

PROCEEDINGS REPORT:
***En Avant:* Implementing an Impact-Focused
HIV/AIDS Research Strategy for African,
Caribbean and Black Communities in Ontario**

Presented by:
African and Caribbean Council on HIV/AIDS in Ontario
and
Ontario HIV Treatment Network



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EN AVANT WORKING GROUP MEMBERS

The *En Avant* Working Group was established by the ACCHO Research Committee and the following members collaborated to coordinate the workshop:

Henry Luyombya (co-Chair)
Hugues Loemba
LaRon Nelson (co-Chair)
Mbaka Wadham
Rupert Kaul
Shamara Baidoobonso

Sonia Gaudry
Tola Mbulaheni
Valérie Pierre-Pierre
Wangari Tharao
Winston Husbands

NOTE TAKERS

Desmond Miller
Joanita Nakamwa

Jude Tamale
Warren Clark

REPORT

This report was prepared by Michael Antwi on behalf of ACCHO and the OHTN.

BACKGROUND

En Avant: Implementing an Impact-Focused HIV/AIDS Research Strategy for African, Caribbean and Black Communities in Ontario is a long-term, strategic initiative being implemented by the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) in partnership with the Ontario HIV Treatment Network (OHTN) to advance HIV/AIDS research with African, Caribbean and Black (ACB) communities in Ontario. *En Avant* (French for 'Go Forward') is designed to accelerate the translation of impact-focused research ideas into action. This translation of ideas will be accomplished by identifying and engaging "champions" in research, who will lead studies that align with the *Ontario HIV/AIDS Strategy to 2025* (Ontario Strategy) and the [Ontario HIV/AIDS Strategy for ACB Communities 2013-2018](#) (ACB Strategy). The initiative will also engage a network of community, program and policy champions who together will strive to create program and policy environments that support success in ACB HIV research development, implementation and translation to practice.

En Avant targets three (3) broad research priority areas derived from the [3rd Ontario African, Caribbean and Black Research Think Tank](#) (Thank Tank), a one-and-a-half day event that sought to build a research agenda to enhance the response to HIV within ACB communities in Ontario through evidence-based approaches:

1. Research and evidence-based practices in HIV prevention, treatment and care
2. Clinical and immunological issues across the lifespan
3. Methodological innovations in HIV research

The ACCHO Research Committee established a working group to organize an action planning workshop that would facilitate the development of research in these priority areas.

ACTION PLANNING WORKSHOP

Objective

Pursuant to the goals of *En Avant*, on October 29, 2015 ACCHO in collaboration with the OHTN held an action planning workshop at the OHTN. The objective of the workshop was to engage champions in developing action steps that will accelerate ACB HIV research productivity in Ontario. Ultimately, the workshop sought to produce 6-9 action-oriented, impact-focused research concepts that will further be developed into research proposals to be submitted to funding agencies. Through a combination of presentations, discussions and breakout-sessions, the workshop encouraged participants to outline a plan for how they will work together to move these action steps forward.

Participants

The workshop attracted a broad spectrum of participants from across the province. Participants included academic researchers, students, AIDS service organization (ASO) workers, policymakers and persons living with HIV. In total 58 individuals, representing 32 organizations were in attendance (for a full list of participants, see Appendix 2).

Event Program

Please see Appendix 1 for the workshop agenda.

Workshop Welcome

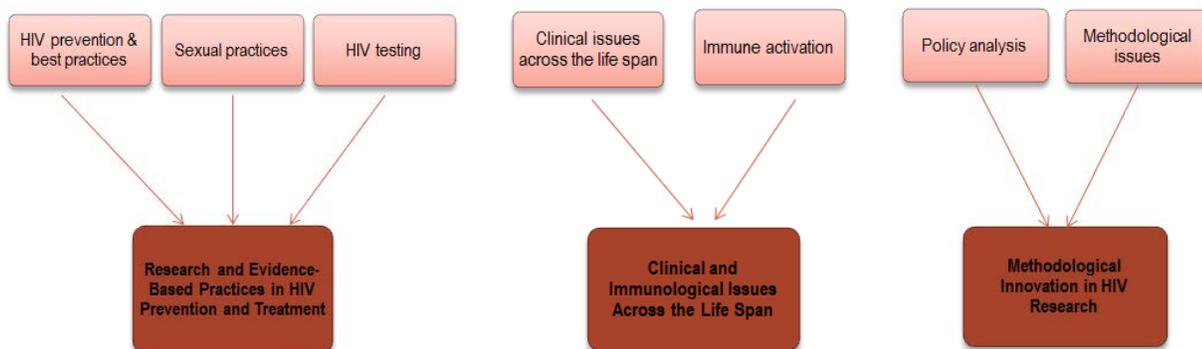
The workshop began with an official welcome by the Working Group co-Chairs, Dr. LaRon Nelson and Henry Luyombya. In their opening remarks, they emphasized that the event intended to foster knowledge exchange on how individuals and organizations can champion HIV/AIDS research in ACB communities. This could be accomplished by creating partnerships or “synergies” and creating concepts and research proposals that can be submitted for funding.

Additional opening remarks were provided by ACCHO Director, Valérie Pierre-Pierre, and Director of Applied Epidemiology at OHTN, Dr. Mark Gilbert. Valérie re-emphasized the importance of developing collaborative research proposals aligning with the research priorities identified in the Research Think Tank coordinated by ACCHO. Dr. Gilbert closed the opening welcome by thanking all participants on behalf of the OHTN.

Review of Prioritization Process

In order to set the context of the event, Tola Mbulaheni, the ACCHO Research Coordinator, provided an overview of the process to prioritize broad research areas that preceded the workshop. The research prioritization process officially began in December 2012 when ACCHO held its 3rd Ontario African, Caribbean and Black Research Think Tank (Think Tank). The Think Tank was a one-and-a-half day event that sought to build a research agenda to enhance the response to HIV within ACB communities in Ontario through evidence-based approaches. This event gathered approximately 30 diverse stakeholders including researchers, service providers, community members, as well as government representatives.

The objectives of Think Tank were met through a series of presentations and small group discussions that generated a list of thematic priorities. The themes were later reviewed by the ACCHO Research Committee and refined into a list of eight (8) priority research themes, six (6) of which were voted to be top priorities. In order to ensure that these priorities resonated with key stakeholders and community members, particularly people living with HIV/AIDS (PHAs) who were unable to attend the Think Tank, a validation process was undertaken. The validation process incorporated input from 62 additional stakeholders through a combination of group discussions and online surveys. These stakeholders were asked to review and confirm the importance of the identified research priority areas. All eight (8) priorities were validated with HIV testing being identified as a top priority. The *En Avant* Working Group decided to collapse the priorities into three (3) broad research priority areas forming the basis of discussion for the action planning workshop:



Stigma was also identified as a research priority. However, the Working Group felt that stigma cut across all research areas and therefore decided to integrate it into all research priority areas.

Priority Areas Overview Presentations

The priority areas overview presentations were prepared and delivered by Ciann L. Wilson, Assistant Professor at Wilfrid Laurier University and PhD Candidate at York University, Dr. Rupert Kaul, Professor at the University of Toronto, Lori Chambers, PhD Candidate at McMaster University and Dr. Lawrence Mbuagbaw, Assistant Professor at McMaster University. As Dr. Mbuagbaw was unable to attend the workshop, Lori Chambers presented on his behalf.

Research and Evidence-Based Practices in HIV Prevention, Treatment and Care – Ciann L. Wilson

Evidence-based practice (EBP) refers to the integration of the best available research evidence, expertise and client values into direct practice for optimal service provision. In practice, EBP requires the identification of an issue to be resolved, a search and critical appraisal of relevant available information, and ultimately using this information to inform decisions about next steps. During the search and appraisal stage, biomedical researchers employ a research evidence hierarchy that places greater reliance on certain forms of research evidence over others. For instance, this hierarchy suggests that systematic reviews and randomized control trials (RCTs) are the most robust forms of evidence, whereas anecdotal evidence is among the least robust. As such, systematic reviews have become the cornerstone of EBP, especially reviews of RCTs.

The use of systematic reviews and RCTs to inform EBP presents many challenges, especially for HIV research with ACB communities:

1. The literature that the majority of EBP research is based on does not take into consideration evidence that points to the social determinants of health, as well as to systemic, colonial and structural issues, which are important contextual factors for health outcomes of ACB communities in Ontario and Canada.
2. Not all research questions can be answered using RCTs due to practical and ethical reasons.
3. Qualitative methods, which are commonly used in research with ACB communities, do not fit within the frameworks offered by conventional systematic review methodology (e.g., they employ study designs such as focus groups and interviews that rank low on the research evidence hierarchy).

In addition to these research challenges, some organizations struggle to incorporate research findings into their programs due to a lack of research training among practitioners and the researchers' inability to translate their findings into practical information. Perhaps due to these challenges, there is little evidence to suggest that EBP informs programs and services for ACB people living with and affected by HIV/AIDS.

In order to improve uptake of EBP in programs and services for ACB communities, there needs to be greater capacity to deliver evidence-based interventions. This can be accomplished by:

1. Conducting more research using theories and frameworks that inform intervention development.
2. Evaluating interventions using robust methods.

3. Building capacity to deliver evidence-based interventions by providing training and resources to support service providers.

The presentation outlined current exemplars of HIV research to inform EBP in ACB communities. This included the Black Coalition for AIDS Prevention 3MV (Many Men, Many Voices) intervention; the collaborative Black Pastors Raising Awareness & Insights of Stigma through Engagement (Black PRAISE) intervention study; Women's Health in Women's Hands (WHIWH) is leading the Women Involved in Life Learning from Other Women (WiLLOW) intervention study; and other new research in development to strengthen EBP with ACB communities.

Clinical and Immunological Issues across the Lifespan – Dr. Rupert Kaul

Researchers believe there are clinical issues that may have differential outcomes within general populations of PHAs and among ACB PHAs. These issues can be grouped into three (3) broad categories: (1) retention in care, (2) ACB-specific health issues, and (3) inflammation and HIV transmission.

Results from the OHTN Cohort Study¹ suggest that heterosexual ACB men and youth experience challenges accessing treatment and care. While the need to improve HIV treatment and care is not unique to ACB heterosexual men, they represent a large proportion of the ACB people living with and affected by HIV/AIDS. Moreover, there may be cultural issues that need exploration in order to better improve the delivery of treatment and care to this population. Youth transitioning to adulthood also face challenges accessing treatment and care as they outgrow pediatric care and transition into adult care. These challenges need to be better understood in order to be addressed.

ACB PHAs may have clinical issues that are different from those of non-ACB PHAs. These issues involve vertical transmission or mother-to-child transmission (MTCT), co-morbidities and pre-exposure prophylaxis (PrEP). Regarding MTCT, more research is needed to understand the knowledge, attitudes, practices and beliefs of ACB people. Further, a better understanding of the implications of viral reservoirs and early treatment in babies in relation to transmission of the virus is also needed.

Co-morbidities occur when there is a presence of two (2) or more chronic diseases at once. Moreover there are certain clinical issues that disproportionately affect ACB communities. Research should explore any heightened challenges that co-morbidities present to ACB communities, from youth to adulthood and old age. Such co-morbidities include: HIV coupled with hypertension, kidney disease, bone disease caused by Vitamin D deficiency, diabetes, herpes, hepatitis B and hepatitis C.

Pre-exposure Prophylaxis (PrEP) may also have differential impacts on ACB communities and this should be further investigated.

¹ The OHTN Cohort Study (OCS) is a community-governed, scientifically rigorous research initiative, designed to improve the health and well-being of people living with HIV in Ontario by promoting and supporting scientific, community-based and policy-relevant research. The OCS is a multi-site research study that collects clinical and socio-behavioural data on a cohort of participants living with HIV over time. The mission of the OCS is to develop, support and sustain a unique research database and cohort, governed by people living with HIV in Ontario and used in partnership by scientists, community-based researchers and other stakeholders.

<http://ohtncohortstudy.ca/index.php>

Inflammation plays a key role in HIV transmission, replication and immune activation. In addition, inflammation also increases with age and heightens susceptibility to chronic conditions including cardiovascular disease. This dual role presents unique challenges to PHAs as they age. ACB PHAs are particularly impacted by this due to their increased risk of cardiovascular disease and other chronic diseases. Understanding the inflammation profile of ACB communities (including PHAs and non-PHAs) versus non-ACB communities across different age groups could be key to understanding HIV risk, effectiveness of treatment and long term effects of HIV in ACB people. Moreover, understanding the profile of the gut and genital microbiome – naturally occurring microorganisms that protect against infection – may also provide insights on the inflammation process in ACB communities.

Methodological Innovations in HIV Research (Quantitative and Qualitative) – Lori Chambers & Lawrence Mbuagbaw

Reviews of current quantitative HIV research all suggest the need for more HIV clinical trials to address methodological limitations of current studies. A large portion of current HIV research is conducted in high prevalence countries such as South Africa, Kenya, Uganda and Zimbabwe. However, not all high prevalence countries are represented in current research. Countries that require greater attention include Swaziland, Botswana and Mozambique.

Current knowledge gaps and challenges with quantitative research that require more attention include: vulnerable populations, with special emphasis on young people (i.e., infants, children and adolescents), duration of research studies (i.e., studies that follow participants for greater lengths of time), pragmatic interventions (i.e., those that take into account the social and environmental circumstances of communities), and economic evaluations (to better understand feasibility of interventions). Quantitative research provides important information that can be used to inform policies and programs. However, qualitative research is also important for greater appreciation of the experiences of people living with and affected by HIV/AIDS. While there is an appreciation for qualitative research by some quantitative researchers, these researchers represent a small percentage of the research community.

Qualitative research methodologies for ACB communities have been in use in the global south as well as within Indigenous and ACB communities for many years. These methodologies are grounded in the ways ACB communities communicate with one another and share knowledge. Due to this grounding, qualitative methodologies are more culturally-responsive to the needs of ACB communities. Methodologies such as Indigenous/Diasporic knowing, anti/de/"post"-colonial thought, community-based research, participatory action research and arts-informed research all employ a culturally-responsive approach. This research approach acknowledges that research is deeply intertwined with people's social worlds and therefore has political and ideological implications. Culturally-responsive methodologies that are innovative can be grouped as follows:

1. Performance-based Knowing Practices: These are experiential approaches that place all participants (researcher, participants, performer and audience) actively within the setting being interpreted. It involves hands-on participation with the audience that fosters connection, reflection and interaction. Examples of these practices include verbatim theatre, which uses narratives from qualitative interviews to develop plays of real life stories to raise awareness on issues experienced by a particular community, and theatre of the oppressed, which allows people who have lived experience with a topic to become the producer of theatrical pieces that actively engage audience members in dialogue with performers.

2. Visual-based Knowing Practices: These approaches integrate the visual arts within data collection, analysis and knowledge translation and exchange (KTE). Examples include photo-voice, which is a process by which people can identify, represent and enhance their community through photography, and cellphilm, which uses cell phone video footage, often with no editing, to convey a message.
3. Storytelling/Narrative Knowing Practices: These approaches are grounded in everyday practices of remembering, relaying and sharing personal and collective experiences. These approaches also allow for multiple modes of expression (textual, oral and visual through metaphor, emotions, social media, poetry, and graphic and/or literary novels). Examples include digital storytelling, which employs a digital medium (e.g., audio, video podcast, etc.) to share a personal narrative, and talking circles, which employ a social discourse between individuals in which every individual is given an opportunity to speak to communicate a message.
4. Cultural Reclamation/ Memory Work Projects: These approaches employ analysis of written memories of people in order to understand an experience. Examples include oral histories, which develop first-hand accounts specific experiences through narrative approaches and memory boxes, which facilitate the retrieval of memory and encourage one's own narrative by creating a box that stores memorable items of certain experiences.

Please see Appendix 3 for additional examples of each practice as well as a list of projects currently employing these practices.

Research Development Format

After the priority areas overview presentations, participants were separated into three (3) groups. Each group was tasked with discussing and developing research proposals and action steps that will accelerate ACB HIV research productivity in Ontario in each of the research priority areas.

Each group was encouraged to discuss the priority area in depth and to develop one or more research concepts that could be further developed into funding proposals (please see Appendix 4 for research concept outlines). Five (5) cross-cutting issues were presented to all participants for consideration as they discussed their respective priority area:

1. Stigma and discrimination [one of the original research priorities that was integrated into each of the three (3) revised priority areas]
2. Social determinants of health
3. Systemic or institutional policies
4. GIPA/MIPA and social justice
5. Capacity building

Note takers were selected by each group to ensure that the information and ideas were documented. Groups were given over four (4) hours for discussion (with lunch and a break interspersed in this time). Groups then selected a presenter to report the main points of their discussions and resulting research concepts to all workshop participants.

In addition to the information captured in the three (3) priority area presentations, participants were encouraged to also consider HIV cure, effects of menopause when living with HIV and

sexual dysfunction as an adverse effect of medication, as additional areas of potential research. These issues were identified as research priorities at the Optimizing Research Uptake and Participation amongst African, Caribbean and Black People Living with HIV/AIDS in Ontario: Knowledge Translation and Exchange (KTE) Forum, a KTE event coordinated by ACCHO and WHIWH that allows PHAs to engage with researchers on past research outcomes and future research topics.

Research Concept Development – Research and Evidence-Based Practices in HIV Prevention, Treatment and Care

The breakout group in priority area 1, Research and EBP in HIV Prevention, Treatment and Care, discussed many key issues that merit research. These included HIV testing, mental health, family planning, harm reduction, PrEP and knowledge networks. After discussing the merits of each issue the group narrowed their focus to three (3):

1. **HIV testing** presents an issue for ACB communities due to existing barriers. Current research suggests that ACB people have low testing rates. Part of the issue is that ACB people experience challenges identifying with the health care settings and health workers that typically administer tests. Identifying best practices for how health workers can make testing more accessible for ACB communities is a needed area of research (see Appendix 5). Factors such as individual barriers, clinic environmental factors, transportation and/or physical accessibility of testing sites and gender sensitivities to testing need to be considered in order to make testing more acceptable and accessible for ACB communities. Known practices that may have potential in the ACB community include home-based testing and anonymous testing.
2. HIV can have stark effects on **mental health**. Furthermore, participants believe that the added mental health impacts of racialization, minority stress and trauma places ACB PHAs in an especially challenging situation. Research is needed to understand and address mental health issues in ACB communities in relation to HIV. Areas of intersection between HIV and mental health that require research attention include whether HIV/AIDS service providers inquire about the mental health of service users, how to deal with people who may have experienced trauma (i.e., trauma-informed care), assessing mental health (i.e., quality indicators of mental health), and barriers to mental health service (see Appendix 6 for research concept sheets).
3. **Harm reduction** presents many challenges to ACB communities. There appears to be a lack of knowledge on how substance use and harm reduction manifests within ACB communities. This lack of understanding is dangerous because substance use increases the likelihood of HIV infection and co-morbidity with hepatitis C. Participants suggested that what is currently known is that there are changes in the substance use patterns of ACB communities. Marijuana used to be the most commonly used drug in the community. However, as of late, service providers have noticed an increase in party drug usage (i.e., crystal methamphetamine or crystal meth, MDMA or 3,4-methylenedioxymethamphetamine, GHB or gamma hydroxybutyrate and ketamine). Research is needed to review how people define substance use and harm reduction, as well as the efficacy of harm reduction practices (see Appendix 7).

Although research concepts were not developed for family planning, PrEP and knowledge networks, this group recognized the importance of each of these areas. Family planning and parenting for male ACB PHAs and sero-discordant couples are underexplored areas of

research. Participants suggested that knowledge of PrEP is higher among some ACB community members. For instance, gay and bisexual men are said to have low levels of knowledge and experience difficulties accessing PrEP. Research is necessary to better understand knowledge and practices around PrEP and how to effectively promote knowledge.

Knowledge networks are important for developing EBP guidelines. There are currently many great research projects under way in the ACB community. However, there is a need for a knowledge network, which could include a knowledge database, to provide information on all ongoing projects and to facilitate the translation of knowledge.

Other issues that were discussed by this group include the importance of culturally appropriate therapeutic techniques, needs of the ACB Trans community and support for PHAs working or volunteering in the HIV sector.

Research Concept Development – Clinical and Immunological Issues across the Lifespan

The breakout group on priority area 2, Clinical and Immunological Issues across the Lifespan, discussed many key issues that merit research. These included comorbidity, youth, inflammation and aging or ‘inflammaging’, perinatal transmission and more specifically infant feeding, microbiome, PrEP, community-specific supplements infant reservoir care, immigration and care and heterosexual men and care. After discussing the merits of each issue the group narrowed their focus to three (3):

1. Participants suggested that when it comes to **co-morbidities**, several chronic diseases, including diabetes, cancer, vitamin D deficiency, neurocognitive disorders, hypertension and other cardiovascular diseases, are known to be more common in ACB communities. Although these diseases are commonly associated with adult populations, these conditions are often relevant in ACB youth as well. Unfortunately, not much data are currently being collected on youth. Therefore more research is needed on co-morbidities as they relate to ACB communities in general, and to ACB youth more specifically. Fortunately, co-morbidities can easily be incorporated in the *Profile of African, Caribbean and Black (ACB) People in HIV care in Ontario* study that is currently being led by Wangari Tharao and others. Participants decided that follow up is needed to see what incorporating this will require. As a result, a concept was not developed for this issue.
2. **HIV research on youth** is currently lacking. In addition to co-morbidities, youth face unique challenges as they transition from pediatric care to adult care. These challenges need further exploration. Participants suggested that as the majority of youth living with HIV are ACB, special consideration needs to be made of the intersections of HIV and mental health and the social determinants of health as they relate to ACB youth (see Appendix 8).
3. Research suggests that inflammation may increase the risk of HIV transmission. More research on the effects of inflammation and HIV is needed to better illustrate this relationship. Moreover, participants suggested that inflammation tends to increase with age, and that some research from the United States suggests that African American women have higher levels of inflammation. As such, research on the implications of ‘inflammaging’ and HIV pertaining to ACB people, and specifically women, is needed (see Appendix 9).

Although research concepts were not developed for infant feeding, immigrants and heterosexual ACB men, participants recognized the importance of each of these areas. With regard to infant feeding, the risks involved with breastfeeding and the needs and challenges of new mothers who are HIV-positive need investigation. Accessibility of PrEP to ACB communities is an area that requires additional research. There is currently a study of PrEP being led by Dr. Darrell Tan entitled *Exploring the Acceptability and Feasibility of New HIV Prevention Technologies for African, Caribbean and Black Populations in Toronto*. Communicating with Dr. Tan and requesting him to expand his Toronto study to include Ottawa, in addition to incorporating development of PrEP guidelines for ACB people may further highlight this understudied area.

New immigrants often experience challenges navigating their new social environment. Many are unaware of the healthcare services that are available to them in their new communities. A research study on the accessibility and retention to care of new immigrants should be initiated. Also, possible human rights violations during the immigration process may cause stress to new immigrants which could impair their health.

Heterosexual ACB men are also not being adequately engaged by the HIV sector although some of them are at risk of acquiring or currently living with HIV. A better understanding of the barriers to care for this population is needed. Lastly, the role of community-specific supplements such as those derived from Moringa may shed light on alternate therapies.

Research Concept Development – Methodological Innovations in HIV Research

Methodological Innovations in HIV research consider the expansion of the repertoire of methodologies used in health research. While different research questions require different methodologies, too often some research methods are prioritized over others. It is important to appreciate the effectiveness of various methodologies in different contexts and communities. Researchers working with ACB communities have a rich history of conducting impactful research that addresses the complex challenges faced by this community. This breakout group discussed how researchers with experience working with ACB communities can help expand what the broader research community deems to be strong research evidence.

This breakout group discussed many key issues that merit research. These included research ownership, control, access and possession (OCAP), research uptake, data storage, research evidence, disclosure, greater engagement of community members, and the social determinants of health.

Discussions on research methodologies transcended the methods used for data collection and included all aspects of research, spanning from the conception of a research project to the impact it has on the community. Problems with self-determination, as expressed by participants, arise from the onset of the research process. Storytelling and narratives are mediums that ACB people feel comfortable using to convey their experiences. Due to this, many ACB researchers employ qualitative methods that allow research participants to convey their messages in the manner they are most comfortable. However, challenges arise when these researchers apply for funding. Research funding bodies and peer review committees often have preconceived, “acceptable” forms of research they prefer to fund. These “acceptable” forms are generally quantitative in nature. As a result, ACB “oral histories” and other qualitative research methods have limited chances of receiving funding. This funding bias demonstrates how racism emerges in academic research. To make matters worse, researchers interested in understanding and addressing racism in research and in relation to

health and wellbeing struggle to receive funding because their research is not considered “impactful”.

Beyond the challenges faced by ACB researchers in their attempts to produce research that empowers ACB communities, community members also experience challenges with research. Very often, research conducted in ACB communities, by both ACB and non-ACB researchers, fails to produce tangible benefits. In many cases, researchers neglect the nuances of ACB communities’ stories by condensing their histories and experiences into short, bullet-point presentations at research conferences. However, much of this is due to restrictions placed on researchers that prevent them from providing much depth on their findings. Due to these and other limitations placed on researchers, research should rather be disseminated to ACB community members and the general public through innovative ways. The usual paradigm of conducting research for publication and conference presentations does not meet the needs of researchers and ACB communities. Communication of findings should be multilingual and incorporate multi-media platforms that are effective with community members and provide researchers more flexibility to present their findings.

The group narrowed their focus to three (3) areas:

1. Based on the complex challenges that ACB researchers and community members face, an investigation should be conducted on the **uptake of research** studies five (5) years after their completion. This project would assess how many studies have actually had an impact on ACB communities (see Appendix 10).
2. Also, a set of principles, similar to the principles of **Ownership, Control, Access and Possession** (OCAP) for First Nations communities, that allow the community to own, protect and control the data collection process and how information is used, needs to be developed (see Appendix 11). These principles would outline the data collection methods deemed effective by ACB researchers and community members as well as ensure accountability and integrity in the research that is being done “on behalf/in the interest of” ACB communities, including PHAs.
3. Also discussed was conducting a knowledge synthesis of current methodologies employed with ACB communities. This research would seek to critically understand what constitutes **research “evidence”**, how different research methodologies may expand how research becomes “effective” for ACB communities, and how we may reframe what is understood as “implementation science” (see Appendix 12 for research concept sheet). This research could also inform a special edition of a journal on methodological issues in research with ACB communities.

Several other ideas were discussed by the group. One was creating a searchable database of current ACB research that will avoid redundancy and make research findings more accessible to service providers. Moreover, an effort that may increase the likelihood of funding for ACB communities is to seek representation on peer review committees and to ensure that proposals are submitted to the correct funding agencies. ACB researchers may enjoy greater funding success if they modify their proposals and apply to a range of funders.

The final topics discussed were HIV disclosure, greater engagement of community members, and the social determinants of health. Participants emphasized the importance of using oral history approaches to conduct research with ACB people and disclosure without reference to criminalization. ACB people need to be able to tell their stories of when and how they chose

to disclose in order to empower those who are looking to disclose. Moreover, in all research conducted there should be greater engagement of PHAs and all ACB communities, especially Francophone communities. Francophone communities are sometimes neglected in the research process due to the preponderance of Anglophone researchers and community members. Lastly, the social determinants of health and racism in particular have important impacts on the lives of ACB people. Therefore research needs to be conducted to better measure the effects of this determinant of health on ACB people.

Action Steps for Moving Research Concepts Forward

Participants were asked what steps were necessary to move research concepts forward and what practical role can ACCHO play. Participants suggested that the most important action step is to follow through. All participants, including researchers, service providers and community members need to work together to ensure the research concepts developed at the workshop are developed into full proposals and submitted for funding. In all endeavours accountability and integrity are paramount to ensuring research meets the needs of community members. In addition to this, there are three (3) key actions that participants believed will increase the success of ACB HIV research:

1. **Peer review committee representation:** Funding is a critical component of research. Peer review committees that are tasked with reviewing research proposals for funding therefore exert a great deal of power and influence over the types of research projects that receive funding. It is crucial that ACB researchers are represented on these committees in order to ensure the interests of ACB communities are expressed. Not only do these committees look for academic representation, but they also seek community representation.
2. **Incorporate secondary proposals into existing research:** In the absence of peer review committee representation, some of the secondary research ideas put forth at the action planning workshop (those that were not presented as stand-alone research ideas requiring funding) can be incorporated into existing research studies. This is an immediate way to begin implementing some of these research ideas.
3. **Encourage colleagues to take up ideas:** Some research ideas proposed at the workshop do not fall under the research domains or interests of workshop participants. It is crucial that participants encourage their colleagues who have the capacity and interest to conduct research in certain areas to develop research proposals and apply for funding. Each funding body has its domain of research for which it provides funding. In order to increase likelihood of funding, applicants would need to ensure that their research proposals are submitted to the appropriate funding body.

The *En Avant* Working Group will meet to discuss how ACCHO can support next steps, and also to organize follow-up meetings to facilitate progress on research proposal development and implementation. Moreover they may engage additional stakeholders, based on the action steps identified and the diversity of knowledge, skills and experience needed to move the research forward.

APPENDIX 1: Event Program



En Avant:

Implementing an Impact-Focused HIV/AIDS Research Strategy for African, Caribbean and Black Communities in Ontario

Ontario HIV Treatment Network (OHTN), 1300 Yonge Street, Toronto, ON M4T 1X3
October 29, 2015

Agenda

- 8:30am** **Breakfast & Registration**
- 9:00am** Welcome
Henry Luyombya, Co-Chair, *En Avant*
AIDS Committee of Toronto
Valérie Pierre-Pierre, Director
African Caribbean Council on HIV/AIDS in Ontario (ACCHO)
Mark Gilbert - Director, Applied Epidemiology
Ontario HIV Treatment Network
- 9:15am** Review of Prioritization Process
Tola Mbulaheni, ACCHO
- 9:25am** Priority Areas Overview Presentations
Ciann L. Wilson, Wilfrid Laurier University
Research and Evidence-Based Practices in HIV Prevention and Care
Rupert Kaul, University of Toronto
Clinical and Immunological Issues across the Lifespan
Lawrence Mbuagbaw, McMaster University
Methodological Innovations in HIV Research – Quantitative
Lori Chambers, McMaster University
Methodological Innovations in HIV Research – Qualitative
- 10:00am** Research Development Format
Wangari Tharao, Women's Health in Women's Hands
Chair, ACCHO Research Committee
- 10:30am** **Break**
- 10:40am** Research Concept Development
- 12:00pm** **Lunch Break (*working lunch thereafter*)**
- 12:30pm** Research Concept Development – continued...
- 2:30pm** **Break**
- 2:45pm** Research concept presentations
- 3:45pm** Action Steps for Moving Research Concepts Forward
- 4:15pm** Closing Remarks
LaRon Nelson, co-Chair, *En Avant*
University of Rochester

APPENDIX 2: Participant List

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation(s)</u>
Alexander	Asamoah	Peel HIV/AIDS Network (PHAN)
Barbara	Fowler	Peel Health Department
Barry	Adam	Ontario HIV Treatment Network (OHTN)/University of Windsor
Carmen	Logie	University of Toronto
Charu	Kaushic	McMaster University
Ciann	Wilson	Wilfred Laurier University
Clemon	George	University of Ontario Institute of Technology (UOIT)
Constance	Scott	Walden University
Desmond	Miller	Ryerson University
Edna	Aryee	Toronto
Eleanor	Maticka-Tyndale	University of Windsor
Eno	Akan-Essien	AIDS Committee of Ottawa (ACO)
Francisca	Omorodion	University of Windsor
Gladys	Kwaramba	Toronto
Haoua	Inoua	AIDS Committee of Ottawa (ACO)
Henry	Luyombya	AIDS Committee of Toronto (ACT)
Hugues	Loemba	University of Ottawa
Isaac	Luginaah	Western University
James	Murray	Ministry of Health and Long-Term Care, AIDS Bureau
Joanita	Nakamwa	St. Michael's Hospital
Joseph	Nguemo Djiometio	Toronto
Josephine	Wong	Ryerson University
Jude	Tamale	St. Michael's Hospital
Judith	Odhiambo	Committee for Accessible AIDS Treatment (CAAT)
Lance	McCready	University of Toronto
LaRon	Nelson	University of Rochester - Center for AIDS Research
Lori	Chambers	McMaster University
Lori	Lyons	Ontario HIV Treatment Network (OHTN)
Lydia	Makoroka	Ontario HIV Treatment Network (OHTN)
Lynne	Leonard	University of Ottawa
Mark	Gilbert	Ontario HIV Treatment Network (OHTN)
Marvelous	Muchenje-Marisa	Women's Health in Women's Hands Community Health Centre (WHIWH)
Maureen	Owino	Committee for Accessible AIDS Treatment (CAAT)
Mbaka	Wadham	Regional HIV/AIDS Connection (RHAC)
Mercy	Gichuki	Women's Health in Women's Hands Community Health Centre
Michael	Antwi	Centre for Addiction and Mental Health
Michelle	Sumner-Williams	African and Caribbean Council on HIV/AIDS in Ontario

Mona	Loutfy	Women's College Hospital/Maple Leaf Clinic
Nakia	Lee-Foon	University of Toronto
Nomusa	Mngoma	Queen's University
Paul	Mkandawire	Carlton University
Roberta	Timothy	Continuing Healing Consultants
Rupert	Kaul	University of Toronto
Ruth	Cameron	AIDS Committee of Cambridge, Kitchener, Waterloo & Area (ACCKWA)
Sarah	Flicker	York University
Shamara	Baidoobonso	Ontario HIV Treatment Network (OHTN)
Shannon	Ryan	Black Coalition for AIDS Prevention (Black CAP)
Sonia	Gaudry	Ontario HIV Treatment Network (OHTN)
Soraya	Blot	African and Caribbean Council on HIV/AIDS in Ontario
Stan	Read	Sick Kids' Hospital
Tola	Mbulaheni	African and Caribbean Council on HIV/AIDS in Ontario
Trevor	Hart	Ryerson University
Valérie	Pierre-Pierre	African and Caribbean Council on HIV/AIDS in Ontario
Wangari	Tharao	Women's Health in Women's Hands
Warren	Clarke	Toronto
Wesley Jordan	Oakes	Africans in Partnership Against AIDS (APAA)
Winnie	Murombedzi	Positive Living Niagara
Winston	Husbands	AIDS Committee of Toronto (ACT)

APPENDIX 3: Qualitative Research Methodologies

Qualitative Methodology Group	Examples and Current Research
Performance-Based Knowing Practices	<ul style="list-style-type: none"> • Examples: <ul style="list-style-type: none"> ◦ Performance/Collaborative Ethnography ◦ Verbatim Theatre ◦ Theatre of the Oppressed • Verbatim Theatre <ul style="list-style-type: none"> ◦ David Lewis-Pearl (in collaboration with Project: Humanity and Black CAP): Young, Gifted and Black: (Re)telling Stories of Survival and Thrival for Young Black Men (2012) (using performance ethnography) ◦ Project: Humanity: The Middle Place (2009-2011) (using collaborative ethnography) http://www.projecthumanity.ca/ • The Process and Collaboration for Empowerment and Discussion (PACED) approach (based on Theatre of the Oppressed model) <ul style="list-style-type: none"> ◦ Ghana: <i>Asetena Pa</i> Concert Party project (Boneh, 2011) ◦ Malawi: <i>This is My Story</i> (Jaganath, 2014)
Visual-Based Knowing Practices	<ul style="list-style-type: none"> • Examples <ul style="list-style-type: none"> ◦ Photovoice ◦ Participatory Video ◦ Body Mapping ◦ Cellphilms ◦ Collage • Relebohile Moletsane (University of Kwazulu-Natal) Naydene De Lange (Nelson Mandela Metropolitan University) & Claudia Mitchell (McGill University) <ul style="list-style-type: none"> ◦ What Can a Teacher Do With a Cellphone? (Cellphilms) (Mitchell, & De Lange, 2013). ◦ What Can a Woman Do With a Camera? (Photovoice) (Moletsane et al., 2009) ◦ Fire + Hope (Participatory Video) (Mitchell & De Lange, 2011). • Africans in Partnership Against AIDS (APAA), the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) and the AIDS Committee of Toronto (ACT) with support from The CIHR Social Research Centre in HIV Prevention (SRC) <ul style="list-style-type: none"> ◦ The Test (Participatory Video)
Storytelling/Narrative Knowing Practices	<ul style="list-style-type: none"> • Examples: <ul style="list-style-type: none"> ◦ Digital Storytelling ◦ Graphic Narrative (e.g., e-zines) ◦ Composite Storytelling ◦ Talking Circles ◦ Creative Non-fiction ◦ Poetic Narrative Inquiry (e.g., data poems) ◦ Counterstorytelling ◦ Composite Storytelling

	<ul style="list-style-type: none"> • WHIWH/WCRI <ul style="list-style-type: none"> ◦ Women CBR Project: (Digital storytelling as KTE and stigma intervention) • Ciann Wilson <ul style="list-style-type: none"> ◦ Let's Talk about Sex (talking circles, photovoice, interviews)^o Women in Health Working Towards Health (digital storytelling) ◦ Sex and YOUth project (digital storytelling)^o Beyond the Colonial Divide (talking circles, mural making) • Lori Chambers <ul style="list-style-type: none"> ◦ Because She Cares (oral narrative interviews, creative non-fiction/poetry) • ASAAP <ul style="list-style-type: none"> ◦ More than Fiction (creative non-fiction, photovoice) http://www.catie.ca/en/resources/more-fiction-poz-women-share-their-stories ◦ Storytelling for Sexual Health (storytelling as sexual health education intervention)
<p>Cultural Reclamation/Memory Work Projects</p>	<ul style="list-style-type: none"> • Examples: <ul style="list-style-type: none"> ◦ Oral Histories ◦ Memory Boxes ◦ Quilting • African American AIDS Activism (oral history) https://afamaidsoralhistory.wordpress.com/ • The Sinomlando Centre for Oral History and Memory Work (oral history; memory boxes) http://sinomlando.ukzn.ac.za/

APPENDIX 4: Research Proposal Template

Priority Area	
Title	
Problem	
Purpose	
Primary objective(s)	
Secondary objective(s)	
Design	
Population	
Study size	
Setting	
Study regimen	
Intervention	
Study duration	
Community collaborators	
Scientific collaborators	

APPENDIX 5: Research and Evidence-Based Practices in HIV Prevention, Treatment and Care – HIV Testing

Area	Research and Evidence-Based Practices in HIV Prevention, Treatment and Care.
Title	TBD
Problem	Low levels of HIV testing noted in ACB community.
Purpose	Promotion of HIV testing.
Primary objective(s)	Utilize research findings to increase the acceptability of HIV testing.
Secondary objective(s)	Identify Barriers to testing and developing a model from the findings applicable to a particular context/group/environment.
Design	<p>Focus groups with the ACB population and service providers in 5 sites using a set of validated questions.</p> <p>Formative research will be conducted to develop an intervention.</p> <p>Need to do a sample survey about sites for testing in the different locations all over Canada and make a comparison e.g. testing sites in Toronto in relations to those in Ottawa, Montreal, Windsor.</p>
Population	ACB adults 16+, men and women, heterosexual.
Study size	To be determined after data on ACB population is known.
Setting	Toronto, Peel region, Windsor, Ottawa, London.
Study regimen	TBD
Intervention	Recruiting more people for HIV testing. Will be based on research and literature review of what has been done elsewhere.
Study duration	4-5 years.
Community collaborators	ACCHO, service providers at ASOs, AIDS Bureau.
Scientific collaborators	TBD

APPENDIX 6: Research and Evidence-Based Practices in HIV Prevention, Treatment and Care – Mental Health

Area	Research and Evidence-Based Practices in HIV Prevention, Treatment and Care.
Title	TBD
Problem	HIV can have effects on mental health. The added mental health impacts of racialization, minority stress and trauma places ACB PHAs in an especially challenging situation.
Purpose	Promote the mental health well-being in ACB communities.
Primary objective(s)	To address mental health issues in the ACB community using ACB relevant strategies.
Secondary objective(s)	To address issues that have received less or no attention such as substance use, trauma, mental challenges.
Design	Mixed methodology; qualitative and quantitative to explore service users' and providers' perception and acceptance of existing evidence informed interventions. Pilot in 2-3 ASOs and evaluate the pilot.
Population	ASO service users, service providers including those who are and those who are not PHAs, and the management/decision makers in the relevant ASOs.
Study size	30 service providers & 30 organizations decision makers, 30 PHAs.
Setting	Focus groups involving service providers, mental health organizations/institutions, ASOs, community health centers in 5 cities in Ontario namely, Ottawa, Toronto, Niagara, Windsor, Kitchener, & Waterloo using one organization in each city.
Study regimen	Based on data from the CBT, motivational interviews, acceptance and commitment therapy (ACT).
Intervention	Use of stress management group therapies such as social cognitive therapy, motivational interviewing using trained persons (not experts).
Study duration	2-3 years.
Community collaborators	To be accessed through ACCHO.
Scientific collaborators	Will select those that uphold the social justice principle, through ACCHO.

APPENDIX 7: Research and Evidence-Based Practices in HIV Prevention, Treatment and Care – Harm Reduction

Area	Research and Evidence-Based Practices in HIV Prevention, Treatment and Care.
Title	Harm Reduction, HIV and Substance abuse.
Problem	There's lack of knowledge of what substance abuse really is.
Purpose	Gather baseline data in ACB population.
Primary objective(s)	TBD
Secondary objective(s)	HIV and Hepatitis C testing as prevalence is really unknown.
Design	Review existing data e.g. at Black CAP. Recruitment: In community naturally occurring environments.
Population	TBD
Study size	TBD
Setting	TBD
Study regimen	TBD
Intervention	Developing a survey to be used community wide, peer driven survey, focus groups, deliver survey province-wide.
Study duration	TBD
Community collaborators	TBD
Scientific collaborators	TBD

APPENDIX 8: Clinical and Immunological Issues across the Lifespan – Youth

Area	Clinical and Immunological Issues across the Lifespan.
Title	Challenges of Retention in Care for ACB Young Adults.
Problem	HIV research on youth is currently lacking. In addition to comorbidities, youth face unique challenges as they transition from paediatric care to adult care.
Purpose	TBD
Primary objective(s)	What are the barriers to retention in care?
Secondary objective(s)	What would it take to overcome these barriers (enhance retention as care)? What are the roles of parents/care givers? What do the youth think would be helpful for HIV education? Defining co-morbidities in this population.
Design	Mixed methods design.
Population	ACB Youth 15-29 living with HIV and previously in pediatric care.
Study size	100 or 150 youth.
Setting	Toronto, Ottawa, Hamilton.
Study regimen	TBD
Intervention	Youth Strategy for engagement in care.
Study duration	3 – 5 years.
Community collaborators	ACCHO/ AIDS Committee of Ottawa/ Positive Youth/APAA/WHIWH.
Scientific collaborators	Mona Loutfy, Carmen Logie, Lindy Samson, Rupert Kaul, Irving Salit, Marvelous Muchenje-Marisa, Mbaka Wadham and Soraya Blot.

APPENDIX 9: Clinical and Immunological Issues across the Lifespan – Inflammation

Area	Clinical and Immunological Issues across Lifespan.
Title	Inflammation and HIV “From the womb to the tomb”.
Problem	Cardiovascular markers are increased in the ACB communities. However, how does HIV affect that? Inflammation drives susceptibility and HIV illness worse in the ACB people. There is an increase of inflammation in the 50 plus ACB people
Purpose	Define biomarkers in adults and young individuals. Genital biomarkers in positive and negative HIV ACB people.
Primary objective(s)	TBD
Secondary objective(s)	TBD
Design	Cross sectional study.
Population	TBD
Study size	TBD
Setting	TBD
Study regimen	TBD
Intervention	TBD
Study duration	TBD
Community collaborators	TBD
Scientific collaborators	TBD

APPENDIX 10: Methodological Innovations in HIV Research – Self-Determination

Area	Methodological Innovations in HIV Research.
Title	TBD
Problem	ACB Communities do not have control over who conducts research in their communities and what is done with the data.
Purpose	To establish principles, similar to OCAP principles for First Nations communities, that allow the community to own, protect and control the data collection process and how information is used. To ensure accountability and integrity in the research that is being done “on behalf/in the interest of” ACB communities, including PHAs.
Primary objective(s)	TBD
Secondary objective(s)	TBD
Design	TBD
Population	TBD
Study size	TBD
Setting	TBD
Study regimen	TBD
Intervention	TBD
Study duration	TBD
Community collaborators	TBD
Scientific collaborators	TBD

APPENDIX 11: Methodological Innovations in HIV Research – Research Translation and Dissemination

Area	Methodological Innovations in HIV Research.
Title	TBD
Problem	There is a great deal of research conducted with the ACB people but a lack of change in community conditions.
Purpose	To investigate the translation of research projects conducted on ACB communities 5 years after their completion.
Primary objective(s)	TBD
Secondary objective(s)	TBD
Design	TBD
Population	TBD
Study size	TBD
Setting	TBD
Study regimen	TBD
Intervention	TBD
Study duration	TBD
Community collaborators	TBD
Scientific collaborators	TBD

APPENDIX 12: Methodological Innovations in HIV Research – What Is Evidence? A Knowledge Synthesis

Area	Methodological Innovations in HIV Research.
Title	TBD
Problem	Methodologies employed in research with the ACB community are not considered strong evidence by some members of the research community.
Purpose	To critically understand what constitutes “evidence”, how different research methodologies may expand how research becomes “effective” for ACB communities, and how we may reframe what is understood as “implementation science”.
Primary objective(s)	TBD
Secondary objective(s)	TBD
Design	TBD
Population	TBD
Study size	TBD
Setting	TBD
Study regimen	TBD
Intervention	TBD
Study duration	TBD
Community collaborators	TBD
Scientific collaborators	TBD