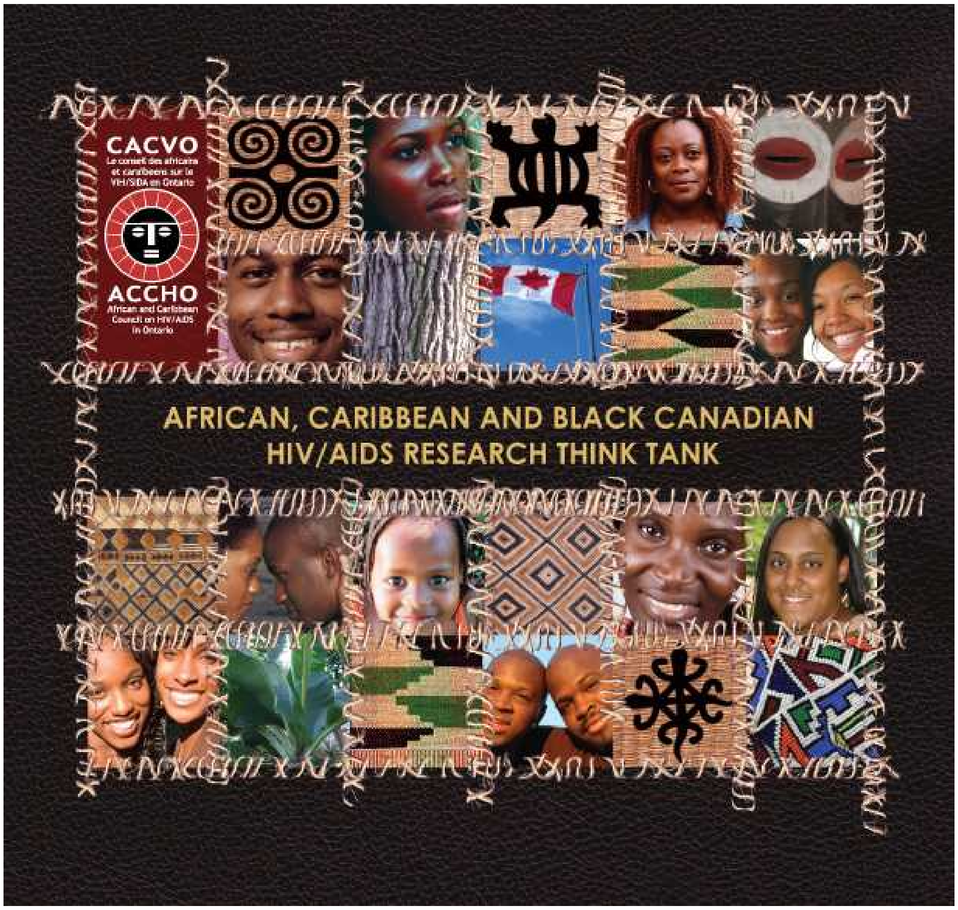
African, Caribbean and Black Canadian HIV/AIDS 2009 Think Tank Report



The Way Forward...

Acknowledgements

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ACCHO, African and Caribbean Council on HIV and AIDS in Ontario
AIDS Bureau, Ontario Min of Health and LTC
Canadian Institute of Health Research (CIHR)
Committee for Accessible AIDS Treatment (CAAT)
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Interagency Coalition on AIDS and Development (ICAD)
Ontario HIV Treatment Network (OHTN)
Ottawa Public Health
Public Health Agency of Canada
Toronto Public Health
Women's Health in Women's Hands (WHIWH)
Planning Committee Chair: LLana James
Research Think Tank, Planning, Coordination and Implementation by**:** LLana James, Incwell Consulting

Sponsors

AIDS Bureau, Ontario Ministry of Health and Long-term Care
Ontario HIV Treatment Network
GlaxoSmithKline Pharmaceutical Company

Think Tank Participants

Research Presenters: Charu Kaushic, Ken Rosenthal
MGIPA Panel: Marvelous Muchenje, Lena Soje , Lisungu Chieza, Winston Husbands
Roundtable Chairpersons and Facilitators
Volunteers
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Venue: Ramada Hotel & Suites, Scott Thompson

CACVO

ACCHO

AFRICAN, CARIBBEAN AND BLACK CANADIAN
HIV/AIDS RESEARCH THINK TANK

An opportunity for Researchers, Policy Makers, Service Providers and
Funders to meet and identify HIV/AIDS related research gaps and priorities

Monday - Wednesday April 6-8 2009. By invitation only.
Ramada Inn Downtown Suites 300 Jarvis Street, Toronto Ontario

wheelchair accessible, travel and accommodation scholarships available
for further information contact LLana James, email: [illegible]

African, Caribbean, Black Canadian Think Tank Report 2009

Background

ACCHO's provincial and national capacity building work ramped up in 2005 supported by grants from the Public Health Agency of Canada (PHAC), Population Health Fund, the AIDS Bureau, and the Ontario Ministry of Health. The PHAC grant provided the core resources for the engagement activities, workshops, the African and Caribbean HIV Transmission Guidelines and Manual to be developed and published as well as start up funding for the 2006 HIV/AIDS Research Summit. In 2005, the OHTN (Ontario HIV/ AIDS Treatment Network) provided technical support and the AIDS Bureau, provided financial contributions for the 2006 African and Caribbean HIV/AIDS Research Summit.

The 2006 HIV/AIDS Research Summit was a key step towards increasing the African, Caribbean, Black Diaspora's interest in research and created an opportunity to network. The African and Caribbean Council on HIV/AIDS (ACCHO) and Women's Health in Women's Hands Community Health Centre (WHIWH) provided an environment for the community to engage with and learn more about research.

The 2009 African, Caribbean, Black Canadian HIV/AIDS Research Think Tank is the result of the engagement activities that took place from 2005-2009. Resources for hosting the 2009 African, Caribbean and Black Canadian HIV/AIDS Research Think Tank were provided by ACCHO, the OHTN, the AIDS Bureau and GSK (GlaxcoSmithKline).

The core theme of the 2006 Research Summit and the 2009 Think Tank was **self-determination**. The theme of self-determination is not arbitrary, it in fact arose in the town halls, and community forums that preceded the inception of ACCHO. The theme of self-determination and the momentum it gained prior to 2005 carried forward the present moment. The term *self-determination was defined* then as it is now, by the fierce commitment of *black African, Caribbean and Canadian people taking a leadership* *role in defining the issues and identifying both the processes and pathways to constructive action and outcomes, in collaboration with allies and partners*. The 2009 Think Tank is one of many steps towards embodying the message of self-determination, where allies are appreciated but their contributions are balanced.

Objectives

The objectives of the Think Tank were to:

- Determine research needs, gaps and set research priorities
- Share knowledge and information on current and ongoing research
- Promote and facilitate meaningful and appropriate community and academic relationships
- Share effective knowledge translation and exchange methods and strategies

Format: A Summary of the Proceedings

The 2009 Research Think Tank was a three day working meeting with presentations on day one from provincial and federal agencies that provide HIV/AIDS specific programs and/or funding. Research presentations took place on day one as well as a panel on MIPA (meaningful involvement of people living with HIV/AIDS). The CIHR, OHTN, PHAC and the AIDS Bureau Ontario Ministry of Health and Long-term Care provided an overview of the initiatives and funding opportunities. PHAC provided a pre-launch overview of the Population-Specific HIV/AIDS Status Report, People from Countries where HIV is Endemic, Black People of African and Caribbean descent living in Canada. Details of the panel discussion are in, **Section 2 Panel Discussion Highlights** of this report.

The Roundtable portion took place from the afternoon of Day 1 and ended in the late afternoon of Day 3. The Roundtable portion consisted of participants self selecting a research track; socio-behavioural, clinical, epidemiology or basic science, they were best suited to contribute to. CIR (community initiated research) and CBR (community based research) iframeworks were integrated across tracks. Participants then worked through a series of preselected questions, a chair person (randomly selected per roundtable) and group facilitator were present at each roundtable. The Chair participated in the roundtable exercises, ensured that they remained focused and that their roundtable reached consensus. The facilitator's only role was to help the roundtable participants remain organized, flip chart their responses, ensure items were not overlooked as well move through the exercises as per the timelines. At the end of the morning exercises on Day 2 participants prepared powerpoint presentations based on their flip charted responses. In the afternoon of Day 2 during the Roundtable Report Back each of the four roundtables presented their research priorities (based on the exercises) to all the participants, and responded to questions. The outcomes of the exercises produced the research priorities, see **Section 3: Research Priorities**.

The Think Tank concluded on Day 3 with two activities, a moderated discussion and a Timeline Exercise. The moderated discussion, A New Culture of Research: Considerations, Dilemma's Doing it Right and Bridging the Gaps was an opportunity for participants to discuss four questions, see **Section 4**. The Timeline for Change exercise provided participants with an opportunity to identify which research priorities they 'voted' as short, intermediate and long term activities, see **Section 5**. Each participant received a limited number of colour coded dots and allocated them to the priorities presented during the Roundtable Report Back. The 2009 African, Caribbean, Black Canadian HIV/AIDS Research Think Tank ended with a heartfelt *Thank you* to everyone.

Section 2: Panel Discussion Highlights

Meaningful and Greater Involvement of African/Black People of the Diaspora Living With HIV/AIDS

The panel discussion provided an opportunity for participants to learn from and be challenged by people of African/Black Diaspora living with HIV and affected by HIV. The panelist shared their experiences of research, the challenges and benefits. A question and Answer period followed each panelists presentation. The four panelists were: Lena Soje, Marvelous Mucheje, Lisungu Chieza and Winston Husbands (*each of their contributions in the report are excerpts from their presentations, with core content and nuances preserved as much as possible*.)

Lena Soje self identifies as living HIV positive for over eighteen years, she has been support worker for fifteen years at Black CAP the oldest Black HIV/AIDS organization in Canada

MGIPA: Lena began her presentation by stating that she has always been engaged in HIV/AIDS research as a subject or advisory board member. My experience with MGIPA and my personal experience with research is that GIPA is not always involved in research. Lena stated that ‘I don’t get involved unless I know certain things;
-What is the impact? Is it of value to PHA’s?
-What is the impact on me as a black female PHA?
-Would it hamper, hinder or help my community?
-Will the info that is being gathered on me/us - will something beneficial be done with it?
-When researchers get the findings will it be put on a shelf, what will be done with it?

CBR (Community Based Research): Most of the research I’ve been invoved in has been CBR (Community Based Research).
I will talk about the impact it has on me;
CAAT - Mental Health Research was excellent because PHA’s were involved at all levels. PHA’s presented the findings back to the community. PHA’s can be researchers with support.

Fertility Research: The Fertility Research Project impacted me as a support coordinator. My clients were not being welcomed in fertility clinics the project was another step in breaking down barriers to accessing fertility services.

Trauma Triggers: Researchers need to be mindful that many issues come up when filling out surveys and people get triggered. Old trauma(s) get revealed. As a support coordinator in the Fertility Study my role was to help them complete the survey whether it was a language barrier or triggers. In that role, being a PHA was valuable to the participants.

Lisungu Cheiza: has held several roles in the research process: subject, research coordinator and community research advisory member because of Lisungu's education and training as a microbiologist and as being a person living with HIV, she has often felt caught in the crosshairs of research which has her continually challenging herself and the research process.

Lisungu greeted everyone in more than five African languages. She shared her perspective on the key challenges of the research. Lisungu had powerpoint slide that depicted wolves howling at the moon.

Challenges: lack of recognition, recruitment and dissemination of results, post participation care, language barriers and the lack of understanding/relevance to research participants.

Lisungu said the powerpoint slide depicting the wolves bore great symbolic significance and accurately represented how she felt about sharing her experience in research, 'the Wolves represent HIV+ people such as myself. The question is, 'Is anybody listening or are we speaking only to ourselves?'

Lack of recognition: Researchers recognize funders and partners but not always the PHA's (people living with HIV/AIDS). If my efforts of participation in research are not recognized or appreciated, do researchers think about what the research would be if only partners and funders were there? It is very important to acknowledge PHA's, because it boosts morale. When it comes to Epi Data; if we are not there to be counted what would you have?

Recruitment and Dissemination of results: Researchers are very good at recruiting - you will do whatever it takes, you will invade my community space, however when you disseminate results its the opposite. You disseminate at conferences and PHA's don't often get the opportunity to go due to funding and often the language used in the materials makes it inaccessible because our literacy level has not been built up. When you've done the research and you are going to share findings do it the same way you did the 'all out' recruitment/efforts; child care, tokens, food and let us know "this is time to talk about our findings.

Post Participation Care: Depending on the type of research, my emotions may be triggered. I will use the analogy of taking off my clothes to describe how your 'research questions and surveys' may affect me, a person living with HIV. You ask me when I come to Canada - start by taking off my shoes, then you ask me when I started having sex - I take off my jacket, before you know it I am naked then the questions/survey is done and you thank me for my participation and send me on my way and lead me to the door. I feel vulnerable, I am sent into the street naked and I am left to cover myself with my hands. What I am simply asking is that during that stage there is someone onsite to talk to.Yes, you give a list of phone numbers but I need someone to physically talk to: so that I can leave the vulnerability you brought to the fore there with the study and then I can go back into the world covered/clothed. It takes too long to book an appointment possibly two weeks later, that's too late.

Lack of relevance of understanding of questionnaires: Research participants usually do not know why you are asking the question. We need a context, to understand what we are being asked and what the question really means.
-You ask me, when I started having sex?
-The number of partners over past six months?
-Did I use condoms?
-You ask me about my income; maybe I earn $500.00 and I see up to $10K I wonder are you going to give me more money
-I need to understand the implications of the questions
If I don't understand the questions I cannot answer effectively. Come into my space and give me research 101, increase my research literacy. It will help if you come to my space and educate me about the language, what is the questionnaire getting at.

Language Barriers:
–Your tools are always in English, consent forms in English maybe French. They say "mother tongue speaks to the heart".When the interview process is done in my language it allows me to accurately and truly express myself
–There are many of us who speak many languages, you are always quick to run to professionals - why don't you train us? Train us so we can do our own counseling

In closing Lisungu brought participants back to the Slide (wolves howling at the moon). I've been invited to many conferences where there is a panel; you encourage us to speak, bring our issues. I wonder is it to say 'we had the PHA's', in the end there are controversial comments 'who do they think they are? 'You don't give us feedback if our comments were taken seriously or if we were just making noise.Are we making an impact? Give us feedback – it is up to you now to engage the dialogue, we have taken the risk to participate and say 'this issue that you mentioned this is how we feel'. We need to know that we are not treating PHA's as window dressing

Mavelous Muchenje is an advocate and activist. She coordinates one of the most highly attended skills building groups for women living with HIV. Marvelous has been living with HIV for over a decade and has recently made Canada her permanent home, alongside her native Zimbabwe.

I called Lena - “I’m going to present my perspectives on being a Peer Research Assistant”, Lena asked were you a PRA? I said “yes, but Lena remember the Fertility Study, were we Site Coordinators or PRA’s?”

I’ll break my contribution into three parts: benefits, participation and challenges, using the Fertility Study as an example.
Benefits for me:
-It was easy for me to recruit due to my position, I knew the women from the program and they were comfortable with me
-I offered other women living with HIV a role model; they don’t understand the questions, I explain it, break it down.
-Peers (such as myself) often have extensive knowledge;
    -When the client comes to me I often know who is shy and how to get them to open up and share information.
    -I am able to break and come back to the survey questionnaire when it gets to be overwhelming.
    -I also have the willingness to share my experience
    -I was able to give feedback to the PI and the Advisory, regarding what I was finding as problems. I had open discussions at Advisory meetings or at my personal appointments.
    -I participated in Questionnaire development and the Pilot. I knew what was in the survey.
    -I see my participation in research as a shift of the power base and research process from academic to the community.
For me these were the benefits - I call myself a PRA (Peer Research Assistant)
Participation:
    -The peer relationships are more mutual and offer more personal feedback.
    -If I am doing research with the women I know already they give the whole answer. They don’t have to worry where the information goes.
    -PRA’s,such as myself may disarm participants, they are more open, less guarded. Fertility study may know what is going on in my life because of what I have disclosed in group etc.
    -Participants will speak frankly.
    -Peers may be more likely to be flexible with their schedule. I am not new in their houses so they are not worried about who is in their home negotiating with them.
Challenges:
    – My experience in research was limited to one research project until approximately two years ago. Prior to that I had only participated in research in Zimbabwe as a subject in the DAT trial regarding the effectiveness of drug holidays.

– In the Fertility Study, if some one had not worked though their issues and their grieving, they could get support from the Site Coordinator

–I would sometimes need to step back from the survey/questionaire, because when there is shared experience and rapport, people are more open, the interviews are more emotional

–Research triggered PRA's and participants; prior trauma - I remained strong in the interview knowing that we both needed counseling.

–Onsite support is needed

- Are peers and researchers ready to put aside their agenda in the research.

Confidentiality:

-Is the consent form between/with the PI and the participant, is it with me (Marvelous) and participant, what is the guarantee?

-If they (research participant) goes and shares infomation shared in confidence in the community what is my recourse?

Use of Acronyms:

-It was my duty to learn the survey question in case I am asked any questions from the participants, when you interview different levels of participants there are some who are more educated than you.

Historical Memory:

-Negative experiences regarding PHA's being used to recruit have an impact on the present

Cultural Differences: (African/Black Diaspora is a heterogeneous population)

-I still must find ways to speak across cultures

Being Blamed:

– If the honoraria too low, the one who is recruiting is the person perceived as responsible for the issues at hand

Before Recruiting:

–We need to be trained from the beginning to understand the flow of information and process

-Limit the jargon

Marvelous concluded by challenging everyone to "Rethink research, not only ideas but how we are going to be doing it by/with service providers, PHA's and researchers."

Winston Husbands, is the Director of ACCHO and has a long history of involvement being an ally to people living with HIV and other populations. Winston offered his perspectives as an ally and offered a critical perspective of the context and structural issues that influence research by, about and for African and Caribbean populations living with and affected by HIV.

Winston began his presentation by agreeing with the challenges and successes noted by my colleagues, fellow panelists.

Context: Sometimes we limit our frame of discussion about research to the actual day-to-day actions of implementing research. The scope of research and the development process is often much broader than that. There are decisions that are made long before the implementation of the day-to-day research process. Quite often decisions made by people who are not the researchers or who do not even do research period make decisions about what is possible, likely or even probable and, at that point when researchers go to implement their projects some of the wonderful ideas they may hear are impossible to implement because of decisions that have been made elsewhere.

Research Process: We need to think more expansively about the research process and development process. Such as developing research needs and priorities and how people living with HIV can be involved in the process. We can also think about how funding decisions were made;

✦ Who makes decisions about who gets funding and on the bases of what information? These are two areas that we don’t often think about when we talk about MGIPA, this is where the discussion begins.
✦Who is making decisions and who has access to the decision makers?
✦What/who guides decision making at that level of MGIPA in setting needs and priorities?
✦ The other level is, what funders actually do; (OHTN, CHIR or PHAC AIDS Bureau) with that information
✦ The extent to which PHA’s, people such as my colleagues sitting at this table can influence decision making at that level

Looking at research in a more expansive way, means that research with Black people living with HIV would not be possible without the everyday work that Lena, Marvelous and Lisungu do in terms of engaging people who are living with HIV day in and day out. Black people regardless of wether they are living with HIV or not are not going to step forward and voluntarily answer questions and without understanding what is in it for them. This is a particular issues for Black people living with HIV.

Structural Issues in Research: The interface between research and its various processes and decision makers often, is a disjointed, curious and uncomfortable environment. Sometimes researchers do not understand that the work they do and the prestige they get is built on the work that is done at the service provision level. Researcher’s work is often built on the backs of people who engage and mobilize people, bringing them into the fold so that they will be willing and capable to step forward and answer questions and ask questions of you researchers.There are certain institutional policies and practices that limit the ability of Black people living with HIV to participate in research;

✦ If you research in a university: people with foreign credentials who are well educated and come with experience often face a precipitous decline in income and limited access to employment, while at the same time there is a claim that there aren’t people that have appropriate qualifications to fill the roles higher up in the hierarchy. When something gets too fashionable for example the PRA role, while it gives some people skills and income, I become pessimistic because we are creating another kind of ghetto.

✦ We have to be careful of our best intentions, in trying to treat people living with HIV with respect and dignity and involve them in our work substantively. We have to be looking beyond what we think is possible.

✦ The PRA opportunity, as a particular program response to a problem may be okay for now and is a good thing for now. However, we have to think at the same time of the limitations of what we're doing and see beyond that or end up creating another ghetto for Black people and we live in too many ghettos already.

Winston concluded with a challenge for change that "there is a need for institutional change. To challenge involvement."

Section 3: Research Priorities

Note: When the *asterisk is in the column header, all items in the column are priorities. When the asterisk is on an item within the column the item is the priority.

Basic Science Track

*Pathogenesis	*Prevention	*Transmission
Immune Activation	Microbicides	Effect of innate factors on mucosal transmission
Transmission: Sexual & MTCT re ACB women and specific to being in Canada	Vaccines	Effect of hormones in contraceptives on transmission
Genetic Influence: Are there specific influences between & among ACB heterogeneous populations	Immunotherapy	
Viral Factors: What if any are specific to ACB populations?	Contraceptive	
Co-infections which co-infections are most to least common what are the factors and the resiliencies?	New Prevention Technologies	

Epidemiology Track

*Lack of Data	*Timeliness	*Methodological Issues
Of ACBC populations; Local	Epi research data lags	Lack of appropriate mechanisms to for studying ACBC populations
Provincial	Mismatch of Epi data with reality on the ground	Operational: Tools may not be appropriate nature and or location
National		

Clinical Science Track

Linkages/Communication	Population Specificity	Treatment
Better KTE and dissemination practices	*Aging-Life span approach applied to clinical research	Pharma interventions: How do or don't they affect ACB populations across a) life span and natural disease process
Meaningful community relationships (MIPA)	-Children: Pharma and natural/herbal interventions equally researched and the impacts on development identified, instruments may need to be revised to capture children, family needs not just clinicians	Herbal/Natural interventions: Invest equal time and energy into research of Herbal/Natural interventions
Trust- take into account historical, non-beneficial practices, stop minimizing	-Youth: Pharma and natural/herbal interventions equally researched and the impacts on development identified, instruments may need to be revised to capture youth, family needs not just clinicians	Co-infections: examined form as clinical as well as a Determinants of health perspective
*Develop pool of trusted clinical practitioners who respect populations concerns,	-Adults: Women, Men Pharma and natural/ herbal interventions equally researched and the impacts on development identified, instruments may need to be revised to capture youth, family needs not just clinicians	ACB populations need to play a central role in leading investigations, mentoring and or less gate keeping may be needed
Prioritize ACB researchers as investigators that demonstrate anti-oppressive practice	*Accountability to ACBC populations	Identify promising practices and improve

Socio-Behavioral Track

Prevention	*Systemic & Sectoral Accountability	*Maturing PHA's (use a Lifecourse/span approach)
Evaluative research for prevention programming	Institutional barriers to services/lack of co-ordination	What do we and don't we know about how BPHA's are affected by aging
Identify Best Practices in prevention programming	Impact of racialization and racism on populations	Services need to be tailored to reflect the issues and joys of maturing
*Identify and include how power imbalances and domestic violence affect HIV prevention	Link between racism, poverty & challenges implementing health promotion strategies	Identify & respond to isolation and issues of: relationships, engagement,& involvement
Sex health education education for all youth esp. 13yrs + , follow up info learned in the Toronto Teen Survey (HIV prevention may need to star earlier using age appropriate materials if action needs to be implemented in the teen years, info to acknowledge kids are Poz too)	Employment	What steps & resources are in place in senior housing/homes to address the issues of stigma and chronic disease that may affect BPHAs

Socio-Behavioral Track

*Criminalization & Disclosure	Capacity Building	Population Specificity
Impact on BPHA's and their respective communities	Greater involvement of Black researchers from various disciplines	*Focused in-depth research concerning ACB women and reproductive health
Increase in cases of black PHA's being prosecuted	Mentoring by PI's of ACBC researchers	Delivery of health services should be anti-racist, anti-oppressive
More dialogue regarding disclosure: why/when/who/where and related legalities	BPHA involvement in research should not be limited to PRA's/Coordination level only	Specific trials that address the needs and concerns re: medications prescribed ACB women

*Involvement/Engagement of Heterosexual Men	*Second Generation HIV Positive Youths
How do we engage heterosexual men in sexual health	Capacity building/empowerment
Space and services for HIV+ heterosexual ACB men	Positive spaces - more culturally appropriate & non-oppressive services for ACB youth
How to evaluate and share from existing/emerging programs	Understand the issues and challenges faced by positive ACB youths
There is not enough dialogue about sexual education between older men and young men	Programming to support ACB youth move through the developmental and identity challenges inherent to tween/teens within the context of ACB community, recognizing race, gender, sexuality etc

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By:LLana James, Incwell Consulting

Top Non Negotiable Priorities Across all Tracks & Discussions

➢Acknowledge *ongoin**g** impact* of racialization, racism, gender power imbalances, homophobia, immigration and structural limitations on social mobility, prevention, diagnosis, and treatment for African Diaspora in Ontario (i.e. replication of global patterns)

➢ Acknowledge that due to the multiple and intersecting systemic challenges facing African/Black Diaspora populations that HIV has to be approach from a holistic perspective/determinants of health. HIV prevention, diagnosis and support has to be considered with the context of real life, with competing challenges

➢Assertively address HIV discourse that seeks to locate the human rights and lives of individuals living with HIV as unimportant or less valuable than the human rights and lives of people with unknown or negative HIV status.

➢Meaningful involvement of African/Black people living with HIV overall, breaking the glass ceiling of participation

➢Real time data collection i.e. of epidemiologic data and sharing, as well as supporting linkage to programming where relevant and appropriate

➢ Take an inventory of all research, prevention, diagnosis, treatment and programming targeting black African, Caribbean and Canadian populations (need to know where we've been to map forward) and identify the value provided to the communities targeted, the organizations involved and benefit to the African/Black Diaspora as a whole

➢Capacity Building and infrastructure enhancement of African, Caribbean and Black Canadian leadership, researchers and resources to facilitate community initiated/based self-determination per sub-population (one size does not fit all)

➢Establish a HIV/AIDS Black African, Caribbean and Canadian Research Network

➢Thematic research that blends; population priorities, scientific/Epi data and front line information with a 5 year outlook including benchmarks and resources

➢Evaluation & Accountability: Changes required in HIV sector, research and service provision culture, embedding anti-racist, anti-oppressive practices and processes. Evaluation of organizations, service provision and prevention programming

➢Enhanced tools and relevant training to increase quality, scope, usefulness and timeliness of research

Section 4: A New Culture of Research?

The moderated discussion, A New Culture of Research? Considerations, Dilemma's Doing it Right and Bridging the Gaps was an opportunity for participants to discuss the following four questions:

1) How has ACCHO influenced the culture of research?
2) What challenges, tensions, successes and lessons learnt do you perceive or know ACCHO may have /are experiencing?
3) What are the structural resources/supports that ACCHO's needs to continue the research?
4) How have/does ACCHO's choices impact the sector specifically: a) implications for other ethnoracial organizations b) implications for other organizations in Ontario and beyond?

Answers

1) ACCHO has influenced the culture of research by being a:

- successful voice for African, Caribbean and Black Canadian people infected and affected by HIV
- advocate on social, cultural and political issues
- resource to others on issues affecting African, Caribbean and Black Canadian people infected and affected by HIV
- influence in field of prevention for support via research funding
- unified and harmonized voice for African, Caribbean and Black Canadian people infected and affected by HIV
- touchpoint for partners outside Ontario on issues/research related to African, Caribbean and Black Canadian people that acknowledges the realities of race/ racialization
- informed partners in research
- capacity building engine
- helpful organization by developing service/programs
- link to and for service providers
- model in showing how we use research to do work (research to practice)
- influence process of K.T.E. (knowledge translation and exchange)
- organization that involves communities (e.g.. Stigma Study)
- innovator, developing systemic model (terms of reference) and research processes in working with research institutions
- stimulator of new ideas for research
- touchpoint for advice/support to government, policy makers/policies and reports
- facilitator of community participation and encouragement

2) ACCHO's challenges, tensions and lessons learnt are:

- working with the diversities within African, Caribbean and Black Canadian people communities and issues of visibility/invisibilty
- changing leadership
- hard to have 1 (one) black voice, given populations heterogeneous nature
- mandate - provincial but requests are from across Canada
- how to manage the broader role it is being asked to take on, as a result of requests
- how to effectively, orient new council members
- how to facilitate people who want to get involved, given ACCHO's very small and fledgling infrastructure
- how to manage affiliation(s) with other institutions/universities since it is not a legal entity
- resource limitations in influencing policies
- ownership of research (vs. universities) as ACCHO is not a legal entity and unable to 'own' anything
- more focus on care/support is needed
- partnership with Aboriginal communities needs to be grown and solidified

* implementing MGIPA in ACCHO
* difficulty accessing research funding criteria designed for 'mainstream' populations to study African, Caribbean and Black Canadian people
* need to implement O.C.A.P. and make them a more concrete and prominent part of ACCHO's practice

2) ACCHO's successes:

* bringing stakeholders and partners together
* sharing resources
* Stigma Campaign
* Keep it Alive Campaign
* focus on prevention
* credibility in sector
* secure funding
* impact on 'Canada' and 'International' dialogue regarding African, Caribbean and Black Canadian people and HIV
* more fully incorporating sociopolitical context in different research projects

3) ACCHO needs the following structural resources/supports to effectively continue their research efforts:

* "small network - need to 'expand' and build an "African, Caribbean, Black HIV Research Network"
* to caucus/plan/dialogue for African, Caribbean, Black researchers who can make meaningful contributions
* overall resource support needed from WHIWH, OHTN, AIDS Bureau
* fruitful, good partnerships with funding agencies
* Federal and Provincial strategy specifically addressing African, Caribbean, Black people
* linkages between clinical, basic science, socio-behavioural, epidemiology and service provision sectors
* harness further resources via partnership, CIHR, ACAP
* dedicated core research funding and staff
* human resources - need for greater mentorship, especially research
* coalition building of broader communities
* outreach to communities via events and other networks
* own/have our own independent space
* more room for student practicum (research)
* mobilize more human volunteer resources

4) ACCHO's impact on ethnoracial organizations and implications for other organizations in Ontario and beyond:

* highlight inclusiveness in research process vs. mainstream practices
* showed important role in capacity building
* students use ACCHO as a hub- get access to information, other researchers etc
* legitimize community leadership/approach to research
* facilitate coalition building and mobilize communities
* need more "group" mentorship to breakdown institutional barriers
* help define research direction (e.g. co-infections)
* broaden ACCHO membership to include other non-HIV focused researchers
    * focus on social political as well as mainstream issues
* inform broader communities
* academic partnerships - meaningful linkage of research to strategy
* model of " African, Caribbean, Black Strategy workers" across Ontario
* models for others, groups and provinces
* membership to students from ACB communities
* define and document a CBR model re:
    * partnering with others (e.g. universities)
    * Capacity building for other provinces
    * KTE for other ethno-racial groups (models/research partnership)
    * nationalizing our strategy

Section 5: Timeline for Change

The Timeline for Change exercise provided participants with an opportunity to breakout of the group format, to respond as individuals and to 'vote' their concious. The charts below provide a snap shot in time. Each participant received colour coded dots and placed them next to the priorities identified by roundtable tracks.

BASIC SCIENCE	SHORT-TERM	MEDIUM	LONG-TERM	TOTAL ‘votes’
Pathogenesis: Basis for understanding infection and disease progression Further understanding will help to design tools for treatment and prevention Important to look at host and viral factors including genetic, immune and environmental factors	2	2	8	12
Transmission: Need to understand mechanisms of transmission to better control spread of HIV	0	8	7	15
Prevention: Require new prevention technologies Need to develop new treatments for immune modulation (altering the immune response)	10	10	8	28

EPIDEMIOLOGY	SHORT-TERM	MEDIUM	LONG-TERM	TOTAL
Ongoing collection and sharing of service-level/local/provicial Epi data to influence service delivery (real time)	12	9	5	26
KAPB study of ACB populations to get baseline info across identified priority sub-populations & identified range of topics.	13	7	5	25
Methodological/Operational research to develop tool for accessing & collecting info on ACB populations	7	4	6	17
Comprehensive listing on current & past studies on ACB populations in Canada (on-going inventory)	7	4	2	13

CLINICAL SCIENCE	SHORT-TERM	MEDIUM	LONG-TERM	TOTAL
Capacity Building: (empowerment, informing the community of research findings)	10	3	3	16
Responsible research: To change policy, to modify the system, research that includes the community	4	0	2	8
MIPA (meaningful involvement of people living with HIV/AIDS)	5	1	1	6
Funding (advocacy, mentorship, role models - list of Black PI's, community based process)	8	6	9	23
Stigma (education at all levels)	8	5	4	17
Trust (transparency, accountability)	5	0	1	6

SOCIO-BEHAVIOURAL	SHORT-TERM	MEDIUM	LONG-TERM	TOTAL
Criminalization & Disclosure	25	7	9	41
Evaluative research for prevention programming	16	6	8	30
Power imbalances & domestic violence	2	7	3	12
Institutional Barriers	4	7	8	19
Racism, ongoing issues & the history of HIV/AIDS	6	5	6	17
Black Caribbean & African researchers - capacity building	31	7	3	41

2009 African, Caribbean and Black Canadian HIV/AIDS Research Think Tank
By:LLana James, Incwell Consulting

Appendix

Appendix
2009 Africa, Caribbean, Black Canadian Think Tank Agenda

A Demographic Snap Shot…

The black African, Caribbean and Canadian population (hereafter referred to as African/ Black Diaspora) in Canada consists of 783,795 according to 2006 census data. People of the African/Black Diaspora are 2.5% of the Canadian population and constitute 15.5%[1] of the population Canada defines as 'visible minority'[2]. The African/ Black Diaspora population increased by 31%, while the Canada's population grew by 10% and Canada's visible minority population grew by 58% from 1991-2001[3].

The African/Black Diaspora population is largely concentrated in Ontario (62.1%) and Quebec (23%), with most people living in metropolitan areas. Toronto and the greater Toronto area (GTA) have 47% (310, 500) of the Diaspora population and 4% (139,300) reside in Montreal[1]. In 2005, approximately 16% of new HIV infections in Canada were attributed to heterosexual exposure of people whose place of birth was in an HIV endemic country[2]. The infection rate was 12.6 times higher that of other Canadians (note that 20-60% of HIV infections occur inside of Canada[3]).

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[1] Population specific HIV/AIDS Status Report,
http://www.phac-aspc.gc.ca/aids-sida/publication/ps-pd/africacaribbe/index-eng.php

[2] Visible minority applies to persons who are identified according to the Employment Equity Act as being non-Caucasian in race or non-white in colour. Under the Act, Aboriginal persons are not considered to be members of visible minority groups.

[3] Milan A, Tran K. Blacks in Canada: A long history. Canada Social Trends 2004;1-7

[1] Remis RS, Medrid MF. The HIV/AIDS Epidemic among Persons from HIV-Endemic Countries in Ontario: Update to December 2002:Ontario HIV Epidemiological Monitoring Unit, University of Toront; 2004 June

[5] HIV endemic country: According to surveillance data reported to the UNAIDS the countries deemed endemic are mainly located in the Caribbean and sub-Saharan Africa where populations are predominately Black

However, the number of infections is likely underestimated because anyone whose exposure category was attributed to all other categories such as men who have sex with men (MSM), heterosexual/non endemic, recipients of blood transfusion or clotting factors, intravenous drug use (IDU) and occupational exposure are excluded from the heterosexual HIV endemic exposure category. Each category is mutually exclusive, meaning if you are counted in one category higher in the exposure hierarchy you cannot be counted in another exposure category. For example, in Ontario from 1980-2004, 55.9% of HIV infections are attributed to heterosexual people born in HIV endemic countries, 21.2% were among African/Black Diaspora men who have sex with men, 20.4% ‘other’, 1.6% intravenous drug use, .95% IDU-MSM [1] for a total of 100% of infections attributed to the African/Black Diaspora.

2009 African, Caribbean, Black Canadian HIV/AIDS Research Think Tank Itinerary

Day 1
Welcome
Language & Identity: What's in a name?
Presentations:
- ▪Andrew Matejcic, CIHR
- ▪Dr. Sean Rourke, OHTN

ACCHO's Role as a Catalyst: Why we are gathered here today
Preview of the Public Health Agency of Canada Status Report on Populations from HIV-Endemic Countries
Research presentations:
Charu Kaushic Mc Master University,
Ken Rosenthal, McMaster University
The Way Forward:
- ▪Greater Meaningful Involvement of People Living with HIV and AIDS
- ▪The role of Policy Makers and Funders

LUNCH
Roundtables Exercise:
- ▪Part 1-Brainstorming
- ▪Part 2-Gaps identification

End at 5pm

Day 2
Welcome Back
Roundtable Exercises:
Part 3-Priority setting exercise
Part 4 KTE Continuum, CIR-CBR
Preparation of Report Back Presentations
Roundtable Report Back
LUNCH
Report Back
Presentations based on different disciplined
Q & A for input from other groups
End 5pm

Day 3
Moderated Discussion:
A New Culture of Research? Considerations, Dilemma's Doing it Right and Bridging the Gaps
A Timeline for Action Exercise: Long, Intermediate and short Term Identification

Discussion: Galvanizing a Collective Commitment (omitted due to time constraints)

End 3pm