



BRIEFING PAPER

Strengthening Africa Civil Society Capacity For Biomedical HIV Prevention Research Advocacy: Home Grown Solutions To Local Challenges

KEY ISSUES

- African Civil Society Organizations (CSOs) leadership in advocacy for HIV research including New HIV Prevention Technologies (NPTs) remained sub-optimal partly due to limited institutional capacity strengthening and funding.
- In 2012, International AIDS Vaccine Initiative (IAVI) launched a partnership with selected African CSOs to increase their leadership in NPT agenda setting and advocacy. We analyzed key achievements and milestones of the CSOs programs in achieving the identified goals.

KEY ACHIEVEMENTS

- Increased political will on domestic financing as evidenced by establishment of new mechanisms for financing health research in Africa partly due to advocacy by the Africa CSO platform on Health, coordinated by WACI Health.
- Increased and sustained interest and engagement of African youth in NPT research as evidenced by 336,800 youth reached with NPT messages, 554 youths actively participating in NPT dialogues from across Africa and formation of two research advisory groups for young women in Kenya and Zimbabwe by GYCA and partners.
- Increased engagement, ownership and participation of Men who have Sex with Men (MSM) and Lesbian Gay, Bisexual and Transgender (LGBT) populations in HIV research as evidenced by the formation of four national community-led LGBT research advisory groups in Kenya, Rwanda, Zambia and South Africa that provide input in protocol development, recruitment and retention strategies and joint Sexual Orientation and Gender Identity (SOGI)

agenda setting. This has also led to joint publications with researchers in Kenya and the development of an innovative on-line platform for community engagement.

- Increased awareness of gender considerations in HIV prevention research and programming, as demonstrated by commitment of 417 advocates, research leaders and policy makers to advocate for and/or integrate gender in the design, conduct and dissemination of HIV research.
- Improved engagement of faith leaders as evidenced by the development of their home-grown advocacy strategy and implementation plan to reduce stigma associated with some NPTs and Key Populations participation in research.

KEY RECOMMENDATIONS

- African CSOs are well positioned to develop homegrown solutions to local challenges provided they own the agenda and leadership.
- Research sponsors and implementers should provide scientific technical support to African CSOs and should form joint partnerships on science advocacy to sustainably influence domestic financing, research with adolescents and integration of gender issues in HIV research.
- Funders should consider supporting both short and long-term institutional and human capacity strengthening aspects to ensure that African CSOs integrate Biomedical HIV prevention research into their institutional agendas.
- African CSOs and advocates engaged in biomedical HIV prevention research need to develop a cohesive agenda and monitoring and evaluation framework that can help them track progress at national, regional and continental levels.



INTRODUCTION

Africa Civil Society (CS) leadership and engagement in biomedical HIV prevention research on the continent is critical in creating demand, support and ownership for New HIV Prevention Technologies (NPTs). However, African Civil Society Organizations (CSOs) leadership in advocacy for HIV research including New HIV Prevention Technologies (NPTs) remained sub-optimal partly due to limited institutional capacity strengthening and funding.

In 2012, International AIDS Vaccine Initiative (IAVI) launched a partnership with selected African CSOs with their leadership in identification and implementation of advocacy and policy agendas in NPTs. An estimated total of USD 150,000 with an average range of USD 25,000 – 40,000 grant money per organization was annually and gradually allocated to each CSO.

The policy advocacy goals included; increase domestic financing for HIV research, increase engagement of African youth and key populations in HIV research, ensure greater consideration for gender and sex in HIV research, and increase Religious Leaders' support for NPT research.

APPROACHES

Five CS Organizations were purposely selected to lead advocacy efforts based on NPT research pipeline and epidemic distribution in Africa, CSO geographical reach, defined constituency, clarity of mandate and proposed theory of change (home-grown solutions to local challenges). Organizations selected included; WACI Health (a secretariat of the Africa Civil Society Platform on Health bringing together over 60 CSOs from across Africa), Global Youth Coalition against AIDS (a youth-led global network of over 7,500 young leaders and allies fighting the spread of HIV and working to secure sexual reproductive health and rights in over 170 countries worldwide), International Community of Women Living with HIV – Global (a network of over 15,000 individual women living with HIV in over 120 countries), Gay and Lesbian Coalition of Kenya (GALCK) and International Network of Religious Leaders Living With or Personally Affected by HIV – Kenya Chapter (INERELA+).

SUMMARY OF ACHIEVEMENTS

WACI Health – Increased domestic financing and enhanced demand and backing for NPTs from African CSOs

WACI Health mobilized and partnered with East African CSO partners to advocate for the establishment and financing of the East Africa Health Research Platform. It also worked with the Africa CSO platform on health to advocate for the establishment of the African Centers for Disease Control (CDC). In collaboration with AIDS Accountability International, WACI Health developed a domestic financing gap analysis, financing options and advocacy roadmap to guide future policy advocacy projects.

To sustain demand and backing for NPTs by Africa CSOs; WACI Health in partnership with New HIV Vaccines and Microbicides Advocacy Society (NHVMAS) and other partners, strategically secured official status for the Biomedical HIV Prevention Forum (BHPF) as an official ICASA pre-conference. The 2015 ICASA Pre-conference was attended by 300 delegates. They also jointly held 3 NPT pre-conferences at international conferences such as HIV Research for Prevention (R4P); reaching an estimated 795 conference delegates between 2014 and 2015.

GYCA – Africa: Mobilize, create awareness and increase engagement of African youth in Biomedical HIV prevention research

Mobilizing and creating awareness: Young people are disproportionately affected by HIV globally. 25% of infected persons are between 10-24 years. Those aged 15-24 comprise 35% of new infections. The greatest burden of HIV among young people is in sub-Saharan Africa (SSA), where young women have almost eight times the HIV prevalence as same-age men with an annual HIV incidence estimated at 8%. (*J Acquir Immune Defic Syndr.* 2013 Jul; 63(0 2): S155–S160).

Despite this, very few biomedical HIV prevention research is conducted with adolescents. GYCA and partners sought to change the paradigm and increase African youth leadership and engagement in NPTs.

GYCA developed differentiated strategies in partnership with other African Youth Organizations. They integrated use of technology including social media, and film making in NPT advocacy while ensuring the needs of out of school youths and youths living in rural areas are not left behind. In two years, it is estimated that 336,800 African youths were reached directly with information on NPTs using innovative platforms (e.g. live twitter chats, the Award nominated “Beyond 5 senses” videos and country dialogues). GYCA and partners initiated and included an official session on Youth and NPTs at major international conferences. At the time of this publication, three sessions on NPT research had been conducted at two ICASA youth pre-conferences (Cape Town and Harare) and at the International AIDS Conference 2016 (Durban), reaching a total of 773 youth participants at these meetings.

Provide photos or link to Beyond Five senses videos and Social media platforms for Youth NPT engagement



Increasing engagement: GYCA in consultation with HIV researchers initiated two research advisory groups for young women formed in Kenya and Zimbabwe to support microbicides and HIV vaccine research conduct among young women. These advisory groups will provide guidance to researchers on issues that affect adolescents and young women as per the recommendations of Good Participatory Practices.



GYCA additionally initiated a training and leadership of African youth leaders on NPTs. 15 African youth leaders from seven countries in Africa were mentored as NPT champions to promote NPT research at platforms they have access to including the AU and the UN. As a result, they wrote two opinion pieces on the need for NPTs and the role of young people in HIV prevention research advocacy published in the Huffington post, Connect Africa Development blog, and several others. (<http://www.connectafricadevelopment.org>, <http://www.gyca.org> <http://devsanfro.com/archives/176>, <https://www.facebook.com/ICASAYouthFront/>).

MSM/LGBT CSOs: Ensure meaningful community involvement in, and ownership of Research among MSM and LGBTs

Conducting HIV research with stigmatized and criminalized populations in resource constrained environments requires ownership and leadership by local and national institutions and coalitions that represent the voice of each population and sub-populations.

In partnership with national LGBT coalitions, amfAR and Clinical Research Center (CRC) partners, four national community-led MSM & LGBT research advisory groups in Kenya, Rwanda, Zambia and South Africa have been established. An estimated 100 MSM and LGBT leaders have been trained on research and NPTs and six abstracts by MSM/LGBT leaders on NPTs presented at international conferences. In view of attacks on CRCs conducting HIV research with MSM and violation of human rights of

participants, these advisory groups were instrumental in developing a guiding strategy and guidelines on security of data and participants that were captured in the revised global guidance document on conducting HIV research with MSM and LGTB (*Respect Protect Fulfill Guidance* published in November, 2015)

These advisory groups have also provided input in protocol development, recruitment and retention strategies and in countries such as Kenya, they developed joint Sexual Orientation and Gender Identity (SOGI) research agenda with scientists and jointly published an article.

In Kenya, GALCK has spearheaded the establishment of an on-line platform for engaging MSM/LGBT communities in HIV research (see the Integrated LGBQ Community Online Platform at www.icop.or.ke), development of violence prevention mechanisms and supports implementation of a SOGIE community engagement roadmap in HIV research of the Kenya Advisory Group - The G-10 (The www.galck.org; www.icop.or.ke)



ICW Global: Ensure greater considerations of gender and sex in HIV research

ICW Global prioritized increased considerations of gender and sex in HIV research and identified key priority research and advocacy through consultative meetings with women and girls living with HIV and researchers. (ICW global advocacy priorities, call to action and check list on <http://www.iamicw.org/CampaignProcess>). To implement the advocacy plan, they trained 45 African women leaders from Eastern and Southern Africa on advocacy for gender and sex integration into HIV research design, conduct and dissemination. The 45 women leaders were then deployed to secure commitments from researchers, policy makers, and civil society advocates on gender and sex integration and data disaggregation in HIV Research, leading to 417 commitments over a 1 year period.



To ensure a grass-root/grass top and bottom up advocacy strategy, ICW developed community and friendly tools and check list on “What women should look out for when approached to participate in research”. These tools were developed, validated and disseminated on-line to an estimated 15,000 members of ICW’s global network.

INERELA+ Kenya - Increase support of religious leaders for NPT research

Religious leaders’ support of NPT and choice of population cohorts is crucial in ensuring a conducive environment for HIV research. INERELA conducted a survey to identify the Knowledge Attitude and Practice (KAP) of Religious leaders on HIV vaccines, microbicides and ARV based prevention options. The key barriers to religious leaders support of NPT research were limited knowledge of the state of the field, limited engagement of religious leaders in the research process, fear of being held accountable for negative research consequences if they support a research study, and fear of an upsurge in promiscuity due to misuse and abuse of the increasingly new array of prevention tools (the full report can be found here <http://www.inerelakenya.org/wp-content/uploads/2015/01/KENERELA-Survey-Final-Report-June-22nd.pdf>).

Based on the KAP findings, key religious leaders in the network in collaboration with INERELLA developed an education and engagement advocacy strategy based on fundamentals of faith. The newly developed Religious Leaders NPT advocacy agenda will be anchored within the Kenya National Faith Based Organizations (FBO) Action Plan, under the Kenya National AIDS Control Council’s leadership to support attainment of the Kenya AIDS Strategic framework (KASF) goals. It aims to improve religious leaders’ correct knowledge of NPT by 75% by end of 2019, reduce stigma by 20%, and improve perceptions of NPT research by 75%.

LESSONS LEARNT AND RECOMMENDATIONS

African CSOs are well-grounded and fully capable to develop home-grown solutions to local challenges that face the HIV biomedical prevention research. There is increased ownership and accountability when Africa CSOs are empowered to

develop their own agenda and strategies that fit their contexts and populations. African CSOs can leverage higher credibility and validation when NPT advocacy is integrated within their institutions and led by reputable CSOs which are already anchored within existing national, regional, continental and global HIV or health research mechanisms. These approaches can be more cost effective and more impactful than previous methods used that targeted individual CSO champions or outside of established mechanisms. However, despite such incredible achievements there were few challenges.

Evolving complexity of Science and Science Advocacy: African CSO capacity to understand and master the complexity of HIV biomedical science needs to be approached as a process and not a one-time workshop event. There is need for greater linkages between clinical research centers conducting NPT research with broader African CSOs in addition to their existing community and stakeholders’ advisory mechanisms. African scientists also faced challenges in understanding community and advocacy needs. Their busy schedules often limited their engagement for policy changes in collaboration with Africa CSOs. A science advocacy strategy in partnership with African scientists is crucial for sustainability and greater impact of NPT advocacy, especially in areas of domestic financing, integration of gender and sex and ethical engagement of adolescents in HIV research.

Inadequate funding and scopes of partnership: Advocacy for NPTs is a long-term endeavor that requires both short-term and long-term strategies. African CSOs involved in these projects were often faced with the challenges of limiting their activities to short-term strategies due to inadequate funding or lack of assurance for long-term funding. In the absence of long-term commitment or funding for institutional capacity strengthening, the integration and mainstreaming of NPT activities were strategically questioned by board members or respective community constituencies as a diversification of their already stretched resources. There is thus a need for sponsors and funders of NPTs to ensure an integration of institutional capacity strengthening component and strategic discussions and commitments to both short and long-term impacts.

Inadequate framework for monitoring and evaluation: In addition to lack of long-term perspectives in the nature of such grants, African CSOs faced the challenges of identification of clear measurement of milestones, impact and reliable measure of attribution. Advocacy and policy processes are often conducted in conjunction with multiple players and include different processes and stages (both short and long-term) of decision making. It was very difficult to establish causality and attribution of success to a certain organization or specific strategy. Future grants will need to ensure better framework for monitoring and evaluation of impact and milestones between sponsors and Africa CSOs. These should include both qualitative and quantitative and should be flexible to accommodate the changing political and social environmental challenges that Africa CSOs operate in.



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www.iavi.org
 info@iavi.org