



MISSING THE TARGET

8

Rationing Funds,
Risking Lives:
*World backtracks on
HIV treatment*

On-the-ground research in India, Kenya, Latvia,
Malawi, Swaziland, and Venezuela

April 2010

The International Treatment Preparedness Coalition

(ITPC) is a worldwide coalition of people living with HIV and their supporters and advocates.

Its overall goals and strategies are signalled in its mission statement: **Using a community-driven approach to achieve universal access to treatment, prevention, and all health care services for people living with HIV and those at-risk.**

As of the end of 2009 thousands of individuals in 125 countries were directly affiliated with ITPC and working to achieve these goals at the local, regional and international levels.

The Treatment Monitoring & Advocacy Project (TMAP), a project of ITPC, identifies barriers to delivery of AIDS services and holds national governments and global institutions accountable for improved efforts. The *Missing the Target* series of reports remains unique in the world of AIDS and global health, offering a comprehensive, objective, on-the-ground analysis of issues involved in delivery of AIDS services that is conducted and “owned” by civil society advocates themselves.

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ACRONYMS AND ABBREVIATIONS

The following acronyms and abbreviations may be found in this report:

ANC =	antenatal care
ART =	antiretroviral treatment
ARV =	antiretroviral
CBO =	community-based organization
CHAI =	Clinton HIV/AIDS Initiative
EU =	European Union
Global Fund =	Global Fund to Fight AIDS, Tuberculosis and Malaria
GP =	General Practitioner
IDP =	internally displaced person
IDU =	injecting drug user
LIC =	Latvian Infectology Centre
MoH =	Ministry of Health
MDG =	Millennium Development Goal
MP =	Member of Parliament
MSM =	men who have sex with men
NAC =	National AIDS Commission (Malawi)
NACO =	National AIDS Control Organisation (India)
NASCOP =	National AIDS and STI Control Programme (Kenya)
NERCHA =	National Emergency Response Council on HIV and AIDS (Swaziland)
NGO =	non-governmental organization
OI =	opportunistic infection
PEPFAR =	U.S. President's Emergency Plan for AIDS Relief
PLHIV =	people living with HIV
PNS =	National AIDS Program (Venezuela)
STI =	sexually transmitted infection
TB =	tuberculosis
TRIPS =	Agreement on Trade-Related Aspects of Intellectual Property Rights (of the World Trade Organization)
UN =	United Nations
UNAIDS =	Joint United Nations Programme on HIV/AIDS
UNGASS =	United Nations General Assembly Special Session
UNODC =	United Nations Office of Drugs and Crime
VCT =	voluntary counselling and testing
WHO =	World Health Organization

Note on text: All "\$" figures are U.S. dollar amounts, unless otherwise specified.

FOREWORD

In March 2010, I was invited to give testimony before the U.S. Congress by the House Subcommittee on Africa and Global Health. The focus of the gathering, at which I was joined by other health and HIV advocates from around the world, was the Obama administration's budget request for the 2011 fiscal year for the landmark U.S. President's Emergency Plan for AIDS Relief (PEPFAR). The proposed budget would increase funding for PEPFAR by 2.2 percent.

First and foremost, I would like to express our thanks and great appreciation to the American people for PEPFAR. More than three million people are now getting lifesaving antiretroviral treatment (ART) in resource-constrained countries, most of them in Africa. These people—and their mothers, husbands, wives and children—got a chance to live. This is a chance they simply would not have without these drugs.

However, the AIDS crisis is not over. On the contrary it has gotten worse because it was left to get far out of hand before any serious international intervention took place. The logical response

following the start of PEPFAR (in 2003) and the launch of the Global Fund (in 2002) was a long-term commitment to match funding support with the inevitable rise in demand, while building up the capacity of the hard-hit countries until the back of the epidemic is broken. That commitment was made, most noticeably at the summit of G8 leaders in Gleneagles, Scotland in 2005. Within three years, however, most countries had abandoned it.

Yet even in light of the fact that about 60 percent of people in urgent need of lifesaving ART are still not accessing it, some would say, and have said, that even matching last year's level, let alone an increase, is remarkably generous given the current economic and political climate in the United States and much of the world. I don't agree. Along with other major donor nations, the United States made a commitment at Gleneagles to significantly ramp up funding and support for pressing global development concerns, including HIV/AIDS. It is not alone in having failed to honour that pledge in recent years, and a paltry increase of 2.2 percent for PEPFAR will do nothing to get it back on track. The gravity of the situation being as it is, there is nothing generous about this development or trend.

Donor governments' inability or unwillingness to meet their commitments is one of the main reasons the ambitious—but certainly never irrationally unobtainable—goal of achieving universal access to HIV treatment by the end of 2010 will not be met. The consequences are dire both for the millions who have been able to access lifesaving treatment in recent years and the millions more in need.

In my home country, Uganda, lower-than-anticipated funding support from PEPFAR and other donor entities in the past couple of years has forced many facilities to turn away new HIV-positive patients seeking ART. Individuals already on treatment and their health care providers are worried that insufficient funding could force a rationing of care that would lead to some patients having their ART access revoked entirely unless they pay for it—if the medicines are even available in pharmacies and at clinics—out of pocket. Given the costs of ARVs and high levels of poverty, that is not an option for most people in Uganda or elsewhere in the developing world.

The findings of this issue of *Missing the Target* make it painfully clear that Uganda is not alone. The invaluable research by local advocates in the six focus countries – India, Kenya, Latvia, Malawi, Swaziland and Venezuela – acknowledges and highlights the remarkable progress made over the past decade in increasing access to HIV treatment, prevention and care services around the world. Yet even though contexts and challenges differ in the six countries, all face major constraints on their ability to increase and sustain HIV treatment scale-up. They need substantially more, not less or incrementally increasing, financial and technical support. Their own governments can and must do more, but they cannot cover the gaps on their own. Nor should they be expected to. The international community must remember that achieving universal access was once seen as a necessary global priority toward which all partners would contribute.

This step should be complemented by redoubled efforts by advocates and policymakers to understand and combat another trend gaining influence in recent years: that “too much” money is spent on AIDS. This argument, which is part of the so-called backlash against disease-specific funding and programming (including for HIV/AIDS), is based on a belief that money spent on AIDS would be better spent from a cost-benefit analysis on addressing other health needs or for broader investments in health systems.

Such assumptions and calculations are not only heartless but misguided. For one thing, there is no finite amount of resources for global health or – as evidenced by the hundreds of billions of dollars found by the United States and other governments for domestic economic stimulus in the past two years – for any other priority. AIDS should have been on a priority list for stimulus money, considering the sheer numbers and carnage in its wake. It doesn’t get too much money; instead, it and other global health needs all get far less than they should. Political will, not available resources, is the real obstacle.

This *Missing the Target* report is an important reminder that despite all we have gained, we stand to lose it all and much more. The HIV epidemic is a global epidemic that requires global solutions. The drive for universal access was such a solution because not only did it (at least initially) more closely link countries of different needs and resources, but it also began the important process of closing gaps within countries. HIV remains a highly stigmatized disease. It can only become less so when treatment is available to all in need, including members of vulnerable populations such as women, injecting drug users and men who have sex with men. Without the promise of treatment, these individuals will remain on the margins of society in many countries, thereby reinforcing discrimination and stigma. The future of all nations and the world overall cannot afford to let that happen.

Peter Mugenyi
Executive Director
Joint Clinical Research Centre
Kampala, Uganda

EXECUTIVE SUMMARY

The six country reports of *Missing The Target 8* show early warning signs of the negative impact of the global backtracking on AIDS commitment and funding—some governments are beginning to cap the number of people enrolled in treatment programmes and drug stockouts are more frequent. If this trend continues, the result will be suffering and death for millions of people around the world currently living with HIV and the millions more who will be newly infected this year and the years to come.

Funding from major donors such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is stalling or flatlining, and reports from several African countries over the past year (the Democratic Republic of Congo, Mozambique, South Africa, Uganda and Zambia, for example) indicate that their government-run antiretroviral treatment (ART) programmes are turning patients away because of cuts in both domestic and external funding.¹²³⁴

Stalling the AIDS response dooms the effort for stronger health systems that is now popular among major donors. It will not be possible to build sustainable, credible health systems as the waiting lines for AIDS drugs grow. The report's findings clearly demonstrate that programmes that have achieved hard-won successes against AIDS are now being starved of financial support—a development that prevents them from coming close to the goal of delivering universal access to HIV treatment, prevention and care by 2010.

Today, some 4 million people have access to HIV treatment but another 6 million people who need treatment do not have it. New guidelines from the World Health Organization (WHO) recommend that ART be started sooner in the course of HIV infection to preserve health and prevent transmission. Millions of lives depend on the continued scale up of treatment programmes.

The world's progress in tackling AIDS has also had substantial benefits for health systems strengthening; training of health care workers; the treatment of TB and other infections; health care for marginalized and vulnerable groups; and the engagement of civil society in setting national health policy. Strong political leadership and increased funding have been crucial to this progress.

1 PlusNews. "DRC: Funding crunch threatens ARV rollout," 15 April 2010. Online: <http://www.plusnews.org/Report.aspx?ReportId=88718>

2 IRIN PlusNews, "SOUTH AFRICA: Lives lost as state coffers run dry", 25 February 2009. Online: www.plusnews.org/Report.aspx?ReportId=83138.

3 Esther Nakkazi, "Uganda: ARV shortage sets in as AIDS funding falls", 3 August 2009. Online: <http://allafrica.com/stories/200908031372.html>.

4 Farah Stockman, "US seeks to rein in AIDS program", *Boston Globe*, 11 April 2010. Online: http://mobile.boston.com/art/25/news/nation/washington/articles/2010/04/11/us_seeks_to_rein_in_aids_program/?p=5.

AIDS FUNDING CUTBACKS

WRITING CHEQUES THAT BOUNCE

G8 and the Global Fund

Promised: \$10 billion a year

Delivered: \$3 billion a year

2001: Created with the full support of the G8 club of rich nations, the Global Fund was intended to be a “war chest” worth \$10 billion a year.

2008: Paltry donations followed the bold promises and by 2008, donors scraped together only \$3 billion a year.⁵ In 2009, ambitious and sound proposals from developing countries were met with “efficiency” or budget cuts of 10–25%.

2011–2013: In March 2010, the Global Fund estimated that it would need \$20 billion over the next three years if it is to expand its funding and help meet the health-related Millennium Development Goals (MDGs).

Donors are using the global economic crisis as an excuse to continue short-changing the fund. Some warn that raising even \$13 billion (the lowest scenario, which would mean a dramatic slow down in pace of delivery) is a “huge stretch.”

President Obama and PEPFAR

Promised: \$48 billion over 5 years

Delivered: Flatlined funding trajectory

2007: Barack Obama pledges \$50 billion over five years for PEPFAR during his campaign.⁶

2008: U.S. Congress commits to \$48 billion over five years in bipartisan legislation endorsed by candidates Obama, McCain and Clinton.

2010: The global economic crisis is being used as an excuse to flatline PEPFAR funds compared to much higher year-on-year increases in previous years, especially from 2006–2009. The effects are already visible with new patients being turned away from treatment in PEPFAR-funded programs in Africa.

SHORT-CHANGING HEALTH

African leaders

2001: In the Abuja Declaration, African leaders pledged to allocate at least 15% of their annual budgets to health spending.

2007: Of the 52 nations, only three countries (Botswana, Djibouti and Rwanda) attained the target in 2007, while three others (Burkina Faso, Liberia and Malawi) attained the target for some of the period between 2001–2007, leaving 46 countries that have yet to fulfil their commitment even once.

President Obama and the Global Fund

2007: During his campaign, Barack Obama pledges to contribute the United States’ fair share to the Global Fund.⁷

2010–11: U.S. Congress allocates \$1.05 billion to the Global Fund, which is about \$1.7 billion less than the country’s fair share towards the Fund’s overall needs. In 2011, President Obama is proposing to cut funding to the Global Fund and provide only \$1 billion.

AIDS FATIGUE

Prime Minister Gordon Brown and the Global Fund

Gordon Brown was the UK finance minister when Prime Minister Tony Blair led the 2005 G8 Summit to commit to universal access to HIV treatment by 2010. But once again money did not follow words.

The United Kingdom has committed £1 billion to the Global Fund for the period 2008–2015. This long-term commitment sets a commendable precedent, but the UK is still not paying its fair share. According to the Stop AIDS Campaign UK, the country needs to almost double its annual commitment to contribute its fair share (a total of £827 million, or \$1.27 billion) of the \$20 billion needed by the Global Fund in 2011–13.⁸

Private donors

Excluding funding from the Gates Foundation (which contributed to an overall increase), estimated expenditures by U.S.-based philanthropies remained flat from 2006 to 2007 and decreased slightly (by approximately 3%) from 2007 to 2008.⁹

Total funding for HIV/AIDS by European-based philanthropies was lower in 2008 compared with 2007 by approximately €1.7 million (1%), and total funding has decreased by approximately €5 million (7%) since 2006.¹⁰

5 Global Fund press release, 8 March 2010. Online: http://www.theglobalfund.org/en/pressreleases/?pr=pr_100308

6 Organizing for America website, “A Statement from Barack on Global AIDS Day”. Online: <http://my.barackobama.com/page/content/globalaidsday>.

7 Ibid.

8 Stop AIDS Campaign UK website: <http://www.stopaidscampaign.org.uk/>

9 Funders Concerned About AIDS. U.S. Philanthropic Support to Address HIV/AIDS in 2008. November 2009. http://issuu.com/fcaaid/docs/resource_tracking_2009/1?viewMode=magazine&mode=mbed

10 European HIV/AIDS Funders Group (EFG). European Philanthropic Support to Address HIV/AIDS in 2008. November 2009. <http://www.efc.be/Networking/InterestGroupsAndFora/HivAids/Documents/European%20Philanthropic%20Support%20to%20Address%20HIVAIDS%20in%202008.pdf>

The response to AIDS has been remarkable over the past decade, but the successes are fragile and are vulnerable to quick collapse. Abandoning the AIDS response now will inevitably lead to a return to headlines about people dying of AIDS that we read at the beginning of the decade. Without the continued political will in tackling AIDS, there is no chance of the world meeting the 2015 Millennium Development Goals (MDGs) by 2015. The consequences of a retreat on AIDS are severe: millions of needless deaths.

FIVE CURRENT MYTHS V. CURRENT REALITIES

MYTHS	REALITIES
Too much money is being spent on AIDS	<p>Funding for AIDS is billions of dollars short of what is needed¹¹</p> <ul style="list-style-type: none"> • Needed in 2010: \$25.1 billion • Invested in 2008: \$13.7 billion • Funding gap for 2010: \$11.4 billion – assuming the world maintains its pre-economic crisis commitment to AIDS.
Money spent on AIDS is at the expense of other health needs or investment in health systems	<p>The total amount of development assistance for health quadrupled from \$5.6 billion in 1990 to \$21.8 billion in 2007¹² – much of this catalyzed by the increased funding and commitments to HIV/AIDS. Although the Global Fund and PEPFAR are among the largest global AIDS funders, they are also some of the biggest investors in health systems, with 35%¹³ and 32%¹⁴ of their respective funding devoted specifically to health systems strengthening.</p>
Strengthening health systems alone will help address health problems including AIDS	<p>Strong health systems alone do not guarantee equitable and universal health care. Past public health approaches failed to reach the most marginalized – women, MSM, sex workers, IDUs, the very poor and those living in rural areas. Health systems need both breadth and focus.</p>
Prevention is more important than treatment	<p>Activists never pit prevention and treatment against each other – on the ground they work together. Treatment can enable more effective prevention by reducing transmission and encouraging testing and prevention makes treatment affordable.</p>
AIDS has been addressed unlike maternal health or other diseases	<p>The AIDS crisis is not over. AIDS activists have been the most effective advocates for health in history. The energy and passion of AIDS activists can be used to build stronger health systems, and tackle maternal and child health – since all these issues are interlinked in the first place. Let's stop pitting disease against disease.</p>

11 UNAIDS, "What countries need: Investments needed for 2010 targets", February 2009.

12 Ravishankar N, Gubbins P, Cooley R, et al, "Financing of global health: Tracking development assistance for health from 1990 to 2007", *Lancet*. 2009; 373: 2113–24.

13 The Global Fund to Fight AIDS, Tuberculosis, and Malaria, "Scaling up for impact results report", 2007:1–112. Online: www.theglobalfund.org/documents/publications/progressreports/ProgressReport2008_en.pdf.

14 Piot P, Kazatchkine M, Dybul M, et al, "AIDS: Lessons learnt and myths dispelled", *Lancet*. 2009; 374: 260–63.

“Although we are provided with free ARVs, we have to pay for treatment of OIs at health facilities. But most of us are not working, and also poor. The problem is even worse when one is admitted at the hospital, and one has no money to pay.”

Person living with HIV at Women Fighting AIDS in Kenya (WOFAK)

COUNTRY FINDINGS

Research conducted for *Missing the Target 8* in six countries (India, Kenya, Latvia, Malawi, Swaziland and Venezuela) has revealed that access to treatment for people living with HIV (PLHIV), while making some gains, remains hindered by a variety of barriers in their countries.

From high-burden and relatively poor nations in sub-Saharan Africa (such as Kenya, Malawi, and Swaziland), to large emerging economies (India), to middle-income countries with relatively small epidemics (Latvia, Venezuela), in-country researchers found that the future of even the currently inadequate treatment programmes are in question. At a time when international guidelines are calling for more people to be put on treatment both for their own health and to more effectively control the AIDS epidemic, countries are headed backwards. Governments are finding various ways to cap the number of people enrolled in treatment programmes. Stock-outs of medicines to treat opportunistic infections (OIs) have become more common, and diagnostics machines are lacking in quantity and/or quality at the very time that they are needed more than ever, given the changes to the WHO guidelines for treatment initiation.

In all of these countries, PLHIV are struggling to cover the many uncovered costs of, for example, OI medications, medical consultations, transport costs, food, and second-line medications. Also in many countries, laws to protect vulnerable and marginalized groups like MSM and sex workers are still lacking, and many PLHIV interviewed spoke of high levels of discrimination in health care settings. Several countries continue to give confusing advice about infant feeding options and use single-dose nevirapine as the prophylaxis to prevent vertical transmission of HIV contrary to WHO guidelines. Finally, weak health systems, many plagued by great shortages of health care workers, lead to poor conditions and services that impede AIDS treatment and broader health care access.

In addition to these overarching themes, there were unique findings in each country:

- In **India**, a financing gap of \$67 million remains for the implementation of the National AIDS Control Programme (2007 to 2012). The government has yet to meet its commitment on diagnostic testing in terms of the frequency, affordability, or quality of the tests. In addition, important medicines for the treatment of OIs and TB are not always available at all facilities, while access to second-line ART is severely limited because of strict eligibility criteria for the government program and high cost in the private sector. Prevention of vertical transmission programmes do not focus on the woman’s own health and continue to use a less effective antiretroviral prophylaxis that is not in line with the latest WHO guidelines.
- In **Kenya**, donor cutbacks and a lack of adequate domestic funds will cause the financing gap for HIV/AIDS treatment and services

to further widen this year – making it even more unlikely that the government will meet its universal access goal by 2013. PLHIV struggle with the burdens of the costs of important health care services, including medicines, consultations and diagnostics to treat OIs and many inpatient services, as well as transportation and nutrition costs. Lack of sufficient – and sufficiently trained – health care workers is a chronic problem, and in rural areas in particular, there are too few facilities providing ART. HIV-related stigma throughout society continues to hinder many people from seeking out HIV services, from testing to ART.

- In **Latvia**, as part of its budget-tightening steps in the face of a severe economic downturn, the government is cutting the HIV and health services budget and imposing restrictions on the number of PLHIV provided with ART free of charge. Generic medicines are not procured, and as a result, the cost of treatment to the government is shockingly high compared to many other middle-income countries. Many primary care providers are reluctant to treat PLHIV because they have insufficient or limited knowledge about HIV, or because of the stigma associated with illicit drug use. This makes efforts to decentralize services difficult (currently there is only one main comprehensive ART centre in Latvia). Lack of integration of HIV care and drug treatment services is another key reason why injecting drug users – an especially vulnerable and affected population in Latvia – lack access to HIV treatment.
- In **Malawi**, cutbacks in government support for the National AIDS Commission are causing a reduction in the depth and scope of HIV/AIDS services. The health care system suffers a severe shortage of qualified doctors and nurses. The burden of transport and other out-of-pocket costs bar access to treatment and services for many PLHIV, and a high percentage of PLHIV entering hospitals for treatment are not aware of their HIV status. Second-line drugs are not available to PLHIV, while OI drug stock-outs and limited CD4 testing availability have also been reported.
- In **Swaziland**, the government has yet to meet the 2001 Abuja Declaration commitment to allocate at least 15 percent of its annual budget to the health sector (allocating just 13.5 percent in its most recent budget, unveiled in April 2010). A lack of HIV awareness and testing, and trust in traditional health beliefs and practitioners who are not grounded in the science of HIV, prevent people from accessing necessary treatment. TB is the leading cause of death of PLHIV in Swaziland, yet TB programmes have high default rates. Long lines and delays are reported at hospitals, where doctors and nurses are too few in number and there is a limited amount of diagnostic equipment. The costs of obtaining OI medicines (which are not provided free of charge), consultations, and transportation bar access for PLHIV to comprehensive HIV treatment.
- In **Venezuela**, the National AIDS Program (PNS) lacks up-to-date and reliable data on the number of people living with HIV and those in need of ART, however most advocates believe it is growing.

“The MoH has mandated us to open new sites as long as our assessment shows a reasonably high number of people in need of access in a particular area. We have identified two sites in Mzimba, but we are failing to scale up because the ministry has yet to send us staff to be posted to those health centres.”

District health officer in Malawi

“There is no money for bus fare to Mankayane hospital...and even if you get there, at times there are no drugs.”

Swazi woman living with HIV

The National AIDS Strategic Plan of 2003–2007 is out of date and civil society is calling for a new plan to be drafted in consultation with civil society organizations. Currently, there is a lack of coordination between government and civil society organizations in delivering services for PLHIV. In most rural areas, patients must rely on small outpatient-oriented facilities that provide only basic services – and most do not offer HIV/AIDS care, including ART. Limited HIV awareness is a major barrier to early treatment uptake across the country, and PLHIV cite a lack of support from health care workers among the reasons for low adherence to ART regimens. Consequences of a weak health system – such as long delays for routine services, unsafe and unhygienic conditions, lack of adequately trained personnel, low salaries, deterioration of facilities, and shortages of basic materials – have had negative impacts on the quality and effectiveness of HIV treatment services.

Treatment access needs remain great, and backtracking will stall efforts to deliver other health care goals as well. Improving the AIDS response has improved health care systems, including by establishing reliable methods of medicine delivery for all populations, ensuring quality and availability of diagnostics equipment, reaching out to vulnerable populations, supporting more doctors and nurses, and so on – all fundamental blocks of strong health care systems.

And let us not forget: AIDS is not only a major killer of people but devastates communities and economies. World leaders who rushed to plow money and effort into bailing out the financial institutions that caused the global economic crisis cannot justify short-changing a crisis that kills over 5,000 people each day. Let’s prevent the tragedy of letting our progress fall apart, just at a time when the return on investment – lives saved – is beginning to pay off.

OUR RECOMMENDATIONS

Priority actions at the global level aimed at improving access to AIDS treatment and care include the following:

1. Donor governments: Pay up – contribute your fair share to the global fight against AIDS.

Rich countries and leaders should not abandon their political commitment to tackling AIDS just as we see some glimmers of hope. Sixty percent of people who need HIV treatment still do not have it and many more should receive treatment if we are to stop over 7,000 new infections every day.

2. Developing country governments: Make the health of your citizens a top priority in your budget.

Hungry and sick people cannot contribute to the growth of their nation. The economic and political cost of not saving the lives of your people is far higher than the increased resources required to effectively control HIV/AIDS or meet their basic health needs.

3. UNAIDS: Reject universal access targets set by some governments that do not aim to provide equitable access for all.

Setting a low bar does nothing to advance the cause of why AIDS should continue to remain high on the global political agenda. The goals are achievable and the excuses are wearing thin.

4. Health and social justice movements: Unite to demolish the “AIDS backlash” that seeks to pit disease against disease or food against medicines.

Activists know that communities do not live their lives in separate programmatic areas – a young HIV-positive woman in a rural area does not just need ARVs, but a means of earning a living, adequate food to feed herself and her family, a functioning antenatal clinic and the right to live free of discrimination and violence. We need to mobilize against the false debates taking place in hallowed circles far away from the realities of this young woman.

5. Donors and international agencies: Put your money where your mouth is and pledge extra resources to end the crisis of health workers and health systems.

It is not AIDS that is starving the health systems but wrongheaded macroeconomic policies and decades of underinvestment. The answer is not to cut AIDS or vertical funding and go back to old ways of providing “generalized health support”. The latter did not achieve as much for the health of people as the AIDS movement which has delivered measurable progress in numbers of lives saved; in reducing the cost of medicines; in building up crumbling health systems; in improved training for nurses and doctors and most importantly in securing more resources for other neglected diseases and health overall.

6. Governments and international agencies: Build on the public health lesson that AIDS has taught us – without reaching women, children, MSM, sex workers, IDUs, your efforts to control AIDS will fail.

Public health can be advanced only when the fundamental human rights of the most marginalized and vulnerable groups are respected, protected and fulfilled. Criminalizing MSM, sex workers and IDUs and discrimination and violence against women remain major barriers to effective AIDS programmes and the goal of universal access. The AIDS response has shown how much more can be achieved when governments meaningfully engage and work together with representatives of civil society, in particular, those most affected by the disease.

Country Reports

India

Kenya

Latvia

Malawi

Swaziland

Venezuela



India

Authors and primary researchers: Pawan Dhall and Saumitra Poddar

Support provided by Kajal Bhardwaj, Mohammed Gulrez, Sudha Jha, Sarika Kar, Subhadip Roy and Aditi Sharma

KEY FINDINGS

1. A financing gap of \$67 million remains for the implementation of the National AIDS Control Programme—2007 to 2012.
2. Access to second-line ART is severely limited, because of strict eligibility criteria for the government program and high cost in the private sector. In addition, important medicines for treatment of opportunistic infections (OIs) and TB are not always readily available for the prescribed duration at all facilities.
3. The government has yet to meet its commitment on diagnostic testing (CD4, viral loads and resistance) in terms of the frequency, affordability, or quality of the tests.
4. Prevention of vertical transmission programmes in India continue to use a less effective antiretroviral prophylaxis, not in line with the latest WHO guidelines.
5. Civil society advocates are optimistic that the long-pending HIV legislation will finally be passed into law.

RESEARCH PROCESS AND METHODOLOGY

Research for this report was conducted from November 2009 through January 2010. It was impossible, given the country's population and size, to conduct research in more than a handful of areas. Researchers therefore focused only on the capital, Delhi, and three states—Andhra Pradesh, Manipur and West Bengal—that have quite different yet equally worrying HIV epidemics.¹⁵ Research included a literature review (primarily online); interviews with various stakeholders; and three focus group discussions with PLHIV, one each in the three states (excluding Delhi). Among those interviewed in person were the following: two PLHIV, one each in Andhra Pradesh and Manipur; one physician at a government hospital in West Bengal; three PLHIV and MSM activists; and two representatives of UN agencies in Delhi. Officials from the National AIDS Control Organisation (NACO) responded by email to a list of questions submitted by the researchers.

1. OVERVIEW OF COUNTRY SITUATION

As of November 2009, some 285,000 people—17,000 of them children—were receiving ART in India through government health centres, and another 35,000 people through private health facilities.¹⁶ According to Delhi-based UN representatives interviewed for this report, the total represents roughly 40 percent of the number of people estimated to be in need of ART in India. Overall, according to recent estimates from UNAIDS, about 2.5 million people are living with HIV in India. Prevalence is relatively low in India, however, because of the large population this is the second highest number in the world, after South Africa.

The government's National AIDS Control Organisation (NACO), which coordinates most HIV-related services and policies at the national level, has set a target of having 650,000 people on ART by "early 2016". This target is part of its universal access effort. NACO's 2016 target also assumes that 20 percent of patients will be receiving ART through the private sector. Private providers of ART are expected to follow national treatment protocols, and authorities reportedly plan to more closely monitor and regulate private providers as ART scale-up continues.

15 For example, the HIV epidemic in Manipur is concentrated primarily among injecting drug users. In most of the rest of India, including Andhra Pradesh and West Bengal, the main mode of transmission is through heterosexual sexual activity. The following article offers more in-depth information about the epidemic in India: Robert Steinbrook, "HIV in India—A complex epidemic", *New England Journal of Medicine* 356: 1089–1093 (March 2007). Online: <http://content.nejm.org/cgi/content/full/356/11/1089>.

16 Aide memoir, "UA mission, New Delhi, India", 3–4 November 2009. Summary of findings and recommendations.

NACO's 2016 target is relatively narrow in terms of how it defines ART access: it refers only to access to first-line ART regimens. According to a UN representative interviewed for this report: "Under NACP-III,¹⁷ the government has scaled up treatment services...but higher targets need to be set and provision for second-line ART needs to be made. The government programme started late but then achieved rapid escalation and soon exceeded their targets. Now the targets need to be set higher." (It should be noted that the government's targets were set on the number of people identified as being in need. The UN, meanwhile, uses the estimated total of people to be in need of ART, which is nearly always a higher number.)

2. SOURCES OF HIV TREATMENT DELIVERY AND RELATED ISSUES

At present, there are 226 government-run full-scale ART centres across India, located mostly in state capitals and other large cities. The government also operates 208 "link ART centres" at secondary health facilities, which distribute ARVs but do not provide diagnostic services such as CD4 count or viral load testing, in less populous cities and towns. The government's current plan aims to scale up to 450 link ART centres by 2012. It is focusing on such facilities as part of its effort to facilitate decentralization of services provided by the main ART centres and to make it easier for patients in rural areas and smaller cities to obtain ARVs.

All government-run ART centres provide ARVs free of charge – although, as noted in Section 1, only first-line regimens are currently widely available. The following first-line regimens are available for adults:

- 3TC + d4T (30) + NVP
- 3TC + d4T (40) + NVP
- 3TC + d4T (30) + EFV
- 3TC + AZT + NVP
- 3TC + AZT + EFV

The following regimens are available for children:

- 3TC + d4T (6) + NVP
- 3TC + d4T (10) + NVP
- 3TC + d4T (30) + NVP
- 3TC + d4T (6) + EFV
- 3TC + d4T (10) + EFV
- 3TC + d4T (30) + EFV
- 3TC + AZT + NVP
- 3TC + AZT + EFV

17 NACP-III = National AIDS Control Programme – Phase III (2007–2012).

Based on the data noted in Section 1, a significant share (from 10–15%) of people on ART currently get their medicines through the private sector. This option continues to be used – and is likely to expand, under the government’s universal access plans – at least in part because competition among generic drug manufacturers in India has helped drive down prices for first-line ARVs at private pharmacies. Many civil society and patient advocacy groups are concerned about the lack of effective regulation of private-sector health care providers, however. They are seeking tighter regulations and expanded monitoring in the future.

“A person who earns 5,000 rupees (\$110) or 6,000 rupees per month does not come under the below-poverty-line category. Can we expect him/her to spend 6,000 rupees per month on medicines alone? What will he/she eat?”

Loon Gangte, president, Delhi Network of HIV Positive People (DNP+), 23 December 2009

3. FACTORS INFLUENCING ACCESS TO TREATMENT

SECOND-LINE ART

One of the most serious concerns around ART services is the scarce availability and provision of second-line ARV drugs. More than three years ago, PLHIV networks began campaigning for the need for a second-line ART rollout at government centres. But NACO has yet to respond adequately or quickly. In 2008, second-line ART was piloted at two government ART centres, and is now available free of charge at only 10 centres. Of the 3,000 or so people thought to be in need of second-line ART, only about 750 were receiving it as of December 2009.¹⁸

NACO continues to impose strict eligibility and provides free second-line ARVs through government centres only to individuals living “below the poverty line, widows and children”. Other patients, meanwhile, are only eligible if they have been receiving first-line ART through a government centre for at least two years.

Most people cannot use the other option – the private sector – because the prices of second-line ARVs remain prohibitively expensive. According to both NACO and PLHIV respondents, the monthly cost of a first-line ART regimen at private pharmacies is about 400 rupees (\$8.65). The comparable cost of a second-line ART regimen ranges from 2,700 rupees (as per NACO’s estimates) to 9,000 rupees (as cited by some PLHIV respondents); the difference is based on who or what is buying, with the government able to negotiate lower prices because it buys in bulk. The main reason for the continued high cost of second-line ARVs is that generic manufacturers have not begun large-scale production of them. Most are holding back because of uncertainty over patent issues.

¹⁸ As cited in an email to the researchers by a NACO representative in December 2009.

There is little doubt that the lack of easy and affordable access to second-line ART has tragic consequences. One respondent, a physician who treats PLHIV, gave the following example¹⁹:

[An HIV-positive person] was referred to the STM, a teaching hospital and tertiary HIV/AIDS referral unit in Kolkata by a private physician in Chhatisgarh state. When the patient developed severe complications he was referred to STM. We found him with a very low CD4 count and he was advised to begin on second-line ART immediately. But we could not get him access to a second-line regimen through a government ART centre because he was not technically eligible: he had not received ART from the free ART roll-out programme.

ADHERENCE

Adherence is critical for the long-term success of ART. However, there are no mechanisms or policies in place to focus on adherence among those receiving ART through the public sector. According to one PLHIV respondent – Deepak,²⁰ secretary of the Manipur Network of Positive People (MNP+) – government health care providers are unable to monitor adherence successfully. He and others attributed this inability to insufficient levels of staffing at most government ART centres. Caregivers (including ART counsellors) are simply overworked in many cases, which means they cannot or do not choose to counsel patients on adherence and help monitor it.

DIAGNOSTIC TESTS

NACO stipulates that all people enrolled in its ART programme can receive two CD4 tests free of charge each year. Several respondents said the government is not currently meeting its pledge, in terms of frequency of tests; or ensuring uniform quality assurance (i.e., using accredited laboratories every time). Some PLHIV said their local ART centre was often unable to offer CD4 tests regularly because of equipment problems and lack of qualified personnel. This has cost implications for PLHIV who are thus forced to pay out-of-pocket for a test at a private laboratory.

One PLHIV respondent said the following:²¹

Sometimes machines at government facilities are not working, technicians are absent, and there is a scarcity of reagents. Overall, it takes too much time both to get tested and to get the results, even though the service is available free of cost.

19 Interviewed in Kolkata on 27 November 2009.

20 He is identified by only one name throughout this report, as per his request.

21 Deepak, secretary of the Manipur Network of Positive People (MNP+), interviewed on 27 November 2009.

“We want the doctors and health care providers at the government hospitals to treat us with love and care. Sometimes they treat us differently from others [who are not HIV-positive]. The ways they look at us are different from how they look at other patients. We want them to treat everybody equally. Conditions have improved from before but still there is room for improvement.”

HIV-positive male, 34 years old, participant of focus group discussion of men living with HIV in Imphal, Manipur, 16 December 2009

Viral load and drug-resistance tests are essentially unavailable to most people on ART in India. The government’s programme currently provides viral load tests free of charge only to PLHIV receiving second-line ART, for example.

4. OPPORTUNITIES AND CHALLENGES

OPPORTUNITY: IMPROVING ADHERENCE

Although no formal adherence-focused mechanisms exist, some PLHIV participants highlighted a model that directly addresses some of the concerns early on. Participants in a focus group discussion comprising women living with HIV in West Bengal said that the concept of community care centres (CCC) had proven to be effective. In this model, PLHIV are encouraged to stay in a CCC for 5–7 days after ART is initiated from ART centres. While at a CCC, new patients learn about the importance of adherence and other key treatment-related issues. Other respondents noted, however, that the number of CCCs is inadequate.

In another hopeful sign, PLHIV participants at a focus group discussion in Andhra Pradesh discussed a community initiative that focuses on improving adherence.²² District level positive networks of Andhra Pradesh in association with the government, has established an innovative adherence-monitoring model. Every month a meeting is held between the physicians for the ART centres in the state and representatives of the PLHIV networks. The physicians provide the network members with names of the individuals on the ART drop-out list. The network members follow up with these individuals, encouraging and assisting them to continue the therapy. The state’s 23 district level PLHIV networks are involved in this exercise.

OPPORTUNITY: FEDERAL HIV/AIDS LEGISLATION

Civil society advocates continue to press for the federal government to pass an HIV/AIDS bill that would protect the rights of PLHIV and in particular marginalized communities (e.g., MSM, sex workers, and IDUs). It also has an extensive focus on the rights of women and children. While the proposed law is primarily an anti-discrimination law, it also covers issues of informed consent and confidentiality. Advocates believe that NACO’s guidelines in regard to such issues are weak and mostly legally unenforceable, especially in the private sector. The bill would, among other things, force all health service providers – government and non-governmental – to comply with NACO’s guidelines and protocols.

Civil society organizations believe that the law will also strengthen the government’s HIV treatment programme and efforts to meet its commitment to universal access. The bill was first proposed more than six years ago as a joint initiative of government and civil society and was drafted after extensive research and consultations across the

²² The focus group discussion took place on 19 December 2009.

country. It currently is being held up by officials at the Ministry of Law and Justice, who reportedly have objections to certain provisions. Advocates are working with key Members of Parliament (MPs) in an effort to ensure that the draft bill is tabled in Parliament as soon as possible—a critical first step to having it passed into law. As of December 2009, several MPs had promised their support in the next session of Parliament. Many civil society groups are increasingly optimistic that the political will to pass this bill is increasing.

CHALLENGE: ADEQUATE FINANCING

A total of \$2.57 billion is required by NACO to implement NACP-III over the period from 2007 to 2012. However, as of January 2010 NACO had raised only \$1.9 billion.²³ Around 67 percent of the budget is allocated for HIV prevention services, though only 26 percent for high-impact targeted interventions. The initial budget allocated for care, support and treatment was 17 percent, but this has been increased to 26 percent.

At least in part due to strong advocacy on the part of civil society groups involved in drafting NACP-III, greater emphasis on prevention and treatment for “high risk groups”, including MSM, IDUs and sex workers, reportedly is being considered.²⁴ Advocates have not been as successful in increasing awareness of and attention to key mental health and human rights issues, however.

According to UN representatives interviewed for this report, a key government programme sustainability concern is that most ARV drugs are sourced through funding from the Global Fund. There is no guarantee that this source of funding will be available after the current grants end within six years, even as new enrolments continue for first-line ART. Alternatives need to be explored, with one possibility (supported by some government officials) a much greater role for the private sector. Most civil society groups, however, do not support that option. They believe that an expanded government role accompanied by greater oversight and accountability would be the best way to build and ensure sustainability.

CHALLENGE: IMPROVING ACCESS TO SERVICES FOR PREVENTION OF VERTICAL TRANSMISSION OF HIV

NACO guidelines currently recommend that HIV-positive pregnant women receive a single dose of the ARV nevirapine at the onset of labour and single dose to the baby soon after birth in order to prevent transmission of the virus to their newborns. However, nearly all respondents agreed that access to and uptake of this intervention remains low in many states in India. Contributing factors include lack of knowledge, stigma and unavailability of prevention of vertical transmission services for women delivering at home, in the private sector and in rural areas.

²³ Aide memoir, “UA mission, New Delhi, India”, 3–4 November 2009. Summary of findings and recommendations.

²⁴ Ibid.

- PLHIV participants from a focus group discussion in Andhra Pradesh said that there is lack of adequately trained human resources for providing quality counselling on vertical transmission, even at specialized facilities that are supposed to focus on the issue. They argue that confidentiality violations continue to occur, and sometimes counsellors' caseloads are too high for them to be able to deliver quality information and advice in a timely manner.
- Women living with HIV in a focus group discussion in West Bengal noted that although HIV-related stigma continued to be widespread in both the public and private health care sector. One participant gave the following story: "An HIV-positive pregnant woman was admitted with great difficulty to a government hospital. But she was discharged two days later. The doctors said, 'If the attendants don't work, what could we do?'"

Also of importance is the fact that NACO's guidelines do not reflect international best standards on prevention of vertical transmission. As one respondent, a Kolkata physician, remarked, "Treating with a single dose of nevirapine is...a crime."²⁵ He and most advocates agree that all HIV-positive pregnant women should be provided with more effective prophylaxis and also ART for their own health if they need it.

Many advocates believe that NACO's retention of the current guidelines reflects a bias toward saving newborns from being infected – and clearly indicates that there is less concern for protecting the health of mothers. Such an observation is not uncommon in India, where longstanding neglect for women's health and lives continues to have serious consequences and violates their rights. Advocates are seeking to change NACO policies in order to ensure that all HIV-positive pregnant women are automatically eligible for free first-line ART at government centres. They have a long road ahead of them. According to one UN representative interviewed, possibly "less than 10 percent" of HIV-positive pregnant women in even high prevalence Indian states currently receive ART for reasons related to their own health.²⁶

CHALLENGE: ACCESS TO MEDICINES TO PREVENT AND TREAT OIs

Most PLHIV in India access OI treatment services through the outpatient departments of tertiary government hospitals (medical colleges and hospitals located in the national/state capitals and other bigger urban centres), and district level hospitals located in district headquarters. But it is usually only physicians' advice that they get, whereas required medicines for preventing and treatment of opportunistic infections are not always available for the prescribed duration at all the hospitals.

According to PLHIV participants of a focus group discussion in West Bengal, there is often scarcity of important medicines like acyclovir, fluconazole and cotrimoxazole at hospitals in their

²⁵ Interviewed in Kolkata on 27 November 2009.

²⁶ Interviewed in Delhi on 17 December 2009.

state.²⁷ Their observations were echoed by an HIV-positive counsellor working with a PLHIV network in Andhra Pradesh.²⁸ A PLHIV activist in Manipur added that even when OI medicines are available, their quality is unknown and some times nearer to the expiry.²⁹

CHALLENGE: ACCESS TO TB MEDICINES

The National AIDS Control Programme has ensured clear and established links between HIV and TB services in recent years. Drugs to treat TB are available free of charge at government facilities for all in need. Many respondents, however, said they had doubts about the quality and efficacy of the drugs provided at such facilities. One participant in the West Bengal focus group discussion said – and others in the session agreed – that “doctors in Kolkata hospitals tell us to buy TB medicines from private medicine shops rather than from the government’s centres” because those available in private pharmacies are of better quality.

“For people from far off places, it is a problem because they come, have to stand in queue and sometimes spend the whole day without food... These difficulties are faced by people who are not in the city.”

HIV-positive male, 29 years old, participant in a focus group discussion of men living with HIV in Imphal, Manipur, 16 December 2009

CHALLENGE: DECENTRALIZING SERVICE DELIVERY IN AN EFFECTIVE WAY

NACO has declared decentralization of HIV treatment services to the district level to be a key element of the National AIDS Control Programme – Phase III (NACP-III). Most PLHIV and civil society advocates support this goal in the belief that it will ease patients’ ability to obtain services closer to home, etc. Most observers agree that progress has been slow, however, and quality uneven. According to one PLHIV respondent, “The physicians at some district hospitals do not pay as much attention as medical college hospitals”³⁰

CHALLENGE: HIV-RELATED STIGMA AS A BARRIER TO HIV TREATMENT ACCESS

In spite of years of educational and sensitization activities undertaken by the government and civil society groups, HIV-related stigma remains common across India. Such stigma crosses class and economic divides, and even pervades personnel in the health care system (who should know better). PLHIV respondents note that some health care providers – medical and paramedical staff – still stigmatize and discriminate against PLHIV. Few reportedly refuse to touch the patients, often carrying out the diagnosis of an illness purely based on observations.

Attitudinal and cultural barriers often have a gender and sexual orientation dimension. In West Bengal, according to participants of a focus group in that state, some women who have children have not been able to access community care centres (CCCs) when starting ART. They face strong stigma because their neighbours start enquiring about their whereabouts if they are not seen at home for a long time.

²⁷ The focus group took place on 28 November 2009.

²⁸ Interviewed on 19 December 2009.

²⁹ Interviewed on 18 November 2009.

³⁰ HIV-positive widow, 26 years old, participant of a focus group discussion of women living with HIV in and around Kolkata, West Bengal, on 28 November 2009.

5. RECOMMENDATIONS

1. **The HIV/AIDS bill must be pushed through Parliament.** Civil society campaigners who are part of the National Coalition on the HIV/AIDS Bill must persist with dialogue with MPs of all parties to table the bill for discussion in Parliament in the current budget session or the next monsoon session. The issue must also be kept “alive” in the media with the focus on the benefits of the legislation. If made into law, the bill would be the single most important tool to fight discrimination around HIV in health, workplace and other settings.
2. **Special orientation sessions should be organized to ensure attitudinal changes of health care providers towards MSM, transgendered people, sex workers and IDUs.** Civil society groups must advocate with NACO to tie in these sessions with their existing training and orientation programs. The sessions need to be designed after analysis of similar work done in the past to check what did not work. Sensitized and supportive medical personnel must be enlisted to conduct these sessions to ensure greater receptivity among the learners.

As a follow-up to such orientation sessions, a community-based monitoring and performance appraisal mechanism should be created in all government health centres to act as a bridge between patients and health care providers, and to thwart denial of treatment. Civil society groups need to engage NACO and state-level Departments of Health and Family Welfare in this regard. While the HIV/AIDS legislation would provide legal teeth against treatment denial, it should perhaps be used as a last resort if none of the collaborative approaches work.

3. **The state and central government health authorities must ensure un-interrupted availability of key medicines for managing and preventing common OIs from all government health centres.** Where possible, through linkages with the National Rural Health Mission (NRHM), the government’s flagship health initiative in advanced stages of rollout, the availability of drugs for OIs should be decentralized down to the primary health facility level. While government bodies work out the administrative procedures, NGOs with technical expertise can assist the government in preparing medical personnel at the primary level to prescribe drugs for OIs.

4. For the long haul, advocacy and civil society pressure on the government to enhance health budgets and strengthen health systems must continue, if necessary, through a national campaign. But in the short term, **dialogue is needed with NACO to revise its criteria for second-line ART and increase its budgetary allocations for treatment services.** Programs based on greater synergy between prevention and treatment activities may allow for such reallocations. The support of UN bodies should be sought in this regard.
 5. **All ART recipients should be linked up with local PLHIV networks for adherence, psycho-social and nutrition support.** Monthly review meetings should be conducted by ART counsellors with network representatives in order to track ART recipients and support them to maintain adherence. Drop-outs should be followed up through outreach workers of the networks. Confidentiality concerns need to be built into the tracking strategies.
 6. **Civil society groups should engage NACO, NRHM and donors to initiate a mapping exercise to determine where and what gaps remain in the government's drive for prevention of vertical transmission of HIV.** A large number of pregnant women still remain outside the HIV testing net and strategies are needed to minimise this number. Additionally, the government should be asked to revisit the protocols for preventing vertical transmission to ensure that both mother and child receive the best standards of health care.
 7. **The government must ensure a scale-up of human resources in health centres to match the increasing caseloads.** Apart from intensive training drives, government and PLHIV networks can work out collaborations wherein the skills base of experienced PLHIV can be enhanced to help them function as lay counsellors for provision of HIV prevention, pre and post test, ART adherence and nutrition counselling.
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Kenya

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Support provided by James Kamau, Elvis Kirui, and David Njuguna

KEY FINDINGS

1. As a result of donor cutbacks and lack of adequate domestic budgets, the financing gap for HIV/AIDS treatment and services in Kenya will further widen this year – making the government’s universal access goal by 2013 unlikely.
2. Poor PLHIV struggle with the burdens of the costs of important health care services, including medicines, consultations and diagnostics to treat OIs and many inpatient services, as well as transportation and nutrition costs.
3. Lack of sufficient – and sufficiently trained – health care workers is a chronic problem in Kenya.
4. HIV-related stigma throughout society continues to hinder many people from seeking out HIV services, from testing to ART.
5. In rural areas in particular, there are too few facilities providing ART.

RESEARCH PROCESS AND METHODOLOGY

Research for this country report was conducted in November and December 2009. Both quantitative and qualitative approaches were utilized. Data collection consisted of reviews of documents, a focus group discussion with PLHIV, and interviews with policymakers, health providers, and NGO representatives. A non-probability sampling method was applied in selecting individuals to be interviewed. The 18 total respondents consisted of PLHIV (nine people); health care providers at a public health facility (two), an NGO care and treatment facility in Nairobi (two); policymakers at the MoH (four); and one representative each from two advocacy NGOs, Women Fighting AIDS in Kenya (WOFAK) and the Kenya Treatment Access Movement (KETAM).

1. OVERVIEW OF COUNTRY SITUATION

Kenya has made significant progress in the fight against HIV and AIDS, especially in recent years. Nevertheless, the Modes of HIV Transmission Study (MoT 2008) and Kenya AIDS Indicator Survey of 2007 (KAIS 2007) show that the country still faces major challenges ahead. The KAIS indicated that HIV prevalence in the key adult age group (15 to 49) rose from 6.7 percent as reported in Kenya Health and Demographic Survey of 2003 to 7.4 percent four years later. Incidence remains high, with an estimated 125,000–133,000 new cases annually among adults and 32,000 new paediatric infections per year.³¹ The number of HIV-positive adults (15–64 years old) is estimated at 1.42 million people.

Treatment and care is a core component of the national response to the epidemic. However, progress toward achieving universal access targets has been slower than expected. The original universal access target, specifically set by the Kenya National AIDS Strategic Plan (KNASP III) as reaching at least 80 percent of those in need, is not expected to be achieved until 2013. The plan defines “universal access” as including access to ART, OI prophylaxis, OI treatment, and home-based care, among other services. Recent trends make even that 2013 goal sound optimistic. Although the number of people on ART has been increasing over time, the number of people in need is increasing at an even faster rate. The National AIDS and STI Control Programme (NAS COP) currently estimates that at most about 68 percent of the nearly 570,000 people in need of ART will be receiving it in June 2010.

According to KNASP III and NAS COP, the targeted number of people to be put on treatment over the current and upcoming four fiscal years is as follows: 388,998 (2009/10 fiscal year); 489,935 (2010/11); 587,620

³¹ According to the Kenya National AIDS Strategic Plan, KNASP III, which was released in February 2010.

(2011/12); and 639,452 (2012/13). However, the commitments made so far by the government and development partners add up to far lower numbers in terms of people on ART during those years. In fact, due to the discontinuation of support in 2010 by one major current funder (the Clinton HIV/AIDS Initiative), the total number of people on ART is expected to decline from a high of 393,453 in the 2010/11 fiscal year to 344,000 over the next two years. If these figures and trends are accurate, the gap between the government's ART access target and reality will have widened to nearly 300,000 people by the year 2013.

The financing of HIV and AIDS services has been increasing in the country. The National AIDS Spending Assessment carried out in 2009 showed that a total of \$419 million was spent in the 2006/07 fiscal year, \$660 million in the 2007/08 fiscal year, and \$687 million in the 2008/09 fiscal year. The bulk of this funding (about 90 percent) came from development partners, with the Kenyan government contributing the remaining 10 percent. The government contribution includes indirect funding through the MoH; otherwise, direct, earmarked financing from the government makes up about 3 percent of the total spending on HIV and AIDS activities in the country. The Global Fund channels its support through the government, but most other development partners (e.g., bilateral agencies) channel their funds through NGOs.

2. SOURCES OF HIV TREATMENT DELIVERY AND RELATED SERVICES

The main sources of HIV treatment services are hospitals and other health facilities such as dispensaries and clinics. By the end of 2009, a total of 732 facilities were providing ART services, including ARV provision, laboratory monitoring, OI treatment, and OI prophylaxis.³² Three quarters of these facilities (a total of 546) are government-run. (Not all of these services are available in each facility, however.)

Of the total people on ART as of the end of 2009, about 97 percent were on first-line regimens with the remaining 3 percent on second-line regimens.³³ Both first-line and second-line ART are provided to patients free of charge through the public sector and most NGOs. Diagnostic and monitoring tests are also offered free of charge. Patients (HIV-positive or not) must meet some or all of the cost of other potentially important health care services, however, including medicines to treat OIs and many inpatient services.

3. FACTORS INFLUENCING ACCESS TO TREATMENT

A number of political, economic and social factors affect access to treatment in Kenya. One relatively recent event, the ethnic-based violence that followed the disputed general elections in December 2007, was particularly disruptive to efforts to scale up treatment. It resulted in the displacement of tens of thousands of people, and many Kenyans around the country could not access treatment or other HIV services

³² As per data provided by the National AIDS and STI Control Programme (NAS COP).

³³ Ibid.

for several weeks at least.³⁴ In addition, some health workers were also displaced from their places of work. The following quote from a local newspaper one year later underscored the lingering problem:³⁵

[B]eneath the 'nomadic-like' life of the IDPs ([internally displaced persons]) lies a sad tale of a silent minority, those living with HIV/AIDS. Rights activists and HIV and AIDS control campaigners have raised concern [that] IDPs living with the virus risk failing to access the life-prolonging drugs (ARVs). This is because many fled their former locations where they used to access the drugs. Interruption of ARV therapy could also make them develop resistance to the drugs, according to the World Health Organisation. At the height of the skirmishes, many IDPs on ARVs are said to have missed their monthly prescriptions.

FINANCING GAP AND SHORTFALLS

Efforts to achieve universal access also hinge substantially on the availability of financing. In Kenya, HIV and AIDS services – including the provision of ARVs – traditionally have been largely financed by development partners. The main sources of external funding and service provision are the U.S. government (through PEPFAR), the Global Fund, the World Bank, the Clinton Foundation, Médecins Sans Frontières (MSF), and other international NGOs.

As noted in Section 1, the government's direct contribution accounts for about 3 percent of the overall spending on HIV/AIDS in the country. The amount it provides has barely increased: in the last three years, for example, the government has allocated the same amount – KES 500 million³⁶ (\$6.5 million) – for purchasing ARVs, even though demand is growing and reductions in the cost of medicines are not sufficient enough to meet the demand. The government's reluctance to increase its share of funding for ARVs is a major concern given estimates that the total amount needed for that purpose is expected to double, from KES 6 billion to KES 12 billion (\$156 million), by the 2012/13 fiscal year.³⁷

Additionally, the flow of this money to the public health sector is not automatic. Recently, it took a lot of persuasion and lobbying by the Ministry of Medical Services to have the money released by the Treasury. This suggests a major lack of political will to providing resources for the national HIV/AIDS response.

The global crisis did not have a major impact on the country's economy. However, financing challenges have arisen that may be attributed to the global financial downturn. Most notably, the Clinton HIV/AIDS Initiative (CHAI) has said it will discontinue support for

34 Most of the people who fled their homes – known as IDPs (internally displaced persons) – had been resettled by January 2010. Often, however, they were not able or willing to return to where they had been living.

35 John Oywa, "Displaced people infected with virus struggle for ARVs", *The Standard*, 12 February 2009.

36 As cited by Irene N. Mukui, ART programme officer at NASCOP, in an interview on 14 January 2010.

37 Arthur Okwemba, "Crisis looms as surge in HIV patients drains drug stocks", *The Daily Nation*, 20 February 2010.

paediatric ARVs and second-line treatment in 2010; PEPFAR has capped the number of patients it will support to 190,000 patients for the next couple of years;³⁸ and MSF has been transferring its facilities and patients to the government in its phase-out plan. The implication of these developments will be an increase in the financing gap, starting this year – and this is one reason why a growing number of observers do not think the government will be able to meet its universal access goal by 2013, as it currently claims it will.

Another major funder in recent years, the Global Fund, also has not been able or willing to commit additional financing. In November 2009, the Global Fund announced that two HIV/AIDS-related applications from Kenya had been rejected.³⁹ The rejections were based on the fact that the country had not done a good job of spending the money already provided (from Rounds 3, 4, 5, 6, and 7). According to AidsSpan, an independent watchdog of the Global Fund, Kenya was on average nearly nine months behind schedule in implementing and reporting on Global Fund grants, with some activities more than three years behind schedule.⁴⁰ Although this is a serious problem, it is not apparent that measures are being put in place by the government to address them.

An interview with officials at the National AIDS Control Council (NACC) indicated that the government has not yet developed a proposal or plan to address the overall financing gap. However, the NACC currently is undertaking a financial sustainability exercise to consider possible options and strategies for bridging the gaps. In addition, the NACC is in the process of organizing a national conference on HIV/AIDS financing to involve all stakeholders, including development partners, all relevant government agencies (especially the Ministry of Finance and Kenya Revenue Authority), and representatives from the private sectors.

HIV-RELATED STIGMA AND DISCRIMINATION

Persistently high levels of HIV-related stigma and discrimination are a major factor affecting PLHIV's ability and inclination to access HIV services, including treatment. One respondent noted the following about the difficulties MSM face in receiving important HIV services:⁴¹

There is a big problem of disclosure by MSM mainly due to stigma, and also given the illegal nature of the practice [it is punishable for up to seven years in prison]. Health providers exhibit strong negative attitudes towards them, and they are not accepted by the society. In addition, for the MSM who access services, there is a relatively high ART default rate that is linked to higher levels of drug and substance use in the population.

38 Ibid.

39 Both applications were for Round 9 programming. The country's proposals in the previous year (2008) were also rejected. Additional information about the ongoing programmes is available at the Global Fund's website: www.theglobalfund.org/programs/country/?countryID=KEN&lang=e.n.

40 As cited, for example, in "Government protests Global Fund rejection", IRIN Plus News, 10 November 2009. Online: www.plusnews.org/Report.aspx?ReportId=86969.

41 Dr. Duncan Chepcheng, medical officer at Liverpool VCT, Care and Treatment in Nairobi, interviewed on 22 December 2009.

“Although we are provided with free ARVs, we have to pay for treatment of OIs at health facilities. But most of us are not working, and also poor. The problem is even worse when one is admitted at the hospital, and one has no money to pay.”

PLHIV at Women Fighting AIDS in Kenya (WOFAK)

Discrimination is not limited to vulnerable and marginalized populations, however. It is also common in workplaces and health care facilities. According to one respondent, “Those whose status is HIV-positive are shunned by fellow workers. As if that is not bad enough, many employers do not provide them with health insurance, forcing them to meet medical expenses personally.”⁴² Findings from a study released in 2006 indicated that 40 percent of health workers stigmatized and discriminated against HIV-positive patients.⁴³

PERSONAL FINANCIAL BURDENS OF THOSE ON ART

Poverty rates remain high in Kenya, so it is not surprising that many PLHIV face ongoing financial problems that affect their access to ART. In comparison with most other poor people, however, they have greater obstacles – physical, financial, emotional, etc. One PLHIV respondent said, for example: “Although we are provided with free ARVs, we have to pay for treatment of OIs at health facilities. But most of us are not working, and also poor. The problem is even worse when one is admitted at the hospital, and one has no money to pay.”⁴⁴

The problem of poverty is exacerbated by the fact that, as noted in Section 2, many important treatment-related expenses must be met by patients out of pocket. These include medicines to treat OIs, which are often not provided free of charge at either public or non-governmental facilities. (The major exception is TB treatment, which is available for free. Otherwise, patients seeking care for OIs must pay fees for medicines, consultations and diagnostic evaluations.) Additionally, many patients find it difficult to meet the cost of transport to and from facilities, especially if they live in rural areas far from clinics.

Despite such huge burdens, there are no plans by the government to reduce or eliminate the fees, though services at government health facilities are subsidized. The AIDSRelief programme supported by PEPFAR provides free outpatient services (drugs, tests, other services) for HIV-positive clients. However, not all patients can access PEPFAR-supported programs and treatment.

INADEQUATE ACCESS TO SERVICES ACROSS THE COUNTRY

Even as HIV treatment access slowly increases in Kenya, the mismatch between location of service delivery points and higher prevalence settings persists, according to KNASP III. Interviews with representatives from KETAM and WOFAK revealed that in rural areas in particular, there are far too few facilities providing ART. At a very basic level, this sometimes means that people in some rural and isolated

⁴² Interview with an HIV-positive respondent at Mbagathi Hospital in Nairobi on 4 December 2009. As noted in Section 2, although ART and other key HIV treatment services are available free of charge, regardless of whether a patient has health insurance, no such guarantee covers many inpatient services.

⁴³ Health Policy Initiative, “Measuring the degree of stigma and discrimination in Kenya. An index for HIV/AIDS facilities and providers”, July 2007.

⁴⁴ Interviewed at the offices of Women Fighting AIDS in Kenya (WOFAK) in Nairobi on 30 November 2009.

communities are not even aware that ART is available or where they might go to be tested for HIV and/or receive treatment. The relative lack of easy access means that those in need must travel long distances, often several hours each way, just to reach a clinic. This contributes to the lower rates of ART adherence in rural areas compared with urban ones.

LIMITED HUMAN RESOURCES

Lack of sufficient – and sufficiently trained – health care workers is a chronic problem in Kenya. There are only about 17 doctors for every 100,000 people in the country; the situation is not much better for nurses and other caregivers. As a result, personnel at most health care facilities are overworked, and all patients (including PLHIV) face long queues whenever they seek assistance. During interviews at Mbagathi Hospital in Nairobi, one respondent complained about the long waiting times, saying, “I arrived at 6 a.m. and then had to wait for several hours. It was at 1 p.m. when I was finally served.”⁴⁵

4. OPPORTUNITIES AND CHALLENGES

The following positive trends in regards to access to HIV services are considered key **opportunities** for continued improvement:

- Through the National AIDS Control Council (NACC), the government has established a highly inclusive coordination framework within which all stakeholders make inputs and participate in the national response to HIV and AIDS. The NACC’s KNASP III provides a road map on the response in the country.
- Treatment services in terms of ARVs, monitoring tests and OI prophylaxis are provided free in the country at public and non-governmental health facilities. This reduces the financial burden on HIV-positive people and therefore enhances access to these services.
- The government and PEPFAR have a formal arrangement in which they share ARVs when one has worryingly low levels in stock. This arrangement has ensured that the country has never experienced stock-outs of ARVs.
- The policy and guidelines for integration of HIV and TB services are already in place. At TB clinics, 87 percent of patients are currently being screened for HIV. Similarly, patients receiving HIV care are routinely screened for TB.

The following are among the major **challenges** to improved and enhanced HIV treatment scale-up in Kenya:

- Kenya faces a serious financial gap in its attempt to scale up its HIV treatment programme. The financing gap will be exacerbated by the move to comply with new WHO recommendations that ART be initiated when a patient has a CD4 count of less than 350 cells/mm (the previous level was 200 cells/mm³). This change, which is

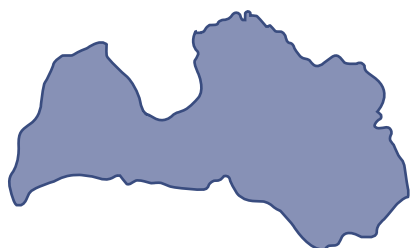
45 Interview with an HIV-positive respondent at Mbagathi Hospital in Nairobi on 4 December 2009.

expected to be formally implemented in July 2010, will mean that far more people will be clinically eligible for ART and the number of those officially in need will surge.

- Knowledge of HIV status among the population is low; for example, the 2007 Kenya AIDS Indicator Survey (KAIS) indicated that nearly 84 percent of Kenyans did not know their status. The study also revealed that more than half of HIV-positive people with CD4 cell counts of less than 200 cells/mm³ were not aware of their status. (Those individuals are already eligible for, and in need of, ART—but are not receiving it.)
 - Lack of access to adequate nutrition is a major reason for poor adherence among many people on ART. Some PLHIV interviewed stressed the need to include a package on nutrition in the issuance of ART.
 - HIV-related stigma throughout society—at the workplace, within families and communities, at health facilities, etc.—continues to hinder many people from seeking out HIV services, from testing to ART.
 - Most hospitals are severely overstretched in terms of resources. This is of particular concern because most people on ART currently receive treatment at hospitals.
 - The legal environment places major obstacles on efforts to target HIV programming, including treatment, more directly to members of high-risk vulnerable populations (i.e., sex workers, IDUs and MSM) and to take these programmes to scale. Sex work, homosexuality and drug use are all illegal in Kenya. (Programmes have been working with all these groups for many years, but under constraints.)
 - As stressed throughout this report, human resource limitations remain major challenges for HIV treatment scale-up. The limitations are heightened by the fact that many existing staff are not adequately trained to provide high quality HIV/AIDS services.
 - Financial sustainability is a challenge given that about 90 percent of resources for the HIV response come from development partners. This challenge is even greater since the Global Fund rejected two funding proposals in November 2009.
 - Government officials, policymakers and politicians lack political will to increase financial allocations earmarked for HIV/AIDS services.
 - Passed by Parliament in December 2008, the Anti-Counterfeit Bill, 2008 aims to address issues related to counterfeit and fake products (including medicines) in Kenya. HIV advocates are concerned, however, that it could adversely affect access to essential medicines (including ARVs) by blocking the importation and distribution of lower-priced generic drugs. The bill has been challenged in court by several leading advocacy groups, including KETAM; the first hearing took place in February 2010.
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5. RECOMMENDATIONS

1. The government should explore ways to mobilize resources domestically to fill the financing gap and to ensure sustainability of the ART programme. The Ministry of Finance should take the lead in this process. The first strategy should be to allocate more funds from the national budget for HIV/AIDS services, including purchases of ARVs. Other options might include raising funds for HIV/AIDS services from specially earmarked taxes on purchases of beer and cigarettes, and on cellphone use.
 2. The National Health Insurance Scheme should cover all the costs of inpatient health services as part of its standard package for PLHIV. This would include all medicines to treat OIs and side effects. This step would help ease the financial burden on many patients and increase access to treatment.
 3. Poor patients should be reimbursed for transport costs incurred to travel to and from facilities. An already existing program targeting poor pregnant women is a useful model. Developing and implementing such a program is the shared responsibility of the Ministry of Medical Services and the Ministry of Public Health and Sanitation. The Ministry of Public Health and Sanitation should also increase access to treatment services by providing ART services at the health centres, since these facilities are located in rural areas where more ART facilities are needed.
 4. Policies and guidelines aimed at reducing HIV-related stigma and discrimination should be developed by NASCOP in collaboration with other stakeholders, especially the Federation of Kenya Employers and the Central Organization of Trade Union. Included in this effort should be guidelines prohibiting discrimination in workplaces and clear policies on how violations can be reported (i.e., confidentially and with guarantees against retaliation). All stakeholders must work to ensure that once implemented, the policies and guidelines are strictly enforced.
 5. The low coverage of services for paediatric HIV care, including ARVs, is a serious problem in Kenya. It will only get worse now that CHAI is pulling out. The government should make it an immediate priority to allocate funds to replace CHAI support and to expand access to ART for children.
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Latvia

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KEY FINDINGS

1. As part of its budget-tightening steps in the face of a severe economic downturn, the Latvian government is cutting the HIV and health services budget and imposing limits on the number of PLHIV provided with ART free of charge.
2. The government has also so far refused to base its ART eligibility criteria on the new WHO guidelines for initiation of ART.
3. Generic medicines are not procured, and as a result, the cost of treatment to the government is shockingly high compared to most other middle-income countries. In January 2010, for example, the annual cost per patient for the most commonly used first-line ART (EFV+3TC+AZT) was 3,170 LVL (\$5,882).
4. Many primary care providers are reluctant to treat PLHIV because they have insufficient or limited knowledge about HIV, or because of the stigma associated with illicit drug use. This makes efforts to decentralize services (currently there is only one main comprehensive ART centre in Latvia) difficult.
5. Lack of integration of HIV care and drug-treatment services is another key reason why IDUs – a most vulnerable and affected population in Latvia – lack access to HIV treatment.

RESEARCH PROCESS AND METHODOLOGY

Research for this report was conducted between November 2009 and January 2010. It consisted of an extensive literature and policy documentation review; a review of letters sent by PLHIV in recent years to Apvieniba HIV.LV, a leading HIV advocacy group; and in-depth interviews with a total of 18 people. Individuals interviewed included HIV/AIDS program managers; health care workers and service providers; representatives from the Ministry of Health, Ministry of Justice, international organizations, and NGOs working in the HIV advocacy field; and eight PLHIV.

1. OVERVIEW OF COUNTRY SITUATION

The first HIV-positive person in Latvia was not registered until 1987, when the country was part of the Soviet Union. The number of HIV cases was relatively low over the next decade, with most transmissions attributed to sexual contact (the majority of them among MSM). In 1997, however, HIV started spreading rapidly among IDUs, a community in which it reached epidemic levels within a couple of years.

The number of registered known new infections reached a high of 807 in 2001;⁴⁶ of those individuals, more than 80 percent were IDUs. Since then the registered number of new infections has decreased annually. The most recent data (for the year 2009) shows the lowest number – 275⁴⁷ – of new HIV registered cases in one calendar year since 1999. The share of new infections attributed to injecting drug use has declined in recent years, but observers do not agree on whether this means the epidemic is no longer concentrated in that population. A WHO mission report from 2009⁴⁸ concluded that the Latvian HIV epidemic remains concentrated among IDUs and their sex partners, but some Latvian specialists consider the epidemic to have become more generalized.⁴⁹

46 The term “registered” is commonly used in many countries, including in Eastern Europe, to refer to individuals who have had contact with health care facilities and whose status and health-seeking information are therefore able to be recorded and collected by government officials. It is important to keep in mind that the number of “registered” cases is nearly always far smaller than the number of actual (“real”) cases in a country. That is because many HIV-positive individuals do not know their status or have not had any contact with a facility that would provide services such as HIV testing or care.

47 Latvian Infectology Centre, 2010. Official statistics on new HIV infections in Latvia.

48 Joncheere K. et al. “Evaluation of access to HIV/AIDS treatment and care in Latvia”, WHO and UNODC (May 2009). Online: www.unodc.org/documents/balticstates/Library/Other/Report_ART_Latvia.pdf.

49 The authors of this study report that this observation is based on a variety of formal and informal discussions over the past few years with Latvian health care officials and providers.

HIV and AIDS rates in Latvia are among the highest in the European Union (EU).⁵⁰ The HIV incidence rate in the country in 2008 was nearly three times higher than in the EU overall: 157.6 per million population, compared with 60.6 per million.⁵¹ By the end of 2009, a total of 4,614 HIV cases had been registered in Latvia since 1987.⁵² Around 60 percent of the total are among former or current IDUs.

About two-thirds (3,082) of the 4,614 people officially registered as having HIV are also registered with the Latvian Infectology Centre (LIC).⁵³ This means that about one-third of all Latvians who have tested positive for HIV have not sought out treatment at the only facility in the country that provides specialized care for HIV infection.

Many of the HIV-positive individuals registered at the LIC are co-infected with other serious infections. Most notably, nearly two-thirds (1,888) of LIC-registered HIV-positive patients have also tested positive for hepatitis C, a virus that is common among IDUs. Smaller but still significant levels of co-infection have been recorded in regards to hepatitis B (250 patients) and TB (72 persons).

UNIVERSAL ACCESS

Government officials have not specified universal access targets. The National HIV/AIDS Strategy⁵⁴ does state that all in need (100 percent) should receive HIV treatment, including ART, treatment for OIs, and social services for those on treatment. Yet neither that plan nor other relevant policy documents actually indicate how “those in need” is defined.

Estimates vary widely in the absence of specific definitions. According to representatives from one NGO, the number of persons currently in need of ART who are not receiving it is at least 130.⁵⁵ They add that ideally, assuming the clinical threshold for ART initiation were raised above its current CD4 level of 200 cells/ mm³, the number of persons who could be eligible for treatment and would benefit from it might be between 1,000 and 1,500. Those estimates are based on initiating treatment among all PLHIV with CD4 counts below 500 cells/ mm³. As one respondent noted, the higher threshold is preferable because “clinical research studies suggest better outcomes, including a decreased likelihood of developing resistance to drugs, if treatment is started at an earlier stage.”⁵⁶

50 Latvia became independent in 1991. It joined the EU in 2004.

51 European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2008. Stockholm: European Centre for Disease Prevention and Control; 2009.

52 As in most other countries, the actual number of PLHIV is thought to be much higher. In Latvia, for example, some WHO and UNAIDS estimates suggest that up to 10,000 Latvians – twice as high as the number of cases registered since 1987 – may be living with HIV.

53 The LIC is the only facility in the country providing HIV treatment.

54 Cilvēka imūndeficīta vīrusa (HIV) infekcijas izplatības ierobežošanas programma 2009–2013.gadam (National Programme for Limiting HIV and AIDS in Latvia 2009–2013).

55 Interview with Agita Sēja, NGO DIA+LOGS, in January 2010

56 As per Aleksandrs Molokovskis, a co-author of this report (January 2010).

According to some treatment specialists, meanwhile, there are around 800 people who need treatment. If true, that would mean that, as one said, “ART is received by roughly one-half of persons who need it.”⁵⁷

2. SOURCES OF HIV TREATMENT DELIVERY AND RELATED ISSUES

Currently there is only one facility in Latvia, the LIC, that provides a comprehensive suite of services free of charge for HIV-positive people—including provision of ART, HIV-specific diagnostic tests, treatment for OIs and social support. In 2007, a total of 328 patients were on ART through the LIC; by January 2010, that number had risen to 439 individuals (including 26 children). Of that total, 189 (43 percent) were IDUs and 301 (69 percent) were male.⁵⁸ The data on IDUs suggests that members of this vulnerable population are far less likely to be on ART. They comprise about two-thirds of all people who have ever tested positive for HIV, yet their share of PLHIV on ART is much lower.

Of the 439 PLHIV receiving ART through the LIC, a total of 35 were receiving it in prisons (as of the end of December 2009). At the time data for this report was being collected, 20 HIV-positive pregnant women were receiving ART as part of an effort to prevent vertical transmission.

A total of 25 ARVs currently are available free of charge in the public sector. This compares favourably with neighbouring Estonia, for example, where only 13 first- and second-line medicines are available free of charge.⁵⁹ In total, first-line treatment regimens were prescribed to 312 patients, or 71 percent of all people on ART. The most commonly used first-line treatment regimen was efavirenz (EFV) in combination with lamivudine (3TC) and zidovudine (AZT), which was prescribed to 203 patients as of 1 January 2010. (See Table 1 for information on first-line regimens used in Latvia.)

TABLE 1.
MOST COMMONLY USED FIRST-LINE ART REGIMENS IN LATVIA

	1 March 2009 (number of patients on each)	1 January 2010 (numbers of patients on each)
EFV+3TC+AZT	139	203
EFV+ABC+3TC	41	54
ABC+3TC+AZT	10	16
EFV+3TC+d4T	11	12
EFV+3TC+ddI	10	7
Other first-line treatment regimens	14	20
TOTAL	225	312

57 Interview with Dr. Inga Janušķēviča from the LIC, January 2010.

58 Data obtained from the Latvian Infectology Centre in January 2010.

59 See www.ehpv.ee; accessed February 2010.

Second-line ART is available free of charge to patients as well. As of 1 January 2010, a total of 110 patients had been prescribed a second-line regimen. The most commonly used second-line treatment regimens were those involving lopinavir/ritonavir (Kaletra): regimens with that medicine were prescribed to 50 patients, and commonly it was used in combination with 3TC and AZT. (An additional 17 persons were on individual “salvage” treatment regimens.)

ARV COSTS

In March 2009, as the consequences of the economic crisis on the Latvian government’s national budget became more apparent, the LIC proposed to set a limit on the number of ARVs available free of charge to patients. That proposal, which was expected to have reduced the number of ARVs provided for free, was eventually abandoned in the face of strong opposition from NGOs represented on the national HIV coordination council. Most physicians supported the NGOs because they believe, as two noted, that patients “should be treated with the best medicines and doctors should not take costs into consideration.”⁶⁰

Although the LIC backed down, there has been no subsequent effort to address the main reason behind its proposal: the high cost of all medicines used to treat HIV. In Latvia, all ARVs used in treatment are solely originator brands. As a result, the cost to the government is relatively high in comparison with countries where generic medicines are available. In January 2010, for example, the annual cost per patient for the most commonly used first-line ART (EFV+3TC+AZT) was 3,170 LVL (\$5,882). That total was less than what the government was paying in March 2009 (3,714 LVL). However, it remains several times higher than the cost per patient of a few hundred dollars when generic versions are used – including in other middle-income countries.

DECENTRALIZATION EFFORTS

Under new HIV treatment guidelines, patients can obtain a one-month supply of ARVs at the pharmacy of their choice. (Those who have demonstrated regular adherence can, if their doctors approve, receive a three-month supply each time.) Perhaps more importantly from the standpoint of simplified access to HIV treatment, the system is slowly changing towards a more decentralized approach. This means that although the treatment regimen still can be set only by the medical council at the LIC (consisting of four doctors), medicines can be prescribed by infectious diseases specialists throughout the country once a month. Moreover, steps are being taken to permit practitioners (GPs) to prescribe medicines, a development that would make ART even more accessible across Latvia.

60 Interview with two physicians (Drs. Janušķēviča and Kūse) from the LIC in January 2010.

There are some concerns, however, about whether decentralization will be effective, at least initially. Respondents to this study identified current and potential obstacles, including the following:

- lack of specialists in many regions of the country outside of Riga, and
- many GPs' unwillingness to be involved in HIV treatment.

The first obstacle may in fact be easier to address because it is simply about numbers. The second, though, is more complicated. Many primary care providers are reluctant to treat PLHIV because they have insufficient or limited knowledge about HIV in general or treatment specifically. Some, however, would rather not be involved with PLHIV because of the stigma associated with illicit drug use.⁶¹ Their actions and behaviour raise serious concerns about HIV-related human rights violations.

A final point about HIV treatment sources is worth noting. Recent policy changes also allow NGOs to apply for funding for social care for PLHIV from municipal budgets. According to respondents, most NGOs consider this a good idea but are not certain as to how useful it will be. Their uncertainty stems from lack of clarity so far as to whether the available funds would be sufficient for them to hire full- or part-time staff to provide such services on their own.⁶²

3. FACTORS INFLUENCING ACCESS TO TREATMENT

Numerical limits on ART access. The LIC's medium-term strategy (2005–2009) placed implicit caps on ART access. It specified that with initial levels of funding (in 2005), the government would be able to support ART provision to a total of 250 individuals – and added that with additional funding, up to 470 people could receive treatment.⁶³ Advocates consider such prescribed limits to be a major obstacle to efforts to reach real universal access in Latvia. They also believe the limits essentially make it impossible for the government to meet its vow to provide treatment to everyone in need – a vow that was made with no specific indication of numerical limits for any reason whatsoever.

IDUs' access to ART. As noted in Section 1, IDUs' share of all HIV infections has declined over the past few years. However, the longstanding association of the epidemic with IDUs and their sex partners has led to some controversial policies over the years based on persistent drug use-related stigma and discrimination across society.

For example, until recently, active drug use was a contraindication for access to ART through the government health care system. Officially

“On paper the guidelines have changed, but do you think the situation has changed in reality?”

Head of the Project Office for the Baltic States at the United Nations Office on Drugs and Crime (UNODC)

⁶¹ As noted during interviews with representatives from NGOs and the LIC.

⁶² As per Aleksandrs Molokovskis, a co-author of this report (January 2010).

⁶³ The LIC's new strategy from 2010 was still being developed when this report was finalized. Specific information about possible numerical caps and limits was therefore not available.

that is no longer true: the new pharmacological HIV treatment recommendations developed and revised in 2009 by the Centre of Health Economics specifically exclude drug use as a factor in deciding whether an individual is eligible for receiving ART.⁶⁴ The change in policy has not necessarily changed health care providers' attitudes and behaviour, however. Many respondents said that stigmatization and discrimination of drug users remains extensive among the general population as well as among specialists. As one respondent noted, "On paper the guidelines have changed, but do you think the situation has changed in reality?"⁶⁵

Care and treatment for HIV-positive IDUs in prisons. IDUs' share of the prison population is, perhaps unsurprisingly, several times higher than their share in the general population. Many are HIV-positive, and many continue to use drugs while incarcerated. Since 2006, Latvia and its Baltic neighbours (Estonia and Lithuania) have received funds through a United Nations Office on Drugs and Crime (UNODC) project aimed at reversing the spread of HIV among IDUs in prison settings. The project not only helps support ART provision, but also helped create programs to provide methadone maintenance treatment to both HIV-negative and HIV-positive drug users. Project grants also support health education activities among inmates and prison personnel. These efforts have helped increase uptake of key health services, including HIV testing.

4. OPPORTUNITIES AND CHALLENGES

This section summarizes two of the major **challenges** to improved and enhanced HIV treatment scale-up in Latvia.

GOVERNMENT BUDGET CUTS FOR ART PROVISION

Latvia has been hit particularly hard by the global economic downturn. Unemployment has surged and its gross domestic product (GDP) has fallen by double digits over the past two years. In response to the crisis, the government has embarked on a fiscal austerity plan that emphasizes severe spending cuts across the board. Its spending on health and HIV services has not been spared.

The government's reimbursement system for medicines does not have a separate budget line for ARVs. However, its annual budgets are based on estimated costs for ART provision. The most recent budget, for 2010, allocates total spending for the system of about 1.20 million LVL (\$2.32 million). That budget was calculated based on 365 patients receiving ART, a number far less than the 439 people currently on treatment. As a result, advocates are concerned not only that treatment scale-up will be halted, but that some people currently on ART will be dropped due to lack of funds.

64 Veselības ekonomikas centrs. Racionālas farmakoterapijas rekomendācijas no valsts budžeta līdzekļiem apmaksātai antiretrovirālajai terapijai HIV/AIDS infekcijas ārstēšanai, 2009. (The Centre of Health Economics, Rational pharmacotherapy guidelines for antiretroviral treatment of HIV/AIDS from the state budget, 2009.)

65 Interview with Signe Rotberga, UNODC, in January 2010.

In response to advocates' concerns, health officials have said that ART will continue to be provided free of charge to all in need. They have not yet stated, however, how they intend to keep their guarantee in light of the restricted budget. Among the options reportedly being considered by both government officials and advocates are i) removing legal and patent-related barriers to the import and use of cheaper generic medicines, perhaps by using flexibilities in the World Trade Organization's TRIPS agreement (which Latvia has signed)⁶⁶; ii) seeking support from other EU member-states that are not facing such a substantial economic crisis; and iii) applying for assistance from global agencies and initiatives such as the Global Fund, a step that would require special permission because of Latvia's EU status and relatively high per capita GDP.

Although officials say they will not revoke no-cost ART from anyone already receiving it, they have implemented some policies in response to the budget crisis that will have the effect of limiting HIV treatment scale-up. For example:

- New regulations at the LIC require patients to present a valid passport every time they visit the centre. This can be problematic for people who for one reason or another do not have valid documentation. According to some NGO respondents, a handful of people on ART have had difficulty obtaining ARVs since the new regulations were passed.⁶⁷
- The new HIV treatment recommendations state that "within the limited health care budget possibilities the level of CD4 to initiate treatment is 200 cells/mm³", which is much lower than the new WHO recommended level of 350. That decision holds down the number of people in need of ART, according to the government's clinical definition. Yet it represents a major threat to the health of hundreds of Latvians who could conceivably benefit from initiating treatment at an earlier stage in disease progression.

"We do not have access to this population."

HIV treatment specialist at the Latvian Infectology Centre (LIC), in regards to IDUs

LIMITED INTERACTION OF ART AND DRUG-TREATMENT SERVICES

Recent policy decisions to expand access to methadone maintenance treatment suggest that drug-treatment specialists' attitudes are changing for the better and drug use-related stigma in the medical and social care fields is declining. This is an important trend, but integration of HIV care and drug-treatment services – both important for HIV-positive drug users – remains limited.

This lack of integration makes it far less likely that members of the population most vulnerable to and affected by HIV (IDUs) are able and willing to access both crucial services in the most convenient and

⁶⁶ TRIPS = Agreement on Trade-Related Aspects of Intellectual Property Rights. The agreement includes specific provisions under which signatory countries can override otherwise strict patent-protection regulations when, for example, they claim it is necessary to address public health threats and emergencies.

⁶⁷ As observed by personnel and clients of Apvieniba HIV.LV.

effective way possible. IDUs are less likely to be on ART in the first place and are more likely to be non-adherent to ART and to drop out of treatment altogether. As one HIV specialist observed, that is because “we do not have access to this population.”⁶⁸

One potentially useful step would be to allow HIV treatment (including ART provision) to be provided directly by “medium level” medical personnel at low threshold centres for drug users. Those individuals could also be trained to help guide IDUs to HIV testing; to initiate HIV treatment, if deemed necessary; to provide adherence support; and to provide referrals to social and legal services used by PLHIV.

5. RECOMMENDATIONS

Recommendations for the Latvian government:

- Adequate funding must be made available to provide ART free of charge to all in need. This priority should be taken into account during all budget discussions and decisions.
- Adequate funding must be ensured for all activities and priorities identified in the National HIV Strategy.
- The purchase and use of generic ARVs should be a priority, given that it would greatly lower the government’s costs per patient and create more flexibility in HIV/AIDS programming. The first step in this effort should be to make necessary amendments in national legislation to utilize flexibilities in the World Trade Organization’s TRIPS agreement, such as parallel importing and compulsory licensing.

Recommendations for the Ministry of Health regarding access:

- The MoH should take the lead in ensuring that all stakeholders (the LIC, NGOs, etc.) agree on one, clear set of values, priorities and principles to guide the HIV treatment and care response in the future. Such efforts should include more specific data on the number of people in need of ART and understanding of universal access goals and targets.
- The MoH should immediately carry out the prime minister’s explicit order to allocate HIV-specific funding to NGOs on an annual basis. Those additional financial resources should be used primarily to provide counselling and support services for PLHIV, services that are currently provided almost exclusively at government-run treatment facilities.

68 Interview with Dr. Inga Janušķēviča from the LIC in January 2010.

- The MoH should fund the development and implementation of integrated drug treatment, harm reduction (e.g., methadone maintenance) and HIV treatment services across the country. This step could help to improve IDUs' access to ART and other crucial services, and to increase relatively low rates of ART adherence among members of this population.
- The MoH should take the lead in working with NGOs to develop strategies to improve awareness and outreach among hard-to-reach populations (e.g., IDUs and sex workers).
- The MoH should establish a protocol and system to increase HIV treatment literacy among all health care workers in the country. This would help improve efforts to scale up ART access outside the main urban centre, Riga, and in prisons.

Recommendations regarding treatment guidelines:

- The MoH should oversee a process in which national treatment guidelines are revised to comply with international best standards as determined by WHO. This would include, most importantly, a requirement that ART be initiated when a patient's CD4 count falls below 350 cells/mm³.
- The Centre of Health Economics should conduct an effectiveness study of treatment regimens currently being used in the country. The findings of the study should directly influence the revision of national treatment guidelines.

Recommendation for advocacy partners:

- NGOs should take the lead, in cooperation with the MoH, to develop information and educational materials to help increase treatment literacy. A wide range of materials should be created in order to target different vulnerable groups, each of which has different needs and expectations. Civil society groups should also focus on working with the MoH to draft materials for health care workers, with particular focus on reducing HIV-related stigma and upholding human rights standards.
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Malawi

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Rosemary Kambewa and Trevor Phoya assisted in data collection

KEY FINDINGS

1. Cutbacks in government support for the National AIDS Commission are causing a reduction in the depth and scope of HIV/AIDS services.
2. The health care system is further weakened by a severe shortage of qualified doctors and nurses.
3. The burden of transport and other out-of-pocket costs bar access to treatment and services for many PLHIV in Malawi.
4. A high percentage of PLHIV entering hospitals for treatment are not aware of their HIV status.
5. Second-line drugs are not available to PLHIV in Malawi; OI drug stock-outs and limited CD4 testing have also been reported.

RESEARCH PROCESS AND METHODOLOGY

Research was conducted by the Malawi Health Equity Network (MHEN). The National Association of People Living with HIV and AIDS in Malawi (NAPHAM) provided logistical support in field work, especially in linking up the research team with the PLHIV support groups. Thirteen focus group discussions involving a total of 60 PLHIV were conducted during the research process. Researchers also interviewed 20 representatives from governmental institutions (the MoH, district hospitals and district assemblies); multilateral agencies (UNAIDS and the United Nations Population Fund); and the civil society sector.

1. OVERVIEW OF COUNTRY SITUATION

An estimated 1 million of Malawi's 14 million people are HIV-positive, which corresponds to adult HIV prevalence of about 12 percent.⁶⁹ Over the past two decades in particular, HIV has placed heavy, consistent pressure on the country's already weak health system.

According to a report by Concern Universal 2009,⁷⁰ about four-fifths of HIV cases are attributed to unprotected heterosexual sex, with vertical transmission (from mother to child) accounting for most of the remainder. The report further highlights that the main driving forces of the epidemic include: i) gender inequalities (the subordination of women in sexual relations); ii) the presence of STIs that increase transmission likelihood (e.g., gonorrhoea and chlamydia); iii) mobility, especially husbands leaving their homes for long periods of time without their spouses (usually to find work); iv) risk-enhancing traditional practices such as *kulowa kufa* (death cleansing, a practice in which a widowed woman is forced to sleep with a relative of her dead husband); and v) certain strong attitudes regarding sex, in particular the belief among men that using a condom inhibits sexual pleasure.

Also of note are the close links between HIV and poverty, with each reinforcing the other. In rural areas – where most Malawians live – for example, AIDS reduces productivity on farms both directly (when one or more member of the household is ill or has died) and indirectly, when members must spend time and resources caring for the sick. The reduced productivity leads to food insecurity as a result of poor harvests from the fields and, consequently, poor nutrition. The vicious cycle of poverty persists.

69 Jamie Robertson, "HIV/AIDS Funding in Malawi: Major Contributors to HIV Programming Budget". Posted online at Suite101.com on January 15, 2009: http://aids-hiv-in-africa.suite101.com/article.cfm/hivaids_funding_in_malawi.

70 Concern Universal (2009), "The changing nature of poverty and vulnerabilities in contemporary Malawi". Online: www.concernuniversal.org/images/uploads/File/Malawi/Vulnerability%20Report%20FINAL.pdf.

A poor country, Malawi has limited domestic resources and is heavily donor dependent. Despite such challenges, the government has managed to put more than 250,000 people on ART in recent years, of whom nearly 185,000 were on treatment in September 2009.⁷¹ Of those, more than three-fifths (61 percent) were female and nine percent were children aged five or younger.

The 185,000 level exceeded the government's initial prediction of having 170,000 people on ART by that date. However, that earlier number was based on a low estimate of the number of people in need of ART (200,000). At the time, the government assumed it would exceed its universal access target of 80 percent. More recent government figures indicate that 300,000 people are eligible for ART, and even though more people than originally predicted are on treatment (185,000), the coverage share is lower (60 percent, instead of 85 percent). Therefore, the government had not, as of the end of 2009, met its universal access target. (It is worth noting as well that the estimated number of people in need of ART will rise sharply in light of the new WHO clinical recommendations for initiation of treatment, which the government has pledged to follow and write into national treatment guidelines.⁷² Once that is done, at least 500,000 Malawians will be eligible for ART, according to civil society advocates.)

Hopeful developments include i) a decline in HIV-related deaths; ii) a tripling, to 45 percent from 15 percent, of HIV-positive pregnant women with access to prevention of vertical transmission services from 2005 to 2008;⁷³ and iii) a slight decline in adult HIV prevalence since 2004, and an even more significant decline in prevalence (from 15.7 percent in 2003 to 11.9 percent in 2008) among 15–19 year olds.

In 2004 the Malawian government initiated a series of reforms in the health sector aimed at addressing poor health outcomes amidst a human resource crisis. The Programme of Work (POW) 2004–2010 launched the Essential Health Package (EHP), which identified 11 cost-effective interventions to be provided free of charge to all Malawians, and the Emergency Human Resource Programme (EHRP), which focused on addressing the human resource crisis. The POW has been supported and financed by the government and development partners through a sector-wide approach (SWAp), with a common framework for planning, budgeting, and performance monitoring.

These health sector reforms have had some important positive outcomes over the past five years in the country's HIV/AIDS response. The number of PLHIV on ART increased from 3,000 in 2003 to some 185,000 just six years later, a higher level than in many other African countries of similar population and HIV burdens. This surge is a major

71 Médecins Sans Frontières (MSF) 2003–2009 program report, "Increasing Access to Antiretroviral Care in Rural Malawi". Online: www.msf.org.za/Docs/Increasing_access_to_ARV_Care_Malawi_2009.pdf.

72 The agency's new recommendations call for ART to be initiated when a patient's CD4 count falls below 350 cells/mm³. The previous level was 200 cells/mm³.

73 World Bank, "Malawi poverty vulnerability assessment: Investing in our future". December 2007. Available on the World Bank's website: www.worldbank.org.

factor behind the decline in maternal mortality from 1,120 deaths per 100,000 live births to 807 by 2009. A similar trend in infant and child mortality, also linked to greater access to ART, has Malawi on track to meet its MDG 4 goal before 2015.

HIV prevention, treatment and care activities currently are financially supported by a number of external partners, including the World Bank, the Global Fund, WHO, UNAIDS, and bilateral aid agencies in Canada, Norway, the United Kingdom and the United States. There are concerns, however, about the sustainability of such support over time, including for the continued scale-up of ART. Such concerns were heightened recently when the country's proposal for HIV/AIDS funding through the Global Fund's Round 9 was rejected in November 2009.⁷⁴

Global Fund support in the mid- to long-term affects the National AIDS Commission (NAC) in particular. Although the MoH is the main government provider of treatment (including ART) and prevention services, the NAC has important responsibilities such as coordination, oversight and funding NGOs and community-based organizations (CBOs) to undertake HIV-related projects. Currently the commission is funded entirely by Global Fund money that flows through the national budget. Its funding has been drastically reduced due to the global economic downturn, with the allocation in the government's budget for the 2009/10 fiscal year 40 percent less than what was originally promised. This reduction is particularly worrying for prevention activities, many of which are implemented by grassroots CBOs that are supported directly by the NAC.

2. SOURCES OF HIV TREATMENT DELIVERY AND RELATED ISSUES

Despite a dire shortage of health workers and high levels of poverty, the Malawian government has introduced a public health model of care that relies on non-physician clinicians to deliver ARVs. By the end of June 2009, there were 224 ART clinics and 96 mobile sites in Malawi. Of the 224 stationary clinics, 165 are government-run while 59 are operated by private hospitals, the Christian Health Organization of Malawi and NGOs. Thus the government provides 74 percent of ART services in the country, according to the ART programme report for the first quarter of 2009.

ARVs, all diagnostic kits and other treatment materials are sourced mainly with support from the Global Fund. The United Nations Children's Fund (UNICEF) procures these supplies on behalf of the government and the MoH, which then distributes services through its HIV and AIDS Unit. The Central Medical Stores is responsible for distribution across the country. All main HIV services, including first-line ARVs, diagnostic tests and consultations, are available free

⁷⁴ The Global Fund had previously approved three applications from Malawi for HIV/AIDS funding: in Rounds 1, 5 and 7. According to the Global Fund's website (www.theglobalfund.org/programs/portfolios/?countryID=MLW&lang=en), a total of \$375 million had been approved, with about \$250 million disbursed to date.

of charge in the public health sector—a government guarantee that, according to findings from focus group discussions, it appears to be meeting largely successfully. The main out-of-pocket cost for patients is for transportation to health facilities, a cost that is burdensome primarily for those with long distances to travel.

3. FACTORS INFLUENCING ACCESS TO TREATMENT

HIV TESTING ACCESS

Personnel from the Department of Medicine at the Queen Elizabeth Central Hospital in Blantyre recently completed a study that found that some 70 percent of patients admitted to the hospital are HIV-positive. Although often very ill when admitted, most of them were not aware of their HIV status, a finding that underscores persistent difficulties in increasing uptake of HIV testing. In Malawi as elsewhere, the effectiveness of ART is much lower when people do not begin treatment until they are sick with one or more OIs and their immune systems are extremely compromised.

The government has sought, through various campaigns, to encourage more people to utilize voluntary counselling and testing (VCT) services. Yet even though such campaigns highlight the subsequent availability of free treatment if deemed necessary, they have not been as successful as many health officials would like. As an initial step to address this problem and promote earlier uptake of treatment, a growing number of health care professionals now recommend that the government make HIV testing mandatory for all patients entering hospitals (currently patients are only offered tests, and many refuse). Some NGOs and advocates oppose this proposed requirement because of concerns that it would violate patients' rights.

ACCESS TO PREVENTION OF VERTICAL TRANSMISSION SERVICES

While there has been progress in scaling up sites offering services and the number of women benefiting from vertical transmission services, the data is unreliable due to double counting⁷⁵. In 2009, the vast majority of women received single dose nevirapine and none received prophylactic regimens using three antiretroviral drugs. The UNGASS Consultation Process, 2009–2010 also highlighted that “There are significant challenges in the scale-up of the PMTCT Programme, among them, drug stock-outs and logistical issues. In October 2009, an assessment of 253 sites visited for ART supervision found that 47% of these facilities had any stock for PMTCT.”

HIV AND TB SERVICES INTEGRATION

Strides have been made towards integrating HIV and TB services. HIV-positive patients are screened for TB and those diagnosed with TB are also screened for HIV. Once an HIV-positive patient has been diagnosed

75 UNAIDS, Malawi HIV and AIDS Monitoring and Evaluation Report: 2008-2009, UNGASS Country Progress Report. 31 March 2010. Online: http://data.unaids.org/pub/Report/2010/malawi_2010_country_progress_report_en.pdf

with TB, he or she receives treatment for both HIV and TB. A report by the National TB Control Programme indicates that 70 percent of TB patients in Malawi are HIV-positive; hence the importance of integrating treatment and care for the two conditions. Apart from TB, the other two most common diseases killing HIV-positive patients are diarrhoea and malaria, according to a recent study from MHEN.⁷⁶

4. OPPORTUNITIES AND CHALLENGES

The following positive trends in regards to access to HIV services are considered key **opportunities** for continued improvement:

- Although **women** are highly marginalized and vulnerable in Malawi, they have benefitted from ART scale-up at levels and rates in line with their share of HIV cases: more than 60 percent of all Malawians receiving ART are currently women. This is attributed to two key factors: i) women seek treatment earlier than men; and ii) the government has adopted an integrated approach in which pregnant women undergo routine testing for HIV.
- **Behaviour change.** Evidence exists of changes in sexual behaviour that could help reduce HIV transmission. Most notably, anecdotal evidence indicates that the frequency of older men having sex with girls below 18 years old has dropped. Such changes are attributed to a high-profile awareness-raising campaign about HIV/AIDS and sex and more thorough and effective prosecution of those who illegally have sex with minors.
- ART can be scaled up more efficiently through **task-shifting**. A key policy that has supported the rapid expansion of HIV testing at the primary health care level in Malawi is the deployment of health surveillance assistants (HSAs), a lower cadre of health care workers.

The following are among the major **challenges** to improved and enhanced HIV treatment scale-up in Malawi:

Insufficient funding remains a major challenge to the scale-up of ART in Malawi. Officials in all districts report that their ability to implement programmes at district level is affected by budget cuts and budget ceilings set by the MoH. Most notably, the recent steep cuts in the NAC budget are forcing CBOs and NGOs that rely on funding from the commission to reduce the extent and scope of services.

The NAC budget plays a key role in the fight against HIV and AIDS since it is responsible for coordinating all HIV and AIDS interventions in the country. The ART program in Malawi is 100% funded by the Global Fund, whose funds are channelled through NAC. Most interventions on impact mitigation by CBOs and NGOs are also funded through NAC, hence the reduction is likely to result in a reduction in funds for those interventions. The 2009/2010 budget reduces funds for

⁷⁶ Ministry of Health, 2008. "Treatment of AIDS: Guidelines for the use of antiretroviral therapy in Malawi", third edition.

bursaries and for orphans and vulnerable children, making this group more vulnerable because of engagement in risky behaviour as a coping mechanism.⁷⁷

Human resource shortfalls. Widespread human resource inadequacies persist in Malawi. According to statistics from the MoH, the country needs at least 160,000 additional health workers across all levels to adequately provide efficient health services. However, the country is now only able to train and deploy about 10,000 per year. Moreover, of the trained health workers, few are trained as ART providers because medical schools do not have dedicated programmes for that specialization. The lack of qualified health workers in the public sector, where they are needed most, is further exacerbated by non-responsive recruitment and deployment processes and bottlenecks; the continued drift of health workers to NGOs and research institutions; and overseas migration of highly qualified nurses (approximately 100 per year) to the United Kingdom and other countries.⁷⁸

Respondents reported that, among other negative effects of the shortage of health care workers, ARVs are distributed only two days in each week everywhere in the country. This is done so that the workers can concentrate on other duties during the other days of the week.

The following comment from a district health officer in Nkhata Bay illustrates the problem:⁷⁹

The MoH has mandated us to open new sites as long as our assessment shows a reasonably high number of people in need of access in a particular area. We have identified two sites in Mzimba, but we are failing to scale up because the ministry has yet to send us staff to be posted to those health centres. In addition to short supply, many health workers are not willing to work in rural remote areas because of the hard conditions.

Donor dependency. External sources such as the Global Fund, World Bank and several bilateral organizations (e.g., the UK Department for International Development, or DFID) provide a significant share of the government's health budget. This high level of dependency is of particular concern during the global economic downturn because of the very real possibility that donors will reduce levels of support both in the short and long-terms. The government could conceivably pick up some of the slack, but it has far too few resources on its own to match current levels or to increase spending in the future—especially if ART scale-up continues.

77 Malawi Health Equity Network (MHEN). 2009–2010 Health Sector Budget Analysis. July 2009.

78 UNAIDS Malawi country report, 2008. See www.unaids.org/en/CountryResponses/Countries/malawi.asp.

79 Interviewed on 19 November 2009.

Drug stock-outs. Respondents reported that although stock-outs of ARVs are infrequent, shortages of medicines to treat OIs are common, especially in government health centres. Several HIV-positive respondents said that even though ARVs are usually available, changes in regimens and drugs are often required with little or no warning or information. One PLHIV gave the following account at a focus group discussion:⁸⁰

I was on Triomune 40 but later I was moved to Triomune 30. I was not told of the reasons for the switch. Since I was put on this new medicine, I have experienced several side effects... the upper part of my body is growing bigger than the rest of my body. But whom do I ask? I unofficially heard from a health worker that we were switched to Triomune 30 because government had run out of Triomune 40.

Transportation and logistical difficulties. Mobile ART sites require transportation and other logistical arrangements to operate efficiently. However, due to infrequent availability of transport, fuel and other logistical support from district hospitals, sometimes ARV stock-outs occur at these sites.

Access to second-line ART. While the government has made major efforts to ensure that first-line ARV regimens are available to those in need, the country is not able to purchase adequate drugs for those in need of second-line regimens. The most common first-line regimen used in Malawi is d4t + 3TC + nevirapine. Of the nearly 185,000 people on ART in September 2009, 94 percent were on that first-line regimen, 5 percent were on an alternative first-line regimen, and fewer than 1 percent were on a second-line regimen.

Distance. Most people interviewed said that they must travel long distances to access treatment. Almost half said, for example, that they must travel from 5 to 35 kilometres (up to 20 miles) to reach the closest site. Thus, although ART is free at the point of delivery, there is a cost implication attached to it in terms of transport and other overhead costs for those living in rural areas.

HIV-related stigma and discrimination. Though strides have been made by the government towards reducing HIV-related stigma and discrimination, most respondents agreed that stigma persists. This has prompted some PLHIV to stop taking ART and others to choose to access treatment at sites far from home to avoid being identified by

80 As cited at a focus group discussion in Blantyre on 24 November 2009.

neighbours as being HIV-positive. A comment from one respondent illustrates both the important positive developments in recent years and the lingering concerns:⁸¹

I was among the first women to publicly declare that I was HIV-positive. The stigma at that time was high and really unbearable. If I had chosen not to be strong, I would have died by now especially because there were no ARVs available then. The church has played a big role in sensitizing its members on the need not stigmatize. The decrease in stigma and discrimination has contributed to many people coming out in the open to declare their status and go openly and without worry to clinics. However, we need to continue sensitizing people so that more go for VCT.

Vulnerable groups. Insufficient information exists as to the ability of marginalized groups such as MSM and sex workers to receive HIV services, including ART. This is partly because they (legitimately) fear harassment and discrimination and also because same-sex relations and sex work are illegal – which means that the government does not recognize such vulnerable groups or target HIV prevention and treatment interventions toward them.

Gender inequality. Malawi remains a patriarchal society in which women have fewer social and legal rights. Among the impacts of such gender inequality is that in many families, women have little choice but to put their own health at risk when faced with demands for unprotected sex from partners (including husbands) whose HIV status is uncertain or questionable.

Inadequate access to CD4 testing. Many ART sites lack CD4 testing materials and/or trained personnel to offer tests. This obstacle will become an even greater problem in regards to ART scale-up once the new WHO clinical guidelines for treatment initiation are officially adopted. That change will make it even more imperative for PLHIV to obtain CD4 tests regularly to determine whether they are clinically eligible for ART and, therefore, should begin treatment.

5. RECOMMENDATIONS

Recommendations to address financial challenges and donor dependency:

- The government should increase its contribution from domestic revenue to HIV and AIDS instead of relying so heavily on donors.
- HIV/AIDS district budget ceilings must be increased so that district assemblies can implement more essential initiatives, such as outreach programmes.

81 Interview with Lilian Dindia, a PLHIV activist in Mzuzu, on 18 November 2009.

- Drug budgets for district hospitals must be increased in order to eliminate stock-outs of crucial medicines to treat OIs and to ensure that ARV stock-outs do not occur in the future as scale-up continues.

Recommendations to address human resource shortfalls as they pertain to HIV service provision:

- The government should be more flexible and seek to involve other players such as NGOs and private institutions in the provision of ART treatment.
- The government should tap volunteers at CBOs who are already engaged in key services such as outreach and awareness-raising. These individuals could be trained to provide ART and other services and, ideally, be employed quickly.
- All personnel across the health system should receive regular training on HIV/AIDS care and treatment. This could help improve not only care and treatment provision, but also reduce HIV-related stigma.

Recommendations to address gender inequality:

- Prevention of vertical transmission service provision should involve men as well as women. This could help boost understanding of the need to respect the rights of HIV-positive women regarding family planning and sexual activity. At the same time, greater efforts must be made to increase awareness throughout all communities of the importance of all pregnant women to be tested for HIV and, if they test positive, to go on treatment. Such efforts must take into account high levels of illiteracy, especially in rural areas.
- The MoH, civil society organizations and the legislature should formulate policies that uphold and enforce the right of HIV-positive women to make their own decisions about whether to become pregnant. This step should be accompanied by sufficient access to family planning services for both women and their male partners.

Recommendation to address HIV-related stigma and discrimination:

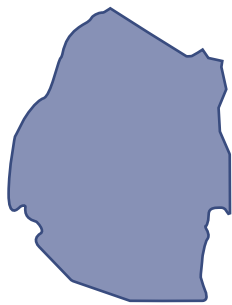
- Community sensitization efforts regarding HIV/AIDS should be continued and expanded. Special emphasis should be placed on encouraging people to go for VCT and to help boost treatment adherence. These efforts should be the responsibility of the government in partnership with NGOs, district assemblies and district hospitals.
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Recommendations to address poor logistical coordination:

- The MoH should turn the Central Medical Stores, the government agency in charge of ARV procurement, into a trust. This could help make the procurement process more robust and efficient by reducing the level of bureaucracy involved in procurement.
- The MoH must mandate that pharmacists in all the health centres more closely and effectively monitor the availability of ARVs and seek to control stock-outs.

Recommendations to address challenges related to distance and travel:

- The MoH, NGOs and CBOs should open more ART clinics in rural areas and, at the same time, increase the number and quality of mobile ART clinics. This would enable the rural poor to save on money for transport and increase uptake of services across the country.
 - The MoH, donor partners, private health providers and NGOs should develop a plan and system to provide affordable, easier transport for people from remote areas who wish to visit health facilities. One option could be a stipend or voucher that helps reduce out-of-pocket costs.
 - The number of days each week during which ARVs can be accessed should be increased in all district hospitals and health centres.
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Swaziland

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KEY FINDINGS

1. The government of Swaziland has yet to meet the Abuja Declaration commitment made in 2001 in which it pledged to allocate at least 15 percent of its annual budget to the health sector (allocating 13.5% in its most recent budget – April 2010).
2. A lack of HIV awareness and testing, and trust in traditional health beliefs and practitioners who are not grounded in the science of HIV, prevent people from accessing necessary treatment.
3. TB is the leading cause of death of PLHIV in Swaziland, yet TB programs have high default rates.
4. Long lines and delays are reported at hospitals, where doctors and nurses are too few in number and there is a limited amount of diagnostic equipment.
5. The costs of obtaining OI medicine (which is not provided free of charge), consultations, and transportation bar access for PLHIV to comprehensive HIV treatment.

RESEARCH PROCESS AND METHODOLOGY

This report is based on research conducted between November 2009 and February 2010. The research included desk reviews and in-depth interviews. The desk reviews involved accessing databases on the Internet as well as examining relevant reports from UNAIDS and WHO offices. A total of 15 key informants were interviewed, including officials working in NGOs involved in HIV and AIDS programs, health workers, PLHIV and advocates.

1. OVERVIEW OF COUNTRY SITUATION

HIV is by far the most serious health issue in Swaziland today. Adult HIV prevalence—currently estimated at about 26 percent of people aged 15 to 49—is the world’s highest. Nearly one-third (31 percent) of women in this age group are living with HIV, as are about 20 percent of men. Transmission continues unabated: an estimated three of every 100 HIV-negative individuals (in a country with a total population of 1 million) seroconverts every year. This indicates that Swaziland has an HIV incidence rate of about 3 percent.⁸²

There are some indications that the political will to combat HIV and AIDS exists in Swaziland. The king declared HIV and AIDS a national disaster in 1999 and the national coordinating body, the National Emergency Response Council on HIV and AIDS (NERCHA), was established through an act of Parliament in 2002 with a mandate to coordinate and mobilize resources for an expanded, scaled-up, coordinated national multisectoral response to HIV and AIDS.

These steps have been important, but they failed to halt the spread of the epidemic that has had such a devastating impact on society. In 2009 NERCHA launched a new approach to the national response. This new approach involves 10 guiding principles:

- results-based management of the HIV response;
- evidence-based planning;
- gender equality and equity;
- mainstreaming human rights approaches;
- systems approach and mainstreaming;
- promotion of greater involvement of empowerment of people living with HIV and AIDS;

82 National Emergency Response Council on HIV and AIDS (NERCHA), “National HIV and AIDS Response: Annual Report”, 2009.

- programming based on the “Three Ones” principle⁸³;
- community engagement and participation in, and ownership of, HIV and AIDS interventions;
- knowledge management; and
- a commitment for Swaziland to address its regional and international HIV and AIDS obligations and adherence to international HIV-related protocols.

NERCHA has based its efforts to provide HIV treatment, care and support on increasing access to ART; clinical management of OIs; diagnostic testing and counselling; institutional and home-based care; palliative care; and nutritional support and mental health services for those in need.

The first large-scale roll out of ART began in Swaziland in 2003, with scale-up undertaken primarily as part of WHO’s ‘3 by 5’ initiative. In 2006, a new protocol was put in place for the initiation of clients on ART, and in the following year NERCHA set national universal access targets—to have 50 percent of all people in need of treatment on ART by 2008 and 60 percent by 2010.⁸⁴

The most recent data suggest that the 2010 target could be met. According to information from September 2009, there are an estimated 220,000 people living with HIV in Swaziland. Of them, nearly 63,000 were thought to be in need of ART; by the end of September 2009, a total of 45,856 people were on ART. Based on those data and estimates, more than 70 percent of people in need were receiving ART. Of those on ART, far more females (26,579) than males were enrolled in ART programmes. Meanwhile, a total of 4,885 children were enrolled.

Of all HIV-related OIs, TB is the most common cause of death among HIV-infected people. (This is perhaps not surprising given that Swaziland has the world’s highest TB prevalence—1,155 per 100,000 population.) Every diagnosed TB patient is screened for HIV and every HIV-positive person is screened for TB. Co-infection is rampant: for example, the 10th HIV sentinel surveillance report in 2006 revealed that nearly 80 percent of TB patients were infected with HIV.⁸⁵

Though plans are afoot to effectively and efficiently integrate HIV/AIDS and TB treatment, the plans are beset with many challenges. It is recognised for example that there has been no vigorous TB literacy

83 This refers to three principles for the coordination of national AIDS responses that were developed and endorsed in 2004 by multilateral agencies, donors and implementing countries. The goal is to achieve the most effective and efficient use of resources, and to ensure rapid action and results-based management. The “Three Ones” are the following: i) one agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners; ii) one National AIDS Coordinating Authority, with a broad-based multisectoral mandate; and iii) one agreed country-level monitoring and evaluation system.

84 NERCHA, “National HIV/AIDS monitoring and evaluation: Annual report”, 2008.

85 Ministry of Health and Social Welfare Swaziland (2006), “10th Round of the national HIV serosurveillance in women attending antenatal care, sexually transmitted infections clients and tuberculosis patients.”

program to address drug resistant TB and HIV and TB co-infection, the diagnosis of TB in children is a problem, and the country's HIV and TB policy guidelines have not yet fully taken advantage of the benefits of the combination of antiretroviral and TB treatment.

To manage HIV and TB co-infection the government in 2008 launched a TB/HIV Technical Working Group, which has developed a TB/HIV communication strategy and work plan to facilitate implementation of TB/HIV collaborative activities. In 2008 a total of 9,656 cases of TB were reported in the country, and 5,699 of those individuals were found to also be HIV-positive. The government and NGOs have the medicines and resources to provide TB treatment for all in need, but they rarely are able to do so effectively. The case detection rate is put at just 60 percent while treatment is successful in less than half (44 percent) of cases. The growing number of cases of multi-drug resistant TB (MDR-TB) is part of the reason for such dire figures.

FUNDING AND FINANCING

The finance minister in his 2009/2010 budget speech⁸⁶ referred to HIV and AIDS as “one of the greatest challenges this country has ever faced” and enumerated treatment as the second challenge after prevention. He appeared to back his claim by increasing, by \$1.34 million over the previous year, the amount allocated to new health care staffing and the purchasing of medical supplies and equipment. Though the 2010/2011 budget allocation expenditure was reduced for many sectors, the health sector was awarded an increase of 2.5 percent, with the drugs budget increased in anticipation of increased enrolment in the ART programme.

Yet even so, the government has not met some of its main commitments in regards to health spending in general. Most notably, Swaziland was a signatory to the 2001 Abuja Declaration in which African countries pledged to set a target of allocating at least 15 percent of their annual budgets to the improvement of the health sector. However, the government has yet to reach that level; it allocated 13.5 percent to health (including for HIV/AIDS) in the most recent budget (which began in April 2010).

In terms of external assistance, Swaziland continues to receive millions of dollars for HIV/AIDS programs every year from the Global Fund (through programmes approved in Rounds 4 and 7) and the U.S. government.

2. SOURCES OF TREATMENT DELIVERY AND RELATED ISSUES

There are 70 health facilities offering ART services in Swaziland. Thirty of the sites focus exclusively on initiating ART while the other 40 are outreach sites that are primarily used to refill ARVs only. Only 28 health care facilities in the country have the capacity and conditions to

⁸⁶ The budget year is April to March in Swaziland. This speech referred to the budget year that began in April 2009.

provide an advanced level of HIV and AIDS care and support services. Nearly half are in Manzini, the most populous region.

Wherever ARVs are provided in Swaziland, they are available free of charge (both first- and second-line regimens). In most health facilities, however, patients must pay a consultation fee and for medicines to treat OIs out-of-pocket. Access to diagnostic tests is relatively limited: there are only 10 CD4 count machines in the country, and viral load counts are only available in the Mbabane government hospital. Delays and long queues are common in most health facilities.

The MoH has formed partnerships with some international agencies to help distribute food packages as part of an effort to improve the nutritional status of ART clients. Most notably, WHO and the World Food Programme provided operational guidelines on food support in ART programs. The objective was to encourage the integration of nutritional support into national responses, to enable care and treatment providers to include food and nutrition in HIV care, and to develop an agreed upon framework for monitoring and evaluation.

LACK OF HUMAN RESOURCES AND HOME-BASED CARE

Rising morbidity levels since the beginning of the HIV epidemic some two decades ago have increased demand and need for all HIV-related services. Unfortunately, there has been a reduction in the capacity to provide these services – in part because HIV has claimed the health and lives of so many health care workers.

Home-based care⁸⁷ is one of the services being used to absorb the demand for health services. It is provided by a wide range of organizations in both the government and non-governmental sectors. Most of the providers of this service are faith-based organizations and community-based organizations; others, called rural health motivators, are supported directly by stipends from the MoH. There are currently some 6,000 home-based care clients in Swaziland. A manual has been developed to guide home-based care givers with the goal of improving the quality of service.

PREVENTION OF VERTICAL TRANSMISSION SERVICES

In Swaziland, prevention of vertical transmission interventions include primary prevention of HIV infection among child-bearing women; prevention of unintended pregnancies among HIV-positive women; reduction of mother-to-child transmission among HIV-positive pregnant women; and care and support for HIV-positive mothers and children. A total of 172 health facilities provide antenatal care (ANC) services. The centres providing prevention of vertical transmission services increased from 110 in 2006 to 132 in 2008.

⁸⁷ In the Swaziland context, home-based care refers to a system in which services are provided at patients' homes. They are especially helpful for chronically ill individuals who have difficulty traveling to clinics. The services are provided by women volunteers who are given basic training in HIV-related care and treatment training. Some NGOs also provide these services with qualified medical staff, especially nurses.

In 2009, 65 percent of HIV-positive pregnant women received ART prophylaxis to reduce vertical transmission in accordance with the national protocol. When this program was first introduced, single-dose nevirapine was the primary method of ART prophylaxis. More recently, however, a number of sites have begun providing combination therapy regimens that are considered much more effective and are now recommended as per international guidelines. In 2009, a total of 27,313 pregnant women tested for HIV, and but only 24,592 received their results and had post-test counselling when attending ANC services. This constitutes follow-up coverage of 90 percent.

TRADITIONAL HEALTH PRACTITIONERS AND BELIEFS

There are about 8,000 traditional health practitioners in Swaziland and it is estimated that over 80 percent of Swazis use their services at least occasionally. The 2008 National Strategic Plan Joint Review pointed out that some people opted out of ART in favour of care and support from traditional health practitioners and replaced ARVs with other medicines or formulas that are untested and unproven as ways to fight HIV. The strong and persistent belief in witchcraft among many people has also had a negative effect on HIV and AIDS treatment in Swaziland. Those who hold such beliefs often assume that they can be cured not by medicines, but by the removal of spells placed upon them. Such beliefs have caused delays in sick people visiting health facilities and reduced levels of treatment adherence. No data exist as to the impact of witchcraft on HIV treatment and care, but it is thought to be quite extensive.

The government has had to tread lightly so far in responding to these problems. Officials recognize that most people in Swaziland greatly respect the views of traditional health practitioners and so their participation in the treatment and care of HIV and AIDS is vital to the success of any HIV and AIDS program. The MoH acknowledges their role as critical and wishes to ally with them as ART and TB treatment adherence promoters. They could also advocate for increased access to prevention of vertical transmission and for male involvement in HIV and AIDS programs.

“There is no money for bus fare to Mankayane hospital...and even if you get there, at times there are no drugs.”

Swazi woman living with HIV

3. FACTORS INFLUENCING ACCESS TO TREATMENT

Swaziland is a small country and compared with many countries in sub-Saharan Africa, accessibility to all places is very easy. The transport system is relatively good and so access to health facilities is not itself a problem – if you have enough money. Several respondents noted that they have often had problems affording transportation costs; for example, one 41-year-old HIV-positive woman, Thandi Ngwenya, said the following, “There is no money for bus fare to Mankayane hospital... and even if you get there, at times there are no drugs”.

Poverty is the underlying problem behind such difficulties, and thus is one of the major problems preventing people from accessing treatment. ARVs and TB drugs are free but the majority of residents have difficulty paying the consultation fees required at health centres.

Decentralization of refill depots has brought some ease, though. Another HIV-positive respondent, Elizabeth⁸⁸ from the Ngcamphalala area, said, “I now travel only 2 kilometres to refill after two months and this has made matters easy for me. Before this change I had to travel to Siteki, Good Shepherd Hospital”, which is much farther away.

4. OPPORTUNITIES AND CHALLENGES

There are some important benefits in regards to HIV treatment services due to Swaziland’s small size and relatively homogenous population. For example, compared with many countries with larger populations, donors do not have to give massive sums of money to have an impact. Other beneficial factors (**opportunities**) include:

- Treatment literature is – and need only be – printed in two languages.
- There is a great possibility that the goal of universal access will be achieved because the country is small.
- The government and donor community have good relations, in general. This increases opportunities for meaningful collaboration.
- Home-based care services have provided opportunities for PLHIV to participate in the response to HIV and AIDS as volunteers. This has helped raise awareness about HIV and reduce levels of stigma.

Many **challenges** persist, however, despite the many opportunities:

- In addition to the chronic shortage of health workers in government facilities, there is a general lack of capacity in most HIV-focused NGOs. This has limited their ability to intervene in certain cases, thereby reducing their effectiveness even when they have sufficient levels of other resources like funds and equipment.
- Doctors and nurses complain about pay levels, poor job satisfaction, insufficient professional recognition, work-related risks, lack of career development opportunities, and absence of quality nursing education.
- TB treatment is fraught with problems: high treatment default rate, incomplete recording, poor evaluation at the end of treatment, migration of patients between Swaziland and neighbouring countries, lack of proper observation of patients undergoing treatment, and high mortality rates among TB patients.
- The general absence of dieticians in hospitals makes it difficult to carry out nutritional programs in public health facilities. There is also insufficient information on nutrition for PLHIV.
- In the major hospitals the long queues discourage a lot of people from accessing treatment. The situation is not much better when

88 She did not want her last name listed in the report for confidentiality reasons.

they actually get to see a provider. Many patients report that the negative and unhelpful attitudes of health care workers discourage them from returning.⁸⁹

- Drug shortages are also a major problem. There is rarely a shortage of ARVs—although orders for second- and third-line regimens often are delivered late—but medicines to treat common OIs are often unavailable.
- People do not want to be tested for HIV and so do not know their status. Often, it is only when they are sick that they are tested—and often they are so ill that they do not respond to treatment.
- There is only one central laboratory for viral load testing. This means that patients often must wait weeks for a test, which raises the risk that changing regimens will not be done in a timely manner even if or when deemed necessary by the identification of the virus's resistance to a drug. One HIV-positive patient, Busisiwe Dlamini, said that although happy with the current state of treatment she felt that her movement is restricted by the location of where she must obtain services: "I wonder when technology can ease communication between refill clinics so that I do not have to travel all the way back to St. Philip's just for a refill."

5. RECOMMENDATIONS

1. Although the government has mentioned the critical gap in sufficient levels of health care personnel across the country, it has done far too little to respond. **The government must consider the human resources shortfall a matter of urgency** and begin working with development partners and civil society organizations to develop a clear, viable plan of action.
2. NERCHA should take the lead in **increasing treatment literacy among all PLHIV and the population in general**. It should work with national media and community-based groups in this effort.
3. NERCHA and the MoH should take the lead in **developing policies and programs to reduce HIV-related stigma and discrimination**. They should work closely with all other key stakeholders, especially community groups and PLHIV. Such efforts are crucial to ensure scale-up of treatment access.
4. NERCHA should take the lead in **building the capacity of researchers so that the effects of phenomena such as the belief in witchcraft are more properly understood**. This will help ensure that they can be responded to more effectively in the future. NERCHA should work closely with development partners to build and sustain such research capacity at the national level.

⁸⁹ Interview with Fikile Dlamini, an HIV-positive respondent from Luyengo-Mgwenyameni, in November 2009.

5. The MoH needs to **improve its supply-chain management system**. The new procurement unit must prioritize the elimination of corruption and bottlenecks to ensure continuous supplies of all crucial items (pharmaceuticals, vaccines, testing kits, laboratory supplies, etc).
 6. The MoH should mandate that **all HIV-positive pregnant women be initiated on triple-combination ART**. This step will require improving the capacity of ANC staff regarding HIV/AIDS.
 7. The MoH through the Swaziland National AIDS Programme (SNAPS) and NERCHA should **identify traditional health practitioners who are amenable to scientific explanations of health care in general, and HIV transmission and care specifically**. These individuals should be supported with information and resources to spread awareness among their fellow traditional practitioners.
 8. The government should make it a **priority to meet its commitment, as per the 2001 Abuja Declaration, to allocate 15 percent of its national budget to health care**. This step should be accompanied by stronger efforts to reduce corruption in government procurement processes.
 9. In order to attain full integration of HIV and TB treatment, NERCHA and the MoH should **spearhead the continuation of the implementation of the nine priority strategies identified in the 2009 – 2014 National Multisectoral Strategic Framework for HIV and AIDS** and strengthen the project's monitoring and evaluation system.
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Venezuela

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Supported by Renate Koch, ACCSI

KEY FINDINGS

1. The National AIDS Program of Venezuela (PNS) lacks up-to-date and reliable data on the number of people living with HIV and those in need of ART.
2. In most rural areas, patients must rely on small outpatient-oriented facilities that provide only basic services—and most do not offer HIV/AIDS care, including ART.
3. Limited HIV awareness is a major barrier to early treatment uptake across the country, and PLHIV cite a lack of support from health care workers among the reasons for low adherence to ARV regimens.
4. Consequences of a weak health system—such as long delays for routine services, unsafe and unhygienic conditions, lack of adequately trained personnel, low salaries, deterioration of facilities, and shortages of basic materials—have had negative impacts on the quality and effectiveness of HIV treatment services.
5. There is a lack of coordination between government and civil society organizations in delivering services for PLHIV. In most other countries, such collaboration helps increase and sustain access to HIV treatment.
6. The National AIDS Strategic Plan of 2003–2007 is out of date and civil society is calling for a new Plan to be drafted in consultation with civil society organizations in Venezuela.

RESEARCH PROCESS AND METHODOLOGY

Research for this report took place from November 2009 to January 2010. It consisted of the following activities: reviewing documentation and materials; designing and conducting a survey that was distributed to 12 people living with HIV from six different states (Aragua, Bolivar, Carabobo, Caracas, Aragua, Lara and Merida); and interviewing five key players and stakeholders: the coordinator of the National AIDS Program of the Ministry for Health, the head of the Pan American Health Organization (PAHO) mission in Venezuela, two HIV-positive activists (the secretaries of the Venezuelan Network of Positive People and the Venezuelan Network of Positive Women), and an infectious-disease specialist from the Department of Adult Infectious Diseases of the University Teaching Hospital of Caracas.

1. OVERVIEW OF COUNTRY SITUATION

Largely in response to civil society advocacy—including community sector mobilization and lawsuits—the Venezuelan Supreme Court ruled in 1999 that the government is obligated to provide a wide range of HIV treatment services to all in need in the country, including both Venezuelan citizens and foreign residents. Such services, which the government is required to provide free of charge, include ARVs, other medicines to treat HIV-related OIs, and relevant laboratory tests. The National AIDS Program (PNS) of the Ministry for Health has overall responsibility for ensuring that all of these services are available.

Research undertaken 10 years later indicates that the government has not met its basic obligations. Access to ART is reported to be adequate, though there are still certain problem areas that affect the quality of the overall treatment program. HIV treatment services are guided by several standards, including the HIV/AIDS National Strategic Plan (2003–2007), the Guide for the Management of ART Among PLHIV (2008–2009), and Technical Rules for Improving Compliance with ART in Venezuela (2008). As noted in the following table,⁹⁰ there is evidence of an upward trend in access to ART, both in terms of number of patients and financial resources devoted to HIV service provision:

⁹⁰ The government was unable or unwilling to provide information that would ensure directly comparable data for each year. Therefore, in regards to the first column for example, it was only possible to obtain (and from different sources) cumulative totals of PLHIV and no specific figure for the year 2009. Total government spending amounts are also estimates provided directly by the head of the National AIDS Program.

Year	Cumulative total number of PLHIV recorded since 1982	Number of PLHIV receiving ART ⁹¹	Total government spending on ARVs, US\$ ⁹²
2009	72,000 ⁹³	32,195	\$93 million
2008	72,248 ⁹⁴	27,266	\$79 million
2007	65,462 ⁹⁵	22,265	\$47 million

The figures and trends look mostly promising, but many observers say they are misleading. For one thing, the acquisition and supply of ARVs and reagents takes up almost all the budget that has been allocated to PNS.⁹⁶ Also, according to Estevan Colina, secretary of the Venezuelan Network of Positive People (RVG+), the numbers are not likely to be accurate or up to date because “national accounts are not systematized in Venezuela”. Colina said that in some meetings “the government has acknowledged that it does not have clear figures, because there are certain expenditures devoted to AIDS-related activities that are not specified in any of the budgets.”⁹⁷

One of the major concerns that emerged during this research is the lack of a current HIV/AIDS National Strategic Plan – the last one expired in 2007. This has led to a lack of proper data on the epidemic and standard guidelines for provision of HIV services. Most importantly, without a strategic plan that lays out targets and priorities it is hard for civil society to assess progress made in the national program on AIDS or engage meaningfully in this program.

According to Dr. Deisy Matos, the head of PNS, most people currently on ART in Venezuela are between the ages of 24 and 45. Four-fifths (80 percent) are male, and the same share live in urban areas. The seven states with the highest number of PLHIV (and receiving ART) are, in descending order: Caracas, Zulia, Mérida, Nueva Esparta, Aragua, Carabobo and Bolívar. Unfortunately, the agency lacks crucial data about disease progression, with PNS representatives unable to estimate the number of PLHIV in need of ART. One respondent, the secretary of the RVG+ network, said that “even though government officials may say that they do not have any figures, PNS Regional Offices report... that there has been a significant increase in the number of new cases of HIV that have been detected.”⁹⁸

91 “Corte Anual de Pacientes atendidos por el Programa Nacional de SIDA - ITS” (Annual number of patients serviced by the National AIDS / STI Program), People’s Ministry of Health, November 2009.

92 Figures in this column were obtained during an interview with Dr. Deisy Matos, head of PNS, on 21 December 2009.

93 Estimate cited by Dr. Deisy Matos, head of the National AIDS Program (PNS), in “Discrimination against Children Who Live with HIV”, an article from the 30 November 2009 edition of the Venezuelan newspaper *Ultimas Noticias*.

94 Interview with Dr. Deisy Matos, head of PNS, on 21 December 2009).

95 “Situación de los Derechos Humanos en Venezuela, Informe anual, octubre 2008–septiembre 2009” (Situation of Human Rights in Venezuela, Annual Report, October 2008 to September 2009), El Programa Venezolano de Educación-Acción en Derechos Humanos (PROVEA), p. 151.

96 Community Report - Venezuela 2008, UNGASS AIDS 2008, ACCSI and AVESA, 2008, p. 25.

97 Interview with Estevan Colina, secretary of RVG+, on 28 December 2009.

98 Ibid.

PNS officials were able, however, to provide researchers with specific information about the ARVs that are currently available free of charge through the public health system to patients in need. (PLHIV can obtain other medicines only if they pay for them out-of-pocket in the private sector.) National guidelines recommend that HIV-positive patients first receive a three-drug combination consisting of one non-nucleoside reverse transcriptase inhibitor (NNRTI) and two nucleoside reverse transcriptase inhibitors (NRTIs).⁹⁹ Patients have several options, depending on clinical need.

With the exception of the following medicines, all ARVs available through the public sector are provided in generic versions:

- Trizivir (abacavir + 3TC +AZT)
- Kivexa (abacavir + 3TC)
- Reyataz (atazanavir)
- Prezista (darunavir)
- Intelence (etavirina)
- Fuzeon (T20)
- Telzir (fosamprenavir)
- Kaletra (lopinavir/ritonavir)
- Isentress (raltegravir)
- Norvir (ritonavir)
- Invirase (saquinavir)

In terms of key diagnostic tests, national treatment protocol calls for each person on ART to receive at least two viral load tests and CD4 tests each year.¹⁰⁰ Official guidelines are not always met, however, and the situation is quite different in reality. As of December 2009, viral load testing was available at only a handful of facilities in four states (Carabobo, Caracas, Mérida and Zulia).

Moreover, according to RVG+, some PLHIV in other states have reported being forced to pay out-of-pocket for CD4 and viral load testing, even though such tests are supposed to be provided free of charge to all who need them. The individual fees can be as high as \$14 per test, a substantial burden for poorer residents. Many must pay additional sums for transportation and accommodation if forced to go to a large urban area, such as Caracas, to be tested free of charge at a public facility.

2. SOURCES OF HIV TREATMENT DELIVERY AND RELATED ISSUES

PLHIV who are covered under the government's social security system can obtain ARVs at certain specific pharmacies and PNS clinics and administrative offices. The medicines are distributed through PNS.

99 Guide for the Management of ART Among PLHIV (2008–2009)

100 "Guía para el tratamiento antirretroviral de las PUVs en Venezuela" (Guide for the antiretroviral treatment of PLHIV in Venezuela), PNS/MPPS (National AIDS Program / People's Ministry for Health), 3rd edition, 2008–2009.

For care in general in the public sector, PLHIV are seen in the infectology, internal medicine or immunology departments of the main public hospitals; all such services are available free of charge. In Caracas, some NGOs have outpatient medical care services for PLHIV, with at least one of these NGOs offering a wide range of services with different medical specialties. HIV-specific care is also available in the private sector, including at private hospitals, for PLHIV who are able and willing to pay for it.

There are huge differences between health services offered in urban rural areas. The public hospitals, pharmacies and private hospitals with experience in HIV care and services, including ART, are located primarily in urban areas. In most rural areas, however, patients must rely on small outpatient-oriented facilities that provide only basic services. Most do not offer HIV/AIDS care, including ART provision.

This situation forces many PLHIV from rural areas to travel long distances for care and, as a result, spend additional money on transportation, accommodation and food. Many find it difficult if not impossible to find the necessary resources to undertake such journeys on a regular basis.

“There is a shortage of HIV-trained physicians in Venezuela and there are no health professionals trained to see HIV patients in all regions of the country, a situation that further exacerbates the stigma and discrimination against PLHIV.”

Respondent from the Venezuelan Network of Positive People (RVG+)

3. FACTORS INFLUENCING ACCESS TO TREATMENT

A major ongoing PNS effort has been to identify ways to secure sufficient quantities of ARVs at lower prices. To that end, it has signed agreements with the Cuban and Argentinean governments to import ARVs and has sought to develop domestic capacity to produce generic versions of important HIV medicines. The latter effort has largely failed so far, however – including a proposed technology transfer project with Brazil (in 2004) via PROULA, a pharmaceutical company owned by the University of the Andes, and a project for building a factory with technology provided by Cipla, an Indian generic-drug company.

Such failures highlight the Venezuelan government’s difficulties in meeting a high-profile goal: improving health care delivery in general. Although the goal is good, the execution has been poor and the overall situation has deteriorated in many respects. Reports persist of long delays for routine services at health facilities, unsafe and unhygienic conditions, lack of adequately trained personnel, low salaries across the public health system, deterioration of facilities, and shortages of basic materials.

All of these developments have had negative impacts on the quality and effectiveness of HIV treatment services, a trend that PNS has acknowledged.¹⁰¹ According to a respondent from the RVG+ network, “There is a shortage of HIV-trained physicians in Venezuela and there are no health professionals trained to see HIV patients in all regions of the country, a situation that further exacerbates the stigma and discrimination against PLHIV.”¹⁰²

101 Interview with Dr. Deisy Matos, head of PNS, on 21 December 2009.

102 Interview with Estevan Colina, secretary of RVG+, on 28 December 2009.

PREVENTION OF VERTICAL TRANSMISSION

The government has clear policies and guidelines aimed at preventing vertical transmission of HIV. For example, all pregnant women who present at both public and private health facilities are required to be tested for HIV. (The policy mandates as well that all women receive pre- and post-test counselling and information.) All women who test positive receive ART, with the standard regimen being a three-drug combination of AZT + 3TC + lopinavir/ritonavir. (If that regimen is not available, the national protocol recommends saquinavir + ritonavir; in cases of drug resistance, PNS recommends tenofovir + AZT + 3TC.) The protocols also specify that AZT should be administered at birth to both mother and newborn.

According to the head of PNS, Dr. Deisy Matos, a total of 380 HIV-positive pregnant women were receiving ART through the agency in 2009; in comparison, 335 and 374 were treated in 2008 and 2007, respectively. She said that follow-up care and services are regularly available to new mothers, adding that “health services and departments offer guidance and counselling to HIV-positive mothers regarding how they must feed their children.”¹⁰³ Among the things caregivers tell HIV-positive mothers, she said, is that they “cannot breastfeed their babies”. Civil society advocates point out that this advice is based on the national guidelines, which do not meet the latest WHO guidelines on infant feeding.

Some respondents to this report noted that efforts to prevent vertical transmission and provide adequate treatment to HIV-positive mothers continued to face several challenges. The most important is lack of awareness of HIV status and late diagnosis of HIV making treatment less effective.¹⁰⁴ Another challenge is that many women, particularly in rural areas, do not attend antenatal clinics.

4. OPPORTUNITIES AND CHALLENGES

The following are among the major challenges to improved and enhanced HIV treatment scale-up in Venezuela:

- **Drug stock-outs.** Until recently, there was never a problem with ARV stock-outs in Venezuela. Yet in the last two months of 2009 that record was broken: shortages were reported of seven different ARVs as well as of several drugs for OIs and crucial nutritional supplements. An estimated 50 percent of people on ART did not receive all of their drugs during those months. Representatives from both civil society and the government agreed that the government was primarily responsible for the shortages, with one government official noting that they resulted from “the financial problems of the [health] ministry in meeting its obligations with the pharmaceutical and medical supply companies,”¹⁰⁵ which

103 Interview with Dr. Deisy Matos, head of PNS, on 21 December 2009.

104 Interview with Dr. Ana Carvajal, on 29 December 2009.

105 Interview with Dr. Deisy Matos, head of PNS, on 21 December 2009.

“The government does not take [the civil society sector] into account when making decisions.”

Secretary at the
Venezuelan Network of
Positive People (RVG+)

led to “non-payment of the outstanding amounts owed to the pharmaceutical companies that produce them.”¹⁰⁶ Drug companies halted their dispatches of ARVs and other key products in response.

The situation was resolved when, partly in response to advocates’ pressure, the government paid off a portion of its debt and pharmaceutical companies resumed supplying ARVs in early January 2010. Those who were interviewed shared the opinion that the ARV shortage crisis was brought about by the impact of the global economic recession.

- **Limited civil society engagement.** Government officials and agencies rarely consider civil society to be a useful and important partner in the HIV/AIDS response. As a leading RVG+ representative observed, the civil society sector “does have some influence...but there is no coordination because the government does not take [the sector] into account when making decisions.”¹⁰⁷ Also there are concerns that the government selects only certain NGOs to represent the voice of civil society even if they are not the most knowledgeable or experienced on these issues. Several PLHIV respondents agreed that the national HIV/AIDS response would be more effective if the government started a serious dialogue with, and sought to work with, civil society groups and other sectors with important skills and resources.
- **Late uptake of HIV services, including ART.** Many PLHIV only seek health care and assistance when they are at an advanced stage of AIDS and, therefore, are suffering from serious OIs. This highlights an ongoing challenge of raising awareness about HIV and encouraging greater uptake of HIV testing services.
- **High rates of non-adherence to ART regimens.** Both civil society and government respondents acknowledged relatively high rates of non-adherence among PLHIV on ART, with one study estimating that up to one-third of all people on ART are not adherent.¹⁰⁸ The main reasons cited for these high rates of non-adherence are ARV side effects, lack of support from families and relatives, lack of support and information from health providers, and bad decisions made by health care workers who decide on regimens. The final two reasons noted above—both of which result specifically from poorly trained health personnel—are considered especially troubling by many advocates. They pointed to evidence from 2006–2007 indicating that some 15 percent of decisions regarding the initiation of ART had “flaws and mistakes”.¹⁰⁹ The

106 This comment was made by Hector Corobo, the MoH’s director of goods and services, in an interview with the Bolivarian News Agency. The interview was in an article titled “MinSalud garantiza tratamientos de VIH/SIDA hasta enero de 2010” (Ministry of Health guarantees HIV/AIDS treatments until January 2010) that was published on the website of the El Nacional newspaper on 9 December 2009.

107 Interview with Estevan Colina, secretary of RVG+, on 28 December 2009.

108 “Adherencia a los Medicamentos Antirretrovirales y Situación de los servicios de Consejería para la prevención del VIH en siete estados venezolanos” (Adherence with ARVs and the Status of Counseling Services for HIV Prevention in Seven Venezuelan States). ACCSI study (2009).

clear risk of non-adherence, whatever the reason, is drug resistance, which limits effective treatment options for people in need.

- **Effects of deterioration of public health system.** As noted in Section 3, the quality and effectiveness of the public health system are deteriorating. Health care workers are underpaid and must work in substandard conditions. Many are poorly qualified and receive little or no follow-up training. All aspects of HIV service delivery are increasingly affected.
- **Weak legal and policy framework to protect the rights of HIV-positive individuals and members of vulnerable populations.**¹¹⁰ There are no laws in Venezuela that provide specific protections for PLHIV and members of most vulnerable populations, including MSM. Most civil society advocates say that the lack of such laws hinders the ability to raise awareness about HIV among the general population and reduce stigma and discrimination against PLHIV and those at risk.

OTHER BARRIERS AND CHALLENGES

Civil society respondents to this report identified numerous other barriers and challenges to more widespread and comprehensive access to HIV treatment and care services in Venezuela. Among them are the following:

- Poor coordination among various departments and units within the public health system. This is considered a main reason for recent problems related to ARV procurement and supply.
- Lack of commitment to increasing financial resources for ART scale-up.
- Lack of social services aimed at supporting PLHIV (e.g., to adhere to ART regimens).
- Lack of sufficient numbers of medical and non-medical staff trained in HIV treatment and prevention.
- The high cost charged by pharmaceutical companies supplying originator-brand ARVs to the MoH.
- Managerial weakness at PNS and the MoH.
- Lack of standards and policies aimed at more equitably distributing HIV services (including not just ARVs but also key testing materials) throughout the country.
- Lack of official standards or protocols for the provision of counselling to PLHIV on issues such as treatment adherence.

109 Ibid.

110 Community Report—Venezuela 2008, UNGASS AIDS 2008, ACCSI and AVESA, 2008, p. 21.

- Lack of adequate and updated epidemiological data that could help officials plan more effectively and efficiently for the future, including in terms of procuring and distributing ARVs.¹¹¹
- Difficulty in identifying patients who are in need of treatment but are not receiving it “because they are not familiar with the treatment, do not know that the Venezuelan state has an official policy that offers access to treatment, or do not even know that they are infected.”¹¹²
- Limited access to ARVs and regimens that are relatively simple to take (e.g., combination pills that are taken once a day).
- Persistent stigmatizing behaviour and discrimination on the part of health care providers based on patients’ HIV status and association with vulnerable groups (such as MSM).

5. RECOMMENDATIONS

1. **The MoH, which originally created the National AIDS Commission (CONASIDA), should take the lead in reactivating the commission.** Reactivation is necessary because the commission is essentially inactive and dormant. Its absence means there is no effective multistakeholder agency involving representatives from all important constituencies engaged in treating and caring for PLHIV in Venezuela. This situation is a key reason for the fragmented and disorganized HIV/AIDS response in the country.
2. The MoH should update **the National HIV/AIDS Strategic Plan**. Attention should be focused on the entire document, including issues related to HIV treatment and care, human rights, and prevention.
3. **The MoH should update and improve the epidemiological surveillance system** as part of an effort to provide more extensive information on the extent and impact of HIV/AIDS in the country. This should include a registry of information (presented confidentially) about all PLHIV on ART.
4. The National Assembly should implement guidelines and mechanisms to **ensure greater compliance with existing human rights legal frameworks** as a key part of an effort to reduce HIV-related stigma and discrimination.
5. The MoH should seek to **ensure greater compliance with existing policies and regulations regarding sexual and reproductive health**.
6. The National Assembly and the federal government (in particular

111 “Adherencia a los Medicamentos Antirretrovirales y Situación de los servicios de Consejería para la prevención del VIH en siete estados venezolanos” (Adherence with ARVs and the Status of Counseling Services for HIV Prevention in Seven Venezuelan States). ACCSI study (2009).

112 Interview with Dr. Deisy Matos, head of PNS, on 21 December 2009.

the MoH) should make it a priority to **increase government budget support for HIV care and treatment.**

7. The MoH should **improve the management and administration of PNS** so that it can have a stronger impact on decision-making related to health treatments and services.

8. The MoH, working in collaboration with advocacy groups and PLHIV, should **design and implement awareness and training strategies related to treatment and care of HIV infection for all health care personnel.** These programs should be implemented across the health care system. Important areas of focus should include ART compliance and care for vulnerable populations.

9. The government should **ensure that civil society organizations** with experience in the field of HIV/AIDS – and particularly those representing PLHIV – should **be part of the national policy making process**, as outlined in the Declaration of Commitment.

10. The MoH and Venezuelan Society of Infectology should ensure that **HIV care is included in all different health programs and services**, starting with first level care. This would help increase early diagnose of HIV and co-infections (e.g., TB and hepatitis C).

