

Drawing on the PEPFAR Experience to Inform the Response to the Domestic HIV/AIDS Epidemic



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As mandated by the United States National AIDS Strategy, the Office of the Global AIDS Coordinator at the Department of State provides these recommendations for improving the government-wide response to the domestic HIV/AIDS epidemic, based on lessons learned in implementing the President's Emergency Plan for AIDS Relief (PEPFAR) program.

PEPFAR's Experience

Responding to the extraordinary crisis of global HIV/AIDS, President George W. Bush and a bipartisan Congress launched the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) in 2003. As the largest commitment by any nation to combat a single disease internationally, the program has been a historic step forward in global public health.

U.S.-supported activities through PEPFAR have been wide-ranging. Guided by clear, quantifiable goals, the program has built the human capacity and infrastructure necessary to deliver services in low-resource settings. PEPFAR has supported a diversity of efforts across the continuum of HIV prevention, treatment, and care. It has worked in a remarkably varied array of countries and communities, from places where epidemics are concentrated among specific populations to those where HIV infection is widespread among the general population.

During the past seven years of PEPFAR, the U.S. has made enormous strides in advancing the world's knowledge of prevention, care and treatment. It has proven that interventions can work in even the lowest-resource settings. Through PEPFAR, more than 3.2 million people are currently receiving lifesaving antiretroviral treatment. More than 11.3 million people benefit from its care programs, including nearly 3.8 million orphans and vulnerable children. In the past year alone, more than 33 million received HIV counseling and testing, a key gateway to needed services. Through programs to prevent mother-to-child transmission, approximately 450,000 children have been born free of HIV to date.

Because of PEPFAR, the U.S. has not only had an impact on the millions of people touched by its programs, but also their families and communities. In fact, in addition to achieving Congressionally-mandated targets, the program has also had far-reaching health impacts at the global level. A May 2009 study published in the *Annals of Internal Medicine* found that HIV-related mortality had dropped by 10.5% in 12 PEPFAR countries analyzed by researchers - implying that about 1.2 million deaths were averted due to the work of PEPFAR.

AIDS is still a global emergency, but PEPFAR has brought hope.

During these seven years, the success of PEPFAR has advanced the world's understanding of best practices in delivering prevention, treatment, and care. While there are significant differences between the HIV/AIDS contexts of many partner

countries and that of the U.S., lessons learned from the PEPFAR experience should be considered for their relevance to the domestic arena.

What follows in this report are some practices that help to demonstrate the power that partnerships can have in combating HIV, both in the United States and abroad. These examples represent just one piece of the dialogue between our domestic and international responses, with the promise to strengthen both. The Office of the Global AIDS Coordinator at the Department of State, the Office of National AIDS Policy, and other government organizations will continue to collaborate in highlighting practices that should be used across both our global and domestic epidemics.

This report contains examples of PEPFAR successes in the following areas: care and treatment, prevention, supportive services, and health systems. These examples may be considered for implementation by the government and its other partners in combating the HIV epidemic in the United States. They represent only a few of the successes that have been found in PEPFAR, and more information on the scope of the program and its best practices can be found at www.pepfar.gov.

Care and Treatment

Services for persons living with HIV must address care and treatment for both HIV and their larger health needs. In PEPFAR, the program has worked to provide care and treatment for people in low-resource settings across the developing world. In doing so, it has developed practices that support not only the person living with HIV, but the larger community impacted by the epidemic.

Family-Centered Care

PEPFAR programs support family-centered care – reaching not only the person living with HIV, but their partner, children, and larger family as well. Doing so has allowed PEPFAR to partner with communities to create networks of support and care for those living with HIV, rather than stigmatizing or isolating them.

Co-locating treatment services, coupled with extensive clinical scale-up, has enabled PEPFAR to support ART for over 3.2 million people. Programs in Ethiopia and Tanzania, for example, combine the availability of services for adults and children by providing antiretroviral treatment (ART) as well as services to prevent mother-to-child transmission (PMTCT). By doing so, they have optimized site-level opportunities to retain entire family within the service setting. Pediatric and adult treatment programs are co-located, appointments co-scheduled, and

clinic hours extended to weekends and evenings where possible, or at the sites closely linked for efficient referral.

These co-location successes speak to the importance of providing care to families in a setting where all of their health needs can be met, as well as the ways in which such integrated care can reduce stigma and make it easier for persons living with HIV to access care.

Home-Based Care

In addition to providing comprehensive family-based services at clinics, PEPFAR also supports home-based care. The services provided by home-based care workers, peer support groups, and community health workers can help to improve both health outcomes and quality of life when a person is not at a clinic. Home-based care complements comprehensive facility-based clinical care. PEPFAR maintains oversight and linkage relationships between clinical, home- and community-based care to ensure that HIV-infected individuals have access to a full range of clinical care services. Expansion of health center-level support and supervision occurs in concert with expansion of home-based care, in order to ensure adequate quality in both home and facility settings.

In Thailand, PEPFAR supports a home-based care group of HIV-positive outreach workers to serve populations who face stigma and discrimination. Providing comfort, understanding, and knowledge from their own experiences, the group encourages its members to seek and adhere to ART and other needed services.

In rural southern Malawi, PEPFAR supports a home-based care group that cares for community members living with or affected by HIV and educates fellow community members about the virus and its consequences. The group has played a key role in encouraging people to seek HIV testing and care and treatment as needed, and to seek government benefits to which they may be entitled, such as food support.

Bringing Services to Rural Populations

In countries where PEPFAR works, people living with HIV often reside many miles from the nearest clinic, making it important to bring services to these populations rather than waiting for them to seek them on their own.

PEPFAR supports mobile ART in Zambia's rural Central Province, because many clients are unable to reach hospitals. Covering seven remote locations across Central Province, the team (including community health workers) provides

services, while also training local rural health center staff. Over time, program responsibility is shifting to the health center, freeing the mobile team to expand services to new locations

Other solutions for rural populations rely on innovative technology, as in the case of Health at Home/Kenya, a groundbreaking public-private partnership that includes the Government of Kenya, the Global Business Coalition, and PEPFAR. The partnership works to bring HIV counseling and testing, TB screening, and malaria bed nets to 2 million people in remote households in western Kenya. Health workers use hand-held devices to enter data regarding the family's health, record test results, and document the physical location of the household to guarantee education, counseling and data collection follow-up. Any person identified as HIV-positive during counseling and testing is given an appointment for follow-up clinical care. The program also provides those who test negative for HIV with prevention interventions.

Saving on Drug Costs

Saving money through efficiencies leads directly to saving more lives. To support the increased availability of safe, effective, low-cost, and generic antiretroviral drugs, the Food and Drug Administration reviews drugs for safety and approves them for purchase under PEPFAR. This process has led to 114 antiretroviral drugs being approved for use in PEPFAR programs. By 2008, generics accounted for almost 90% of the 22 million ARV packs purchased, increasing from 14.8% in 2005, and resulting in an estimated cumulative savings of \$323 million. PEPFAR is continuing to work to increase the procurement of generics to increase savings.

PEPFAR has also used its buying power to negotiate volume-based pricing for ARVs. In 2009, PEPFAR purchased 50% of ARVs through pooled procurement via the Supply Chain Management System (SCMS), a consortium of organizations developed and supported by PEPFAR.

In support of country ownership, PEPFAR works with partner governments to support regulatory and policy changes that help to make drugs more accessible through locally-supported supply chains. For example, PEPFAR provided an additional \$120 million to South Africa in 2009/2010 for ARV procurement and to build provincial capacity for planning and forecasting ARV needs. After substantial work by the USG team in country, working closely with SCMS, the South African Government (SAG) made several exceptions to existing restrictive regulatory policies to allow the USG to negotiate for purchase of ARVs at best SCMS prices. To date, over 11 million monthly ARV packs have been purchased and the cost

savings, compared to prices that would have typically paid, are over 50%. Using the USG's experience as a proof of principle, the SAG used a reference price list based on the USG's prices to obtain similar discounts on the drugs it purchases for its national treatment program – the largest in the world.

Overcoming Stigma and Discrimination

Using its public health work as a foundation, PEPFAR supports HIV prevention, care, and treatment activities as a mechanism to advance the rights of people who are marginalized, stigmatized, discriminated against, and denied access to essential care. Advances in expanding access to quality services in low-resources settings have highlighted the discrimination that still exists. For example, stigma results in individuals not adhering to treatment because doing so will mean explaining to others exactly why they are taking medication. Fear of disclosure means that children stop receiving HIV services because their mothers can no longer pass off frequent clinic visits as routine pediatric monitoring. PEPFAR works with its partner countries to provide impartial, science-based information, education, care and support services.

One key area of emphasis is support for marginalized populations as an essential part of country engagement. Discussions with partner governments are addressing the need for health and social service structures that are responsive to all people living with and at-risk for HIV. Doing so requires policies that address the drivers of the epidemic and provide equitable access to quality services for marginalized populations. By demonstrating the public health benefits that result when prevention, care, and treatment are provided to otherwise stigmatized communities, PEPFAR is emphasizing the importance of a comprehensive, inclusive response. PEPFAR works with health care workers to address the issues around adherence and retention in care that arise when people who are HIV-positive are unable to disclose their status in unsupportive communities. In particular, PEPFAR trainings, guidance, programming, and engagement with countries are geared to help with the identification and targeting of “double stigma.” This term refers to the stigma faced by people who are both HIV-positive and part of a marginalized population – for example, HIV-positive men who have sex with men (MSM).

Another area of focus that combats discrimination is intensive engagement with persons from most-at-risk or targeted populations in the planning and implementation of national HIV programs. Representatives from key populations, including people living with HIV (PLWH), are included in all aspects of the programming that serves them. PEPFAR is working with partner governments and others to incorporate PLWH in planning, prioritization and implementation of

national HIV programs. Greater involvement of intended recipients of services enables programs to be culturally appropriate and configured for optimal effectiveness.

Prevention

Tailoring Combination Prevention to Country Context

PEPFAR seeks to focus appropriate prevention interventions at the right scale targeted to the right populations. The Global Health Initiative has brought a heightened commitment to inform global health programming with the best available scientific knowledge, and PEPFAR thus emphasizes using data to adapt and improve programs – by understanding where, why and in whom infections are occurring, both in terms of geography and in terms of vulnerable populations, and tailoring programs accordingly.

By combining quality biomedical, behavioral and structural interventions -- known as "combination prevention" -- countries can work over time in given geographic areas to craft a comprehensive prevention response adapted and prioritized to specific contexts. In this second phase of PEPFAR, the program is intensifying its support for focused combination prevention efforts that mirror the progress in treatment achieved through combination therapy.

Behavioral interventions are geared to motivate behavioral change in individuals, couples, families, peers groups or networks, institutions, and entire communities. PEPFAR is dramatically strengthening biomedical interventions (e.g. medical male circumcision, prevention of mother-to-child transmission, and blood and injection safety) that block infection or decrease infectiousness. And PEPFAR is working with countries to promote structural interventions that change the context that contributes to vulnerability and risk, such as restrictions on property ownership or inheritance for women, and laws that marginalize at-risk groups and limit their ability to access services.

In order to help identify populations most in need of prevention interventions, PEPFAR works with national governments to strengthen national HIV biologic and behavioral surveillance and information systems. This data collection allows for documentation of HIV-related epidemiological and social trends pertinent to key populations, including vulnerable women and girls, sex workers, men who have sex with men, and injection drug users. Programs are working with countries to establish and implement clear national HIV prevention plans with specific, time-bound targets based upon these survey results. A new priority for the program is

the development of affordable, user-friendly tools to identify, characterize, and measure key social drivers that contribute to HIV risk and vulnerability.

At the country level, PEPFAR encourages combination prevention activities that provide comprehensive coverage for the most affected populations and localities, and program content that directly addresses the key drivers of the epidemic. This is resulting in some realignment of activities to ensure that both “hot spots” (areas of high transmission) and key populations are covered with sufficient intensity of quality interventions. It is akin to the increased domestic focus on addressing populations – such as young gay men of color – who have experienced increased incidence.

In order to better document the demographics of the epidemic, PEPFAR is supporting countries to complete rapid assessments, mapping, and size estimation activities for most-at-risk populations (MARPs) and other vulnerable populations, to determine the amount of coverage needed, identify locations where interventions can reach the targeted groups, and tailor services for the local context.

For example, PEPFAR supported the Government of Kenya’s Ministry of Health in conducting a Kenya AIDS Indicator Survey (KAIS), in order to understand the drivers of the country’s epidemic at a detailed level. Following the data collection and analysis, PEPFAR and the Ministry supported a series of HIV Prevention Summits, which fed findings from the KAIS into a National HIV Prevention Strategy. This Strategy was then reflected in the Partnership Framework between the U.S. and Kenya, which relied on the data to establish joint prevention objectives, with numerical goals where appropriate, and indicated which partner is responsible for which activities for each activity. For example, the survey data indicated a need to provide additional prevention efforts for the MSM community in specific regions, and PEPFAR has collaborated with the government to address that need through increased activities for these populations. As a result, comprehensive programming for the MSM community now exists in all eight regions of Kenya, compared to three regions in 2009. This programming is complemented by an ongoing public health surveillance effort which will inform the government on how to better meet the needs of the MSM community.

The Kingdom of Swaziland has the world’s highest national HIV prevalence, as well as low prevalence of male circumcision (MC), which was scientifically validated in recent years as highly protective against HIV infection. The PEPFAR team saw the value of MC as a central piece of a combination prevention strategy tailored to the drivers of the national epidemic. Using epidemiological data and cost modeling, PEPFAR built the government’s understanding of the potential of

MC as part of its HIV prevention strategy, along with behavioral, structural and other biomedical interventions such as PMTCT. For a country with Swaziland's epidemic, it became clear that MC is an excellent investment, as it is a one-time intervention that provides lasting prevention benefits. The majority of the expenditure required to saturate a country with high levels of adult male circumcision takes place in the first 1-3 years, depending on the speed of the program, and expenditures drop precipitously following this initial investment to support neonatal and adolescent boys. The discussions led to Swaziland's Accelerated Saturation Initiative, an unprecedented effort to roll out MC for HIV prevention to achieve rapid coverage at a national level. The initiative will provide voluntary MC to between 125,000-175,000 Swazi males 15-49 years of age in a 12-month period. Mathematical modeling studies suggest that circumcising 80% of 15-49 year old HIV-negative males within one year may prevent one new HIV infection for every 3-4 male circumcisions performed.

Confronting Gender-Based Violence

In much of the world, the face of HIV is a woman's face. One contributing factor to this reality is the tragedy of gender-based violence (GBV), which is a driver of global AIDS. While the roots of GBV are complex, HIV programs can play an essential role in protecting women and girls.

The U.S. worked with the Ugandan government and other partners to design the Northern Uganda Malaria, AIDS and Tuberculosis program (NUMAT) to address GBV. The stress induced by years of war and violence, tight living quarters, constant threats to safety, and limited access to safe drinking water, food and shelter has resulted in psychological trauma and a high incidence of alcohol and drug abuse. These factors have deeply fractured normal human relationships and normalized violence in Northern Uganda, especially GBV. With PEPFAR support, NUMAT brings police, community leaders, women and young people together to raise awareness and strengthen reporting, treatment services and systems that address GBV. The program works with communities to show members the connection between HIV transmission and GBV and provides solutions to eliminate this problem. It nominates "animators," individuals trained to identify GBV, report incidents, and refer victims for medical and psychosocial treatment. Animators also provide mediation services, offer consultation and advice, and escort victims to the police or health clinics for treatment. Through this multisectoral approach that brings law enforcement together with women who are leaders among their peers, PEPFAR has been able to address several of the structural issues limiting care and treatment for GBV and its associated HIV risks.

Couples Counseling

Too often, another point of vulnerability for women is receiving an HIV diagnosis. Partners of women who receive a positive diagnosis sometimes react violently, creating risks for women. Women who test positive may have trouble seeking care and treatment without the consent of their partners. An important strategy that addresses GBV risk in the context of HIV prevention is couples counseling, where both partners receive their test results together in the presence of a trained counselor who can provide information, condoms, and other support to help the couple see a hopeful future. Doing so helps to ensure that women and men get the post-test care and treatment that they need, and that they can live healthier lives. PEPFAR supports couples counseling in countries such as Zambia and Kenya, and is working with Lesotho as that nation revises its HIV testing policy to support couples counseling.

Working with Men to Address Gender Norms

Prevention for women necessarily involves working with men, particularly men facing elevated risk. To cite one example, PEPFAR supports military-to-military partnership to prevent new HIV infections and improve the quality of life for people living with HIV. PEPFAR supports efforts to train peer educators in HIV prevention and hold group counseling sessions before soldiers are tested for HIV. Soldiers provide fellow military members with educational materials for reference prior to deployment and organize follow-up HIV education sessions at deployment sites. In their units, these peer educators also serve as role models for behavior change.

Meeting the Needs of Most-at-Risk Populations (MARPs)

PEPFAR supports the creation of environments that are supportive of services for MARPs. Its programs include country-driven, evidence-based interventions, based on current epidemiology and developed and implemented with respect for human rights of MARPs. Country leadership, including engagement with multiple sectors of government and collaboration with civil society, has proven essential in developing and implementing, at all levels, the necessary supportive legislation, policies and regulations that facilitate the creation of enabling environments and scale-up of services. PEPFAR has taken a number of actions, building on international consensus, to increase access to an evidence-based comprehensive package of prevention, treatment, care and support.

PEPFAR has provided guidance to the field on comprehensive HIV prevention for IDUs. It describes a package designed to ensure effective country-level responses to preventing the further spread of HIV in this population, including: needle and

syringe programs (NSPs), expansion of methadone and other medication-assisted-therapy (MAT) for HIV- negative and HIV-positive IDUs, ART, community-based outreach, condom distribution, HIV testing and counseling and other services related to prevention of STIs, and TB care.

PEPFAR programs promote comprehensive HIV prevention for MSM, responding to the urgent need to strengthen and expand HIV prevention for MSM and their partners and to improve this population's ability to access HIV care and treatment. Programs address elements such as community-based outreach, distribution of condoms and condom-compatible lubricants, HIV testing and counseling, active linkage to health care and ART, targeted information, education and communication and STI prevention, screening and treatment. PEPFAR is also convening regional meetings on IDUs and MSM to support country teams to plan, implement and monitor high-quality, high-volume, and evidence-based comprehensive interventions.

In Indonesia, PEPFAR supports a community-based organization to provide prevention services to MARPs, including female sex workers. Through PEPFAR support, the local organization has worked with local government leaders to highlight HIV risks facing women in prostitution. This ultimately resulted in a new local ordinance on the HIV response, which enshrined support for PLWH in law and committed the local government to delivering HIV services to all populations.

Supportive Services

Income Generation and Economic Stability

People living with HIV often not only face health challenges, but challenges of poverty that can limit their ability to seek care for HIV. PEPFAR thus supports activities focused on income generation and economic stability for people living with or affected by HIV. Programs provide not only prevention services and medical treatment to help people stay healthy, but a variety of microcredit and income generation projects that allow persons living with HIV or at risk for HIV to make a living and sustain themselves and their families.

These programs target a variety of populations in need of support. In Ethiopia, PEPFAR has supported urban gardening projects that serve both HIV-positive women and vulnerable children. The gardens have allowed the women and children to earn a living, while also supporting them to adhere to treatment and stay in school.

People at high risk of HIV often benefit from programs to provide income generation options. A program in Guyana supports women engaged in sex work, providing them with alternative opportunities for income to survive. Many have been able to leave prostitution as a result, and some have taken on the role of peer educators, attempting to show the possibility of a better life.

Health Systems

Innovative Technology for Patient Monitoring

Patient monitoring provides special challenges in the developing world, where infrastructure is limited and many people live far from the nearest health center. PEPFAR has partnered with private sector organizations (such as Accenture Development Partners, GSM Association, Motorola, MTN, and Voxiva) in an innovating effort to use technology to ease the burden. Phones for Health is currently operational in Kenya, Tanzania, and Rwanda, supporting HIV monitoring, infectious disease surveillance and response, blood transfusion services, and other health data collection and reporting services. With these services, rural providers and residents can seek preventive care in a timely manner, rather than seeking more expensive treatment only when they are gravely ill.

Health Worker Task-Shifting

Task-shifting is an effective strategy for expanding the health care workforce. Through task-shifting efforts, health care workers are trained to engage in targeted tasks that alleviate the burden on doctors and nurses, thus expanding the reach of the health care system. Policy change to allow task-shifting from more specialized to less specialized health care workers is one strategy with immediate effect on increasing the pool of health workers to deliver HIV/AIDS services. Ethiopia, Mozambique, Kenya, and Malawi are among the countries which created new cadres of health care workers to assume tasks formerly provide by doctors and nurses. Appropriate training, supportive supervision and re-training of these cadres are essential for effective task-shifting. Training health and community workers is fundamental to implementing high quality programs, and from 2004-2009 PEPFAR trained and retrained over 5.2 million individuals to perform a broad range of HIV-specific services.

Streamlining Commodity Logistics

PEPFAR established a Supply Chain Management System (SCMS) to strengthen commodity delivery. Working through SCMS, PEPFAR has become more efficient in shipping needed medicines in a timely fashion by using water and land delivery systems instead of air freight, reducing costs by as much as 90%. In 2009,

PEPFAR through SCMS, saved over \$3.2 million by using sea freight for appropriate ARV shipments. Sea freight charges for products PEPFAR moved through SCMS were \$520,000, while moving the same volume by air would have cost an estimated \$3.8 million. Similarly, in 2009, PEPFAR saved \$557,000 on purchases through SCMS by use of road freight. Road freight charges for the product PEPFAR moved through SCMS were \$395,000, while to move the same volume by air would have cost an estimated \$953,000.

Using PEPFAR Platforms During Disaster Response

Natural disasters and conflict create situations of stress for entire health systems. During these times, persons living with HIV may require care and treatment in addition to their medication. PEPFAR works in places emerging from conflict and supports emergency and follow-up care in places with natural disasters. Following the tragic Haiti earthquake, PEPFAR has worked closely with NGO partners with significant PEPFAR-supported infrastructure to ensure continued availability of HIV services, and to make their capacity available to address the range of health needs. PEPFAR's 109 sites formed the backbone of the response both in the immediate aftermath and reconstruction post-earthquake. More broadly, PEPFAR engaged the outpouring of support from companies and individuals, working with the NGO community and UN Health Cluster to effectively match high-value donations to the needs on the ground. PEPFAR has reached out to other partners, including medical service providers and social support programs, to assess their status and needs. Through PEPFAR and other child-centered programs, the U.S. is actively involved in supporting programming targeting the survival, safety, and psychosocial needs of orphans and vulnerable children, while strengthening the capacity of families in Haiti to care for their children.

Drawing on Private Sector Core Competencies

PEPFAR collaborates with the private sector through public-private partnerships (PPPs), leveraging its core competencies to accomplish PEPFAR's goals of HIV/AIDS prevention, treatment and care. PPPs help ensure sustainability of programs, facilitate scale-up of interventions, and leverage private-sector resources. Partners include U.S. and non-U.S. businesses, small and medium-sized enterprises, business and trade associations, labor unions, foundations, and philanthropic leaders, including venture capitalists.

To date, PEPFAR has leveraged nearly \$190 million in planned contributions from the private sector in 22 country programs, including cash, in-kind technical expertise, and access to networks and innovative approaches. The value of public-private partnerships is not measured in money spent, but rather impacts amplified,

especially health systems strengthened through building the technical and managerial capacity of country counterparts. PEPFAR PPPs would not have the impact they do through government or NGO activity alone – it takes the unique know-how of the private sector to make it happen. PEPFAR also taps the creative energy of the private sector to drive innovation in approaches to prevention, health financing, and disease management.

Key examples of leveraging the core competencies of the private sector to meet HIV/AIDS challenges include:

- Working with Warner Bros. to create a cutting-edge interactive HIV prevention video game in Kenya
- Partnering with MTV to create a hard-hitting docudrama (“Shuga”) that promotes HIV prevention and care and that aired pan-Africa and beyond
- Bringing in Becton Dickinson experts to improve laboratory and blood-drawing practices of African health workers
- Working with the Nduna Foundation and others to address the epidemic of gender-based violence (GBV), a key driver of HIV, by mapping GBV threats and tailoring responses to local situations