



African and Caribbean Council on HIV/AIDS in Ontario

Guidelines for ACCHO's Participation in Research

1. Purpose

The purpose of this document is to establish principles guiding ACCHO's roles in research collaborations.

2. Goals of Research

ACCHO¹ collaborates on research to reduce the incidence of HIV and improve the quality of life for those living with and affected by HIV/AIDS among African, Caribbean and Black (ACB) communities in Ontario. ACCHO also participates in initiatives to ensure effective translation and exchange of knowledge between and among all stakeholders to improve the response to HIV in ACB communities.

3. Framework of Research

Research that ACCHO collaborates on must promote anti-racism, anti-oppression (ARAO)² and community-based research frameworks, MIPA principles³ as well as ACCHO's core principles and the strategic research-related priorities outlined in the *Ontario Strategy for African, Caribbean and Black Communities – 2013-2018* (the ACB Strategy).

4. Research Review Considerations

Projects ACCHO is involved in must be conducted in accordance with the ethical research principles outlined in the [Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans 2010 \(TCPS 2\)](#). As part of the agreement to collaborate with researchers, the ACCHO Research Committee (ARC) will raise ethical concerns to ensure research undertakings are respectful, support self-determination and autonomy, and benefit ACB communities. Research will be approved by recognized Research Ethics Boards thus ensuring adherence to the ethical research principles identified above.

¹ ACCHO is a provincial coalition of organizations and individuals committed to HIV prevention, education, policy, advocacy, research, treatment, care and support for ACB communities in Ontario.

² An anti-racism, anti-oppression (ARAO) framework is a perspective that understands and confronts all aspects of injustice and inequality within society's institutions, structures, systems and practices. Research within this framework aims to better understand and eradicate the vulnerability of ACB populations to HIV infection and the difficulties in accessing information, treatment and support.

³The MIPA (the Meaningful Involvement of People Living with HIV/AIDS) principle recognizes the meaningful and purposeful involvement of people infected with and affected by HIV/AIDS in the response to the epidemic. It is recognized that the GIPA (the Greater Involvement of People Living with HIV/AIDS) principle preceded MIPA and formed the foundational framework for the important contribution people living with and affected by HIV/AIDS make in all aspects and stages of the response.

5. Roles and Responsibilities

The Executive Committee must approve the involvement of ACCHO in research undertakings in any capacity. ARC, ACCHO Council or staff members cannot by themselves engage in research as representatives of ACCHO without this approval.

5.1 Where ACCHO is engaged in a leadership role (as an initiator or as part of the research team), the research team:

- Must acknowledge and agree to support the principles of co-ownership, control, and access to the research data for projects conceptualized and/or originated from ACCHO or projects that are dependent on ACCHO's involvement. To facilitate this, at least one of the co-principal investigators must be a member of the ACCHO Council or staff.
- Must agree that it will collectively make decisions on research design, data collection tools, data management and analysis/interpretation, report preparation and on knowledge translation and exchange (KTE) strategies.
- Must agree that it will strive to present a balanced portrait of HIV/AIDS issues in ACB communities. As such, the research team understands that it will review draft findings prior to submission for publication or presentation. The research team will strive to eliminate or mitigate any negative impact on ACB communities that may result from the research findings.
- Must acknowledge that the data and findings will remain the intellectual property of ACCHO and the other research partners.
- Must provide meaningful and appropriate research capacity-building for members of the ACB communities involved as research team members and/or as Community Advisory Committee (CAC) members.

Required components for an effective research partnership agreement:

- Project design, budget, timelines, assignment of responsibilities, dissemination strategy, and other components of the research set out in the proposal.
- Hiring of staff for the project and recognize that the supervision of project staff is the responsibility of the co-principal investigators.
- Responsibility of co-principal investigators for the project, even though the team will work collaboratively.
- Establishment and maintenance of a Community Advisory Committee, or equivalent body.
- Attendance at research team meetings.
- Collaboration on project activities.

- Collective ownership and sharing of research data among the partners.
- Acknowledgement of the contributions of all partners and team members.
- Respecting the confidentiality of all participants (i.e., interviewees and informants).
- Participation on the research team in a way that ensures healthy and beneficial relationships among the team, the project staff and Community Advisory Committee.
- Role of the co-PIs in addressing all concerns raised by team members with tact and understanding and in a timely fashion.
- Adherence to the following methods of communication among the team members:
 - Between team meetings, raise or discuss issues pertaining to the project and project staff with the co-principal investigators before communicating with the rest of the research team.
 - Communicate any personnel matters directly to the co-principal investigators.
 - Acknowledge the research participation and contribution of the remaining partners in publications that are not developed by all partners jointly.

ACCHO reserves the right to suspend research or terminate its involvement in the project when research activities are not being conducted in accordance with the aforementioned guidelines or core principles and values promoted by ACCHO.

ACCHO reserves the right to suspend research in any research activities if circumstances no longer allow for its continuation, or if research activities contravene the original agreement between ACCHO and the researchers involved.

5.2 Where ACCHO is engaged in a supporting role (as part of the research team, but not in a lead capacity), the research team:

- Must acknowledge and agree to support the principles of co-ownership, control, and access to the research data for projects supported by ACCHO.
- Must agree that research team members will collectively make decisions on research questions, data collection, interpreting results, drafting research reports and on the dissemination of findings.
- Must agree that it will strive to present a balanced portrait of HIV/AIDS issues in ACB communities. As such, the research team understands that they will be provided an opportunity to review draft findings prior to submission for publication or presentation. The research team will strive to manage any negative impact on ACB communities that may result from the draft research findings.

- Must acknowledge that the data and findings will remain the intellectual property of the research team lead(s), their respective organizations/associations and ACCHO.
- The research team agrees to provide meaningful and appropriate research capacity-building for members of the ACB communities involved as research team members and/or as CAC members.

Required components for an effective research partnership agreement:

- Project design, budget, timelines, assignment of responsibilities, dissemination strategy, and other components of the research set out in the proposal.
- Hiring of staff for the project and recognize that the supervision of project staff is the responsibility of the co-principal investigators.
- Responsibility of co-principal investigators for the project, even though the team will work collaboratively.
- Establishment and maintenance of a Community Advisory Committee, or equivalent body.
- Attendance at research team meetings.
- Collaboration on project activities.
- Collective ownership and sharing of research data among the partners.
- Acknowledgement of the contributions of all partners and team members.
- Respecting the confidentiality of all participants (i.e., interviewees and informants).
- Participation on the research team in a way that ensures healthy and beneficial relationships among the team, the project staff and Community Advisory Committee.
- Role of the co-PIs in addressing all concerns raised by team members with tact and understanding and in a timely fashion.
- Adherence to the following methods of communication among the team members:
 - Between team meetings, raise or discuss issues pertaining to the project and project staff with the co-principal investigators before communicating with the rest of the research team.
 - Communicate any personnel matters directly to the co-principal investigators.

- Acknowledge the research participation and contribution of the remaining partners in publications that are not developed by all partners jointly.

ACCHO reserves the right to terminate its involvement in the research team when research activities are not being conducted in accordance with the aforementioned guidelines or core principles and values promoted by ACCHO.

5.3 Where ACCHO is involved on a Community Advisory Committee (CAC):

ACCHO must serve as a link between the community and the research team. ACCHO is a knowledge resource on HIV/AIDS issues and ACB communities and will assist in providing a platform for the presentation and discussion of community issues and needs. Moreover, members of the CAC have the capacity to make recommendations for research undertakings and policy development. As community members, they also play a significant role in KTE strategies targeting ACB communities.

The Community Advisory Committee (CAC) will:

- Contribute to defining the research questions which will not only reflect academic interests but strive to ensure that the research is relevant and beneficial to ACB communities.
- Reflect the perspectives of the communities its members are representing. With the capacity to engage issues as their representatives, they will evaluate research protocols to assure that they honour and protect the values of the communities. Input on the ideas, concerns and needs will mirror those of the communities that the CAC represents.
- Contribute to the research project within a framework that acknowledges and respects ACB communities' rights to self-determination and autonomy including the right to make decisions on and play a role in research in their communities.
- Promote meaningful and equitable participation from ACB community members. The communities must be involved in the entire research process, from the formulation of research questions through to data collection, analysis and dissemination of research findings.
- Strive to present a balanced portrait of HIV/AIDS issues in ACB communities. As such, the research team understands that they will be providing an opportunity to the CAC to review draft findings prior to submission for publication or presentation. The research team will strive to manage any negative impact on ACB communities that may result from the draft research findings.

In addition:

- The research team agrees to provide meaningful and appropriate research capacity-building for members of the ACB communities involved as research team members and/or as CAC members.
- In dissemination strategies to ACB communities, the CAC will contribute in the negotiation and tailoring of research products, language and the manner of sharing, ensuring they are within acceptable and appropriate parameters.

- Members of the CAC will be co-owners in the knowledge produced from the research project.
- The CAC partnership agreement will include clauses on:
 - Attendance at CAC meetings.
 - Contribution in the development of the project design and other components of the research as outlined in the research proposal.
 - Provision of strong insider knowledge of ACB communities and advising the research team throughout the entire research process.
 - Collaboration on project activities.
 - Participation in developing knowledge dissemination strategies to ACB communities.
 - Participation in a way that ensures healthy and beneficial relationships among the CAC, the project staff and research team.
 - Respect and acknowledgement of the contributions of all partners and team members.

ACCHO reserves the right to terminate its involvement in the CAC when research activities are not being conducted in accordance with the aforementioned guidelines or core principles and values promoted by ACCHO.

5.4 Where ACCHO is providing a letter of support:

ACCHO is committed to supporting both burgeoning and established researchers working with ACB communities. ACCHO is not only open to the opportunity to provide a letter of support for research proposals, it is also keen to collaborate with the researchers in a consulting role throughout the research process.

The proposed research:

- Must incorporate the meaningful involvement of ACB communities ensuring that the research is beneficial and relevant to them. It must acknowledge and allow for ACB communities to make decisions in and play a role throughout the research process, fostering autonomy and self-determination.
- Must be reviewed and approved by ARC and assessed for adherence to ethical research principles, as stipulated in the [Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans 2010 \(TCPS 2\)](#).
- Must be led by a researcher with research interests aligned with the mandate and research principles of ACCHO and/or an affiliation with ACCHO.

- Must be led by a researcher committed to presenting an accurate portrayal of HIV/AIDS issues and ACB communities. ACCHO can facilitate this by advising throughout the research process in a consultative capacity on community-based research (CBR), KTE strategies and other pertinent issues.

Upon the provision of a letter of support, the researcher(s) will agree to provide ARC with quarterly updates on the progression of their research and to share their final research report.

To ensure that the findings of their research are brought back and made accessible to the community, the researcher(s) will commit to engaging in KTE with ACB communities.

In order for letters of support to be provided by ACCHO, researchers are expected to meet the following expectations:

- Provide ACCHO with a copy of the proposal along with the request for a letter of support.
- Give ACCHO a minimum of three (3) weeks' notice to allow for the review of the proposed research and the request for a letter of support to be considered/produced.
- Engage ACCHO to discuss the proposed research undertakings, get feedback.
- Collaborate with ACCHO throughout the research process or draw on them as a knowledge resource.
- Collaborate or consult with ACCHO on KTE strategies throughout the research process.

ACCHO reserves the right to terminate its support when research activities are not being conducted in accordance with the aforementioned guidelines or core principles and values promoted by ACCHO.