

Anti-retroviral therapies for HIV/AIDS in Africa: Using Advocacy to increase access and deepen impact¹

By Yinka Adeyemi²

INTRODUCTION

It is generally agreed that in the absence of a curative HIV/AIDS vaccine, about 24 million Africans who are living with HIV/AIDS will probably die within the next few years. This is why research into vaccine development has gained momentum in recent years³. Indeed, in 2005, the Yaounde Statement and Recommendations of the African AIDS Vaccine Programme (AAVP), an instrument for furthering the AU/NEPAD Health Strategy, called on African leaders, the AU, NEPAD and the RECs to integrate HIV/AIDS vaccine development into national HIV/AIDS plans. African health ministers in eastern, central and southern sub-regions have also passed a resolution⁴ calling for the development of HIV vaccines.

In Zambia, where HIV prevalence in the general population is 16 percent, the first vaccine trials have begun and will be completed in December 2007. In Kenya, six HIV/AIDS vaccine trials have taken place while another one, on multi-Clade, vaccine is underway. However, none of the trials registered immunogenicity high enough to warrant further trials. Such is the fate of six other vaccine trials in Uganda which have been similarly discontinued⁵.

Currently, there are 30 vaccine candidates in the pipeline for trials in Africa but there is no guarantee that any of these vaccines will deliver protection either at pre-exposure, point of transmission or post-infection stages⁶. Therefore, for Africa's millions who are living with HIV/AIDS, treatment with anti-retrovirals (ARVs) is the only viable option, especially since they have been proved to reduce HIV/AIDS mortality by as much as 80 percent. In 2005, for instance, between 250,000 and 350,000 lives were saved with treatment. In the same year, about 2.8 million people still died of the pandemic.

¹ Paper presented to the African Civil Society Forum 2007 on "Democratizing Governance at Regional and Global Levels to Achieve the MDGs", Addis Ababa, 22-24 March 2007. I gratefully acknowledge the valuable suggestions by Gladys Mutangudura, Amson Sibanda, Monique Nardi, Israel Sembajwe and Dr. Mathias Lademan, the Chief Medical Officer of ECA..

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³ In October 2006, the African Union organized a technical consultation with a broad participation of African stakeholders – experts on vaccine research and development, regional economic communities, and UN agencies, to examine the status of HIV vaccine research in Africa and steps to accelerate it.

⁴ The 42nd Conference of the Health Ministers of the Eastern, Central and Southern Health Community (ECSA), in Mombasa, February 2006.

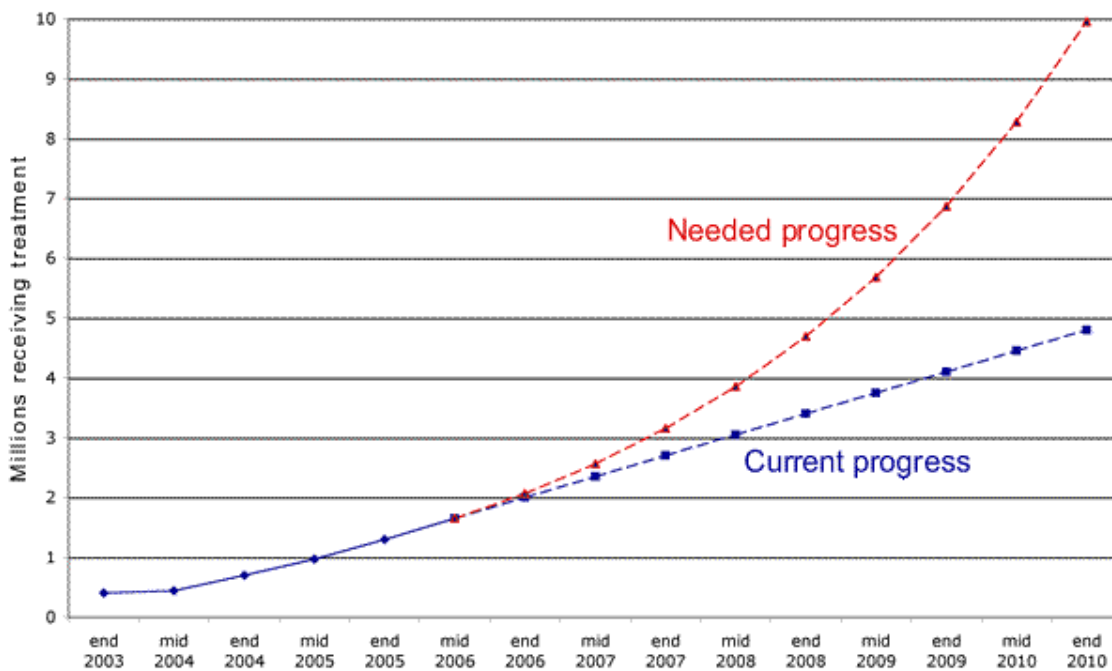
⁵ The immunogenicity vaccines have generally shown less than 50% of efficacy in preliminary trials.

⁶ Vaccine research is necessarily time-consuming and expensive. In the African context, human volunteers, who are imperative for trials, are hard to come by. See Yinka Adeyemi, A Media Handbook for HIV Vaccine Trials for Africa (UNAIDS 2000).

But despite the sharp reduction in price, especially of generics, (98 per cent since 1996), ARVs are still beyond the reach of millions who need treatment⁷, although remarkable progress has been made in expanding access. In Africa, one in six people who needed treatment received ARVs by December 2005. Uganda and Botswana are covering close to 50 per cent or more of their population who need ARVs, while in South Africa, ARV coverage grew from under 5,000 in 2004 to over 150,000 by August 2005⁸. This progress, however, masks the widening gap between those in need and those who actually receive the treatment.

For Africa, the realities are still daunting: Over 80 percent of global new HIV infection; 60 per cent of the new infections are amongst the 15-25 years age group; over 77 per cent of global mortality and 90 percent of the global estimates of children born with the virus through mother to child transmission. Yet, as Fig 1 shows, at current pace, less than half of those eligible for treatment will receive it by 2010. Of about 10 million people, mostly Africans, who will need ARV treatment by 2010, less than 5 million will actually receive the treatment.

Fig 1 : Projected number of people needing HIV treatment by 2010 (Global)



Source: www.avert.org

Of the 20 countries with the highest unmet need⁹ in antiretroviral treatment, 16 are in sub-Saharan Africa with a coverage of 11 percent¹⁰. In that sub-region, according to

⁷ In Mozambique, in 2004, less than 1 percent of those clinically eligible for ARVs were on treatment.

⁸ See UNAIDS, 2006 Report on the global AIDS epidemic, pp 151-152

⁹ The World Health Organization defines unmet needs as the total number of people (0-49 years old) in need of ART in 2005 minus the estimated number of people receiving treatment in June 2005”.

¹⁰ www.who.int/hiv/facts/unmetneed/en/index.html

WHO an estimated 4.7 million people needed ARV treatment that could not be met as at June 2005¹¹. Specifically, consider the following: In Nigeria ARV coverage is between 4-8 percent; in Ghana, about 5 percent; in Zimbabwe, less than 5 per cent. In South Africa, 866,000 people who need ARVs are not getting it, while in Uganda, which has one of the best access rates in Africa, (35-43 percent), about 90,000 people who need treatment are still not getting it.¹² This is the clearest rationale for improved advocacy for HIV treatment.

The CSO Advantage

CSOs and NGOs are vitally important if Africa is to redress this situation for two reasons: There is the **Teflon Factor**. To a large extent, these organizations are not vulnerable to the maneuverings of government agencies. Very few get their funding from internal sources, and, ipso facto, are more vocal and committed than governmental agencies who pursue the same goal. Secondly, CSOs are able to use confrontation more effectively (although many mistakenly see collaboration with government, even when warranted, as a sign of weakness and cooptation). This paper attempts to make a few concrete suggestions on how CSOs and NGOs can carry forward the ARV treatment agenda for Africa.

What would it take to put more Africans on ARV treatment, strengthening health systems and saving lives? In 2003, the World Bank, in partnership with the Economic Commission for Africa (ECA) and the World Health Organization (WHO) initiated pilot studies in “Treatment Acceleration Programme” (TAP) in three African countries – Mozambique, Ghana and Burkina Faso. The Programme will end in September 2007 after documenting many valuable lessons for replication in other African countries. This short paper draws on lessons from one of the TAP pilot countries, Mozambique, in advancing some advocacy strategies for strengthening the advocacy capacity of civil society organizations (CSOs) for scaling up ARV treatment of people living with HIV/AIDS (PLWHA) in Africa. In the next sections, we outline some critical issues which are central to an advocacy campaign.

Issues in HIV treatment in Africa

There are many issues pertaining to HIV treatment advocacy in Africa.¹³ Some of the key issues are:

Cost: There is so much money around for HIV/AIDS¹⁴; ARVs are very cheap and available, however they are not affordable in many African countries where many live on less than \$1 a day. That is why, “every day, 8,000 people are dying from a disease which

¹¹ www.who.int/hiv/facts/cov0605/en/print.html

¹² See www.who.int/facts/20UNMETNEEDweb.jpg

¹³ The new HIV/AIDS Learning Team at the ECA will, in future, deal with many aspects of these issues.

¹⁴ Annual funding for the response to AIDS in low and middle income countries increased 28 folds from \$300million in 1996 to \$8.3 billion in. There is additional money from the US President’s Emergency Fund for AIDS Relief (PEPFAR) and the World Bank.

can be treated, but which all too often isn't." (www.avert.org/aidstarget.htm). The challenge remains **securing health financing with a continuation strategy**¹⁵. The goal must be free service (clinical tests and lifetime supply of drugs) for all Africans who need HIV treatment. To accomplish this, African countries need to raise more money and target a huge chunk of the \$40.2 billion which UNAIDS estimates would be required for AIDS response in low and middle-income countries in 2007 and 2008 alone.

Testing and associated stigma: One of the by-products of the intense stigma and discrimination surrounding HIV/AIDS is that people choose not to obtain voluntary testing and counseling (VCT) in their immediate neighborhoods. Consequently, they travel long distance away from home, creating caseload problems at the receiving end, especially in situations where equipment and personnel pose a serious challenge in a centralized system. The target here should be minimizing HIV/AIDS-related stigma by integration VCT into the regular health services.

Adherence¹⁶: In many African countries, ART is initiated only after three adherence counseling sessions and only when a patient presents a family member or friend who can assist in monitoring and facilitating adherence to treatment regimens. This is usually difficult in the context of stigma, discrimination and the need for privacy. A reduction of stigma and discrimination will result in increase in adherence as support becomes easier to secure.

Nutrition: In many African countries, PLWHA and undergoing treatment need to augment their immune system with good nutrition because many of the drugs have to be taken after meals for the desired impacts¹⁷. In many TAP trial sites, the World Food Programme provides food for up to three months. The challenge is to push for continuation of nutritious food supply for those who are receiving HIV treatment.

Opportunistic Infections (OIs): There is the additional costs associated with treatment of OIs, mostly TB in PLWHA who are undergoing ART.

Infrastructure: Even when ARVs are available, the transaction costs associated with delivery to dispersed populations may be huge and usually unaffordable for African countries. This is one reason treatment is usually centralized. Unfortunately, centralization negatively impacts VCT and adherence and, may promote drug resistance.

Stock-out and Personnel: Treatment centers need a constant stock of needed ARVs and key personnel – Clinicians, Nurses, Follow-up and Adherence Counselors, many of who have left the most critical areas in Africa through migration and direct target-employment by Western countries who can afford better salaries and conditions of service¹⁸.

Frequently, these pose a challenge.

¹⁵ ECA and its partners are committed to examining how African countries can actualize this policy. See, "Align budget allocations between prevention and treatment, Jannah urges African countries", UNECA, 12 April 2006.

¹⁶ In a forthcoming study, ECA will examine some social determinants of adherence to treatment. For more information, contact the Human and Social Development Section at hsd@uneca.org

¹⁷ Generally, malnourished patients are less likely to benefit from ARV treatment. See, Paton NI, Sanggeetha S, Earnest A and Bellamy R, "The impact of malnutrition on survival and the CD4 cell response in HIV-infected patients starting antiretroviral therapy", in *HIV Medicine* 7(5) July 2006.

¹⁸ See "Where do African migrants go to?" in UNECA, "international Migration and Development: Implications for Africa (2006)

Over the last three years, TAP has addressed many of these challenges and ECA's HIV/AIDS Learning Task Team is planning to do further study on the rest in the near future.

Treatment Acceleration Programme (TAP)

TAP is a \$60 million, three-year programme which seeks to strengthen countries' capacity to provide comprehensive, quality care and treatment which is effective, affordable and equitable for people living with HIV/AIDS. At the time the programme began, in September 2004, only about 100,000 of four million Africans who needed ARVs in order to forestall the onset of AIDS, were receiving treatment. Without treatment, millions were certain to progress onto AIDS and die.

TAP was a convergence of mutual interests for all the partners involved. For the pilot countries, the programme was an opportunity to stop the spread of HIV/AIDS, extend the lives of PLWHA, and reverse the negative impacts. For the World Bank, scaling up treatment in Africa would protect its multi-sectoral investment portfolio, which was already under threats from AIDS. For ECA, TAP was an opportunity to sharpen its focus and deepen the quality of its advocacy for response against an epidemic which has ravaged Africa most and whose impacts would be felt years to come. For WHO, TAP was a natural ally to its 3 by 5 initiative through which it aimed to encourage the treatment of 3 million people in 5 years.

To implement the Programme, the World Bank channeled funds through sub-grants managed by local NGOs or the private sector¹⁹ working in partnership with the Ministry of Health in pilot countries.

Using Advocacy to increase access to ARV

There is incontrovertible evidence in Africa and elsewhere that advocacy, when properly targeted and packaged, is effective in reversing wrong HIV/AIDS policy²⁰. This is because advocacy preys on the weaknesses of policy makers: *fear of being on the wrong side* and *a craving for popular support and social endorsement*. Advocacy works best when it is planned, continuous and implemented in a milieu of concentric contingencies, where practitioners anticipate change and rise up to them without derailing the campaign. Essentially, those at the fore-front of the campaign must be conscious of the proverbial rules of the gambler: know when to show; know when to fold; know when to walk away. Advocacy usually fails when there is a disconnect between evidence and argumentation. This disconnect crucially and negatively affects the construction of goodwill which

¹⁹ In Burkina Fasso, AIDS Empowerment and Treatment International (AIDSETI), Sainte Camille and CICDoc; in Mozambique, Comunita di Sant'Egidio, Health Alliance International and Pathfinder International; and in Ghana, Private Enterprise Foundation, Family Health International and National Catholic Health Service all under the guidance of the respective country's Ministry of Health.

²⁰ See various case studies in Neill McKee et al, Strategic Communication in the HIV/AIDS Epidemic (Sage Publications, 2004).

encourages believability and mass followership that advocacy needs to succeed amongst the general public, the mass media and policy makers..

Essentially, for the purpose of HIV/AIDS treatment scale-up, advocacy is “a *continuous* and *adaptive* process of gathering, organizing and formulating information into argument to be communicated through interpersonal and media channel” to raise resources, gain political or social leadership and prepare society for its acceptance. (McKee et al 2000)²¹

In South Africa, among other examples, advocacy campaign built on equity and emergency, effectively put governments and pharmaceuticals on the defensive, opening up the field for efficacious generics and getting more people under treatment.

Elements

A few elements of advocacy/strategic communication become useful in campaigning for a scaled-up response to HIV/AIDS treatment in African countries:

1. A *relentless* and *refreshed* information acquisition regarding the status of HIV treatment (ARV access, drug resistance, determinants of adherence to treatments, etc) . CSOs must increase their thirst for cutting edge information with a uni-directional objective: getting more people under treatment with better first line drugs. Since the field is very dynamic, dedicated persons should be assigned to harmonize data, check facts and renew evidence needed to strengthen argumentation.
2. Burst myths surrounding treatment: Two of the most common of such myths are that anti-retroviral therapies cannot be sustained in resource-poor settings or amongst high-risk groups; and that first line single dose treatment of AIDS-infected pregnant Africans with nevirapine, which would be considered unethical in some Western countries²², was best for African countries because of resource constraints.. Nemes et al (2004)²³ have shown that patients in low income countries adhere to ART equally, or even better than patients in high-income countries.
3. Push **Universal Access**, the African position which encapsulates the spirits of the Brazzaville Commitment. The African position contains sufficient targets for an effective advocacy.

Push for increased demonstrable political commitment: There is a need to operationalize the various commitments to fighting HIV/AIDS made by African leaders at various forums. Often this has not been done because of the clash of national priorities

²¹ McKee Neill, Manoncourt, E, Chin, SY and Carnegie , R (eds), “Involving People, Evolving Behaviour, New York and Penang, UNICEF. Quoted in Neill McKee et al, “Strategic Communication in HIV/AIDS Epidemic”, Sage Publications 2004.

²² For a critique of this argument, See Leonardo Palombi et al, “HIV/AIDS in Africa: treatment as a right and strategies for fair implementation. False assumptions on the basis of a minimalist approach” in AIDS: Volume 19(5) March 2005 p 536-537.

²³ MIB Nemes, et al, (2004) Antiretroviral adherence in Brazil, AIDS, 18 (Suppl. 3).

on a platform of scarce resources. CSO should not get drawn into the debate on which priority government should address first; it is a useless exercise, which will not increase HIV treatment. Instead, push for on-the-spot assessments at the highest political level. Priorities often change when leadership gets involved in HIV treatment. That was the case with Sofala, Mozambique, (pop 1.5 million) with one of the highest HIV prevalence in Mozambique (26 per cent).

Mozambique: scaling up with increased political commitment

In 2005, of the 50,000 people in need of treatment; only 3,000 were being treated in six centers. Only about 10 per cent of children in need of ART. Although VCT was available in almost every district, there was only one laboratory in the Province for CD4 counts. The CD4 equipment does not automatically produce CD4 counts: the lab usually did CD4 from White blood cells count, which could not be easily stored in the computer due to personnel shortages. Accordingly, patients, who usually traveled up to 17 kilometers to learn about their results and to begin treatment, often were told to return at a later date. Many never bothered to return.

In 2006, the government of Mozambique embarked on a series of programmes beginning from February with Presidential assessment visits to HIV/AIDS endemic areas, the first national meeting of STI/HIV/AIDS, the nomination of Provincial Coordinators, Directive to commence early initiation of ART in HIV/AIDS patients who are also infected by TB, nomination of senior staff of Ministry of Health to provide technical support to each Province and the announcement by the Prime Minister to expand HIV treatment sites to every district by March 2007.

The initiative worked beyond Sofala. By December 2006, Mozambique had more than 150 sites offering ART. Treatment was provided in 105 of its 125 districts and the number of patients on ARVs increased drastically to 44,100 from about 10,000 in April 2005. And by changing the nomenclature from VCT which is closely associated with HIV/AIDS into ATS (Sites for Assisting and Testing for Health), Mozambique also drastically reduced AIDS-related stigma and increased the number of those testing for HIV. ATS focuses on testing and counseling for all chronic diseases.

Fulfilling past commitments

One instrument that has not been effectively used for HIV treatment advocacy is the African Peer Review Mechanism (APRM) process. Yet, it is a powerful and formidable tool. APRM addresses HIV/AIDS in two ways: It assesses how the country under review is addressing the pandemic and assesses the country in the framework of Goal 6 of the MDGs:

African heads of state specifically mention HIV/AIDS in three APRM documents²⁴. In the **Declaration on Democracy, Political, Economic and Corporate Governance**, they undertook to work towards the enhancement of Africa's human resources...and "better health care, with priority attention to addressing HIV/AIDS and other pandemic diseases." In the **Objectives, Standard, Criteria and Indicators for the African Peer Review Mechanism**, one of the key objectives cited is the strengthening of "policies, delivery mechanisms and outputs in key social development areas (including education for all, combating of HIV/AIDS and other communicable disease).

Lastly, in the APRM **Self-Assessment Questionnaire**, African leaders made extensive references to the protection of vulnerable groups, including PLWHA and children orphaned by HIV/AIDS, and the inclusion of HIV/AIDS on the list of socio-economic development indicators.

CSOs can influence this process on two fronts:

1. Monitor when a country is up for the APRM and push authorities and reviewers to give serious and thorough consideration to the issue of HIV/AIDS; and
2. Prepare advocacy materials to either validate or question official position on HIV/AIDS.

Since less than half of Africa has signed up for APRM, CSOs will find another instrument, The African Common Position on HIV/AIDS, which encapsulates the Brazzaville Commitment to Universal Access. Led by the African Union Commission, the Brazzaville Commitment was concluded in March 2006 after national consultations in 41 African countries. These consultations involved more than 5,000 stakeholders, including national governments, UN organizations, community-based organizations, civil society groups, and PLWHA. Notwithstanding the hiccups suffered by the Common Position during the last UNGASS in New York²⁵, it remains the African position and leaders can be held accountable to it.

Fundamentally, the African Position calls for, among other measures, the development of national account systems to monitor expenditure and resource allocations to accelerate the achievement of the existing target by African leaders to allocate 15% of total budget for health, including HIV and AIDS; the setting up of regional and national bulk purchasing, technology transfer, south-south collaboration and sub-regional production of HIV-related medicines and commodities; the development of Africa's capacity to use the

²⁴ For more information, see Nnadozie, Emmanuel, APRM as an instrument of response to HIV/AIDS, TB and Malaria, a presentation to Inter agency meeting on coordination and harmonization of HIV and AIDS, TB, and Malaria strategies, Addis Ababa, November 6-8, 2006

²⁵ After painstakingly conducting over 40 national consultations, a Stakeholders meeting in Brazzaville, African Heads of State, meeting in Abuja, adopted the Brazzaville Commitment as the African position. However, in New York, during the 2nd UNGASS, some African countries submitted motions in which they argued that the Common Position, which was presented by the Chair of the African Union, during a session chaired by UN Secretary General Kofi Annan, should be considered as a mere technical paper from Abuja, and not an African position.

World Trade Organization global trade rules, such as TRIPS; and the strengthening of relevant laws, jurisdictions and policies, to reduce stigma and discrimination and empower PLWHA.

Conclusion

The future of an accelerated ARV treatment in Africa will depend on intense advocacy by stakeholders in NGOs and CSOs who are best suited to hold leaders to account. But they will be successful only to the extent that they effectively use information. CSOs should also forge crucial broad partnerships beyond their traditional allies in pursuit of a new regional agenda to offer free HIV/AIDS services to everyone who needs them, regardless of the ability to pay.

