

Universal access by 2010

10 challenges on the way

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Introduction

In 2003, the WHO set an ambitious target: three million people living with HIV/AIDS in low and middle-income countries would be treated with life-prolonging antiretroviral treatment (ART) by the end of 2005. This was an important step towards achieving the G-8 goal set in July 2005, namely to come as close as possible to universal access by 2010.

As of December 2005^[1] approximately 1,3 million people in need of ART were actually receiving it. The aim of 3by5 was to provide treatment for 50% of the estimated need in 40 focus countries by the end of 2005. However, this target was only met by 18 of the focus countries. In Sub-Saharan Africa coverage increased from 2% in 2003 to 17% at the end of 2005. About 1 in 6 of the 4.7 million people in this region who are in need of treatment were actually getting it. The estimated coverage in Asia was 16%.

In this policy brief, we highlight ten challenges that need to be addressed to ensure that universal access becomes a reality by 2010 and positive health outcomes for PLWA (People living with HIV/AIDS) are guaranteed. Health workers, policymakers and ART users from 14 countries

put forward these challenges in the course of rapid appraisals, which were conducted by Health Action International (HAI), the International Treatment Preparedness Coalition (ITPC) and University of Amsterdam in 2005.

Dramatic increases in access to treatment and extremely high levels of adherence (at least 95%) are essential to ensure positive treatment outcomes for PLWA. However, this is hard to achieve because health systems tend to be weak in the countries that have been hardest hit by the epidemic. This policy brief argues that governments must move beyond the focus on ART supply and confront the social and economic conditions which pose obstacles to access and optimal health outcomes. Furthermore, governments need to integrate ART in a continuum of AIDS related healthcare and to improve community participation. Treatment targets should be accompanied by detailed implementation plans and ongoing monitoring and evaluation to ensure that programme activities are suitably adjusted when problems occur. The stakes are high. If effective treatment programmes are not achieved, drug resistance may well become a major obstacle to the success of future ART programmes.

The 10 challenges are:

1. **Inequities in ART coverage**, both between and within countries.
2. **Procurement problems**, due to a lack of coordination between both donors and actors at a national level.
3. **Treatment interruptions due to stock-outs** of both first and second-line drugs, and paediatric formulas.
4. **Inaccessible diagnostic tests**, which means that not enough people are aware of their HIV status, and monitoring of treatment needs and efficacy is suboptimal.
5. **Recurrent transport costs, and user-fees**, which challenge continued access and adherence to ART.
6. **Overburdened health workers**, due to a lack of investment in health services and the rapid scale-up of ART.
7. **Continuing stigma and discrimination** of people in need of treatment, especially affecting intravenous drug users and other vulnerable groups.
8. **Lack of adherence and nutritional support for ART users.**
9. **Uncoordinated action** at all levels of planning and implementation, resulting in missed opportunities for a better continuum of HIV-AIDS care.
10. **Planning for sustainability** of ART programmes, including future needs for second line treatments.

Findings are presented in more detail below, followed by recommendations for action.

Recommendations for action

The following recommendations for action have been formulated by our country teams on the basis of the 14 rapid assessments. They complement and reinforce the recommendations that were made in the UNAIDS Assessment of Progress towards Universal Access, which has been submitted to the UN Special Session on the Implementation of the Declaration of Commitment on HIV/AIDS, to be held in New York, from May 31st to June 2nd 2006^[1]. The UNAIDS process were based on a series of country and regional consultations. The appraisals involved listening to the voices on the frontlines of ART programmes.

1. **Advocacy for Universal Access:** all stakeholders must join forces to advocate universal access at the country level and work more with civil society in doing so. Specific access targets need to be set for children and vulnerable populations.
2. **Reducing obstacles to equitable access to ARVs:** national governments and international donors should aim to reduce recurrent costs for users by eliminating user-fees for AIDS treatment, the costs of diagnostic tests and second line treatments should be reduced substantially, and transport and food support provided to PLWA, especially during the early stages of treatment.
3. **Strengthen AIDS treatment and care:** Governments, UN-agencies, civil society, private healthcare providers and international donors need to collaborate in:
 - a. Building local capacity to forecast the need, procurement and supply of essential AIDS medicines. Governments should make sure that PEPFAR and other agencies involved in ART programmes do not establish separate ART procurement and supply programmes.
 - b. Ensuring access to a range of ARVs, including first line drugs for TB and hepatitis patients, second line regimes and paediatric formulas.
 - c. Strengthening and updating the ARV guidelines for settings with poor resources to help health services deliver comprehensive AIDS care, which is integrated in primary healthcare, mother and child care, sexual and reproductive health, tuberculosis and other related programmes. Governments should ensure the national implementation of the integrated guidelines.
 - d. Scaling-up training of health professionals to provide a continuum of care, including training nurses, counsellors and pharmacists in ART management.
 - e. Developing models for the community level provision of ART to increase access and reduce recurrent costs.

[1]http://data.unaids.org/pub/InformationNote/2006/20060324_HLM_GA_A60737_en.pdf

- f. Strengthening adherence support mechanisms, treatment monitoring and clinical management to ensure positive health outcomes for ART users.
 - g. Scaling-up treatment literacy activities, to increase awareness of ART and enhance informed use.
 - h. Setting up mechanisms to involve PLWHA in the planning and implementation of ART programmes at both a national and local level.
 - i. Implementing a system of independent monitoring and evaluation, with operations research to assess service delivery treatment outcomes, and levels of resistance.
 - j. Responding rapidly to implementation barriers identified by dissemination of better practices, guidelines, manuals and country level assistance.
4. **Ensuring sustainable resource flows:** There is international consensus that the resource base for ART programmes must be expanded dramatically in order to achieve universal access by 2010. Specific recommendations resulting from the appraisals are:
- Governments and international donors should diminish bureaucratic delays in applying for, transmitting and managing external resources for their ART programmes.
 - Governments and international donors should allocate sufficient resources to treatment scale-up, taking into consideration current and future treatment needs, including needs for second line treatments. Budgets tend to be based on ART targets, rather than adequately forecasted needs. National governments should ensure affordability of second line treatments and diagnostics by negotiating for price-reductions, by using the flexibilities of the World Trade Organization, Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS agreements) including the use of voluntary and compulsory licensing and local production.
 - Investments are needed in the development of paediatric ARVs.

It is now known that ART can be delivered in all environments. The challenge is to learn by confronting obstacles and building on successes, to ensure that health care systems worldwide deliver optimal care to all who need ART. This will require coordinated action in countries, between countries, and between donor-organizations.

10 Challenges on the way

1. Inequities in coverage

The studies established that ART coverage differs dramatically between and within countries. Thailand, Botswana and Uganda, where the governments rapidly responded to treatment needs, are now treating more than half of those requiring ART. Other countries, like Tanzania, India, Nigeria, Vietnam and Ghana have extremely low coverage, see table 1.

Table 1. ART Coverage in the fourteen countries included in the appraisal, December 2005^[2].

| Country | Estimated number of sites | Estimated number of people (0-40 years) in need of ART | Percentage in need actually treated |
|--------------------------|---------------------------|--|-------------------------------------|
| Ghana | 5 | 61,000 | 7 % |
| Botswana | 32 | 84,000 | 85% |
| Uganda | 175 | 148,000 | 51% |
| Tanzania | 44 | 263,000 | 3% |
| Kenya | 250 | 273,000 | 24% |
| Nigeria ^[III] | 71 | 636,00 | 7% |
| South Africa | 183 | 983,000 | 21% |
| Vietnam | 74 | 25,000 | 12% |
| Thailand | 890 | 135,000 | 60% |
| India | 74 | 785,000 | 7% |
| Moldova | 2 | <1000 | 39% |
| Peru | 50 | 12,000 | 52% |
| Dominican Republic | ... | 15,000 | 17% |

To ensure equitable access, the coverage of treatment sites has to be nationwide. In Ghana and Kenya, both the northern and the north-eastern regions were found to have very limited access to treatment. In South Africa most people receiving treatment were concentrated in three provinces (Gauteng, Western Cape and KwaZulu Natal^[III]). In the Dominican Republic, there is a lack of access to treatment in the poorest regions in the southwest, along the Haitian border, and in several eastern cities and towns with relatively high rates of HIV-AIDS^[III]. In India, the government prioritised the implementation of its ART programme in hospitals attached to medical colleges in states with a high prevalence of the disease.

[2] WHO. Progress on Global Access to HIV Antiretroviral therapy: a report on "3by5" and beyond. WHO/UNAIDS, 2006.

“People living with HIV in India should be able to get their ARVs wherever they live. NACO (the National AIDS Commission) should not discriminate against PLWA living in certain states of India by establishing ARV centres only in “high prevalence states” ...Is it my fault that I happen to live [in] a “low prevalence state?” (treatment activist, Gujarat India [1]).

2. Procurement problems

As scale-up continues, increasingly more patients present at facilities, underlining the need for the establishment of systems to procure and manage the supply of ARVs. Essential drug programmes exist in most countries and have expertise in these processes. Nevertheless, this expertise is often not utilised, since the ART programmes are run by governmental AIDS commissions and NGOs, who until recently had little to do with medicines. In Moldova and Peru, we found that the agencies procuring drugs had made miscalculations in both the quantities procured and the administrative procedures required for rapid approval. In Moldova, for example, the drugs ordered through the IDA (International Dispensary Association) in the first quarter of 2005 were insufficient to meet the needs of the 136 patients who were on first-line treatment in the country. There was only enough Lamivudine and AZT to treat about 54 patients. Our research team in the Dominican Republic found that there was not only a general lack of communication, but also what can only be described as a power struggle between COPRESIDA (the government AIDS agency receiving Global Fund resources) and the Ministry

of Health, which depends on COPRESIDA for the funds to procure medicines^[1].

The procurement of second line treatments proved particularly complicated. Governments must negotiate prices with suppliers, since these drugs are not yet available in cheap generic formulation (2nd line treatments cost between US\$1,880 and US\$4,000 per person per year^[3]). In Peru and Vietnam, policymakers reported that multinational company representatives attempt to influence procurement procedures through promotional activities in which the safety and efficacy profiles of branded drugs are highlighted, and price-reductions offered. In India, the research team found that the National AIDS Commission had not negotiated with Indian pharmaceutical manufacturers to bring down prices of second line treatments. In the Dominican Republic, respondents feared that the recently signed Central American Free Trade Agreement between the United States and six other countries including the Dominican Republic, would undermine access to affordable second-line AIDS medicines due to the US's insistence on safeguarding patents for originator-brand ARVs^[1].

[3] WHO. Progress on global access to HIV antiretroviral therapy: a report on “3by5” and beyond. WHO-UNAIDS, 2006.

Moreover, donor procurement procedures also pose problems for ART programmes. In South Africa, national regulations stipulate that ARVs must be approved by the medicine control council, while PEPFAR requires FDA approval^[11]. Treatment programmes funded by PEPFAR thus have to procure drugs, which are both Medecine Control Council (MCC) and FDA approved. In Ghana, the Ministry of Health was forced to set up separate procurement procedures for the Global Fund, as the head of the unit reported “they want things done their own way, and we also want things done our way...”

Given that resource-poor countries have difficulty in monitoring the quality and safety of drugs, the WHO has set up a prequalification project to evaluate drugs. The Global Fund requires that the ARVs bought with its resources are pre-qualified by the WHO. Policymakers in Peru, Thailand and Vietnam reported delays in obtaining prequalification for locally produced ARVs, suggesting that the WHO

should support local producers in preparing the dossiers for prequalification assessments and in ensuring good manufacturing practices.

It appears that the more donors a country has, the more procurement mechanisms it must also deal with. In Vietnam, for example, there are three different procurement mechanisms. With Global fund resources, the government procures first-line generic drugs from India through UNICEF. Through PEPFAR the government is obliged to import branded drugs as first-line treatment that are approved by the US-FDA. In the Esther programme, which is funded by French bilateral aids, both generic and branded first-line drugs are procured from a variety of sources.

Harmonisation of procurement requirements would be an important step in the right direction, with a focus on building local capacity to strengthen existing essential drugs programmes.

3. Treatment interruptions due to stock-outs

Continuity in the supply of ARVs is crucial to success of ART programmes. When stock-outs occur, patients' treatment is interrupted. This not only diminishes the likelihood of positive health outcomes for individual users, but also threatens the sustainability of ART programmes since drug resistance may emerge, which means that people might need to switch over to more expensive second line ART regimes.

Instances of stock-out of first-line drugs were reported in half of the countries in which we conducted rapid assessments. It was found that Efavirenz, a first-line drug necessary for patients with TB, was frequently out-of-stock (in Thailand, Vietnam and Peru).

In Peru, six out of the nine facilities assessed had had some kind of stock-out throughout the past year. In Tanzania, this was the case for two of the seven facilities visited.

Table 2. Kinds of stock-outs reported in health facilities in Peru (N=9)

| Location | ARV out of stock | Period in which stock-out occurred |
|------------------------------------|---|---|
| Hospital in Central Lima | Lamivudine and Efavirenz Stavudine, Didanosine | November 04 to January 05 March 2005, May 2005 |
| Hospital in South Lima | Stavudine | May 2005 |
| Hospital in Central Lima | Lamivudine, Efavirenz and Abacavir | July 2005 - September 2005 Occasional stock-outs |
| Hospital in Eastern Lima | Efavirenz | May-September 2005 |
| Hospital in North Lima | Efavirenz | August 2004 - March 2005 |
| Regional Hospital (Chimbote) | No shortages reported | |
| Regional Hospital Iquitos | Stavudine | May 2005 |
| Regional Hospital Piuria | None | |
| MSF health Centre (El Salvador) | None | |

When Nevirapine shortages occurred in the Dominican Republic, patients were given just a few days of drug supplies and told to come back for more later^[11]. Some doctors even purchase medicine stocks abroad themselves and transport them to the Dominican Republic by plane in order to have a stock of ARVs.

“ This is a small country with relatively good roads to all the sites that need ARVs.

It is inexcusable that orders are not filled monthly on a timely basis. It is inexcusable that there are waiting lists open for months, when there are ARVs in customs or in the warehouse, ticking towards expiration. This is truly a crime” (PLWA, Dominican Republic).

In 2003, delays in purchasing new drug supplies, together with the over-enrolment of clients, led to ARV stock-outs lasting for over two months in many Nigerian centres thus forcing PLWA to share or interrupt their treatments^[11].

Most countries report a lack of paediatric formulations as a specific problem. Parents are thus forced to break up or crush adult tablets, which may lead to over and/or under-dosing. In fact, there are very few paediatric formulations on the market. More research and development is needed to test the safety and efficacy of first and second-line ARVs for children, and to develop child-strength fixed dose combinations.

4. Inaccessible diagnostic tests

If people are not aware that they are HIV positive, they will generally only find out that they require treatment when they are seriously ill, which may already be too late. Universal access to ART requires better accessibility to HIV tests and counselling.

Respondents in South Africa suggested that the current model of voluntary counselling and testing does not work well. Routine testing would allow healthcare workers to manage patients during the initial stages of treatment. Positive HIV-tests should be followed up by a CD4 test to check and track whether PLWAs should be receiving ART. Once treatment has been started, regular CD4 counts must be done to monitor treatment outcomes. We observed a lack of such follow-up care for women who tested positive in PMTCT (Prevention of Mother to Child Transmission) programmes, and for their children (including early HIV testing through PCR)^[4], despite current guidelines, which state that such care should be provided^[11].

In Botswana, Tanzania, Uganda and the Dominican Republic, it was found that health facilities lacked

the laboratory facilities necessary for conducting CD4 counts to monitor the health status of PLWA. The facilities send samples away for CD4 and viral load testing. This meant that people who were very sick had to wait for at least two weeks before they could be put on therapy. Even if CD4 machines were actually available, the reagents could be out of stock.

In addition, despite CD4 equipment being in place, tests are not always accessible to PLWA. In nearly all the countries that we visited, people have to pay for HIV and CD4 tests (around US\$ 6 on average) themselves, even though ART is generally free. This amount may seem paltry, but it restricts access to treatment for the poor, especially when the prescribing physicians request that other tests be done. In Peru, half the ART users interviewed reported that they had paid around US\$ 30 for testing before their treatment had even started.

In Vietnam, respondents reported the following additional costs

Table 3. Treatment related costs reported by the respondents in Vietnam

| Items | Cost US\$ |
|---|-----------|
| Consultation per visit | 0,30 |
| Elisa test | 3 |
| CD4 testing using flow cytometry | 12 |
| CD4 testing using dynabeads technique | 4 |
| Liver function | 2 |
| Chest X ray | 1.50 |
| Sputum smear (x3) | 3 |
| Other costs: counselling, psychological support; transportation, food per month | 30 |

[4] PCR - Polymerase Chain Reaction

5. Recurrent costs for users

In countries where there are still a limited number of facilities providing ART and where geographical distribution is skewed, transport costs are reported to be another serious problem, which limits access to ART. Facilities usually require patients to come back to get monthly refills, which means that these transport costs are recurrent. Ironically, the monthly follow-up visits are intended to monitor adherence; in practice they may reduce it. Many ARV users complain about very long waiting times. These are an additional burden, which often mean a loss of income, or even worse, the loss of employment. In India, some treatment centres only provide a week's supply of ARVs, which forces PLWA to undertake costly and time-consuming travel to get their refills on a weekly basis.

"I came from very far over 50 kilometres from here. Before I come to the hospital I have to plan the money for a journey fare to the clinic. In fact my extra drugs got finished yesterday." (Male ARV user, Uganda).

"I once missed my appointment for refill because there were no vehicles coming here. I was in the stop from early morning and by noon I went back home. Fortunately I still had some medications." (Male ARV user, Botswana).

"Sometimes I do not have bus fare to come here for my drugs so I miss out while others get them (Kenyan ART user)

"I have very many people in the village, they are dying because they don't have money to transport themselves to the hospital. You need to have this money monthly. Like me, from the village where I come from, getting up to this place costs 15,000 (US\$8.5). To and fro is 30,000 (US\$ 17) , which is a lot of money. And getting that money is a problem. So maybe, like people in Kyoga, if they can send that drug up to Kyoga, I think that could be good. Right now only Lira Referral Hospital gives ARVs, and that is 130 kilometres from our place (Kyoga). Very far!" (Ugandan ART user)

"Some people have failed to report to the clinic on time because they failed to get transport to reach the clinic. Some people come from the islands, and they will tell you that they did not get money to cross the waters and that is why they did not come on time. And when you are told that, you cannot do much but to hope that when the next visit comes, he can afford to come on time."(health worker from Uganda).

Furthermore, in some countries people also have to pay user fees to obtain the services that provide treatment. This is, for example, the case with public health facilities in Kenya where people reportedly paid between US\$ 0.7 and 7 to gain access to the services providing treatment. In Thailand, ART is provided under the 30 Baht scheme (0.8 dollar); this is the user-fee for visits to the health facilities for the essential health services provided by government. These costs may not seem high, but since they are recurrent they can still pose a significant financial problem to ART users.

6. Overburdened health workers

The key to providing an appropriate range of care is well-trained front-line health workers. In countries like Peru and Kenya, where the scaling-up process has been rapid, health workers stressed that a high workload was a key problem in the ART programmes. They also point to the need for more training in the management of HIV and AIDS. In Kenya, all of the staff involved in the ART programme complained about suffering from burnout due to the ART patient workload. Where staff is forced to work under such pressure, ART users tend to have to wait for a long time to get their refills.

In Tanzania, the average time spent at the clinic was six hours. About half (12/28) of the Tanzanian health workers interviewed identified long waiting times as a significant problem.

“if the situation remains like this, doctors will be tired and the last patient will not be attended properly.” (FGD respondent in Tanzania).

In Botswana, most respondents reported that they generally spent around 4 hours at the clinic. In Uganda, ARV users in private clinics were better off: their average waiting time was just one hour, whereas those in public facilities generally had to wait for 5 hours.

Health workers in Thailand did not perceive workload as a problem. Here the government has invested more in the development of the health systems to allow for adequate coverage and a good quality of care in its ART programme.

7. Continuing stigma and discrimination

Stigma affects access to drugs everywhere, but it was reported as a primary obstacle to access in India, Kenya, Nigeria, Moldova and Russia.

“It is all a matter of stigma, no really, because the general public attitude up to this day is very simple: HIV-positive people, all of them are drug addicts, prostitutes, homosexuals or whatever else. ...and the worst thing is that health professionals share this attitude. It is terrible to observe many of them being happy that their patients don't come to see them!! ‘Let them all die; it's not their problem’ - that's what doctors think.” (PLWA, Russia^[10]).

“ Once I revealed I was HIV-positive, no one wanted to assist me at delivery”

(Kenyan woman)

“ Young girls like me have not accessed treatment because we are afraid of what people like nurses will say, and we are scared of being recognized as HIV positive.” (Kenyan woman)

“Stigma discourages people from coming out and getting tested. Nobody wants to test positive because of negative societal attitude towards those who are HIV positive

(Nigerian living with HIV^[11])

“I cannot take my drugs when people are watching. I always go and hide when I take them.

Otherwise, people start whispering about you all the time.”

(PLWHA women’s group discussion, Uganda).

“I usually miss my medications when I visit friends because I have not told them about my HIV and so I do not want them to see my medications.” (Male ARV user, Botswana).

Intravenous drug users are the most heavily discriminated group. In Ghana they are even explicitly disqualified from entering the treatment programme. In Thailand this is not the case, though in practice health workers reportedly often denied intravenous drug users (IDUs) access to ART. In India one of the requirements to enter the programme is that the “patient understands the implications of ARV therapy”^[11]. This requirement is used to withhold drugs from IDUs on non-medical grounds.

8. Lack of adherence and nutritional support for ART users

To ensure positive treatment outcomes, ARV users need to have very high levels of adherence; without this, treatment may fail and the risk of resistance tends to increase. A continuous supply of ARVs is thus essential (see above). If stock-outs occur, adherence is not possible. Further to this, facilities should also have systems to follow-up users and provide support when they experience adherence

problems. Many programmes only pay heed to adherence during the treatment initiation phase. In Kenya, Moldova, Peru and Ghana, people in need of treatment had to prove that they are disciplined medicine users by demonstrating that they are able to properly adhere to a daily regime of cotrimoxazole (a drug to prevent opportunistic infections), before they are granted access to ART.

In addition, they have to bring someone with them who will support them in using ARVs; a so-called 'treatment buddy'. The effectiveness of such pre-treatment adherence measures has not been validated and may potentially also limit access.

ART programmes should include counselling not only to ensure that people know how to use ARVs properly, but to also deal with social or medical problems during treatment. Few programmes were found to have appropriate counselling facilities and there also tended to be a lack of educational materials. This is a problem, since people need to understand how ART works in order to take these medications properly. In India, the government had no written education materials for patients. In Nigeria, our researchers found that ART users were not counselled properly on adherence and issues related to making treatment work. Some patients

stopped treatment on their own initiative, either because they felt better or developed side-effects.

One exception is Thailand, where with the Global Fund support, the Thai Network of PLWA (TPN+), MSF and Access have established centres for comprehensive and continuous care (CCCs) in 140 health facilities. The CCCs train PLWA to provide support to others with HIV-AIDS, to conduct educational activities on ART, adherence support activities and home visits. Health workers in Thailand reported that PLWA participation in the CCCs actually reduced their workload.

ARV users in situations with poor resources, who tend to be severely ill when they start treatment, experience increased appetite as their health condition improves. Indeed, supplementary nutritional support during the initial stages of treatment can accelerate recovery.

"The problem I have with ARVs is related to food. I have no money and ARVs increase appetite. I am not capable of buying food." (Male ARV user, Tanzania).

"I want to eat all the time and fear the hunger will eat into my stomach, since I have ulcers already. Sometimes I wake up in the night to eat food. This is a difficult situation for me." (Male ARV user, Uganda).

"Majority of people say the ARV treatment makes them to eat a lot. They go to an extent of begging for old age pension from their grand parents. Others quit the treatment because they complain about the lack of food." (FGD participant, Botswana).

"Some patients have expressed lack of food as a reason for not wanting to swallow the life-saving drugs. In fact we have one woman who has declined her life saving drugs because she does not have enough food to feed herself." (Health worker, Uganda)

"Truly speaking, the food you eat will have a direct effect on your progress (Kenyan ART user).

9. Uncoordinated action

In 2004, UNAIDS launched its 'Three Ones' strategy: One agreed HIV/AIDS Action Framework, One National AIDS coordinating authority, and One agreed country level monitoring and evaluation system. The underlying idea was that coordination plays a key role in dealing with the epidemic. Our country studies suggest that the achievement of such coordinated action in ART treatment scale-up is still a long way off. One of the complicating factors for ART scale-up is that national AIDS coordinating authorities must work closely with the Ministry of Health who are usually responsible for the public health facilities. Moreover, there is a need to coordinate public and private sector ART initiatives.

The studies suggest that the governments of several countries are not yet taking an adequate leadership role. For example, ITPC found that the political leadership in the Dominican Republic was slow in establishing a public sector ART programme, which led to delays in GFATM funding^[11]. In South Africa, the national leadership has questioned the effectiveness of the ART programme, thus resulting in slow implementation. By creating a false dichotomy between good nutrition and treatment, the health minister has succeeded in confusing ART users. In some parts of the country, the minister's open opposition to ART has resulted in patients

refraining from seeking treatment until a very late stage in the disease progression.

There are also problems of coordination within governments. In Kenya, for instance, many respondents reported that there had been bureaucratic delays in releasing GFATM funds. The Ministry of Finance is the main recipient of most GFATM assistance - and from there the funds must be transferred to the Ministry of Health and to the National AIDS Control Council (NACC) for disbursement to NGOs and the health facilities that provide treatment.

Many of the countries surveyed received funds for ARVs from both PEPFAR and the Global Fund. However, the supply, clinical management and monitoring systems of these two funding agencies all differ (see also the aforementioned procurement problems). In Nigeria, respondents felt that PEPFAR should do a better job of working together with other treatment programmes in the country. As one healthcare worker noted, it "must align more towards other programmes". At the health facility level, different funding sources translate into ART programmes with different eligibility criteria and different payment structures operating side by side, as illustrated by the following quote and case study from the Vietnam Report.

A case study about interactions of ARV treatment programmes in one hospital in Vietnam:

In one urban hospital, there are two ARV treatment programmes, one with branded drugs and one with generics. Some hospital staff are involved in both projects, and receive different allowances for their work. There is competition among the staff regarding what ARV treatment programme they are allowed to work for, and this is decided by the hospital leader. Some staff offer money to their boss so that they can work for the rich ARV treatment programme with more benefits. The quality of work is thus different between these two projects. The decision to select patients to be eligible to participate in which ARV treatment programme (rich branded or poor generic) is made by the treatment doctor. In this case, the rich patients may be put in the richer ARV treatment programme, and the poor patients may be put in the poorer ARV treatment programme. Some PHAs offer money to the doctors so that they can participate in the richer ARV treatment programme.

The research team learned that the Thai AIDS cluster had to hire extra staff to do separate reporting for the 10.000 ART beneficiaries funded by the Global Fund grant. The Global Fund reportedly demanded the names of the patients being treated with their funds. The patients are treated in the government hospitals, which also receive Thai government funds that cover an additional 34.000 ART users.

The lack of coordination is reflected in the eligibility criteria of treatment programmes and the difficulties with which patients are confronted when switching between ART programmes and/or treatment sites.

In Thailand and Vietnam, people actually have to be treatment naive to enter the government

programme. In India, the research team found that people who are receiving treatment, but whose current CD4 status is more than 200, are not enrolled in the national ART programme.

The survey also uncovered some lack of coordination between health programmes, especially between ART and TB and harm-reduction programs for IDU. Opportunities for testing for HIV and screening for TB among HIV patients are missed in TB programmes. In Nigeria, the research team found that very few respondents working in the field of HIV-AIDS were able to provide information on the incidence of TB, and treatment of the disease among PLWA, even though intensified screening for TB among PLWA is a priority in the national health policy^[1].

“I was registered to start ART in Kilimanjaro Christian Medical Centre in Moshi a year ago. At that time there was no ART clinic near my village. Now there is a clinic near my home but I am denied transfer from KCMC to my home clinic. KCMC is very far from here, about 170 km away. Some times I do not have the fare to travel KCMC, hence I miss my doses.” (Male ARV user, Tanzania).

In Russia, there are very high rates of HIV-TB co-infection and TB is the most common cause of death among PLWA. Nonetheless, TB and HIV are managed by two separate centralised vertical programmes. Isoniazid and cotrimoxazole are therefore available in some pilot sites, but not universally throughout the healthcare system^[11].

IDUs are generally the group with high HIV prevalence. Harm reduction services are a good point of entry for this highly stigmatised group of PLWA. However, stigma and discrimination against IDU, plus a lack of resources, tend to lead to the minimal coverage of such programmes. IDUs tend to have liver problems and treatment regimes therefore need to be adapted. Nevirapine is contra-indicated in those with active hepatitis. Regimes that include Lamivudine may control Hepatitis B infection, but there is a lack of such drug regimens in government treatment centres.

Co-infection of hepatitis and HIV is very common in Russia where it is estimated that 80% of people in need of treatment are also intravenous drug users. Treatment for hepatitis is very expensive, rendering it inaccessible to most of those in need.

In the light of the 'Three Ones' policy of UNAIDS, the lack of coordination between AIDS treatment and prevention programmes is perhaps the most surprising observation of this study. Opportunities for counselling on prevention are missed in treatment programmes; nor do ART programmes

routinely provide access to condoms.

Part of the problem is the unwillingness of PEPFAR to support condom promotion to the general public.

Multi-stakeholder collaboration is key to confronting the HIV-AIDS pandemic. In the absence of treatment, NGOs have played a key role in mitigating the impact of the disease, by establishing PLWA associations and community and home-based AIDS care programmes. When ART became available, they developed treatment literacy programmes to help PLWA access and use ART properly. ART programmes involve life-long treatment and high levels of adherence, which is especially difficult in situations where access is still constrained and the levels of stigma are high. Community participation in ART programmes at all levels appears to be fundamental to addressing these problems. We observed that national ART programmes often fail to link up with existing CBOs (community based organizations) and PLWA associations.

PEPFAR funded programmes are often run by CBOs and faith-based organisations and thus strengthen civil society participation at the local level. The Global Fund has contributed to civil society participation by demanding the establishment of multi-stakeholder country coordinating mechanisms (CCMs) at a national level. The level of involvement varies according to country. In some cases NGOs are principal recipients (for example in Peru and Thailand). In others, the national government is the main party involved in the implementation of ART programmes.

“ Many of us also have hepatitis C or hepatitis B. We may have liver problems but sometimes doctors (in government ART centres) start us on nevirapine-containing regimes. We also need to buy interferon (for hepatitis C) outside, since it is not available in the government hospitals and it costs a lot of money...”.(Ratan Singh, Manipur Network of People living with HIV, India^[11]).

10. Planning for sustainability

The sustainability of programmes was a major theme addressed in the interviews, especially in the Dominican Republic, South Africa and Thailand. In the Dominican Republic, some government officials were concerned about the future treatment costs for the increasing number of people who had started treatment with the help of funds from the GFATM. Some policymakers directly suggested that programme implementation was slow due to these concerns^[4].

In South Africa there are concerns about the sustainability of the PEPFAR programmes, which are due to run until 2008. These are often not well integrated into the government health programme, relying heavily on relatively expensive brand name medicines^[4].

In Moldova and Uganda it was not only the government policymakers who were concerned about the sustainability of ART programmes.

Users were apprehensive about starting ART therapy, because they would then become dependent on the drugs and are not convinced that the state will be able to continue providing the drugs in the future.

The future sustainability of ART programmes is not only dependent on the mobilisation of global resources and adequate government planning. It will also depend on the speed at which resistance to ARVs develops and the extent to which prices of second line treatments, paediatric drugs and diagnostics will decrease. On both fronts, there is little room for optimism. A global HIV drug resistance surveillance network (HIVResNet) has already been set up to monitor resistance. Such data will be of great use to national policymakers. Anecdotal data suggests that resistance levels are high. Indeed in India, a study indicates that already as many as 20% of ART-naïve PLWA may be resistant to first-line ARVs in Southern India^[5].

[5] <http://www.pharmabiz.com/article/detnews.asp?articleid=29346§ionid=6>

End notes

[I] World Health Organization. Progress on Global Access to HIV Antiretroviral therapy: a report on “3by5” and beyond. WHO-UNAIDS, March 2006.

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