reflect on how the issues identified affect you and your friends, family, neighbours, colleagues, and society at large. Also think about what you can do in your community to help.

## How should you interpret this report?

Bear in mind that the numbers provide only a glimpse of the lived experiences of ACB people, and in many instances further research may be required to clarify some findings. The report is not intended to “point fingers” at any groups of people and should not be used to blame anyone. It is also important to consider these findings within the broader societal context in which ACB people live.

The A/C Study was cross-sectional, meaning that it represents a snapshot at a point in time in the lives of ACB people. It is not meant to infer that things have always been or will always be as presented in this report.

If any of the messages in the report are not clear to you, please reach out to the research team for guidance. Our e-mail address is [acstudy@whiwh.com](mailto:acstudy@whiwh.com).

# **Chapter 4: Characteristics of A/C Study Participants**



# Chapter 4:

## Characteristics of A/C Study Participants

### Summary of Participant Characteristics

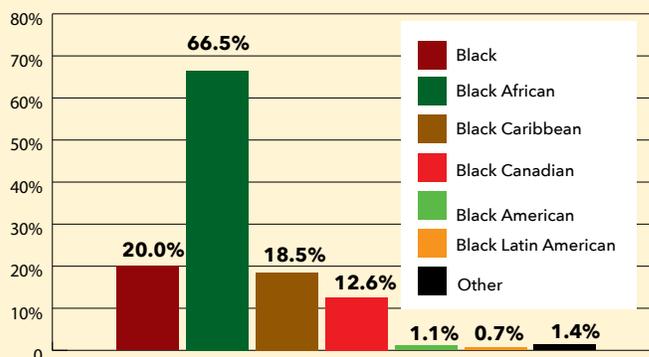
- **1,380 African, Caribbean, and Black (ACB) people aged 15 to 64 years old and residing in either Ottawa or Toronto participated in the survey.**
- **50 ACB people and other stakeholders aged 18 years and older participated in the focus group discussions on Day One, and 57 participated on Day Two.**
- **Survey respondents were diverse as it relates to their Black identity, sexual orientation, age group, education level, and employment status.**
- **Despite the diversity, some groups may have been under-represented/ hard-to-reach. These groups included people from the Caribbean and people aged 50 and older.**

## Who Participated

### Survey

- 61.9% of survey participants resided in the Greater Toronto Area, and 38.1% resided in the Greater Capital Region.
- Survey participants were able to choose multiple ethnic identities; 66.5% identified as Black African, 20.0% as Black, 18.5% as Black Caribbean, and 12.6% as Black Canadian.

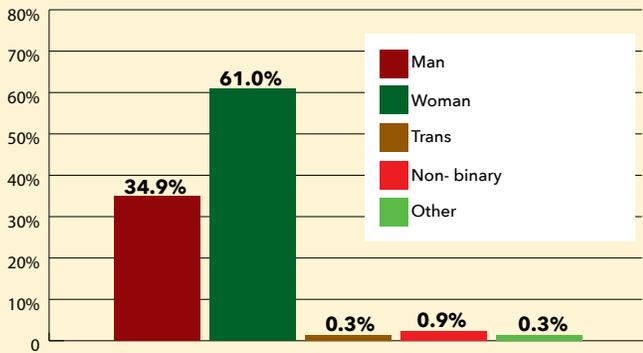
Figure 4- 1: Ethnicity



- 75.1% of the survey participants were born outside Canada and 21.6% were born in Canada.
- 92.5% of participants completed the survey in English, and 7.5% did it in French. It is likely that some Francophone participants completed the survey in English.
- 1.5% of survey participants did not identify as men or women.

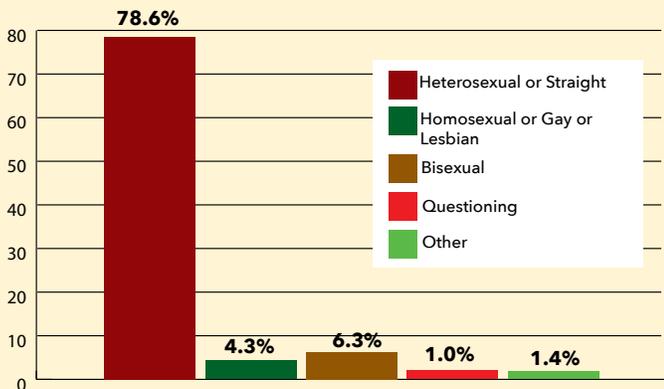
- 30.9% of survey participants were between the ages of 20-29 years old, and only 2.2% were between the ages of 60-64 years old.

**Figure 4- 2: Gender Identity**

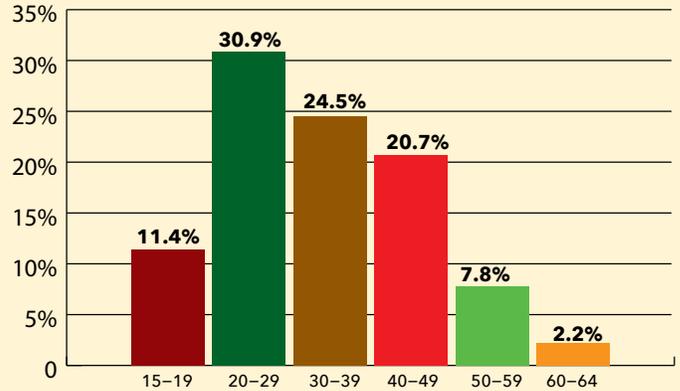


- 78.6% of the survey participants identified as heterosexual or straight, followed by 6.3% and 4.3% identifying as bisexual and homosexual, respectively.

**Figure 4- 3: Sexual Orientation**

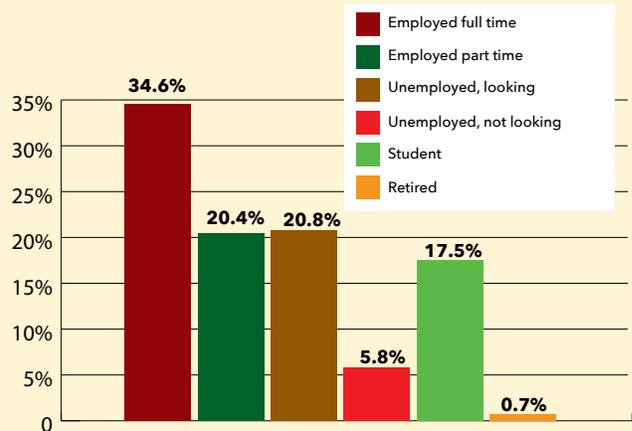


**Figure 4- 4: Age**



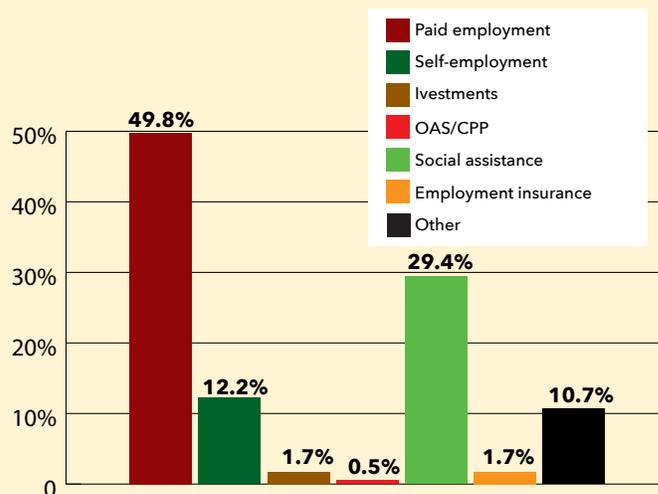
- 36.8% of the survey participants had completed a university degree; 6.4% had completed a university certificate or diploma; 20.9% had completed some college or some university without obtaining a degree, certificate, or diploma; 21.7% had completed high school; and 10.0% had less than a high school education.
- Most participants were employed full-time or part-time; 5.8% were unemployed and not seeking employment for various reasons, such as being a caregiver and being on leave from work.

**Figure 4- 5: Employment Status in the Past Six Months**



- Paid employment was the most common source of income among survey participants (49.8%), and Old Age Security/ Canada Pension Plan (OAS/CPP) was the least common source (0.5%)
- 18.4% of survey participants found it very difficult to meet basic needs in the past 12 months given their household income; 21.1% found it fairly difficult, 28.6% found it a little difficult, and 22.8% did not find it difficult at all.
- 27.5% reported that their housing was very adequate to meet their needs; and 35.7% said it was fairly adequate, 11.3% said it was barely adequate, and 16.7% said it was inadequate.

**Figure 4- 6: Income Sources in the Past Six Months**



Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## Focus Groups

- 12 virtual focus group discussions were held over two days; six on Day One and six on Day Two.
- There was one French group and two English groups for both Toronto and Ottawa participants on each day.
- Day One had a total of 50 participants: 31 females and 19 males.
  - Ottawa had 23 participants (10 males and 13 females)
  - Toronto had 27 participants (9 males and 18 females)
- Day Two had a total of 57 participants: 22 females, 11 males, and 24 people whose gender was not recorded.
  - Ottawa had 28 participants (18 females and 10 males)
  - Toronto had 29 participants (gender was only recorded for the French group, which had 4 females and 1 male)

# Chapter 5: HIV Infections



# Chapter 5: HIV Infections\*

## Key Findings

- **Participants with lower social status, based on social determinants of health, were more likely to test positive for HIV. This was seen for education, immigration experience, employment status, and gender identity.**
- **Participants aged 50-59 years old were more likely to test positive for HIV than younger participants.**
- **People recruited from AIDS service organizations (ASOs) were more likely to test positive for HIV.**

## Key Actions

- **Develop interventions that address structural disadvantages that make African, Caribbean and Black (ACB) people more vulnerable to HIV infection.**
- **Develop interventions that protect the social and economic wellbeing of ACB people living with HIV.**
- **Create an ACB-led governance structure to help guide collection, access, analysis, interpretation, and dissemination of systematically collected disaggregated race and other equity-related data in the health and social services sectors.**

## What We Found

### Supporting Facts

#### Strengths

- Most people were aware of their HIV-positive status, since only 1.9% of people who thought they were negative tested positive for HIV.
- The lowest proportion of positive test results (1.5%) was among those aged 20-29 years old.
- Only 12.5% of those recruited from AIDS service organizations tested positive, which indicated that ACB people accessed ASOs for a variety of reasons, including preventive services and as volunteers.

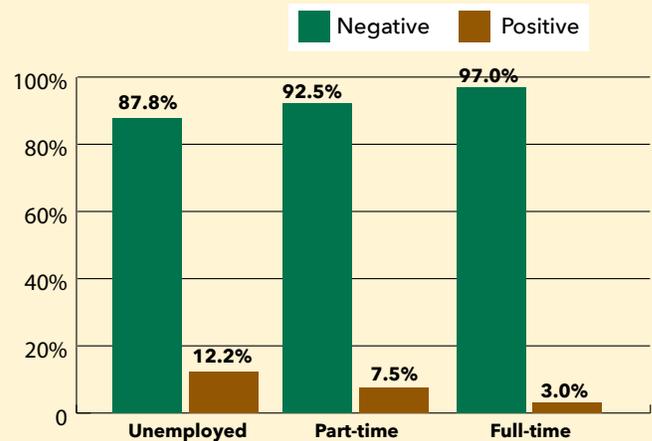
\*These estimates for HIV infection are not the same as HIV prevalence. The A/C Study team is currently working on analyses to estimate the prevalence of HIV in ACB communities in Ontario, and these estimates will be published at another time.

### Threats

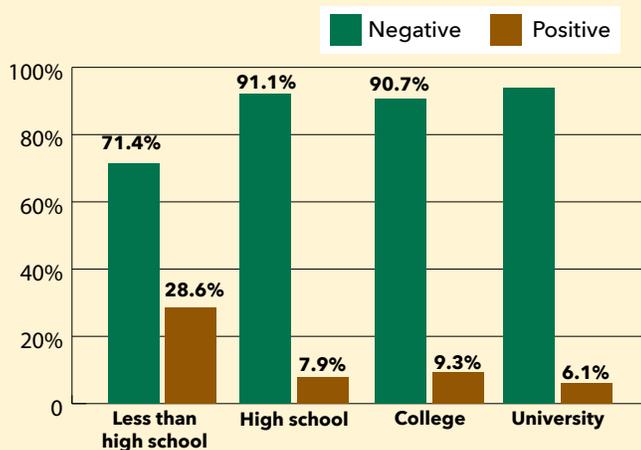
- A positive HIV test was associated with country of birth; 9.7% of immigrants and 1.6% of those born in Canada tested positive.
- Among those who completed the survey in French, 29.6% tested positive for HIV; a much lower proportion of those who completed the survey in English (6.5%) tested positive.
- A positive HIV test result was associated with lower education levels.

- A positive test result was associated with employment status.

**Figure 5- 2: HIV Test Result by Employment Status**



**Figure 5- 1: HIV Test Result by Level of Education**



- 6.8% of participants living in Ottawa and 4.6% of those living in Toronto tested positive for HIV.
- 7.7% of women and 7.4% of men tested positive for HIV; 13.3% of trans and non-binary people tested positive.
- The highest proportion of positive test results was among those aged 50-59 years old (24.6%); and 3.1% of those 15-19 years old had a positive test result.
- Interestingly, 7.8% of survey participants who thought they were HIV-positive tested negative when the dried blood spot HIV test was used.

Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## In Their Own Words

### Strengths

- Several focus group participants identified the need for more integrated/ linked programs to ensure people living with HIV have access to: preventive care, services that support their care, housing, and are able to lead sexually healthy lives.
- Several focus group participants noted that ACB communities are extremely diverse in terms of their economic, political, and social identities including, socio-economic and immigration status, levels of education, countries of origin, faith, and language fluency, etc. All of these identities and experiences impact on levels of vulnerability.
- It was widely acknowledged that intersectionality must be considered in the development and implementation of HIV interventions.

***“Black people organize in different ways, and I think that’s something that [name redacted] was talking about is about our own experience when we come here. If I look at Facebook groups and other places, we do organize in different ways. We organize religious... religiously we organize, socially in like country... as a... coming from different country. So we have to really go back to how we socialize because Black people are diverse. We can’t just be one heterogeneous group and we are seen as this Black. We have to really clearly look at those social organizations within Black people, within our own diversities and ensure that this knowledge goes there.” (Female, Toronto, FG6)***

### Threats

- Several focus group participants spoke about the high rate of poverty in ACB communities, especially among recent immigrants. Other factors that increase vulnerability to HIV included poor housing, employment in precarious or low-wage jobs and lower levels of education. These exacerbate poor health in general, and create barriers to accessing necessary health services (e.g., taking time off work, travel costs, etc.). One participant noted that many of the factors that increase vulnerability to COVID-19 are similar to those for HIV.

***“It’s very interesting because when you look at COVID, right, like since the very beginning, like who are the people, you know, who are at the front lines, like people working at the grocery stores, the gas stations, people doing the personal support work at long-term care facilities where, you know, we have had the highest number of outbreaks, right? There’s a lot of Black people who are working in those jobs and why are they working in those jobs, right? They don’t have the option of working from home. They have the option of being financially stable so they can refuse work. So they’re the ones putting themselves at risk because, you know, they might have precarious immigration status because they are low income, because they have to feed their families. They’re the ones doing the work where you put yourself at the highest risk, right. So I think that all this to say is that there’s a lot of similarities between HIV vulnerability and COVID-19 vulnerability.” (Male, Ottawa, FG5)***

## Implications for Policy and Practice

HIV surveillance data routinely shows that, relative to other population groups, ACB people have increased vulnerability to HIV due to systemic anti-Black racism and social determinants of health, and not behavioural or biological factors. Also, similar to findings from the A/C Study, many studies have also demonstrated that lower social and economic status is associated with higher rates of HIV infection in ACB communities. Taken together, these factors illustrate how systemic anti-Black racism intersects with other forms of oppression to further increase vulnerability to HIV within segments of the ACB community, specifically among immigrants, language minorities, the un- and under-employed, those with lower levels of education, and those who identify as trans or non-binary. These effects of systemic anti-Blackness and social determinants of health are mutually reinforcing. For example, anti-Black racism results in higher rates of un- and under-employment among ACB people compared to their non-ACB counterparts, and in ACB people earning less for the same work than their similarly qualified non-ACB counterparts. These factors result in lower incomes and higher rates of poverty in ACB communities, further increasing HIV vulnerability. At the same time, HIV infection causes episodic disability, which results in un- and under-employment and lower educational attainment, thereby causing or exacerbating poverty. ACB people living with HIV also face the additional burden of anti-Black racism, which increases the risk of poverty and creates barriers to escaping poverty. Addressing HIV vulnerability in ACB communities, therefore requires action at the structural level to simultaneously tackle anti-Black racism and social determinants of health.

# **Chapter 6: Sexual Practices and Sexual Health**



# Chapter 6: Sexual Practices and Sexual Health

## Key Findings

- **Most study participants did not exchange sex for drugs, money, goods, or services.**
- **Factors that affect HIV risk among A/C Study participants included having multiple sex partners (both regular and casual) and low levels of condom use.**
- **Substances, mainly alcohol and marijuana, were commonly used during penetrative sex.**

## Key Actions

- **Estimate the prevalence and incidence of HIV in ACB communities.**
- **Estimate the level of viral suppression among ACB people living with HIV.**
- **Provide education about HIV risk when alcohol and marijuana are used during sex.**
- **Develop interventions that address structural disadvantages that make ACB people more vulnerable to HIV infection.**

## What We Found

### Supporting Facts

#### Strengths

- 17.0% of survey participants had one regular female sex partner, and 26.3% had one regular male sex partner.
- 22.8% of survey participants did not have penetrative sex in the past 12 months, which lowers their risk of HIV infection.
- 37.7% had no casual male sex partners, and 40.8% had no casual female sex partners.
- 1.7% had received, and 3.1% had given, drugs, money, goods, or services in exchange for sex.
- 55.2% of the survey participants had tested for sexually transmitted infections (STIs) at least once in their lifetime.
- Most survey participants had never been diagnosed with the following STIs: hepatitis

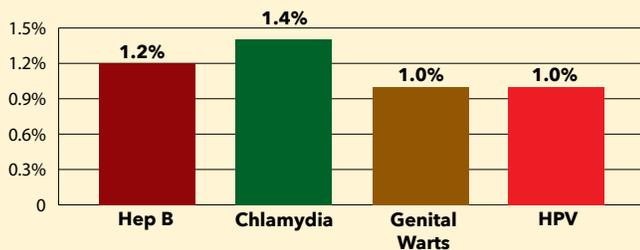
B (88.3%), hepatitis C (88.0%), chlamydia (83.6%), gonorrhoea (87.0%), syphilis (88.5%), genital warts (87.5%), human papillomavirus (86.8%), genital herpes (87.6%) and lymphogranuloma venereum (88.8%).

**Threats**

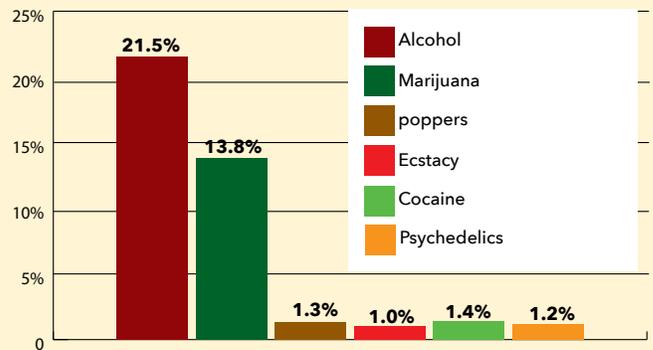
- 19.5% of survey participants who had casual female sex partners never used a condom with these partners; the corresponding proportion for those with casual male sex partners was 19.4%.
- Only 4.0% of survey participants always used condoms with regular female sex partners, 4.2% with casual female sex partners, 5.2% with regular male sex partners, and 4.4% with casual male sex partners.
- Chlamydia and hepatitis B were the most common STIs diagnosed among survey participants in the past six months.

- Use of alcohol and/ or marijuana during sex was fairly common, with 21.5% of survey respondents using alcohol and 13.8% using marijuana during penetrative vaginal or anal sex.
- Less than 1.0% of survey participants used the following substances during sex: ketamine, Gamma Hydroxybutyrate (GHB), heroin or other opioids, methamphetamine or other amphetamines or stimulants, tranquilizers, or other substances.

**Figure 6- 1: STI Diagnoses in the Past Six Months**



**Figure 6- 2: Substance Use during Sex**



Note: Values presented in the figures and text may not add to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## Implications for Policy and Practice

**Sexual practices are individual-level factors that influence vulnerability to HIV infection, but these do not occur in a vacuum. Evidence from other research shows that structural factors such as policies and institutional practices are stronger determinants of HIV infection rates at the population level than individual behaviours. Economic (e.g., poverty, un-/ under-employment, depressed wages), legal (e.g., barriers to Canadian citizenship, criminalization of Blackness), and social (e.g., stigma, discrimination, availability and accessibility of HIV prevention services) factors outside an individual's control influence sexual practices and thereby HIV vulnerability. Additionally, evidence shows that the prevalence of HIV and STIs within one's sexual network, and factors that impede the ability to achieve viral suppression, also play a role in HIV transmission. Hence, interventions that address sexual practices alone will be insufficient to reduce HIV vulnerability in ACB communities. To show effectiveness at the population level, interventions must address structural factors that increase vulnerability by limiting choices and putting ACB people at a disadvantage.**

# Chapter 7: HIV Testing and Counselling



# Chapter 7:

## HIV Testing and Counselling

### Key Findings

- **Most survey participants have tested for HIV at least once, and the vast majority were HIV-negative.**
- **Several individual (e.g., younger age, lower HIV-related knowledge) and structural factors (e.g., HIV stigma and fear, fear of deportation) were found to be related to lower levels of HIV testing.**
- **Providing more HIV testing options, like self-testing, might address structural barriers and thereby increase HIV testing.**

### Key Actions

- **Increase HIV knowledge among young African, Caribbean, and Black (ACB) people and those born in Canada.**
- **Include information about the lag time between HIV exposure and a positive test result in health/ HIV education curricula.**
- **Promote the benefits of early detection (early treatment, longevity, and reduction in HIV spread).**
- **Include HIV counselling and testing as part of routine health check-ups.**
- **Advocate for widespread dissemination of HIV self-tests in Canada.**

## What We Found

### Supporting Facts

#### Strengths

- 68.8% of survey participants have ever tested for HIV, and 89.1% were HIV-negative.
- 30.8% of the survey participants who have ever had an HIV test were tested in the last six months.
- Among survey participants:
  - 10.6% said, "I get tested regularly for HIV and this was a routine test."
  - 11.7% said, "I get tested after starting a new relationship."

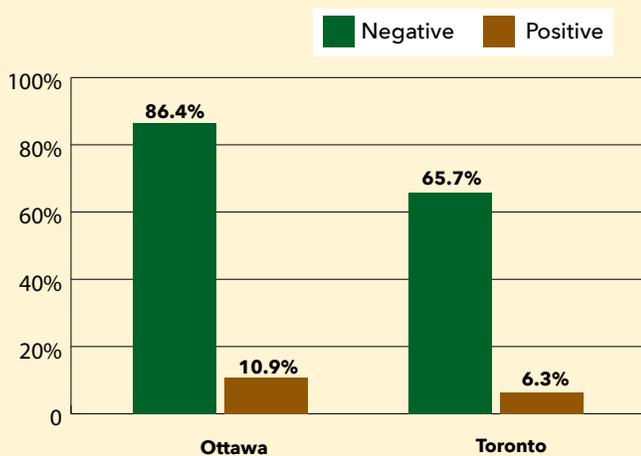
- 7.6% said, "I get tested because I was either pregnant or I planned to have a child."
- 12.7% said, "I get tested for no particular reason."

**Threats**

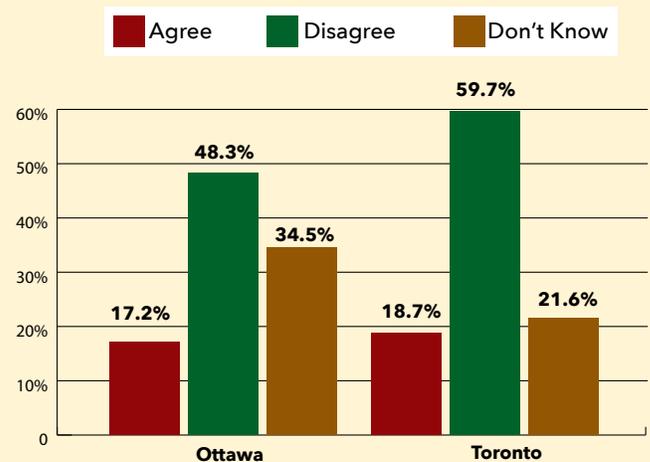
- 23.5% of survey participants have never tested for HIV.
- 5.4% of survey participants overall (and 7.9% of those who have ever had an HIV test) tested positive for HIV. Among those ever tested for HIV, participants from Ottawa were more likely to have a positive HIV test result than those from Toronto.

- Survey participants who were younger, those with part-time jobs, those born in Canada, and those who had intercourse for the first time at older ages were less likely to get tested for HIV.
- Only 48.3% of survey participants in Ottawa and 59.7% in Toronto correctly disagreed with the statement, "Taking a test for HIV one week after having sex will tell a person if she or he has HIV."

**Figure 7- 1: HIV Status among Those Who Have Ever Tested**



**Figure 7- 2: Knowledge Related to Testing Positive for HIV**



Note: Values presented in the figures and text may not add to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response

**In Their Own Words**

**Strengths**

- Some focus group participants described being encouraged to go for testing based on their social location and identity.
- Focus group participants provided advice regarding HIV testing:
  - Some thought people should be encouraged to get tested early, since an early diagnosis would result in better HIV management

- Several recommended that testing be mandatory and/ or part of a systematic health assessment, but others were concerned about the time commitment involved in testing more frequently
- Some felt testing should be associated with risk level, and not be mandatory

***“I think yeah there should be like you should think about your own risk factors but also I think it should just be like whenever you feel like you want to be tested, I don’t think there is anything like over testing. So long as you feel like maybe you’re unsafe or you feel you’re exposed or you just feel like ‘oh, no, now at this time I want to know my status.’ Maybe you went and tested three months ago, I mean, a week and they tell you come back after six months and then you go back. I think that’s my thought.” (Female, Toronto, FG3)***

### **Threats**

- Focus group participants identified several barriers to accessing HIV testing: HIV fear, HIV stigma, fear of deportation in the case of a positive test, lack of information, lack of connection to health care, poor relationships with health care providers, and concerns about confidentiality.
- Some participants felt there were fewer HIV testing options available in Canada.
- Some participants described being denied testing based on the judgements of healthcare providers.
- Many participants were in favour of self-testing kits to reduce the stigma of HIV testing.

***“I think, I think self-testing kits would be very helpful as far as HIV testing is concerned. There’s a general sense of fear still because of stigma that comes with HIV, even in a situation where anonymity is guaranteed. And so having a self-test, it can’t get any better than that.” (Male, Ottawa, FG3)***

## **Implications for Policy and Practice**

**These results demonstrate that efforts to increase HIV testing in ACB communities must target individual and structural factors. While increasing knowledge about HIV will lead to some increases in the uptake of testing, its effectiveness will depend on the availability of HIV testing services and how successfully structural barriers (e.g., HIV stigma and fear, fear about deportation, concerns about confidentiality, poor relationships with health care providers, etc.) are addressed. While more people should get tested, and testing should be more generally available, it is important to promote testing among younger people and those born in Canada. ACB people have many ideas about testing services and options for their communities, and these ideas should drive efforts to normalize HIV testing in these communities.**

# **Chapter 8: Knowledge about HIV Transmission and Acquisition**



# Chapter 8: Knowledge about HIV Transmission and Acquisition

## Key Findings

- Level of education, language, and employment influenced participants' knowledge about HIV transmission and acquisition.
- Most survey participants had accurate knowledge of HIV, although a substantial proportion had inaccurate information or no knowledge at all.
- African, Caribbean, and Black (ACB) community members have expressed concern about decreasing levels of knowledge.

## Key Actions

- Increase the availability and accessibility of HIV-related information for ACB communities.
- Address HIV stigma, which serves as a barrier to accepting and sharing information about HIV in ACB communities.
- Raise awareness about HIV prevalence and incidence in Canada, and in ACB communities especially.

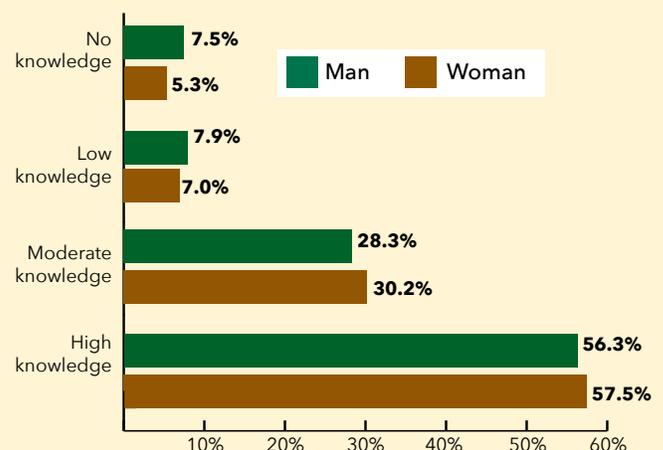
## What We Found

### Supporting Facts

#### Strengths

- 56.4% of the survey participants had high knowledge about HIV.
- HIV-related knowledge seemed to be equal among men and women.

Figure 8- 1: HIV Knowledge by Gender

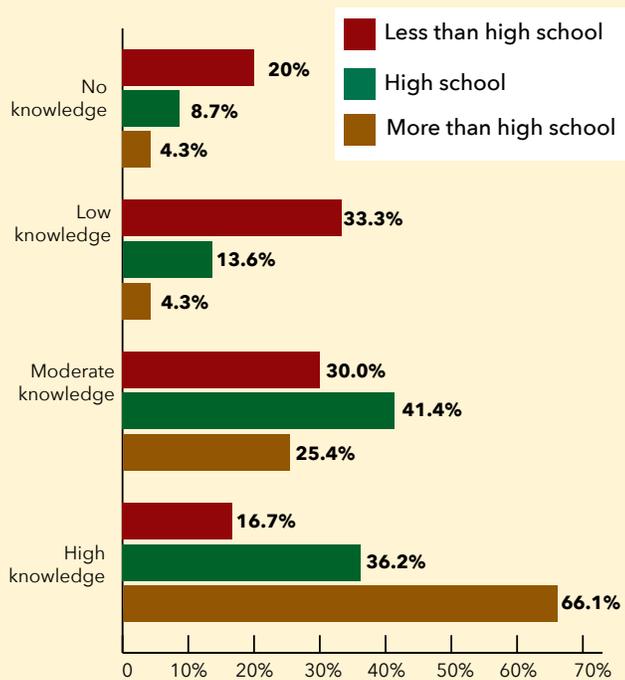


- Survey participants who reported having full-time employment had more knowledge about HIV acquisition and transmission than those who were employed part-time or unemployed.

**Threats**

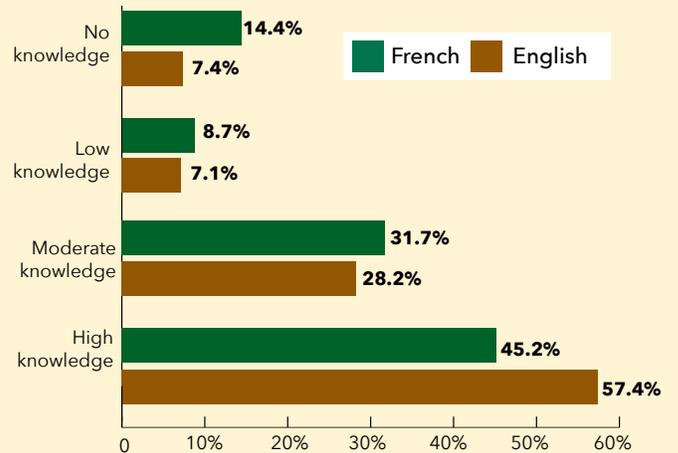
- 15.1% of survey participants had low or no knowledge about HIV.
- HIV-related knowledge was highest among those with the highest levels of education.

**Figure 8- 2: HIV Knowledge by Highest Level of Education Completed**



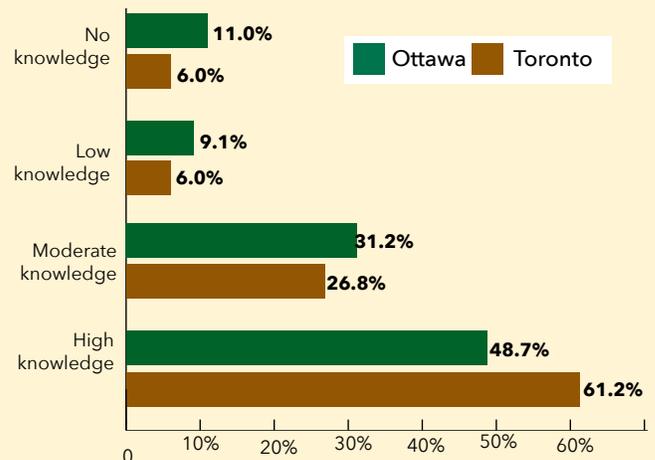
- Participants who completed the survey in English had higher HIV-related knowledge than those who completed it in French.

**Figure 8- 3: HIV Knowledge by Language**



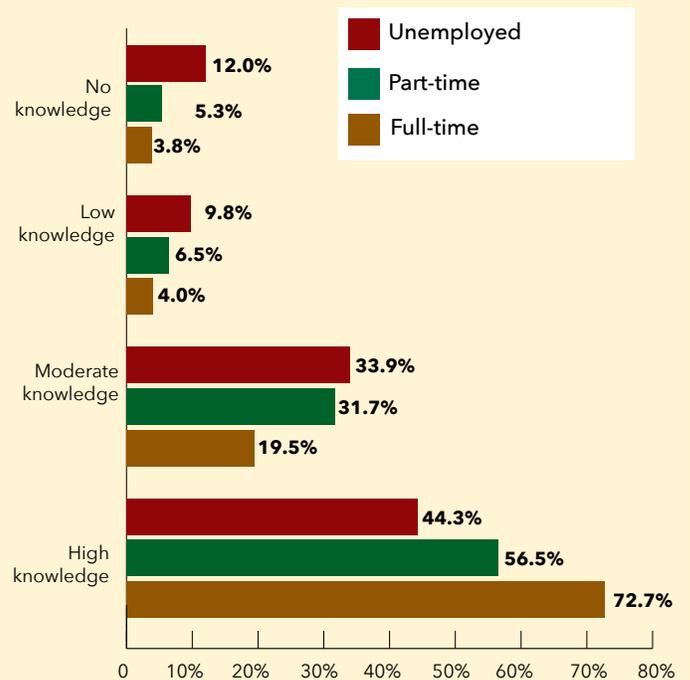
- Survey participants who resided in Toronto were more likely to have high knowledge (61.2%) than participants residing in Ottawa (48.7%).

**Figure 8- 4: HIV Knowledge by City**



- Survey participants who were unemployed had lower knowledge about HIV transmission and acquisition than those who were employed full-time or part-time.

**Figure 8- 5: HIV Knowledge by Employment Status**



Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## In Their Own Words

### Strengths

- Some focus group participants correctly recognized that HIV is no longer a death sentence and that people with HIV are living longer lives.
- Several focus group participants acknowledged the importance of HIV awareness and information sharing.
- Some focus group participants identified the need for general and targeted education activities to increase both individual and community literacy about HIV risk, prevention and available supports, and to normalize testing, treatment, and disclosure.
- Focus group participants viewed increasing community awareness about HIV as a good strategy to reduce stigma associated with HIV, which is a major source of social exclusion and a barrier to seeking help.

***“Instead of us waiting for people to come to the agencies to access services, reach out to them, go where they are, go back to the basics of how people used to do grassroots outreach because that was working and there was the sense that currently, AIDS service organizations or the services out there become too corporatized and going back to the basics of grassroots and that way we will be able to do a better job at doing HIV prevention and education.”***  
***(Female, Toronto, FG1)***

- Many focus group participants spoke about the need for targeted messages about HIV.
- Several focus group participants identified knowledge gaps among ACB children, youth, and immigrants.

### Threats

- Several focus group participants mentioned that there is a lack of HIV-related knowledge in ACB communities.
- Some focus group participants expressed concern about the decreasing levels of knowledge and awareness of HIV in ACB communities and provided some reasons for this.

*“The knowledge base has gone down. They [service organizations] don’t go into schools. They don’t go into communities like they used to. I mean [AIDS service organization] used to go into Jane and Finch, Malvern, do workshop in school from 12-year-old to the old people in retirement home, but they don’t do that anymore.” (Female, Toronto, FG6)*

*“This is specific to Black community, like that immigrate to other countries, like Black community here, I’d say there’s a lack of knowledge of the existence of HIV and AIDS here as well. So it’s almost like this is a disease that’s ravaging Africa, but once you come here, everything is looking good. Everyone is healthy. So people are not really... [looking ill] they become a bit, a little bit lax when it comes to things you’re supposed to do to prevent yourself from getting infected. So it sometimes can come as a shock to realize that it’s also prevalence of HIV here as well.” (Female, Ottawa, FG6)*

## Implications for Policy and Practice

Knowledge alone is not sufficient to prevent HIV transmission or acquisition, but it is an important component of any prevention initiative. Hence, increasing HIV-related knowledge remains a cornerstone of prevention efforts. These results from the A/C Study show that while more than half of survey participants had accurate knowledge about HIV, four out of every ten participants did not. Furthermore, the results demonstrate that HIV-related knowledge is associated with social determinants of health—French speakers, those with lower levels of education, and those who are under-/ un-employed had lower levels of knowledge compared to English speakers, those with higher levels of education, and those employed full-time. It is important to note that structural factors also influence levels of HIV-related knowledge in the population. For instance, access to HIV prevention information and services directly affects knowledge, and HIV-related stigma is a barrier to gaining and sharing knowledge. In addition to increasing knowledge, social and structural factors that serve as barriers to knowledge acquisition and use must be addressed in order to prevent new HIV infections.

# Chapter 9: HIV Care and Treatment



# Chapter 9: HIV Care and Treatment

## Key Findings

- About 87% of survey participants who are people living with HIV (PLWHs) were under the care of a health professional.
- Most (88%) survey participants who are PLWHs were taking prescribed medication for HIV infection.
- About 7% of survey participants who are PLWHs were diagnosed within the last year.

## Key Actions

- Conduct more research on the clinical effectiveness and social impacts of pre-exposure prophylaxis (PrEP)/ post-exposure prophylaxis (PEP) on ACB communities, particularly ACB women.
- Promote PrEP/ PEP as an HIV prevention tool for ACB people.
- Remove socio-economic barriers to accessing PrEP/ PEP.
- Collect or synthesize existing data to assess how ACB communities are doing along the 90-90-90 cascade.
- Guarantee access to HIV care and treatment regardless of residency status or other factors.

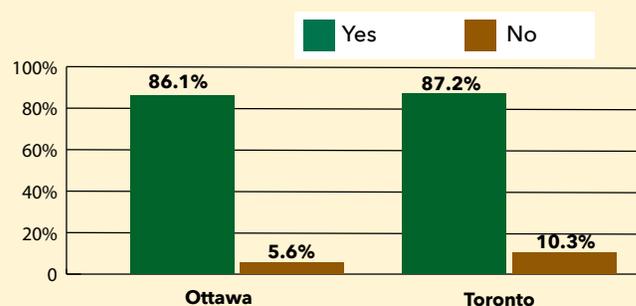
## What We Found

### Supporting Facts

#### Strengths

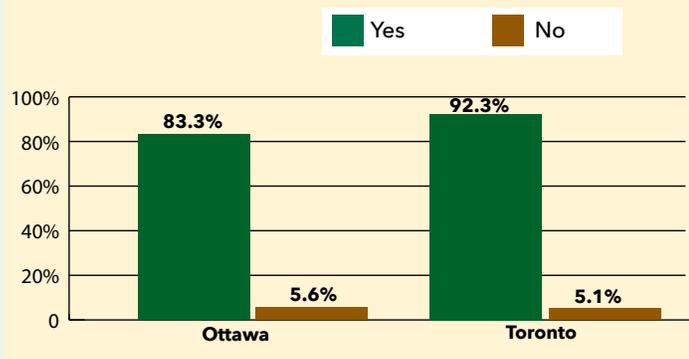
- 86.7% of survey participants who are PLWHs were accessing professional care for HIV infection.

Figure 9- 1: Currently under Professional Care for HIV Infection



- 88.0% of PLWHs who completed the survey were taking prescribed medication for HIV infection.

**Figure 9- 2: Currently Taking Prescribed Medicine for HIV Infection**



### Threats

- 8.0% of the survey participants who are PLWHs were not accessing professional care for HIV infection at the time the survey was conducted.

Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## In Their Own Words

### Strengths

- Focus group participants noted that PrEP and PEP were very effective for preventing HIV infection.

### Threats

- Most survey participants were not aware of and did not have direct experience with the use of PrEP/ PEP.
- Focus group participants suggested that PrEP/ PEP were not known in ACB communities, because these drugs were originally promoted as being for white gay men.

- 5.3% of the survey participants who are PLWHs were not taking prescribed medication for HIV infection.

- Reasons for not taking prescribed medication for HIV included: not having a doctor, having too many difficulties getting HIV medication (e.g., transportation, distance to the pharmacy, clinic or pharmacy hours), not being able to afford them, and not needing them yet.
- 4.0% of the survey participants who are PLWHs were diagnosed within the six months prior to when the survey was conducted; 2.7% were diagnosed seven to 12 months prior, 2.7% were diagnosed one to two years prior, and 82.7% were diagnosed two or more years prior.

***“So even when we go to PrEP, which is the pre-exposure, it’s supposed to be like as gay men say, gay White people say, it’s supposed to be like birth control. You take it. You don’t get pregnant.” (Female, Toronto, FG6)***

- Focus group participants noted that little research has been conducted on the use of PrEP/ PEP in ACB people, particularly women.
- Several focus group participants noted accessibility issues, such as these drugs not being covered by OHIP, and private health insurance plans being very costly and therefore not affordable to many.

- Focus group participants who accessed treatment described feeling stigmatized when requesting PrEP/ PEP and resented the requirement to continually prove their need for treatment.

***“Don’t ask me for... don’t ask me for ID. Don’t ask me for health card. Just give it to me because you just believe that I need it. I wouldn’t come here if I don’t need it. I think that would only... that would help in terms of how we as Black people access PrEP.” (Female, Toronto, FG6***

## Implications for Policy and Practice

**All people living with HIV should have access to HIV care and medications. These findings from the A/C Study are promising, because they show that the vast majority of ACB people who are HIV-positive are accessing these resources, which are essential for a long, healthy, and good-quality life following an HIV diagnosis. Financial barriers threaten access to HIV medication for people living with HIV, as well as access to PrEP and PEP (prevention tools) for people who are HIV-negative. For Ontario to effectively respond to HIV in ACB communities, which face higher rates of poverty and low income, financial barriers to accessing HIV treatment and prevention must be removed. As these barriers are based on public policy, they are entirely modifiable. When people living with HIV access treatment, they are able to achieve viral suppression, which will lead to greater viral suppression and less risk of transmission at the population level, thereby lowering HIV risk for all Ontarians.**

# **Chapter 10: Access and Use of Health and Social Services**



# Chapter 10:

## Access and Use of Health and Social Services

### Key Findings

- Those who completed the survey in French were less likely to have a primary care provider than those who completed it in English, but they were more likely to access medical specialists.
- Most survey participants, regardless of language, had been tested for HIV.
- African, Caribbean, and Black (ACB) people faced many barriers to accessing health and social services.

### Key Actions

- Collect data to assess the extent to which inequities in access to HIV-related information and health and social services exist for ACB people in general, and French-speaking ACB people in particular.
- Provide anti-oppression, anti-discrimination, and unconscious bias training to health and social services providers.
- Develop and evaluate interventions to enhance health and social services providers' knowledge and skills for ethno-racially responsive services for ACB people.
- Identify optimal models for providing health, social, and HIV services to ACB communities.

## What We Found

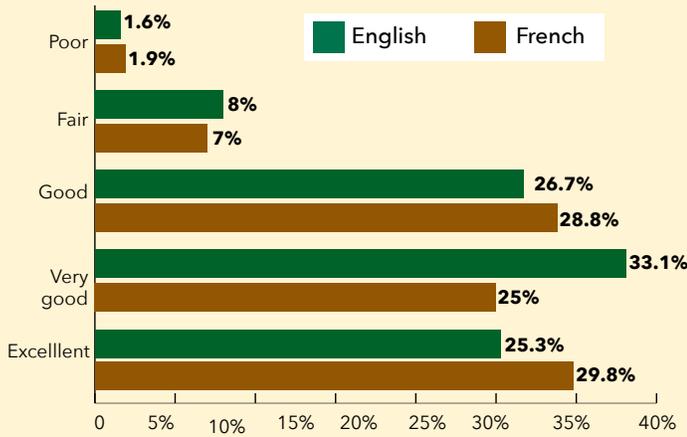
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### Supporting Facts

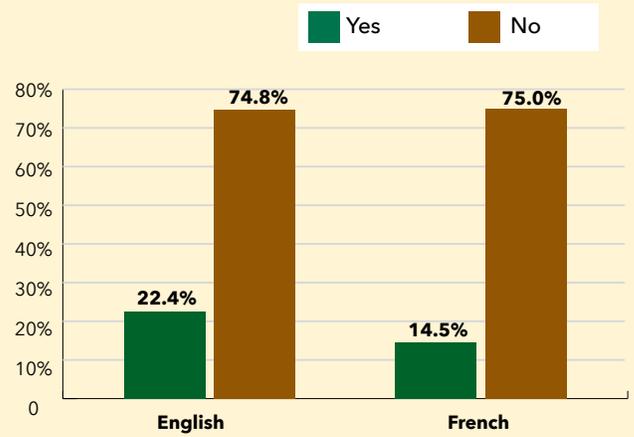
#### Strengths

- The vast majority of survey participants, regardless of the language in which they completed the survey, rated their health as good to excellent.

**Figure 10- 1: Self-Reported Health Status by Language**



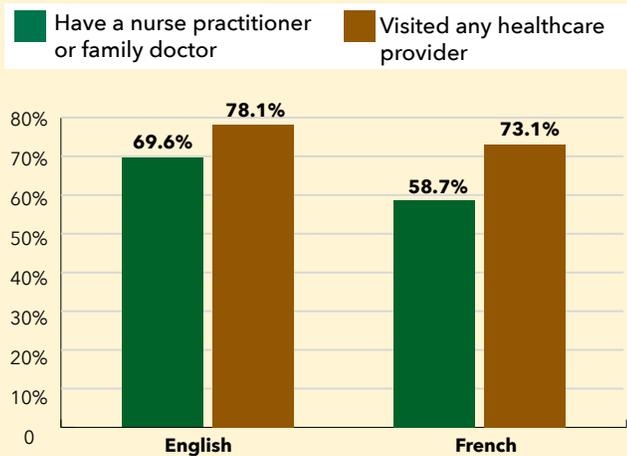
**Figure 10- 3: Difficulty Accessing Health Care by Language**



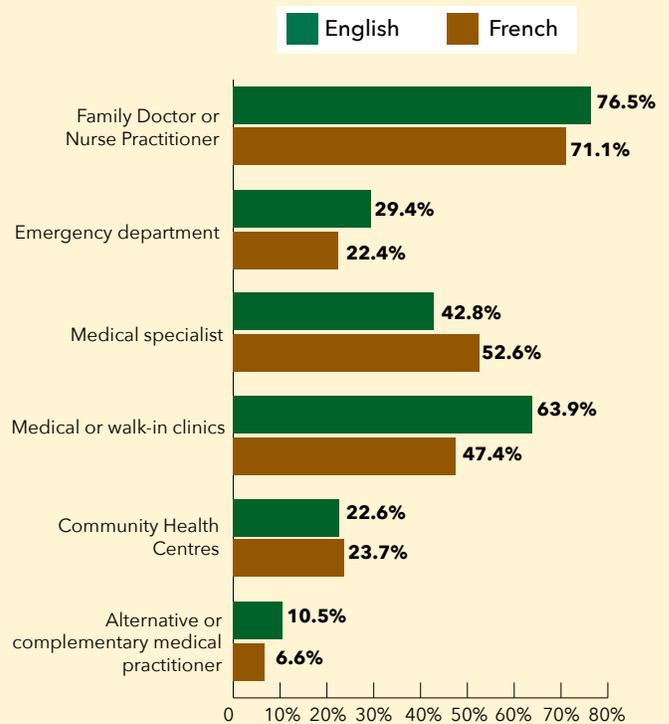
- Overall, 68.8% of survey participants had a family doctor or nurse practitioner; and 78.1% of participants who completed the survey in English, and 73.1% of those who completed it in French, visited a health care provider in the last 12 months.

- Most survey participants who used health care in the past 12 months (76.1%) visited a family doctor or nurse practitioner.

**Figure 10- 2: Access to Health Care in the Past 12 Months by Language**



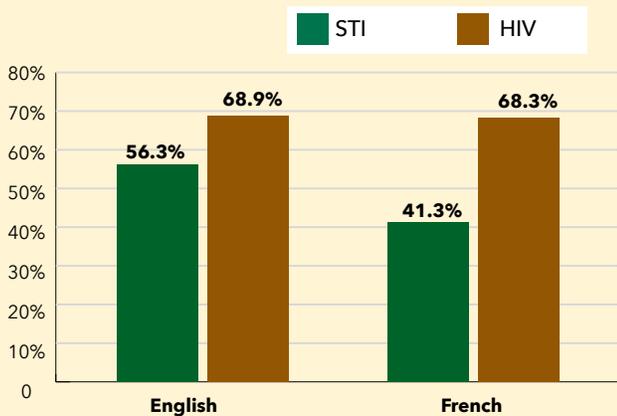
**Figure 10- 4: Use of Medical Services by Language**



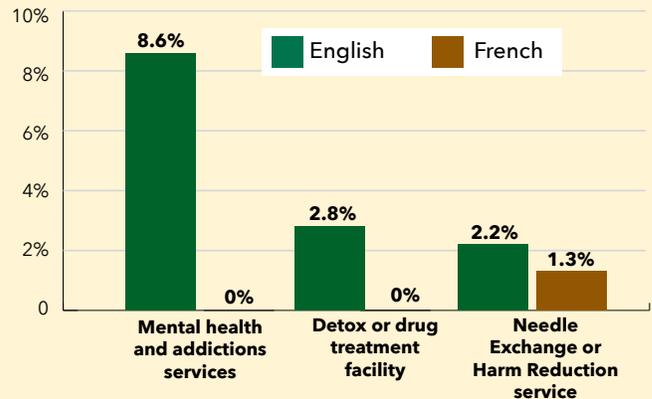
- Most survey participants who accessed health care in the past 12 months (74.8%) reported having no difficulty with access.

- Most survey participants have been tested for HIV, regardless of language, and most of those who took the survey in English have also been tested for sexually transmitted infections (STIs).

**Figure 10- 5: Ever Tested for an STI or HIV**



**Figure 10- 6: Use of Mental Health and Substance Use Services by Language**

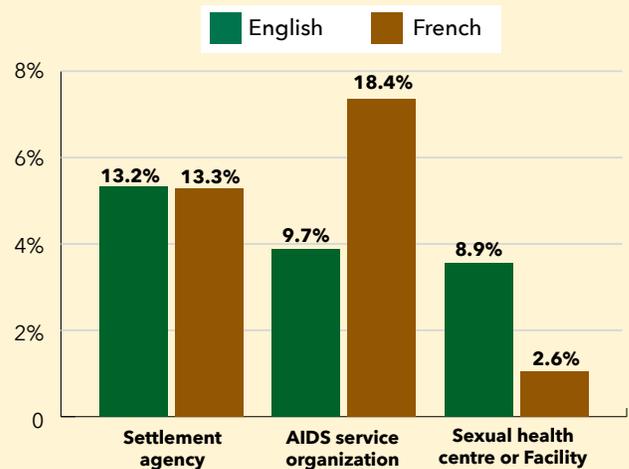


**Threats**

- Those who completed a survey in French were less likely to have a family doctor or nurse practitioner than those who completed the survey in English.
- There were disparities in health care use according to language. Those who completed the survey in English were more likely to access: family doctors or nurse practitioners, emergency departments, medical or walk-in clinics, and alternative or complementary medicine practitioners. Those who completed the survey in French were more likely to access medical specialists, however.
- Use of services for mental health and substance reliance was low overall, but was higher among those who completed the survey in English than among those who completed it in French.

- Overall, 13.2% of survey participants who accessed health care in the past 12 months used settlement agencies (for immigration-related services), 10.3% used AIDS service organizations, and 8.5% used sexual health centres or facilities. There were disparities in access by language, however.

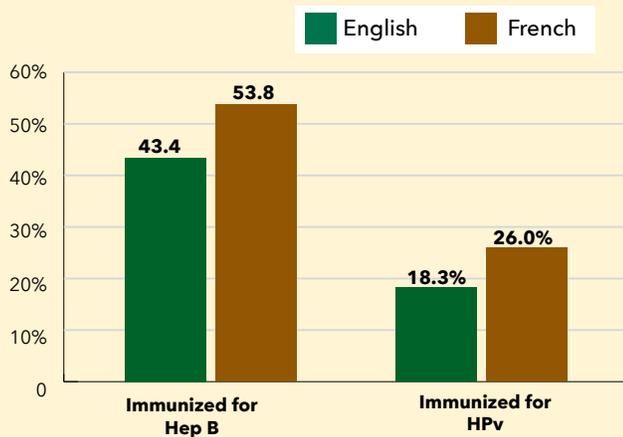
**Figure 10- 7: Use of Health and Social Services by Language**



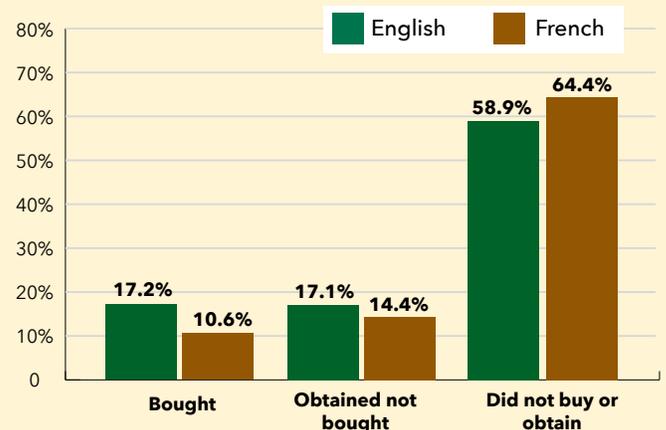
- 21.8% of survey participants who accessed health care in the past 12 months faced difficulty with access.

- Vaccination levels for hepatitis B and human papillomavirus were low overall, and there were disparities by language.
- Overall, most survey participants did not access condoms in the past year.

**Figure 10- 8: Ever Immunized by Language**



**Figure 10- 9: Accessing Condoms in the Past 12 Months by Language**



Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## In Their Own Words

### Strengths

- Focus group participants were aware that condoms are freely available to ACB people.
- In Ottawa, several participants identified a particular organization as a valuable resource that serves both Anglophone and Francophone communities. Participants also expressed a strong need for collaboration among Francophone organizations.

***"I believe that from our point of view, whatever the organization is, for example, [AIDS service organization] is bilingual, it is Francophone, it is Anglophone. We need collaborations with other Francophone organizations so that they can really bring, so that they can conduct awareness-raising campaigns, see how to go even to people who have isolated themselves, how we, I see***

***that this is what we can do, join forces, share, put together, fight, fight together, collaborate well with other organizations that are Francophone and see how we can work and then, to have a great, a great continuation." (Female, Toronto, FG1)***

### Threats

- Focus group participants spoke about how difficult it is for Francophone people to access health and social services in their first language, and that access to health and social services barriers varied with immigration status.
- Francophone focus group participants identified many educational gaps in their community. For example, it was noted that there is only one Francophone community

health agency in Toronto, and its resources are limited.

- Several participants also spoke about the high rate of poverty in the ACB community, poor housing, employment in precarious or low-wage jobs, low levels of education, and systemic racism as barriers to accessing necessary health services.
- Institutional and provider-related barriers to health care included lack of empathy, refusal to provide requested treatments, and lack of confidentiality. These factors contributed to feelings of distrust which led to an unwillingness to seek or return for health care. A participant even raised the issue that many providers do not understand the lived experiences of their ACB patients.

*“I have a love-hate relationship with health care. I personally don’t go to emergency and I don’t go to drop-in clinics. I don’t care. I have to see doctors I know. Because we have a lot of existing trauma, whether it’s trauma that’s generational trauma from you know, colonialism, we have a lot of trauma from... other Black people have a lot of trauma from other things. But trauma from even migrating to this country. And sometimes... and abuse and other things and when you go to seek health care and you start explaining this to people who don’t really understand where you’re coming from, it’s challenging.” (Female, Toronto, FG6)*

## Implications for Policy and Practice

**Results from the A/C Study pertaining to access and use of health and social services must be interpreted in a broader context, as low levels of service use may reflect barriers to access or lack of need to access services. While Canada provides almost universal access to essential health services, it is well-documented that access to health care is not equal for all. For instance, broader evidence shows that, despite being an official language, French speakers face greater barriers to accessing services in Canada than English speakers; findings from the A/C Study also show this disparity. For example, the finding that French speakers have greater use of specialist care than primary care suggests they face barriers to accessing primary care and therefore access specialist care because their conditions are more advanced. In addition to access, experience when using service is also important. Providing linguistically appropriate services is a starting point to providing a positive service environment for ACB people. Providers of services must also take steps to understand the lived experiences of ACB people, such as understanding systemic and institutional anti-Black racism, how these shape ACB people’s experiences, and how these affect their health and wellbeing. Addressing social determinants of health will help improve population health, thereby reducing the need for health services.**

# **Chapter 11: Anti-Black Racism and Other Forms of Oppression**



# Chapter 11: Anti-Black Racism and Other Forms of Oppression

## Key Findings

- **Survey participants reported that racism, sexism, and xenophobia (based on immigrant status) were the top three reasons for unfair treatment.**
- **Many focus group participants described experiences of systemic racism in the health care system and in Canadian society as a whole.**
- **Information about human rights was seen as a way to combat systemic anti-Black racism in the health sector.**

## Key Actions

- **Address racism, sexism, and xenophobia against African, Caribbean, and Black (ACB) people in all interventions aimed at reducing structural disadvantages affecting ACB communities.**
- **Create an ACB-led governance structure to help guide collection, access, analysis, interpretation, and dissemination of systematically collected disaggregated race and other equity-related data in the health and social services sectors.**
- **Create a structure to ensure that ACB stakeholders can make the best possible use of data for program development and policy advocacy.**
- **Strengthen access to information about civic and health consumer rights for ACB people.**

## What We Found

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### Supporting Facts

#### Strengths

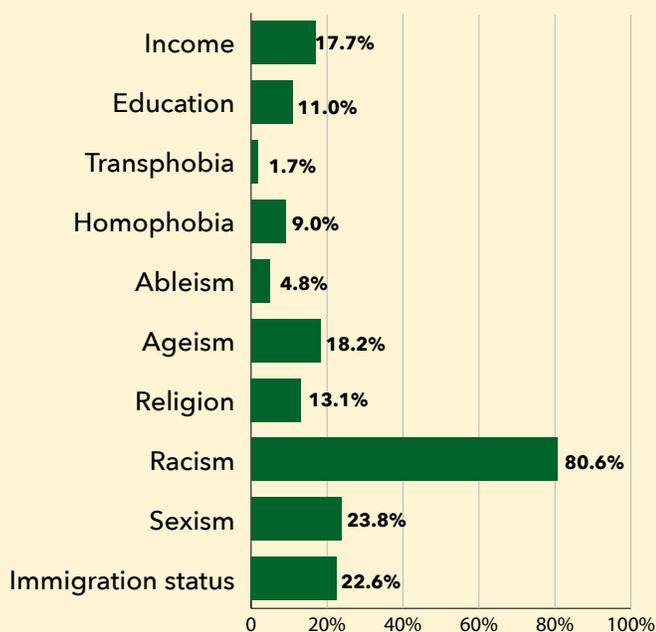
- 24.5% of survey participants had rarely or never been treated with less courtesy than others.
- Among survey participants, 37.8% had rarely or never been offered poorer service than others in a store or restaurant.

- Most survey participants (57.7%) had rarely or never been threatened or harassed.
- 33.8% of survey participants had rarely or never been treated as though they were not smart.
- 43.8% of survey participants reported that people rarely or never acted as though they were afraid of them.

**Threats**

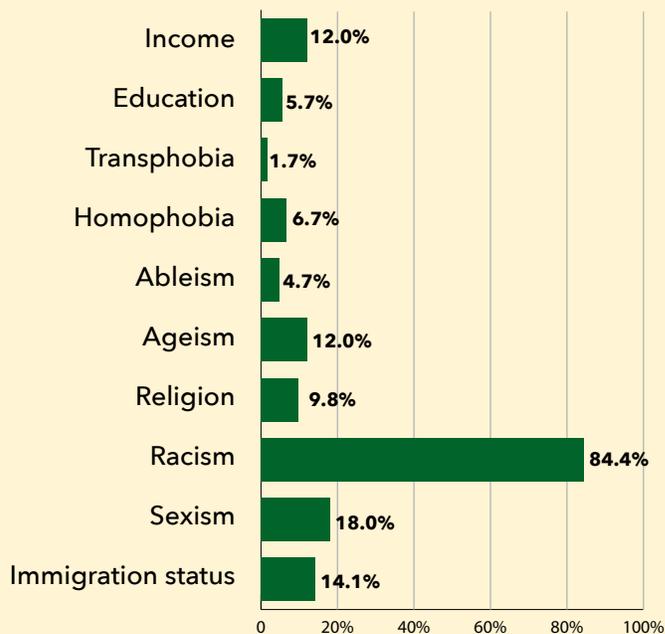
- 59.3% of survey participants were treated with less courtesy than others at least once per year. The top three reasons for this were racism, sexism, and immigration status.

**Figure 11- 1: Reasons for Being Treated With Less Courtesy**



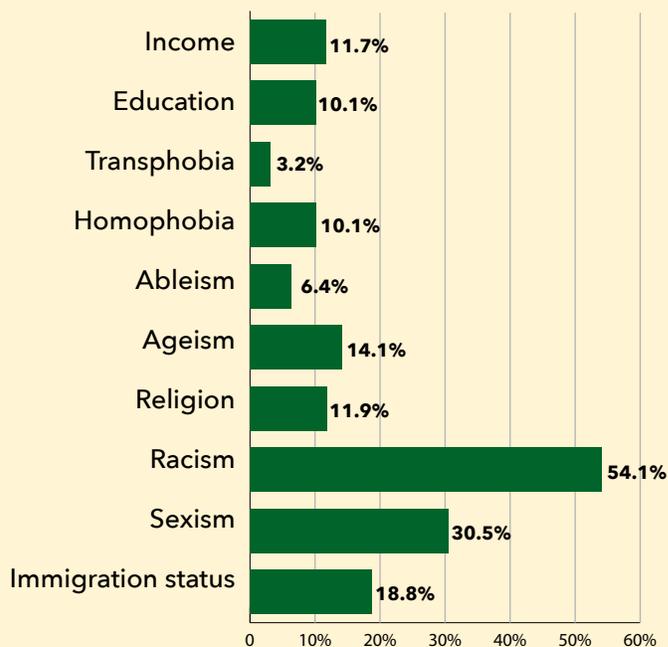
- 43.6% were treated more poorly than other people in restaurants and stores. The top three reasons for this were racism, sexism, and immigration status.

**Figure 11- 2: Reasons for Poor Service in Restaurants and Stores**



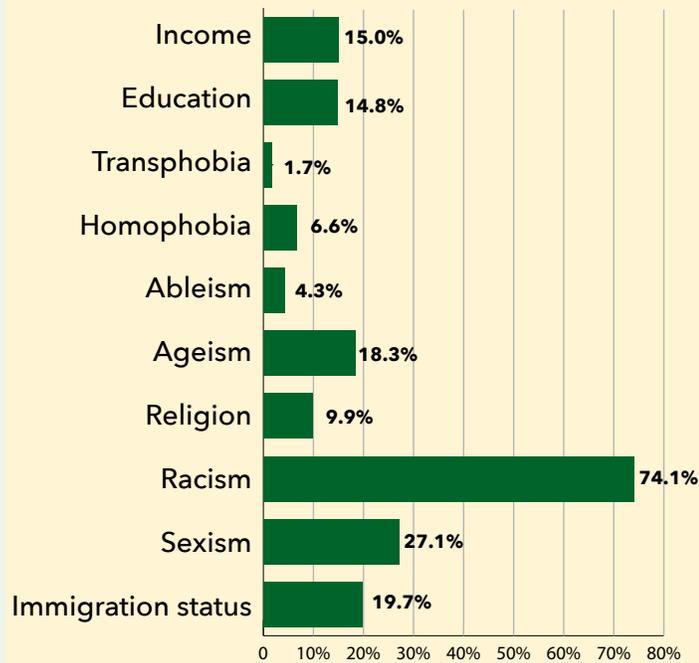
- 27.3% of survey participants have been threatened or harassed at least once per year. The top three reasons for this were racism, sexism, and immigration status.

**Figure 11- 3: Reasons for Being Threatened or Harassed**

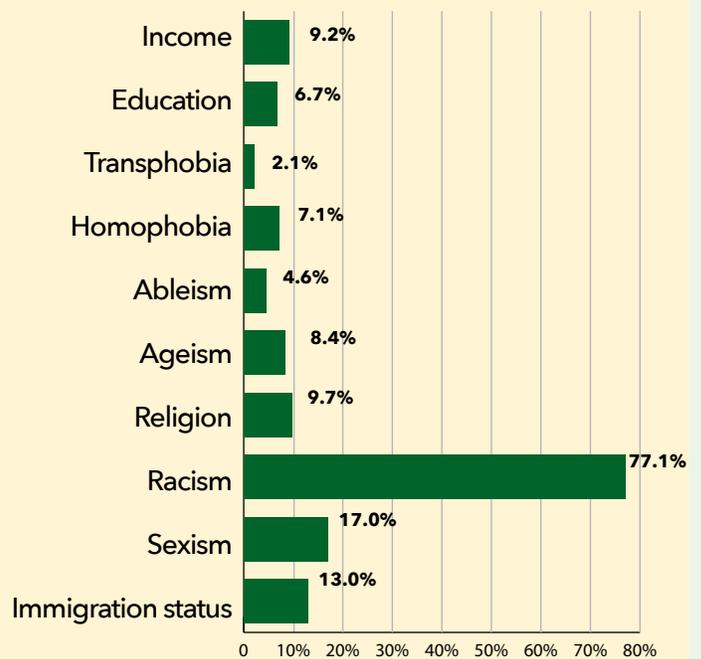


- Among survey participants, 50.4% were treated as though they were not as smart as others at least once per year. Racism, sexism, and immigration status were the top three reasons for this unfair treatment.
- 38.0% of survey participants reported that people acted as though they were afraid of them at least once per year. The top three reasons for this were racism, sexism, and immigration status.

**Figure 11- 4: Reasons for Being Treated as Though Not Smart**



**Figure 11- 5: Reasons for People Acting Afraid of You**



Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response. Also, survey participants could choose multiple reasons for experiencing unfair treatment, so those percentages add up to more than 100%.

## In Their Own Words

### Strengths

- In response to the systemic anti-Black racism faced in Canada’s health care system, several focus group participants spoke about the importance of having information about their civic and health consumer rights in order to advocate for themselves and make informed decisions in the health care system.

***“As we work to improve engagement in the treatment, it is critical that human rights are respected and that people living with HIV and at risk of HIV are empowered to information to make decisions about testing and treatment that are right for them...” (Moderator, Toronto, FG6***

***“...change...Black people’s specific contact with health system by educating Black people in how they have to communicate with their health care providers, how to self-advocate for themselves when they go to access health care, how to have knowledge before they go to access health care.”***  
(Female, Toronto, FG6)

***is subjected to racism on a daily basis and we know what impact it has on the surface when, you know, you have to deal with racism in every aspect of your life. So I think if you want to draw like a direct larger link in terms of HIV vulnerability, I think everything when it comes to, like you know, housing, employment, education, all of the things that, you know, create that vulnerability, all linked to racism and colonization.”*** (Male, Ottawa, FG5)

### Threats

- Structural and institutional factors that contributed to HIV vulnerability included, poverty, anti-Black racism, and barriers to accessing HIV information, HIV prevention, resources, health care, and supports. Participants also discussed systemic racism in Canadian society as a whole.
- Several participants spoke about the high rate of poverty in ACB communities, and recent ACB immigrants in particular. They also noted that immigration status also posed a barrier to accessing services. For example, temporary foreign workers and former students remaining in Canada on a work permit were often unable to access universal health services.

***“But underneath it all what really drives all of this surface factors is racism. African, Caribbean, Black community***

## Implications for Policy and Practice

**Research across the board shows that ACB communities are disproportionately affected by HIV when compared to other races. As findings from the A/C Study show, ACB people commonly experience unfair treatment due to anti-Black racism, sexism, and xenophobia. Structural and institutional anti-Black racism and xenophobia perpetuate vulnerability to HIV through endemic poverty and barriers to accessing resources and services, for example. Anti-Black racism, sexism, and xenophobia create oppressive systems that sideline ACB communities, making them vulnerable to ill health and poor social and economic outcomes. These systems of oppression construct harmful social conditions that fundamentally increase inequities and consequently vulnerabilities. For example, due to systemic anti-Black racism, ACB people are over-represented in pervasive poor housing and precarious or low-wage jobs, which directly and indirectly lead to poor health. When systemic anti-Black racism intersects with systemic xenophobia the effects may be compounded, with immigrant ACB people facing a particularly tough road to full participation in Canada’s society and economy. Additionally, when these intersect with sexism, the impacts on ACB women are even more dire.**

# Chapter 12: Immigration Experience



# Chapter 12: Immigration Experience

## Key Findings

- Immigrants who had lived in Canada longer were more likely to have post-secondary education, be employed full time, have a primary care provider, and have no difficulty meeting basic needs with their household income.
- Survey participants who had lived in Canada for 5-9 years were more likely to have less HIV-related knowledge than other immigrants and those born in Canada.
- As time spent in Canada increased, so did the likelihood of encountering unfair treatment and attributing this treatment to racism rather than immigration status.

## Key Actions

- Develop structural interventions to ensure recognition of professional experience and training of African, Caribbean, and Black (ACB) immigrants.
- Address anti-Black racism, xenophobia, and protectionism in all interventions aimed at helping immigrants to settle and integrate into Canadian society.
- Collect data to assess the extent to which discrimination in the job market exists for ACB people in general, and ACB immigrants in particular.
- Provide continuous education about HIV and available resources to all ACB people, not just new immigrants.

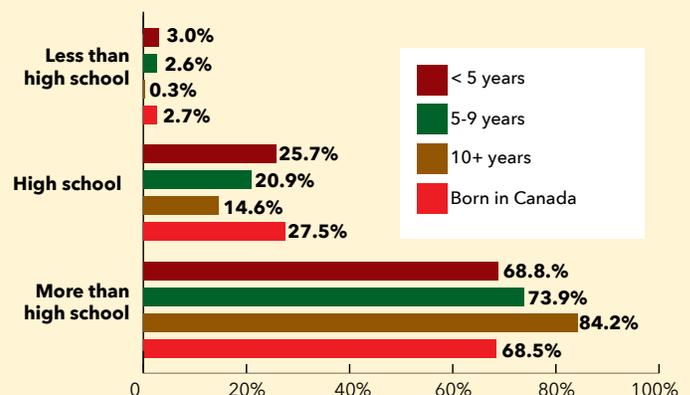
## What We Found

### Supporting Facts

#### Strengths

- Survey participants who were immigrants were more likely to be highly educated, and the longer they were in Canada, the more educated they were.

Figure 12- 1: Highest Level of Education Completed by Time in Canada

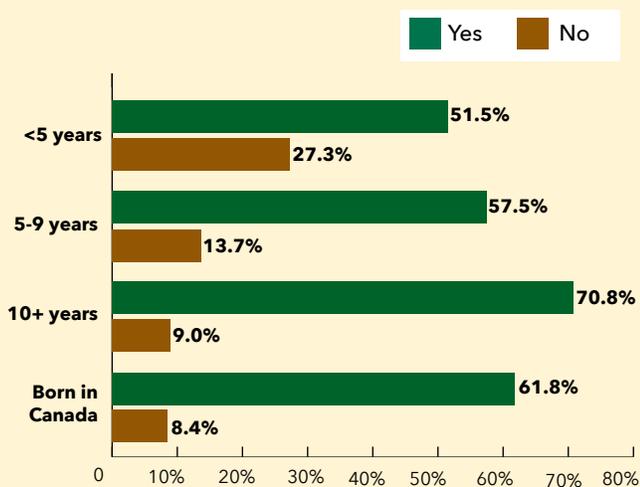


- As time in Canada increased, so did the likelihood of having a family doctor. 55.2% of those in Canada for less than five years had a family doctor, compared to 68.6% of those in Canada for 5-9 years, 85.1% of those in Canada for 10 years or more, and 83.9% of those born in Canada. As time in Canada increased, so did the likelihood of accessing a family doctor or nurse practitioner in the past year.

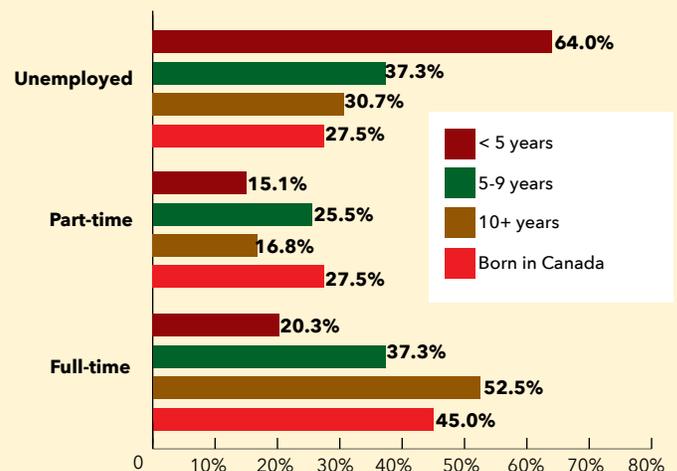
of those with 10 or more years in Canada, and 70.1% of those born in Canada. This means they did not access education or information, volunteer opportunities, or any other services or resources provided by ASOs.

- Immigrants were more likely to be unemployed than participants who were born in Canada. As time in Canada increased, so did the likelihood of having full-time employment.

**Figure 12- 2: Family Doctor or Nurse Practitioner Visit in the Past Year by Time in Canada**



**Figure 12- 3: Employment Status by Time in Canada**



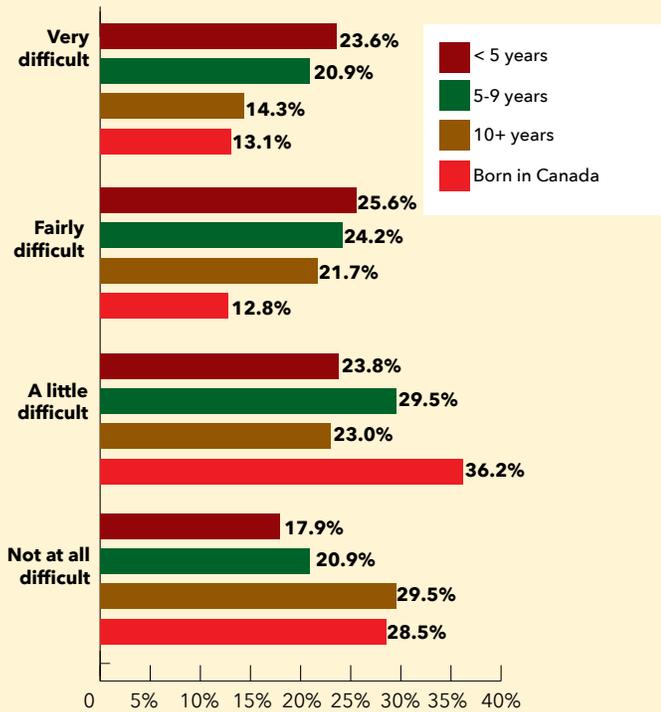
- Regardless of how long survey participants had been in Canada, about half had tested for STIs in the past—57.8% of those in Canada for less than five years, 47.7% of those in Canada for 5-9 years, 56.5% of those in Canada for 10 or more years, and 58.7% of those born in Canada (58.7%).

- Immigrants were more likely to experience difficulty meeting basic needs with their household income than those who were born in Canada. As time in Canada increased, immigrants had less difficulty meeting these needs.

**Threats**

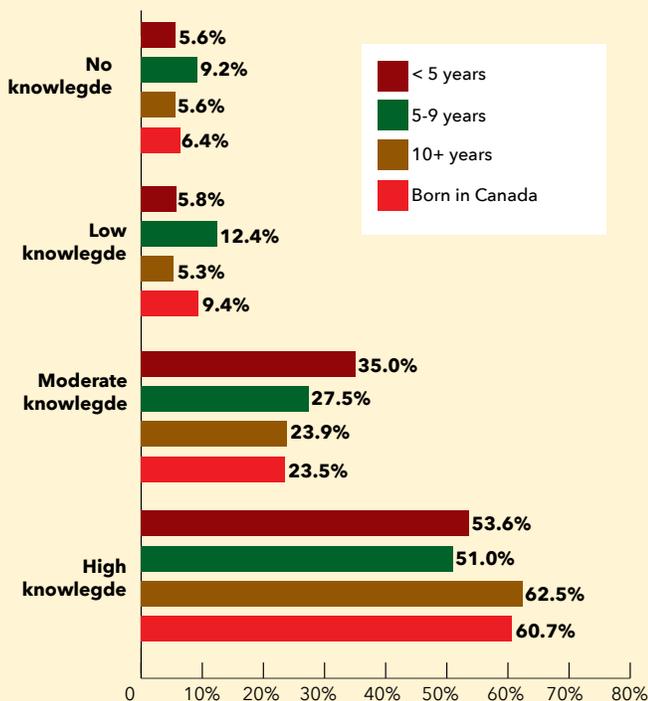
- Most survey participants, regardless of their length of stay in Canada, reported not accessing an AIDS service organization (ASO) in the past year—68.5% of those with less than five years in Canada, 61.4% of those with 5-9 years in Canada, 70.5%

**Figure 12- 4: Meeting Basic Needs with Household Income by Time in Canada**

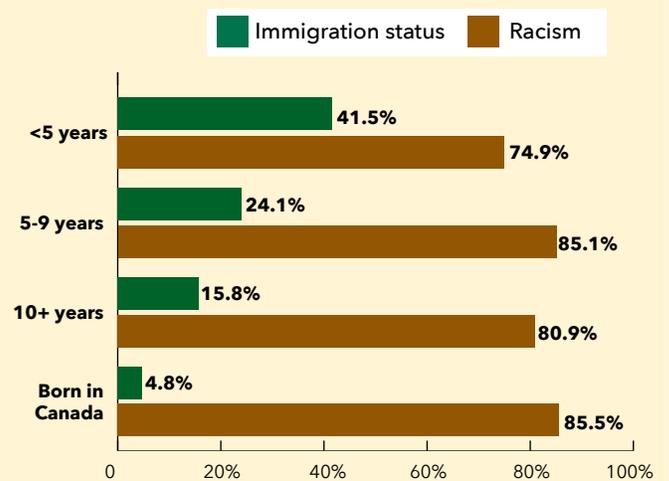


- High HIV-related knowledge was most common among immigrants who had lived in Canada for 10 or more years (65.2%) and those who were born in Canada (60.7%).
- As time in Canada increased, survey participants were more likely to experience being treated with less courtesy than others—50.3% of those in Canada for less than five years, 56.9% of those in Canada for 5-9 years, 66.8% of those in Canada for 10 or more years, and 76.5% of those born in Canada. People who lived in Canada longer were less likely to attribute this to their immigration status.

**Figure 12- 5: HIV-Related Knowledge by Time in Canada**

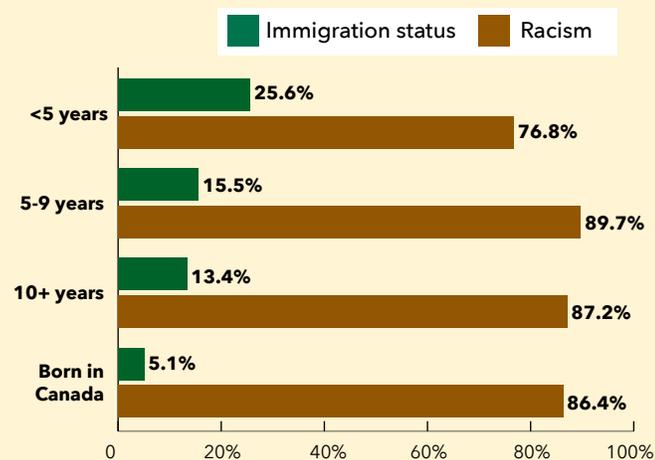


**Figure 12- 6: Reasons for Being Treated with Less Courtesy by Time in Canada**



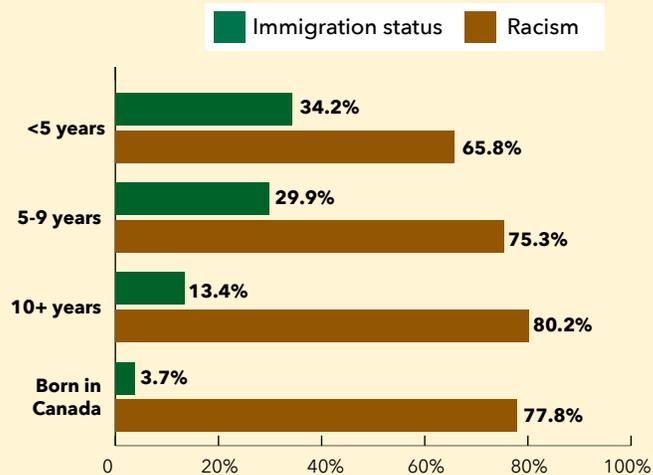
- The likelihood of receiving poorer service than others when in restaurants and stores increased as time in Canada increased—28.7% of those in Canada for less than five years, 37.9% of those in Canada 5-9 years, 55.6% of those in Canada 10 or more years, and 66.4% of those born in Canada. As time in Canada increased, the likelihood of attributing this unfair treatment to immigration status decreased.

**Figure 12- 7: Reasons for Poorer Services in Restaurants and Stores by Time in Canada**



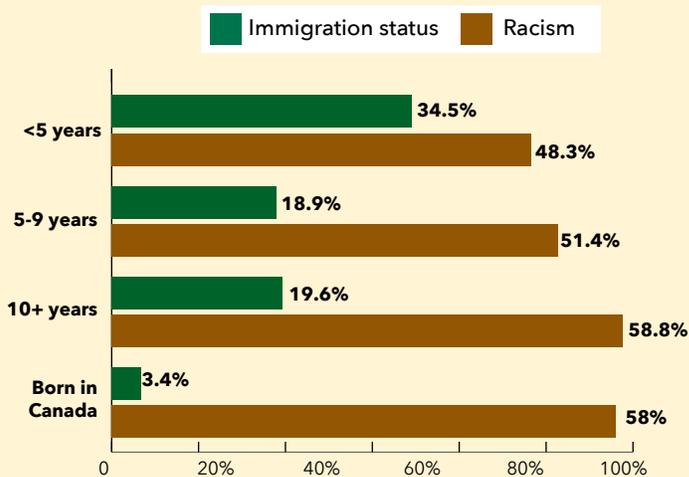
- Being in Canada longer was associated with a higher likelihood of being treated as if they were not smart—42.0% of those in Canada for less than five years, 50.3% of those in Canada for 5-9 years, 58.1% of those in Canada for 10 or more years, and 63.4% of those born in Canada. Those living in Canada longer were more likely to attribute this unfair treatment to racism.

**Figure 12- 8: Reasons for People Acting As If You Are Not Smart by Time in Canada**



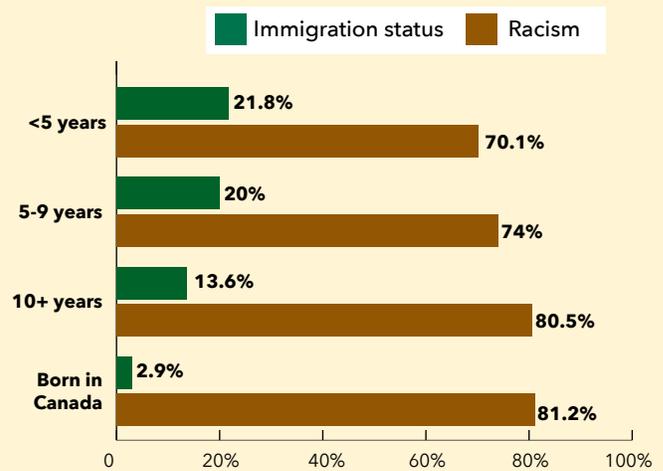
- 39.9% of survey participants born in Canada had been threatened or harassed. The corresponding percentages were 31.7% of those in Canada for 10 or more years, 24.2% of those in Canada for 5-9 years, and 20.3% of those in Canada for less than five years. As time in Canada increased, survey participants were more likely to attribute this mistreatment to racism.

**Figure 12- 9: Reasons for Being Threatened or Harassed by Time in Canada**



- Survey participants who spent more time in Canada were also more likely to experience people acting afraid of them—25.7% of those in Canada for less than five years, 32.7% of those in Canada for 5-9 years, 47.8% of those in Canada for 10 or more years, and 57.0% of those born in Canada. As time in Canada increased, survey participants were less likely to attribute this unfair treatment to immigration status and more likely to attribute it to racism.

**Figure 12- 10: Reasons for People Acting Afraid of You by Time in Canada**



Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## Implications for Policy and Practice

Similar to other evidence, these findings show that, over time, ACB immigrants' experiences become more consistent with those of their Canadian-born counterparts. This is true for both positive and negative experiences. For instance, ACB immigrants were more likely to find full-time employment if they had lived in Canada longer, but they were also more likely to experience unfair treatment. Notably, while most ACB people attributed this unfair treatment to racism, the proportion making that attribution increased as time in Canada increased. This finding suggests that, as time in Canada increases, ACB people are more likely to encounter racism, recognize unfair treatment as racism, or both. Among ACB immigrants, attributing unfair treatment to immigration status decreased as time in Canada increased, which suggests that immigration experience is less of an issue when they become more integrated in Canadian society. Although longer-term immigrants have higher levels of employment than newer immigrants, their level of employment does not reflect their level of education. This aligns with evidence showing that ACB people in Canada, including immigrants, face discrimination in the job market, which leads to higher levels of un- and under-employment when compared to their non-ACB counterparts. Evidence also shows that ACB immigrants also face de-skilling because their professional experience and credentials are not recognized, which is a result of racism, xenophobia, and protectionism combined. The complex interplay of these factors and length of time living in Canada must be taken into account when developing policies, programs, and services to help immigrants integrate and navigate Canadian society.

# Chapter 13: Community Social Support



# Chapter 13: Community Social Support

## Key Findings

- Less than half of survey participants agreed with statements that indicate there was social support in their communities.
- Participants from Toronto were more likely to report lower levels of social support in African, Caribbean, and Black (ACB) communities compared to those from Ottawa.
- Participants identified community organizations, faith-based organizations, and role models as important resources for addressing HIV in ACB communities.

## Key Actions

- Engage faith-based and grassroots organizations in the response to HIV in ACB communities.
- Increase the sense of community and connectedness among ACB people.
- Leverage community assets, including political and religious leadership, in efforts to address anti-Black racism, social, and health issues affecting ACB communities.

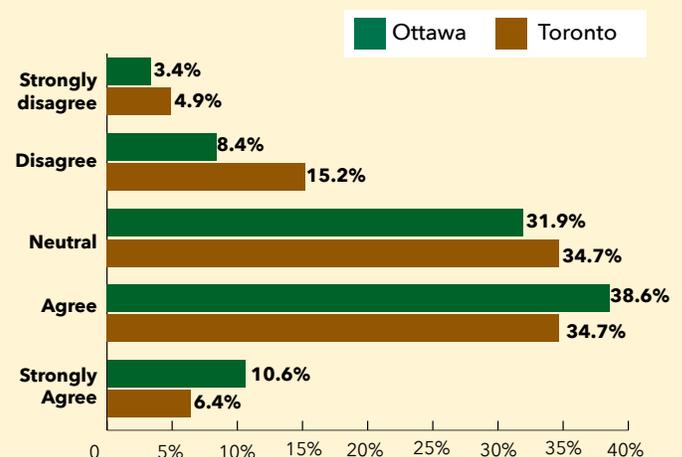
## What We Found

### Supporting Facts

#### Strengths

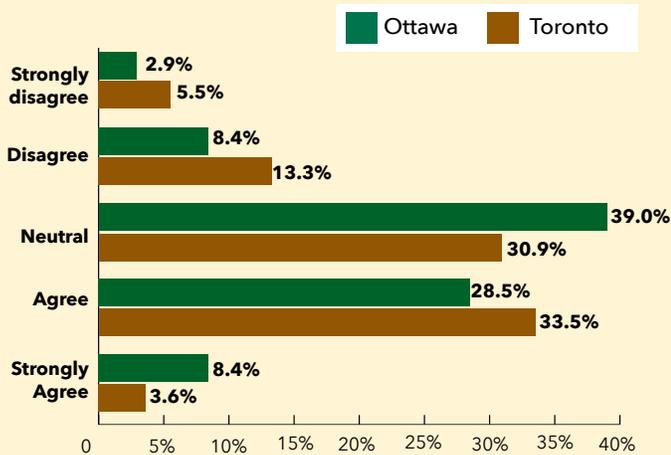
- Overall, 44.2% of the survey participants agreed that ACB people were willing to help each other (49.2% in Ottawa and 41.1% in Toronto).

Figure 13- 1: ACB People Being Willing to Help One Another by City



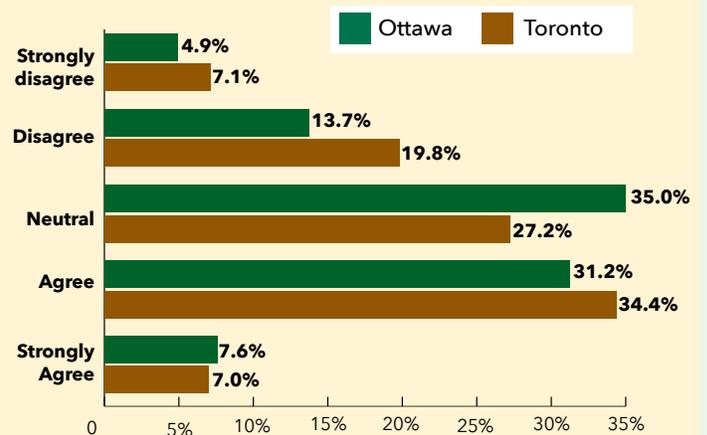
- Overall, 37.0% of survey participants reported that ACB people were a close-knit community (36.9% for Ottawa and 37.1% for Toronto).

**Figure 13- 2: ACB People Being a Close-knit Community by City**



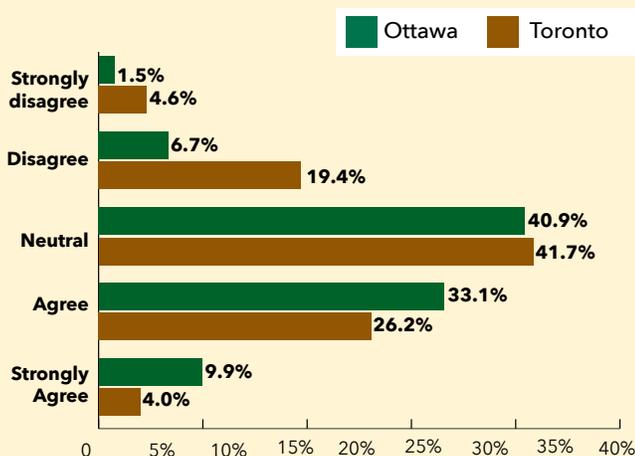
- 40.4% of study participants (38.8% in Ottawa and 41.4% in Toronto) agreed that there were many opportunities to work with ACB people on issues affecting the ACB community.

**Figure 13- 4: There Being Many Opportunities to Work with ACB People on Issues Affecting the Black Community by City**



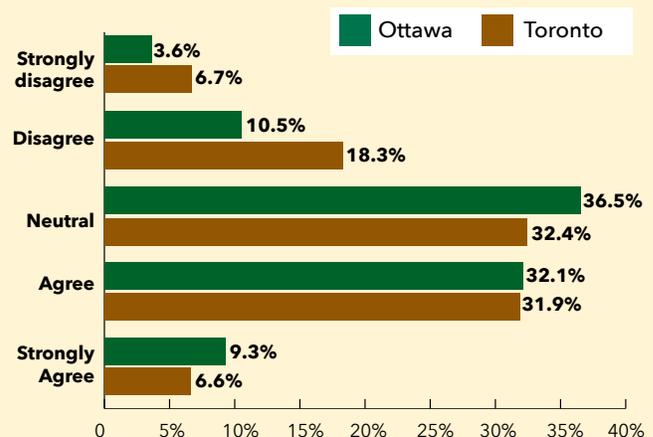
- 43.0% of the study participants in Ottawa believed that ACB people could be trusted, while 30.2% of those in Toronto agreed with this assertion. 35.0% of study participants overall agreed with the assertion.

**Figure 13- 3: ACB People Being Trustworthy by City**



- In all, 39.6% of study participants agreed that ACB community groups supported the community. The percentages by city were 41.4% for Ottawa and 39.5% for Toronto.

**Figure 13- 5: There Being Many ACB Community Groups that Support the Community by City**



## Threats

- 20.1% of participants in Toronto and 11.8% of those in Ottawa disagreed with the statement that ACB people were willing to help each other. Overall, 16.9% of survey participants disagreed with this statement, and 33.6% neither agreed nor disagreed.
- In all, 23.2% of study participants disagreed that ACB people were a closely knit community (16.2% for Ottawa and 27.5% for Toronto), and 34.0% did not agree or disagree.
- 24.0% of survey participants in Toronto disagreed with the statement that ACB people could be trusted. The corresponding percentage for Ottawa was 8.2%. Overall, 18.0% of survey participants disagreed with the statement, and 41.4% neither agreed nor disagreed.
- 30.1% of survey participants were neutral on the issue of whether or not ACB people had many opportunities to work together on issues affecting the ACB community, and 23.8% disagreed. In Ottawa, 18.6% of participants disagreed with the assertion, and 26.9% disagreed in Toronto.
- Overall, 20.8% of survey participants (14.1% in Ottawa and 25.0% in Toronto) disagreed that many ACB community groups supported the community, and 34.0% were neutral on the topic.

Note: Values presented in the figures and text may not add up to 100%. Although missing values are not presented, these were used when calculating the percentages. Hence, the values presented above reflect the percentage of survey participants who gave each response.

## In Their Own Words

### Strengths

- Many participants identified community networks as valuable resources for harnessing social support, which included use of role models, peers, and community organizations. They also spoke about the need for community engagement when addressing HIV.

***“We need to engage our community, maybe through storytelling, dance, acting and someone mentioned that a community prefers going through pamphlets because it is still considered culturally inappropriate to talk about sex and HIV.” (Female, Toronto, FG2)***

- Several focus group participants acknowledged the importance of enhancing peer support for ACB people living with HIV.

***“But that peer-to-peer connection is the most powerful tool that we have at our disposal. There is nothing bigger than that. So having these programs like we do, like Speakers’ Bureau, or Buddy Program, where people go and share their experiences in the community, or we partner them up with somebody else living with HIV but who’s, you know, a novice, as in recently tested positive so they don’t know a lot about it. Those are probably the most powerful tools that we utilize in doing our HIV.” (Male, Ottawa, FG5)***

- Many focus group participants identified faith-based and grassroots organizations as important players for information sharing as well as combating social norms and stigma.
- Focus group participants acknowledged that ACB communities face challenges in working together. Several spoke about the need for ACB communities, despite differences in membership and priorities, to respect each other and to work together to address HIV.

### Threats

- It was apparent that prevailing social norms within ACB communities contributed to stigma, a frequently cited barrier to disclosure of HIV status to family and friends, and to full participation in society. Focus group participants recounted stories of community members being rejected after sharing their HIV status with people who were part of their support networks.

***“So the other point was that Black people need to have unity and not to think that they are better than other Black people and not to kind of come and destroy what has already been done before.”***  
***(Moderator, FG2)***

## Implications for Policy and Practice

**Results from the A/C Study show that community social support and connectedness are crucial for addressing HIV and other issues affecting ACB people. Approaches that leverage community strengths and resources include harnessing community organizations, community leaders, faith-based organizations, peers, and role models, for example. From a socio-ecological perspective, these approaches can help build ACB community capacity to prevent HIV and support ACB people living with HIV. These results from the A/C Study also show that there is a need to increase social support and connectedness in ACB communities, and that community social support and connectedness are higher in Ottawa than Toronto. Increasing community social support has the potential to confer benefits beyond those related to HIV. Other benefits include greater capacity to advocate for structural changes that will combat anti-Black racism and improve social determinants of health for ACB people.**

# Chapter 14: Conclusions & Recommendations



# Chapter 14: Conclusions & Recommendations

## Conclusions

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HIV continues to be a global pandemic, and African, Caribbean, and Black (ACB) communities living in Ontario and Canada remain disproportionately affected by HIV (Government of Canada, 2017; Ontario HIV Epidemiology and Surveillance Initiative, n.d.; Ontario HIV Treatment Network, n.d.). Findings from the A/C Study and other research demonstrate that social determinants of health and structural determinants of health inequities, such as language barriers, stigma, and anti-Black racism, and other forms of discrimination have negative consequences for HIV prevention and linkage to and engagement in care for ACB people living with HIV (PLWHs) in Ontario (Gardezi et al., 2008; Millett et al., 2012; Samson & Spector, 2012; Simbiri et al., 2010).

The disproportionate burden of HIV in ACB communities cannot be understood or addressed effectively without tackling these social and structural factors. For instance, knowledge about HIV on its own is insufficient to decrease transmission, because social and structural factors, such as stigma, pose barriers to knowledge acquisition, and knowledge does not always directly translate into behaviour change (Faust & Yaya, 2018; J. C. Kerr et al., 2014; Mihan et al., 2016; Ojikutu et al., 2012). Additionally, modifying individual behaviours is insufficient to address HIV at the population level, because behaviours are influenced by social (e.g., sexual networks), structural (e.g., HIV

stigma), and other contextual (e.g., community viral load) factors, which are important drivers at the population level that are not under an individual's control (Bailey et al., 2017; Baral et al., 2013; Krieger, 2008; Montaner et al., 2006, 2010; Williams, 2003). Even uptake of HIV testing is influenced by structural barriers and facilitators outside of the individual's control (Bolsek et al., 2015; Kaai et al., 2012). HIV stigma and racial discrimination are also associated with poor retention in and access to HIV care, which is essential for controlling HIV viral load at the population level (Earnshaw et al., 2013; C. Logie et al., 2013; Montaner et al., 2006, 2010). Hence, collaborative, multi-sectoral approaches that apply a social-ecological lens and challenge discrimination and other forms of oppression are necessary for addressing HIV in Ontario's ACB communities.

Immigration experience and xenophobia, language barriers, anti-Black racism, sexism, poverty, and HIV stigma are just a few of the structural factors that cause inequities, increase HIV vulnerability, decrease general health status, and threaten wellbeing for ACB people. It is fundamental that we give sufficient attention to these structural factors, because:

“Determinants of disease distribution are not reducible to mechanisms of disease causation...., (which occur within individuals' bodies)... population patterns of health and

disease constitute the embodied biological expression of ways of living and working differentially afforded by each society's political economy and political ecology, and (2) policies and practices that benefit and preserve the economic and social privileges of dominant groups simultaneously structure and constrain the living and working conditions they impose on everyone else, thereby shaping particular pathways of embodiment (Krieger, 2008)."

Thus, the ways in which ACB communities are integrated into Ontario's social, economic, legal, education, health, and education systems make them more vulnerable to HIV. This phenomenon cannot be fully explained solely by individual-level factors.

This study established that inequitable and anti-Black policies generate multiplicative harms in Black communities. This is illustrated through economic, legal, and social barriers disproportionately faced by ACB communities, such as poverty, under-employment, low wages, challenges to gaining citizenship, poor access to health care services, and intersecting forms of discrimination, among others, that all contribute to HIV vulnerability and lower access to health services (Creese & Wiebe, 2012; Government of Canada, 2020; Jackson, 2017; J. Kerr et al., 2018; Millett et al., 2012; Mullings et al., 2016; The Conference Board of Canada, 2017). These

social determinants fuel pandemics such as HIV (World Health Organization Commission on Social Determinants of Health, 2007). Furthermore, a number of studies in Canada have shown that racialized immigrants face stigma and discrimination on account of both their race and immigration status (C. H. Logie et al., 2016; Simich et al., 2006).

The A/C Study's findings showed that despite Canada having two official languages, French-speaking ACB people faced an additional disadvantage, as language barriers faced by Francophone ACB people emerged as an important theme. Our findings are similar to others attributing lower levels of use of health services among Francophone people to language barriers (de Moissac & Bowen, 2017; Djiadeu et al., 2020). Use of and access to health services are important determinants of health and wellbeing (World Health Organization Commission on Social Determinants of Health, 2007). Additionally, "[i]n some places, the quality of French healthcare services has resulted in avoidance of care by the Francophone living in Anglophone-majority provinces," like Ontario (de Moissac & Bowen, 2017). Even when there are bilingual health care providers, these providers report difficulties in providing quality health services to Francophone patients (Djiadeu et al., 2020). Culturally appropriate care includes linguistically appropriate care (Kreuter et al., 2003).

## Recommendations

ACB leadership is necessary for addressing HIV, anti-Black racism, social and health issues affecting ACB communities. Hence, it is imperative that ACB community resources and leadership capacity be leveraged. Grassroots, faith, and political leaders in ACB communities have important roles to play in advocating for changes. Sense of community, community social capital, and community connectedness

are all important facilitators of community action, and these should be enhanced in ACB communities. Data is an important tool for monitoring and evaluating progress on addressing systemic anti-Black racism, and data about race is sensitive and can be politicized and interpreted in ways that are harmful to ACB communities. Hence, collection, access, analysis, interpretation, governance and dissemination

of disaggregated race and other equity-related data in the health and social services sectors should take place under ACB leadership.

Policy change is needed to resolve the structural factors affecting ACB communities. There is a need for structural interventions to: address disadvantages that lead to HIV vulnerability, protect social and economic wellbeing for ACB PLWHs, make HIV testing a routine part of health services, guarantee access to HIV care and treatment regardless of residency status or other factors, remove socio-economic barriers to accessing pre- and post-exposure prophylaxis, and ensure recognition of professional experience and training that ACB immigrants bring to Canada. Widespread dissemination of HIV self-tests is another policy change that is expected to have a positive effect on addressing HIV in ACB communities.

Research remains an important tool for knowledge generation, intervention development, and advocacy. Two key pieces of information that remain elusive are the prevalence and incidence of HIV in ACB communities. These are important measures of burden of disease that should be estimated routinely. It is also important to know the level of viral suppression in ACB communities and how ACB people are doing along the 90-90-90 cascade, and these too should be estimated routinely. More research is needed on the clinical effectiveness and social impacts of pre- and post-exposure prophylaxis in ACB communities. Finally, given the diversity in ACB communities, the various intersecting forms and discrimination and oppression identified in the A/C Study, and the unique barriers faced by French-speaking ACB people and ACB immigrants, it is important to collect equity-related data on access, use, and outcomes in the health and social services sectors, as well as labour market experiences.

Access to health and social services, as well as the experience one has when using those services are both important. Service providers can improve the cultural appropriateness of their services by addressing language barriers, especially those faced by French-speaking ACB people. Additionally, service providers can work with ACB stakeholders to use ACB-specific data, such as those from the A/C Study, to develop programs and services. Anti-oppression, anti-discrimination, and unconscious bias training can also give service providers tools and skills to improve their ability to provide quality care to ACB people. Interventions aimed at enhancing service providers' knowledge and skills in providing ethno-racially appropriate services should be evaluated.

There is also a need for community-level actions. Social norms within ACB communities, such as those that discourage ACB people from speaking openly about HIV, serve to limit HIV-related knowledge and perpetuate stigmatization and discrimination against PLWHs. It is therefore important to address HIV stigma and increase the availability and accessibility of HIV-related information in ACB communities. Pre- and post-exposure prophylaxis are important HIV prevention tools that should be promoted within ACB communities. Finally, strengthening access to information about civic and health consumer rights to ACB people can help build capacity for self-advocacy when accessing health and social services.

While individual-level factors are insufficient for addressing HIV on their own, they still play an important role in HIV risk. HIV-related knowledge remains important for informed decision-making about health and sexual practices. Efforts to increase HIV-related knowledge should particularly target young ACB people, longer-term immigrants, and those

born in Canada. Topics of importance, based on findings from the A/C Study include: HIV risk when alcohol and marijuana are used during sex, the length of time between exposure to HIV and a positive test result, the benefits of early detection (early treatment, longevity, and reduction in HIV transmission), and HIV prevalence and incidence in Canada's ACB communities.

**Appendix A:**  
Research Methodology

**Appendix B:**  
Research Team, Partners, and  
Acknowledgements

**References**



## Appendix A: Research Methodology

**Design:** The A/C Study used a mixed-methods approach. In Phase One, the team conducted a cross-sectional survey of ACB adults in the Greater Toronto Area (GTA) and Ottawa/ the Greater Capital Region. The survey was used to collect quantitative data as well as blood samples. In Phase Two, the team held a two-day virtual world café event that was used to share results from Phase One and collect qualitative data using focus group discussions (FGDs). In all, there were 12 FGDs—two in French and four in English for the GTA, and two in French and four in English for Ottawa. Six FGDs were held on the first day of the event, and the other six were held on the second day. The study was implemented using the principles of community-based research (CBR)—as “a strong collaborative effort between researchers and community members to conduct research to address a community issue” (Mbuagbaw et al., 2020, pg. 2).

**Eligibility:** The target population for Phase One was people “born in a Caribbean or Sub-Saharan African country or born elsewhere (including Canada) with a parent born in one of those countries” (Mbuagbaw et al., 2020, pg. 3). Participants also had to be aged 15 to 64 years old at the time of survey and reside in the GTA or Ottawa. Participants had to have the “capacity to communicate in English or French [and be] capable of providing informed consent” (Mbuagbaw et al., 2020, pg. 3).

For Phase Two, the target population was ACB adults residing in the GTA or Ottawa and those providing services to ACB people in these cities.

**Target Sample Size:** The sample size for Phase One was based on: a range of values of the estimated prevalence of HIV among first- and second-generation ACB people; “the distribution of ACB populations from the Caribbean (58%) and Africa (42%), derived from the 2016 National Household Survey (NHS);

and the proportion of ACB people in the GTA and Ottawa. Using quotas that reflect these distributions and an HIV prevalence of 2%, [and] applying the Wilson [confidence interval] approach with continuity correction, we derived a [target] sample size of 1500 (1000 in the GTA and 500 in Ottawa)” (Mbuagbaw et al., 2020, pg. 3).

The target sample size for Phase Two was 96 to 120 (8-10 individuals per focus group).

**Recruitment:** Participants for Phase One were recruited in both locales using a peer recruitment strategy. In the GTA and Ottawa, the team “recruit[ed] and train[ed] a diverse cadre of 25 and 17 peer recruiters respectively, who [were] broadly representative of the target population (including people living with HIV). Trained peer recruiters [approached] potentially eligible ACB people through” (Mbuagbaw et al., 2020, pg. 3) social networks (e.g., Black Toronto Community Support and Racial Health Equity Network on Facebook), events (e.g., Afrofest, ACB Health Zone in Ottawa, the Toronto Caribbean Festival, Pride, Blockorama, the Villagefest, Braids for AIDS, the Black Owned Summer and Winter markets), and venues populated by ACB people (e.g., TAIBU and Black Creek Community Health Centres, La Passerele, etc). Venues that are frequented by ACB people were selected with input from local team members and collaborators. Those who were “interested in participating [were] given a card that [was] stamped with the recruiter’s unique code then referred to the study coordinator. Participants who contact[ed] the coordinator [were] asked for the code and [were] scheduled for an interview with a study interviewer. Codes on the recruitment cards [were] also used to track where, when, and how participants were recruited to enhance... efforts to track and monitor” (Mbuagbaw et al., 2020, pg. 3) recruitment patterns. Project staff also attended events and venues that attracted

large numbers of ACB people. Staff recruited participants from those events and venues, after determining their eligibility for the survey. The research team also recruited participants from various venues, events, and online networks where ACB people congregate.

FGD participants were recruited from a two-day virtual world café event (described below). The event was promoted among ACB social networks using social media and a flyer with the registration link and a description of the study's purpose and the event. In total, 87 people participated from both cities on the first day and 84 people participated on the second. Participants included community members and leaders, service providers, decision makers and other knowledge users. Participants in the world café event were asked at registration if they wanted to participate in the FGDs as well, and only those indicating this interest and providing consent were included in the focus groups.

**Consent:** In both phases, taking part in this research study was completely voluntary and participants could refuse to participate entirely, refuse to answer questions or withdraw from the study. Participants were informed that withdrawing from the study would not affect their relationship with any member of the A/C Study team. While written consent was obtained in Phase One, participation in the FGDs in Phase Two was based on verbal consent.

**Compensation:** Every survey participant received an honorarium of CA\$40, and every focus group participant received an honorarium of CA\$30 per focus group.

## Data Collection for Phase One:

**Settings:** Data collection for the A/C Study occurred in the GTA and Ottawa, two major metropolitan centres in Ontario, Canada. Trained peer researchers conducted interviews from different sites in both centres.

**Survey:** “The A/C Study survey consists of a questionnaire available in French and English spanning multiple domains, including: socio-demographic information; sexual [practices]; substance use; blood donation; access to and use of health systems and services; and HIV [knowledge], testing, care and treatment” (Mbuagbaw et al., 2020, pg. 3); HIV stigma; experiences of racism and other forms of discrimination; and community social support. The survey was available as a self-administered or interviewer-assisted questionnaire on a tablet or laptop.

## Specimen collection and laboratory

**testing:** A Dry Blood Sample (DBS) was requested from each survey participant, and “participants were free to refuse and still remain in the survey” (Mbuagbaw et al., 2020, pg. 3). The specimens were tested by the Public Health Agency of Canada (PHAC) for antibodies against HIV. Test results were linked to the survey data for the purpose of analysis, while preserving anonymity.

**Administrative data linkage:** “To examine questions of health service access and utilization, an increasing number of research studies in Ontario are including an option for participants to consent to provide their personal information...[(i.e., Ontario Health Insurance Plan (OHIP) numbers)]... that can be linked to the administrative data at the Institute for Clinical Evaluative Sciences (ICES; <https://www.ices.on.ca/>)” (Mbuagbaw et al., 2020, pg. 4). This was done as part of the A/C Study as well, and the data will be used to initiate an observational cohort of ACB people.

A number of steps were taken to ensure participant confidentiality and data security. Several linking variables were collected, including name, date of birth, sex, and OHIP number. At the time of data collection, these variables were entered (by the study interviewer or participant) into a “black box” software program at the interview site. The software

program used a special algorithm to generate a unique code for each individual, and then automatically purged the individual's name, date of birth, sex, and OHIP number from its memory. The code cannot be traced back to the individual, but the unique code will be sent to ICES where it will be used to link A/C Study questionnaire data to ICES data for individuals with matching unique codes. Only the research team will see the information, and the information will not leave the ICES environment, where it is completely secure. The information is protected based on rules and the laws that are in place to protect the health information of everyone who lives in Ontario.

## Data Collection for Phase Two:

**Virtual world café event:** The research team organized a virtual two-day event (July 30 and 31, 2020) on the Zoom videoconferencing platform to share study results, solicit community input, collect qualitative data and generate recommendations for moving forward. The event was informed by CBR principles. CBR is an enabling mechanism that may transform enhanced capacity into action for knowledge translation. The day's event started with presentations about the A/C Study and its results by research team members. There were three presentations on each day, and the presentations highlighted results related to the study's main objectives. These presentations were followed by a large group questions and answers period and virtual FGDs. The FGDs were followed by a large group report-back period where key points from the discussions were summarized and shared by each focus group's facilitator and note-taker. Each day concluded with a brief reflection on the day's highlights.

**Focus group discussions:** There were a total of 12 FGDs. Each FGD was led by a facilitator who was supported by a note-taker. All facilitators and note-takers were briefly trained in focus group methodology and provided with a bilingual (French and English) FGD guide that included: information for welcoming participants and facilitating introductions, key information from the consent forms, and questions to ask during the FGDs (including probes). There were six FGDs on each day—three with participants residing in the GTA (one in French and two in English) and three with participants residing in Ottawa (one in French and two in English). The focus group participants discussed health research with ACB communities, HIV testing and counselling, and experiences with addressing basic needs on the first day. On the second day, they discussed HIV vulnerability and risk, service access, and HIV-related knowledge. Each FGD was audio-recorded and transcribed verbatim. Chat box texts were noted and comprised part of the field notes from each FGD.

**Analysis:** For Phase One, descriptive statistics (frequencies/ percentages, averages, medians) were computed to characterize the ACB people who participated in the A/C Study and present major findings addressing the key objectives of the study. Where appropriate, multivariable regression was used to determine associations. For Phase Two, each focus group transcript was open-coded<sup>1</sup> and thematic analysis was conducted to identify major themes.

**Ethics Approval:** "The A/C Study was designed with due consideration of conventional ethical standards within the context of community realities and expectations. In addition to collective experience in conducting high-quality [CBR], the research

<sup>1</sup>Open coding is the initial phase of the coding process in qualitative data analysis. Codes are words and phrases used to label and organize qualitative data, and these are used for identifying themes. In open coding, codes are created based on the data itself rather than being pre-specified. It is an iterative process that tends to lead to a more complete identification of the themes within the data.

team made concerted efforts to address important issues related to participant compensation, managing multiple roles (e.g., as researcher, recruiter, community member), informed consent, confidentiality, adequate support for peer recruiters, and strategies to address sensitive, illegal, or stigmatizing topics” (Mbuagbaw et al., 2020, pg. 7).

The Research Ethics Boards of the following institutions approved the study: Toronto Public Health, Ottawa Public Health, Laurentian University, University of Ottawa, and University of Toronto.

## Appendix B: Research Team, Partners, and Acknowledgements

### Research Team (listed alphabetically by last name):

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## Partner Organizations (listed alphabetically):



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