

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?

Please select all that apply.

- Black African (eg: Nigerian, Senegalese, Somali)
- Black Caribbean (eg: Haitian, Jamaican)
- Black Other (eg: Black Canadian, African American)
- Multiracial/"Mixed race", with Black and non-Black heritage (eg. half-Black)
- Other (non-black ethnicity/race only)

What is your age?

- Under 16
- 16-25
- 26-35
- 36-45
- 46-55
- 56-64
- 65+
- Prefer not to answer

Do you currently live in British Columbia?

- Yes
- No

Were you born in Canada?

- Yes
- No
- Don't know
- Prefer not to answer

In what year did you first come to Canada to live?

If don't know, please submit 9999.

In what year did you first come to Canada to live?

- Don't know
- Prefer not to answer

With respect to gender, how do you currently identify?

Please select all that apply.

- Woman
- Man
- Transgender man (Female to Male)
- Transgender woman (Male to Female)
- Gender queer
- Gender neutral
- Intersex
- Two Spirited
- Other, please specify
- Don't know
- Prefer not to answer

Please specify how you identify with respect to gender.

What is the highest level of formal education you have completed?

- No formal education
- Elementary / Grade school
- Some high school / Secondary
- Completed high school / Secondary / GED
- Any Trade or Technical Training
- Any College / CEGEP
- Any University
- Other, please specify
- Don't know
- 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
 No
 Don't know
 Prefer not to answer

What kind of health research did you participate in?

Please select all that apply and feel free to add any that are not listed.

- Questionnaire / Survey
 One-on-one Interview
 Focus Group Discussion / Sharing Circle
 Clinical Trial (eg: vaccine trial, medication trial)
 Studies include sample collection (eg: blood sample, urine sample)
 Other, please specify
 Prefer not to answer
 (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
 Positive experience
 Neither positive or negative experience
 Negative experience
 Very negative experience
 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.

Please select all that apply, and feel free to add any that are not listed.

- Questionnaire/survey
- One-on-one Interview
- Focus Group Discussion/Sharing Circle
- Clinical trial (eg: vaccine trial, medication trial)
- Studies including a sample collection (eg: blood samples, urine samples)
- Any type, as long as the research is done together with the community
- I would NOT be willing to participate in any of the above study types
- Other, please specify
- 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?

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
- Participating in research helps to benefit me and/or my community
- Participating in research is an opportunity to learn something new
- I could receive free healthcare services (eg. general blood testing, STI testing)
- My family/friends participate in research
- I know that the research is done in collaboration with the community (eg. community based research)
- Receiving compensation for my time (eg: honorarium, cash, gift cards)
- Other, please specify
- 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?

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
- I don't fully understand the consent process
- I don't see the value in research
- I don't see how research benefits me/my community
- I don't have anything valuable to contribute to research
- I don't have the time/I have too many other responsibilities
- I don't have anyone to take care of my dependents/children
- It is difficult for me to travel from my home (eg: bus fare, distance, live remotely)
- Language barriers
- Cultural barriers
- Stigma associated with health research
- I find it hard to trust researchers
- I had a negative experience with research in the past
- Other, please specify
- Don't know
- Prefer not to answer

Please specify other reason(s) for why you would NOT participate in health research.

What types of cultural barriers do you experience that may prevent you from participating in health research studies?

Please select all that apply.

- Religion
- Research is not talked about in my culture
- Research is not accepted in my community
- Traditional values and cultural beliefs
- I understand my health and body differently than my healthcare providers do
- Other, please specify
- Don't know
- 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

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?

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)
- Guarantee of privacy, confidentiality, and safety
- Researchers providing a clear explanation of the consent process
- Researchers being open and transparent about the purpose of the study and its benefits and potential harms
- My community/peers support the study and/or encourage me to participate
- Leaders of my community (eg: religious, cultural) support the study
- Recommendation from my healthcare worker
- Findings will be used to benefit me and my community
- Nothing would encourage me to participate
- Other, please specify
- Don't know
- Prefer not to answer

Please specify what else would help make you feel more comfortable about participating in a health research study.

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
 No
 Don't know
 Prefer not to answer

Would you be willing to participate in a health research study on the topic sexual and reproductive health?

- Yes
 No
 Don't know
 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
 No
 Don't know
 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't feel comfortable talking about this topic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't know a lot about this topic/ this topic doesn't apply to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't think research studies on this topic benefit me or my community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't want the researcher to judge me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I don't have support from my personal network (eg: family, friends, partner)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't have support from my spiritual/religious network and/or leader	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I find it hard to trust researchers and research staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel like there is a power imbalance between participant and researcher (researchers have more power than participants do)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't want to have blood work done	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I don't want to be tested for HIV, COVID-19, and/or Sexually Transmitted Illnesses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other, please specify	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?

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)
- Posting on job websites (eg: Craigslist)
- Listing in a newspaper/magazine
- Posters/flyers in community centres, clinics, and/or other public spaces
- Email listserv/emailing group that I am part of
- Word of mouth/hearing about it from my peers
- Recommendation from my healthcare worker
- Recommendation from my spiritual leader / faith group
- A private email/message sent directly to me
- Other, please specify
- Don't know
- 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
- Important
- Neither important or unimportant
- Unimportant
- Very unimportant
- Don't know
- 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)
- Students of Caribbean and African Ancestry (SOCA) at SFU
- BOTA
- Black Women Connect Vancouver
- Kiwassa Neighbourhood House
- BC Community Alliance
- Black Health Alliance
- Unity Centre Association for Black Cultures (UCABC)
- National Congress of Black Women Foundation (NCBWF)
- Meanwhile Black in Vancouver
- Battered Womens' Support Services (BWSS)
- YouthCo
- Black Physicians of BC
- SFU DNA
- Family/friends
- Other, please specify

Please specify how or where you learned about this survey.

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!

Closing Page

Thank you for your time in completing our survey! Please click on the "Prize Draw" button below to fill out your contact information, to be entered in a prize draw for a 100\$ (CAD) giftcard. Once you click the link, you will be directed to a new window to enter your information.