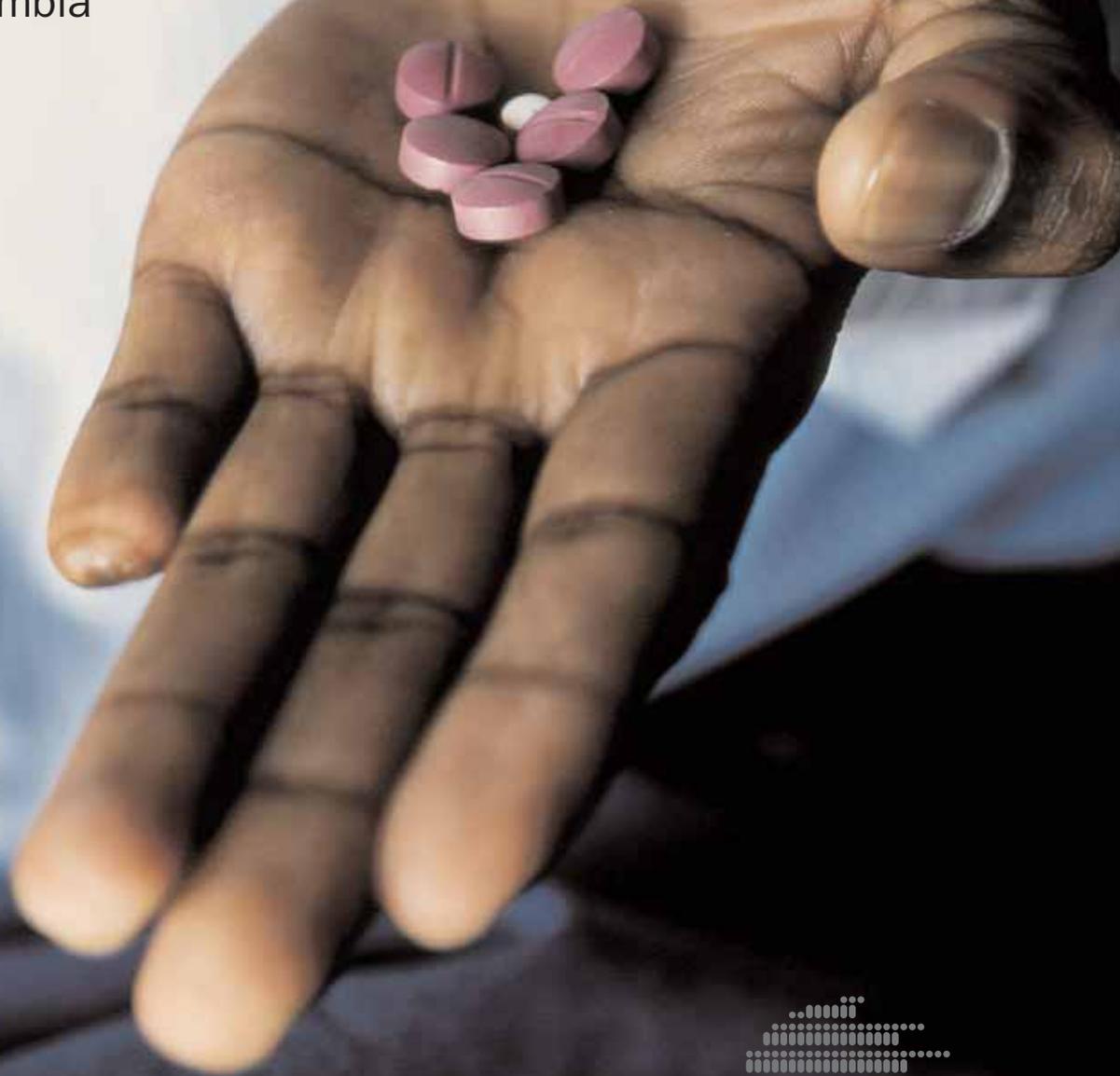


Antiretroviral drugs for all?

Obstacles to access
to HIV/AIDS treatment

Lessons from
Ethiopia, Haiti, India,
Nepal and Zambia



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Acronyms and glossary

Adherence	Correctly following a drug regimen
AIDS	Acquired immune deficiency syndrome
Antiretroviral	The property of a drug to suppress retroviruses such as HIV
ART	Antiretroviral therapy
ARV	Antiretroviral (drug)
CCM	Country Coordinating Mechanism
CD4 cells	Blood cells that play a major role in maintaining the body's immune system
Combination therapy	Prescribing two or more classes of antiretroviral drugs
Compulsory licence	An order issued by a government to override a patent
Drug resistance	When an infection is no longer suppressed by the drug(s) intended to overcome it
Generic	A copy of a drug that is patented or no longer under patent
HAART	Highly active antiretroviral therapy – the use of three or more antiretroviral drugs to combat HIV
HIV	Human immunodeficiency virus
HIV negative	Not living with HIV
HIV positive	Living with HIV
ICASO	International Council of AIDS Service Organisations
ICW	International Community of Women Living with HIV/AIDS
IMAAI	Integrated Management of Adult and Adolescent Illness
LDC	Least developed country
MTCT	Mother-to-child transmission [of HIV]
NAC	National AIDS Council
NGO	Non-governmental organisation
Opportunistic infections	Infections that attack people whose immune systems have been weakened by HIV/AIDS
PATAM	Pan-African Treatment Access Movement
PLWHA	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission [of HIV]
Prophylaxis	Treatment to prevent the onset or recurrence of a disease
Regimen	Taking prescribed drugs every day in the specified dose and at the specified times
Retrovirus	A type of virus which stores its genetic information in an RNA molecule instead of the more usual DNA
Roll out/scale up	Conversion from a small to a larger scale
STI	Sexually transmitted infection
TASO	The AIDS Support Organization
Transitional country	A country in transition from developing to developed country status
Treatment literacy	Understanding the functions and limitations of antiretroviral drugs
TRIPS	International Agreement on Trade-Related Aspects of Intellectual Property Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary counselling and testing
WHO	World Health Organization
WTO	World Trade Organization

Introduction

There is renewed focus on expanding access to HIV prevention, treatment and care and support, building on the momentum gained from years of activism by groups of people living with HIV/AIDS (PLWHA), international commitments including the Millennium Development Goals (MDGs), and the World Health Organization (WHO) and Joint United Nations Programme on HIV/AIDS (UNAIDS) '3 by 5' initiative that aimed to treat at least 3 million people by 2005. As a result, millions more people who need treatment for AIDS have accessed it, but a greater majority (especially in low-income countries) do not have access.

In 2005 the Panos Global AIDS Programme commissioned studies from Ethiopia, Haiti, India, Nepal and Zambia on the extent to which antiretroviral therapy (ART) was available in these countries and the obstacles that needed to be overcome to ensure universal access. Research focused on the experience and needs of people living with HIV/AIDS.

These five countries provide a perspective through which access to ART across the developing world can be seen. In many nations, weak health infrastructures, the cost of patented drugs, stigma and conflicting messages about treatment options prevent men, women and children from receiving the drugs they need. It is evident that to achieve sustainable universal access to HIV/AIDS treatment, there is a need to step up efforts to reduce socio-economic vulnerabilities of individuals and countries.

The obstacles to universal access can be overcome with strong commitment from national leaders, with the involvement of people living with HIV/AIDS at every level of the response to the epidemic, and with the partnership of the donor community.

Journalists have a critical role to play in the response to HIV/AIDS. Concise, accurate reporting backed by in-depth analysis and commentary can stimulate the discussion and debate essential to identify the factors that restrict access to ART. This report provides the news media with the basic information to initiate that debate and with key questions that will enable them to focus on the realities of antiretroviral (ARV) drug provision in their own communities. The questions can be used as a tool to help monitor government and non-governmental organisation (NGO) activities and make them more accountable to people living with HIV/AIDS.

The report contains case studies for journalists to compare challenges and successes in their own countries. It provides key areas and questions for effective reporting on universal access to ART for people living with HIV/AIDS.

We also hope that people living with HIV/AIDS, whose experience lies at the heart of the epidemic but who are too often peripheral to the response, will be able to use the information in these pages to ensure that their demands for life-saving drugs are met.

With every passing day the figures of those accessing treatment change and this report is cognisant of that. We therefore cite dates for which the figures provided are applicable. However, the broad challenges have not changed and will require concerted efforts by all stakeholders.

Ronald D. Kayanja

Director

Panos Global AIDS Programme

Background



Zoliswa Jongile, an HIV-positive activist in Khayelitsha Township, Cape Town, shows off her box of ARV pills. By June 2005, 1 million people were receiving ART globally, while 6.5 million were estimated to be in need of ART.

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How many people in your country are living with HIV/AIDS?

Which geographical areas and social groups are worst affected?

How many young people and how many women are infected?

What is the HIV strain dominating those most affected?

Are there annual antenatal statistics published by the government?

More than 40 million people across the world are living with the human immunodeficiency virus (HIV). Each year about 5 million people contract the virus and over 3 million, including 500,000 children, die of acquired immune deficiency syndrome (AIDS).

The profile of the epidemic varies from country to country, within countries and over time. In some places specific groups are affected, such as men who have sex with men and injecting drug users; elsewhere the epidemic has spread widely in the general population. Overall, the young and the poor are worst affected – 50 per cent of people living with the virus are under 25 years old and over 90 per cent live in the developing world. Sub-Saharan Africa is the worst affected region, with almost 26 million people living with HIV.

Gender and HIV/AIDS are entwined. Many men are unwilling to be monogamous or to practise safer sex and women are often unable to protect themselves by persuading their male partners to change their sexual behaviour. Women are particularly vulnerable to contracting the virus because of the unequal dynamics of many sexual partnerships and the fact that they are biologically more susceptible to HIV transmission during vaginal sex; in sub-Saharan Africa, 57 per cent of adults living with HIV are women. Worldwide, 76 per cent of 15–24-year-olds with the virus are female.

Figure 1 shows the profile of the epidemic in the five countries reviewed for this report. In Ethiopia, Haiti and Zambia, the epidemic is widespread in the general population. India, home to almost one in five of the world's population, has many different epidemics within its borders. These mostly affect marginalised groups – female sex workers, injecting drug users and men who have sex with men – but increasingly also the general population. In Nepal, the two primary groups affected are female sex workers and injecting drug users.

Figure 1: HIV/AIDS in the five focus countries

	Adults and children living with HIV/AIDS	Percentage of adults (15–49) living with HIV	Percentage of adults living with HIV who are women
Ethiopia	1.5 million ¹	4.4% ¹	55% ¹
Haiti	160,000 ¹	3.1% ¹	58% ¹
India	5.1 million ²	0.9% ²	38% ²
Nepal	61,000 ¹	0.5% ¹	27% ¹
Zambia	1 million ³	16.5% ¹	57% ¹

HIV and antiretroviral therapy

HIV attacks the CD4 cells that play a major role in maintaining the body's immune system. Several years after initial infection with the virus, the number of CD4 cells in the blood falls to below 200 per cubic millimetre, leading to infections such as tuberculosis (TB), septicaemia and pneumonia, which people without the virus can usually resist. AIDS is the stage of the disease where the immune system has weakened to the extent that these opportunistic infections appear. Most opportunistic infections can be treated, but as the immune system deteriorates over several years, treatment becomes increasingly ineffective. Without access to ARVs, people with HIV often die within one or two years of the onset of AIDS.

ARVs directly attack HIV. This enables the immune system to continue functioning and to overcome most opportunistic infections. There are over 20 ARVs in four different classes, defined according to the method by which they attack the virus. Because a single ARV cannot suppress the virus effectively, most doctors prescribe three or more ARVs from two different classes. This is known as combination therapy, or ART; when several drugs are taken, it may be known as highly active antiretroviral therapy (HAART).

No combination of ARVs can totally eradicate HIV from the body. People living with the virus must take ARVs for the rest of their lives. ART may require taking several drugs at different times of the day, before, during or after food in a schedule of medication known as a regimen. Regimens have become simpler in recent years, as some combinations of drugs are now manufactured as a single capsule or tablet.

Correctly following the regimen – taking the drugs every day in the specified dose and at the specified times – is known as adherence. Many factors affect adherence. Some people forget to take the drugs or stop taking them because of bad side effects. Others find it difficult to take the drugs at the right time – for example, if they do shift work – or with food and clean water. Some people share the drugs with family members or friends, which means that no one takes the correct dose. Many people must take their drugs with food. This becomes a problem in places where there are food shortages.

What are CD4 cells?

How is HIV transmitted?

What is a super HIV strain?

What does drug resistance mean?

How does ART prevent the spread of the virus?

What ARTs are available in your country?

What effect does nutrition have on ART?

What are the side effects of ART?

Why must the ART regimen be strictly adhered to?

What will drug-resistant HIV mean for your country?

What are the various drugs available in your country?

Some drug options are better than others, and cause less side effects. What are the easier options to use?

¹ UNAIDS website, end 2003 figures

² '3 by 5' (WHO/UNAIDS) end 2003 figures

³ Zambian Central Board of Health, 2005

Failure to follow the regimen at least 90 per cent of the time can lead to drug resistance – where the drug no longer suppresses the virus and the immune system is weakened again.

What is your government's position/policy on providing ART in public health clinics and hospitals?

What is your government's HIV/AIDS prevention programme?

Is there evidence of widespread drug resistance in your country?

There are many possible combinations of ART. Most people begin treatment on a standard 'first-line' regimen; a common such regimen includes stavudine, lamivudine and nevirapine. They then move to a second- and third-line regimen, with drugs such as didanosine and abacavir, when first-line drugs no longer protect the immune system. Standard combinations do not work for everyone, particularly if they have contracted a drug-resistant strain of the virus or if they are taking drugs for other diseases such as TB.

Even when a regimen is followed carefully, drug resistance can occur. Each time a combination fails, the options for treatment narrow. Sometimes it takes several attempts to find the best combination; occasionally all combinations fail and the patient dies.

No cure

ART can be so effective in returning people to fully active lives and reducing the quantities of the virus in the blood to undetectable levels that many people consider it a cure. In industrialised countries this attitude has led to risky sexual behaviour and rising rates of sexually transmitted infections (STIs) among some people who take ARVs. Others who are HIV negative take fewer precautions to protect themselves on the grounds that AIDS is 'curable' or can be easily controlled.

The developing world cannot afford a similar trend. Communication must clearly distinguish between treatment and cure and reinforce the need for everyone, whatever their HIV status and whether or not they are taking ARVs, to practise prevention all the time.

How many people in your country require ART now?

How many will require it in the next two to five years?

Where do these figures come from? Are they universally accepted?

The global picture

Of the more than 40 million people living with HIV, 6.5 million need ART immediately.

Those 6.5 million people are just the beginning of the story. As their immune systems deteriorate, everyone living with the virus will eventually need ARVs. If all HIV transmission stopped today, over 30 million more people would still need to start taking ART at some point in their lives and take it every day until they die. But 30 million is the minimum figure. The number of people who need ART will inexorably rise as millions more contract the virus.

By June 2005, however, only 1 million people were actually receiving ART. In the first six months of 2005 more people died from AIDS-related conditions than the total number taking ARVs. Yet although these figures are low, significant progress is being made. The number of people on ART in sub-Saharan Africa more than tripled between July 2004 and June 2005. In East, South and Southeast Asia, the number almost tripled in the same period, and in Eastern Europe and Central Asia most countries were expected to provide universal access by the end of 2005.

Adherence is as important as access. Before large-scale ART programmes were launched in the developing world there were fears that many people would find it difficult to comply with drug regimens. Among the perceived obstacles were irregular working hours, illiteracy, lack of regular access to food or clean drinking water and few doctors and nurses to diagnose, prescribe and advise on ART. The result, pessimists said, would be widespread drug resistance and little, if any, improvement in people's health.

However, adherence rates in the developing world appear to be high. Surveys in Botswana, Senegal and South Africa show that people living with HIV/AIDS take their medicine regularly about 90 per cent of the time. High adherence leads to high survival rates – people live longer. Studies have shown survival rates of between 80 and 90 per cent among people who have taken ARVs for at least a year, compared to 50 per cent of those with no access to ARVs. Studies in Haiti have showed 87 per cent survival rates for adults and 98 per cent for children, with adherence rates of 96 per cent.

What are the challenges in the provision of ART in your country?

What surveys or studies are being conducted in your country to monitor the impact of prevention strategies and ART?

Figure 2: Numbers of people receiving ART, June 2005⁴

	Estimated number requiring ART	Estimated number receiving ART	ART coverage
Sub-Saharan Africa	4.7 million	500,000	11%
Latin America & Caribbean	460,000	290,000	62%
East, South & S-E Asia	1.1 million	155,000	14%
Eastern Europe & Central Asia	160,000	20,000	13%
North Africa & Middle East	75,000	4,000	5%

Figure 3: Numbers of people receiving ART in the five focus countries

	People living with HIV/AIDS	People requiring ART	People receiving ART (percentage of need)	Unmet need
Ethiopia	1.5 million ⁵	211,000 ⁶	16,400 (7.8%) ⁷	194,600 (92.2%)
Haiti	280,000 ⁵	42,500 ⁶	3,919 (9.2%) ⁷	38,581 (90.8%)
India	5.1 million ⁶	770,000 ⁶	35,000 (4.5%) ⁷	735,000 (95.5%)
Nepal	61,000 ⁵	8,950 ⁸	75 ⁸	2,842 (94.7%)
Zambia	1 million ⁹	200,000 ⁹	33,000 (16.5%) ⁹	167,000 (83.5%)

4 '3 by 5' (WHO/UNAIDS); figures in second column are mid-points of high-low estimates

5 UNAIDS website, end 2003 figures

6 '3 by 5', end 2004 figures

7 WHO, June 2005
www.who.int/hiv/facts/en

8 *Progress on Global Access to HIV Antiretroviral Therapy, a report on '3 by 5' and beyond*, WHO, March 2006

9 Zambian Central Board of Health, 2005

How do any of these global initiatives have an impact on PLWHA in your country?

Does your country have the capacity in terms of human resources and health systems to meet global targets?

Who are the principal donors funding ART in your country?

How long is such funding guaranteed?

What conditions, if any, are placed on funding organisations?

How are the funds allocated for ART being spent?

How is politicisation of HIV/AIDS affecting people's access to treatment?

Are the global issues around patent laws restricting access to treatment?

International agencies

One of the major initiatives aimed at universal treatment was the '3 by 5' initiative set up by WHO and UNAIDS. It aimed to provide ART to 3 million people with HIV/AIDS in developing countries by the end of 2005. Though this target was not met, the initiative has enabled significant progress to be made, including treatment targets being established in 40 out of 49 focus countries.

The new target set by WHO, UNAIDS and the international community is to achieve universal access to treatment (or as close as possible) for all who need it by 2010. But there are those who question what 'universal access' really means. Especially in low-income countries, even where ARVs are available there are many obstacles to access. It is also argued that such global targets are usually arbitrary and that countries should develop their own realistic targets.

Funding for ART in developing countries comes primarily from the Global Fund for AIDS, Tuberculosis and Malaria (subsequently referred to as the Fund), the US President's Emergency Plan for AIDS Relief (PEPFAR) and the World Bank.

By May 2005, the Fund had confirmed 279 grants worth US\$2.4 billion in 125 countries. Almost 48,000 people had been reached with ARVs and the Fund aims to provide 1.6 million people with ART by 2009. However, the level of funding the agency receives is considerably less than it requires. In July 2005, it needed US\$2.3 billion to fulfil its current commitments, but the governments that are its primary donors had confirmed only US\$1.6 billion. The shortfall meant that only 30 per cent of new projects could be funded. For 2006 and 2007, the fund requires US\$7.3 billion but pledges received so far amount to just US\$3.7 billion.

Lack of pledges can be attributed to several causes, including donor unwillingness to respond adequately to HIV/AIDS. There has also been criticism that the mechanisms established in some countries to apply for and manage funds are inefficient or do not respond adequately to local needs. Despite these shortcomings, however, the Fund is one of the most effective instruments fighting three of the world's deadliest diseases.

PEPFAR aims to spend US\$15 billion between 2003 and 2008 'to turn the tide against AIDS in the most afflicted nations of Africa and the Caribbean'. Fifty-five per cent of the total sum is allocated to the treatment of people living with HIV, with 75 per cent of funds in the final three years of the project to be spent on ARVs. Two million people are scheduled to receive ARVs through PEPFAR by 2008. However, the funding is not guaranteed but must be approved by the US Congress each year. Furthermore, there is no guarantee that those who receive ART will continue to do so after the plan comes to an end. Critics also argue that PEPFAR's guidelines are biased towards supplying expensive patented drugs rather than generic versions, limiting the number of people who can get access. PEPFAR is also criticised for pegging access to funds to an unrealistic and confusing 'abstinence only' message.

Other international organisations providing ART include the World Bank, through its Multi-Country AIDS Program (MAP) and Treatment Acceleration Program (TAP) and Médecins Sans Frontières (MSF – Doctors Without Borders), which researches the comparative costs of ARVs worldwide, campaigns against the use of patent law where it restricts access to ARVs, and provides ART through treatment centres in over 20 countries in the developing world. Another institution, the William J. Clinton Foundation, does not provide funding directly but helps countries plan and implement large-scale integrated care, treatment and prevention programmes.

Main obstacles



The Zambian government has announced that ARVs will be provided free of charge for those in need, but universal access is not yet a reality. An estimated 200,000 Zambians are in need of ART, of which approximately 30,000 were receiving treatment by October 2005.

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The five countries reviewed for this report – Ethiopia, Haiti, India, Nepal and Zambia – all reveal a wide gap between the goal of universal access to ART and the reality on the ground. In each country, the majority of men, women and children are unable to get the drugs they need. And among those who do have access, many have severe financial or social problems that prevent them from returning to the life they had before they were diagnosed with HIV/AIDS.

Significant challenges stand in the way of access to ARVs in these five countries and elsewhere. These include weaknesses in health systems, issues around patenting and the cost of drugs, insufficient funding and widespread stigma. Each of these obstacles can only be overcome with strong leadership from governments, firm commitment from every institution providing ART, active participation by the media, and the integration of those affected by HIV/AIDS into all levels of the response to the epidemic.

The longer the response is delayed, the worse the situation will become as the number of people requiring ART inevitably rises. The sooner systems are in place to meet demand, the more effective the response will be. Furthermore, provision of ART is an essential aspect of HIV/AIDS prevention; as more people come forward for testing to see if they are infected and need ARVs, more opportunities are created for prevention messages to reach those who are HIV negative.

Impact on health systems

A successful ART programme requires trained staff and appropriate facilities. That means doctors familiar with HIV/AIDS and trained to prescribe appropriate ART, laboratory technicians who can perform the necessary tests, nurses to provide care, and counsellors to advise people with HIV on a range of issues from safer sex to drug regimens. It also means hospitals with beds for those who are ill, health centres with consulting rooms and the necessary equipment to take blood samples and undertake preliminary diagnoses, laboratories that can undertake a wide range of tests, and counselling centres that offer privacy and essential information on all aspects of the disease.

What are the challenges facing access to ARVs?

What deadlines, targets and time frames have been set to roll out the drugs?

What is the state of your country's health system?

Are there sufficiently trained doctors and nurses to administer ARV drugs?

What is the government doing to train and educate nurses in administering ARV drugs?

Is the public healthcare system regulated and does it have the capacity to roll out ARV drugs?

While these staff and facilities may exist in private hospitals and health centres, very few people with HIV can afford the cost of life-long private treatment. Furthermore, in countries where the private health sector is poorly regulated, the service provided may not match that in less well-funded public health centres. Key aspects of care, such as monitoring a patient's overall state of health, prescribing the most appropriate ART and offering counselling, may be missing. Elsewhere, as in Zambia, it is the private rather than the public health sector which has the greatest expertise in HIV/AIDS and treatment options. In Haiti, the private not-for-profit sector has the greatest expertise with organisations like Groupe Haitien d'Etude du Sarcoma de Kaposi et des Infections Opportunies (GHESKIO) and Zanmi la Sante, reaching nearly 95 per cent of people on treatment.

For most people, therefore, ART is best accessed through public health systems provided by governments or NGOs, including faith-based organisations. The challenge is to ensure that these public health facilities can meet the needs of the increasing numbers of people with HIV who require treatment. That challenge is greatest in the world's poorest countries, where the disease burden is highest and health systems are weakest.

Training and human resource capacity

How is the health system in your country structured?

How effective/overburdened are different health providers?

While the industrialised world spends over 5 per cent of its gross domestic product (GDP) on healthcare, least developed countries (LDCs) spend little more than 2 per cent – an average of US\$38 per year per person. In most wealthy countries there are more than 200 doctors for every 100,000 people, but most LDCs have less than 25 doctors for every 100,000 people. These statistics are nationwide – urban areas tend to have more doctors, while rural areas have even less.

Figure 4: Health facilities in the five focus countries

	Doctors per 100,000 people	Nurses* per 100,000 people	Hospital beds per 100,000 people	Per capita health spending
Ethiopia	2.9 ¹⁰	21 ¹⁰	19 ¹³	US\$21 ¹¹
Haiti	25 ¹⁰	11 ¹⁰	not available	US\$83 ¹¹
India	51 ¹⁰	62 ¹⁰	69 ¹²	US\$96 ¹¹
Nepal	5.2 ¹⁰	26 ¹⁰	15 ¹²	US\$64 ¹¹
Zambia	6.9 ¹⁰	113 ¹⁰	324 ¹⁴	US\$51 ¹¹
Industrialised world	325 ¹²	500–1,000	414 ¹⁶	US\$2,792 ¹⁵

* includes midwives

¹⁰ WHO website, 2004 figures

¹¹ UNDP website, 2002 figures

¹² Figure averaged from top 20 countries on UNDP website, 2002 figures

¹³ WHO SEA office website, India 1998, Nepal 2001/02

¹⁴ WHO Ethiopia strategy document, 2004/05 figures

¹⁵ www.hsph.harvard.edu/ihsq/publications/pdf/No-19.PDF, 1995 figures

¹⁶ OECD, acute care beds, 2003 figures

This shortage of health workers threatens to derail not just access to ART but overall development goals. In Ethiopia, few health workers receive training in ART and staff shortages lead to doctors seeing up to 60 patients with HIV per day. Some PLWHA in Haiti complain that health centres are overcrowded. 'You get lost there,' says one. 'You lose a lot of time. You have to be very ill and want to get cured to keep coming.'

In Zambia, low staffing levels make it difficult to remove personnel from their duties for the two weeks' minimum training in ART management; morale is low, resulting in poor service with little respect for people living with HIV/AIDS. Nonetheless, with the co-operation of the Private Practitioners' Association of Zambia, teams of trainers now operate in all nine provinces and nearly 5,000 health providers were expected to have received some training in HIV/AIDS by the end of 2005.

One solution may be to train nurses to perform some of the tasks currently performed by doctors, such as preliminary diagnosis, while lay health workers and community workers carry out counselling and the supervision of drug intake. Where possible, ARVs can be taken to people's homes, easing congestion in health centres. This approach, the Integrated Management of Adult and Adolescent Illness (IMAAI), is promoted by WHO and has been taken up most widely in Uganda, where one in three people needing ART receives it.

In Zambia, the new post of treatment support worker and mobiliser has been created, filled mostly by trained nurses. These play a critical role in supporting all aspects of treatment. One such worker, Mauld Maila Inaka of Ndola, points out that 'We deal with matters such as side effects, adherence counselling, reproductive health, positive prevention and links to other kinds of support in the community.'

Well-trained health workers can only achieve so much without the appropriate equipment. One key instrument is a machine for testing the level of CD4 cells in the blood, which confirms whether the patient's immune system has deteriorated to the point that he or she needs ARVs. At the time of writing, only one such machine was available in Nepal, while only 12 had been installed in Ethiopia. Zambia had one in 64 of its 72 districts and was aiming to provide the remaining districts with a machine in the near future. These figures represent a tremendous disparity in resources. In Nepal, there is only one CD4 count machine for over 60,000 people living with HIV; in Ethiopia the figure is one in 17,500, and in Zambia one in 2,300.

The availability of essential equipment is only part of the solution. Trained technicians must be available to operate it and access should be easy for those who need it. This means at little or no cost to the patient, which is not always the case, as discussed below.

Is the epidemic worse where there are good health facilities or poor facilities?

Which health providers offer ART?

What steps have been taken to maximise training of health personnel in ART in your country?

What equipment is available and what is needed?

Is there a shortage of trained laboratory technicians?

What are the problems facing health workers?

How are they affected by HIV/AIDS?

How much does the government spend on health and how much is allocated for HIV/AIDS?

Voluntary counselling and testing

How widespread is VCT?

Who provides it?

How many people does it reach?

What training do counsellors receive?

Is counselling available for family members?

What support groups are available for PLWHA?

How does the law protect PLWHA?

Is testing free?

Is counselling before and after VCT implemented?

What do people affected and infected by HIV/AIDS think about counselling?

PLWHA cannot receive ART if they do not know they are living with HIV. Yet UNAIDS estimates that in the 73 countries most affected by AIDS, less than 1 per cent of adults has sought voluntary counselling and testing (VCT) and only one in ten people living with the virus is aware of the fact. That means that 90 per cent do not know they are infected, including many who need ART.

A simple blood or saliva test confirms whether an individual has contracted the virus. For those who test positive, the CD4 count (test) measures the extent to which HIV has already damaged the immune system. Testing is essential to offer ART to those who need it, but because a positive result may have significant psychological and social repercussions, it should always be voluntary and accompanied by counselling – hence the term voluntary counselling and testing.

Counselling requires skills that are acquired through both training and experience. In Zambia, where nearly 2,000 people have been trained, the minimum course of theory and practice is six weeks' duration. Certification and diplomas require 12 and 18 months' study respectively.

There are many reasons why people at risk of infection do not seek HIV tests. Some are unaware that a test exists or they do not know where testing facilities are located, or it may be that facilities are not available. Others are aware that VCT is available but refrain from testing because they do not believe they are at risk, because they think they cannot afford the test (they do not know that it is offered free), or because they are afraid to learn whether they have contracted the virus.

For many, fear of stigma – discussed further below – is a major disincentive. In Haiti and other countries, there are some reports of a client's positive result being revealed to other people, either deliberately or accidentally. Such lack of confidentiality prevents many people from coming forward for VCT.

Where testing does take place, it may be without counselling or without the individual's consent – for example, as part of a job application or when a doctor suspects that a patient has HIV. Failure to offer appropriate psychological support before and after testing, especially when the result is positive, can leave patients psychologically damaged and unprepared to resume their lives.

ART must also be accompanied by counselling. Patients who do not understand the importance of following drug regimens are at risk of increased drug resistance. And whether or not they are taking ART, counselling also offers PLWHA information about all their options to maintain health, including good nutrition, treatment for opportunistic infections and, if available, ART.

ART in Ethiopia

More than 1.5 million Ethiopians are living with HIV/AIDS. In early 2005, 211,000 men, women and children needed ART but only 16,400 were receiving it, some free and others on a co-payment basis. The government's objective is that 58,500 people will be on ART by March 2006, 31,000 through the Fund and 27,500 through PEPFAR.

ART was first offered in July 2003 through 12 government hospitals on a co-payment basis. Around 3,000 HIV-positive people accessed services in one hospital in Addis Ababa from two doctors and two nurses who had received no more than three weeks' training in counselling and ART. Most patients were men between 25 and 44 years old. In January 2005, free ART through the Fund and PEPFAR became available in 22 hospitals.

Significant problems prevent widespread distribution of ART. Drug combinations are limited, and there are major problems in providing drugs in rural and remote areas. Poor infrastructure and lack of skilled health personnel are serious obstacles; only hospitals have the laboratories, pharmacies and trained professionals to diagnose and prescribe ARVs. There is a need not only to train more doctors, nurses and other health personnel, but also to improve motivation, working environment and incentives. However, the Ministry of Health is widely considered to lack the commitment to improve the situation.

While the government response is less than ideal, NGO projects have shown that tasks such as routine follow-ups and counselling can be carried out by trained and supported community workers, as is the case in nearby Uganda. People living with HIV/AIDS point to these as models for the Ethiopian government to follow and argue that more funds for implementation of ART should be dispersed among PLWHA associations and reputable NGOs. However, many PLWHA are reluctant to join associations and those associations that do exist generally lack the capacity to administer funds.

Antiretroviral drugs: availability and access

Millions of people currently require ARVs and tens of millions more will require them in the next decade. Each person will have to take the drugs for the rest of their lives. It is essential to ensure long-term supplies at affordable prices but considerable obstacles remain before that goal can be achieved.

ARVs are a recent development in pharmaceuticals. All ARVs are subject to patent – an exclusive licence to manufacture and sell the product for 20 years. The fact that patents do not extend to every country has allowed some companies to manufacture generics – copies of drugs patented elsewhere. Today, nearly 40 companies in 15 countries manufacture at least one ARV drug. The resulting competition has led to a reduction in the annual cost of some combinations from a forbiddingly high US\$10,000 per person in 2000 to a more affordable US\$140 today.

What is a drug patent?

What are the annual budgetary costs of ART for PLWHA?

How does TRIPS have an impact on generic manufacturers?

What are compulsory licences?

What is the legislation in your country regarding patents?

What impact does the legislation have on the manufacture, import or export of generic drugs?

Since 1995, however, patents have been increasingly regulated through the International Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). Treatment activists argue that this restricts the opportunities for generics to be manufactured and sold. Competition is reduced, prices rise and the goal of universal access to ART is more difficult to reach. Others argue that TRIPS allows competition through compulsory licences – government orders that permit other companies to manufacture or import generic versions of a patented drug. A third position, held mostly by patent holders and others who support a strict interpretation of TRIPS, is that compulsory licensing should be used rarely if at all.

Even where drugs are theoretically available – for example, a total of 93 versions of ARVs have been registered in Zambia – they are not always accessible to those who need them. The complexity of the global market has led to a range of prices for ARVs, determined by several factors, such as who buys the drugs, where they are delivered, which company the drugs are bought from and the quantities ordered. Efforts to standardise prices have made some headway, but still have far to go. The figure of US\$140 per patient per year only applies to a small number of generic drugs and the price is not guaranteed; each new purchase must be separately ratified by both buyer and seller, a process which has failed in several countries. Most patent holders offer ARVs at reduced prices to poorer countries but the rates are not standardised. Many developing countries are left out of pricing schemes and in some countries patent-holder prices may be as high as in the industrialised world.

Which drugs are available in your country, and at what prices?

To what extent has compulsory licensing been used?

Are there any generic companies with the capacity to manufacture ARVs?

In December 2004 Médecins Sans Frontières reported at least six different prices for the second-line drug didanosine, from a minimum of under US\$200 to a maximum of almost US\$1,500 per patient per year. In Ethiopia, where the annual cost of black-market drugs ranged from 24,000 to 72,000 birr (US\$2,755–US\$8,265), the government negotiated lower prices with a group of patent holders, but even those ranged from 3,000 birr (US\$340) to 8,400 birr (US\$960) a year.

Faced with increasing numbers of people needing ARVs, more countries in Africa, Asia and the Americas are turning to compulsory licences either for import or indigenous production. Of the five countries in this study only one, India (see box on page 15), has a domestic pharmaceutical industry. Another, Zambia, has issued a compulsory licence to enable local production of a first-line combination, but it is not clear when the drugs will be mass-produced. Discussions are under way with the Brazilian government for technology transfer, but no date has been fixed for this to happen.

Meanwhile, patent holders and the countries in which they are based, particularly the United States, often wield strong economic, legal and political pressure to discourage governments from taking steps that weaken the stranglehold of patents. Worldwide, relatively few licences have been issued compared to the range of drugs on the market and the need for such drugs to be widely available.

Quality control

How effective are the drugs that PLWHA receive? ARVs purchased by the Fund and some other agencies must meet the 'pre-qualification' standard set by WHO, which recognises many generics on the market. PEPFAR, however, insists that the drugs it buys meet standards set by the US Food and Drug Administration (FDA), which includes relatively few generics. Treatment activists argue that this policy means that PEPFAR's money is mostly spent on expensive drugs, reducing the number of people who get access to ART.

Some drugs that have not been submitted to WHO or the FDA meet national standards and are available for purchase in those countries. A list of all ARVs, where they are manufactured and where they are approved is available at <http://ftp.who.int/htm/AMDS/drugsdatabase.pdf>

Ensuring low prices for basic ARVs is only the first step. Not everyone responds well to first-line regimens. Others who take them now may eventually be affected by drug resistance. As time passes, increasing numbers of people will require second- and third-line combinations. However, these are usually newer drugs subject to stronger patent protection, which means that they are two to twelve times more expensive than first-line regimens. Many funders, including the Indian and Zambian governments, only pay for first-line regimens, which means that increasing numbers of people will find themselves facing drug resistance and unable to continue treatment. This situation will only change when generic versions of all drugs are available – and many treatment activists believe that this will not happen in the foreseeable future.

In Manipur, northeast India, many PLWHA have begun to pay for their own drugs after developing drug resistance to first-line combinations that were offered free. To help defray the costs, some NGOs obtain second-line drugs at wholesale prices and offer free health checks, nutritional support and other medicines.

Other basic issues have yet to be resolved. Although most ARVs are available in different dosages and forms (e.g., powder, pill or liquid) and some are combined with other drugs in a single tablet, only a few combinations are manufactured in easy-to-take formulations, and these are not universally available. This means that for many people, treatment options involve several pills and a complicated regimen that may be difficult to follow.

Corruption, which diverts drugs to the black market, and the availability of counterfeit – and therefore ineffective – drugs, are also issues in some countries. Myths around treatment also persist, preventing adherence and increasing the risk of drug resistance.

Does your country manufacture and/or import ARVs?

Does corruption prevent ARVs reaching poor people who need them?

How many children have HIV/AIDS in your country?

What are the ART regimens available for children?

What are the challenges facing treatment literacy?

What do people affected and infected by HIV/AIDS think about treatment literacy?

Treatment literacy – ensuring that people understand the function and limitations of ARVs (e.g., that they are not a cure for HIV/AIDS) – is also critical and helps to maintain adherence. Treatment literacy is reportedly poor in many parts of India and Zambia. In Haiti, however, the poorest country in the Americas, Roseline Bazile, who coordinates the HIV/AIDS programme in the Albert Schweitzer Hospital, says most PLWHA have no problem with adherence, never missing appointments and taking their drugs regularly. ‘They discuss their pathology and the side effects with others in the family circle [of PLWHA] that they have created.’

Mother-to-child transmission

How many women are reached by PMTCT programmes?

What is the health department's policy with regard to breastfeeding for HIV-positive mothers?

Is formula milk provided to free HIV-positive mothers?

Every year, approximately 2.2 million pregnant women living with HIV give birth; an estimated 700,000 babies contract HIV from their mothers during birth or through breastfeeding. In 2004, UNAIDS reported that less than 10 per cent of pregnant women worldwide had the opportunity to protect their future children from infection.

In wealthy countries mother-to-child transmission of HIV has been almost eliminated through Caesarean births, alternatives to breastfeeding and prophylactic therapy. This usually involves giving the mother one dose of an ARV drug during the thirtieth week of pregnancy and a second dose during labour. The newborn is given one dose within 72 hours of birth. Other options, including use of more than one ARV, are also used.

Preventing mother-to-child transmission (PMTCT) is much simpler and cheaper than providing life-long ART to people living with the virus. However, it requires a number of conditions to be met, including the mother being tested for HIV, the drug being available and birth attendants being trained in its use. In some communities women are not offered the test. In others, they may be reluctant to test without the consent of their husbands and those who test positive may be afraid to tell their partners for fear of divorce or violence.

While PMTCT is an important short-term solution, it should not be seen as an alternative to universal access to treatment. In fact, the short-term use of ARVs in pregnant women, while protecting the health of the child, may lead to drug resistance in the mother and compromise future ART options.

Figure 5: Mother-to-child transmission

	Number of women with HIV giving birth each year
Ethiopia	174,000 ¹⁷
Haiti	7,500 ¹⁸
India	92,000 ¹⁹
Zambia	187,500 ²⁰

17 WHO, *Coverage of selected services for HIV/AIDS prevention, care and support in low and middle income countries in 2003*, www.who.int/hiv/pub/prev_care/en/coveragereport_2003.pdf

18 UNICEF

19 National AIDS Control Organization, government of India, www.nacoonline.org/directory_ptct.htm

20 Zambia sentinel survey 2001–2002 and National AIDS Council

From India to the world

Since 1970, when the Indian parliament passed the Patent Act allowing manufacturers to produce versions of drugs patented in other countries, the Indian pharmaceutical industry has established itself as the world's primary source of generic medicines. One key innovation has been the development of pills that combine ARVs of different classes from different patent holders in one tablet. This makes adherence much easier and simplifies distribution in the developing world, allowing a rapid expansion of treatment programmes.

In March 2005, however, to comply with TRIPS, legislation was revised to grant patents on all new medicines and medicines for which companies filed an application after 1995. Generic drugs already in production may continue to be manufactured on payment of a royalty to the patent holder, but the royalty rate was not specified and production of individual drugs may be interrupted by litigation by the patent holder. Companies that wish to produce generic versions of drugs not currently manufactured in India must wait three years before applying for a licence and production may be further delayed by challenges to that licence.

Currently, more generic ARVs are exported than consumed in India itself (see box below) and the new legislation is likely to have a significant impact on other countries. Generic versions of second-line drugs cannot be manufactured for at least three years. With regard to first-line drugs, it is unclear as to whether TRIPS allows countries without a pharmaceutical industry and with few registered patents to issue compulsory licences to Indian manufacturers.

It is feared the overall result will be that these restrictions on competition will allow patent holders to maintain high prices, particularly on second-line combinations, effectively preventing their distribution in many low-income countries.

India: meeting local demand

In India in 2005 over 5 million people were living with HIV/AIDS, the majority from social and economically deprived groups in rural areas. Of these, 770,000 required ART. The country is the world's primary source of generic medicines and universal access to ART would cost around US\$200 million a year – 2.6 per cent of the health budget – yet no more than 35,000 Indians had access to ARVs. Why?

The answer appears to be the national government's lack of commitment to a long-term strategy. In November 2003 it was announced that ART would be provided initially to women (through government antenatal clinics), children under the age of 15 and adults attending government hospitals. From 2004 the programme would offer fixed-dose combination drugs in eight hospitals and would quickly be extended to another 17 sites in high prevalence states. By the end of 2005 ART would be available in 100 public hospitals across the country.

However, amendments to the original plans have added to perceptions that the government programme is poorly conceived and executed. The initial goal was to have 100,000 people receiving treatment by the end of 2005, but that target was revised several times. More recent announcements amended the figures to 100,000 by the end of 2007 and 180,000 by the end of 2010.

Reports from individual states indicate some of the obstacles to be overcome. These include lack of trained personnel and lack of equipment, or equipment that is out of order. In some parts of the country, the fact that drugs supplies are limited has led to the perception that eligibility criteria are unevenly applied and long waiting lists have built up. Critics argue that the five-day training programme for healthcare staff is too short to learn how to implement and monitor a relatively complex drug regimen. Furthermore, the programme does not collect information on drug toxicity and there are fears that a poorly monitored programme will contribute to increased cases of drug resistant infection. There has been limited involvement of NGOs and community organisations in the government programme in most states.

The result has been a patchwork of responses across the nation. In states where the government does not provide ART, people depend entirely on an unregulated private sector which, it is claimed, promotes expensive, irrational and dangerous treatments. In other states NGOs provide more drugs than the government, sometimes free and sometimes at subsidised cost. Elsewhere, as in Kerala, state governments have begun providing ART through their own healthcare budgets. In at least one case, in West Bengal, subsidised treatment by NGOs was suddenly withdrawn, leaving patients to find all the money for the drugs they needed.

Other problems include the fact that ART centres are in cities, although the majority of people needing treatment are in rural areas. Delhi – a low-prevalence territory – had two centres in the first phase of the programme. Many rural dwellers are forced to travel long distances, involving financial and other costs. Many people forego treatment altogether. The likelihood of marginalised groups such as sex workers accessing ART depends on the strength of the NGOs working with them. And although children are a priority for the government programme, no paediatric formulations are currently available.

The price of ARVs is also a significant factor. The majority of Indians cannot afford ART at even the lowest rates. As economist Sudip Chaudhuri notes, 'about half of all drugs for AIDS in the world come from Indian companies but their use in India is very low'. At a conference in early 2005 that brought together Indian pharmaceutical companies and treatment activists from across the world, the manufacturers pointed out that government taxes of up to 20 per cent, as well as government agency commissions, prevented them from offering the drugs at the same low price for which they could be exported. The change of government in 2004 had also interrupted discussions with the Ministry of Health.

Who pays?

UNAIDS estimates that by 2008, US\$22 billion a year will be required to pay for the global cost of HIV/AIDS prevention and care. Such an amount is minimal in comparison with annual global spending by governments on defence or by individuals on fast food but experience suggests that it will not easily be found. And even if such money were available, weaknesses in bureaucracies and existing health systems mean that it may not be efficiently spent.

What is the estimated cost of prescribing and distributing ART to all who need it today and in the future?

The money to pay for ART and related costs – doctors' fees, CD4 counts and other tests, transport to and from health centres and occasional hospitalisation – comes from a wide range of sources. These include international agencies such as the Fund; governments, through health and social security ministries, the military and other agencies; national and international NGOs; individuals living with HIV and their families; employers and medical insurance. However, although the means of delivery may vary, funding for most ARVs in many countries in the developing world ultimately comes from either the Fund or PEPFAR.

Funding is one issue; diagnosing, prescribing and dispensing is another. Across the world, ARVs and ancillary services are provided by a range of organisations, including government hospitals (sometimes with different branches of government sponsoring different health systems), NGOs and private health systems. Not all facilities are available at all locations. Drugs and services may be offered free, at a subsidised cost or at full price.

In many countries, more than one system is in operation, which can have significant implications for cost. In Guatemala, ART is available from both the state social security system and Médecins Sans Frontières (MSF). The government agency purchases its first-line combination from the patent holder at 20 times the price for the same combination that MSF orders from a generic supplier.

Burdening the individual

Although many people pay for their own treatment, perhaps the least reliable source of funding is the individual. People who pay for ART generally do so because there are no free or subsidised schemes or because they fear that if they register in free schemes others will learn they are living with HIV. But whatever the reasons, the costs of life-long treatment are usually far higher than individuals can bear. After several months or years of paying, patients may find that their money runs out and they risk bankruptcy. Forced to interrupt treatment, they risk worsening health and developing drug resistance.

Some ART schemes run by governments and NGOs require patients to pay a fee for the drugs themselves or for tests. However, many PLWHA live below the poverty line and are unable to afford even subsidised costs. In Haiti, 76 per cent of the population live on less than US\$2 a day. Eighty per cent of Zambians live in poverty and were unable to pay the US\$5 that the government originally charged for ARVs.

It is not only the drugs that cost money. In Nepal, Rajiv Kafle of Navakiran Plus points out that the National Public Health Laboratory is the only organisation to offer CD4 tests. Although the machine and test kits were donated, PLWHA were originally charged 2,500 rupees (US\$35) per test, 'for the sustainability of the project', which Kafle interprets as 'to the government'. The money collected was not used to buy new kits and testing was suspended until another donor bought more kits. The cost is now 100 rupees (US\$1.40), a sum still beyond the means of many Nepalis.

Even if diagnosis, drugs and tests are free, poor people may be unable to access ART. They may not be able to afford the cost of transport to and from the appropriate health centre, or their income might be too precarious to allow them to spend time waiting to be seen by a doctor. In many countries, PLWHA who live in rural areas far from health centres are far less likely to access ART than those who live in cities. PLWHA living in certain areas of Ethiopia live far from treatment centres, and in parts of India and Nepal treatment centres are so far from villages that it takes some people a week to access therapy and return home.

Where does funding currently come from?

How sustainable is such funding?

How many systems for providing ART are there in your country?

How many people in your country currently pay for their own ART?

Do PLWHA have to pay for diagnostic tests?

To what extent is distance and lack of transport an obstacle to accessing ART?

What is the process that PLWHA have to go through to access ART?

How will clinics in rural areas manage to roll out ARVs?

Nevertheless, ART can successfully be brought to rural areas. In Thailand, the government supports over 700 groups of PLWHA and provides training for medical personnel; the result is that rural health centres across the country now have the expertise to provide a wide range of care services, including ART.

Do commercial companies in your country offer their employees ART?

How have corporations implemented HIV programmes while maintaining confidentiality?

Increasing numbers of people in the developing world have jobs that allow them to pay for private health insurance. However, HIV is usually excluded from coverage, which throws the burden of care back on the individual or the government. Occasionally, employers take on responsibility for ART. In sub-Saharan Africa, some companies have HIV/AIDS policies that include ART for employees and, in some cases, family members. Such policies are considered good business practice in that they foster good relations with the communities in which they operate and save the costs of hiring and training new employees. In Zambia, these include large mining companies such as Mopani and Konkola, which run prevention programmes and have hospitals that provide counselling, testing and some treatment for employees and their families.

In Jamaica, all employees of the Manpower and Maintenance Company are on the company's health plan regardless of whether they are living with HIV. Employees who are unable to work due to AIDS-related illness are paid half salary. In Ethiopia, several companies including the national airline cover the cost of ARV drugs for their employees.

Sustainability

What are the comparative figures for annual cost of ARVs and national health spending in your country?

Most individuals cannot afford their own care, few people are covered by the private sector and NGOs are limited in their reach. The only way to ensure that everyone living with HIV gets the ART they need is through efficient government coordination and finance.

Figure 6 (second column) shows the annual cost of providing ART to everyone currently living with HIV/AIDS in the five focus countries. Estimates are based on a figure of US\$300 per person per year (drugs only; other costs such as provision of laboratory equipment and training and salaries of medical staff are not included). Although this figure is hypothetical, since it assumes that everyone who needs ARVs will receive them and that no one else contracts HIV, it provides a useful guideline for comparing need with government ability to match that need. The third column indicates current health spending and the fourth column is the amount the country should spend to reach the benchmark of 5 per cent of GDP met by most countries in the industrialised world.

Does your country's poverty reduction strategy focus on HIV/AIDS?

Figure 6 shows significant differences between the five focus countries. India's vast resources indicate that universal provision of ART (second column) would consume a little over 5 per cent of its optimum national health budget (fourth column). The equivalent figure for Nepal is 6.2 per cent. But while these figures are within the bounds of possibility, the figures for the remaining countries show that universal access cannot be funded even by expanded government budgets unless the cost of drugs falls significantly. Haiti would spend 58 per cent of its theoretical budget on ART, and both Ethiopia and Zambia would spend all their budgets on ARVs and still not be able to ensure universal access. Drugs have to become much cheaper before the world's poorest nations can pay for ART. People living with HIV/AIDS in those countries will be dependent on external financial support for many years to come.

Figure 6: ARVs and national health budgets

	People living with HIV/AIDS	Annual cost of ARV drugs (US\$) ²²	Current annual public health budget (percentage of GDP) ²³	Health spending at 5% of GDP ²⁵
Ethiopia	1.5 million ²¹	\$450 million	\$174 million (2.6%)	\$335 million
Haiti	280,000 ²¹	\$84 million	\$87 million (3.0%)	\$145 million
India	5.1 million ²⁴	\$1,530 million	\$7,808 million (1.3%)	\$30,000 million
Nepal	61,000 ²¹	\$18.3 million	\$83 million (1.4%)	\$295 million
Zambia	1 million ²⁶	\$300 million	\$133 million (3.1%)	\$215 million

Dependency on external funding has its risks, since policies change and political or financial considerations may lead foreign donors to withdraw their support. It is also a major challenge for the leading organisations coordinating the response and providing funding – ‘3 by 5’, the Fund and PEPFAR – to ensure that the mechanisms they establish to increase access to ART are efficient, effective and equitable. Here, significant obstacles remain.

In Ethiopia, US\$400 million has been allocated from the Fund for ART but, activists argue, implementation has been sluggish due to lack of government commitment and limited capacity among the implementing government agencies. Little attention has been given to designing strategies for effective use of available resources while trying to mobilise new funds. Few funds have been allocated to NGOs, including faith-based organisations and associations of PLWHA, despite their prominence and close working relationships with the community. Irregular procurement of drugs is a ‘nightmare’ according to one researcher. All this has significant implications for the future roll-out of drugs, because the amount of funds utilised in one year determines how much money the Fund releases in later years.

In Nepal, the government has announced the launching of a pilot project to treat patients with ARVs. But many PLWHA are sceptical, believing that the 2,600 rupees (US\$37) a month for life for all who need them is beyond the government’s capacity. One man living with HIV said, ‘There has to be a long-term commitment for ART. There is a high turnover of the directors at the NCASC [National Centre for AIDS and STD Control]. Today the director is committed, what will happen to all the individuals on ART if there is a change in leadership tomorrow and the new director is not supportive?’

Rajiv Kafle of Navakiran Plus adds that providing drugs alone is not enough. ‘ART in the absence of a comprehensive care system does not make any sense. There are no voluntary counselling services, no testing services, no machines for CD4 counts and no drugs for opportunistic infections. The government has not taken into account the numbers that might need second-line treatment, which is very expensive.’

Sustainability, therefore, is not just a question of funding, but of establishing systems, including procurement and delivery of drugs, which ensure the most efficient use of those funds.

What long-term plans are there to assure sustainability of ART provision?

What are the prominent HIV/AIDS organisations in your country?

How are they funded?

Are their accounts transparent and available for public perusal?

Are they accountable to a board with members who are PLWHA?

What is your country’s comprehensive care strategy for PLWHA?

²¹ UNAIDS website, end 2003 figures

²² Number of people with HIV/AIDS times \$300

²³ Human Development Report (HDR) website, 2002 figures

²⁴ ‘3 by 5’ end 2003 figures

²⁵ Extrapolated from HDR website

²⁶ Zambian Ministry of Health

Zambia: first step towards universal free access

One million Zambians are living with HIV and 200,000 require ART. Funding for the 100,000 scheduled to be on ART comes primarily from PEPFAR (56,000 people), the Fund (30,000) and the World Bank (4,000). Two thousand people are believed to be paying for private treatment. To meet demand, the number of government centres making drugs available increased from nine in early 2004 to 170 by late 2005. To reduce costs and increase availability of ARVs, the government has issued a compulsory licence to enable local production of a first-line combination.

By October 2005, however, the National AIDS Committee (NAC) announced that 33,000 people were getting the drugs they needed (the Central Board of Health reported 28,000), well below the target of meeting half the country's ART needs by the end of 2005. There was also uncertainty as to when locally manufactured ARVs would be widely available. There are concerns that the scaled-down ART programme will only be sustained with difficulty, while coverage remains poor in rural areas, where many Zambians live. The announcement that the drugs would be provided free has led to congestion at treatment centres and overstretched personnel, while some areas lack laboratory equipment.

Activists claim that this picture is symptomatic of a government response that is more impressive on paper than in reality. Underlying factors include the status of the NAC, which reports to the Ministry of Health rather than to the prime minister or president; this adds a level of bureaucracy and prevents a truly multi-sectoral approach to the epidemic. Furthermore, lack of staff and funds prevents the NAC from fulfilling all its functions. Meanwhile, it has almost four years to formulate and publish an updated national AIDS policy. Some NGOs claim that community-based organisations were not fully involved in the drafting process and are not adequately informed about the policy.

On the positive side, the fact that the government has made a public commitment to ART and thousands of Zambians have access to the drugs they need is a welcome first step in a country where the burden of HIV/AIDS is particularly high.

Stigma

In Niger, the government has funds to provide free ARV drugs for 4,000 people, but by January 2005 only 350 had come forward. 'We have funds, testing is possible, antiretroviral drugs are available, but people simply don't turn up at the treatment centres,' says Abdoulaye Bagnou, a doctor who works as HIV/AIDS adviser to the prime minister's office. What prevents them coming? HIV/AIDS-related stigma.

Stigma is the idea that individuals or groups who do not fit the social norm can be subject to negative discrimination or even violence. It is often based on misperceptions and it implies that those who are stigmatised threaten society. Sex workers, men who have sex with men, injecting drug users and others are subject to stigma because their behaviour is often seen as unacceptable. Others, such as undocumented migrants, are marginalised on economic or cultural grounds. These groups – precisely because they are marginalised and difficult to reach with appropriate prevention messages – are often more vulnerable to HIV and less likely to receive ART.

Have systematic studies of HIV/AIDS-related stigma been undertaken?

How extensive is stigma and discrimination in your country?

What impact does stigma have on ART provision?

HIV/AIDS-related stigma stems partly from the mistaken belief that the disease can be contracted casually and partly from the rejection of people associated with the disease. It fosters wrong assumptions, such as the idea that all women with HIV have had many sexual partners.

The consequences of HIV/AIDS-related stigma can be appalling. People have been attacked, some fatally, because they were open about the fact that they were living with the virus. Women have lost their homes because their husbands have accused them – often wrongly – of bringing the virus into the home. Companies have fired or refused to hire people with HIV. Religious congregations have rejected people with HIV and villages expelled them.

The fear of stigma makes people at risk of contracting HIV reluctant to seek counselling and testing and people living with the virus less likely to seek ART. It can affect adherence; people may be reluctant to visit treatment centres or take ARVs regularly if they think others will become aware of what they are doing. P. Somasekhar Reddy, formerly additional project director in the government AIDS programme in Andhra Pradesh, southern India, comments, 'Monitoring becomes a problem as some Positive People are afraid of breach of confidentiality and give false addresses. Some among them [stop coming for treatment] and when we send outreach workers to trace them we learn that the addresses were wrong.'

Stigma prevents PLWHA responding to HIV/AIDS. 'We have tried involving both sex workers and drug users in planning meetings,' says Asha Basnaya of Family Health International, an international NGO in Nepal. 'Drug users are generally less inhibited and can talk about their concerns openly. Sex workers feel shy to open out in front of men.' Radhika Adhikari, president of the Makwanpur Women's Group, adds, 'Another cause of stigma is ignorance and misconceptions. For that, awareness programmes need to reach each and every village. But most donors and NGOs organise programmes in and near the headquarters with prominent public figures to raise their profile. No one goes to the distant villages.'

Stigma strikes even the family, where people most need support, as the examples on the following pages show. It affects adherence, as people living with HIV/AIDS are reluctant to take their drugs at a time or place where others might see them.

Stigma is frequently encountered in healthcare. Treatment and other forms of care may be delayed or denied or inappropriate treatment given. Patients may be tested without consent and discharged prematurely. Confidentiality may be breached and medical staff may behave inappropriately, shouting or being rude. 'Not so long ago, when a Positive Person was admitted to the government hospital, the staff put up a board next to the bed reading "This is an HIV patient",' says Atul Ravrani of a recently formed Positive People network in Gujarat, India.

Stigma can be overcome. Large-scale treatment programmes have a snowball effect. The more people come forward for treatment, the less they feel stigmatised and the more likely others are to come forward for testing.

Marginalised groups need particular attention. Injecting drug users, sex workers and others may be inhibited from seeking ART by legal sanctions as well as stigma. Broad programmes are needed which advocate and promote appropriate prevention and treatment for these and other vulnerable groups. Anbu, a transgender from Madurai, southern India, says, 'In hospitals we are objects of curiosity. They call students and allow them to see our genitals. It's worse than college ragging.'

What steps are being taken to overcome stigma?

How is the mainstream media in your country having an impact on stigma?

How are religious organisations having an impact on stigma?

How does the government's communication strategy have an impact on sex workers and drug users who are high-risk categories?

How does stigma have an impact on the prevalence rate among young people?

How is reporting on HIV/AIDS eliminating stigma?

Is access to ART resulting in less stigmatisation of PLWHA?

Are there specialised clinics for sex workers?

Reaching the marginalised in Nepal

Can the voices of the marginalised be heard in Nepal? Theoretically, the structures exist. PLWHA are represented on the Country Coordinating Mechanism (CCM) – the national agency responsible for accessing money from the Fund – and each district has an AIDS Coordination Committee (DACC). However, activists claim that the current CCM representation is no more than tokenism and only three of the originally established 62 DACCs are currently operating.

Michael Haihn, UNAIDS Country Director, argues that individual communities of PLWHA need to get together, identify common issues and select a representative. That may be difficult. Some programme managers and policy-makers believe that the people who are willing to be open about living with HIV come from a higher-than-average socio-economic background. Though the issues they raise are relevant, they do not reflect the needs of most PLWHA.

Meanwhile, Mahesh Sharma, an expert on HIV/AIDS and development, argues that DACCs will never represent the community when they are mostly composed of government representatives.

PLWHA agree that they are increasingly involved in the donor and policy environment, but there is disagreement as to how strong that involvement is. 'There is definitely a change in the last two years,' says Rajiv Kafle. 'Today there is a greater awareness of GIPA [the principle of Greater Involvement of People with HIV/AIDS] among the donors and the media. An article written by me was published in a leading national weekly. But we are still not in the driver's seat. We still do not have much say in policy processes and are unable to plan programmes from the money available.'

However, Anjan Amatya, coordinator of the National Organisation of People living with HIV/AIDS in Nepal, feels that their involvement is still limited to tokenism. 'Everyone is talking about GIPA. But why is there not a single person living with HIV/AIDS in UN organisations, NGOs or international NGOs? Why is there no representative in the National AIDS Council? Why do we have a weak representation in the CCM?' Members of the Makwanpur group agree. 'Lawyers and leaders come and talk to us in meetings and promise support but do not acknowledge our presence once outside the meetings, thinking we are immoral women. If this is the attitude, how will they involve us? Even the media is not supportive; we have to continuously run after reporters to get our stories published. Sometimes they promise but do not publish the story.'

Buddies in Haiti

In the last few years increasing numbers of people in Haiti have come out and said they are living with HIV/AIDS and have created PLWHA associations such as the Association of National Solidarity and the Network of People Living with HIV/AIDS. Meanwhile the state has opened 60 voluntary counselling and testing centres and a mother-to-child transmission prevention programme. The price of ARV drugs has fallen to an average of US\$60 a month, but this is still beyond the means of most of the population. Treatment is free in the four official ARV centres, but reaches only a small minority of PLWHA. Some children under 14 years old also receive ARVs under a separate programme.

Some other services are also available. In the Zanmi Lasanté Cange treatment centre there is a buddy system, where a patient is visited once or twice a day. Buddies are responsible for an average of four people and are supervised by a nurse. In addition to a buddy, clients of the centre have monthly meetings with staff and may receive transport costs, enriched milk and other nutritional support, as well as educational support and lodging. In the Albert Schweitzer Hospital, the role of a buddy is taken by a social worker.

Gisèle R, who has been taking ARVs for seven years, is a member of the Association of National Solidarity and has brought several people to the centre. She says that 'The most important thing for someone living with HIV/AIDS in the whole process is to have a buddy. Firstly, they are in a situation where they cannot do everything for themselves. There is also the family with all their problems. Then society, inevitably. I've seen several of my friends die because they faced too many problems and were overcome by them. I believe above all that the best form of companionship helps a Positive Person keep his morale high and helps him share his experiences with others.'

Despite awareness campaigns, PLWHA continue to be the victims of discrimination, including in healthcare centres. Haitian society categorises people living with HIV as 'set apart'. They are often seen as an economic burden by both PLWHA themselves and those on whom they depend. There is a strong fear of being abandoned and a lack of self-confidence.

Several steps need to be taken to improve the situation. These include a clear national agenda that would avoid bureaucratic waste in the distribution of drugs, facilitate the identification and setting up of ARV sites and allow more people to be tested in VCT centres. There is a lack of nutritional and psychological support. There is strong stigma from families and the church, even medical staff.

Altogether, access to ARVs remains a problem, given the number of people living with HIV/AIDS who need the drugs. For a better understanding of the primary stakes and a positioning adapted to the strategy *vis à vis* the challenges to be confronted and difficulties overcome, these challenges are grouped together according to two dimensions: challenges related to lack of money and challenges related to a weak national coverage, because people living with HIV/AIDS and their families face enormous socio-economic difficulties, which influence their ability to follow the demands of treatment.

A global phenomenon

Gillet Bongar (not his real name), a dock-worker in Haiti, has not yet told his wife and children that he has the virus. 'I'm not at all comfortable in this situation,' he says, 'because it makes me lie. And I don't have my family's support. One day I have to tell them. But I don't yet have the courage to do so.' Also in Haiti, Victor H, 25, has been taking ARVs since March 2004. Her relatives are unaware of her condition; she tells them it's a skin infection to justify her taking pills. 'It isn't easy,' she explains. 'I get tired a lot at work. If my family knew, they would understand that in the state I am I can't go on like this. And they'd make sure that I had enough to eat because I can't eat when I take the drugs. But I'm really afraid that if I tell them they will throw me out.'

Also in Haiti, despite awareness campaigns, people living with HIV/AIDS continue to be victims of discrimination. Members of the Association of National Solidarity complain: 'Some hospitals refuse to operate on PLWHA. Or they agree to but impose conditions such as have your own drugs and nurse, be placed in quarantine and accept the notification "significant danger".'

Twenty-six-year-old Ramanjeet (name changed), is living with HIV in Punjab state, northern India, and wants to change his duty hours within the company. He gets tired easily and cannot do night shifts. But he is afraid that if his employers find out about his positive status they will terminate his services. Also from Punjab, Maninder Singh, 32, discovered he was HIV positive a year ago. Despite his doctor's advice he refuses to inform his wife or take her for an HIV test, although he says his wife is not infected because he takes precautions.

In Zambia, as in other countries with a strong religious tradition, HIV/AIDS is sometimes considered the result of 'sin', even among those who have been faithful to their partners. Also in Zambia, stigma can increase in poor households as caring for a sick relative places an increasing burden on the family as a whole. 'They stop buying medicine, saying "we can't manage... all the problems [we have] you have brought into this house"' quotes researcher Virginia Bond. As stated above, Haitian society categorises people living with HIV as 'set apart'. They are often seen as an economic burden, which is particularly acute where there are food shortages as people taking ARV drugs need to eat nutritious food, but many may be thought to be taking food from other family members.

Nutrition

'Without nutritious food, without additional therapies, and without the love and care of those who surround us, drugs do little for us,' explains Alice Welbourn of the International Community of Women Living with HIV/AIDS (ICW). In Haiti, Marie Rose Verneret of the Association of National Solidarity says that most PLWHA cannot guarantee they have good nutrition. The same point is made by the Delhi network of PLWHA in India, who argue that, 'nutrition has to be the first line of treatment'. Everyone who receives ART at two Delhi hospitals lives below the poverty line. While some get good food from public kitchens at Sikh temples, others have little opportunity to feed themselves well.

The same is true for children where the more educated and wealthier are more likely to be targeted. 'In the social mobilisation movement programme among young people, we have observed it is easier to involve school-going children than those working in hotels or factories,' says a programme manager with Save the Children (UK) in Nepal.

Does HIV have an impact on gender?

In each of the five focus countries, as in most of the developing world, women are considerably disadvantaged, economically, socially and psychologically. Coupled with physical vulnerability to HIV through vaginal sex, this usually leads to higher rates of infection among women than men, and particularly among young women. Exceptions are countries like Nepal, where the epidemic has spread fast among men who inject drugs and is not yet widespread in the general population.

Is women's vulnerability to the virus compounded by having less access to ART than men have? The United Nations Development Fund for Women (UNIFEM) reports that men tend to enjoy better access to HIV/AIDS care and treatment in the private sector and through drug trials. Men are more likely to be able to afford treatment and to have access to medical insurance, while researchers are reluctant to enrol women in drug trials because of the potential side effects should they become pregnant.

In many parts of sub-Saharan Africa, women have more access to ART than men, as they tend to have more contact with public health institutions, particularly antenatal services. '3 by 5' reports that worldwide, the numbers are about equal but there are discrepancies. Where countries report treatment figures by gender, some (including Brazil, Honduras, Kenya and Uganda) show that women are under-represented in treatment programmes. In other countries, such as Botswana, Cameroon and Namibia, women are over-represented.

In each of the countries in the Panos survey, however, women appear less likely to access ART than men. In Nepal, where most people living with HIV are men who inject drugs, the voices of women are often unheard. This is partly because the disease is still often seen as a problem that concerns men, and partly because of stigma. Yet women are also affected by the disease, particularly those from the lowest socio-economic groups. Radhika Adhikari of the Makwanpur Women's Group, whose members live with or are affected by HIV/AIDS, points out that many infected women in the community do not have money to pay for rent or food. She criticises donors for supporting awareness-raising activities when there are not even drugs for opportunistic infections in government hospitals. 'Medicines for herpes zoster cost 80 rupees (US\$1.15). How do you expect a poor person to meet the costs? The donors are not blind to our problems. Why is no one taking action? How do we amplify our voices?'

Is good nutrition an issue for people living with HIV/AIDS?

Does the comprehensive policy on HIV refer to the role of good nutrition?

Are women or men more likely to access HIV/AIDS treatment in your country? Why is that the case?

Are married women more vulnerable to contracting HIV than single women?

How is the issue of safe sex between married people dealt with?

What are the gender implications of access to ART?

Are female condoms freely available in health clinics?

How does stigma affect women and men differently?

What is the adherence among women who have gone through the PMTCT programme compared with those who have not?

How many children receive ART?

Does the public health sector have the capacity to roll out ART to children?

Although 40 per cent of Indians living with HIV are women, only 33 per cent of those receiving ART are women. Mekhala, who works with PLWHA in Andhra Pradesh, southern India, says, 'One possible reason is that few women know of their HIV status. And even when they do know, most positive women are faced with more pressing problems. Women have been thrown out of their homes [when it is known they are HIV positive] and are worried about who will look after their children when they fall ill. They must fulfil the dual responsibilities of earning as well as looking after the household.'

In Zambia, men's access to ARVs is facilitated in some cases through the workplace and in others by their superior purchasing power, which allows them to buy the drugs from the private sector.

Drug regimens for HIV-positive children

Over 2 million children are living with HIV and in most cases they and their parents or guardians are unaware of the fact. Without access to ART, over 500,000 of these children die every year. Only 50,000 of the more than 600,000 children – mainly in sub-Saharan Africa – who need ART actually receive it. Children require ART in doses specific to their age. These doses must be available in forms that can be easily used in developing countries, where syrups and oral solutions cannot easily be reconstituted. Furthermore, the components of specific combinations may change as the child grows older.

Activists accuse pharmaceutical companies of not investing enough resources in the development of paediatric formulations since it is a small market of diminishing importance in Western countries. Branded paediatric formulations can cost 50–90 per cent more than the adult versions and generic companies have shown little interest in this market.

Prevention and treatment go hand in hand

Does the government place equal emphasis on care and prevention?

Do care and prevention strategies complement each other?

What is the psychological and emotional impact of HIV/AIDS on a family or orphans?

Prevention and care, including provision of ART, are sometimes seen as separate issues, with greater emphasis given to one or the other. The reality is that they are two sides of the same coin: appropriate prevention activities raise awareness of the disease and encourage people to come forward for treatment; while awareness of care and treatment options encourages people to come forward for testing and underlines prevention measures among those who are HIV negative and those living with the virus.

'3 by 5' reports that the availability of ART leads to increased demand for voluntary counselling and testing. New approaches, including family and couples testing and counselling, VCT being routinely offered in other health settings (such as TB clinics and mother and child services), and home-visit testing and counselling, are all gaining increasing acceptance. Brazil underwent a more than threefold increase in VCT when testing was decentralised to primary healthcare centres. Several countries in Africa, the Americas and Asia report increase testing in a wide range of clinical settings. One district in Uganda saw a major increase (27-fold) in counselling and testing as a result of the introduction of treatment.

In Zambia, it is estimated that by 2010 one in three 15-year-olds will be an orphan. Other countries in sub-Saharan Africa face similar upheaval in family life. The social and economic consequences of a generation growing up without parents, often uneducated and unsocialised, placing a burden on elderly grandparents or living on the streets, are not yet fully understood. To prevent this catastrophe, activists argue that it is essential that universal access be urgently extended to parents.

Tuberculosis and other opportunistic infections

Every year there are almost 9 million new cases of TB and 2 million people die from the disease. One in two people living with HIV develops TB; without prompt diagnosis and treatment, they may die within weeks. Up to 40 per cent of AIDS deaths worldwide are attributable to TB.

TB is preventable; prophylaxis with the antibiotic cotrimoxazole, which costs US\$8–\$17 a year, can reduce HIV-related death rates by up to 50 per cent. When the disease appears, effective treatment for most cases costs less than US\$10 per patient and is free through global TB programmes. However, failure to complete a course of TB treatment can lead to the development of multi-drug-resistant TB, which is significantly more difficult and expensive to cure. The appearance of drug-resistant TB has led to the development of Directly Observed Treatment, Short-course (DOTS), where patients are observed taking the relevant drugs.

Despite the existence of a global TB strategy and the availability of treatment that is cheap, effective and short term, the response to the disease is patchy. In Kolkata, India, 'TB treatment is available freely, but medicines for fungal diseases like oral candidiasis or streptococcal meningitis are not easily obtained,' says Dr Subir Dey of the city's Medical College. 'Around 25 per cent of my patients are suffering from inadequate treatment.'

Elsewhere in India, medicines for many opportunistic infections are not always available. In Goa, Ashpak, coordinator of the Lifeline Foundation, an organisation working on health issues, says, 'The migrants we work among in the Chimbél slums don't see any point in going to the Government Medical College. They don't get medicines, only prescriptions for medicines which they cannot afford to buy anyway.' Similar reports come from many other countries.

How effective are anti-TB programmes?

Has your government managed to have an impact on the TB prevalence?

How has adherence to treatment for TB had an impact on ART among PLWHA?

Can TB and HIV clinics be combined in your country?

Is DOTS working in your country?

Hard work needed: responding to the obstacles



The women pictured are part of a discussion group for health workers and people affected by and living with HIV/AIDS in Addis Ababa, Ethiopia. Communication among groups of people receiving treatment is crucial to support adherence and keep national strategies on treatment effective.

PETTERIK WIGGERS | PANOS PICTURES

What are the success stories in your country?

How are government, organisations, business communities and the media working together to make an impact on the AIDS epidemic?

Has your government signed up to international treatment targets and treaties about health?

Are your country's leaders actively involved in the fight against HIV/AIDS, and efforts to increase access to ART?

As the previous chapter indicates, many issues must be resolved before the goal of universal access to ART is met. At first glance, some of these obstacles appear overwhelming, but experience suggests that they can be overcome and life-saving drugs can be delivered to the millions of people worldwide who need them.

The socio-economic and cultural conditions underlying HIV/AIDS and which determine the details of ART distribution vary from country to country. Nevertheless, there are some factors common to every society that facilitate universal access. These include commitment, networks and partnerships, recognition of local circumstances, participation by PLWHA, communication, access to appropriate information and accountability. Above all, developing countries should be enabled to achieve the MDGs to ensure a socio-economic environment that can lead to sustainable access to HIV/AIDS treatment.

Commitment

In every country the most critical institution in the response to HIV/AIDS is the national government. Governments set (or fail to set) national policy, including a national treatment strategy. Governments determine how much money is available to the health and other ministries involved in HIV activities. Governments negotiate (or fail to negotiate) prices with the companies that provide ARV drugs. Governments pass laws that facilitate or restrict ART initiatives. Governments influence HIV/AIDS messages through official statements, formal or informal censorship and ownership of television and other media outlets. Governments control the civil service, which determines how efficiently ART is integrated into overall healthcare.

Many governments offer lip service to ART – they set goals and state their intention to reach them. However, universal access requires not just lip service, but full and active involvement by national leaders determined to make the life-saving drugs available. Presidents, prime ministers and other leading politicians must use their position and influence to encourage and insist that all stakeholders, including international agencies and pharmaceutical manufacturers, work together to rapidly increase access to ARVs. That means taking such steps as actively chairing national AIDS committees or other agencies which are working towards universal access, increasing health budgets to meet the needs of ART provision, and making public statements in a variety of settings to remind the public of the urgency of the situation.

Such commitment has been seen in a number of countries in the developing world, such as Botswana, Brazil, Senegal, Thailand and Uganda. Regrettably, it has not been reflected in the five countries in this study. These include India, a country which is a world leader in manufacturing pharmaceuticals and which could provide ARVs to every citizen who needs them if the government resolved to do so. In Haiti and Nepal, political instability prevents the government from making such a commitment. The governments of Ethiopia and Zambia have made verbal commitments to the provision of ART, but in neither country has the president or the prime minister ensured that his prestige underlies efforts to reach the national goal. And while both countries were signatories to the 2001 Abuja Declaration on HIV/AIDS, TB and Other Related Infectious Diseases, which committed them to allocate 15 per cent of their annual budget to ‘the improvement of the health sector’, in 2005 the percentage actually spent was 7.6 per cent and 11.8 per cent respectively.

Activists argue that commitment in the South must be matched by commitment in the North. Northern governments should provide funds for ARV drugs and support patients rather than patents in international agreements that affect access to treatment. From this perspective, the commitment of rich countries is decidedly mixed. The total amount of money available to the Fund falls far short of the actual sums needed. The US\$40 billion debt relief for Africa agreed by the world’s richest countries in June 2005 at the G8 summit is only one-sixth of the total debt owed; it leaves out crucial countries such as Nigeria and will not directly convert into increased funds for ART. The primary source of drugs, PEPFAR, will significantly increase the number of people receiving therapy, but it limits the potential numbers through a purchasing policy that favours expensive rather than generic drugs. And the United States and other industrialised countries consistently support interpretations of TRIPS that discourage rather than encourage the manufacture and export of generics in the developing world.

Commitment goes hand in hand with accountability. All stakeholders, from international donors to district health centres, need to be accountable to the communities they serve. Political and institutional processes governing access to ART need to be transparent. This includes openness about the way funds are disbursed, the procurement of drugs, treatment delivery mechanisms, and decisions on who receives treatment in situations where there are not enough drugs to meet the need of the population. Without clearly accountable procedures, treatment programmes run the risk of being accused of inefficiency, of misuse of funds and ultimately failure.

How do the international AIDS community, conferences and targets add value or have an impact on PLWHA in your country?

Is the Global Fund effective in limiting the spread of HIV in your country?

What are the attitudes of PLWHA towards funding from the US and international donors?

Networks and partnerships

Which networks and partnerships exist in your country to strengthen access to ART?

Are they dominated by one or more groups of stakeholders?

What obstacles prevent more efficient partnerships and networks?

How transparent and effective is the CCM?

Is the CCM representative of all groups?

How effective are NGOs?

Are community members paid for their services?

Networks and partnerships are critical in expanding access to ART. Networks bring together people and organisations in the same field. National groups of PLWHA come together in the Global Network of People Living with HIV/AIDS (GNP+). The Pan-African Treatment Access Movement (PATAM) unites activists from across the continent in a campaign for access to ARVs and other essential medicines. The International Council of AIDS Service Organisations (ICASO) is a network of NGOs providing a wide range of services to people affected by HIV/AIDS. The Global Business Coalition on HIV/AIDS brings together over 200 companies worldwide, including BP, Coca-Cola, Ford and IBM, to respond to the epidemic. Each of these networks exists at a national level in many countries.

Partnerships bring together people and/or organisations working in different fields but with a common goal, such as governments, NGOs and groups of PLWHA. While networks usually function with relative ease, organisations in partnerships often have different priorities and may find collaboration more difficult. Nevertheless, effective partnerships – between government and NGOs, between PLWHA and health personnel, between the suppliers of ARV drugs and the people who consume them and so on – are essential to ensure that ART reaches as many people as possible.

Partnerships exist at many different levels, from the international to the community. '3 by 5' estimates that 180 partner organisations have worked with WHO and UNAIDS to increase access to ART since late 2003. These partnerships have led to simplified treatment guidelines, patient tracking systems, training modules for health workers and strengthened drug procurement and supply systems. Common indicators for monitoring and evaluating national ART programmes have been agreed. A global surveillance network is being established to monitor drug resistance. Data is now coordinated with the Fund and the United States Agency for International Development (USAID), and global indicators in monitoring and evaluation have been agreed. Increasing numbers of staff have been trained around the world to ensure standardisation.

At a national level, the key partnership – although it is not always the most effective – is the National AIDS Council (or NAC, though it may operate under a different name). Ideally, NACs combine the strength of government with the expertise of all other stakeholders in the country. The Fund encourages the development of national partnerships through its Country Coordinating Mechanisms (CCMs). These are intended to represent all national stakeholders and each must have at least one representative of PLWHA groups on its board. CCMs are expected to strengthen existing networks, not compete with them, and in several countries the NAC also functions as the CCM. However, as the box on Nepal (page 22) indicates, CCMs do not always have the full support of the partners they are supposed to represent.

National partnerships set, or fail to set, effective national policy. Community partnerships are essential in ensuring that ART reaches the people who need it. Solutions to the challenges described in the previous chapter cannot be imposed from the outside but require communities to come together to create a culturally and socially appropriate environment where ART is made available and where individuals can come forward for it without fear of stigma. The key partners at community level are local government authorities, NGOs (including faith-based organisations), community leaders and, of course, PLWHA.

Successful partnerships may lead to integration – almost all leading national and international agencies working in HIV now include people living with HIV on boards and committees that determine policy and strategy. Otherwise, there is a risk of partnerships being no more than perfunctory, particularly when governments co-opt other organisations onto NACs or other bodies but fail to consult them properly.

People living with HIV/AIDS

People living with HIV/AIDS are the beneficiaries of ART where it is available and, where it is not available, they are the people whose lives are at risk. Without the full involvement of PLWHA at every level of the response to the epidemic, from international policy making to community programme design, universal access to ART will not be achieved.

Although this approach has been accepted for over a decade, there are still too many areas where it is not applied. There are two reasons for this. The first is that, intentionally or not, the participation of PLWHA in different forums is no more than nominal – other stakeholders do not take their opinions and concerns seriously. This is particularly the case when those living with the virus come from marginalised groups such as injecting drug users or sex workers. The second, related obstacle is that because they come from marginalised communities, many PLWHA lack the skills to ensure that their voices will be heard by people in positions of power. Examples of both these obstacles were given above – in Ethiopia, in the committees that decide who will receive ART, and in Nepal, where PLWHA representation on the NAC has been sharply criticised.

Even where most PLWHA do not come from marginalised communities, stigma prevents many men and women from actively participating in the response to HIV/AIDS. In Zambia, where one in seven adults is living with HIV, only half of the country's 72 districts have active chapters of the Network of Zambian People Living with HIV/AIDS. One of the goals of the Strengthening Technical AIDS Response in Zambia (STARZ) project is to build skills among PLWHA to enable them to participate more effectively in prevention and care activities.

To ensure that PLWHA contribute fully to the response to HIV/AIDS, including increased access to treatment, programmes need to include capacity building for individuals and organisations that represent people living with the virus. Until this happens, PLWHA in many communities will remain marginalised from the key processes that are intended to help them.

How well are PLWHA integrated into treatment access programmes in your country?

What are the housing, poverty and literacy challenges facing PLWHA?

How do religion and culture play a role in the stigmatisation of PLWHA?

What is the response of business and corporations to PLWHA?

How well coordinated are communication strategies in your country?

Are the communication strategies effective in having an impact on the spread of HIV?

How well prepared are PLWHA for taking ART?

Testing and treatment

Widespread VCT is a key component of universal access to ART. Encouraging people to seek VCT is a key communication challenge. An environment must be created where counselling and testing are accepted as integral to a healthy lifestyle and where community support is encouraged for testing and for those who test positive.

Communication strategies that address VCT must be tailored to realities. Encouraging testing in areas where counselling facilities and ARV drugs are not available encourages false hope; it is more effective to scale up VCT in partnership with ART. In Botswana, a key lesson learned was the need to implement communication activities before ARV drugs become available. This means carrying out research to determine existing attitudes towards, and knowledge of, testing, counselling and treatment.

Where ART is available, communication must stress 'treatment literacy'. This includes information on the principles of ART, the importance of adherence, potential side effects and, where applicable, the risk of counterfeit drugs. Treatment literacy is particularly important in communities where individuals have access to treatment from health facilities that do not specialise in ART and that provide only limited counselling and information.

Communication

Access to adequate and appropriate information is essential to create and support an environment in which ART is made available to those who need it. Those most affected by the epidemic need to be able to communicate their concerns to policy-makers and programmers to ensure that treatment is available to those most in need of it. Knowledge about treatment empowers patients to make informed decisions about their health and has been proven to greatly increase adherence.

Communication among groups of people receiving treatment is crucial to keep the national strategies on treatment effective. It also enables those receiving treatment to share their experiences with others in ways that promote solidarity and support to ensure adherence. Strategies should therefore be promoted at national and global levels to keep inclusive dialogue and debate open to all stakeholders.

Advocacy – promoting understanding of an issue among policy-makers, health personnel, the general public and others – is an essential element in communication. In ART, advocacy raises awareness of the need to increase access to treatment, and the issues that need to be resolved in order to achieve universal access.

Advocacy can take many forms and involve many stakeholders (the organisations and individuals involved in different aspects of prevention and care). Among these stakeholders, the news media plays a critical role, initiating and encouraging the public debate that influences ART policy. Full debate requires not only comprehensive coverage of the issues raised in this report and elsewhere, but also participation of all stakeholders, particularly those from marginalised groups most vulnerable to HIV.

Who are the organisations of PLWHA?

Are these organisations consulted on the ART and prevention policies in your country?

Is there a civil society movement fighting for the right to ART in your country?

What are the government, religious groups and civil society advocacy strategies to impact on AIDS?

What communication challenges face your country in disseminating information?

Effective social movements like the Treatment Action Campaign (TAC) in South Africa and The AIDS Support Organization (TASO) in Uganda, among many others, have helped to consistently communicate challenges to access to treatment. Such social movements should be supported to provide the kind of debate and dialogue that will ensure that treatment issues remain on the agenda and are addressed at national and global levels.

Further resources

Comprehensive overviews of HIV/AIDS	www.avert.org www.nam.org.uk www.thebody.com
How HIV is transmitted	www.avert.org/trans.htm
How antiretroviral therapy (ART) works	www.who.int/hiv/topics/arv/en/
Information by and for PLWHA	www.gnpplus.net (international network of Positive People) www.nam.org.uk (information on treatment and care)
HIV: global statistics	www.unaids.org
HIV: national statistics	ministries of health, national AIDS committees, national UNAIDS offices
ART: global statistics	www.who.int/3by5/progressreportJune2005/en/
ART: national statistics	ministries of health, national AIDS committees, national UNAIDS offices www.who.int/3by5/countryprofiles/en/ index.html (not all countries included)
'3 by 5'	www.who.int/3by5/en/
Global Fund for AIDS, Tuberculosis and Malaria	www.theglobalfund.org www.aidspace.org
PEPFAR	www.avert.org/pepfar.htm
World Bank	www.worldbank.org/aids
William J. Clinton Foundation	www.clintonfoundation.org
Médecins Sans Frontières	www.accessmed-msf.org
Patents	Patent issues are highly controversial and several sources should be consulted for a complete perspective
Overview	www.accessmed-msf.org/documents/ untanglingtheweb%208.pdf
World Intellectual Property Organization	www.wipo.int
World Trade Organization	www.wto.org
ARVs approved in each country	ftp.who.int/htm/AMDS/drugsdatabase.pdf
WHO pre-qualification	mednet3.who.int/prequal/
Stigma	www.hdnet.org/projectsmore.asp?nid=1
Tuberculosis	www.stoptb.org www.who.int/tb/en/
Treatment Action Campaign(TAC)	www.tac.org.za
AIDS Care Watch	www.aidscareswatch.org
PATAM (Africa)	www.patam.org

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