

## PEER REVIEW HISTORY

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### ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	The A/C study protocol: a cross-sectional study of HIV epidemiology among African, Caribbean and Black people in Ontario
<b>AUTHORS</b>	Mbuagbaw, Lawrence; Tharao, Wangari; Husbands, Winston; Nelson, Laron; Aden, Muna; Arnold, Keresa; Baidooobonso, Shamara; Dabone, Charles; Dryden, OmiSoore; Etowa, Egbe; Hamid, Jemila; Jackson-Best, Fatimah; Kohoun, Bagnini; Lawson, Daeria; Lofters, Aisha; Luyombya, Henry; Mbulaheni, Tola; Mkandawire, Paul; Ndungu, Mary; Nyambi, Agatha; Obiorah, Suzanne; Ongoiba, Fanta; Ongolo-Zogo, Clémence; Oraka, Chinedu; Shahin, Rita; Yaya, Sanni; Hendricks, Andrew; Gebremeskel, Aster; Inoua, Haoua; Etowa, Josephine

### VERSION 1 – REVIEW

<b>REVIEWER</b>	Dr Catrin Evans University of Nottingham, UK
<b>REVIEW RETURNED</b>	29-Jan-2020

<b>GENERAL COMMENTS</b>	<p>Thank you for the opportunity to review this protocol. It is well written and every step is clearly described. The research question is an important one.</p> <p>I have just a few minor comments and questions – generally seeking elaboration as I felt that some sections of the protocol were rather brief, thus making it hard to evaluate fully.</p> <p>This study is represented as community based participatory research. I would like to know more about how the collaboration with the various community groups came about, how the collaboration will work in practice, how the peer/community researchers will be trained and supported and, specifically, in what ways this research is responding to community-identified issues.</p> <p>The topics covered by the survey are appropriate. However, from the perspective of delivering actionable findings, I wonder whether there is any scope for questions on intentions to test, barriers to testing and views on preferred testing options? Likewise, in order to understand some of the issues around testing, would it be possible to ask (linked to the HIV testing question) – where the testing was done? i.e. what kind of testing have the participants previously engaged in? This might yield important insights regarding the kind of HIV testing and support initiatives that would be acceptable to the community in future. Without actually seeing the questionnaire, it is currently hard to fully judge the scientific merit of it.</p> <p>In terms of ethical issues, I have two queries (though I recognise that approval has already been obtained, so this is more a matter of</p>
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	clarifying and elaborating for the benefit of readers). (i) It is noted that point of care testing would be offered to participants. Can you elaborate on the clinical governance & support arrangements for this provision? (ii) Can we have more detail on what arrangements and safeguards have been put into place for participants who may be younger (i.e. the 15-18 year olds)?
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<b>REVIEWER</b>	Zachary Kwena Kenya Medical Research Institute, Kenya
<b>REVIEW RETURNED</b>	28-Mar-2020

<b>GENERAL COMMENTS</b>	<p>This manuscript is a good addition to literature discussing the gaps in provision of health services to the minority and vulnerable populations. Additionally, the manuscripts is well-written except in a few places where clarity is required. I have pointed out these places as below:</p> <p>Page 1 Line 2: Spell out what A/C study means. It may not be obvious to everyone.</p> <p>Page 5 Lines 43-45: Clarify whether the 86% of people reporting 'seeing their family doctor in the past year' are part of the 87% who had family doctor.</p> <p>In the recruitment strategy specified on Page 7 Lines 33 ff, authors need to provide detailed information on how the investigators will control for obvious biases in recruitment</p> <p>Although it becomes clearer much later in the manuscript, the authors need to be clear in the manuscript which data sets are being linked (Page 8 Lines 3-8)</p> <p>In several sections of the manuscript, the authors say that the study is targeting ACB community and ACB-led. The is need to support/demonstrate this assertion somewhere within the manuscript.</p> <p>The author should also clarify how the study will be different if it was not ACB-led.</p> <p>This being community participatory study, it is not clear how the community was involved beyond their reported participation in the design and result feedback meeting.</p> <p>Page 13 Lines 17ff: Some applications of the findings are not neatly linked to either study objectives or expected results (based on Table 1). There is need for authors to link their application of the results to expected study findings. For instance, the statement on Page 13 Line 24 that the findings could inform policy on how to provide equitable services for ACB minorities -- not clear what data they collect that will inform this policy.</p>
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## VERSION 1 – AUTHOR RESPONSE

<b>Reviewer 1</b>	<b>Response</b>
Thank you for the opportunity to review this protocol. It is well written and every step is clearly described. The research question is an important one. I have just a few minor comments and questions – generally seeking elaboration as I felt that some sections of the protocol were rather brief, thus making it hard to evaluate fully.	Thank you for your kind comments.

<p>This study is represented as community based participatory research. I would like to know more about how the collaboration with the various community groups came about, how the collaboration will work in practice, how the peer/community researchers will be trained and supported and, specifically, in what ways this research is responding to community-identified issues.</p>	<p>The research team comprised of ACB people from a wide variety of community health centres, AIDS service organisations and associations for African, Caribbean and Black people in Toronto and Ottawa, and academic institutions to develop safe and culturally acceptable approaches to conduct this study. Two focus groups were held to inform the development and implementation of this study. The ACB researchers and community partners in Ontario have a long standing history of collaboration in research, but particularly with the regularly held ACB Think Tanks –workshops used to set research priorities and support community-based research to develop the knowledge base and inform policy and programs (e.g., issues such as HIV-related stigma, the needs of ACB women living with HIV, and gay and bisexual ACB men, among other issues). This collaboration has been supported by the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO). We applied the following principles: Community stewardship, diversity, capacity building and integrated knowledge translation and action. We have added these details to the manuscript. See page 6, line 27 to page 8, line 2.</p>
<p>The topics covered by the survey are appropriate. However, from the perspective of delivering actionable findings, I wonder whether there is any scope for questions on intentions to test, barriers to testing and views on preferred testing options?</p>	<p>Thank you for raising this concern. Unfortunately, at this stage the questionnaire cannot be modified. Previous research in African, Caribbean and Black communities in Ontario has identified barriers to testing including limited access to health services, stigma and testing.<sup>1</sup> These findings were incorporated in the design of the current study. Further, as part of the study, participants were offered HIV tests.</p>
<p>Likewise, in order to understand some of the issues around testing, would it be possible to ask (linked to the HIV testing question) – where the testing was done? i.e. what kind of testing have the participants previously engaged in? This might yield important insights regarding the kind of HIV testing and support initiatives that would be acceptable to the community in future. Without actually seeing the questionnaire, it is currently hard to fully judge the scientific merit of it.</p>	<p>The purpose of the question on prior HIV testing was meant to ascertain knowledge of HIV status and will be interpreted in conjunction with other data such as barriers in access to HIV care. As mentioned above, barriers to HIV testing in this community are known, and informed the design of this study.<sup>1</sup></p>
<p>In terms of ethical issues, I have two queries (though I recognise that approval has already been obtained, so this is more a matter of clarifying and elaborating for the benefit of readers). (i) It is noted that point of care testing would be offered to participants. Can you elaborate on the clinical governance &amp; support arrangements for this provision?</p>	<p><b>Point-of-care (PoC) testing</b> will be offered to participants who want to know their HIV status (i.e., people who were HIV-negative or never diagnosed). Participants who indicate that they want to have a PoC test will be tested by peers who were trained under guidelines developed by the provincial Ministry of Health, and according to a training program approved by the Ministry. The testing will be separate from the study – the testers are affiliated with an agency that is authorized to undertake PoC testing (i.e., that were not part of the A/C Study team). Furthermore, the research team will not have</p>

	<p>access to the PoC results.</p> <p>The study protocol includes collecting <b>DBS samples</b> from participants who consent separately to this component. The DBS samples will be collected to enable estimates of HIV prevalence. However, survey participants will be asked to give a separate consent for the DBS collection – people can participate in the survey but decline to give a DBS sample. The specimens will be tested by Public Health Agency of Canada (PHAC) for antibodies against HIV. The collection, storage, and transportation of DBS will follow PHAC guidelines on infection control practices and on the collection, temporary storage and transportation of DBS specimens. Only trained interviewers will collect specimens. No genetic testing of human genomic material will be performed on any survey specimens. Specimens will be destroyed immediately after testing. Laboratory test results will be entered into a password-protected surveillance database and linked to behavioural data from the corresponding participant survey questionnaire via the Study ID code. Daily, we will check a random selection of DBS to ascertain whether samples are being correctly captured; and communicate with the lab and PHAC at regular intervals to identify any problems with the DBS samples. The interviewer training includes capacity build on infection control, DBS collection and exposure to blood protocols. We have provided additional details in the manuscript. See page 10, lines 2-5 and page 10, lines 19-21.</p>
<p>(ii) Can we have more detail on what arrangements and safeguards have been put into place for participants who may be younger (i.e. the 15-18 year olds)?</p>	<p>This observational study does not pose greater than minimal risk to participants. Our local partner organizations have services and protocols for addressing a range of adolescent specific needs that may arise during the course of the study. For example, any adolescent who consented to point-of-care HIV testing (which they can without parental consent) has access to counsellors who can ensure that the participant understands the potential implications of a sero-positive test and provide assistance to the youth in planning for next steps after receiving the test result which could include linkage to HIV pre-exposure prophylaxis (PrEP) for individuals without a seropositive test and linkage to medical care and social support to those diagnosed with HIV. Further, the consent forms will be accompanied by information letters written in plain, youth-friendly language that explains the purpose of both components of the study and articulates participants' rights as they relate to the voluntary nature of study participation, confidentiality, anonymity, and privacy.</p> <p>The younger participants will receive a list of local</p>

	<p>resources that specifically serve youth. This allows youth who need support to access it through community resources.</p> <p>We have further elaborated on the ethics of inclusion of youth in</p> <p>On page 15, line 24- page 16, line 2.</p>
<b>Reviewer 2</b>	<b>Response</b>
This manuscript is a good addition to literature discussing the gaps in provision of health services to the minority and vulnerable populations. Additionally, the manuscripts is well-written except in a few places where clarity is required. I have pointed out these places as below:	Thank you for this feedback.
Page 1 Line 2: Spell out what A/C study means. It may not be obvious to everyone.	The acronym A/C refers to the track of research this study falls under as defined by the Public Health Agency of Canada. A/C refers to African/Caribbean (or African Canadian) to denote research in African, Caribbean and Black communities. We have clarified this. See page 6, lines 1-4.
Page 5 Lines 43-45: Clarify whether the 86% of people reporting 'seeing their family doctor in the past year' are part of the 87% who had family doctor.	The 86% reporting seeing a family doctor are not a fraction of the 86% who have a family doctor. We have reworded for clarity. It now reads: "In a 2004-05 survey of 456 people from East African communities in the Greater Toronto Area (GTA), 87% of participants reported having a family doctor and 86% reporting seeing their family doctor in the past year." See page 5, line 24-26.
In the recruitment strategy specified on Page 7 Lines 33 ff, authors need to provide detailed information on how the investigators will control for obvious biases in recruitment Although it becomes clearer much later in the manuscript, the authors need to be clear in the manuscript which data sets are being linked (Page 8 Lines 3-8)	<p>With regards to recruitment, we are recruiting from a wide variety of places that ACB communities congregate. This will limit potential selection biases. The place where the interview is collected is also captured and we will be able to explore any issues with differential recruitment. We have added this to the manuscript. See page 8, lines 26-27 and page 9, lines 3-4.</p> <p>With regards to data linkage, all the databases listed will be used. Each of them contains unique pieces of information that will be put together to create a complete picture. The linkage processes are described in further detail in the supplemental file.</p>
In several sections of the manuscript, the authors say that the study is targeting ACB community and ACB-led. The is need to support/demonstrate this assertion somewhere within the manuscript	<p>Thank you for raising this concern. In other to be eligible for the study, the participant must be African, Caribbean or Black. See page 8, lines 4-8.</p> <p>All the investigators, and authors of this manuscript belong to the ACB community. This is now elaborated under the principle of community stewardship. See page 6, line 27 to page 8, line 2.</p>
The author should also clarify how the study will be different if it was not ACB-led.	If the study was not ACB-led, it would violate some of the principles of autonomy and self-determination in community-led research. We

	have noted this in the manuscript. See page 16, lines 3-4.
This being community participatory study, it is not clear how the community was involved beyond their reported participation in the design and result feedback meeting.	We have outlined the levels of community involvement based on the following principles: Community stewardship, diversity, capacity building and integrated knowledge translation and action. In addition to contributing to the design of the study, members of the ACB community have been trained as peer recruiters/interviewers, MSc students and postdoctoral fellows. ACB community members are also going to be involved in the interpretation and dissemination of findings. See page 6, line 26 to page 8, line 2.
Page 13 Lines 17ff: Some applications of the findings are not neatly linked to either study objectives or expected results (based on Table 1). There is need for authors to link their application of the results to expected study findings. For instance, the statement on Page 13 Line 24 that the findings could inform policy on how to provide equitable services for ACB minorities -- not clear what data they collect that will inform this policy.	Thank you for highlighting this concern. Linked administrative data will provide us with insights into access and use of HIV services in the ACB community and will provide direct evidence of inequalities in health care and health outcomes. The Federal and provincial governments have identified HIV in ACB communities as an important concern, which they have endorsed through program and research funding. The data on their own will not impact policy, but our knowledge translation activities target policymakers. We have elaborated further on this. See page 16, lines 23-24.

## References:

1. Gray K, Calzavara L, Tharao W, Johns A. The East African Health Study in Toronto (EAST): Results from a survey of HIV and health-related behavior, beliefs, attitudes, and knowledge. *The HIV Social, Behavioural, and Epidemiological Studies Unit, University of Toronto* 2008.