



Appendix 25 - weSpeak: Heterosexual Black Men Building Resilience to HIV in Ontario Project

Toronto Site - Participant Consent Agreement (ACB Men Concept Mapping Focus Groups)

You are being invited to participate in Phase 3 of **weSpeak**, a research project funded by the Ontario HIV Treatment Network (OHTN) and Canadian Institute of Health Research (CIHR). Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you fully understand what your voluntary participation will involve.

INVESTIGATORS:

weSpeak is carried out by a large team of researchers in Toronto, Ottawa, London and Windsor. All team members are listed on the last page of this consent form. The principal investigators of this study are:

- Dr. Josephine P. Wong (Professor, Ryerson University)
- Dr. Winston Husbands (Senior Scientist, Ontario HIV Treatment Network)
- Dr. Josephine Etowa (Professor, University of Ottawa)
- Dr. Isaac Luginaah (Professor, Western University)
- Dr. Francisca Omorodion (Associate Professor, University of Windsor)

PURPOSE OF THE STUDY:

The goal of this research project is to (a) reduce vulnerability to HIV among heterosexual Black men in Ontario, (b) promote resilience, and (c) find ways to actively engage self-identified heterosexual African, Caribbean and Black (ACB) men in community responses to HIV. We are recruiting straight (heterosexual) ACB men who are: aged 16 and over; residing in the Greater Toronto Area, London, Ottawa, or Windsor; and HIV-positive or have never been diagnosed with HIV. We will also engage service providers, policy/decision-makers and other relevant stakeholders who work in or with ACB communities to address HIV and other related issues that affect the health and wellbeing of heterosexual ACB men and their communities.

TAKING PART IN THIS STUDY

We have completed Phases 1 and 2 of weSpeak. Phase 1 of weSpeak consisted of focus groups and individual interviews with ACB men on their ideas about gender expectations and social factors that influence ACB men's HIV vulnerabilities and resilience; it also consisted of focus groups with community stakeholders on the same topics. Phase 2 of weSpeak consisted of surveys of ACB men on HIV vulnerabilities and resilience. We are inviting you to take part in Phase 3 to provide ideas on creating a best practices framework to reduce HIV vulnerabilities of ACB men and communities. Taking part in Phase 3 of weSpeak is totally voluntary. You must self-identify as a heterosexual ACB man, aged 16 or over, and living in one of the four project cities – Toronto, Ottawa, London, or

Windsor. In addition, you agree to join the focus group sessions from a space that offers visual and audio privacy. If you choose to participate in Phase 3 of weSpeak, you will be invited to:

- Complete a short demographic and health practices survey, which consists of five questions about you (e.g., your age, annual income, city you live in, ethno-racial identity, and previous participation in weSpeak Phase 1 or Phase 2). The survey is completed using the online platform groupwisdom™. No personal identifying information (e.g name, home address, etc.) will be collected on this survey. Participant responses are grouped together for analysis purposes. It is not possible to know the individual responses of participants.
- Take part in a series of three 2.5-hours online sessions of group discussion using Zoom. The sessions will be video-recorded and stored directly into a password protected weSpeak computer. To protect your privacy and confidentiality, only the host screen will be turned on. All participants' profile pictures will be turned off. You are encourage to rename yourself and use a make-up name or alias. Since the purpose of these group sessions is to collectively develop a best practices framework, your agreement to be video-taped is a criteria to participate in Phase 3 of weSpeak. For more information on Zoom terms of service and privacy, please visit: <https://zoom.us/privacy-and-legal>.
- In *Session 1* the research team will present the results drawn from the survey and interviews with heterosexual Black men that were conducted in 2016-2018, weSpeak (Phases 1 & 2). After the presentation, you will be invited to generate ideas that will be used to develop a best practices model for HIV responses in ACB communities.
- In *Session 2* you will be asked to sort ideas, generated by all participants during Session 1, into piles based on the similarity of each idea. Then you will rate each idea based on how important each idea is and how feasible it is (in other words, how easily it can be done).
- In *Session 3* the research team will present **a concept map** – an image which shows the relationships between different groups of ideas generated by you and other participants during Sessions 1 and 2. You will be invited to discuss with other participants to interpret this concept map and create a best practices model for HIV responses in ACB communities.

To keep the sessions as private as possible, Zoom meeting login details will be shared only with registered participants and basic privacy features will be used (e.g. meeting password). By consenting to participate in the Concept Mapping session (Phase 3 of weSpeak), you agree to keep personal information shared by all participants during these sessions confidential.

VOLUNTARY PARTICIPATION

Taking part in this research study is completely voluntary and you may refuse to participate, refuse to answer any questions or withdraw from the study at any time. Withdrawing from the study will not affect any services that you now receive or will receive from any of the weSpeak partnership agencies (see list of research team members on the last page). Since the group concept mapping activities are designed to allow participants to provide input without any personal identifiable information, once your ideas are entered into the groupwisdom™ platform, weSpeak team members will not be able to identify which participants contributed a given statement. Should you choose to withdraw, we will not be able to identify or remove your individual research data related to brainstorming. For data specific to group discussion and interpretation of the concept maps, we will do our utmost to delete your portion as long as it does not lead to the loss of someone else's ideas and sharing.

CONFIDENTIALITY

All information you provide during the research will be kept private. Your name will not appear in any report or publication of the research. We will use a study code on all the data we collect from you. The consent form and survey results will be stored on a password protected groupwisdom™ account. Focus group interview notes will be kept in password protected documents in a Dropbox folder accessible only to research team members. We will store participant contact information in a password protected document in another folder separate from research data. The video-recorded focus group interviews will be stored in a weSpeak password protected computer and transcribed into written texts as a password protected documents which will be stored on the research team Dropbox and accessed only by team members for data analysis. Once the transcription is completed and verified, we will destroy the video files. All questionnaires, focus group transcripts and notes will be destroyed 5 years after the study has been completed as required by the funding agency.

The research team will keep what you share in the focus groups confidential, except in situations where we are required by law to release the information (e.g., if we hear information that a child has been or is being abused; if we hear that you may harm yourself; or if we hear that someone has threatened your life or someone else's life, etc.).

LIMITS ON CONFIDENTIALITY

Since this focus group involves a number of participants, confidentiality cannot be absolutely guaranteed. Confidentiality is kept only when all of us agree to keep everything that is shared in this room confidential and not share any information with anyone outside of this focus group interview. To protect your confidentiality, we encourage you to think through and decide what you will and will not share in a group setting. To protect everyone's privacy, by consenting to participate in the Concept Mapping session (Phase 3 of weSpeak), you **agree** to keep all personal information shared during these sessions confidential, and will not reveal by speaking, communicating or transmitting this information in written, electronic (disks, tapes, transcripts, email) or any other manner to anyone outside the research team. You **agree** that you will not tell anyone about any personal information that you hear in the group interview sessions, unless the speaker has told you personally that it is okay to do so. You are also encouraged to use a made-up name while taking part in the focus group discussion to enhance your privacy.

RISKS AND DISCOMFORTS

This study is not expected to cause you or others any known harm. However, you may experience some unexpected emotion or discomfort during the discussion. If you feel upset during the focus group, and you wish to express your discomfort, please feel free to approach any member of the research team. You may also refer to the "Community Resources" sheet you received as part of the study information you received. It contains information on support services in the community that may be helpful to you.

BENEFITS OF THE RESEARCH

Although you may not have any direct benefit from taking part in this study, your ideas and sharing may help us develop effective programs and policy to improve HIV programs, services and policies for ACB men and their communities in Ontario.

HONORARIUM

You will receive a \$40 honorarium for each of the three concept mapping group sessions that you attend. You will keep this honorarium even if you decide to withdraw from the study at any point in time.

RESEARCH REPORT AND KNOWLEDGE SHARING

You can access a report on the results of this research project at the weSpeak website (www.we-Speak.ca). If you would like to be notified of our end-of-project community presentations on the finding of this study, you may contact the research team directly using the contact information provided to you during the focus group.

QUESTIONS ABOUT THE RESEARCH

If you have questions about the research in general or about your role in the study, please feel free to contact: Dr. Josephine Wong, Principal Investigator, Ryerson University, at 416-979-5000 ext. 556303, or by E-mail: jph.wong@ryerson.ca;

This research has been reviewed by the Ryerson University's Research Ethics Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study please contact: Research Ethics Board, Ryerson University, at 416-979-5042, or by E-mail: rebchair@ryerson.ca

LIST OF RESEARCH TEAM MEMBERS

| Co-Principal Investigators | Affiliation |
|-----------------------------------|---|
| Josephine P. Wong | Ryerson University |
| Winston Husbands | Ontario HIV Treatment Network |
| Josephine Etowa | University of Ottawa |
| Francisca Omorodion | University of Windsor |
| Isaac Luginaah | Western University |
| Co-Investigators | Affiliation |
| Kenneth Fung | University of Toronto |
| Carl James | York University |
| Jelani Kerr | University of Louisville |
| Erica Lawson | Western University |
| Hugues Loemba | University of Ottawa |
| Lance McCreedy | University of Toronto |
| Paul Mkandawire | Carleton University |
| Wesley Oakes | York University |
| Fanta Ongoiba | Africans in Partnership Against AIDS |
| Maurice Poon | York University |
| Wangari Tharao | Women's Health in Women's Hands Community Health Centre |
| Zhaida Uddin | Ottawa Public Health |
| Mandana Vahabi | Ryerson University |
| Charmaine Williams | University of Toronto |

CONSENT: Pressing the “Accept CONSENT” button below means that you have read and understood the information on this page and have had a chance to ask any questions you have about the study. Pressing this button also means that you agree to take part in this focus group and you understand that you can change your mind at any time. A copy of this consent agreement is available for you to download on the groupwisdom™ platform and it is also posted on the weSpeak website (www.we-speak.ca) with community resources that you may access if needed.

Note: Pressing “Accept” will offer you access to the groupwisdom™ software. You will then be able to access activities for group concept mapping.

Thank you.

Decline
CONSENT

Accept
CONSENT