ESTABLISHMENT OF THE AFRICA COMMUNITY ADVISORY BOARD (AfroCAB) CONCEPT NOTE

4 October 2012
BACKGROUND

Since 1998, one million lives are lost to AIDS annually in sub-Saharan Africa, and the region remains the epicenter of the HIV epidemic. In 2010, about 68% of all people living with HIV resided in sub-Saharan Africa, a region with only 12% of the global population. This region also accounted for 70% of new HIV infections in 2010, although there was a notable decline in the regional rate of new infections. The epidemic continues to be most severe in Southern Africa where, in 2010, almost half of the deaths from AIDS-related illnesses occurred.

By the end of 2010, approximately 5.1 million people in sub-Saharan Africa were receiving antiretroviral therapy (ART), representing only 49% of people in need of treatment. Recent studies have demonstrated that ART is a viable HIV prevention tool for uninfected adults and in prevention of mother to child transmission. Other beneficial outcomes of ART have been documented and understood for many years, most importantly improved quality of life and reduced morbidity and mortality. However, increasingly restricted funding now threatens the progress made in treatment programmes across the continent. Fewer people are being started on ART and many people currently enrolled in ART programmes risk discontinuing treatment as they are unable to afford to meet the financial costs. This situation requires heightened and amplified advocacy to save many lives.

RATIONALE

The concepts around the function and impact of ‘Community Advisory Boards’ (CABs) on public health issues have been recognized and applied in some parts of Africa to support work such as vaccine research. Task shifting efforts involving lay counselors in provision of care services, home-based care and treatment support have also benefitted from the use of CABs, giving communities opportunities to play a limited role in their own care. However, the greater role of CABs beyond support activities is a new concept in the region, and it has not gained a foothold in the African HIV treatment agenda.

This paper espouses the establishment of the African Community Advisory Board (AfroCAB) to serve as a community advocacy and participation hub for country treatment programmes. It introduces the AfroCAB as an advocacy mechanism that has been established to promote greater access to antiretroviral therapy and related treatment through the greater and meaningful involvement of African people living with HIV in all matters affecting them. The AfroCAB will be a living body and will evolve alongside the trajectory of the AIDS/TB epidemics across the African continent.

GOAL OF THE AfroCAB

The overall goal of the AfroCAB is to create a space for and to amplify community voices regarding access to HIV and TB medicines and research on other co-morbidities affecting people living with HIV in communities across Africa.

The AfroCAB will be a vehicle for community input to inform upstream advocacy addressing the need for effective treatment, diagnosis and prevention of HIV, tuberculosis, hepatitis infections and other diseases affecting their lives. It will also allow for more timely feedback on research by offering community views, leadership and guidance for ongoing initiatives.
KEY OBJECTIVES

- To build leadership and advocacy capacity in Africa among PLHIV and advocates on drug development and access issues, particularly around access to essential medicines, including originator and quality generic antiretroviral formulations.
- To create a platform for engagement with the originator and generic pharmaceutical industry as well as other relevant stakeholders.
- To promote and strengthen Africa-focused research through patient and community participation in protocol design, ethics committees, field activities and documentation of findings, including drug resistance monitoring and its impact on communities.
- To support development of country-specific strategies and action plans.
- To facilitate sharing and learning among African PLHIV leaders and advocates around access to ART and the wider treatment issues.
- To promote evidence-based drug safety practices and the development of updated treatment guidelines.

ESTABLISHMENT OF THE AfroCAB

The AfroCAB was formed following the World Community Advisory Board (WCAB) meeting held with pharmaceutical companies (originator and generic manufacturers), representatives of selected National AIDS Councils, UN agencies and other stakeholders in Nairobi, Kenya in 2011. It was established on the premise that people living with HIV in Africa need to promote, advocate for and defend issues affecting them. The AfroCAB consists of community advocates and activists who will play a pivotal role with regard to access to treatment for HIV, TB and other diseases affecting PLHIV. The AfroCAB will also work to spotlight and amplify community voices on issues such as intellectual property rights, Treatment 2.0, country ART guidance among other areas.

The inaugural Nairobi meeting unanimously supported the establishment of a regional CAB for Africa and identified the following as factors in the establishment of this body:

- Africa bears the largest burden of the HIV pandemic and other related diseases which have affected families and communities. There is a need to focus on problems that are peculiar to Africa especially with regard to treatment access issues including research on new drug regimens, service delivery and diagnostics.
- Despite having the largest number of people living with HIV, Africa has major shortfalls in access to antiretroviral treatment.
- African community activists and advocates need to be better engaged as a coordinated body on issues related to the goals and core objectives of the WCAB as they affect the region, especially with regard to ensuring continued uninterrupted access to affordable treatment for tuberculosis and antiretroviral medicines.
- Africans need to actively participate in treatment and cure research, ensuring that such research reflects the needs of the community and protects the rights of trial participants by observing the highest possible ethical standards.
- PLHIV leaders and advocates in Africa must engage more actively and consistently in HIV and health programmes and fora at country, regional and continental levels, including groupings such as UN agencies, ECOWAS, EAC, SADC, and the AU, ensuring that voices of PLHIV are brought to bear on all policy matters, in programmatic HIV responses and in decision-making processes.
A cadre of effective African PLHIV advocates is urgently needed and must be trained and empowered with knowledge and accurate information to enable them to address the challenges and opportunities for treatment access in their countries and communities.¹

**EXPECTED INTERIM RESULTS**

A 5-day capacity development workshop and consultation with 30 participants will be held in December 2012. The results of the meeting will include:

- Review and approval of the AfroCAB Protocol;
- AfroCAB representation from the four African regions (up to 60 members) selected as per Steering Group (SG) prescribed criteria.
- A set of AfroCAB priority advocacy issues for 2013 agreed; to be reviewed and approved in consultation with the SG.

**Note: Secretariat support**
A host organization will serve as the AfroCAB Secretariat for administrative convenience. The organization shall receive, disburse and administer funds on behalf of the AfroCAB. This organisation shall exhibit a high level of fiduciary integrity.

**AfroCAB COMPOSITION AND MEMBERSHIP**

**Member profile**

The AfroCAB would consist of self-nominated community advocates and activists from local, regional and continental NGOs. Selection and qualification for membership shall be through a process agreed by the Steering Group. The AfroCAB will be guided by a protocol that shall be reviewed, approved and put into effect at the first AfroCAB consultation in December.

**Advisory Group**

This will consist of 5-8 eminent individuals, such as respected clinicians, academics, etc., a majority of whom will be African. The Advisory Group members will be individuals in good standing who have made notable contributions in patient rights and to the fight against HIV.

**Steering Group**

This will initially consist of 7 individuals. Five members will be drawn from the general membership and 2 additional external CAB members who will serve on the SG as observers. The current SG membership will serve in an interim capacity through December 31, 2012. The next SG will consist of members who will be elected by the general membership. For institutional memory, the current SG will nominate two members who will continue to serve as part of the next SG.

The current interim membership of the SG is as follows:

Caroline Mubaira – Member Pan African Treatment Access Movement (PATAM) / Southern African Treatment Access Movement Organization (SATAMO) – Zimbabwe

¹ The past few decades have provided valuable lessons: that despite the presence of good people and good intentions within some national governments, multinational organizations, pharmaceutical companies, and global philanthropy, advances in global access to treatment must frequently be driven by the advocacy of PLHIV and advocates.
Dr. Bactrin Killingo – Medical Practitioner and Treatment Activist, TB CAB – Kenya

Obatunde Oladapo – Executive Director, PLAN Health Advocacy and Development Foundation (PLAN Foundation) – Nigeria

Viviane Furaha – Executive Director, Network of Women Living with HIV in Rwanda / International Community of Women Living with HIV (ICW) Global – Rwanda

Kenly Sikwese – Consultant and Treatment Activist, Positive Health Outcomes / Treatment Advocacy and Literacy Campaign (TALC) – Zambia

Nikos Dedes (Observer) – HIV Treatment Access Activist, European CAB – Greece

Wim Vandevelde (Observer) – European CAB/Hepatitis CAB/TB CAB – South Africa

Mohammed Barry – Graduate Student and Youth Treatment Activist – Liberia

**General membership**

There shall be no more than 60 members of the CAB (including the SG). Countries from Central Africa, East Africa, Southern Africa and West Africa regions shall be eligible to nominate one member. Countries with a high number of people living with HIV or elevated prevalence rates may be allowed to nominate one extra member. Criteria for membership will include strong links to community groups among others as set by the Steering Group.

**AfroCAB Coordinator**

AfroCAB operations shall be managed by a coordinator who shall be responsible for day-to-day running of AfroCAB affairs including fundraising. S/he shall also be responsible for liaising with the host organisation on behalf of the AfroCAB steering Group.

Responsibilities of the AfroCAB Coordinator will include:

- Coordinate all activities of the CAB;
- Serve as contact person for the AfroCAB;
- Ensure effective collaboration with stakeholders;
- Collate regional data from group members;
- Lead data analyses, reporting;
- Lead development of position papers and advocacy action points;
- Ensure timely dissemination of group’s outputs.

**ETHICAL ISSUES**

The AfroCAB will ensure that the international human rights principles are respected in the treatment, testing and research guidelines through participation in monitoring and ethical review processes including membership in Ethical Review Boards.
People living with HIV and AIDS will benefit from AfroCAB through greater access to improved and optimum treatment, diagnosis and prevention of HIV, tuberculosis, hepatitis infections as well as other diseases affecting their lives. The AfroCAB will contribute in a concrete way to the attainment of the broader global goal of achieving the “three zeros” — Zero new HIV infections, Zero discrimination and Zero AIDS-related deaths.¹

References


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