

Testing Times:



**Keeping our word in the fight against HIV and
AIDS.**

SCI AF
for a just world

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- Participants in, and the facilitator of, the SCIAF HIV and AIDS Advocacy Training Workshop held in Kampala, November 2006.
- Photo credit: Stephen Martin

Testing times: Keeping our word in the fight against HIV and AIDS.

A crisis of disastrous proportions is affecting humankind today. An estimated 40 million people are infected with HIV. 95% of these are in developing countries and 70% are in sub-Saharan Africa ⁱ. 8000 people a day die from AIDS, leaving behind family, friends and, in many cases, orphaned children.

HIV and AIDS is a personal tragedy for millions of families worldwide. It is also a national tragedy for developing countries trying to win the fight against poverty; in Uganda, Rwanda and Burkina Faso, AIDS is expected to increase the number of people living in absolute poverty by 6% by 2015 ⁱⁱ.

And because HIV impacts hardest upon the 15-49 year old age group ⁱⁱⁱ, it has wide-reaching implications on the economy, depriving some of the world's poorest countries not only of mothers and fathers, but of agricultural labourers, industrial workers, entrepreneurs, health care workers and teachers to educate the next generation. Some studies suggest that GNP decreases by 1% for every 10% of the population infected with HIV ^{iv} whilst other evidence suggests that HIV/AIDS is costing sub-saharan Africa 1% in GDP per year ^v.

These statistics have been summed up succinctly by a community volunteer in Masaka, Uganda, who stated that 'there can be no development without health.'

There is reason for hope, however. In the 25 years since HIV/AIDS was discovered, great medical advances have been made in the form of antiretroviral drugs (ARVs). Although these drugs do not cure AIDS, they greatly prolong the lifespan of sufferers and dramatically improve their quality of life.

James, from Kampala, Uganda is receiving ARVs from a clinic funded by SCIAF. He explains: "Before I started ARVs in 2004 I was almost a dead person. I could not walk, I could not even stand. They (my family) were carrying me and had prepared to take me back to my home village for burial." Two years later and he says he feels 'born again'; he is now able to look after his five children, is an active member of the community and has just started looking for a job.

Whilst James was making his recovery, thousands of miles away key decision makers were also recognising the importance of ARVs. Campaigning pressure ahead of the 2005 Gleneagles G8 Summit in Scotland led to leaders of some of the world's richest nations committing to achieving universal access to ARVs by 2010.

Since then, progress has been made towards this goal. However, information from community organisations with whom SCIAF works in the Democratic Republic of Congo, Tanzania, Burundi and Kenya and interviews conducted in Uganda have revealed the extent of the challenge facing the international community. The task ahead is twofold; to increase the quantity of ARVs available and to increase their quality to ensure that not only do people have access to ARVs, but that these ARVs are able to work as effectively as possible.

‘Free, but not free for all’; scaling up cheap ARV treatment.

Thanks to a variety of factors such as the creation of the Global Fund for HIV and AIDS TB and Malaria, President Bush’s Emergency Plan for AIDS Relief (PEPFAR) and not-for-profit pricing policies of drugs companies, more ARVs are available to more people at lower prices than ever before. An especially important factor has been the role played by generic drugs.

Generic drugs are cheaper versions of medicines originally developed and patented by commercial drug companies. They are essentially ‘copies’, produced using exactly the same ingredients as the branded drug but at a fraction of the cost. These generic drugs are quite literally life-savers and it is imperative that production of generics continues and is able to increase. Half the people currently on ARVs are using generic versions of drugs. In Uganda, the vast majority of people are using generic versions of drugs and these versions are reported to be 50% cheaper than branded drugs.

Progress has clearly been made, not least for the 1.3 million people in the developing world currently receiving ARVs. However, 5.2 million people urgently need ARVs and are unable to access them whilst only 5% of children with the virus are receiving treatment ^{vi}.

It is sometimes easy to be overwhelmed by statistics and to forget that behind the figures lie millions of untold stories. As a practitioner on the frontline of the AIDS battle in Uganda, Doctor Apollo does not have that luxury.

Faced with 8000 patients needing ARVs and only enough drugs from PEPFAR to treat 1050 of them, he is forced to choose which patients receive life-changing treatment and which ones don’t. He tells SCIAF: “It is very disheartening to tell a patient...that ‘there is nothing I can do’...especially when they don’t have anything to buy drugs with.”

Pharmacists working at the SCIAF funded clinic concur. They call on drug company GlaxoSmithKlein—which is based in the UK with a factory in Montrose, Scotland—to work with PEPFAR and other agencies as appropriate to increase the supply of drugs. GlaxoSmithKlein’s role is seen to be especially important as they supply two of the most important ARVs available at the clinic ^{vii}.

In the meantime, Doctor Apollo can only refer patients to other hospitals which are facing similar constraints. Prosy, a 26 year old student in Uganda describes how patients ‘keep on getting referred round in a circle. It is a long search and if it fails you have to buy (them). So drugs are free, but not free for all’.

Despite these problems, it is reassuring to know that the Ugandan government is providing at least some ARVs for free. Across the border in the Democratic Republic of Congo (DRC), the situation is quite different. Medical staff report that patients have to buy their own ARVs at £16 a month for generic copies. Although this is a lot in a country where the average monthly income is £26, it is nothing compared to the price of branded drugs. A doctor currently working in the DRC has told SCIAF:

”These (branded drugs) are available but are very expensive. The typical price is around £330 per person per month so really they are available for the few.”

And price is not the only barrier that potential patients face. In both Uganda and the DRC, patients have to travel long distances to access ARVs, and face additional difficulties once they have them. Some of the drugs given out need to be taken with food, which patients do not always have, and others need to be kept refrigerated. Yet many patients don’t own a fridge, or even much at all. In fact, for some, ‘the drugs are the most expensive thing they own.’

‘Treating the mind, not the patient’; Improving the Quality of ARVs

As the last example shows, increasing the availability of cheap ARVs is not enough. If these medicines are to prolong life to the maximum extent possible, they need to be suitable for people to use in developing countries. The emphasis on quantity must not be lost, but it should be accompanied by a focus on the quality of the ARVs provided. Amongst other things, developing countries need testing machines to use with the drugs and they need to have access to newer ARVs to combat the danger of drug resistance.

‘Like working in the dark’ – the problem of accessing testing equipment.

In order for the drugs to be used as effectively as possible, patients need to be tested to determine just how badly the virus is affecting them. Doctors are then in a position to decide when a patient should start taking ARVs.

This information can be crucial; if left too late, the patient can come close to death. But if given too early, ARV treatment can mean that the patient is exposed to side effects unnecessarily and may also mean that the virus’ resistance to the drugs has more time to develop.

However, SCIAF research has shown that these crucial testing machines (referred to as CD4 machines) are often few and far between. Partners tell us that in the DRC province of South Kivu there is one machine for 1 million people. And in Wakiso district, Uganda, the only government CD4 machine is in the city of Entebbe – meaning patients are faced with a 4 hour combined ferry and bus journey too costly for many of them to afford.

Many patients thus opt to have treatment without taking the test. However, as SCIAF partner Doctor Kalindula explains, leaving it ‘up to the doctor to guess whether a patient is weak and needs ARVs or when HIV is becoming resistant to the drugs...(is) like working in the dark.’

When the drugs don't work: the growing problem of resistance.

Another problem in treating people living with HIV and AIDS is the danger of the virus developing resistance to the drugs. Doctors and patients agree this is a crucial issue which will only become more pressing as time goes on.

A doctor from the DRC explains: "We don't have access to many ARVs, only a few of them are cheap. If HIV becomes resistant to them it will be a big problem." Patients can also foresee problems; a Ugandan patient says: "At first it was not a problem and maybe they had not catered for it. In the future it will because there are many people who have not responded well...and sometimes you have used (the drugs) for so long the regime is no longer effective."

New drugs have been developed to combat this resistance, but many of them are not available in developing countries. In Uganda, pharmacists and doctors have heard of new drugs that are on the market—such as the drug Abacavir by GlaxoSmithKlein — but 'this is considered too expensive for us...such drugs are not available here.'

Abacavir is considered extremely important as doctors want to use it to help people who are not responding to treatment, but 'the drug is considered too expensive for us. We cannot have it unless generic versions are being produced.' Thus doctors may have to distribute drugs they know to be relatively ineffective and, on occasion, have been known to knowingly administer expired drugs – a situation which one doctor describes as 'treating the mind (of a patient), not the patient themselves.'

Disturbing evidence has also emerged that suggests doctors in hospitals run by the Ugandan government are so short of funds that they had to give out a drug whose side effects include a form of paralysis.

Even if new drugs are available, they are often priced out of the reach of ordinary people. In the DRC, patients who have developed resistance have to pay £55 a month for generic copies of second line drugs – double the average monthly income. And practitioners working at Nsambya Clinic in Uganda note that 'patients have to pay for second line treatment; it is not free. They have to pay 150 000 shillings (£44) a month' and sometimes have to pay up to £55.

If patients are to afford these drugs, the prices must come down. But there is a major problem. When the first generation of ARVs were developed, generic drug companies in developing countries played a crucial role in forcing down their prices and in making them accessible to an increasing number of patients. But now there is concern that, second time around, this will not happen.

World Trade Organisation rules called Trade Related Intellectual Property Rights (TRIPs) have recently been implemented in developing countries. These rules make it more difficult for companies to produce cheap generic drugs. Companies that do so could face the possibility of being sued by the rich country firms who developed the drugs in the first place. And TRIPs rules—even with recent amendments—make it difficult for developing countries to import generic drugs from other countries. This must be changed to help give governments the best possible chance of meeting the 2010 target.

Conclusion and Recommendations

If all people living with HIV and AIDS are to access anti-retroviral treatment by 2010, a variety of changes will need to be made by a whole range of actors. As part of a comprehensive solution, SCIAF is calling for the following actions:

Developing country governments should:

- Spend 15% of their budget on health care (promised by the African Union in 2001).
- Improve their governance systems. For example, Global Fund money has only recently begun to be disbursed to Uganda following concerns over financial mismanagement. The Ugandan government must ensure this does not happen again, as the cost is borne not by Ministers but by some of their poorest citizens.
- Strengthen healthcare systems and expand rural outreach programmes

In order to be able to undertake these and other measures, developing countries need support and funding from the international community, including from the UK.

The UK Government should:

- provide its fair share of funding needed for the battle against HIV and AIDS. UNAIDS states that \$20 billion will be needed by 2007 in order to fully fund activities such as prevention, care, treatment and orphan support ^{viii} and the UK should lead the way in ensuring that this target is met as soon as possible.
- as a first step in this process it will need to provide more and better aid, increasing its spending on overseas aid to 0.7% of GDP as promised in 1970. The government will also need to provide its fair share of contributions to the Global Fund to fight HIV/AIDS, TB and Malaria. It should be commended for funding most of its fair share (92%) and should now build on this by funding 100% ^{ix}.
- use its influence within the EU to call for TRIPs rules to be reassessed. The current TRIPs rule (the 2003 waiver) which allows developing countries to import cheap (generic) drugs is so complicated no developing country has ever been able to use it. It should be put to the test as soon as possible and should not become permanent unless and until it can be shown to work.

The G8 should:

- provide more and better aid to fight the battle against HIV and AIDS. As a first step, this would involve meeting last year's MAKEPOVERTYHISTORY demands to:
 - set a binding timetable for giving 0.7% of gross national income as aid
 - provide \$50bn more in aid per annum, effective immediately, and not by 2010 as the G8 are currently committed to.

- Improve aid quality by giving long term funding that is not tied to purchasing goods and services from the donor, that does not include money given as debt relief and is not conditional on implementation of harmful economic policies.
- Work through the IMF, World Bank and other international institutions to cancel the unpayable debts of the world's poorest countries in full and without reference to harmful economic conditions. As a first step, total debt cancellation should immediately be extended to the 60 countries that need it to meet the Millennium Development Goals ^x which would give these countries more resources to spend on healthcare.
- Work through the WTO to call for a reassessment of TRIPs rules as mentioned above.

Drugs companies should:

- Increase their research into ARVs that can be used in developing countries, including research into paediatric drugs and paediatric formulations of already existing drugs.
- Publicly commit to providing all existing and future ARVs (e.g. GlaxoSmithKlein's Breacanovir) at not-for-profit prices to developing countries, the Global Fund and PEPFAR. If drug companies can conclusively prove that providing all ARVs at not-for-profit prices to all developing countries is not economically feasible, they should be provided to less developed countries ^{xi} and to sub-Saharan Africa.
- Substantially and promptly increase the quantity of not-for-profit ARVs available, working closely with the Global Fund and PEPFAR as necessary. For example, GlaxoSmithKlein must scale up provision of its ARVs Zinovudine, Lamivudine and COMBIVIR in Uganda, and work with international funding mechanisms and other relevant bodies to ensure its ARV Abacavir is provided at the earliest opportunity.

These commitments may cost more in money and time but, in the words of a Doctor from the Democratic Republic of Congo, 'the rich people have to think about the poorest people. They can easily help them and can afford to pay for them'. In the end, he says, it comes down to 'a matter of conscience and a choice; 'are you going to leave people to die or are you going to help them?'

ⁱ Statistics from Medicines Sans Frontières: <http://www.accessmed-msf.org/campaign/hiv01.shtm>

ⁱⁱ Access the UNDP report at <http://www.undp.org/hiv/publications/>

ⁱⁱⁱ See <http://www.avert.org/aidsimpact.htm>.

^{iv} United Nations Department of Economic and Social Affairs/Population Division (2003) *Impact of AIDS* http://www.un.org/esa/population/publications/AIDSimpact/91_CHAP_VIII.pdf

^v From Avert op cite

^{vi} Stop AIDS Campaign: (2006) *Policy Briefing: Access to Essential Medicines*

^{vii} Namely two NRTIs or nucleotide reverse transcriptase inhibitors, lamivudine and zidovudine. It also provides them with a combination of the two, COMBIVIR. Many of the examples throughout this

report focus on GlaxoSmithKlein not only because it is one of the world's largest drug companies and based in the UK, but also because it has proved itself willing to make a commitment to increase affordable access to ARVs in developing countries. SCIAF is now asking for GlaxoSmithKlein to build upon this progress by undertaking specific commitments outlined in the final section.

^{viii} UNAIDS: *Fact Sheet; Funding for AIDS. New resource needs estimates.*

^{ix} This will mean spending \$390 million (or £216 million) for 2006-8 as calculated in ActionAid (2006) *3 2 1 Gone? The Global Fund and Round 6*

^x Ibid

^{xi} Less developed countries are classified according to various UN criteria and are meant to represent the poorest of the poor countries.