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# Understanding research participation experiences among persons identifying as African, Caribbean, and Black in British Columbia

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## ABSTRACT

**Background:** Health research in Canada has insufficiently engaged African, Caribbean, and Black (ACB) people, yielding under-representation of their priorities and unmet health needs.

**Objective:** To understand research experiences and priorities among ACB people in British Columbia.

**Methods:** Cross-sectional data from an online survey was summarized using descriptive statistics. Content analysis was used for open-ended text responses. Data collection and analysis was conducted with ACB community partners.

**Results:** Of 56 respondents, 50.0% were aged 16-25; 78.6% identified as women. Although 42.9% had previous research experience, 91.1% were willing to participate. Participation barriers included time constraints (53.1%) and mistrust (30.6%). Facilitators included perceived benefits to ACB individuals/communities (83.9%) and opportunities to share perspective(s) (60.7%). Research priorities included mental health, substance use, and sexual and reproductive health.

**Conclusion:** Findings highlight ACB individuals' willingness to participate in health research, while identifying participation barriers and facilitators. Researchers must build trust through anti-racist community engagement efforts.

**KEYWORDS:** HIV/AIDS, Community-Based Participatory Research, Health Priorities, Community health partnerships, Community health research, Canada,

# INTRODUCTION

There are over 1.5 million African, Caribbean, and Black (ACB) people living in Canada, representing 4.3% of the population. [1] Despite diverse lived experiences and circumstances, ACB people in Canada have shared experiences of anti-Black racism, manifesting in health and social inequities. [2]

Nationally, ACB individuals and communities continue to be underrepresented in health research. [3–6] One consequence is an under-emphasis of ACB health priorities in research, yielding unmet health needs and perpetuating gaps in healthcare access and health outcomes across numerous health conditions. [7,8] To advance health and racial equity, researchers need to meaningfully engage ACB communities and other underrepresented groups in research. Although this need continues to be expressed, actionable strategies have been insufficiently outlined. [9–12]

Few studies have focused on barriers and facilitators to meaningful research participation for members of ACB communities in Canada, [5] however, findings from the American context provide relevant insights. [13] Research among ACB people in the United States highlights that potential research participants are deterred due to inter-related barriers including mistrust of the health care system and researchers, stigma associated with certain health topics (e.g., HIV, mental health), competing time priorities such as childcare demands, and receiving insufficient information about the research purpose and process. [13–18] Moreover, low cultural awareness among researchers and lack of anti-racist practices (e.g., limited training in cultural competence and insufficient investment in community trust building and outreach), further impede recruitment and retention of ACB people in health research. [12–16] On the other hand, practical facilitators, such as compensation for participation, can demonstrate researcher appreciation of participants' time and expertise. Previous research has shown that ACB communities are inclined to engage in research which aims to increase access to health services and information, with higher participation among those with greater awareness about research opportunities and benefits. [9,10,15–18]

Community-based research approaches offer a framework for increasing meaningful research participation among key communities by creating opportunities to share community voices, perspectives, knowledge, and priorities. [19] Such approaches have been employed by ACB researchers and communities to redress extractive and exclusionary research practices situated in racist ideology. [19,20] Moreover, such approaches require action on behalf of the allied research community to be actively anti-racist and integrate anti-oppressive research approaches. [19,21]

As a field, HIV research provides important examples of the need for and value of community-based research. In Canada, ACB people are disproportionately affected by HIV risk and consequences. [22–24] While ACB persons accounted for approximately 4.3% of the nation's population, ACB men and women represented 17.7% and 42.1% of men's and women's reported HIV cases, respectively, among those with non-missing race data. [1,25] ACB women living with HIV are particularly underrepresented in national HIV research and underserved with respect to availability of culturally appropriate services, particularly for those living outside of major urban settings. [5,22] ACB community leaders have suggested that ACB peoples' low engagement in HIV-related research is partly due to unfamiliarity with the research process, mistrust of researchers, experiences of racism in the health system, and stigma. Consequently, health research findings may not be representative and/or applicable to the ACB community, contributing to poorer access to quality health services and information, and inequities in the distribution of health outcomes among ACB people living with HIV. [26,27]

Cognizant of these gaps in meaningful recruitment and retention of ACB communities in health research, we sought to understand research participation experiences and research priorities among ACB people in British Columbia (BC). Our objectives were: (1) To assess research participation experiences, including willingness to participate in general and specific (i.e., HIV, sexual and reproductive health, and COVID-19) health research studies, barriers and facilitators to meaningful research participation, and preferred recruitment strategies; and (2) To identify research topic priorities for ACB people in BC. This analysis is aimed at offering guidance for researchers to meaningfully increase engagement and research participation of ACB persons in approaches grounded in anti-racist practice.

## METHODS

### *Study Design and Sample Population*

This was a cross-sectional study design, whereby participants completed an online survey. The study design and survey questions were developed as a sub-study to improve ACB community engagement and equitable participation within the academic-community collaborative British Columbia (BC) Children and Women: AntiRetroviral therapy and Markers of Aging (CARMA) – Canadian HIV Women's Sexual and Reproductive Health Cohort Study (CHIWOS) Collaboration (BCC3) study. BCC3 is a community-engaged study examining healthy aging among women living with HIV and HIV-negative controls with similar socio-demographic characteristics. [22,28] The BCC3 study meaningfully engages community partners from study conceptualization through knowledge translation. [29] This includes women living with HIV as Community Research Associates (CRAs)[30] and co-Investigators, and an active Community Advisory Board (CAB); all of whom contributed to the planning of this sub-study, with leadership from Patience Magagula, the Executive Director of the Afro-Canadian Positive Network of British Columbia (ACPNet) and a BCC3 study Knowledge User. ACPNet provides support, health education, and advocacy for people living with HIV, particularly those of African descent, and has been a long-term collaborator with BCC3 study team members. [22,31]

The survey instrument was developed, piloted, and revised based on iterative discussions with members of ACB communities, ACB researchers, CAB members, and CRAs, which echoed related literature on how we needed to include questions to determine facilitators and barriers to participation, topics of interest, and health priorities. [13–18] Study inclusion criteria were identifying as African, Caribbean, and/or Black (including mixed race with Black heritage), being 16 years of age or older, and currently residing in the Canadian province of British Columbia (BC).

### *Recruitment*

Using research and personal networks, online searches, and community partner recommendations, we compiled a list of 22 ACB-serving organizations in BC, as well as national organizations with BC branches. We sent emails to each organization describing the study and requesting that they share the study overview and survey link with their membership and networks. We also shared recruitment materials through our research and personal networks, social media platforms (including Instagram, Facebook, and Twitter), and encouraged individuals to share the study information with others who might be eligible and interested in participating.

*Ethical Considerations*

All respondents completed an online voluntary informed consent form at enrollment, where no identifying information was collected. After completing the online survey, respondents were invited to enter a draw for a chance to receive $100 Canadian Dollars, where identifying information was collected (i.e., email and/or phone number). This information was collected and stored separately from the survey data. This sub-study received ethics approval through the University of British Columbia Children's and Women's Clinical Research Ethics Board (H19-00896), as an amendment within the BCC3 study ethics approval.

*Data Collection*

The survey instrument included 24 multiple-choice style questions, each with an open-text field for participants to add additional responses. [32]

The survey included five sections: (1) socio-demographics; (2) previous research experiences, and barriers and facilitators to participation; (3) willingness to participate in specific health research studies (i.e. HIV, sexual and reproductive health, and/or COVID-19); (4) preferred recruitment strategies for future research participation; and (5) health research priorities. This design was guided by our literature review and discussions with community partners and the research team.

ACB community partners encouraged the research team to support respondent learning about scientific advances in HIV treatment and prevention. Accordingly, we included information about the “Undetectable = Untransmittable”, or “U=U” principle, [33] meaning a person living with HIV who is supported to engage in treatment with an undetectable viral load cannot transmit HIV to a sexual partner. To further support respondent learning, we also included a link to the World Health Organization’s “Key Facts” page on HIV after the survey questions about HIV. [34]

The finalized survey, available in English, was programmed into Research Electronic Data Capture (REDCap) software. [35] The survey link was available between October 14th and December 9th, 2020.

### *Data Analysis*

Descriptive statistics were used to characterize distributions of study variables using RStudio Version 1.1.463. [36] Data from open-ended responses were analysed using content analysis and the frequency of each identified theme was reported. [37]

## RESULTS

### *Survey Participants*

Of 99 individuals who accessed the survey, 16 individuals were excluded as they did not meet the inclusion criteria (n=14 were <16 years; n=2 identified as non-Black), and 27 were excluded as they completed less than 50% of the survey (See **Figure 1 below**), yielding a final study sample of n=56. Respondents who completed >50% of the survey were older than non-respondents but otherwise shared similar socio-demographic characteristics.

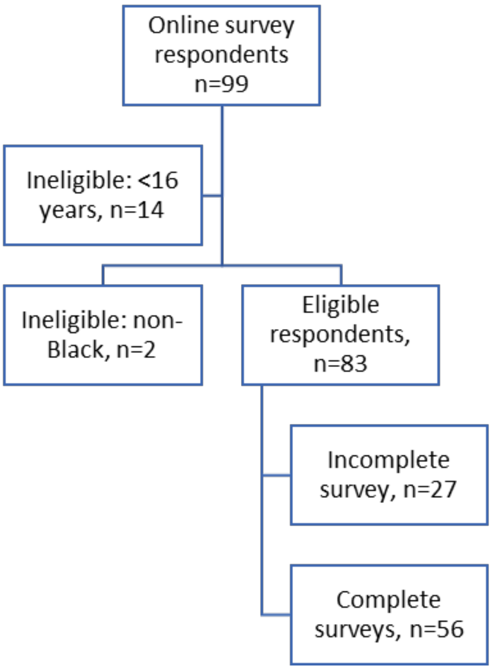


Figure 1: Total respondents who accessed online survey, and final eligible respondents included in this analysis

*Socio-demographic characteristics*

Of the 56 respondents, 28 (50%) identified as African, 17 (30.4%) as Caribbean, six (10.7%) as Black, and 15 (26.8%) as multiracial or mixed race with Black heritage, with participants able to select more than one race category. Forty-four (78.6%), 11 (19.6%), and one (1.8%) respondents identified as women, men, and gender queer, respectively. Half (50%) of respondents were aged 16-25 years while half were 26 years of age or older. Nine (16.1%) had completed high school/ General Educational Development (GED), five (8.9%) had completed any college, and 42 (75%) had completed any university.

*Previous research participation experience*

Regarding the importance of ACB persons' participation in research, 48 individuals (85.7%) indicated this as 'very important' or 'important,' yet less than half of respondents (24, 42.9%)

had previously participated in a research study. Figure 2 below shows the prevalence of each research study type these 24 respondents had participated in.

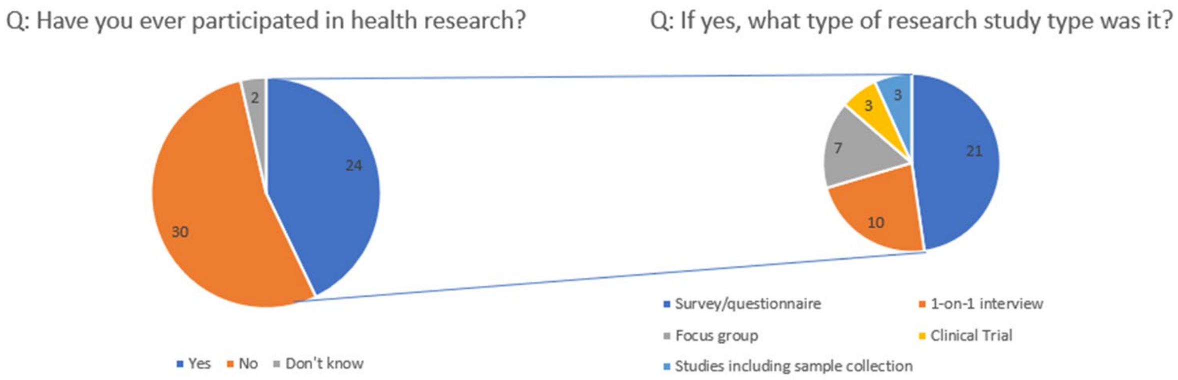


Figure 2: Previous research experience with study type

While most respondents (16, 61.5%) rated their experience as neither positive nor negative, participants provided textbox responses to elaborate on what made their experiences positive: ‘great communication,’  learning a lot, the study being ‘thorough and well-informed,’ the ‘positive attitude and politeness of researcher,’ and the researcher being ‘fully engaged before and after study discussion’.

### *Willingness to participate in future research, including barriers and facilitators*

Overall, 51 participants (91.1%) were willing to participate in at least one future research study type; forty-eight (94.1%) indicated they would be willing to participate in surveys or questionnaires, 38 (74.5%) in 1-on-1 interviews, 33 (64.7%) in focus groups, 17 (33.3%) in studies requiring biospecimen collection, nine (17.6%) in any study type that follows CBR principles, and six (11.8%) in clinical trials.

Fifty-six respondents indicated their principal reasons for participating in health research, including ‘perceived benefits to themselves and their community’ (n=47, 83.9%), ‘research as a good way to share their voice & perspectives’ (n=34, 60.7%), and viewing ‘research as an opportunity to learn something new’ (n=28, 50%).

The most common barriers to research participation were not having enough time/having too many responsibilities (n=26, 47.3 %), finding it difficult to trust researchers (n=15, 27.3%), and not fully understanding the consent process (n=13, 23.6%), not seeing how research can benefit themselves and their communities (n=13, 23.6%), and feeling that they do not have anything of value to add to research (n=13, 23.6%). Cultural and religious barriers were reported as inhibiting research participation (n=3, 5.4%); one participant further specified “trauma from racism in the medical system” as a barrier (n=1, 1.8%).

Fifty-five respondents indicated factors increasing their comfort in research participation, including: a guarantee of privacy, confidentiality and safety (n=44, 80.0%), researchers being transparent about the purpose and benefits of their studies (n=44, 80.0%), findings being used to benefit them and their community (n=35, 63.6%), researchers clearly explaining the consent process (n=31, 56.4%), and receiving compensation for their time (n=27, 49.1%).

The results of respondents’ willingness to participate in specific health research studies such as COVID-19, HIV, and sexual and reproductive health is represented in **Table 1**. This question was applicable regardless of respondents’ HIV and COVID-19 status. **Table 2** outlines reasons why respondents would not be interested in participating in these three study types, aggregated by health topic.

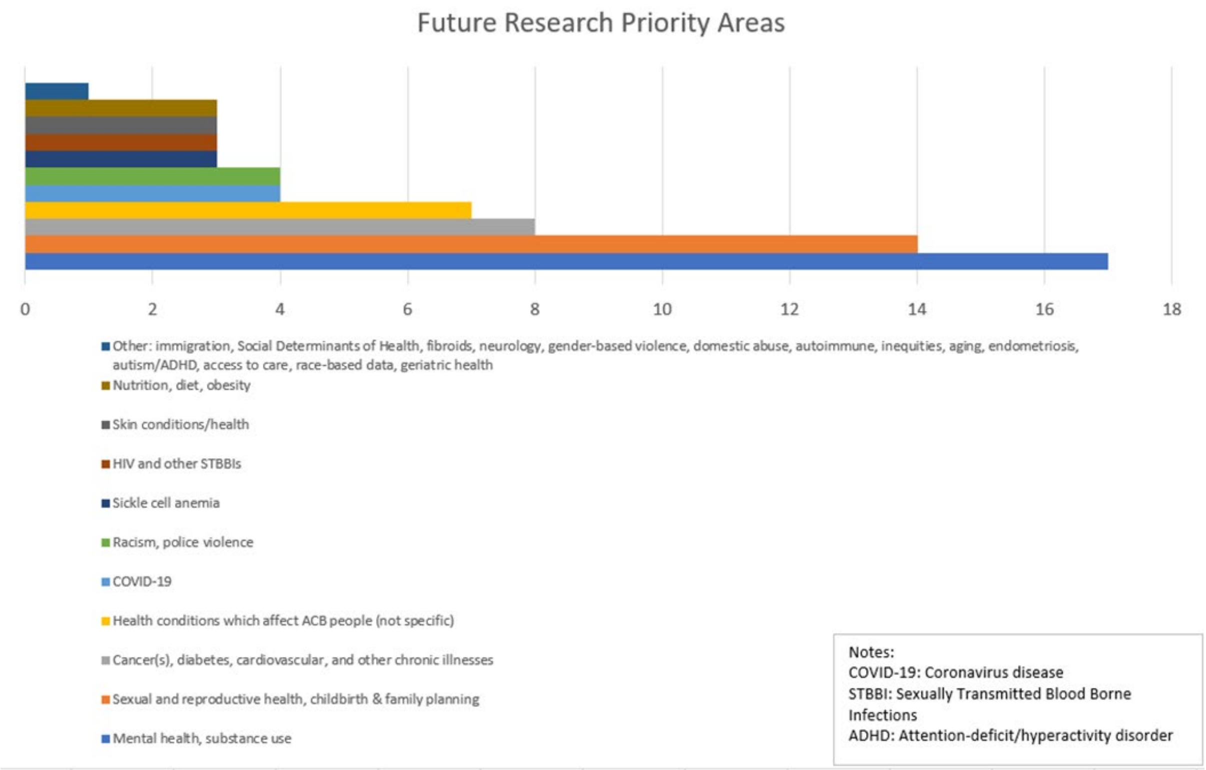
### *Facilitators to Future Research Study Participation*

We asked respondents about their preferred ways to learn about health topics such as COVID-19, sexual and reproductive health, and HIV. While the highest responses were for anonymous online resources and discussions, community spaces were indicated as a principle method for this learning, such as attending in-person events in ACB community spaces, and having community leaders spread more awareness.

The leading response for how to effectively reach participants for recruitment was social media postings in ACB-specific community groups (n=48, 85.7%), followed by word of mouth/from peers (n=26, 46.4%), through a healthcare worker's recommendation (n=23, 41.1%), and via email (n=20, 35.7%).

### *Future Research Priority Areas*

Fifty-three respondents shared written responses on health topics important to them and outlined what should be future research priority areas. The commonly cited responses included mental health and substance use, sexual and reproductive health, and health conditions which are more common among ACB persons. (See **Figure 3** below).



Notes:
COVID-19: Coronavirus disease
STBBI: Sexually Transmitted Blood Borne Infections
ADHD: Attention-deficit/hyperactivity disorder

**Figure 3:** Future research priority areas

## DISCUSSION

In this study, we explored research participation experiences, barriers and facilitators to participating in research for persons identifying as African, Caribbean and/or Black (ACB), as well as future research priorities. The results identified gaps and opportunities for improving engagement of ACB communities in health research. Despite existing knowledge of gaps regarding experiences of ACB persons participating in health research, the observed mismatch between willingness and actual research participation was striking. Together, our data suggest that despite the willingness of self-identifying ACB persons to participate in health research, the research landscape is not conducive to this.

With limited data from the Canadian context, we turned to learnings from the United States to better understand how to bridge the observed gaps. US studies have identified barriers to research participation, including mistrust of researchers and the healthcare system, potential participants not fully understanding the consent process, the belief that research does not benefit the community, as well as logistic barriers such as not having enough time, transport and childcare. [9–12,15–18,38,39] US studies have also outlined facilitators to health research participation (e.g., transparency around protocols/methodology, participant rights including ongoing consent, and risks and benefits to participation), providing avenues for researchers to better engage ACB persons. Given the similarities between these findings and our own, we underscore the importance of grounding efforts in anti-racist practice that serve to dismantle the power hierarchy between researcher and participant and meaningfully engage ACB communities in research to better prioritize their health needs.

Anti-racist research methodologies aim to expose and dismantle underlying causes of racial health inequities. [40–42] Communities want and need researchers to practice allyship by embedding anti-racist practices in their research, some of which are highlighted in our study. Community-based research approaches can create conditions for incorporating anti-racist practice as community members are engaged from the design phase to deciding how data will be used. Community members help frame research questions that are pertinent and relevant to the community in question, ultimately providing input on how to address the health issues they face. In our study, respondents stated that they would be more likely to engage in research with community participatory approaches, and if the research benefited their community. For instance, the CHIWOS and On the Margins studies collaborated with ACB community leaders in BC and Nova Scotia, respectively, to build trust and to design and implement research studies informed by community priorities. Ultimately, this approach yielded research data that was used to inform health services and policies that better served ACB communities. [22, 43] Following similar methodologies and centering ACB communities, especially in BC and the greater Canadian context, is imperative to learning about and improving health outcomes.

However, if we do not approach this task with intentionality, researchers risk exacerbating extractive research practices, worsening barriers and thus continuing to underserve the ACB community and their health needs. Moreover, if we do not engage in participatory approaches, the status quo set by predominantly Eurocentric standards of research will be maintained, continuing to undervalue peoples' living experiences and knowledge. [42] A consequence is that health research and academia are not actively anti-racist and influence policies and practices accordingly, resulting in ongoing unmet health needs of ACB persons and hampering change towards racial equity. [13,44] Canada's complicity is apparent as it has often denied the presence and severity of racial discrimination along with its health impacts, partly due to a lack of race-disaggregated data. [27,45,46] In the past several years, different government counterparts such as the Canadian Institute for Health Information and the BC Government have proposed standards for collecting race-based data through initiatives such as the Anti-Racism Data Act to better understand and address these racial inequities and their causes, however this too must be done purposefully. [47,48,49] By collecting data from self-identifying ACB persons, we are addressing the dearth of information about ACB communities in BC, and hope other researchers will follow in meaningfully engaging ACB persons to continue identifying structural barriers present in research and academia. As a sub-study of the BCC3 study which aims to improve engagement of ACB women to learn about their health needs, this study is instrumental in providing relevant insights on meaningful and equitable engagement. Furthermore, we hope other studies may take lessons from our findings, as well as address the knowledge gap in the research experiences and priorities of ACB persons in the BC and Canadian context.

Beyond research engagement as a study participant, we must also consider the importance of Knowledge, Translation and Exchange (KTE) activities. Rather than only sharing study results in academic journals and conferences, we must also share findings directly with the community. KTE activities can include workshops, virtual open forum discussions, and other accessible community-based platforms and formats. Respondents indicated several preferred methods to learn about health research and various health topics, restating the importance of engagement within community spaces. With these findings in mind, we shared our preliminary findings with the Afro-Canadian Positive Network of British Columbia (ACPNet) membership and are co-creating additional KTE activities. These include using learnings from this study to co-create recruitment posters specific to engaging ACB women for the larger BC CARMA-CHIWOS Cohort (BCC3) Study, and creating short videos to share study expectations to study participants. Additionally, Community Research Associates have co-hosted numerous knowledge mobilization activities to share back BCC3 study data, including Health Aging Talks focused on Heart Health, Liver Health, and Menopause. [50]

*Strengths and Limitations*

The collaborative nature of this study is a strength. The community-based research approach offered better insights into the existing challenges and enhanced our interpretation of study data.

A potential limitation relates to participation bias. We did not reach as many people in older age groups, thus our findings may not represent the research experiences and priorities of older ACB generations. Due to COVID-19 restrictions, we relied heavily on social media postings for recruitment, which likely favoured engagement with a younger demographic. We also enrolled a highly educated sample; 75% of respondents had completed some university. Such participants may be more familiar with research, which may have resulted in a high willingness to participate in future research studies.

Due to limited data from the Canadian context, we defaulted to US data to gain insights on research experiences and health outcomes of ACB persons. This limitation highlights the need to collect race-based data in Canada to better understand and address the health needs and priorities of ACB persons, as well as shape research in a way that is participatory and inclusive of the communities we seek to benefit. We included respondents who completed >50% of the survey to learn as much as possible to guide us in sharing our findings with the broader research and academic community.

## CONCLUSION

We elucidated barriers and facilitators to participation in health research for persons identifying as African, Caribbean and/or Black (ACB), and found that despite existing gaps in recruitment, ACB persons are very willing to participate in future health research studies. This is an opportunity for researchers to adopt actively anti-racist practices to bridge this gap through meaningful engagement of ACB persons within health research, programming, and services, and for Canada to intentionally collect race-based data. These results signal the possibility of a paradigm shift in how research is conducted, and the expansion of accessible culturally safe and relevant health care services. Furthermore, engaging in participatory approaches can support us in reaching our common goal of racial equity.

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**Table 1: Willingness to participate in HIV, Sexual and Reproductive Health, and COVID-19 health research studies among study respondents (N=56).**

| | **N=56** | **%** |
|---|---|---|
| **Would you be willing to participate in a health research study on the topic of HIV, whether you are living with HIV or not?** | | |
| Yes | 41 | 73.2 |
| No | 8 | 14.3 |
| Don't know/Prefer not to answer | 7 | 12.5 |
| **Would you be willing to participate in a health research study on the topic of COVID-19, whether you have tested positive for COVID-19 or not?** | | |
| Yes | 42 | 75.0 |
| No | 6 | 10.7 |
| Don't know | 8 | 14.3 |
| **Would you be willing to participate in a health research study on the topic sexual and reproductive health?** | | |
| Yes | 43 | 76.8 |
| No | 9 | 16.1 |
| Don't know | 4 | 7.1 |

**Table 2: Reasons for unwillingness to participate in COVID-19, SRH, & HIV research studies among the 9 participants who responded accordingly.**

| **Reason for not participating in COVID/Sexual & Reproductive health/HIV studies** | **HIV (Total N = 8) N (%)** | **Sexual & Reproductive Health (Total N = 9) N (%)** | **COVID-19 (Total N = 6) N (%)** | **Not applicable to any of the studies (Total N = 56) N (%)** |
|---|---|---|---|---|
| I don't know a lot about this topic/ this topic doesn't apply to me | 8 (100) | 3 (33.3) | 2 (33.3) | 12 (21.4) |
| I don't feel comfortable participating in research on this topic | 7 (87.5) | 5 (55.6) | 5 (83.3) | 10 (17.9) |
| I feel like there is a power imbalance between participant and researcher (researchers have more power than participants do) | 7 (87.5) | 7 (77.8) | 5 (83.3) | 14 (25) |
| I find it hard to trust researchers and research staff | 6 (75.0) | 7 (77.8) | 5 (83.3) | 13 (23.2) |
| I don't feel comfortable talking about this topic | 5 (62.5) | 6 (66.7) | 1 (16.7) | 16 (28.6) |
| I am afraid of my community/family/friends finding out I participated in the study and that they will think I have/had tested positive | 5 (62.5) | 4 (44.4) | 3 (50.0) | 18 (32.1) |
| I don't want the researcher to judge me | 4 (50.0) | 6 (66.7) | 2 (33.3) | 16 (28.6) |
| I don't have support from my personal network (e.g.: family, friends, partner) | 4 (50.0) | 3 (33.3) | 3 (50.0) | 19 (33.9) |
| I don't want to have blood work done | 4 (50.0) | 5 (55.6) | 5 (83.3) | 16 (28.6) |
| I don't want to be tested for HIV, COVID-19, and/or Sexually Transmitted Illnesses | 4 (50.0) | 3 (33.3) | 3 (50.0) | 18 (32.1) |
| Other | 4 (50.0) | 2 (22.2) | 1 (16.7) | 18 (32.1) |
| I don't think research studies on this topic benefit me or my community | 2 (25.0) | 1 (11.1) | 2 (33.3) | 17 (30.4) |
| I don't have support from my spiritual/religious network and/or leader | 1 (12.5) | 4 (44.4) | 1 (16.7) | 19 (33.9) |

**Note:**

**All questions had an option to add a written response in a textbox after the multiple-choice options.**

## **Supplementary Material 1:** Survey Instrument

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*Page 1*

# Research Engagement

Please complete the survey below.

Thank you!

**This first section will ask questions related to ethnicity/race, age, gender etc. The purpose of this is to determine if certain groups have different experiences with research compared to others.**

| | |
|---|---|
| What do you consider to be your ethnic/racial background?<br>Please select all that apply. | ☐ Black African (eg: Nigerian, Senegalese, Somali)<br>☐ Black Caribbean (eg: Haitian, Jamaican)<br>☐ Black Other (eg: Black Canadian, African American)<br>☐ Multiracial/"Mixed race", with Black and non-Black heritage (eg. half-Black)<br>☐ Other (non-black ethnicity/race only) |
| What is your age? | ○ Under 16<br>○ 16-25<br>○ 26-35<br>○ 36-45<br>○ 46-55<br>○ 56-64<br>○ 65+<br>○ Prefer not to answer |
| Do you currently live in British Columbia? | ○ Yes<br>○ No |
| Were you born in Canada? | ○ Yes<br>○ No<br>○ Don't know<br>○ Prefer not to answer |
| In what year did you first come to Canada to live?<br><br>If don't know, please submit 9999. | __________________________________ |
| In what year did you first come to Canada to live? | ○ Don't know<br>○ Prefer not to answer |
| With respect to gender, how do you currently identify?<br><br>Please select all that apply. | ○ Woman<br>○ Man<br>○ Transgender man (Female to Male)<br>○ Transgender woman (Male to Female)<br>○ Gender queer<br>○ Gender neutral<br>○ Intersex<br>○ Two Spirited<br>○ Other, please specify<br>○ Don't know<br>○ Prefer not to answer |
| Please specify how you identify with respect to gender. | __________________________________ |

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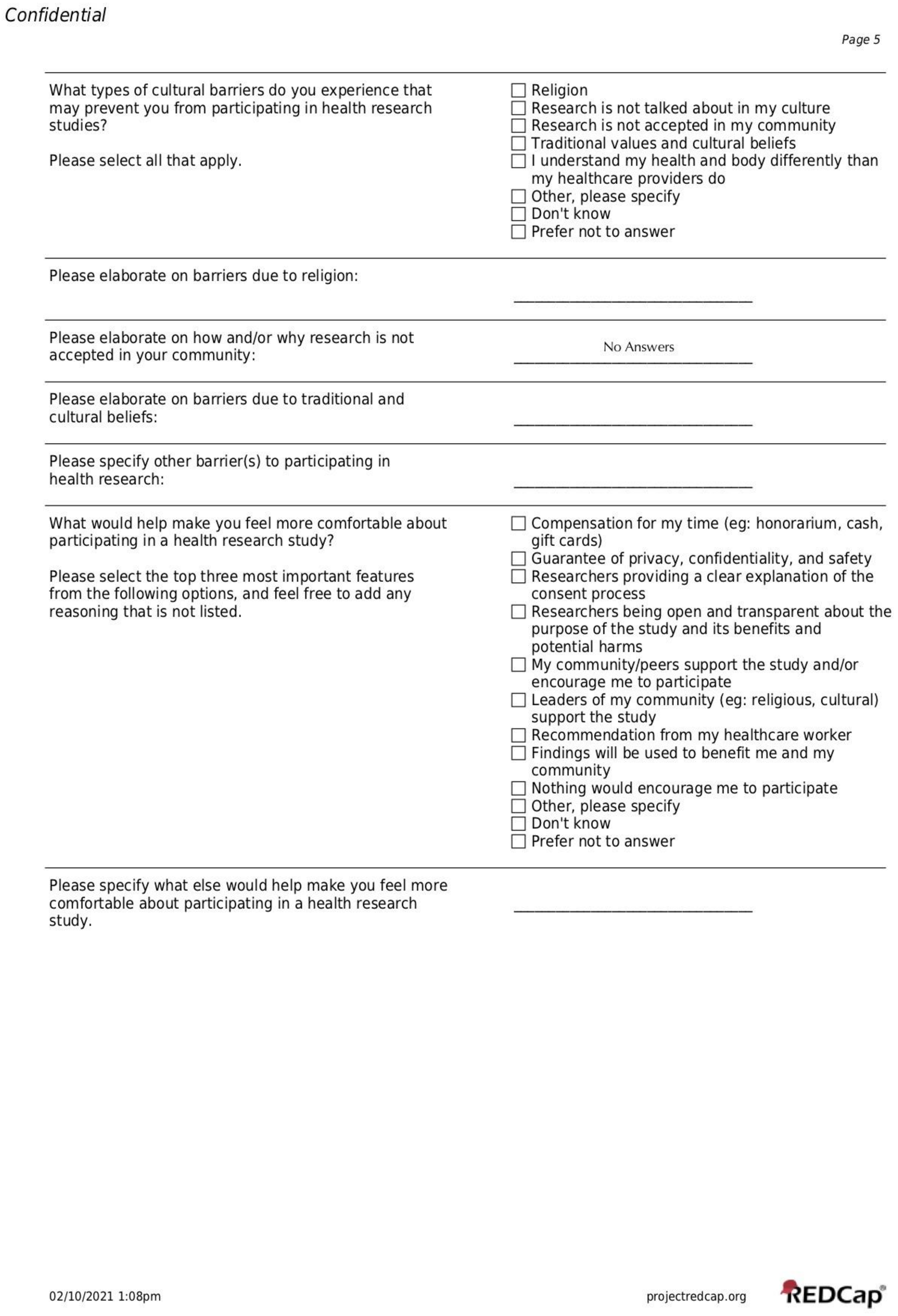
| | |
|---|---|
| What is the highest level of formal education you have completed? | ○ No formal education<br>○ Elementary / Grade school<br>○ Some high school / Secondary<br>○ Completed high school / Secondary / GED<br>○ Any Trade or Technical Training<br>○ Any College / CEGEP<br>○ Any University<br>○ Other, please specify<br>○ Don't know<br>○ Prefer not to answer |
| Please specify what other formal education you have taken and/or completed. | ________________________________ |

**The following questions refer to your thoughts and experiences with health research. Health research is the process of testing ideas, answering questions and finding ways to improve health and treatment options. This process begins with identifying a question related to health. People can sign up to participate in a study, and researchers collect information from them. Researchers then look at this information and try to find answers to their questions.**

**Research can happen in many different ways. Some of these ways include the following:**
**- One-on-one Interviews**
**- Surveys/questionnaires: collection of information through questions (ie: multiple choice, short and long answer)**
**- Clinical trial: participants try new medication(s), treatment program(s), medical devices...**
**- Focus groups: participants are involved in a group discussion about the research topic/question, led by a researcher**
**- Sample collection: this can include participants providing urine, blood, saliva etc., which is then looked at by researchers**

| | |
|---|---|
| Have you ever participated in health research before? This includes completing a health-related survey, participating in a clinical trial, participating in a health-related focus group discussion, and other types of health research. | ○ Yes<br>○ No<br>○ Don't know<br>○ Prefer not to answer |
| What kind of health research did you participate in?<br>Please select all that apply and feel free to add any that are not listed. | ☐ Questionnaire / Survey<br>☐ One-on-one Interview<br>☐ Focus Group Discussion / Sharing Circle<br>☐ Clinical Trial (eg: vaccine trial, medication trial)<br>☐ Studies include sample collection (eg: blood sample, urine sample)<br>☐ Other, please specify<br>☐ Prefer not to answer<br>(Please refer to text above for a more detailed explanation of each type of health research study.) |
| Please specify any other types of health research that you have participated in. | __________________________________ |
| Thinking about the most recent time you participated in a health research study, was it a positive or negative experience? | ○ Very positive experience<br>○ Positive experience<br>○ Neither positive or negative experience<br>○ Negative experience<br>○ Very negative experience<br>○ Prefer not to answer |
| What contributed to your positive experience participating in that health research study? | __________________________________________ |
| What contributed to your negative experience participating in that health research study? | __________________________________________ |

| | |
|---|---|
| Please select all of the types of health research studies that you would be willing to participate in.<br>Please select all that apply, and feel free to add any that are not listed. | ☐ Questionnaire/survey<br>☐ One-on-one Interview<br>☐ Focus Group Discussion/Sharing Circle<br>☐ Clinical trial (eg: vaccine trial, medication trial)<br>☐ Studies including a sample collection (eg: blood samples, urine samples)<br>☐ Any type, as long as the research is done together with the community<br>☐ I would NOT be willing to participate in any of the above study types<br>☐ Other, please specify<br>☐ Prefer not to answer |
| Please specify what other study type(s) you would be willing to participate in. | __________________________________ |
| For what reason(s) would you participate in health research in the future?<br>Please select all that apply from the options below, and feel free to add any reasoning that is not listed. | ☐ Participating in research is a good way to share my voice and perspectives<br>☐ Participating in research helps to benefit me and/or my community<br>☐ Participating in research is an opportunity to learn something new<br>☐ I could receive free healthcare services (eg. general blood testing, STI testing)<br>☐ My family/friends participate in research<br>☐ I know that the research is done in collaboration with the community (eg. community based research)<br>☐ Receiving compensation for my time (eg: honorarium, cash, gift cards)<br>☐ Other, please specify<br>☐ Prefer not to answer |
| Please specify any other reason(s) to participate in health research in the future. | __________________________________ |
| For what reason(s) would you NOT participate in health research?<br>Please select all that apply from the options below, and feel free to add any reasoning that is not listed. | ☐ None; I would always participate in health research<br>☐ I don't fully understand the consent process<br>☐ I don't see the value in research<br>☐ I don't see how research benefits me/my community<br>☐ I don't have anything valuable to contribute to research<br>☐ I don't have the time/I have too many other responsibilities<br>☐ I don't have anyone to take care of my dependents/children<br>☐ It is difficult for me to travel from my home (eg: bus fare, distance, live remotely)<br>☐ Language barriers<br>☐ Cultural barriers<br>☐ Stigma associated with health research<br>☐ I find it hard to trust researchers<br>☐ I had a negative experience with research in the past<br>☐ Other, please specify<br>☐ Don't know<br>☐ Prefer not to answer |
| Please specify other reason(s) for why you would NOT participate in health research. | __________________________________ |



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| | |
|---|---|
| What types of cultural barriers do you experience that may prevent you from participating in health research studies?<br>Please select all that apply. | ☐ Religion<br>☐ Research is not talked about in my culture<br>☐ Research is not accepted in my community<br>☐ Traditional values and cultural beliefs<br>☐ I understand my health and body differently than my healthcare providers do<br>☐ Other, please specify<br>☐ Don't know<br>☐ Prefer not to answer |
| Please elaborate on barriers due to religion: | ________________________________ |
| Please elaborate on how and/or why research is not accepted in your community: | No Answers<br>________________________________ |
| Please elaborate on barriers due to traditional and cultural beliefs: | ________________________________ |
| Please specify other barrier(s) to participating in health research: | ________________________________ |
| What would help make you feel more comfortable about participating in a health research study?<br>Please select the top three most important features from the following options, and feel free to add any reasoning that is not listed. | ☐ Compensation for my time (eg: honorarium, cash, gift cards)<br>☐ Guarantee of privacy, confidentiality, and safety<br>☐ Researchers providing a clear explanation of the consent process<br>☐ Researchers being open and transparent about the purpose of the study and its benefits and potential harms<br>☐ My community/peers support the study and/or encourage me to participate<br>☐ Leaders of my community (eg: religious, cultural) support the study<br>☐ Recommendation from my healthcare worker<br>☐ Findings will be used to benefit me and my community<br>☐ Nothing would encourage me to participate<br>☐ Other, please specify<br>☐ Don't know<br>☐ Prefer not to answer |
| Please specify what else would help make you feel more comfortable about participating in a health research study. | ________________________________ |

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**In health research, it is essential to include the voices of African, Caribbean, and/or Black (ACB) communities, so that findings are representative of their healthcare needs. For instance, if researchers are studying a certain health issue, it is important to have ACB participants who have that diagnosis as well as those who do not have that diagnosis to compare to. This allows researchers to identify any differences between groups living with the diagnosis and not. The inclusion of ACB persons in both groups is necessary when we consider that the social determinants of health result in different health risks and outcomes for ACB persons. Through active community participation, we can better design programs and systems that meet the health needs of ACB persons.**

**We will now ask you about health research on certain topics, and whether you would be willing to participate, whether this topic affects you personally or not.**

| | |
|---|---|
| Would you be willing to participate in a health research study on the topic of COVID-19, whether you have tested positive for COVID-19 or not? | ○ Yes<br>○ No<br>○ Don't know<br>○ Prefer not to answer |
| Would you be willing to participate in a health research study on the topic sexual and reproductive health? | ○ Yes<br>○ No<br>○ Don't know<br>○ Prefer not to answer |
| Would you be willing to participate in a health research study on the topic of HIV, whether you are living with HIV or not? | ○ Yes<br>○ No<br>○ Don't know<br>○ Prefer not to answer |

Please indicate if the reasons below would be a reason for you to NOT participate in either HIV, COVID-19, or sexual and reproductive health-related research studies.

| | COVID-19 studies | Sexual and reproductive health studies | HIV studies | This reason doesn't apply for any of the studies |
|---|---|---|---|---|
| I don't feel comfortable participating in research on this topic | ☐ | ☐ | ☐ | ☐ |
| I don't feel comfortable talking about this topic | ☐ | ☐ | ☐ | ☐ |
| I don't know a lot about this topic/ this topic doesn't apply to me | ☐ | ☐ | ☐ | ☐ |
| I don't think research studies on this topic benefit me or my community | ☐ | ☐ | ☐ | ☐ |
| I don't want the researcher to judge me | ☐ | ☐ | ☐ | ☐ |

| | | | | |
|---|---|---|---|---|
| I don't have support from my personal network (eg: family, friends, partner) | ☐ | ☐ | ☐ | ☐ |
| I don't have support from my spiritual/religious network and/or leader | ☐ | ☐ | ☐ | ☐ |
| I am afraid of my community/family/friends finding out I participated in the study and that they will think I have/had tested positive | ☐ | ☐ | ☐ | ☐ |
| I find it hard to trust researchers and research staff | ☐ | ☐ | ☐ | ☐ |
| I feel like there is a power imbalance between participant and researcher (researchers have more power than participants do) | ☐ | ☐ | ☐ | ☐ |
| I don't want to have blood work done | ☐ | ☐ | ☐ | ☐ |
| I don't want to be tested for HIV, COVID-19, and/or Sexually Transmitted Illnesses | ☐ | ☐ | ☐ | ☐ |
| Other, please specify | ☐ | ☐ | ☐ | ☐ |

Please specify other reasons why you would NOT participate in any of the above studies (COVID-19, HIV, sexual & reproductive health). ________________________________

Science has shown us that when a person living with HIV is taking their HIV medications, the level of virus in their blood is not detectable, so it is called undetectable. When the virus is undetectable, someone living with HIV cannot transmit HIV to their drug or sex partners. Similarly, when a pregnant woman is taking HIV medications and has an undetectable level of virus in her blood, the baby can be born without HIV. This means that the HIV virus is untransmittable. So, undetectable=untransmittable.
Please use this link to learn more: https://www.who.int/news-room/fact-sheets/detail/hiv-aids

In the context of HIV, had you heard of U=U (undetectable = untransmittable) before taking this survey?

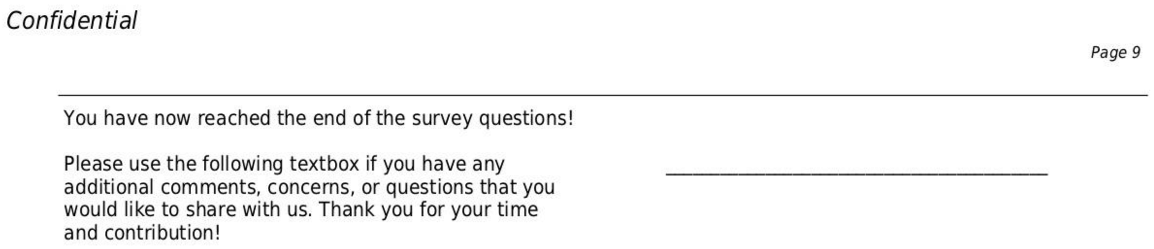
○ Yes
○ No
○ Prefer not to answer

What are some ways that you would want to learn more about topics such as COVID-19, sexual and reproductive health, and HIV?

Please select all that apply, and add any ideas that are not listed.

☐ Anonymous online discussion to share, discuss and learn about health topics by, with, and for ACB people
☐ Attend (in-person) events in ACB community spaces to discuss and learn about health research topics
☐ I would want my community leaders (ie: religious, cultural) to spread more awareness
☐ Online resources shared in community groups (eg: links to books, videos)
☐ Other, please specify
☐ Don't know
☐ Prefer not to answer

| | |
|---|---|
| Please specify other ways you would like to learn more about topics such as COVID-19, sexual and reproductive health, and HIV. | __________________________________ |
| What recruitment method(s)/approaches would be most effective to reach out to you to participate in health research?<br>Please select all that apply, and feel free to add any method that isn't listed. | ☐ Social media postings (eg: in an online group for African, Caribbean, and Black persons)<br>☐ Posting on job websites (eg: Craigslist)<br>☐ Listing in a newspaper/magazine<br>☐ Posters/flyers in community centres, clinics, and/or other public spaces<br>☐ Email listserv/emailing group that I am part of<br>☐ Word of mouth/hearing about it from my peers<br>☐ Recommendation from my healthcare worker<br>☐ Recommendation from my spiritual leader / faith group<br>☐ A private email/message sent directly to me<br>☐ Other, please specify<br>☐ Don't know<br>☐ Prefer not to answer |
| Please specify other recruitment method(s)/approaches that would be most effective to reach out to you to participate in health research. | __________________________________ |
| In your opinion, how important is it for African, Caribbean, and Black people to participate in health research studies? | ○ Very important<br>○ Important<br>○ Neither important or unimportant<br>○ Unimportant<br>○ Very unimportant<br>○ Don't know<br>○ Prefer not to answer |
| As a person who identifies as African, Caribbean, and/or Black, what health topics do you think are important to learn more about in research? | __________________________________ |
| Where or how did you learn about this survey? Please select all that apply. | ☐ Afro Canadian Positive Network of BC (ACPNet)<br>☐ Students of Caribbean and African Ancestry (SOCA) at SFU<br>☐ BOTA<br>☐ Black Women Connect Vancouver<br>☐ Kiwassa Neighbourhood House<br>☐ BC Community Alliance<br>☐ Black Health Alliance<br>☐ Unity Centre Association for Black Cultures (UCABC)<br>☐ National Congress of Black Women Foundation (NCBWF)<br>☐ Meanwhile Black in Vancouver<br>☐ Battered Womens' Support Services (BWSS)<br>☐ YouthCo<br>☐ Black Physicians of BC<br>☐ SFU DNA<br>☐ Family/friends<br>☐ Other, please specify |
| Please specify how or where you learned about this survey. | ________________________________________ |



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You have now reached the end of the survey questions!

Please use the following textbox if you have any additional comments, concerns, or questions that you would like to share with us. Thank you for your time and contribution!

________________________________________

**Supplementary Material 2: Socio-demographic characteristics of non-respondents (n=27)**

| **Socio-demographic Characteristic** | **n** | **%** |
|---|---|---|
| **Ethnicity** | | |
| Black African | 17 | 63.0 |
| Black Caribbean | 8 | 29.6 |
| Black, Other | 2 | 7.4 |
| Multiracial/mixed race including Black heritage | 2 | 7.4 |
| **Age Group (years)** | | |
| 26-35 | 10 | 37.0 |
| 36-45 | 10 | 37.0 |
| 46-65+ | 7 | 25.9 |
| **Gender** | | |
| Woman | 22 | 81.5 |
| Man | 4 | 14.8 |
| Prefer not to answer | 1 | 3.7 |
| **Highest Level of Formal Education** | | |
| Elementary | 1 | 3.7 |
| Some highschool | 1 | 3.7 |
| Completed high school/GED | 5 | 18.5 |

| | | |
|---|---|---|
| Any College/CEGEP | 3 | 11.1 |
| Any University | 13 | 48.1 |
| Other | 1 | 3.7 |
| Prefer not to answer | 3 | 11.1 |
| **Birth Country** | | |
| Canada | 13 | 48.1 |
| Other country | 14 | 51.9 |

**Notes:**

GED: General Educational Development

CEGEP: Collège d'enseignement general et professionnel