

MISSING THE TARGET

*A report on HIV/AIDS treatment access
from the frontlines*



International Treatment Preparedness Coalition (ITPC)

28 November 2005

The International Treatment Preparedness Coalition (ITPC)

was born at the International Treatment Preparedness Summit that took place in Cape Town, South Africa in March 2003. That meeting brought together for the first time community-based treatment activists and educators from over 60 countries. Since the Summit, ITPC has grown to include over 600 activists from around the world and has emerged as a leading civil society coalition on treatment preparedness and access issues.
See appendix at the end of this report for more information.

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Executive Summary

The campaign for global AIDS treatment delivery has reached a defining moment. The first years of programme scale up demonstrated that AIDS treatment can be delivered effectively, even in the poorest settings. But “3 by 5”, an initiative by the World Health Organization (WHO) to treat three million people by the end of 2005, is coming to an end—and it has fallen at least one million men, women and children short of the target. This leaves at least four million people who urgently need anti-retroviral drugs today in order to have any hope of survival. Although progress has been made over the past few years, we cannot call this success.

G8 leaders have pledged a new goal of coming as close as possible to universal AIDS treatment access by 2010. This will be a hollow promise unless governments and international agencies learn the lessons of the early years of treatment delivery and dedicate increased resources, capably address barriers, collaborate more effectively, and hold themselves accountable for steady, measurable progress.

The “3 by 5” initiative failed to treat even 50% of people in need of antiretroviral treatment (ART). If the organisations responsible for carrying out this programme are to accomplish an even greater goal in five years’ time, it will take courageous new leadership from all parties to confront the monumental task ahead. The status quo will not get us there.

Will the international community rise to this challenge? The fate of millions of people around the world hangs in the answer to that question.

The International Treatment Preparedness Coalition (ITPC) is a global alliance of over 600 treatment activists that includes people living with HIV/AIDS (PLWHA) and their advocates. The ITPC AIDS Treatment Report is the first systematic assessment of treatment scale up based on the research of people living in communities in six countries where the epidemic has hit the hardest—the Dominican Republic, India, Kenya, Nigeria, Russia and South Africa. The report is based on their experiences and first-hand knowledge of the situation on the ground. Each country used a case study methodology, which emphasizes interviews with carefully selected key informants.

Clearly, much more work needs to be done to understand the complexity of this challenge. But what we found tells an important story—of individuals exhibiting dedication and courage while caught in desperate situations; and of institutions often struggling to transition, be efficient, and throw off bureaucratic obstacles that stand in the way.

The ITPC AIDS Treatment Report is a prescription for the future. As ART has started to roll out in these six countries, the ITPC research teams have identified barriers that could imperil efforts to make treatment more widely available. The teams have also made concrete recommendations for governments and international institutions.

These recommendations must be taken up with urgency if the goal of universal access by 2010 is to be achieved.

Major roadblocks to success include the following:

- inadequate leadership at the national level that fails to dedicate sufficient resources or mobilize governments;
- a global system that does not collaborate speedily and efficiently to address bottlenecks;
- inadequate and uncertain funding levels for programs and financing mechanisms such as the Global Fund to Fight AIDS, TB and Malaria (GFATM)—a situation that keeps countries guessing about the sustainability of services and the meaning of pledges like “universal access”;
- bureaucratic delays that prevent urgently needed resources from reaching treatment programs;
- procurement and logistics challenges that demand more comprehensive and effective technical assistance; and
- pervasive stigma against people living with HIV/AIDS that requires moral leadership from national and global communities.

Need for improved leadership at the national level

In every country surveyed there were concerns about inadequate leadership at the national level and the subsequent failure to dedicate sufficient resources or mobilize governments. We heard about the necessity for a well-functioning national AIDS programme that can provide this leadership, implement a comprehensive national AIDS plan, and compel international and domestic organizations to abide by that plan. Sadly, the state of national AIDS programmes in these six countries did not make the grade. Scale up of treatment will not happen unless countries fulfill their responsibilities to those living within their borders—and national governments must be the primary engine for increasing access to care.

In addition, in just about every country we saw a failure to link TB and HIV programming effectively, missing opportunities to diagnose and treat these interconnected diseases and establish coordinated systems of health care.

We also found that each country has a different constellation of challenges and potential solutions.

- In the **Dominican Republic** bureaucratic delays and power struggles between agencies delayed implementation of a Global Fund grant for months. Many of those initial problems have now been overcome, but

delivery of ARVs is still hampered by lack of political leadership; stigma and discrimination; supply problems with ARVs, treatments for opportunistic infections, and CD4 tests; and continued lack of coordination between programs.

- In **India** treatment remains unavailable for the vast majority of the millions of people living with HIV. Although the government has signaled increasing commitment to ART delivery, the national AIDS program has failed to act on several critical issues and national treatment guidelines are under-enforced and have several significant gaps. Many people seeking care are forced to travel long distances, and shortfalls in funding and human resources threaten efforts to expand the response.
- In **Kenya** treatment services are being scaled up through new funding from the Global Fund, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), and other programs. Yet people in need of care and service providers from around the country are confronting significant obstacles that include widespread stigma and discrimination against PLWHA and women, misinformation, lack of treatment literacy, and insufficient resources to meet basic nutrition needs or afford travel to health clinics for care.
- In **Nigeria** the government has set new and ambitious targets for treatment delivery, but services remain concentrated in a few "cluster zones" while people in rural areas struggle to get care. Lack of adequate funding and human resources complicate treatment expansion. The high costs of CD4 and viral load tests put these diagnostic tools out of reach of most people in treatment. Stigma and a lack of treatment literacy programs both undermine scale up efforts.
- In **Russia** efforts are underway to significantly scale up ART delivery in response to a fast-growing epidemic concentrated among injection drug users (IDUs). Yet multiple bureaucratic obstacles stand in the way, including a faulty drug procurement system, lack of collaboration among providers, absence of a national treatment protocol, a Global Fund Country Coordinating Mechanism (CCM) that is widely described as ineffective, and lack of leadership from government agencies. Widespread discrimination against IDUs inhibits scale up at an even more fundamental level.
- In **South Africa** activists and providers have forged ahead with treatment delivery even as the national government continues to drag its feet and fails to combat misinformation and pseudo-science. Multilateral agencies have been largely invisible and the CCM is widely criticized. Many practical problems inhibit scale up as well, including a severe shortfall in nurses and other providers, limited access to HIV testing, and inadequate availability of drugs.

Introduction and Overarching Recommendations

The “3 by 5” initiative challenged the world to provide treatment for three million people living with HIV in less developed countries by the end of 2005. Even though this goal was always only a partial one—six million people are in urgent clinical need of antiretroviral treatment (ART) now—it still proved impossible to achieve. Developments toward this goal over the past few years have demonstrated that AIDS treatment delivery can work, even in the poorest settings, yet delivering it is much more difficult and complicated than “3 by 5” campaigners originally anticipated. Hundreds of thousands of lives have been saved, but millions of other HIV-positive individuals have not benefited.

Now the campaign for global AIDS treatment delivery has reached a defining moment. Governments and non-profit service providers are grappling with implementation challenges. The Global Fund to Fight AIDS, TB and Malaria (GFATM) is struggling to raise necessary resources. Dr. Kevin DeCock is replacing Dr. Jim Yong Kim as head of the HIV/AIDS office at the World Health Organization (WHO). As the “3 by 5” assessments are being prepared, will the governments and multilateral agencies involved in AIDS treatment delivery learn from challenges that have been encountered, systematically address barriers, and hold themselves and their partners accountable for steady, measurable progress?

The movement for access to treatment is irreversible—and will continue to be driven by people living with HIV/AIDS (PLWHA) and their advocates. The commitment of the rest of the international community is less certain, however. The priorities outlined and decisions made over the next few years by all involved in the global HIV/AIDS response will directly affect the lives and livelihoods of millions of people in every part of the world. Goals mean nothing unless the will and resources to achieve them are in continuous supply at all levels, from multilateral entities to each and every individual affected by the virus.

This report from the International Treatment Preparedness Coalition (ITPC) is a prescription for the future. It examines treatment scale up efforts in six less developed countries, identifying barriers to wider delivery and making recommendations for governments, the United Nations, and other multilateral institutions. The report documents systems in transition that need to continue to learn and change if the catastrophe of tens of millions of deaths from AIDS is to be averted.

The first years of treatment scale up revealed barriers to wider access to antiretroviral treatment (ART), many of which are discussed in detail in this report. If left unattended, these barriers will undermine the new G8 goal (announced in July 2005) of “universal treatment access”, just as they caused “3 by 5” to come up short. None of the challenges are easy, but they all have solutions. One solution is improved leadership at the national level. Another is a better functioning global

system that efficiently assists countries in recognizing and tackling problems. This report identifies several specific areas where many countries need additional assistance, including: management of expanded programmes, drug procurement, provision of treatment literacy education, anti-stigma efforts, promotion of adherence, and human capacity development.

ITPC is a leading civil society coalition of treatment activists. A year prior to the “3 by 5” deadline, its members agreed that AIDS treatment scale up needed a performance appraisal. We set out to do a systematic analysis of the barriers to scale up from the perspective of advocates not wedded to the fortunes of any particular agency or organization. Six countries (Dominican Republic, India, Kenya, Nigeria, Russia, and South Africa) were selected by ITPC to be the focus of this report, based on the number of people in need of treatment and the availability of ITPC members to commit substantial time to research and writing. A research team was assembled in each of the six countries and the teams all developed research plans. A case study interview template was developed for use and adaptation in each country.

From June through September 2005, country teams completed between 12 and 20 interviews with representatives of governments, multilateral agencies, provider organizations, advocates, and PLWHA. (Kenya was an exception: in that country, 113 people completed a questionnaire compiled by report organizers.) Most people and organizations we contacted were happy to participate, although some did not respond.

Analysis of the results is presented in the individual country case studies in this report. Each country used a case study methodology, which emphasizes interviews with carefully selected key informants. Although each country followed a standard outline, the six country reports are distinct both in findings and in presentation, and writing styles vary depending on researchers’ approach and background. While each team focuses on the specific issues that most affect HIV/AIDS treatment access in their country, many common themes nonetheless emerge. Most center on urgent policy issues as discussed by policymakers, providers, and advocates. The Kenya case study is based on the personal experiences of over 100 PLWHA and their service providers. Taken together, these six case studies provide a rich picture of the state of AIDS treatment access as seen from the frontlines.

What we found — country level results

Respondents in each country stressed the need for a well-functioning national AIDS programme that can provide leadership, implement a comprehensive national AIDS plan, and compel international and domestic organizations to collaborate within the plan’s broad outlines. Sadly, the national AIDS programmes—and by association, the national governments—in these countries did not make the grade. Scale up of treatment cannot happen efficiently and consistently unless national governments

become the primary engines for increasing access to care within their borders. We found many common barriers in the countries surveyed, including those related to procurement and logistics, bureaucratic delays, stigma, and lack of sufficient leadership and coordination. In addition, in just about every country we saw a failure to link TB and HIV programming effectively, thus missing opportunities to diagnose and treat these interconnected diseases and establish coordinated systems of health care.

In six months, we want to see the governments of these six countries address the issues raised in this report and to greatly scale up their own investment and engagement in access to treatment. We also want key government officials to meet with PLWHA groups and their advocates as part of a greatly enhanced effort to move forward together on treatment access. This has been impossible to date in many of these six countries, and is a symptom of the disregard those governments have for PLWHA. Such attitudes must be changed so that governments and those on ART now or in the future can work collaboratively to ensure that treatment is scaled up effectively. In addition, African countries need to live up to their commitment as part of the Abuja Declaration to commit 15% of their budgets to addressing health priorities, including HIV/AIDS.

What we found — the major multilaterals and bilaterals

Most multilateral entities, such as WHO and the Joint UN Programme on HIV/AIDS (UNAIDS), have strengths that are needed in AIDS treatment scale up—but these agencies are not yet collaborating effectively. A 2005 analysis produced by some of these agencies themselves, in collaboration with international donors, concluded that the international response is “unevenly coordinated”.¹ Reports from the six countries in this document frustratingly reinforce that conclusion. Better coordination means many things, from strategic planning among agencies in Geneva to closer communication on the ground to maximize effective use of resources.

UNAIDS, WHO, GFATM, and PEPFAR and other bilaterals must do a better job of working collaboratively to identify and quickly address impediments to flow of resources and delivery of services. These agencies are now working on a plan to “operationalize” universal access. This plan should include defined country-specific strategies and goals with hard timelines and milestones, as well as clear assignments of responsibility for specific tasks.

- **GFATM** is playing an essential role in AIDS treatment scale up, providing vital resources and using its funding to drive needed reforms at the country level. By focusing on the three major pandemic diseases in developing countries and by allowing investment in health care capacity, GFATM aids efforts to rehabilitate health sector capacity that has been undermined by decades of structural adjustment, under-financing, and privatization. From its inception, GFATM has placed high priority on good fiscal management, accountability for results, and sustainable country ownership. These are

laudable goals that, unfortunately, have proved difficult to meet in many countries. This report documents numerous cases of delays or even outright barriers to the flow of GFATM resources to those in need. Among the reasons for substandard flows are in-country financial mismanagement, problems with a principal grant recipient, and dysfunction at CCMs. As one study found, GFATM requirements often reveal longstanding tensions between partners at the country level that need to be addressed to promote sustainability of service delivery.²

Substantially increased funding is urgently needed to sustain and expand GFATM grantmaking. Without increased resource commitments, the G8-declared goal of universal access is a hollow promise. Where country-level impediments limit the planned scope and reach of grants, GFATM, UNAIDS, WHO, PEPFAR, and other funders have a responsibility to work together closely to address problems and ensure that the money reaches its planned recipients, including those providing treatment. GFATM needs to ensure that countries have reliable access to high quality technical assistance, improve structures for monitoring implementation, and play a stronger role in pushing CCMs to function properly.

Substantially increased and sustained funding for GFATM is a top priority in AIDS treatment delivery. In six months we want to see more resources not only pledged but disbursed to GFATM, and more examples of the multilateral system working collaboratively to accelerate delivery of grants and supporting implementation of AIDS treatment programmes.

Note: GFATM disbursements are ongoing so numbers used in this report may not always coincide with most recent GFATM numbers. The GFATM website is updated daily and provides information on disbursement amounts <http://www.theglobalfund.org>.

- **WHO** deserves a great deal of credit for setting the “3 by 5” target, and for struggling to re-organize its bureaucracy to better serve scale up efforts. Jim Yong Kim, outgoing head of the AIDS programme, should be congratulated for his willingness to identify countries that are lagging, as well as those that are succeeding, in their scale up efforts. Other notable strengths of WHO's efforts include publication of ARV guidelines in resource-poor settings; establishment of the WHO Prequalification project; technical assistance to GFATM; and provision of training modules and training resources on ART delivery. But it is cause for concern that most of the people contacted for the report did not know what WHO does in their country.

As the chief technical agency on global AIDS treatment, WHO needs to be a more visible leader on specific implementation challenges that are encountered

in countries, be more of an advocate at the country level, and work more closely with civil society. WHO also needs to set more detailed treatment goals that include specific targets for children and marginalized populations, such as IDUs, women, migrants, commercial sex workers, and men who have sex with men (MSM). The agency should create targets for delivery of second- and third-line regimens based in part on observed resistance trends and prevalence of side effects. The agency should take the lead in responding to anticipated drug resistance. Information to guide providers in addressing resistance should be more widely available.

In six months we want to see detailed action plans for treatment scale up for all of the countries that have told WHO they want to be part of “3 by 5.” These plans must have timelines, deadlines, and milestones for countries and for WHO itself. Countries and WHO should then be held accountable for meeting these goals.

- **UNAIDS** has been an outspoken advocate for the rights of women, sex workers, gay and bisexual men and other marginalized groups even while some countries persecuted these groups and other UN organizations failed to champion their needs. UNAIDS is the global communicator on AIDS, a technical assistance provider, repository of information, and preeminent convener. The agency has spearheaded efforts to bring greater harmonization to planning and monitoring at the national level. While this report documents UNAIDS’ good work in several areas, many of the people interviewed want to see more advocacy and other tangible efforts from the agency in support of AIDS treatment scale up at both the global and country levels.

No voice should be louder than UNAIDS in championing the principle of universal access to treatment within each and every country of the world. As the coordinating body of the multilateral system, UNAIDS needs to be increasingly answerable for accelerated, coordinated treatment scale up at the country level. Where funding is held up, or management or other deficits stand in the way, UNAIDS should ensure that resources from somewhere in the UN system are devoted to fix the problem.

In six months we want to see UNAIDS’ visibility in countries greatly improved. We also want to see more concrete examples of UNAIDS acting as a problem solver, resolving barriers to treatment scale up in countries by bringing the resources of the entire UN system to bear on these obstacles.

- **PEPFAR** has initiated HIV/AIDS assistance efforts in 15 countries over the past two years. Many report interviewees praised PEPFAR for quickly setting up treatment programmes with measurable goals and for operating in a determined and efficient manner. However, the programme has attracted

considerable criticism at the same time. A 2004 assessment of PEPFAR from the U.S. General Accounting Office identified “coordination difficulties among both U.S. and non-U.S. entities” as a major challenge.³

This report corroborates that shortfall with examples of PEPFAR creating separate systems of care and failing to coordinate with others. PEPFAR is saving lives today; the question is whether it is building sustainable systems that will survive for the long term. More immediately, there are grave concerns around PEPFAR-imposed policy prescriptions, including disallowing grantees from providing counseling on abortion; requiring grantees to adopt a policy specifically opposing sex work; promoting abstinence-only prevention approaches; and forbidding the use of PEPFAR funds to purchase medicines that are not approved by the U.S. Food and Drug Administration. These policies undermine efforts to reach women at elevated risk, implement evidence-based prevention programmes, and utilize quality generic and fixed-dose combination drugs.

The U.S. Congress must increase funding for PEPFAR and repeal destructive policies. Investment in PEPFAR is also no substitute for the U.S. government’s responsibility to fully support GFATM financially and programmatically. PEPFAR programme managers should work more closely with country partners and nurture local investment in scale up.

In six months, we want to see PEPFAR delivering treatment to thousands more and pointing to specific examples of how it is building sustainable health care systems in its 15 target countries. PEPFAR also needs to coordinate its medicines portfolio with country-owned national treatment protocols, procurement, and supply chain management systems. PEPFAR needs to focus much more intensely on creating capacity in-country and supporting country ownership of HIV/AIDS programming. We want specific and independently verifiable evidence that PEPFAR is seeking to fully integrate its activities on the ground with other partners.

- While the shortage of health care workers in developing countries has many reasons, some of the blame must lie with the **International Monetary Fund (IMF)** and the **World Bank**. Often, loan agreements with these institutions directly or implicitly mandate national macroeconomic policies that restrain public sector spending and lead to cutbacks in basic government services, including health care. We agree with ActionAid’s recommendations that “finance ministries or treasury departments need to take concrete steps on the Executive Board of the IMF to stop loan conditions that call for ‘tight’ monetary policies that constrain public spending at unnecessarily low levels [...] in order to allow the ‘fiscal space’ necessary to hire the many more doctors, nurses and teachers necessary for fighting HIV/AIDS effectively.”⁴

In August 2004 ITPC wrote a letter with signatories from over 35 countries to the managing director of the IMF and the president of the World Bank on this matter. The reply from both organizations was an unsatisfactory defense of current policy and indicates an ongoing lack of understanding of their loan provisions' potentially devastating effects. These international financial institutions need to be confronted directly and vigorously by advocates and governments around the world, and urged to reform their policies and procedures.

ITPC is committed to pursuing the recommendations in this report and has developed a set of principles and a plan of action that follows.

¹ UNAIDS. Global Task Team on improving AIDS coordination among multilateral agencies and international donors. Geneva, 14 June 2005.

² Brugh, R, et al. Global Fund tracking study: a cross-country comparative analysis, 2 August 2005.

³ General Accounting Office. US AIDS Coordinator addressing some key challenges to expanding treatment, but others remain. Government Printing Office, Washington, DC. July 2004.

⁴ ActionAID. Square Pegs, Round Holes, Why You Can't Fight HIV/AIDS with Monetarism. An issue briefing by Rick Rowden, ActionAid International USA, that outlines ways in which the IMF is obstructing progress in fighting HIV/AIDS. ActionAid International USA. March 2005.

Principles and Follow-Through Plan

ITPC and the report's authors have developed a set of principles and a plan of action designed to move forward on the report's findings and recommendations. In this plan we look at the past in order to learn how to do better in the future. The immediate goal is to use existing and future resources to ensure that three million people are on life-saving ART as soon as possible.

If, as the optimists say, the goal of getting three million people on treatment is reached by spring of 2006, we will celebrate the success and reset the goal for the rest of 2006. Each goal met sets the baseline for the next goal.

Principles

1. What gets measured gets done

If the mission of getting treatment to millions of people was run like many businesses, specific goals would be defined and agencies and their managers would be responsible for having specific plans to reach these targets. Although AIDS treatment scale up is not a business, the effort could benefit from a much more pragmatic approach to accomplishing goals. To date, there are only broad targets established by WHO and by some of the countries that have expressed interest in participating in the "3 by 5" initiative. Far more detailed and rigorous international and country-level planning is needed in the future. Milestones and deadlines need to be reached and honored—shifting milestones forward in time is not a solution for success, but instead represents a recipe for perpetuating failure.

2. Continuing global and multilateral commitment are essential

UNAIDS, WHO, GFATM, and bilaterals like PEPFAR must continue to provide funding, apply pressure, and keep the world's vision focused on the importance of treatment scale up. They must implement organizational changes to increase effectiveness and decrease redundancy. Excuses about "the nature of the UN" or "the national politics of the United States" cannot be used to avoid the requirements for better coordination and greater accountability.

3. Some barriers can benefit from shared solutions

Many of the issues discussed in the report's individual case studies cut across all countries. Some are reflections of the deep-seated prejudice of people towards each other, but many are organizational or logistical, such as drug procurement and distribution. The mechanical issues, at least, are fixable in the short term—and in our recommendations we call for the best minds of the world to work at fixing them. For instance, stock-outs of drugs should not be happening in any programme,

yet we see several programmes around the world at risk of running out of medicines for the thousands of PLWHA on ART in these countries. UNAIDS, WHO, GFATM, and bilaterals must collectively monitor these barriers and assign task teams to address them in an expeditious manner.

4. All implementation is local

In-country implementation is the make or break for reaching treatment delivery goals. In each of these countries there is a large gap between the number of people needing treatment and the number of people receiving it. A tailored set of solutions is required because there is a different constellation of barriers in each country. Greater focus and investment need to be given by both governments and on-the-ground multilaterals to honestly assess the problems with treatment delivery in countries and to develop local strategies for resolving them—instead of seeking solutions from generalized guidance provided by technical agencies and others from afar.

5. Treatment access is not only drug access

The ultimate unit of success for treatment delivery is the number of PLWHA retaining decent health and prospering. The country reports document that poverty, lack of access to food, very long travel time to clinics, and discrimination against marginalized groups all remain important barriers, even when ART is available. Consequently, each country report includes recommendations for addressing those issues. It is clear that some of the problems with delivery of treatment are part of the larger problems of human development in less developed countries. However, treatment advocates' work would seem even more overwhelming if HIV/AIDS were simply folded in among these broader problems.

The push for access to AIDS treatment thus should be seen as a wedge to mobilize communities and other stakeholders around these broader issues while always maintaining a focus on achieving the goal of universal access by 2010. Expanded delivery of evidence-based HIV prevention interventions should also be a top priority. Treatment scale up provides many opportunities—at testing sites, in clinical settings, and elsewhere—to increase the reach of HIV prevention and awareness initiatives.

ITPC Action Plan for 2006

ITPC has created a follow-through plan and timeline for taking action on the report findings. Members of the coalition will place top priority on the actions and objectives listed below.

First quarter 2006

- Meet with senior representatives of each major multilateral, bilateral, and other funders included in this report to review findings and develop specific and measurable goals, timelines, and action points
- Meet with senior representatives of country governments
- Meet with national AIDS organizations in each of the report's six target countries to review findings and develop specific country-level implementation plans
- Define specific target number goals (by quarter for 2006-2007) for people on treatment for each of the six countries
- Work with major players (global and country-level) to develop an integrated process for counting the number of people on treatment

Second quarter 2006

- Issue update bulletin on treatment access progress against the plan
- If the target of having three million people on ART is met, set new target for remainder of 2006; if not met, identify top issues and provide action points for acceleration
- Develop Level Two Report process to ensure in-depth follow-up in the six countries
- Identify six additional countries to begin Level One Report analysis

Third quarter 2006

- Issue update bulletin on treatment access progress against the plan
- If the target of having three million people on ART is met, set new target for remainder of 2006; if not met, identify top issues and provide action points for acceleration
- Provide report update and forum to discuss results and actions among global players at International AIDS Conference or another venue

Fourth quarter 2006

- Issue AIDS Treatment Access Report II, including update on the six initial countries, first level analysis on six more countries, and overall global progress report
- If the target of having three million people on ART is met, set new target for remainder of 2006; if not met, identify top issues and provide action points for acceleration
- Develop and share top-level plan for 2007

Country Reports

The six case studies in this report are listed in alphabetical order by country name. HIV prevalence and ART availability differ widely, as do other important indirect and direct factors that play a role in determining effective national HIV/AIDS responses — such as political commitment, economic growth, civil society strength, and underlying levels of stigma and discrimination related to HIV and risk behaviors. Each country therefore offers a unique and instructive lens through which to consider the successes and failures of global ART roll out to date.

The recommendations at the end of each case study are for the most part specific to the country's situation. However, individuals and organizations advocating for faster and more efficient treatment scale up in any country are likely to find useful lessons from these country studies. In addition, these country reports offer important lessons for use at both the global and national levels.

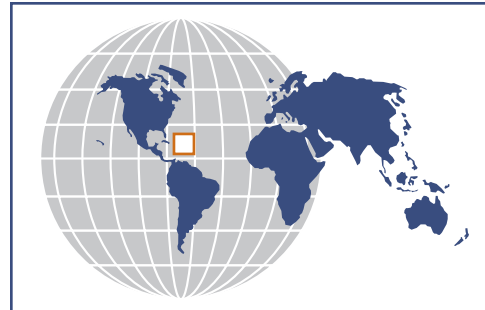


HIV/AIDS has claimed the lives of tens of thousands of Dominicans in recent years, while less than an hour and a half away, in Puerto Rico, Florida, and Cuba, ART and diagnostic tests have been available for almost a decade. Now, finally, access to ART is gradually improving in the Dominican Republic. As of September 2005, more than 2,000 PLWHA in the country were receiving free ART subsidized by GFATM, an extraordinary change from just a year or two ago. Antiretroviral drugs are theoretically available to those who need them in more than 20 Comprehensive HIV/AIDS Treatment Centres throughout the country, and plans had been announced to open at least 16 more centres in the future.¹

There is ample reason to be excited about the important progress made—progress that has saved and improved the lives of thousands. However, the allocation of funds, expansion of treatment centres, and upgrading of necessary health infrastructure has come unacceptably late and presented many difficult challenges. It is estimated that 10,000-15,000 people in the country are still in need of ART today.

Many critical barriers to AIDS treatment access remain and have been identified through interviews and research for this report. Overcoming these barriers must now become a significantly greater priority for the Dominican government and international donor agencies.

¹ The Spanish acronym for these centers is "UAI."



How the research was conducted

- 12 confidential interviews with representatives from UN agencies, government, civil society, treatment sites, and others
- Site visits to public hospitals, clinics, prisons, and rural areas
- Review of key documents, including the Global Fund proposal

Major barriers to treatment delivery:

- Delays in implementation of GFATM grant
- Lack of high-level political will
- Limited CD4 testing capacity
- Discrimination against Haitians living in the country
- Shortages of ARVs
- Chronic lack of treatments for opportunistic infections
- Minimal linkage of HIV and TB care
- Power struggles and lack of coordination among agencies

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Treatment scale up must be integrated into a larger and sustained effort to improve the quality and level of care for hundreds of thousands more people living with, and all too often dying from, HIV/AIDS, tuberculosis, and other treatable and preventable diseases.

It is important to note that although this country report focuses on the Dominican Republic, its HIV/AIDS response has a significant effect on the lives of many people from Haiti, the other nation on the island of Hispaniola. Haiti is the poorest country in the Western Hemisphere and has the most severe HIV epidemic in the Americas. Hundreds of thousands of Haitian migrants live in the Dominican Republic, both legally and illegally, and they are frequently last on the priority list for AIDS treatment and other services.

Moreover, migration and tourism within, to, and from the Caribbean (and beyond) means that the spread of HIV and lack of effective treatment programmes on the island is not only a concern for the Dominican and Haitian governments. The epidemic also affects individuals, hospitals, and communities in places with large numbers of both Haitian and Dominican immigrants, such as Puerto Rico, Florida, New York, the Bahamas, Spain, France, Canada, and elsewhere. The AIDS epidemic and deteriorating social and economic conditions brought a sharp halt to most tourism in Haiti in the 1980s; if left unchecked, HIV/AIDS could have the same effect in the Dominican Republic. In some ways the damage has already been done: in cities and communities near popular beach resorts on the northern and eastern coasts, areas that attract millions of tourists each year, studies among pregnant women reveal some of the highest rates of HIV in the Dominican Republic.

Research methodology

Research for this chapter was conducted over several months through September 2005. In-country research included a dozen formal, confidential interviews. These were performed based on a template prepared specifically by the ITPC report organizing committee, which was translated into Spanish by the Dominican Republic country team. Among those interviewed were key representatives from the U.S. Agency for International Development (USAID), UNAIDS, the Clinton Foundation HIV/AIDS Initiative, the National AIDS Programme, the National Association of People Living with AIDS (REDOVIH), and physicians from several ART sites.

Researchers also reviewed the GFATM country proposal and interim progress reports as well as other documents supplied by the Ministry of Health. The thoughts and concerns of additional health workers, NGOs, and “ordinary” non-affiliated PLWHA in treatment centres were also sought out and considered. Numerous site visits were made to public hospitals, clinics, prisons, and rural areas with high rates of HIV/AIDS, in order to assess the barriers limiting access to ART and to review overall treatment preparedness in these settings.

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Few of those consulted for this research could answer all of the questions posed to them, especially those related to the treatment programme nationwide. This indicates the overall lack of transparency and incomplete sharing of information related to many aspects of the National AIDS Programme—and represents a key barrier to better treatment access and coordination among providers. Difficulties also arose in trying to maintain accurate, up-to-date information given substantial changes in the national response over the course of the research period. Some of the specific obstacles affecting treatment access in May or June subsequently were resolved, others became more noticeable by September, and still others remained unchanged and therefore need to be addressed with urgency.

In a few cases officials from government and donor agencies did not respond to repeated requests for interviews and information. However, it was encouraging that most people approached were extremely supportive of this research and were willing to participate and share their opinions.

Key barriers

The GFATM grant represents a vital opportunity for improving treatment access in the Dominican Republic, given that the government and other donors have generally not been willing to fund the purchase of ARVs. However, ongoing delays and difficulties have stymied its effectiveness so far.

Presidential elections in the middle of 2004 and ensuing political changes led to the replacement of several key decision makers at COPRESIDA (the government agency selected as the principal GFATM recipient) and the Ministry of Health. These steps were taken not only as part of regular changes stemming from political shifts, but also in order to address inefficiency and alleged corruption among administrators.

Still, nearly everyone interviewed for this project—including public health authorities and political appointees—said that lack of political will at the highest levels remained one of the most significant barriers to improved treatment access. The establishment of a high-quality public sector HIV/AIDS response, including ART provision and prevention education, has not been a priority for the Dominican political elite, although there are some signs that this is finally changing.

GFATM delays have brought the national treatment programme to a virtual standstill on occasion, largely because neither the previous nor current administration has dedicated adequate resources for ART. As a result, in comparison with nearly every other country in Latin America or the Caribbean (Haiti excepted), the Dominican Republic has one of the lowest percentages of PLWHA with access to ART and the largest number of people still dying without ever getting treatment.

Lack of, or extremely limited supply of, CD4 testing is another critical barrier to care because CD4 testing is often a prerequisite for initiation of therapy. There is also a

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shortage of treatment centres, treatment advocacy and literacy campaigns, and overall preparedness in rural areas. The shortages are particularly noticeable in the poorest regions all along the Haitian border, in the southwest, and in several eastern cities and towns with relatively high rates of HIV/AIDS.

Another major problem is that Haitians and Dominicans born to Haitian parents without legal documents are marginalized and stigmatized throughout society. They are less likely to seek out and receive ART because of language and legal barriers as well as racial discrimination that frequently flares into violence and harassment. The Dominican government has made no special attempts to open treatment sites that reach out to or provide ART to poor Haitians with AIDS. The result is that many people of Haitian decent are denied their human rights and even minimal public health services, despite the high rates of numerous diseases in their communities.

Waiting lists, sometimes hundreds of people long, are common in many areas where ART and CD4 tests are available. Although reportedly smaller now, these waiting lists remain a recurring problem that is sometimes alleviated for a month only to become a seemingly worse problem again as more individuals come forward for treatment and lab diagnostics each week.

Someone's job has to depend primarily on getting ARVs to the sites. This is a small country with relatively good roads to all the sites that need ARVs. It is inexcusable that orders are not filled monthly on a timely basis. It is inexcusable that there are waiting lists open for months when this is such a small area of coverage, and there are ARVs in customs or in the warehouse, ticking towards expiration. This is truly a crime.

— Anonymous

There have been acute shortages of even basic first-line ARVs like nevirapine, one of the cheapest ARV drugs on the market. As recently as June 2005, few individuals were able to start taking medicines and others were given just a few days' supply of pills and told to come back for more. There are stories of doctors being forced to improvise to ensure that all in need have access to medicines. For instance, a limited supply of medicines prompted some physicians to give adults huge amounts of liquid from children's drug formulations in order to maintain and adhere to their correct treatment cocktails. Some doctors reported having brought drugs into the country in suitcases on commercial flights from neighboring islands in order to prevent treatment interruptions at their sites.

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Patients come in to refill, or to start therapy, and we have to postpone initiation in people who desperately need it—prioritizing in ways that are totally inappropriate (by level of mortality risk, “first come, first served,” “adherence potential,” or just pure lottery). [Treatment] has to be rationed unfairly, because there really is no fair way to do this. It puts us in a desperate bind. We ended up just putting adults on paediatric preparations, having them come in every two to three days to pick up their meds, to stretch the supplies out. [We] stopped doing home visits to deliver ARVs to patients in bateyes, shantytowns and others with limited mobility. Although we were able to avoid anyone being more than 72 hours on two ARVs only, even this is wretched, and goes against what we try to emphasize to the patients.

— Physician

The absence of an efficient system for CD4 testing nationwide has meant that many people living with HIV only enter the treatment system after they become extremely sick. For some, this is too late to benefit from care. CD4 tests need to become cheaper; they need to be administered regularly (every six months to those who are HIV-positive); and they need to be provided to the newly diagnosed as well as to people with symptoms of advanced AIDS.

Other critically important issues needing attention include expanded treatment literacy and preparedness programmes, access to second-line medicines and viral load testing, and provision of infant formulas. People need to better understand the danger of treatment interruptions. Something must be done to secure reliable electric power necessary for cold chain storage. There is also a total lack of resistance testing, which will become a critical need in the near future.

Another concern has been the chronic lack of medicines for opportunistic infections (OIs) at ART sites. According to some sources, procurement for these medicines had yet to take place by July 2005. At the time research was undertaken, even the cheapest and most basic medicines—like cotrimoxazole, which is taken as prophylaxis for pneumocystis carinii pneumonia and other bacterial infections—were frequently unavailable. In many cases it was the responsibility of patients to buy these medicines at private pharmacies, which often charge prices beyond the reach of most poor people. Although there have been some limited donations or local purchases and distribution, respondents said that relatively expensive medicines—such as fluconazole, acyclovir, and gancyclovir—were largely unavailable in public clinics and only found on the shelves of private pharmacies at prices that either further impoverished or were well beyond the reach of most

PLWHA. Poor coordination between COPRESIDA and the health authorities was frequently cited by interviewees as an important factor in procurement and supply problems with drugs for OIs.

HIV/TB treatment and care

The challenges to providing effective diagnosis, prevention and treatment programmes for HIV/TB are somewhat different in the Dominican Republic because TB medicines are generally provided through a more established government programme. Some respondents mentioned the need for guaranteed access to drugs for potential cases of multi-drug resistant TB, which are not regularly included in all areas served by the national TB programme. Only one out of more than a dozen ART centres visited also provided TB treatment in the same facility in an integrated fashion, and this was one of the smaller, newer sites. Many interviewees pointed out that most doctors are simply not trained in managing HIV/TB co-infection. Equally problematic is that lack of knowledge about HIV co-infection is common among many individuals who work in HIV/AIDS advocacy, prevention, and treatment provision in general.

The need to better integrate HIV/TB care remains inadequately addressed at the clinical level and poorly understood at most other levels of the care system. Many PLWHA are at risk for contracting TB, especially those not on ART and people living in areas where rates of TB are highest—such as jails, slums, hospitals, and poor urban and rural areas experiencing an influx of Haitian immigrants. (In Haiti both TB and HIV and HIV/TB co-infection are proportionally even greater problems than they are in the Dominican Republic.) For many who are poor, sick, and weak, especially those traveling larger distances to receive HIV-related care, all the appointments, tests, and other challenges of TB care can become prohibitively difficult and costly. Unlike HIV/AIDS, TB remains a largely invisible epidemic in much of the country. It is a disease few people talk about, even those living with HIV (who are among those most at risk for TB).

Coordination and communication challenges

The country has a plan but only on paper. Without money nothing happens. Treatment access is almost exclusively based on funding from GFATM.

— Anonymous

Coordination of HIV-related care remains a major problem in the Dominican Republic. There have been numerous meetings and a wealth of resources spent on conferences and training sessions attended by providers, civil society, donor agencies, and public sector representatives. Yet many people consulted as part of this research were often unaware of what was being done by others. In general,

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numerous respondents said that UNAIDS maintained a very low profile and minimal role in the Dominican Republic related to treatment access, which is unfortunate considering the stated purpose of the organization.

Several other respondents said that the Pan American Health Organization (PAHO) played an important role in the CCM but had done almost nothing related to the “3 by 5” initiative to improve treatment access by the end of 2005. With several month delays in procurement, disbursement, and waiting lists for treatment and lab tests throughout much of 2005 (and previous years), “3 by 5” risks becoming a meaningless slogan in the Dominican Republic.

There also appears to be an overall lack of communication and struggle over power and resources between COPRESIDA and the Health Ministry, which depends on CORPESIDA for the purchase of medicines and other funds. As seen during the crises related to treatment interruptions, this can cause major tensions at all levels. Blame is passed from grassroots organizations and PLWHA to doctors and clinics to national administrators to politicians to agencies and governments abroad from Washington to Haiti to Geneva. Whoever is to blame, the end result is the same—too few of those who need ART actually receive it, and fingers are pointed back and forth while many people are left to die. While the actual figure is hard to determine with any precision, respondents in this survey estimated that only 5-15% of those needing ART in the country have access to it today.

The Dominican Republic is a small country with decent infrastructure and a lower HIV prevalence than many other countries discussed in this report. Universal access to ART is a real possibility in the country—if the government makes it a top priority. The delays in scaling up treatment over the past two years offer full proof that all involved in the HIV/AIDS response, notably the government and GFATM, need to find a better way to ensure that treatment access can be prioritized and rapidly improved.

What is needed now?

- Increased government investment in AIDS treatment
- The securing of a long-term funding commitment from GFATM
- Collaboration—not competition—among providers of services
- Improved access to CD4 testing across the country
- Lower prices for second-line treatments
- Greater protection for the human rights of people living with HIV/AIDS
- Strengthened public treatment sites
- Expanded community-based advocacy

Recommendations

- **Expand access to CD4 testing.** Affordable CD4 tests must be made available so that all who know they are HIV-positive can regularly be tested. It is possible that the national government lab where these tests will be performed will be functioning by the time this report is printed, but this facility is already several years late in opening. Many other countries in the region are able to perform low-cost CD4 tests for about \$5-\$10 per test; there is no reason why a similar solution cannot be found for the Dominican Republic. Without regular or affordable access to viral load tests or genotypic resistance testing, CD4 tests are one of the few scientific tools available to confirm that ARV medicines are working properly, and they are also important in accurately determining the best time to start ART.
- **Secure access to second-line therapies.** Second-line treatment regimens remain very expensive in the Dominican Republic, and their high prices threaten to drain resources from other important aspects of the National AIDS Programme and overall health system. This issue should be addressed as soon as possible because as more PLWHA remain on ART for longer periods of time, more will develop resistance and need access to affordable second-line medicines. Several pharmaceutical companies have offered significant price reductions for their ARV drugs in the Dominican Republic, and the Clinton Foundation has negotiated further reductions in the prices of generic equivalents. Now governments in the region—and the Dominican government in particular—must be pressed to purchase second-line medicines for those who need them and negotiate better prices for these medicines. Many fear that the recently signed Central American Free Trade Agreement (CAFTA) between the United States and six other countries, including the Dominican Republic, will undermine access to affordable second-line AIDS medicines because of U.S. insistence on safeguarding patents for originator-brand ARVs.
- **Commit government and GFATM resources for the long term.** Numerous respondents raised concerns about the sustainability of programmes funded by GFATM. This uncertainty is used by some administrators as a rationalization—and even directly referred to as such by some health workers—for not providing treatment to all those who need it now because of concerns that the government may not be able to afford to keep all people on treatment after GFATM aid dries up. Yet in the Dominican Republic as in many other countries, the availability of GFATM monies has provided an excuse for governments to not invest more of their own funds more quickly in ensuring treatment access for PLWHA. Neither the government nor GFATM should allow such an excuse to gain credence or influence policy in any form. The government must commit to expanding ART over the long term and allocate resources to achieve scale up for as long as necessary.

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- **Expanded and strengthened civil society advocacy.** Treatment advocacy groups are essential for a successful and sustained response to AIDS in the Dominican Republic. Some respondents observed that cooperation and collaboration among activists, community-based organizations, and advocacy groups have been damaged by competition for GFATM resources. The scramble for securing salaries, project support, travel, equipment, and other necessary items can become destructive and occasionally lead civil society actors to focus on obtaining resources instead of on appropriate service delivery. This is a worrying trend that has potentially negative implications for the future of the movement for universal treatment access. Treatment advocacy needs to continually be redefined based on changing circumstances and needs of PLWHA. Without strong and interlinked community-based advocacy and activism, there is the risk that very little will change for most HIV-positive people in the Dominican Republic and elsewhere.
- **Strengthen public treatment sites.** Vocal and sometimes heated debates have occurred among donors, the government, and the health sector about the most effective approach to expanding treatment access. One area of disagreement is where to dedicate funding: toward NGOs, religious organizations, or private clinics, or perhaps for broadening the public health sector in general? One key factor is that large differentials in salary, quality of care, and infrastructure exist among different treatment sites. Some see NGOs and private clinics as more efficient than public clinics because they often have nicer facilities, more flexibility in terms of hiring new staff, and greater capacity to absorb new funds.

However, it is important that the public sector be provided an appropriate share of resources as part of an overall effort to ensure consistent quality of care for the long run. There are significant challenges to raising the quality of public sector treatment facilities. For one thing, public clinics continue to shoulder the largest burden of treating poor PLWHA, a situation that places great strain on their capacity on a regular basis. Secondly, many charge that politics and patronage have strongly influenced hiring practices, the flow of resources, and selection of new treatment sites. Thirdly, treatment sites are not as widely distributed as they should be. There are now over a dozen different treatment sites in Santo Domingo, the capital, yet several other cities and regions still lacked any treatment sites at the time research for this report was conducted. Even those in Santo Domingo frequently operate in substandard conditions, lacking access to a logistics system and medical records archive that could improve coordination with other sites and central health authorities. In general, staff must be better trained, and resources must be found to cover the high costs of electricity, rent, furniture, computers, and other necessary materials.

There are a number of positive signs that the situation is beginning to change. It is important, however, that site expansion be designed with the goal of serving the most vulnerable and needy people instead of based on political patronage or influence.



*by Dr. Venkatesan Chakrapani, M.D.
Indian Network for People living
with HIV (INP+)*

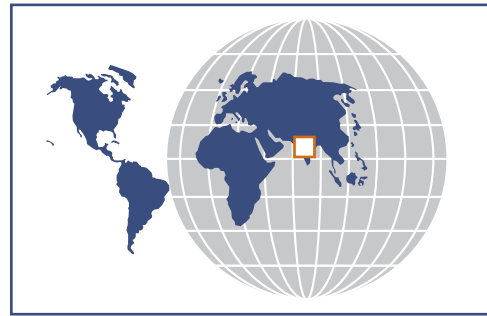
It is estimated that over five million Indians were living with HIV by the end of 2004. WHO estimated that at that time, 770,000 were in need of ART. Yet as of August 2005, only about 12,000 people were receiving ART through the government AIDS treatment programme.

Research methodology

The report for India was prepared by a research team consisting of K. K. Abraham, president of INP+; Dr. Venkatesan Chakrapani from INP+; Dr. Joe Thomas from FXB International; Murali Shunmugam of the Social Welfare Association for Men (SWAM) and Daisy David from INP+.

The following methods were used:

- In-depth interviews with six men and five women receiving ART from government treatment centres in different states
- Key informant interviews with community leaders: PLWHA network leaders (two people), an HIV-positive MSM, and an HIV-positive ex-IDU
- Key informant interviews with NGO staff (two people)
- E-mails sent to the National AIDS Control Organization (NACO) and India offices of WHO and UNAIDS



How the research was conducted

- 16 confidential interviews with PLWHA, NGO staff, and community leaders
- E-mail communication with NACO and UN agencies
- Three group discussions with INP+ workshop attendees
- Analysis of key documents and postings on e-forums
- Review of the draft report by Indian PLWHA activists

Major barriers to treatment delivery:

- Ever-shifting deadlines to achieve targets committed for ART delivery
- Lack of need-based target-setting by NACO
- Critical gaps in national treatment guidelines and inadequate enforcement of some guidelines
- Shortfalls in human resources and funding
- Inadequate response from national AIDS program on several key issues
- No plan to ensure second-line treatment regimens
- Need for many people to travel long distances for care
- Threats to continued and expanded manufacturing of generic drugs
- Lack of effective coordination between HIV and TB programs

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- Three group discussions with PLWHA who came from various states to attend a capacity-building workshop sponsored by the Indian Network for People living with HIV/AIDS (INP+), held from 28 September to 1 October 2005. These groups discussed three topics: ART access in “high prevalence states”; ART access in “low prevalence states” (NACO recently decided to change the term to “highly vulnerable and vulnerable states”); and treatment issues of HIV-positive IDUs
- Presentations made by PLWHA activists at the national meeting “ARV access in India: NACP-III and Beyond” in Delhi on 28-29 October 2005. (NACP-III refers to the National AIDS Control Program–Phase III, 2006-2011). The draft report of this study was circulated to the PLWHA activists who attended, and their suggestions were incorporated in the final version
- Analysis of resources including information on NACO’s website (www.nacoonline.org); approved funding proposals submitted by India to GFATM; presentations made by NACO on the NACP-III draft framework in various meetings; working group meeting reports of NACO’s NACP-III planning process; discussions in the e-consultation of NACO on NACP-III; and information on the National TB programme’s website (www.tbcindia.org)
- Analysis of relevant postings in AIDS-India e-forum

Major barriers

The research identified several major barriers to scaling up India’s national ART programme.

Ever-shifting deadlines to achieve targets committed for ART delivery

Targets are useful because they can set concrete goals and promote accountability. Unfortunately, the Indian government’s deadline for targets for ART delivery keeps slipping. In 2004, the government announced that it would provide free ART to 100,000 PLWHA by the end of 2005.¹ In an official release, the government stated the following objective (as cited by the Human Rights Law Network): “To place 100,000 AIDS cases on structured ART by the end of 2005 and be able to provide treatment to an additional 15%-20% of AIDS cases each year, thereafter, for a period of five years.”² However, the target date was then shifted to 2007, and recently once more, to 2008.³

It is important to note that many PLWHA in India have access to treatment outside of the national free ART program. For instance, some central government institutions, including Indian Railways and Uniformed services, have their own ART programs for employees. However, there is no systematic information regarding how many PLWHA are on ART through such programs, the corporate sector, or NGOs. In the latest version of the NACP-III strategic plan, NACO estimates that a total of nearly 40,000 PLWHA might be receiving ART in India through both the public and private sectors.

Lack of need-based target-setting by NACO

While WHO's "3 by 5" initiative states that at least 355,000 Indian PLWHA should be on ART by the end of 2005, NACO repeatedly noted in several forums that 180,000 PLWHA would receive ART by the end of 2010. This is actually the target mentioned in the successful Round 4 proposal submitted to GFATM by NACO. The numbers lead one to wonder whether NACO is depending only on GFATM for its national ART programme without trying to mobilize more resources. In its latest draft of NACP-III plan, NACO mentions that the number of PLWHA to be provided with free ART by 2011 is "200,000, 40% of the total number who need ART." During a national meeting of Indian PLWHA activists on 28-29 October 2005, NACO's director general, Dr. SY Quraishi, expressed his support for universal access to ART in India; this, however, needs to be stated explicitly in the final NACP-III strategic plan.

Lack of enforcement of national ART programme implementation guidelines

Among other eligibility criteria, NACO's guidelines state that persons with an AIDS-defining illness should be started on ART. Yet in actual practice, in most of the ART centres, emphasis is placed on a patient's CD4 count regardless of the presence or absence of symptoms. Only persons whose CD4 count is less than 200 are started on ART even if they have had an AIDS-defining illness.

Critical gaps in the national ARV program implementation guidelines

NACO needs to develop a concrete plan for providing ARVs to all those who need treatment. We should no longer give excuses that we [India] have limited resources. Develop a roadmap for universal access to ARVs in India; get support of various partners; and mobilize necessary resources.

— K. K. Abraham, president, Indian Network for People living with HIV/AIDS

Numerous gaps and inconsistencies exist in the implementation guidelines for the country's national ART program. First, people who have already started on ART through corporate hospitals but whose current CD4 count is more than 200 are not enrolled in the national ART programme. As some Ugandan doctors have pointed out, this "restricted access strategy" may prevent some patients from revealing that they are already on ART if they know that only the treatment-naïve will qualify.⁴ It could also result in the selection of drugs that will increase resistance. At the PLWHA activists' meeting on 29 October 2005 (see above), NACO argued that enrolling persons who are currently on ART using their own money in the national programme would decrease ART access by PLWHA who are living below poverty line. However, it was clearly pointed out by activists that if these persons are not enrolled in the national programme, then they would soon be living below the poverty line if they continue to pay for ART using their own money.

Second, policy guidelines do not address situations in which it may not be appropriate for PLWHA to receive all three medicines in the standard first-line regimens. For example, if a person is taking two first-line drugs along with a protease inhibitor through a private clinic, he/she cannot get the first-line drugs alone from a government centre—even if that person says he/she will be buying the protease inhibitor from private pharmacy.

Third, there is no uniformity with regard to refilling prescriptions. Though many centres refill ARVs on a monthly basis, some provide ARVs for only one week, thus forcing PLWHA to undertake complicated and time-consuming travel every week to receive their medications. Fourth, there are no clear guidelines on providing ART to HIV-positive IDUs who are co-infected with hepatitis B and/or hepatitis C viruses; as it stands now, most ARVs available through government programmes are contraindicated in patients with active hepatitis or will produce liver problems in co-infected patients. Though lamivudine-containing regimens may control hepatitis B infection, there is no treatment given for active hepatitis C infection. (Patients co-infected with hepatitis-C virus need to spend a significant amount of their own money on interferon injections since they are not available in government centres.) Also, buprenorphine is not mentioned as a possible substitution treatment in NACO's ART guidelines; furthermore, although the guidelines specifically refer to methadone as a potentially effective and useful substitution treatment, the medicine is not available.

Many of us [HIV-positive IDUs] also have hepatitis C or hepatitis B. We may have liver problems but sometimes doctors [in government ART centers] start us on nevirapine-containing regimens... We also need to buy interferon [for hepatitis C] outside since it is not available in the government hospitals—and it costs a lot of money.
— Ratan Singh, Manipur Network of People living with HIV

Finally, national ART guidelines do not address how to ensure equity in ART access. This means that the following are unlikely to have equal access to potentially lifesaving treatment: the poor, people in rural areas, prisoners, and members of marginalized groups such as sex workers, MSM, hijras (transgender women), and IDUs.

MSM who are very feminine face discrimination in the government centers and thus many do not want to go to visit them. In addition, many MSM are reluctant to seek ART access because they are afraid that other MSM will find it out.
— Vijay Nair, community leader in Maharashtra

Lack of availability of second-line regimens in the government ART programme

No significant steps—including negotiating with Indian pharmaceutical manufacturers to bring down the prices of second-line ARVs—have been taken by NACO to ensure second-line regimens are available for those PLWHA who are now taking first-line regimens. A new study has shown that as many as 20% of ART-naive PLWHA may be resistant to first-line ARVs in southern India.⁵ This means there is an urgent need to plan for and keep stock of second-line ARVs in national ART centres.

There is yet another reason why second- and third-line ARVs such as efavirenz and protease inhibitors should be widely available: several studies have shown relatively high prevalence of HIV-1 and HIV-2 coinfection -- as high as 33% in some states in India.⁶ NACO guidelines state that for “HIV-2 infections, only the triple NsRTI and PI-based regimens should be used because of inherent resistance of these viruses to NNRTI compounds.” However, in almost none of the government ART centres are efforts made to identify the type of HIV infection before beginning ART. Therefore, HIV-2 infected persons on ART through the government ART programme are not specifically identified and are essentially on dual-drug therapy (since nevirapine does not work against HIV-2).

Non-availability of paediatric formulations in the government ARV programme

Neither paediatric ART formulations nor paediatric dosage tablets are available at government ART centres. Children therefore must take split-up adult tablets or powdered adult tablets, which often results in under- or over-dosage.

Waiting lists in many ART centres may reflect staff shortage and lack of adequate stock of ARVs

The state government of Kerala has started its own ARV programs without waiting for NACO to provide ARVs in their states. Why then can't other state governments start similar programs in their states or provide support to the central government sponsored national ARV rollout programs in their states? NACO needs to initiate dialogues with the state governments about this.

— Aasha Elango, national advocacy officer, Indian Network for People living with HIV/AIDS (INP+)

Many treatment centres have long waiting lists of individuals who wish to initiate ART. Often this results from an inadequate number of doctors. For example, at the Government Hospital of Thoracic Medicine, only three doctors are available to see an average of 800 outpatients daily, of whom about 350 are PLWHA. Sometimes waiting lists grow because of inadequate stock of ARVs. In mid-2005, there was an ARV stock crisis in Manipur that interrupted the enrollment of PLWHA. Consequently

the number of PLWHA in the waiting list of JN Hospital (an ART centre) rose to some 600 patients at the end of July 2005.⁷

Practical challenges faced by PLWHA

People living with HIV in India should be able to get ARVs wherever they live. NACO should not discriminate against PLWHA living in certain states of India by establishing ARV centers only in “high [HIV] prevalence states” Is it my fault if I happen to live in a “low prevalence state”?

— Daxa Patel, Gujarat State Network of People living with HIV/AIDS (GSNP+)

NACO and all providers also need to address the practical issues faced by PLWHA. First-line drugs are now provided primarily through hospitals attached to medical colleges; many people thus must travel long distances to get ART. People who are traveling from one state to another often have difficulty getting ART because proof of local residence is required by many national ART rollout centres. Many centres close at 2 p.m., forcing PLWHA coming from other districts to stay overnight. At many treatment centres, CD4 testing is only done on certain days.

No treatment education materials are available for PLWHA and there are no government programmes that explicitly focus on treatment education. Though national ART guidelines mention treatment adherence, they are silent on how patients should be educated about ART and helped to make informed decisions about their treatment options. In India, it is primarily the INP+-affiliated networks that are providing treatment education programmes, often establishing treatment counseling centres on the campuses of ART centres in high prevalence states. So far, neither NACO nor the State AIDS Control Societies (SACS) has produced treatment educational materials for PLWHA.

Patient interaction with doctors and counselors is usually very limited because there are a large number of patients and limited human resources. This situation limits the ability of health professionals to fully discuss treatment adherence.

One of the eligibility criteria for enrolling PLWHA into the national ART programme is that the “patient understands the implications of the ARV therapy.” This requirement could be used by some physicians to withhold medicines from otherwise clinically eligible patients (particularly PLWHA who are IDUs). One of the interview participants mentioned that a patient was denied ART because the doctor thought he would become sexually active if he started feeling healthier. Another interviewee said that there seemed to be some hesitancy in prescribing ART to PLWHA who are middle-aged or older. He reported an incident in which a doctor asked, “Why do you need this [ART] at this age?” Though this patient finally received treatment, the incident clearly shows the doctor’s insensitivity and also the humiliation that some people living with HIV continue to face.

Active referrals to PLWHA networks at the district and state level should be done in all ART centres. In the GFATM-supported project, INP+-affiliated networks are supposed to develop linkages with government ART centres to provide treatment adherence support to PLWHA. However, there are significant bureaucratic obstacles in getting approval from government hospitals to allow network personnel to contact PLWHA receiving ART through public centres. For example, the PLWHA network is required to get permission to undertake this activity from the dean of the government hospital, a project director from the State AIDS Control Society (a government body), and government officials in the state department of medical services. In addition, some government health care providers are reluctant to refer their patients to the networks under the pretext of preserving patient confidentiality.

Threats to access to generic drugs

For decades, India has been a leading producer and exporter of generic medicines because the government excluded medicines from patent protection. However, World Trade Organization (WTO) rules required India to grant patents and other forms of intellectual property rights on medicines as of 1 January 2005. WTO-mandated 20-year patent terms will prevent Indian generic companies from making cheaper generic versions of second generation and second-line ARVs not only for local consumption, but also for export to developing countries that depend on Indian generic industry. The price cuts resulting from generic competition of pre-January 2005 medicines will be impossible to duplicate without changes to Indian law. Public health and HIV organizations are pressing the government to make production of generic versions of medicines without the consent of the patent holder streamlined and straightforward.

In addition, the government is now considering amending the provisions of the Drugs and Cosmetics Act to provide protection of test data submitted to the Drug Controller of India for marketing approval in the form of an exclusive marketing right. Public interest groups are concerned that amendments to the Drugs and Cosmetics Act will include "data exclusivity" measures that will impact access to generic drugs as they are designed to limit generic competition and the ability of the government to make use of safeguards in their patent laws to protect public health. Data exclusivity is not required by the WTO, but lobbies representing the originator companies, as well as the U.S. government, are lobbying the Indian government to accept it.

TB and HIV

In India, the Revised National Tuberculosis Control Programme (RNTCP) and NACO come under the Ministry of Health and Family Welfare. Even in the wake of the successful Round 3 GFATM proposal to address HIV and TB co-infection (with a total five-year funding request of \$14.8 million and a two-year approved grant funding

of \$2.6 million), there are still many unmet needs and gaps in the coordination of the national TB and HIV programmes. The gaps are summarized below:

- **No effective implementation of the 'Joint Action Plan' of NACO and RNTCP.** The RNTCP's TB status report (2004) mentions coordination between NACP and RNTCP. Similarly, NACO's annual report (2002-04) mentions a "joint action plan" between NACP and RNTCP, including joint training activities. However, there is no widely available public document that outlines a joint TB/HIV plan. It appears that the coordinated activities outlined in NACO and RNTCP plans are not being scaled up even though funds were made available for this purpose.
- **No meaningful involvement of PLWHA in TB/HIV coordination activities.** RNTCP's TB status report (2004) mentions the presence of TB/HIV coordination activities in 14 states. While the exact level of coordination between the TB and HIV programmes in these states is not clear, PLWHA do not appear to be involved in the TB/HIV coordination activities in a majority (if not all) of these states.
- **Lack of articulation of internationally recommended TB/HIV collaborative policy and programme guidelines.** The National TB Control Policy (from RNTCP) and the National HIV/AIDS Policy (from NACO) do include references to TB/HIV programme coordination, but there remain many important gaps in these policies. Some of the major policies that are not articulated and have a great impact on the lives of PLWHA co-infected with TB include: 1) no strong recommendation with regard to the WHO-recommended isoniazid preventive therapy for PLWHA with latent TB infection; 2) no articulation with regard to the WHO-recommended cotrimoxazole preventive therapy for TB-infected PLWHA; and 3) no articulation with regard to how a TB-infected PLWHA will be connected to the NACO's national ART roll-out programme.
- **No joint plans with regard to achieving the global targets for TB control.** NACO and RNTCP do not specifically mention action steps in their individual or joint plans with regard to how their programmes will achieve the following global targets: G8 Okinawa 2010 targets ("to reduce TB deaths and prevalence of the disease by 50% by 2010") and the Millennium Development Goals ("to have halted by 2015, and begun to reverse, the incidence of priority communicable diseases, including TB").

Major players in AIDS treatment in India

UNAIDS and WHO are providing technical assistance to NACO in various areas of treatment scale up. An "ARV consultant" has been appointed by WHO to assist NACO in its ART programme. WHO and UNAIDS offices in India also provide technical assistance to NACO; this includes, among other things, assistance in

drafting and finalizing the NACO ART guidelines and policy. It is not clear how the technical assistance tasks are divided between the UNAIDS secretariat office in Delhi and WHO's Delhi office. Since NACO does not seem to take seriously the "3 by 5" targets articulated for India by WHO and has instead set its own targets (which are grossly inadequate), it seems that the level of coordination between WHO/UNAIDS and NACO in relation to ART scale up is quite limited.

GFATM and Country Coordinating Mechanism (CCM). India has received GFATM grants in Rounds 1 through 4 for HIV/AIDS, TB and Malaria. Except for one NGO principal recipient in Round 4, the Indian government itself has been the principal recipient of all GFATM grants. So far, India has been promised a total of \$389 million for the lifetime of all its GFATM grants. However, our information is that of the \$107 million approved for Phase 1 grants (initial two years of each agreement), only \$23.8 million has been disbursed. For HIV/AIDS, a funding request of \$241 million over five years has been accepted by the GFATM, with \$48 million approved for Phase 1. Funds disbursed to date for HIV/AIDS total just \$12.5 million.⁸

GFATM approved a proposal for \$100 million over five years and granted \$26.1 million over two years in Round 2 with a focus on preventing mother-to-child transmission, implementing a comprehensive care package for mothers living with HIV/AIDS and their infants and partners, and enhancing access to antiretroviral therapy through public-private partnerships. About 4,500 women (and their partners and children) will be receiving ART through this grant support.⁹

India also submitted a successful Round 4 proposal to GFATM for \$140.8 million over five years. The proposal, with \$21 million granted for two years, focuses on launching a large-scale, phased initiative on ART access closely linked to expanded prevention and support as well as increasing the engagement of the private sector and civil society, including PLWHA.¹⁰ About \$4.3 million has been disbursed so far.¹¹

The objective of the GFATM Round 4 proposal is to provide 180,000 people with ART in the public sector by 2010. There were two principal recipients in the GFATM Round 4 agreement: the Indian government and Population Foundation of India (PFI), the leading agency in the NGO consortium.¹²

Initially there was considerable delay in approving money from GFATM to be used for these programmes because of stalling by the government's Department of Economic Affairs. During that period, INP+ wrote to the health minister, asking him to speed up the process (a reasonable request since the minister once mentioned, "I would like all the bureaucratic red tape to be cut and converted into red ribbon").¹³ The vice chairman of the Indian CCM is K.K. Abraham, president of INP+. Many reforms are being considered for the CCM, including the establishment of a CCM Secretariat in Delhi.

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USAID/PEPFAR: India has been chosen as the one of the countries to be provided funds through the PEPFAR program. It is not clear how much money will be allocated for India through PEPFAR.

The government of India as well as NGOs are very concerned about the policies of USAID/PEPFAR in relation to HIV prevention and care programmes for marginalized populations like sex workers. Recently, Sangram, an NGO working with the female sex workers, decided not to accept USAID money because it refused to comply with the conditions imposed by the U.S. government's Leadership Against Global HIV/AIDS Act of 2003. Sangram explicitly stated that it "oppose[d] the conditions and moral strings that the U.S. conservatives attach to foreign funding."¹⁴

Earlier this year, even the Brazilian government refused a grant of \$40 million from the United States. Pedro Chequer, director of Brazil's AIDS programme and chair of the national commission that decided to refuse the grants, viewed the Bush administration policy as "interference that harms the Brazilian policy regarding diversity, ethical principles and human rights."¹⁵ It would not be surprising if the Indian government also refuses to accept the U.S. government's money since the NACP-III draft strategic plan explicitly articulates a "rights based approach" and states: "HRGs [high risk groups] continue to face legal and structural impediments to adopting safe behaviors such as criminalization and violence. Unless these constraints are removed at local, state and national levels they will find it difficult to adopt and sustain safe behaviors."

The Clinton Foundation HIV/AIDS Initiative signed an agreement with NACO in September 2004 to support scaling up of care and support programs of government of India. The Foundation will assist the government through training of medical professionals and upgrading laboratories administered by the ART program.¹⁶

The Bill & Melinda Gates Foundation's India AIDS initiative ("Avahan") focuses primarily on prevention among vulnerable groups (notably mobile populations and sex workers) and not on ART delivery or care. Some PLWHA networks are supported through Avahan projects.

The **expanded UN Theme group** in India usually invites all the major partners for its meetings, including USAID, the UK Department for International Development (DFID), and the Bill & Melinda Gates Foundation. This forum should be utilized for joint planning to scale-up ART in the National AIDS Control Programme's new strategy (NACP-III) and beyond.

WHO estimates that between \$290 million and \$307 million is required to support scale up of ART delivery to reach the WHO "3 by 5" treatment target of 355,000 people on treatment in India by the end of 2005. The Indian government had committed \$85 million (including funds from a repayable World Bank loan) to scaling up ART during 2004–2005; taking this and other funds committed to date

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into account, WHO estimated that India would face a funding gap of between \$178 million and \$196 million to reach the “3 by 5” target.

Five million dollars is the total amount allocated by the Indian government for the 2005-2006 fiscal year for ART provision and service expansion. The World Bank has provided a loan of \$57 million to the government for further ARV scale up and expansion. DFID is the largest bilateral donor agency in India and provided \$44 million to National AIDS Control Program in the current fiscal year (2005-2006). USAID provided additional funds of \$7.95 million this year. USAID supports two umbrella agencies (Nodal NGOs): AIDS Prevention and Control Project (APAC), Tamil Nadu; and AVERT, Maharashtra.¹⁷ (GFATM-allocated funds for ART initiatives amount to \$12.1 million during the current fiscal year.)

What is needed now

- Direct public ART centres to enroll PLWHA even if they satisfy only one of the eligibility criteria
- Be flexible in eligibility criteria with regard to PLWHA who are already on first-line ART using their own money
- Develop a plan to provide second-line regimens
- Provide paediatric formulations for ART
- Develop a policy to ensure equity in ART access
- Develop a plan for universal access to ART across the country
- Multilateral and bilateral agencies and donors should provide increased support and technical assistance for treatment delivery.
- Linkages to care, support and treatment programs should become an essential component of all prevention programs, including those supported NACO and outside agencies and donors.

Recommendations to NACO

1. NACO must direct all public ART centres to enroll PLWHA even if they satisfy only one of the various eligibility criteria (rather than solely depending on the criterion of CD4 count less than 200). This is necessary because even those PLWHA who have had or who currently have an AIDS-defining illness are not enrolled in the programme if their CD4 count is more than 200 (irrespective of whether they are currently on ART). NACO should strongly advise public ART centres to follow NACO's implementation guidelines in relation to the enrollment criteria. An order should be issued to the ART centres by the end of January 2006.

2. NACO needs to be flexible in its eligibility criteria with regard to PLWHA who are already on first-line ART on their own money. Since PLWHA who are personally paying for first-line ART often have CD4 counts higher than 200, they are not eligible to be enrolled in the government programme. Many of these PLWHA may not be able to continue to afford even first-line ART out of their own pocket, however. It is therefore important that the eligibility criteria for this subpopulation of PLWHA be flexible, allowing them to access ART at government centres even if their CD4 counts are above 200.

3. NACO must develop a plan and mobilize resources for providing second-line regimens in addition to uninterrupted supply of first-line regimens. Because of viral resistance and side effects, many PLWHA who are currently on first-line regimens may eventually need second-line ones. Also, those PLWHA who are currently on second-line ART regimens (using their own money) may not be able to continue to afford paying for these drugs. It is crucial that a plan to provide second-line ART in public health centres be developed at least by the end of February 2006 and that second-line regimens be made available by April 2006. NACO can consider the formation of a dedicated "treatment fund" to pool resources from the Indian government and various donors towards ensuring an uninterrupted supply of first-line ARVs and purchasing second-line ARVs.

4. NACO must place high priority on providing paediatric ARV formulations in national ART centres. Currently, children living with HIV who need ART are given adult tablets that are split or powdered; this can result in over- or under-dosage. NACO must develop mechanisms to supply paediatric formulations of ARVs in public ART centres. The agency should issue a plan to achieve this goal by February 2006, and the paediatric formulation should be made available at the centres by April 2006.

5. NACO should develop a policy to ensure equity in ART access. This will require reaching out to marginalized populations who have difficulty accessing government ART services. At present, more men than women are enrolled in the government ART programme—according to NACO, at the end of August 2005,

some 7,660 men and 3,790 women were on ART through public centres. Also, only 523 children were receiving ARVs at the end of August 2005, even though the estimated number of children living with HIV in India is 150,000 to 200,000. Marginalized populations including sex workers, MSM, hijras (transgender women), and IDUs often have difficulty accessing government ART services. As one doctor at an ART centre noted, “We are seeing only the clients of [female] sex workers in ARV centres. Where are the sex workers?” NACO must make a greater effort to achieve equity in terms of gender, urban-rural residential status, and access to ART for marginalized populations. A plan for ensuring and monitoring equity should be available by February 2006.

6. NACO must develop a plan for universal access to ART in India, in collaboration with multilateral agencies including UNAIDS, WHO and development partners. The NACP-III draft strategic plan mentions that approximately 200,000 PLWHA will be provided with ART through the public sector by 2011. This target is far too low given the size and scope of the epidemic and the number of those likely to need treatment over the next six years. In collaboration with multilateral/bilateral agencies and PLWHA networks, NACO needs to develop a plan for universal access to ART by July 2006.

Recommendations to the multilateral/bilateral agencies and other major funders

- UNAIDS and WHO should provide technical assistance to prepare a plan for universal access to ART in India by July 2006.
- Bilateral agencies should allocate specific funds to support ART delivery in India in their developmental aid budgets.
- Major funders should donate money for ART delivery (in government or nongovernmental programs) in addition to supporting prevention programmes in India.
- Referrals to and strong linkages with existing care, support and treatment programs should become an essential component of all prevention intervention programs, including those supported by NACO, the Gates Foundation, DFID, USAID, AusAID and others.

ENDNOTES

- ¹ WHO. Country profile fact sheet. June 2005
- ² <http://health.groups.yahoo.com/group/AIDS-INDIA/message/3162>
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- ⁴ Colebunders R et al. "Free antiretrovirals must not be restricted only to treatment-naïve patients." *PloS Medicine* 2 (10): e276, 2005.
- ⁵ <http://www.pharmabiz.com/article/detnews.asp?articleid=29346>
- ⁶ Kulshreshtha R, et al. "HIV-2 prevalence in Uttar Pradesh." *Indian J Med Res.* 1996 Mar;103:131-3; Rubsamen-Waigmann H, et al. "High proportion of HIV-2 and HIV-1/2 double-reactive sera in two Indian states, Maharashtra and Goa: first appearance of an HIV-2 epidemic along with an HIV-1 epidemic outside of Africa." *Zentralbl Bakteriol.* 1994 Jan;280(3):398-402.
- ⁷ Information directly collected from the JN Hospital by Ratan Singh, Manipur Network of People living with HIV (MNP+)
- ⁸ From the presentation of Anandi Yuvaraj, board member of GFATM, in the national meeting, "Access to ARVs in India: NACP-III and Beyond." Oct. 28, 2005, Delhi, India.
- ⁹ Summary of the proposal submitted by India to round 4 GFATM grant.
- ¹⁰ WHO, Country Profile Fact Sheet. June 2005
- ¹¹ <http://www.theglobalfund.org/search/portfolio.aspx?countryID=IDA> - Accessed on Nov 15, 2005
- ¹² In an application to Round 4 of the Global Fund, a group of NGOs including INP+ formed a consortium and submitted a joint proposal to the Fund with PFI as the lead agency.
- ¹³ NACO newsletter, Vol-1, Jan 2005
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- ¹⁵ Phillips, M., et al. "Brazil Refuses U.S. AIDS Funds Due to Antiprostitution Pledge." *The Wall Street Journal*, May 2, 2005.
- ¹⁶ NACO Newsletter. March 2005. Vol-3. P-2. Available online at www.nacoonline.org
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By Elizabeth Owiti,
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In the world out there people will not be very kind to you once they find out that you're HIV-positive.

— Kenyan living with HIV

The Kenyan government declared HIV/AIDS a national disaster and a public health emergency in 1999. Five years later, in 2004, it instituted guidelines for HIV testing in clinical sites. Today, between 820,000 and 1.7 million people are thought to be living with HIV/AIDS in Kenya, and at least 180,000 die from HIV/AIDS each year. There are more than 1.2 million children under 15 who have been orphaned because of the AIDS-related death of parents.

Approximately 220,000 Kenyans need ART as of 2005, and the WHO "3 by 5" target was 110,000 people (based on 50% of need). The country's own national treatment target for 2005 is to reach 95,000 people. In 2003, the government provided ART to an estimated 1,000 people, and an additional 10,000 individuals received treatment from other sources. Disbursements from a Round 2 GFATM grant are expected to enable treatment of 4,000 more people over two years and will fund the training of 1,800 health workers. PEPFAR has said it plans to provide 45,000 Kenyans with ART treatment by the end of 2005. Other sources may support treatment of an additional 7,000 people.¹

¹ Based on WHO and Global Fund documents.



How the research was conducted

- 113 confidential survey forms filled in by PLWHA and their direct service providers in several regions
- Review of key documents, including GFATM proposals and reports as well as PEPFAR and WHO documents

Major barriers to treatment delivery:

- Stigma and discrimination
- Inadequate treatment literacy programs
- Food and nutritional issues
- High poverty levels
- Delays in releasing funds
- Poor infrastructure

Research methodology

The Kenya report emphasizes the collection of information and opinion from a relatively large number of PLWHA and people who interact with them directly, including their doctors, nurses, and community group leaders.

Three researchers were identified, recruited, and trained as to the objectives of the study and the data collection tools. Training lasted one day and principally consisted of discussion of the survey tools and adjustments to the instrument where needed. The data was collected using structured questionnaires, which were filled out by each survey participant. Several literature sources were also reviewed during the study.

Over 100 people were interviewed. These included PLWHA (78 individuals), health care workers (23), and staff from the National AIDS Programme team, PEPFAR, faith-based organizations, community-based organizations and other institutions involved in treatment scale up (14). There were three researchers and three research assistants on the Kenyan country team. The survey was carried out among more than 20 organizations.

It is important to note that some individuals in key government agencies declined requests to participate in the survey. Although it was not possible to collect information from them and from some other relevant sources, the size and scope of the research offer a unique perspective on the barriers to treatment access. Moreover, the recommendations are derived in large part from comments and insight from individuals directly involved in service delivery: PLWHA and front-line health care workers. This is in sharp contrast to the fact that even some supposedly qualified doctors were not well versed in HIV/AIDS care and treatment, ART issues, and the barriers to treatment scale up.

Key barriers

Stigma and discrimination

Research indicated that stigma and discrimination are the most significant barriers to treatment scale-up. Even when ART is available and financially viable, the social barriers remain strong.

Patriarchal cultures in almost all communities have caused gender inequalities. In one community, women needed permission from their husbands to enroll in an ART programme. Neglect, abandonment and, in one of the communities, “mercy” killing are persistent practices.

Myths and misconceptions are significant barriers to HIV treatment. In some areas HIV infection is still seen as a curse, which therefore means there is no need for

medical intervention. No cure exists, hence there is no need to take medication; death is inevitable.

Some religious groups encourage faith healing in place of conventional medical intervention. Although some traditional healers have played an important role in helping PLWHA get access to ART, many others have discouraged HIV-positive people from seeking proper, acceptable and well-researched modes of therapy. Nomadic life causes difficulty in initiating and following up with treatment. Few if any programmes focus on the needs of the large number of refugees and internally displaced people in Kenya. There are no fora to address the specific treatment needs of women.

The study found that many of the PLWHA surveyed had resisted seeking HIV/AIDS care and treatment because of fear of how their own immediate family members would react if they discovered their HIV-positive status. Some respondents also expressed concern about how they would be treated by care providers themselves once their HIV status was revealed. HIV-related discrimination is common in the workplace, with PLWHA at high risk of being fired if their status is known to an employer. Factors such as this mean that many PLWHA do not seek out care even when they really need it.

Among the specific instances of discrimination against PLWHA described in the research were the following:

- Some treatment sites have rooms specifically named “HIV clinic”, which dissuade some people from seeking assistance because they fear being identified.
- Medical records such as enrollment cards have different colors for PLWHA, making them distinct from others.
- HIV-positive in-patients do not get the same quality of care that is given to others. This is common in government-run hospitals.
- Those with advanced AIDS are often neglected and/or abandoned in hospitals and left to die.

The following comments from survey respondents provide examples of how extensive discrimination and fear regarding HIV/AIDS are in Kenya.

I disclosed my HIV status to some health workers at a dispensary. They refused to treat me, and referred me to Kenyatta National Hospital instead.

— Kenyan living with HIV

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The discrimination I experienced from the nurses was serious. Once I revealed I was HIV-positive, no one wanted to assist me at delivery.

— Kenyan living with HIV

In the world out there people will not be very kind to you once they find out that you're HIV-positive. Even though the disease has been around for a long time and awareness is greater, people are still scared to seek treatment or even testing when they suspect they are infected.

— Kenyan living with HIV

The stigma associated with ART drugs and HIV/AIDS is another big barrier, as people would rather not be seen with the drugs.

— An ART co-coordinator at a district hospital

Young girls like me have not accessed treatment because we are afraid of what people like nurses will say, and we are even scared of being recognized as HIV positive.

— Young Kenyan living with HIV

Inadequate treatment literacy programming and resources

There are no comprehensive treatment literacy programmes in place at most of the sites visited. ART awareness campaigns are often passive, uncoordinated, inappropriate, irregular, and ineffective—and appear to have little effect on eliminating misinformation among both HIV-positive and negative people about the disease and ART. Consequently, many PLWHA are not visiting health care centres or following recommended ART regimens. Since many PLWHA do not know about or understand when they should seek care or why, they often wait until they are too sick for treatment to help.

Many PLWHAs surveyed also pointed to a lack of comprehensive literacy programmes in most care and support centres they visit. They added that where there is information, it is incomplete or confusing and may not even be available in local languages.

These issues are highlighted in the following comment from a survey respondent:

Most people here are still ignorant about treatment. They do not understand the advantages and benefits of treatment.

— An ART treatment co-coordinator at a district hospital

Food and nutritional issues

Many PLWHA are unable to afford enough food, let alone a balanced diet. Some respondents expressed concern that without good nutrition ART could not be effective since some PLWHA were already very weak—and that this was not due to their HIV status but to lack of adequate food.

Without proper nutrition, it's pointless to take drugs as they are absorbed into the blood stream faster and hence their action is short lived as compared to when you eat and absorption is systematic and very little drug goes to waste through excretion. Food will also build the body and make one stronger, without which drugs may overpower the PLWHA.

— Kenyan nurse

Truly speaking, the food you eat will have a direct effect on your progress.

— Kenyan living with HIV

High poverty levels

Poverty was also highlighted as a major barrier to treatment scale up. Some of the respondents indicated that they were unable to afford some or all of the following: transport to health care centres; payment for even the most basic tests that were necessary before treatment could begin; nutritious food for themselves and family members; or medications for opportunistic infections even when ART was provided for free.

These issues are highlighted in the following comments from survey respondents:

Poor people do not have the money to be able to access health care, even those provided free of charge such as VCT.

— Nurse

Sometimes I do not have bus fare to come here for my drugs so I miss out while others get them.

— Kenyan living with HIV

People in rural areas and even here in Nairobi are finding it very costly and tiring to go to concentrated health centres for services even though they are free. Sometimes one is too sick to go to the hospitals, which are often too far away. There is no energy to walk those long distances.

— Kenyan living with HIV

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Delays in releasing funds

Many respondents identified bureaucratic delays in releasing GFATM money and other promised aid as a major barrier to scale-up. The GFATM process on its own seems unnecessarily cumbersome. The Ministry of Finance is the principal recipient of the lion's share of GFATM assistance in Kenya, and from there the funds must be transferred to the Ministry of Health. We have been told that from there, funds are supposed to flow to the National AIDS Control Council (NACC) for disbursement to NGOs and health care facilities that actually provide treatment and service.

Poor infrastructure

Many health centres are not well equipped for treatment scale up. The number of centres devoted specifically to HIV/AIDS treatment has increased as PEPFAR and other programmes have scaled up their efforts, but many PLWHA are still far away from the nearest ART centre and thus have problems accessing care. Recent figures on the type and number of facilities providing ART in Kenya are noted below:

Type of facility	No. of Sites
Public hospitals	94
Mission hospitals	61
Private hospitals	10
NGOs	5
Research institutions	24
Total	194

In general, the health sector does not have sufficient experience or capacity to handle rapid ART scale up. Nearly all partners are earmarking money and other resources toward capacity building and training to address this situation. These shortfalls persist even though Kenya has a large number of trained health care workers currently unemployed because the government cannot afford to pay them.

Accountability: the major players

It is important to note that most of the PLWHA interviewed did not understand the role of most multilateral or bilateral organizations involved in Kenya's HIV/AIDS response. A significant number did not even know that such institutions exist.

GFATM

The Kenya GFATM programme aims to greatly expand voluntary counseling and testing (VCT) so that it is available to one million Kenyans within five years. GFATM

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monies will also be used to provide care services, including ART. Furthermore, the grant includes funds to build institutional capacity in government and civil society structures.

Many respondents agreed that GFATM assistance has been quite successful to date in two notable areas: funding key CBOs and NGOs, and coordinating activities with those of the government's National AIDS Strategic Plan.

GFATM administrators need to find a way to improve monitoring and evaluation of activities to ensure proper programme implementation. They should also increase the rate at which funds are disbursed so that implementation delays are reduced. GFATM should also mobilize more funds to increase treatment scale up in especially resource-constrained settings.

UNAIDS

Most respondents were not aware of the roles and responsibilities of UNAIDS in Kenya. Those who were aware said they see it as a provider of up-to-date information and evidence-based documentation on HIV/AIDS.

World Health Organization

If WHO is known at all (and it was not by most respondents), it is recognized as the world health governing body with a mandate to respond to diseases at a global level. Respondents said that more attention should be given to Africa, the continent hardest hit by the HIV/AIDS pandemic.

WHO needs to interact more closely with individuals (such as PLWHA) and organizations (such as advocacy groups and NGOs) involved in responding to HIV/AIDS outside of government structures such as the Ministry of Health. One respondent, a doctor, said that WHO should offer revised guidelines for rural versus urban situations.

PEPFAR

Only respondents working in PEPFAR-sponsored facilities seemed to know about PEPFAR. To them, its main role appeared to be to provide funds for prevention as well as care, treatment and support of PLWHA.

PEPFAR funds entities at the local level directly and has helped put many Kenyans on ART. The few respondents who know and work with PEPFAR said they found it more effective than the government in getting funds to treatment providers and ART to PLWHA. A few said that PEPFAR needs to link up with other bodies, but they were not specific in how this might work.

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National AIDS Control Council (NACC)

NACC, the main government agency focusing on HIV/AIDS, coordinates all HIV-related activities in Kenya, including provision of HIV/AIDS treatment guidelines. It also funds treatment, care and support programmes through grants to NGOs, FBOs, and CBOs working in HIV/AIDS field. Concerns about corruption have been raised in the past, but the agency now seems to be addressing them. Respondents' main concern was the length of time it takes funds to flow from other layers of the government to NACC for disbursement to those providing direct services.

What is needed now?

- Address stigma and discrimination issues through anti-stigma programmes and other efforts
- Launch major treatment literacy campaign
- Coordinate with the World Food Programme and other organizations to address food and nutritional issues
- Provide free drugs and stipends for transportation for PLWHA
- Cut down delays in releasing funds
- Work with donors to hire and train more health care workers

Recommendations

Systematically address stigma and discrimination issues

- Establish national policies on discrimination
- Develop specifically targeted social marketing campaigns to combat discrimination
- Establish more fora and programmes to address cultural issues of discrimination against women
- Establish a commission to identify and remove obstacles refugees face in access to ART

Launch a major treatment literacy campaign

- Set up fully funded comprehensive literacy programmes
- Ensure the comprehensive involvement of PLWHA in literacy programmes, formulation of information, education, and communication (IEC) strategies, and aggressive awareness campaigns
- Translate materials into local languages so that trainers and counselors are able to communicate more effectively with all people

Coordinate with the World Food Programme and other relevant organizations to address food and nutritional issues

- Set up a coordinated national project to address food shortages and nutritional inadequacies
- Work more closely with international agencies on these issues
- Explore providing supplements and food as part of an ART package of essential interventions

Provide free drugs, stipends for transportation, and other assistance for PLWHA

- Make testing and OI drugs free for people receiving ART
- Provide income-generating projects for PLWHA
- Provide transportation stipends for PLWHA
- Obtain more mobile units to bring ARVs and supporting treatments closer to PLWHA's homes

Cut down delays in releasing funds

- Streamline how funds flow through the government bureaucracy
- Reduce the steps needed to get funds from GFATM to primary treatment providers

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- Conduct fund flow process audits to ensure that all funds that should be going to provide treatment are indeed getting there. Analyze overhead costs at each level of bureaucratic transfer and seek to ensure that corrupt “skimming” practices are eliminated
- Set a specific deadline (e.g. 10 days) for time from release of GFATM monies to Ministry of Finance to their disbursement to treatment centres
- Determine process so that more funds can go directly to providers (rather than through multiple layers of government)
- Ensure that all recipient health care facilities, NGOs, FBOs, and CBOs operate transparently and efficiently—and are free from corruption. Develop policies, processes, grading and punitive measures to enforce

Hire and train more health care workers

- The Kenyan government, donors, and international agencies should put specific plans in place to ensure that there is very little health care worker unemployment in Kenya—thus reducing the strain on the health sector caused by human capacity shortfalls
- The macroeconomic policies of the International Monetary Fund and World Bank tend to discourage increased public spending, therefore restricting expansion in the health sector. These institutions should acknowledge their role in perpetuating ongoing shortfalls in the supply of health care workers. Furthermore, they should be lobbied to reverse constricting policies and to work closely with the Kenyan government to provide sufficient resources to boost health sector capacity and expertise
- Implement subsidies and enhanced compensation plans to decrease “brain drain” of doctors
- Work with donors to hire and train more health care workers (PLWHA should be trained to be peer adherence counselors and educators)



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There must be a willingness on the part of government to channel resources to the programme. Political will must drive the process of policy implementation.

— NGO care provider

Background: HIV/AIDS in Nigeria

HIV/AIDS is a leading health problem and developmental challenge in Nigeria. An estimated 3.5 million Nigerians are living with the virus, and about 500,000 currently require ART. The government's decision to initiate a subsidized ART programme was announced by President Olusegun Obasanjo in 2001 at the African Heads of State Summit. At that time the target was to provide treatment to 10,000 adults and 5,000 children. Now, four years down the line, the stakes are much higher. More PLWHA need treatment, and enormous resources are required.

In June 2005, the president set a new target, aiming to place 250,000 PLWHA on ART by the end of 2006. Currently, with additional funding from GFATM and PEPFAR, over 30,000 people are receiving ART. While efforts are ongoing to rapidly scale up treatment to meet the new targets, several limitations pose significant challenges.



How the research was conducted

- 14 key informant interviews with representatives from the government, multilaterals, service providers, NGOs and FBOs, and PLWHA support groups
- Literature review, including national treatment plan, policies and guidelines on ART, and media reports

Major barriers to treatment delivery:

- Inequitable distribution of treatment centres in the country
- Lack of financial, human, and infrastructure resources
- High cost of treatment and CD4 and viral load tests
- Inadequate coordination among providers, the government, outside agencies, and TB programmes
- Bureaucratic delays
- Stigma against people living with HIV
- Lack of treatment literacy programmes

Primary barriers to treatment scale up include insufficient resources (financial, human and infrastructure); poor decentralization and uneven distribution of treatment centres by government and development partners; poverty; high costs associated with treatment; stigma; lack of youth-friendly services; and bureaucratic delays.

Research methodology

Information for this report was gathered primarily through interviews with 14 individuals working in different areas of the response to HIV/AIDS. The research team interviewed representatives of the National Action Committee on AIDS (NACA), multilateral and bilateral organizations, public and private ARV service providers, international NGOs, and PLWHA receiving ART at treatment centres across the country.

Key barriers

Five years ago, accessing ART in many parts of sub-Saharan Africa was a rather expensive venture, prohibitively so, for most PLWHA in the region. The situation was the same for PLWHA in Nigeria. Access to treatment was very limited and when available it costs as much as N15,000 (\$120) a month. However, the launch of a subsidized national ARV treatment programme in January 2002, as well as initiatives by private NGOs and PEPFAR, have contributed to expanding the number on treatment to some 30,000 people. This is an important development, but a daunting challenge lies ahead to increase that to 250,000 people by the end of 2006. As 2006 draws near, several hurdles stand in the way of making expanded treatment access a viable possibility.

The stress of having to travel a long distance to access ARVs is almost unbearable for people living with HIV. Donor agencies concentrate too much of their activities in the cities leaving the communities.

— Coordinator of a PLWHA group in Ekiti state

Inequitable distribution of treatment centres

In 2002, the national treatment programme commenced in 25 centres across the country. These 25 centres are located in only 17 of Nigeria's 36 states, with seven centres situated in the Federal Capital Territory alone. Donor preferences contribute to the uneven distribution of centres, as funders tend to concentrate their activities and service provision in specific states. For instance, the PEPFAR programme currently operates predominantly in the same states where the federal government is implementing its treatment programme, although PEPFAR also plans to expand services to other states soon.

Several PLWHA who are not residents in any of these “fortunate” states have to travel distances of up to 300 kilometers (in some cases more) in order to access ART. PLWHA spend an average of four to five hours traveling between their home and treatment centres, and the travel costs are significant.

As one care provider based in the southeastern part of the country observed, “The sites are not enough. People travel days and miles before they can have access to the sites. Clients pay heavily on transport and accommodation.”

Insufficient resources (financial, human, and infrastructure)

Available resources are not sufficient to treat the number requiring treatment.

— Official of the National Action Committee on AIDS (NACA)

There are simply not enough resources available as yet to meet the need. Capacity to deliver services at all levels is seriously constrained by the lack of skilled human resources.

— Staff member of an international NGO providing HIV/AIDS services

Although African heads of state at the Abuja Summit had committed to spending 15% of their annual budgets on health, this commitment is still not being fulfilled in Nigeria. Today, less than 7% of the annual budget is devoted to the health sector. Scaling up to provide ART for 250,000 PLWHA will require enormous financial, human, and infrastructure resources. The funding at hand is grossly insufficient. In 2004, the government allocated N1.5 billion (\$11.58 million) for procurement of ARVs. This excludes other associated costs such as staff salaries, monitoring tests, and laboratory equipment. As a result, scaling up to 250,000 people will require about 12 times more money than what was budgeted in 2004.

Nigeria has received some funding from GFATM to scale up its ART programme. More recently, with the commencement of the PEPFAR programme, additional support is now available for treatment scale up. But pumping financial resources into health care facilities is just one of the many interventions required for making a change—the existing health care system needs to be strengthened as well. “Poor health infrastructure for scaling up of ART is a major limitation that also needs to be addressed,” one interviewee said.

Additional burdens are being placed on the health sector as a result of new and emerging diseases, brain drain, and poor working conditions. Health care personnel are overburdened and underpaid, a situation that has resulted in frequent strikes by health care workers in government facilities in recent years.

As a care provider in one of the treatment sites observed, “There is a heavy workload on health care workers. This has reduced the contact time we spend with our patients. Manpower should be increased all over the country so that patients need not crowd a particular centre.”

In addition, most of the ART centres still lack facilities for preparatory training and counseling of patients prior to commencing treatment as well as adherence support. A PLWHA who is also a care provider noted that “proper education or counseling is generally not done in our hospital settings.”

Poverty and affordability of treatment

Fees for services constitute a major barrier to access and utilization.
— Service provider in Nigeria

Several respondents said that cost remains an important barrier to treatment for many PLWHA. Although beneficiaries on the federal government and PEPFAR programmes must pay N1,000 monthly (\$8) a month for ART, the total out-of-pocket expenses (an estimated \$300 annually) incurred by clients on ART is burdensome to many who are barely making ends meet. These costs are even higher when drugs are obtained from private foundations or NGOs offering treatment. (One international NGO currently offers treatment free to PLWHA in Lagos.)

Most clients still have to pay for the associated costs of diagnostic tests, transportation, and treatment of opportunistic infections. Those who are able to access treatment at the federal ART centres still pay about \$50 every quarter to undergo CD4 and viral load tests. This cost represents a major impediment to care for many. Although the PEPFAR treatment sites now offer free CD4 count and viral load tests for clients, these sites are not located in all the states.

Many PLWHA still need to travel long distances to access any services, regardless of the provider. Good nutrition is essential to achieving the maximum benefits of ART, yet many PLWHA are poor and unable to purchase nutritious food.

The federal government is not putting in enough money for the comprehensive treatment of patients. Patients bear 35% of the cost of ART. They have to pay for costly monitoring tests and drugs for opportunistic infections.
— Member of the National ART Committee

Stigma

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

— Nigerian living with HIV

The fear of stigmatization causes some PLWHA to go to remote areas in search of treatment.

— Nigerian living with HIV

Late presentation of patients due to the stigma is a major concern. Health workers in both public and private sectors need to be more compassionate and receptive towards PLWHA.

— Care provider

A number of PLWHA interviewed reported that some of their colleagues do not access services in certain centres because of the discriminatory attitudes of care providers. This situation is even worse if a client also suffers from TB/HIV co-infection. One respondent observed, "Hospital personnel tend to stigmatize patients that are coughing." Several respondents also noted that some of the existing sites are not youth-friendly.

In tandem with concerns about affordability, stigma most likely represents the main reason that treatment uptake remains rather slow in some areas of the country. As a clinician in one of the "concentrated" states observed, "We do not have any major barriers so to speak, except that we need more people to be enrolled in our scheme because we have capacity for more."

Also notable is that accessing treatment from the public programmes is a distasteful option for the few PLWHA who can afford to purchase their medications privately from pharmaceutical companies, at a cost of about \$40 per month.

Some individuals who are not yet on the treatment do not want to enroll in government sites because of their non-friendly dispositions. Many on treatment are opting out.

— NGO representative

Poor coordination among actors

Donors tend to run parallel programmes rather than support the national programme.

— NACA representative

Several respondents emphasized the need for better coordination among the key players providing treatment, stressing the need for the government “to demonstrate firm leadership and ownership of programmes, particularly with respect to funding, structures, and implementation of activities in order to guarantee programme sustainability.”

Respondents also highlighted the importance of buying into the government programme rather than creating parallel structures, which is what PEPFAR is frequently accused of doing. A unified structure is consistent with what is being advocated under UNAIDS’ “three ones” principle.

At the international level, donor agencies should respect, identify with and submit to the good directions of countries and play down their own agenda.

— Member of an international NGO providing HIV/AIDS services

Insufficient treatment literacy

The lack of proper knowledge and treatment possibilities creates a vacuum, and provides the opportunity for religious groups and all kind of charlatans to lure PLWHA into spending their meager resources on their alternative treatment options instead of going for ARVs.

— Service provider

Accessing treatment is only the first step for PLWHA on ARVs. Often, those who access ART are not adequately counseled at the point of service provision about adherence, compliance, and issues relating to making treatment work. Some PLWHA have reported stopping treatment without consulting their physicians because they felt better or developed side effects. Although a number of PLWHA support groups and other NGOs have commenced treatment literacy workshops/ training programmes for PLWHA and care providers, scale up of such interventions is needed in order to enable PLWHA to make informed decisions about their own health.

Bureaucratic delays

It takes time to implement even accelerated directives by policy-makers. The civil service procedures are slower than is needed for rapid responses to the epidemic

— UN agency representative

There are too many hurdles and protocols in government activities leading to delays in releasing funds for HIV/AIDS activities. The purchase of drugs and disbursement to centres as well as scale up are slow.

— Nigerian living with HIV

Treatment scale up efforts in Nigeria have been plagued with several delays. After the ART programme commenced in January 2002, it was expected to scale up from 25 to 100 treatment centres within a year. Scale up has indeed moved forward, although quite slowly. The paediatric arm of the programme, which was supposed to begin in 2002, only started operating in early 2005. At the initial stages, managing the existing National ARV programme proved problematic. In 2003, delays in purchasing new drug supplies, coupled with over-enrollment of clients, led to ARV stock outs for up to two months in many centres, thus forcing some PLWHA to share medications or interrupt their treatment.

TB and HIV

Mechanisms exist for linkage between TB and HIV; however, they are not well established.

— Care provider

There is no intensified effort presently to screen for TB among all HIV patients. However, those patients with a chronic cough are screened for TB.

— Care provider

Other than the clinicians interviewed, very few respondents working in the field of HIV/AIDS were able to provide information on the incidence of TB, treatment of the disease among PLWHA, or the roles of the National TB and Leprosy Control Programme. This in itself indicates a troubling lack of coordination among the HIV and TB programmes in Nigeria. Information on TB-related activities is still limited to policymakers and health care providers, and PLWHA do not appear to be widely aware of TB services.

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There is a draft national strategic plan for TB/HIV collaborative activities, and intensified screening for TB among PLWHA is listed as a priority. Guidelines developed for the administration of ART recommend the administration of isoniazid preventive therapy in PLWHA who are infected with latent TB. It also recommends cotrimoxazole preventive therapy for HIV-infected TB patients. However, only one of the care providers interviewed for this report said he administered isoniazid.

Cotrimoxazole administration is not being routinely provided in existing centres. Clearly there is still limited awareness about the policies on TB and HIV and discordances between policies and practice still exist.

The work of the key players

Several respondents said that there was poor coordination among many of the multilateral, bilateral, and national partners working on ART delivery, and that each of these organizations seemed to be pursuing its own separate agenda. Other respondents had only vague ideas of the roles and responsibilities of the various domestic and international organizations involved in scale up.

PEPFAR and GFATM were both repeatedly identified as organizations that were doing their “own thing” and failing to align their work with partners. Many respondents emphasized the need for the organizations to recognize the national coordinating authority as well as respect its views in the response to HIV/AIDS.

WHO and UNAIDS

Several respondents highlighted the fact that WHO is responsible for meeting the “3 by 5” target. A few felt that WHO had not been particularly visible in Nigeria; others said that WHO works largely with the government but should expand its interaction with and support for NGOs.

Respondents noted that UNAIDS had been quite successful in its coordination with other partners, particularly with regard to promoting the implementation of the Three Ones principles, its support of the national response, and its provision of technical assistance to the government in the formulation and implementation of HIV/AIDS policies.

Interviewees urged UNAIDS to play a more supportive role with civil society groups, improve networking with people at the grassroots level, and expand its presence to every state. Several interviewees said that UNAIDS and WHO need to improve their coordination with PEPFAR and other organizations involved in scale up.

GFATM

GFATM’s important role in supporting the implementation of HIV/AIDS (particularly in expanding access to treatment) and malaria programmes in the country was

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recognized by the majority of the respondents. A few said they did not think that the work of the Fund was well coordinated with other partners.

Some respondents also stressed that the CCM must be more effective in order to foster greater collaboration. According to one interviewee, “The CCM needs to work more closely with all partners at all times, and not only for proposal writing. The Global Fund needs to be less bureaucratic.”

Particularly worrying is the fact that GFATM has judged both of Nigeria’s two main Round 1 GFATM grants for HIV/AIDS—for the expansion of the national PMTCT and ART programmes—to be non-performing. This means that they are at risk for termination rather than Phase 2 renewal.

GFATM administrators are concerned that Nigeria has not demonstrated sufficient capacity to achieve the grants’ goals because of slow disbursement of funds, insufficient and unreliable data, and late and insufficient reporting. Both the Principal Recipient, the National Action Committee on AIDS (NACA), and the sub-recipient, the National AIDS and STD Control Programme (NASCP), have been specifically criticized by GFATM for limiting the grants’ effectiveness.

Failure to secure Phase 2 renewal grants could have devastating consequences for the thousands of Nigerians who benefit from the GFATM-supported services now or would likely do so in the future. It would also mean that the country would fall further behind in its efforts to reach the target of treating 250,000 PLWHA by 2006. Several civil society representatives have created a pressure group to address the GFATM-related challenges, including lobbying to strengthen the grants’ implementation and ensuring renewal.

PEPFAR

The PEPFAR programme currently supports both prevention and treatment services in Nigeria and operates in different locations across the country. There is a general understanding that the programme aims to support the national treatment programme. It is responsible for “provision of drugs and laboratory services at subsidized rates.”

A number of respondents felt that PEPFAR should do a better job of working with other treatment programmers in the country. It “must align more towards other programmes,” according to one respondent. Others called for the programme to expand services beyond the current “cluster areas”, strengthen treatment education services, engage more closely with communities, and ensure youth-friendly services.

One respondent suggested PEPFAR provide free access to ART, and another urged the programme to use fixed-dose combination (FDC) therapies. “PEPFAR needs to consider use of FDCs instead of branded drugs in the first line,” he said.

National AIDS programme

In recognition of the need to scale up a multisectoral response from all sectors of government and civil society, the federal government established key institutions including NACA and the President’s Committee on AIDS. One of NACA’s key responsibilities is coordination of the national response to HIV/AIDS. As outlined by one respondent, NACA is responsible for “setting national priorities; ensuring coordination; and effective utilization of resources for greatest impact.”

Respondents said that NACA needs to work to strengthen human capacity (particularly programming capacity) and increase its engagement with civil society. NACA should play the leading role in the implementation of the national ARV programme. “Its role needs to be acknowledged by partners,” one person said.

National AIDS and STD Control Programme (NASCP)

A division of the Federal Ministry of Health’s Department of Public Health, NASCP manages the health sector’s response to HIV/AIDS. NASCP is responsible for

- formulating and disseminating national health sector HIV/AIDS policies and guidelines;
- providing training and technical support to state and local government control programmes, health care facilities, and development partners; and
- facilitating the procurement of ARVs for the government’s plan of action for broad access to ART.

NASCP provides technical oversight for the government’s ART programme. However, none of the respondents referred to its role in the course of the interviews, probably because the interview template did not ask about the organization. (Interviews with a member of the NASCP staff were slated and a questionnaire provided for his perusal. However, despite several follow-up calls and visits, no response had been obtained by the time this report was prepared.)

Civil society: Civil Society Network on HIV/AIDS in Nigeria (CISNHAN)

Several civil groups exist in Nigeria. CISNHAN serves as the umbrella body comprising PLWHA support groups and diverse HIV/AIDS service organizations focusing on prevention, care and treatment. Many survey respondents observed that the group is still evolving. One respondent commented that the civil society network has “an important, but yet unrealized role to play.” Respondents pointed out that CISNHAN needs reorganization and refocusing and requires significant outside investment.

National TB Control Programme

The National TB and Leprosy Control Programme (NTBLCP), under the Federal Ministry of Health, is responsible for controlling the spread of TB as well as planning and implementation of TB control activities in Nigeria. The country ranks fourth out of the 22 high TB-burdened countries in Africa.

Most respondents had no comment on the activities of the programme, explaining that they did not have sufficient information.

Although the incidence of HIV has contributed to a resurgence of TB in the country, many of the respondents observed that the linkage between TB/HIV programmes is still weak and needs to be strengthened. This would, they said, improve the capacity of the NTBLCP to achieve its mission.

What is needed now?

- Expand geographic reach of services beyond cluster zones
- Include more NGOs in service provision
- Live up to resource commitments
- Make treatment and CD4 and viral load testing free
- Work with donors to strengthen the overall health system

Recommendations

Several actions, listed below, should be undertaken immediately to facilitate ART scale up in Nigeria.

1. Expand geographic reach of services and partner with NGO providers

Government and key actors need to work together to ensure that services are equitably distributed and placed within the reach of those who need them. Donors should support creation of new treatment sites and move away from concentrating services in “cluster zones”. Credible NGOs should be supported in providing services at more sites. As one interviewee said, “Decentralize the centres! Donors should work with more organizations and not necessarily concentrate on those they have worked with previously. In negotiating with the government, donors should encourage work with NGOs and community-based groups that are closer to the people.”

2. Live up to resource commitments

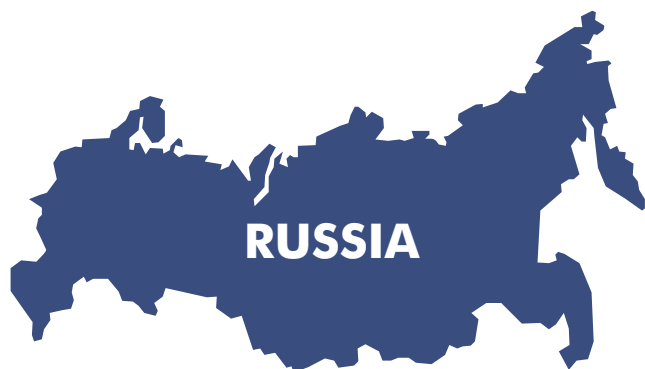
The simple truth is that greater resources are needed from both donors and the national government to significantly expand, and sustain, the reach of ART. The national government should fulfill its commitment to the Abuja Declaration and invest 15% of the national budget in health care. As one interviewee said, “The government needs to properly budget for the ART programme and release the funds when due. There must be transparency and accountability in the use of the drugs from the top to the bottom.” Another urged the Nigerian government to “considerably beef up its financial and human investment in the primary healthcare sector in order to make HIV/AIDS care possible.”

3. Make treatment free

When AIDS treatment and associated tests cost money, poor people are denied life-saving care. ART roll out so far in Nigeria demonstrates that ART and other HIV-related services must be provided free if the poor are to benefit, and the government needs to take the lead in making free care a reality. One respondent put it simply: “Drop the user fees and provide free and comprehensive care.”

4. Strengthen the health system

The government, with support from its international partners, needs to place greater emphasis on health systems strengthening—providing the necessary infrastructure for efficient scale up as well as hiring and equipping health care workers with the required skills to carry out their duties. Remuneration of health care providers should also be reviewed appropriately.



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If we fail, our shame will be infinite.
— Anonymous representative from the Russian
Ministry of Health and Social Development

Russia, home to Europe's largest—and the world's fastest-growing—HIV epidemic, is entering an era of rapid preparation for ART scale up. Because the HIV epidemic started later in Russia than in most other countries, there is a unique opportunity to scale up ART before HIV-related morbidity and mortality rise sharply. Of an estimated 50,000 people currently in need of ART, only around 3,000 currently receive it. But within a few years, two major GFATM projects, together with governmentally funded programmes, are aiming to make ART accessible to up to 75,000 people. Though it now appears that adequate financial resources will be available, major barriers stand in



How the research was conducted

- 13 confidential interviews with representatives of government, activist, NGO, and PLWHA organizations in several regions
- Review of key documents, including GFATM proposals

Major barriers to treatment delivery:

- Faulty drug procurement system
- Lack of communication and collaboration among providers
- No national treatment protocol
- Stigma against IDUs
- Inadequate support for adherence
- Limited connection between TB and HIV services
- Inadequate responsiveness from the Ministry of Health and the AIDS Centre system
- Ineffective CCM

the way of efficient, equitable and sustainable treatment scale up. These include weak health care infrastructure, pervasive stigma, and lack of support services for the most vulnerable groups (especially IDUs).

Research methodology

Information for this report was gathered through interviews with 13 people who work in various regions and sectors in the field of HIV/AIDS in Russia. The research team interviewed representatives of the federal Ministry of Health and Social Development, international organizations, regional governmental service providers, and activists from federal and regional PLWHA organizations. The research team felt it important to gather information from both the federal level and Russia's regions, as distance and differing settings can yield quite different perspectives. The research process was managed by the Community of People Living with HIV/AIDS, an organization comprising HIV-positive people in Russia. Organization staff conducted interviews in Moscow with, among others, representatives of federal governmental institutions and international organizations. During a conference in Moscow, Community of PLWHA staff interviewed PLWHA activists from three regions; those activists subsequently interviewed regional governmental health authorities in their own regions. Audio recorders were purchased for regional activists, and they were given a small honorarium for conducting and typing up the interviews.

Key barriers

For many countries, one of the primary barriers to adequately scaling up access to treatment is a lack of financial resources. This is no longer a key constraint in Russia. Two large GFATM grants have been approved for Russia: one, for which \$34 million has been approved for Phase 1 (the initial two years) beginning in September 2005, is focused mostly on AIDS treatment, care and support, including ART provision. Also in September, the Russian presidential administration announced that \$107 million would be released from the governmental Stabilization Fund for use in the year 2006, mostly for HIV/AIDS treatment. In the coming few years, the success of AIDS treatment delivery will depend on how well these funds are spent.

Drug pricing, procurement and distribution

Thanks in large part to the drug pricing requirements established by GFATM, in 2004 the yearly cost of a first-line ART regimen in Russia fell to \$1,800 per patient, from \$12,000 the year before. Although the price reduction is significant, it does not bring drug costs down far enough to make treatment access sustainable in the long term in Russia. In governmental tenders, drugs are still purchased for as much as \$8,000 per patient per year.

RUSSIA

Drug procurement in Russia is not done through a centralized procurement mechanism; instead, public sector drug purchases are made by both the federal and regional authorities. Russia has 89 administrative regions, and each regional purchase is made through a separate tender. Generic ARV drugs have still not been registered in Russia, even though attempts have been made to register them. There have been discussions regarding local production of ARVs—which would be less difficult than in many other countries, given Russia’s relatively developed capacity for pharmaceutical production—but no concrete steps in this direction have been taken. Some off-patent drugs have been produced locally, including, for example, an AZT analogue.

Russia is likely to face serious problems with maintaining an uninterrupted supply of ARVs. Already, in fact, interruptions in ART due to stock outs have become a frequent reality. The country has limited experience in dealing with medicines that require such precise supply-chain maintenance. Russia does not have a central store and centralized system for managing storage and distribution. Moreover, personnel at local AIDS centres have limited training in how to accurately estimate the quantities of drugs to be purchased.

Another important drug pricing and access issue is availability of medicines for hepatitis. There are high rates of co-infection with hepatitis B, C, and D among PLWHA in Russia. Since health care providers often recommend that hepatitis be treated prior to initiation of ART, access to hepatitis treatment will have a direct impact on ART delivery. Treatment for hepatitis in Russia is available, but is extremely expensive, making it inaccessible for the overwhelming majority of PLWHA in need.

Infrastructure

We have to change the whole structure.

—Anonymous respondent from the Ministry of Health and Social Development

They need to stop painting the situation in bright colors. [They need to] report the existing problems and demand their solutions.

—Activist living with HIV

In the late 1980s, after the first case of HIV was detected in the Soviet Union, the government responded by setting up a vertical structure of AIDS centres and delegated responsibility for dealing with the epidemic to these institutions. This strategy prompted staff members at other public institutions to view HIV/AIDS as “not my problem.” As a result, referral services and coordination among medical services are very weak. One person interviewed for this report commented, “Why

can't we establish communication? Well, the first thing is because only one organization is authorized to deal with treatment of people living with HIV."

The vertical AIDS centre structure continues to use a very "soviet" system of management: information and statistics flow upward and directives flow downward. Too often, information has not been used for decision making and quality improvement. Most NGOs, especially those working on social issues that have an impact on the epidemic, also report within their donor-driven command economies. Thus, the information and experience they generate is often reported only to their donors and rarely used to alter the HIV care system as a whole; this is a particular shame given that NGOs often develop and employ some of the most innovative approaches to health promotion.

Interaction among governmental and non-governmental structures remains weak, though there are recent signs of improvement. At the same time, though, recent restructuring in the Ministry of Health has made the lines of command within AIDS centres even more unclear. In general, the reforms have maintained many of the disadvantages of the vertical structure while eliminating one of its few advantages—the ability to integrate learning, identify model programmes, and direct programme and policy changes from the centre. That kind of centralized leadership could be extremely valuable as disparate treatment centres work to rapidly scale up AIDS treatment.

Since its establishment, the AIDS centre system has used most of its resources to support an extensive mass testing programme. Nearly 20 million HIV tests per year have been conducted since testing began in the late 1980s, even as prevention, treatment, care and support were neglected. Since HIV transmission began to grow rapidly in Russia only in 1996 (considerably later than in many other countries), AIDS cases are only beginning to be seen, and medical professionals have little experience treating AIDS patients. Russia now faces the challenge of rapidly equipping these AIDS centres and training personnel. This effort is hampered by the fact that the country still does not have a standard ART protocol—in many parts of the country, monotherapy or bi-therapy are common.

Stigma, inertia and lack of support for treatment uptake and adherence

Let them all die, it's their problem—that's what many doctors think!
— Anonymous respondent

Even the best lab equipment in the world, a seamless system of delivering pills, and thoroughly trained clinicians will not provide the kind of psychosocial support necessary to promote adequate treatment uptake and adherence to therapy. Herein lies Russia's major barrier to treatment access. As one respondent commented, "I believe that this problem is more of a social than medical problem."

RUSSIA

The degree to which drug users are stigmatized in Russian society cannot be overestimated. The impact of this stigma is seen at every level—from national policy to interactions between patients and doctors. At every stage, stigma creates barriers to successful ARV treatment.

It is all a matter of stigma, no really, because the general public attitude up to this day is very simple: HIV-positive people, all of them, society believes, are drug addicts, prostitutes, homosexuals, or whoever else. In other words, they are not decent folk. And the worst thing about it is that health professionals generally share this attitude— it is terrible to observe many of them being happy that their patients don't come to see them!! Let them all die; it's their problem—that's what many doctors think! And believe it or not, many people actually agree with this attitude, they find it very appropriate. From their heart they agree with it. They feel, "What the heck! Why should anybody bother with them? These sick people, they were given money, there are doctors to help them, there are resources allocated, what else do they need? Let them all die! Good riddance!"

— Anonymous respondent

Lack of support for treatment uptake

In neighboring Ukraine, ART scale up started earlier than in Russia, but treatment uptake has been disappointing. The same can be expected in Russia. In regions where ART is available through the Round 3 GFATM project there are still no information campaigns to promote awareness that treatment is available. Most people do not even know that HIV can be treated at all. Aggravating the problem is the profound lack of good quality post-test counseling. Though mandated by law, appropriate counseling rarely occurs and most health care workers are not adequately trained in its importance and practice.

Even if good counseling and mass information campaigns provided information about the availability of treatment, special attention would need to be given to the needs of the most affected groups. It is estimated that in Russia more than 80% of those in need of ART are IDUs. This highly stigmatized, vulnerable group often does not have access to even basic medical care. Even possession of small amounts of an illegal narcotic is criminalized, a fact that serves to drive drug users underground. If a drug user seeks help for addiction, he/she will be registered in the system officially. Once registered, the person is guaranteed a lifetime of difficulty. For example, many employers require job applicants to present proof that they are not "registered" drug users. Fear of being registered seriously inhibits access to care among IDUs.

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The attitudes of many medical professionals towards drug users also are strongly negative, further discouraging service uptake. Many health care workers believe that IDUs are not capable of adhering to treatment and providers often deny access to life-saving ART based on this erroneous and discriminatory assumption—even though evidence shows that with the appropriate support drug users can achieve adequate levels of adherence.

Evidence from around the world proves that harm reduction services serve as effective points of entry to health care and other services for drug users. They are far more likely to come forward when contacted by tolerant and caring outreach workers. But in Russia, persistent opposition by many policymakers to harm reduction services and inadequate financing means that coverage is woefully inadequate. Stigma and discrimination against drug users at all levels of society limits the expansion of harm reduction services to meet national needs. Recently, though, GFATM approved a 5th Round proposal that would allocate funds to scale up harm reduction services in Russia. This application for critically needed services had to be submitted to GFATM as a non-CCM proposal—even though Russia has a CCM—due to the lack of governmental support for harm reduction activities and inadequate governance procedures for Russia's CCM.

Another factor inhibiting service uptake is the propiska system through which a person can access state-funded medical services only in the region where he/she is registered to live. This barrier is especially significant for vulnerable groups such as sex workers and migrant workers. Since treatment is available only through AIDS centres, many patients (even those who live in the districts where they are registered) have to travel a significant distance to receive care; this travel proves too costly, time-consuming, or exhausting for many of those in need.

Programmes that reach out to other vulnerable groups, including sex workers, MSM, and former prisoners, are also underdeveloped and often not linked with services that provide ART access.

Lack of adequate adherence support

Those patients who do enter ART programmes need extensive support to adhere to their regimens. Unfortunately, most AIDS centres are not yet able to offer this kind of support. Medications that were recently added to the WHO Essential Drug List can play an important role in promoting ART adherence among IDUs, but these medicines are not legal in Russia. Political will to change this situation is absent, to a large extent due to strong resistance within Russia's drug control agency and drug treatment service structure. Without adequate drug treatment and rehabilitation services and, for some, substitution therapy, many Russian PLWHA who are drug users are practically condemned to death.

Providing the psychological and social support that patients need to adhere to potentially life-long ART will be a new and challenging undertaking for AIDS

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centres, NGOs and PLWHA community organizations. Evidence from around the world has shown that a trusting relationship between the patient and health care worker is a crucial factor in promotion of treatment adherence. Russian doctors and PLWHA generally belong to different social groups in Russia, so building this trusting relationship will be a particular challenge requiring ongoing efforts to reduce stigma aimed at IDUs. Anti-stigma programmes run by community-based NGOs, as well as the work of peer educators, can help build this trust. To date, though, these kinds of programmes remain underdeveloped in Russia.

HIV/TB

In Russia, there are very high rates of HIV/TB co-infection, and TB is the most common cause of death among PLWHA in Russia. Inadequate integration of services sometimes leaves patients without adequate care for co-infection. TB and HIV are managed by two separate centralized “vertical” systems that are remnants of the Soviet system. Horizontal cooperation and information flow at both the regional and federal levels remain substandard. Recently some efforts have been made at both levels to encourage cooperation and information sharing, but the results are not yet clearly visible. TB and HIV advisory committees have been established at the federal and regional levels, but several people interviewed for this report mentioned that they have yet to see any progress in cooperation. As one respondent noted, “On paper they do cooperate, but people receive no real interdepartmental assistance.”

In general, TB patients are tested for HIV and HIV-positive patients are tested for TB. Isoniazid and cotrimoxazole prophylaxis seem to be available at the pilot level, but not universally throughout the health care system. A doctor interviewed said that the main barrier to broad application of the TB prophylaxis is not the cost—the medicines are relatively inexpensive, he said—but difficulties in setting up comprehensive and accessible services. One activist said that it was not uncommon for TB clinics to try to send HIV-positive patients to the AIDS centre and for AIDS centres to try to send their HIV-positive patients with TB to the TB service—just to try to “get rid of” them.

Accountability: the major players

Ministry of Health and the AIDS centres

For years the Ministry of Health and the AIDS centre system were not particularly responsive to calls from the international community and the country’s civil society organizations to utilize a human rights and evidence-based scientific approach to public health. Now there is increasing attention from the federal government to change the situation. After years of mostly silence, President Putin mentioned AIDS four times in a six-week period in 2005, and in September he released \$107 million for HIV programmes from the Stabilization Fund, a 20-fold increase in the government’s HIV/AIDS budget.

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As a result, the Ministry of Health will be under more pressure than ever to show tangible results. Though the response is still far from ideal, some positive steps have been taken recently. To an increasing degree, governmental structures at the federal and local level (in some localities) are showing more willingness to interact constructively with civil society organizations and strategically share with them the burden of work. There are recent indications that governmental funds may become available to NGOs, which up to now have been essentially dependent on foreign funds.

WHO and UNAIDS

Many respondents interviewed for this report were not aware of the activities of WHO and UNAIDS in Russia, perhaps because these agencies are focused on working with federal level NGOs and government partners. Both agencies have seen an increase in funding and staff size in their Russian offices, allowing them to expand their roles. Within the last year, both WHO and UNAIDS have been increasingly able to help establish more solid links among civil society organizations and governmental entities.

WHO's "3 by 5" targets for Russia were not clear. Regardless, though, Russia's late start toward scaling up treatment access means that significant increases in the number of people receiving treatment likely will not be seen by the end of 2005.

GFATM

We noticed that they [the Global Fund] don't just provide the financing. The very process of preparing a grant application according to their requirements affects the national HIV/AIDS policy development process in some way.

— Ministry of Health official

GFATM played an important role in lowering pharmaceutical prices and in pressuring recipients to use evidence-based, sound practices in delivery of care. This pressure has had some interesting and fruitful results. The Fund's communication strategy seems to be a problem, however. Many people remain unaware of GFATM's accomplishments. Its drive to report output indicators may overshadow the need to produce useful information about programme approaches and outcomes. A more significant problem is that Russia's CCM is not perceived as credible or effective, at least in part because it currently lacks concrete rules for decision making. Recently GFATM has taken initiative to facilitate the improvement of CCM governance but considerable work is still needed to ensure a fair mechanism that can adequately respond to both civil society and governmental initiatives.

What is needed now

- Develop treatment protocols
- Build collaborations between civil society and government
- Provide training and support for human resources
- Promote treatment uptake among vulnerable populations
- Tap expertise of PLWHA and vulnerable communities
- Use monitoring to improve programs
- Advocate for appropriate services for IDUs
- Provide adherence support
- Improve drug procurement
- Work against stigma

Recommendations

- **Develop treatment protocols.** The establishment of treatment and other protocols for the management HIV-related services should be of highest priority. The Federal Scientific Methodological Centre for Prevention and Combating HIV/AIDS should cooperate with WHO to design these protocols, which have been promised for years. As one participant at the recent Russian National AIDS Conference said, “It is unbelievable that we are 15 years into the epidemic in this country and we still don’t even have treatment protocols.”
- **Build collaborations between civil society and government.** Cooperation between governmental and civil society organizations will be vital for developing programmes that provide comprehensive services. At the federal level, UN bodies have begun and should continue to take an active role in promoting communication and cooperation among governmental entities and their non-governmental counterparts. National level networking organizations such as the NGO Forum, the Network of PLWHA and the Harm Reduction Network, as well as the AIDS centre system, should take an active role in encouraging local organizations in their networks to cooperate at the local level.
- **Provide training and support for human resources.** Throughout the country, and in both the NGO and governmental sectors, human resources development is critical. More extensive HIV/AIDS education for employees in the health care system, NGOs, and PLWHA community organizations is needed on a grand scale. Guidance from UN agencies on appropriate (evidence-based) content and approaches would be instrumental in this regard.

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- **Promote treatment uptake.** A strategic approach has to be taken to promoting treatment uptake, which was neglected in the original GFATM proposals (an omission that could prove to be a major pitfall for treatment programmes). Government, NGO, and PLWHA cooperation will be necessary. Treatment literacy of PLWHA and other community based initiatives should be improved, as should their capacity to engage in community outreach for treatment uptake. Also essential will be improving VCT efforts, launching mass media campaigns, and scaling up of harm reduction and NGO and governmental referral services. If treatment indicators for GFATM are not met, the Fund should insist on strengthening the above strategies for improved treatment uptake rather than simply allowing revision of the indicators.
- **Tap expertise of people living with HIV/AIDS and vulnerable communities.** The mobilization of PLWHA and vulnerable communities and the promotion of their constructive interaction with governmental services are needed. The capacity of these groups to promote treatment literacy, build awareness of human rights, provide services, and advocate for necessary changes must be acknowledged, developed and supported. Both the Russian government and international donors should recognize the importance of civil society's role and provide support. This support should be not only financial, but also come in the form of capacity building services that these young structures need to thrive.
- **Use monitoring to improve programmes.** A strong and unified monitoring and evaluation system is desperately needed. It is vital for decision makers to know what does and does not work. UNAIDS' focus on these systems within the Three Ones model may prove to be a good catalyst for change. Monitoring should not just be performed for the sake of reporting to a funding source—it also should be used to learn lessons and improve programme functioning. Greater involvement of PLWHA and other vulnerable communities in the evaluation of treatment scale-up efforts sponsored by donors and governmental organizations would be quite beneficial.
- **Advocate for treatment, harm reduction and other services for IDUs.** Major advocacy efforts need to be taken to promote effective treatment and rehabilitation services for drug users and to increase the availability of harm reduction and substitution therapy at the local, national and international levels. Efforts should target some of the most intractable opponents of these programmes: the Narcology Service and the State Drug Control Service. UN agencies and other international organizations could potentially be quite helpful, because Ministry of Health officials often find it difficult and professionally risky to promote such unpopular approaches.

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- **Provide adherence support.** A considerable investment is needed in developing effective approaches to adherence support, notably through peer counseling, case management, and provision of psychological, social and material support. Peer educators are known to be particularly effective among groups facing dual stigma, such as drug-using PLWHA. Peer educators are employed by a few of Russia's AIDS centres (mostly in those funded by the GFATM Round 3 project), but this approach is still utilized rarely in Russia. The Ministry of Health does not yet recognize that peer educators have an essential role to play in the AIDS centres. PLWHA community organizations and WHO should provide evidence of the effectiveness of this approach and advocate its employment on a broad scale in Russia.
- **Improve and centralize drug procurement.** The government should be pressured to develop a drug management system based on international best practices and on local needs. Training in methodologies for drug quantification, storage and distribution will be critical. The government should be pressured to procure pharmaceuticals centrally, register generics and consider expanding local production. The UN structures, community advocacy groups and NGOs should continue to pressure the government to ensure that it is allocating resources rationally. Appropriate UN agencies should offer technical assistance in drug procurement, storage and distribution methodology.
- **Work against stigma.** Reducing stigma is one of the most important and challenging activities in the effort to promote and increase ART access. Individuals who need treatment are far more likely to seek it out when they do not face such overwhelming stigma and discrimination on the part of many medical professionals as well as within society at large. Among the ways that stigma can be reduced are to raise awareness that treatment is available, encourage openness about serostatus, and support PLWHA to become educated equal partners in the treatment preparedness effort.

One activist's TB story

I can only list several examples. Bad examples, for that matter. We have a rehabilitation centre, and it's a bit "chaotic." It is located on the former premises of a military detachment, the troops having left five years ago. They created a Nazareth Centre, with no legal registration. Some 60-80 people are in there all the time. The work is quite effective. Well, perhaps not 100 percent. They have no electricity, no heating, no water, and it is somewhere in the steppe. But they do work, although they have no funding. They do get some support from a Christian organization, people get food three times a day, so people keep coming to this centre. The centre was created to work with the poorest part of the population—people who don't have documents, people who are lost in life. They come to this centre, get some spiritual support, get help in acquiring new documents. Some people call it "a nest of disease ."

We tried to involve the Ministry of Health. Well, not really involve...I got a phone call, they asked me to help a person dying from TB, a really heavy case. I said I would try to help, went to the TB dispensary, to the chief doctor, and told him about the dying man. It turned out this man had been registered as a TB patient since his very childhood at this TB clinic. The chief doctor said that in half a year he would have a place in his clinic. Well, a place in half a year! He is dying now. He's in that centre and it's dangerous to have him around for other people who live there. I had to do something.

For two days I tried to reach several other organizations – no effect. Then I called to Vesti Dona—the head of the TV programme is a friend of mine. I told her, "Let's write a shocking story about this." She said, "I would love to, but you know it's fraught with consequence, this TB story, so I can't help you. But I can advise you. A new minister of health has just been appointed, why don't you call her personally and mention my name." Well, I'm a frequent visitor of this programme; they all know me and often broadcast controversial stories with my participation. I went to the Ministry of Health, could not get the minister, but did get acquainted with the deputy minister. As a result there was a line-of-duty investigation. In four hours this dying man was admitted to hospital by the chief TB doctor of the Rostov region. All important tests were taken in 15 minutes. The man had active TB, HIV, and late stage syphilis. The chief doctor asked me to bring him the next day. I told him that I would of course come the next day but this guy stays here, right in front of your door. Buy him some pancakes, or bury him at least—if he dies. So they found a place. Had an official investigation. This is how it works here.

The first step was taken—with so much crap along the way, though! So what kind of opinion can I have—having seen all that? When a homeless bum with HIV and active TB can only be hospitalized if a deputy minister of health personally orders it?

— Activist living with HIV



By Fatima Hassan,
AIDS Law Project

“Without Greater Vigour”

Since 1998, the Treatment Action Campaign (TAC) and its allies have led a lengthy public campaign for access to ART through the public health sector. Eventually, on 8 August 2003, the Cabinet made a commitment to provide ART treatment, and two months later the government published the Operational Plan on Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (the Operational Plan).

By the beginning of 2004, several of the nine provinces in South Africa had started implementing the Operational Plan. At that time, fewer than 5,000 people were on ART in the public sector in the whole country. By the end of 2004, all nine provinces had fully commenced with implementation.¹ Nearly one year later, according to the National Department of Health (NDoH), there were 192 public health facilities providing HIV/AIDS-related services, including ART.²

The estimated total number of people who need treatment in South Africa is between 500,000³ and 700,000. Preliminary unconfirmed actuarial estimates indicate that only about 18% of all those in need of treatment in the public sector are accessing it.⁴ Given the need, patient numbers in the public sector are significantly lower than what the demand actually requires. A more aggressive approach to scaling up is needed to avoid falling further behind as the AIDS epidemic matures.⁵



How the research was conducted

- 15 confidential interviews with representatives of public, not for profit and private sector providers and organisations (Staff from the National Department of Health and the HIV/AIDS Directorate did not respond to repeated interview requests)
- Review of key policy documents

Major barriers to treatment delivery:

- Lack of effective national political leadership
- Denialism and pseudo-science
- Shortage of human resources, especially nurses
- Inadequate access to VCT
- Inadequate drug supplies and formulations
- Lack of integration of TB, HIV and PMTCT programmes
- Inadequate donor co-ordination and concerns about sustainability of funding
- Dysfunctional GFATM CCM
- Invisibility of multilateral agencies
- Inadequate response from the private sector

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By August 2005, the total number of people on treatment in both the public and private sector stood at about 150,000: some 70,000 people were accessing ART in the public sector, with an additional 70,000–80,000 receiving it in the private sector.⁶ Several reports of good outcomes are available.

The majority of the approximately 70,000 patients (both adults and children) receiving public sector care are concentrated in three provinces (Gauteng, Western Cape, and KwaZulu Natal). Most of the patients are women and about 10% are children. Paediatricians and children's rights activists are particularly concerned that very few children are accessing treatment. They estimate that at least 50,000 children need ART now, but that currently only about 10,000 are receiving it. The total public sector figure also hides huge inter- and intra-provincial disparities in patient numbers. It is also worrying that very few men are accessing treatment in the public sector.

Several donors partially or fully fund patients accessing ART in the public sector and contribute towards the costs of staff or medical equipment. For example, many provinces have entered into partnerships with donors such as Médecins Sans Frontières, Absolute Return for Kids, One2One Kids, Catholic Relief Services, the South African Medical Association, and PEPFAR. Without this support, the public sector patient figures would be even lower.⁷

The private sector figures include treatment provided by NGOs (community treatment programmes funded by internal and external donors),⁸ workplace treatment programmes (funded by employers), medical insurance and aid schemes to which the employer and employee contributes^{9,10} and the unfunded private sector (self-paying patients).

While the total public and private numbers of patients on treatment are a step forward, the public sector numbers indicate that treatment is far off for many adults and children who need it urgently. In many cases where patients have received treatment, it has arrived too late. This means that many PLWHA are suffering needlessly and that we will continue to witness the premature deaths of thousands of people.

Therefore, unless the pace of implementation is substantially improved, thousands of people who are in need of treatment will either suffer or die prematurely.

Against this backdrop, the South African government has come under severe criticism from local advocacy and trade union organisations. In particular, most recently, Zwelinzima Vavi, the secretary general of COSATU, the country's largest trade union federation, publicly stated that President Mbeki and his health minister, Manto Tshabalala-Msimang, had betrayed "our people and our struggle" because of the lack of government leadership on HIV. As noted in this case study, people interviewed for this report unanimously agreed with Vavi and some expressed even stronger rebukes. President Mbeki, in his State of National Address on 11 February

2005 said that the national government would respond to the AIDS epidemic with "great vigour." The sentiment of all participants was that the programme is not being led "with great vigour ."

Background

From July through October 2005, a total of 15 confidential interviews were conducted among individuals representing public, not for profit and private sector organisations and providers. Regrettably, the NDoH and, in particular, the head of the HIV/AIDS directorate, did not respond to repeated telephone and e-mail requests for an interview. The NDoH's views are, therefore, not included in this report.

Limitations

Many of the respondents were unfamiliar with the TB programme, and therefore were not in a position to comment on the TB section of the interview (section 3). This is because they had not heard of the TB programme, felt that they had insufficient knowledge or information about it, or believed that the TB programme and response to the TB/HIV epidemic was inadequate and lacking. Due to the paucity of responses on the national TB programme, the summary below contains limited information about TB.¹¹ This is in itself telling.

Key barriers

Participants identified the following barriers, which they felt were affecting the speedy implementation of the Operational Plan. They are not ranked in any order of importance. However, the first two barriers listed below were the most frequently identified. These barriers are dealt with in detail in the recommendations section.

- Lack of effective national political leadership coupled with denialism and a flirtation with pseudo-science
- Operational issues, including:
 - Shortage of human resources, in particular nurses
 - Inadequate access to VCT
 - Inadequate drug supplies and formulations
 - Lack of integration of TB, HIV and PMTCT programmes
- Inadequate donor coordination, including concerns about the sustainability of donor-funded programmes
- Ineffective functioning of GFATM's Country Coordinating Mechanism (CCM)
- Invisibility of multilateral agencies
- Inadequate response from the private sector

What is needed now?

- Create a true national AIDS program
- Train nurses and other health care workers to provide treatment consistent with international standards, and develop programmes to retain them once trained
- Greatly expanded access to voluntary counseling and testing services
- Develop a new, more effective CCM—or initiate a new process for soliciting and overseeing the implementation of GFATM grants
- Establish true civil society representation on the CCM
- Demand fewer restrictions and more collaboration from PEPFAR
- Assure the ability to use generics through PEPFAR-funded programs
- Increased visibility and leadership from UNAIDS and WHO
- Expanded involvement from civil society in treatment expansion

Recommendations

The following recommendations emerged from the interviews.

1. Launch an international campaign to hold government accountable.

The major obstacles are political—so we need a political solution—and we need to address the silence.

—Staff member from leading legal research and advocacy group

Most participants felt that the political impasse created by the president and the health minister is hampering the country's overall ability to effectively respond to the epidemic. Many participants felt that a strategic international campaign should be directed at the South African government to hold the health minister accountable and/or remove her from office on the basis that she is showing no leadership and continues to undermine the international, regional and local struggle against HIV/AIDS.

South Africa needs to get to the point where the AIDS programme has its own momentum and it is willingly implemented. It should not require ongoing vigilance from civil society. No one is championing the programme. More groups and people should be less complacent and less reliant on TAC and the ALP to do the dirty work.

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The following specific concerns on leadership were identified:

- First, the health minister refuses to act in a transparent and open manner, thus limiting access to information about the HIV/AIDS programme. It was felt that multilaterals should be more critical and vocal about the lack of leadership of the AIDS programme and the deep levels of mistrust and secrecy that characterize the minister's actions. As one participant observed, "There is no programme driver."
- Second, ambiguous messages issued by the health minister about ARVs have led to confusion among many PLWHA. For example, many respondents held the minister responsible for creating a false dichotomy between nutrition and HIV/AIDS. They argued that this is because, in addition to issuing ambiguous statements about nutrition and ARVs, she has refused to act against false claims by persons who are associated with AIDS denialists and with the minister herself. Most participants felt that international organisations and agencies should consider the minister's inaction to be not only scandalous, but deadly—and to directly confront her and the government as part of an effort to cease discouraging patients from taking ART. The interviews noted that in some parts of the country, the health minister's open opposition to ART has prompted many patients to hold off on seeking treatment until a very late stage in their infection, thus endangering their lives and creating additional burdens on the health care system.¹²
- Third, the minister's attempt to centralise key decision making powers (such as accreditation of treatment sites) makes politically weaker provinces dependent on the national department for leadership and support. Most participants felt that the minister simply has too much power. Again, this is an issue of leadership.

Almost all respondents questioned the effectiveness of the National AIDS Programme (NAP). Most stated that in their view the programme is inefficient, non-existent and even "an embarrassment ." For example, paediatric treatment guidelines were only publicly available in October 2005, nearly two years after the Operational Plan was adopted. The government's National HIV /AIDS Strategic Plan expires at the end of 2005, but a plan for 2006 and beyond is not yet available.

Positive comments

The Khomanani programme (government communications component of the AIDS programme, which includes TV, print, radio advertisements and information materials) was considered by one participant to be a worthwhile component of the NAP. In addition, at the provincial government level, progress seems to be made in fostering a better working relationship with the NDoH. Aside from this, there were no other positive comments about the NAP.

What should the NAP do?

People are afraid to do anything or to say anything. National and provincial should be honest about what they need help with and do so regularly. They have created this tension between nutrition and ARVs, which is just ridiculous. They should be accountable and report to the country about treatment, participate in the programme, encourage testing and CD4 tests—or else why would people volunteer to get tested?

— Staff member from nonprofit treatment funder

Given that most participants agreed that for all intents and purposes there is no existing NAP, it is useful to list what they identified as the crucial components of an effective NAP:

- Lead, coordinate and deliver on the Operational Plan by assisting weaker provinces and ensuring that monitoring and evaluation is regularly carried out
- Ensure that the programme is not exclusively hospital-based.
- Monitor and improve policies, guidelines and systems that will ensure that the health and well-being of poor people are promoted and protected as mandated in the Constitution
- Act in a transparent manner, provide access to information, include civil society in deliberations, provide leadership, act with a sense of speed and increase the pace of rollout
- Appoint suitable people with the right skills to run the programme.
- Issue unambiguous messages
- Publicize outcomes

2. Expand human resources

We have large numbers (truckloads) of patients who need help, but not enough qualified staff to measure their blood pressure, take their medical history and check for OIs and TB, which is a huge problem in this area. We just need to train them to listen to a patient's chest. We have very few staff and they are unskilled. We have in our province the highest prevalence of MDR-TB in the world— 80%. What do we do?

— Non-profit treatment provider

Many participants identified inadequate human resources as a major barrier to scaling up treatment. According to them, the pace of implementation is being hampered by a lack of trained doctors, nurses, pharmacists and other health care

providers. Therefore, attracting, retaining and training health care workers is critical. The ongoing crisis in human resources is a result of poor working conditions, low salaries, lack of incentives, and the international poaching of health workers. Without a reasonable, flexible human resources plan that addresses short, medium and long term needs, the Operational Plan will continue to be undermined.

In particular, most participants regarded nurses as the backbone to scaling up treatment in South Africa, especially in primary health care settings. In addition, participants believed that nurses must be trained to administer ART with appropriate doctor supervision. Incentives to attract, retain and professionally develop nurses are also urgently needed. This requires the intervention of multilateral agencies to ensure that foreign governments and the private sector do not poach nurses who are needed in the public sector.

One interviewee argued that given the prevalence of HIV among health care workers, government, trade unions and international agencies have to embark on a national campaign to assist nurses who are living with HIV to access VCT, early diagnosis and timely access to treatment. That respondent suggested that if such an effort were not undertaken and made successful, the health care system would collapse in the next few years because of the direct burden of HIV/AIDS on health care workers.

3. Expand VCT access

Many participants felt that the current model of VCT was not working. In order to scale up more speedily, they felt that a new VCT model was necessary—one where counseling and testing is available routinely, more widely and before treatment becomes necessary. This would allow health care workers to better manage patients during the initial stage of infection and provide them with treatment at an appropriate time. Some participants suggested introducing the routine offer of testing at all health points, mass counseling, and self-testing. Others felt that a new model could include the aggressive marketing of testing at all public places, including schools, universities, shopping centres, places of worship, TB clinics, PMTCT clinics, general health wards and clinics, workplaces and places of recreation and leisure.

Some recommended that CD4 testing should be routinely available with VCT, a development that would assist health care workers with patient tracking and management, reduce unnecessary waiting lists and lengthy delays in treatment commencement, and in many cases limit loss related to patients' failure to follow up. In terms of the Operational Plan, a CD4 test result is a prerequisite for commencing treatment. Participants therefore suggested that it would make practical sense to couple CD4 testing with VCT.

In addition, many participants suggested that children should be tested much earlier after birth. They felt that it is vital that PCR testing is available at all health facilities

to diagnose children early enough and avoid losing them later in the system. As with adults, early testing assists with patient tracking and management.

The role of multilaterals

Varied responses were received from participants regarding the role of UNAIDS, WHO, GFATM and PEPFAR. Responses differed according to the proximity of the participant to the relevant organisation. Some bias in responses is therefore evident and should be acknowledged.

GFATM

There are two key issues in regard to GFATM. The first concerns GFATM itself, and the second is the appropriateness of the South African National AIDS Council (SANAC) as the CCM. Most participants agreed that the role of GFATM is mainly to be a financing mechanism. Some felt that GFATM operates as a willing listener and acts from the “ground up”—that it respects local priorities, is transparent and flexible, and provides incentives for meeting targets. Others argued that it is inefficient, bureaucratic, and has not met its mandate. Some could not comment on GFATM given that they had no dealings with it or felt that GFATM had “no impact on [their] work.” Some participants considered GFATM’s accounting requirements too rigid. Questions were also raised about who the key contact person for GFATM is in South Africa and to what extent GFATM has attempted to truly identify local needs and fund smaller community based organisations.

SANAC is invisible. It is not meeting, it is not transparent, it is not working. Who is heading it now?

— Staff member from nonprofit treatment provider

Many participants contended that SANAC is not a fit CCM and is instead undermining and hampering grant applications. Given the political complexities in South Africa, respondents suggested that either GFATM should allow direct applications or actively insist on a new CCM that is not under the control of the NDoH. One participant suggested that GFATM should invest resources in training and for the appointment of a full time secretary.¹³ An external evaluation of SANAC was also suggested. Given that Provincial AIDS Councils are all represented on SANAC, one of the recommendations was that more resources should be spent on strengthening weaker councils to ensure that their representation at SANAC is more meaningful.¹⁴

In October 2005, it was learned that South Africa's Round 5 proposal to GFATM had been rejected, a development that most observers attributed to the failure of SANAC to function as a proper CCM. This means that an important organisation like Soul City has been deprived of funding from GFATM. South Africa's proposals to all three of the most recent GFATM rounds have now been rejected, primarily

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due to the substandard performance of SANAC and the health minister's lack of leadership. These rejections have deprived the country of as much as 2 billion rand (\$297 million) in funding for HIV, TB and malaria. As such, GFATM has referred the issue of future funding for the Lovelife prevention program (they were successful in Round 1) back to SANAC, which has been asked to revise the original Round 5 proposal and resubmit it. The GFATM board decision requires that the revised request also address the issue of an effective governance structure and CCM oversight. The problem is there has been absolutely no CCM oversight of any of the grants to date. This is despite the fact that over the last two years repeated requests have been made to SANAC for better reporting on the status of grant applications, the amount of money received by GFATM beneficiaries, and how funds have been spent.¹⁵

While some participants recommended bypassing SANAC and submitting applications directly to GFATM, two respondents warned against that step because they felt that a single and central coordination body is necessary so that country applications are based on a country's real, overall needs. Allowing direct applications to GFATM would lead, they said, to a situation in which only strongly written proposals were accepted, regardless of overall impact. Most participants felt that GFATM should follow PEPFAR's lead and award smaller, more targeted grants to key community organisations. They noted that as things stand now, reliance on the CCM to prepare and submit country applications means that GFATM money mainly benefits larger community organisations to the detriment of smaller ones.

Other recommendations for GFATM include the following:

- Improve GFATM's local profile so that people in South Africa are aware of its role, its funding successes and limitations, etc.
- Provide easily available access to information about where, how, and when to apply, including details of the main GFATM contact people in the country
- Ensure that GFATM has enough money to continue to fund the 128 countries that it is currently supporting (i.e. ensure sustainability)
- Fund smaller treatment projects—but not through the current CCM
- Address the current failings of the CCM, including its ongoing exclusion of effective civil society participation in decision-making processes regarding grant applications
- Replace the current CCM in its entirety with a new one that is more consultative
- Coordinate regularly with other treatment providers in the country

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PEPFAR

So far PEPFAR funds the “big fish”—but it needs to target smaller groups. PEPFAR is unclear about what it is NOT doing. It has major resources but it is politically tip toeing with the South African government.

— Staff member from nonprofit treatment funder

PEPFAR has been a lightning rod for controversy since it first began operating in South Africa in 2004. It is undeniably providing substantial assistance in the HIV/AIDS area, but its methods remain questionable.

Most participants regard PEPFAR as a parallel funding mechanism that is inappropriately taking resources away from GFATM. One participant disagreed and argued that PEPFAR is investing huge resources and providing intensive technical assistance for treatment purposes. While several participants recognised that some elements of PEPFAR are providing necessary and useful support for public sector treatment efforts that are as yet unfunded, others criticized PEPFAR administrators for taking credit for treating patients who are not receiving PEPFAR-funded care. There is also some concern about how national PEPFAR patient numbers are calculated.

Mainly, though, participants were worried about the conditions attached by PEPFAR regarding the procurement of drugs as well as the Bush administration’s policies regarding condom use, termination of pregnancy and contraception—all of which have implications for reproductive health rights and access to appropriate prevention programmes.

Some participants contended that PEPFAR is part of a broader political agenda of the U.S. government to boost his credibility in the face of anti-Bush sentiments—i.e., to make him appear human. It was recognized, however, that PEPFAR may be creating a solid foundation to improve access to treatment for many people and that it could become a critically important program if certain political and ideological barriers were removed. Having said this, several respondents argued that PEPFAR very often does not meet local needs and is contributing to turf wars within provinces because PEPFAR does not allow two different organisations to work at the same site. One of the main concerns about PEPFAR is that it “simply does its own thing” (in Western Cape, for example) without due regard for what is happening at a national or provincial level.

According to the US health attaché, not for profit providers must meet two conditions in order to receive PEPFAR funds: they must only use U.S. Food and Drug Administration (FDA) approved drugs, and they must sign a declaration that the organization will not promote sex work. However, PEPFAR-funded programmes and partners indicated that the only condition that is strictly applied and observed is the one requiring that ARVs be approved by the FDA.

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It should be noted that SA's own medicine regulatory system requires a drug to be approved or authorized by its Medicine's Control Council (MCC). In other words, drugs used by a provider funded by PEPFAR will require both FDA and MCC approval.

Ironically, at government facilities that are PEPFAR funded, PEPFAR cannot impose the FDA registration requirement because the SA government is only obliged to use drugs that are registered and approved by the SA MCC. The FDA requirement is therefore not imposed at government facilities. It is unclear if the SA government has been asked to sign the declaration on sex work.

Many participants argued that more patients could be treated if PEPFAR-funded ART projects were allowed to buy lower-cost generic drugs that have not been approved by the FDA; many of them, they point out, have been cleared for use by WHO and South Africa's MCC.

As noted above, many respondents were concerned about official PEPFAR prevention policies that place higher priority on abstinence and being faithful than on encouraging condom use. Some participants noted that because of such policies, organisations in the developing world that are dependent on U.S. money are no longer able to promote condoms directly. In Uganda, for example, this has resulted in a number of community organisations closing down. Most respondents were aware of PEPFAR and its international implications; few, however, were aware of the potential long-term implications of its programmes for prevention and treatment in South Africa.

A significant and positive aspect of PEPFAR reported by participants is its regular (every three months) monitoring and evaluation of site and programme implementation. PEPFAR was also commended for its efficiency and speed in paying laboratory and other bills. Many participants were also of the view that it is easier to apply for funding from PEPFAR than from GFATM.

The programmes funded by PEPFAR are concerned about how the government plans to "take over" (fully fund) patients that PEPFAR has begun treating, especially after PEPFAR funding ends (perhaps as soon as 2008). In other words, while in the short term patients are benefiting from PEPFAR, there are concerns as to whether sufficient attention and thought has been given to exit strategies in the medium and long terms.

Other recommendations for PEPFAR include the following:

- Drop the "global gag rule": money for treatment should be de-linked from prevention. Either PEPFAR should support prevention separately or simply drop its "anti-choice" conditions.
- Drop the rule that requires all PEPFAR-funded ARVs to be approved by the FDA. If poor countries have to get FDA approval to use generics, it

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increases the costs of putting patients on treatment and takes more time for products to enter the market. Respondents noted that if more generics were used, many more patients could be put on treatment. Until this provision is dropped, treatment advocates should lobby the FDA to fast track the registration of generic ARVs

- PEPFAR should be clearer about what it does and does not fund, and how it will ensure sustainability
- Ensure that PEPFAR reporting requirements are not cumbersome at a project level. Participants felt that too much detail about programme activities was required too often
- Ensure easier application processes for small grants and fund smaller NGOs
- Stop political tiptoeing with the health minister and demand certain assurances from the government. (Still, it was suggested that PEPFAR is more sensitive to the political complexities than UNAIDS and WHO.)
- PEPFAR should be part of a centrally coordinated treatment programme in the country, and not be allowed to operate independently
- The programme should be more transparent in its leadership and decision-making processes regarding grant applications

UNAIDS

Most participants viewed UNAIDS as a facilitator yet at the same time they were unaware of its activities South Africa; it was thought to be “invisible” and had “no presence.” According to local UNAIDS staff, this perception is due to a number of factors: for one thing, until recently the country coordinator was the only technical person employed in the South Africa office (at the end of 2004 a monitoring and evaluation officer was appointed, and in October 2005 a partnership officer was appointed).¹⁶ Also, according to UNAIDS staff, much of its work supports the programmes developed and implemented by co-sponsors and thus is largely “behind the scenes.”¹⁷

This to some extent explains why participants felt that UNAIDS has been silent during crucial campaigns for treatment in the last few years. However, with respect to the Geneva offices, participants recognised and were supportive of the role that UNAIDS plays in providing annual analytical and epidemiological information, as well as its significant contribution in making information available, particularly on the global epidemic.

Other recommendations for UNAIDS include the following:

- Increase its profile and presence in South Africa and in each country where it operates by conducting awareness campaigns to let people know its roles and functions
- Increase or start consultation with key partners in South Africa¹⁸

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- Act more forcefully as an advocate for PLWHA, which would include being willing to criticize government policy in South Africa
- Be more supportive of civil society and advocacy efforts in South Africa
- Talk more openly, directly and supportively about ART and the government's Operational Plan
- Influence strategy direction of GFATM and assist with raising money for it
- Scale up and increase pressure to support the treatment and care of children and adolescents in South Africa and elsewhere (working with UNICEF)

WHO — including "3 by 5" staff

There is no WHO office in South Africa or dedicated WHO staff person for the country; instead, the Southern African office is based in Zimbabwe. This may be part of the reason that of all the multilaterals surveyed, WHO received the worst assessment from participants. Most participants asked, "Who is the WHO?" in South Africa and questioned whether it plays any constructive role in the country. Save for its work on preparing and issuing international treatment guidelines and facilitating the WHO drug pre-qualification process, participants were hard pressed to comment positively about WHO.

One participant lamented that the organization has "lost its focus ." However, this is difficult to assess given that at the time of writing this report, the WHO did not have senior staff in the country. It is possible to imagine the government has not been welcoming of a WHO presence. Recently, UN Special Envoy to Africa Stephen Lewis said he had been banned from carrying out his duties in South Africa for the past year.¹⁹

It is therefore recommended that WHO and the South African government should work together to ensure that senior WHO staff are stationed in South Africa. Given the magnitude of the AIDS epidemic in the country, this is now extremely urgent. Other recommendations for WHO include the following:

- Like UNAIDS, WHO should increase its profile and presence in South Africa and the region
- Actively support the work of GFATM in South Africa and elsewhere
- Consider developing and issuing guidelines on health systems and human resources, as well as guidelines on using and improving existing health systems to provide essential health services. In addition, develop recommendations on addressing the human resource crisis in Africa: this could include scope of practice, retention strategies, incentives, training and professional development
- Engage in South Africa (not just the international community) on essential medicines

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- The WHO pre-qualification programme should be more aggressive; for instance, it should put pressure on generic manufacturers to submit their products for inclusion in the review. While most participants believed that the WHO pre-qualification programme was a good concept, many felt that it is under-resourced and lacked a consistent plan of action
- Consult with local stakeholders and providers and be more inclusive of African health care workers

Civil society

Most participants felt that the health minister was excluding civil society from deliberations about the Operational Plan, with channels of information being deliberately closed and monitored. For this reason, many health care workers said they were afraid to speak out for fear of losing their jobs.

Many participants acknowledged the role that the Treatment Action Campaign (TAC) in particular has played in challenging the government's HIV/AIDS policies. Most argued that aside from TAC, AIDS Law Project and Médecins Sans Frontières, very few organisations have directly and consistently challenged the South African government. All of the participants were supportive of the newly established Joint Civil Society Monitoring Forum (JCSMF) and felt that it was doing work that should be done by the government.²⁰

Some participants suggested that the current relationship between TAC and the health minister is too antagonistic, and that therefore solutions must be sought to reduce tensions. However, others felt that the confrontation posed by TAC is appropriate and timely. Some respondents recommended that TAC and other civil society organisations concentrate on treatment preparedness and literacy at community and clinic levels. In addition, several participants said that all members of civil society in South Africa (and not just TAC) should collectively address denialism and the lack of proper, rational leadership in the country.

Other recommendations for civil society include the following:

- Identify additional resources to carry out community mobilisation and treatment preparedness programmes
- Find a coordinated and less fragmented voice and be more critical about the existing political barriers that hinder ART scale up
- Create partnerships at different levels, especially with smaller community organizations
- Focus on good outcomes in treatment scale up, and not just on the negative outcomes
- Get more involved in addressing the operational issues of the national programme by improving clinic level advocacy, by helping the government move away from a hospital-based programme, and by ensuring that primary health facilities offer treatment

ENDNOTES

- ¹ The 2005 budget shows an ongoing financial commitment by the government to address HIV/AIDS. With respect to resources set aside for the procurement of ARVs, more than 3.4 billion rand (\$504 million) has been allocated for the period up to the end of 2007. But the award of the drug tender was only announced on 2 March 2005, some 13 months after the drug procurement process commenced and more than 16 months after the Operational Plan was adopted.
- ² These facilities are spread across all the 53 districts in the country and cover at least 62% of local municipalities.
- ³ There are about 5.5 million people living with HIV/AIDS in South Africa. Of these, approximately 200,000 are children.
- ⁴ Information compiled by the AIDS Law Project, September 2005.
- ⁵ The Operational Plan set its first patient targets at 53,000 for the first year of its implementation. The target was then shifted twice: first by the health minister and then by the president in his 2004 State of Nation address. In her 2005 Budget Speech, the health minister refused to engage in any debate about patient targets and argued that the initial targets were estimates—and nothing more. She stated that patient targets are not important and that instead the debate should be about quality of care. See here Hassan F. Joint ALP/TAC Report issued in June 2005: “Let them eat cake” – A short assessment of provision of care and treatment 18 months after the adoption of the Operational Plan. Available at www.alp.org.za and www.tac.org.za.
- ⁶ By the end of August 2005, the government estimated that at least 78,000 people had been initiated on ART in these facilities.
- ⁷ Médecins Sans Frontières supports four public sector sites in the country; Absolute Return for Kids supports 17-19 sites in the Western Cape; One2One Kids through Kidz Positive supports two sites in the Western Cape, and PEPFAR supports 112 primary sites. Of these, about 30 are in the public sector and the rest are in the not for profit (private) sector or are public-private partnerships. Catholic Relief Services supports three sites in the Free State.
- ⁸ Some of the community projects run by international donors and local donors, faith-based organisations or local communities include the South African Catholics Bishops Conference (which runs treatment projects at 20 sites with funding from PEPFAR and one site through non-PEPFAR funding); the TAC Treatment Project (which started in May 2003, is currently funding over 100 patients nationally); ACTS Mpumalanga (which started in 1996, is funded by Right to Care and PEPFAR and receives some money for operating costs from the NDoH); Ndlovu HAART programme (which started in 2001, and is the only community project in the country with its own HIV monitoring laboratory).
- ⁹ Many private sector programmes are administered by disease management programmes (DMPs).
- ¹⁰ Some of the larger companies that provide HIV/AIDS treatment for workers who cannot afford to belong to a medical scheme include: Eskom; Anglo American; Ford Motor; Daimler Chrysler; BP and Engen; Sasol; Tiger brands; Cape Town Municipality; Mtel; BMW; and Unilever.

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- ¹¹ Zackie Achmat and Reid Roberts in *Steering the Storm: TB and HIV in South Africa*, a policy paper for the Treatment Action Campaign. Available at www.tac.org.za.
- ¹² Recently, the WHO Consultation on Nutrition and HIV/AIDS in Africa (co-hosted by the national department of health) confirmed that everyone requires good nutrition, including PLWHA. But the WHO Consultation Statement also noted that there is no scientific evidence to suggest that good nutrition alone can treat HIV. This is in accordance with official government policy as articulated in the nutrition chapter in the Operational Plan.
- ¹³ The national budget has not allocated any money to SANAC since 2001-2002, despite the fact that international protocols such as UNAIDS's Three Ones Principles call for strengthening of national coordinating bodies accompanied by allocation of sufficient resources. The Three Ones Principles aim to ensure that national governments and their partners develop strong coordinating mechanisms, partnerships and funding mechanisms that would urgently respond to and reduce the impact of HIV and AIDS. SANAC's location within the health department in its first term actually undermined its authority to oversee and encourage HIV and AIDS activities in all government sectors. Strode and Grant (2004: 26) reported that SANAC has finally managed to move its secretariat out of the NDoH to offices outside of any government department. For SANAC's second term of office, a trust fund has been set up and all its finances will be managed by the trustees." The Trust was established in 2002. According to the auditor general, "inadequate progress was made in achieving the objective of the Trust" due to failure to submit budgets to the Board of Trustees as is required by SA law; not submitting monthly and quarterly reports on income and revenue; and lack of monitoring and involvement by the Trustees. The auditor general also found evidence of "fruitless and wasteful expenditure, to an amount of 571,114 rand."
- ¹⁴ Similarly, it was suggested that the PLWHA, children and women sector in SANAC must be strengthened so that it operates effectively within and outside of SANAC.
- ¹⁵ SANAC minutes of 17 March 2004; 19 June 2004; 7 October 2004.
- ¹⁶ Because UNAIDS technically is not a UN agency but is instead a collective of 10 co-sponsors (other UN agencies) it regards itself as a "supporter" as opposed to an implementer. As such, its country level role is determined by the programme activities of the co-sponsors (e.g. WHO, UNICEF). At present, each country office (globally) including the South Africa office has been tasked with working on five core areas, identified as: supporting existing leadership for an effective national response; supporting partnerships between public/private and civil society actors; promoting and strengthening country management of strategic information; capacity building to track, monitor and evaluate the national response; and facilitating access to financial and technical resources.
- ¹⁷ For example, UNAIDS has assisted in supporting the continued functioning of the AIDS Consortium, an umbrella body of AIDS service organizations in South Africa, after it almost closed down. It is supporting programmes currently being carried out by the South African National Defence Force with a view to replicating the

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model with UN peacekeeping forces; it acts as the secretariat for the SA Donor coordinating forum which meets every two months and is made up of government, the UN and bilateral funding agencies; it assisted SANAC with putting together proposals to the GFATM; in 2005 it assisted Soul City to put together its GFATM proposal; and in 2004 it assisted provinces that had previously not applied to GFATM for funding to submit proposals to the CCM.

¹⁸ This is now possible given that the UNAIDS office in South Africa has appointed a full time “partnership” officer.

¹⁹ In his book *Race against Time*, Lewis singles out the South African government and President Thabo Mbeki for what he calls bewildering policies and a lackadaisical approach to treatment of millions of people living with HIV. According to Lewis, “Virtually every other nation in eastern and southern Africa is working harder at treatment than is South Africa with relatively fewer resources, and in most cases nowhere near the infrastructure or human capacity of South Africa.” See LaFraniere, S. “U.N. Envoy Sharply Criticizes South Africa’s AIDS Program.” *New York Times*. 25 October 2005.

²⁰ The JCSMF is currently composed of the following civil society organisations: AIDS Law Project (ALP); Health Systems Trust (HST); Centre for Health Policy (CHP); Médecins Sans Frontières (MSF); Public Service Accountability Monitor (PSAM); Institute for Democracy in South Africa (IDASA); Open Democracy Advice Centre (ODAC); Anglo American; Southern African HIV Clinicians Society (SAHCS); UCT School of Public Health and Family Medicine; and Treatment Action Campaign (TAC). The JCSMF aims to assist with the monitoring and assessment of the implementation of the Operational Plan from a public health and human rights perspective. Its objective is to provide government and the public generally with an ongoing and accurate assessment of the programme’s implementation, to act as an early warning system for problems, and to help communicate successes. To date, the JCSMF has met on five separate occasions and has accordingly issued five reports, which contain the findings of each meeting. These reports are publicly accessible.

INTERNATIONAL TREATMENT PREPAREDNESS COALITION (ITPC) Fact Sheet

What is the ITPC?

The international Treatment Preparedness Coalition (ITPC) is a worldwide coalition of people living with HIV/AIDS and their advocates. The ITPC advocates for universal and free access to treatment for AIDS for all HIV+ people and greater input from HIV+ people in decisions that affect their lives. We work to achieve these goals at the local, regional and international level.

History of the ITPC

In 2002, a group of treatment activists from around the world identified the need for a stronger international response to address the need to provide HIV/AIDS treatment to millions of people who require it around the world. In March 2003, one hundred and twenty five people with HIV/AIDS and their advocates from sixty-seven countries gathered in Cape Town, South Africa at the International Treatment Preparedness Summit to discuss strategies to establish and strengthen:

- Local and regional efforts to educate communities about treatment and mobilize them to demand access to these drugs and;
- local, regional and international efforts to secure the commitment and policy changes needed from governments, multilateral institutions and the private sector to expedite access to treatment for HIV/AIDS.

The ITPC grew out of this meeting as activists from around the world sought to join forces to advance these strategies.

What Makes the ITPC Unique?

ITPC is the only international coalition of people living with HIV/AIDS and their supporters solely devoted to advocacy on HIV/AIDS treatment access. It is a broad coalition of people from all affected regions comprised of people working in and for the community in their own countries and with strong expertise in HIV/AIDS treatment and related issues. As a community voice, it combines the knowledge of the grassroots with technical expertise, and has been successful in communicating the concerns of people living with HIV/AIDS who need treatment to governments, United Nations agencies, the large pharmaceutical manufacturers among other public and private bodies that influence the progress of the establishment, scale-up and sustainability of HIV/AIDS treatment programs.

Collaborative Fund for HIV Treatment Preparedness

Currently, the ITPC has embarked on a partnership with the Tides Foundation, to form the Collaborative Fund for HIV Treatment Preparedness to directly fund local and regional treatment literacy and advocacy efforts. The Collaborative Fund has set up Community Review Panels in each region to locally define funding priorities and make funding decisions on specific projects. Treatment advocacy and literacy workshops have been held or are scheduled in every region and a grant-making program has been initiated to support local organizations' work on these topics. So far, the ITPC and Tides Foundation have raised over US \$5 million for Collaborative Fund activities from various donors some of which include the World Health Organization (WHO), the Rockefeller Foundation, and the Open Society Institute.

Other Activities & Accomplishments

- **Solidarity Day in Support of Treatment Access in South Africa.** In April 2003, ITPC members joined in demonstrations in their own countries to urge the South African government to sign and implement a national treatment and prevention plan that includes antiretroviral treatment for people living with HIV/AIDS.
- **Solidarity Day in Support of Thai Drug Users Network.** In June 2003 ITPC members joined in demonstrations in their own countries to protest the extra-judicial killing of Thai drug users and to press for HIV/AIDS treatment for Intravenous Drug Users.
- **First meeting of people with HIV/AIDS with the Director General of WHO.** In November 2003, a delegation of eight people with HIV/AIDS and their advocates from ITPC travelled to Geneva for the first meeting between a Director General of the WHO and people living with HIV/AIDS from around the world. The group discussed the WHO's 3X5 initiative to scale-up antiretroviral therapy to 3 million by 2005. The group also met with senior staff at UNAIDS and the Global Fund to fight HIV/AIDS, Tuberculosis and Malaria to discuss access to treatment.
- **Inclusion of active drug users in the WHO 3X5 initiative.** In February 2004, ITPC members, supported by over two hundred people which included drug users, HIV-positive people and their advocates from around the globe, called on the Director General of the WHO to ensure the equal involvement of active drug users in the scale-up of antiretroviral therapy proposed by the WHO and take a leading role in recommending governments to make healthcare principles a priority over the law enforcement approach to illicit drug use.

- **Inclusion of Methadone on the WHO's List of Essential Drugs and Medicines.** In collaboration with harm reduction advocates across the world. ITPC members pushed for the inclusion of methadone on the WHO's list of essential drugs and medicines as a part of a comprehensive approach to HIV/AIDS care. Methadone was approved for inclusion on the list in March 2005. This issue was first raised in the ITPC meeting with the WHO Director General in November 2003.
- **World Community Advisory Board Meetings with Brand-Name and Generic Pharmaceutical Companies.** In February 2004, ITPC members met with Boehringer Ingelheim, Glaxo Smith Kline and Roche to discuss concerns about drug pricing and research practices. In particular, ITPC advocated for new policies by multinational companies on pricing for middle-income countries. In January 2005, ITPC members met with generic drug makers, Cipla, Ranbaxy, Hetero and Strides, to discuss quality control over generic manufacturing, paediatric formulations, second-line regimens and pricing policies.
- **Solidarity Day with FrontAIDS in Russia.** In December 2004, ITPC members sent faxes to protest to the police station in Kaliningrad Russia, where dozens of activists from FrontAIDS were being held after staging a demonstration to demand access to treatment and human rights for drug users. All activists were promptly released from custody.
- **Advocacy for the revision of the antiretroviral procurement list in Moldova.** In 2003, ITPC members in the Newly Independent States discovered that Moldova was procuring an expensive, sub-optimal antiretroviral regimen with its grant from the Global Fund. Through advocacy with the Global Fund, the WHO and others, ITPC was instrumental in rectifying this situation.
- **Protest on Health Sector Spending Caps by the International Monetary Fund and the World Bank.** In September 2003, ITPC members sent a letter to the Managing Director of the IMF and the President of the World Bank to urge them to modify macroeconomic policies that keep health sectors from growing to meet the needs of the AIDS epidemic.

Governance & Structure of the ITPC

The ITPC is a social movement, a coalition of individuals committed to treatment access, not a non-governmental organization or a network with a secretariat. This loose structure allows us to invest our energies and resources in our treatment advocacy and literacy work instead of having to sustain an organizational structure and move quickly to adapt and evolve to the changing realities of the epidemic. A Code of Governance for the ITPC is available at:

http://health.groups.yahoo.com/group/internationaltreatment_preparedness

International Steering Group, Regional Advisory Committees and Thematic Working Groups

An International Steering Group (ISG) provides strategic guidance to the movement and deals with critical operational issues. The ISG is comprised of 30 treatment activists, 15 men and 15 women, from the following regions:

- Central & Western Africa;
- Eastern Africa;
- North Africa & the Middle East;
- Southern Africa;
- East Asia & the Pacific;
- South Asia;
- South East Asia;
- Caribbean;
- Central America;
- South America;
- The Baltic's & the Newly Independent States;
- Eastern Europe;
- Australia, New Zealand & Japan;
- Western Europe;
- The United States & Canada

Regional Advisory Committees (RACs) have been established to foster treatment literacy and advocacy efforts in their respective regions and identify issues to be addressed in the international setting.

Funding

The ITPC does not raise funds for day-to-day activities. Members donate their time voluntarily. Funds have been raised for certain projects initiated under the aegis of ITPC (e.g. meeting with generic antiretroviral drug manufacturers), but allied organizations act as the fiscal sponsor and provide financial management for these activities.

Membership

As of December, ITPC had over 600 members from over 100 countries. Membership is invited from all those individuals, people living with HIV/AIDS and their advocates, who are committed to fight for HIV/AIDS treatment access. Members are expected to participate and contribute to the best of their ability. While members are free to act under the name of the movement, they may only act in capabilities that enhance access to treatment, but may not act in formal capabilities such as fundraising without the approval of the International Steering Group. There is no fee or other requirements for membership in ITPC. The ITPC is a coalition of individuals, although members may be active participants or leaders in other local, regional or international networks, NGOs or other groups. Membership in the ITPC is initiated by joining the ITPC email group at <http://health.groups.yahoo.com/group/internationaltreatmentpreparedness>.