PEPFAR: MEASUREMENT AS A MANAGEMENT TOOL

A CORE VALUE FROM THE BEGINNING

A REPORT SERIES ON LESSONS LEARNED FROM PEPFAR'S SUCCESS
VOLUME 1

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The President's Emergency Plan for AIDS Relief (PEPFAR)

PEPFAR is the largest commitment by a nation to combat a single disease. Launched by President George W. Bush in 2003, it has invested almost $100 billion to date, both directly and through the Global Fund to Fight AIDS, Tuberculosis, and Malaria and other multilateral institutions. PEPFAR has saved more than 20 million lives over the last 20 years. It has enjoyed overwhelming bipartisan support across four successive administrations, within Congress, and among a diverse array of stakeholders, including civil society and the faith-based community. This series of papers will examine critical lessons learned from PEPFAR and make recommendations for the program's future as well as continued U.S. global engagement.

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THE BUSH INSTITUTE'S PERSPECTIVE

Visionary leadership is critical for tackling seemingly intractable problems. Americans should be proud of how many lives they have saved and changed around the world through their generous contributions via the President's Emergency Plan for AIDS Relief (PEPFAR). At the George W. Bush Institute, we are committed to celebrating and continuing the program and to using our voice to ensure the United States can reap the benefits of its lessons. We believe PEPFAR's success derives in large part from its focus on accountability, made possible by its collection and use of real-time data to drive constant programmatic improvement and efficiencies, which have allowed for the expansion of lifesaving services despite a flat budget. PEPFAR has been a win for both the countries it serves and for U.S. foreign policy. Congress and the American people should continue to support its critical work.

Introduction

When President George W. Bush announced the President's Emergency Plan for AIDS Relief (PEPFAR) in his State of the Union address in January 2003, he was harnessing the generosity of the American people to confront a crisis that was devastating many resource-limited countries. The president committed the U.S. government to step up and challenged the rest of the world to do the same. His vision for PEPFAR was a comprehensive response that would combat HIV and AIDS by combining prevention, treatment, and care for the first time. He outlined an innovative approach to managing foreign assistance that became equally important as well as integral to PEPFAR and its later success: a new, whole-of-government structure and required, quantifiable results linked to the investment (initially $15 billion over five years).

Clear Goals and Expected Results

When Congress authorized PEPFAR in May 2003, it also did something new: It formalized the link between PEPFAR's funding and results. The law codified the president's goals of reaching 2 million people with lifesaving treatment for AIDS; preventing 7 million new infections; and caring for 10 million children and adults either living with or affected by HIV, including orphans and vulnerable children who had already lost parents to the disease. Progress was to be measured every six months. Linking dollars to specific results enabled a swift humanitarian response to the devastation of AIDS around the globe.

These clear goals drove and sustained the program's achievements and incentivized building accountable partnerships that fit the specific requirements of each country. PEPFAR hasn't been just about saving lives, but doing so in the most-effective, highest-quality manner with the greatest impact. This is only possible through the constant collection and use of data.

Outputs to Outcomes

PEPFAR has continued to evolve over the past two decades, moving from counting the dollars spent and the numbers of adults and children reached to tracking identifiable outcome measurements. This has allowed the program to chart a clear roadmap to control the HIV epidemic. The outcome measurements include

ensuring undetectable levels of virus in the blood of everyone living with HIV so that they can survive and their families can thrive. The program uses real-time data to drive continuous improvement, to detect fraud, and to make certain every taxpayer dollar has measurable impact. PEPFAR did not adopt this approach for the purpose of reporting to Congress, but to create an adaptive program that responds to changes quickly and provides beneficiaries with the best possible prevention, care, and treatment services.

At the beginning, PEPFAR only tracked the total number of children and adults on treatment for HIV, without breaking out sex or specific age bands from every service-delivery site. The pandemic's disproportionate impact on women and young girls was a special concern for President and Mrs. Bush, but not all PEPFAR site were counting men and women separately. It also distinctly did not count orphans and vulnerable children (OVCs) under 14 or the number of people reached with prevention messaging. Despite the limited collection of data, PEPFAR made tremendous progress in treatment within the first year, tripling the number of people taking antiretroviral therapy (ART) in sub-Saharan Africa, according to PEPFAR's first annual report to Congress. The sickest – who were already coming to clinics and hospitals deathly ill – finally began to receive lifesaving medicines. By January 2007, PEPFAR was treating 1.4 million people, and had achieved its initial goal of 2 million people on ART by the end of 2008, as stated in PEPFAR's annual reports to Congress in 2008 and 2009.

Changing Practice and Policy

Advancing from that promising start to mass treatment required constant attention to costs as well as making the best medications available to the program. The George W. Bush Administration pushed the U.S. Food and Drug Administration to issue tentative approvals for new, cheaper generic versions of patent-protected antiretroviral drugs (ARVs), including new, highly effective combination regimens for adults and children. These approvals allowed PEPFAR and the Global Fund to purchase nearly 200 new HIV drugs and provided a powerful incentive for more global generic manufacturers to enter the market. Within a few years, this greatly expanded the types of highly effective, low-cost ARVs available to PEPFAR's clients.

At the same time, data drove the needed policy changes in host countries to ensure access to both prevention and treatment services across all communities, ages, and risk groups. Some of the essential innovations came not from clinical research trials but from bold actors at the country level. For example, the World Health Organization (WHO) originally recommended ART only for those with late-stage disease. In 2010, the government of Malawi moved unilaterally to provide lifelong treatment for all HIV-positive pregnant women, regardless of the stage of their infection. This courageous policy, known as "B-Plus," ensured all moms could live to raise their children and simultaneously decreased HIV acquisition by unborn babies during pregnancy and infections related to breastfeeding among infants. Data from the successful countrywide implementation in Malawi pushed the WHO to recommend the widespread adoption of B-Plus, a move that began changing the course of the global HIV pandemic.

New Goals Require New Data

The groundbreaking experience in Malawi led UNAIDS, the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and PEPFAR to recognize that receiving treatment could both lower the amount of virus in the blood of HIV-positive clients (called viral load) and prevent transmission. Together they began to push for a "treat all" strategy: starting all people living with HIV on ARVs at the time of their diagnosis, rather than waiting for them to get significantly ill with severe destruction of their immune system. In 2015, the global community committed to end AIDS by 2030 as part of the U.N. General Assembly's sustainable development goals,

and UNAIDS seized the moment in partnership with PEPFAR to set the “90/90/90” objectives. These called for 90% of people to know their HIV status, 90% of those HIV-positive to be taking lifesaving treatment, and 90% of those treated to have undetectable levels of virus in their blood by 2020. The objectives were subsequently updated to 95/95/95 for 2030, with added goals of zero new infections, zero deaths, and zero discrimination.

Because leaders of PEPFAR-supported countries were committed to the global goals, PEPFAR created a new, comprehensive response to the HIV pandemic – reevaluating all its data elements and reporting structures to ensure its programming was consistent with the new worldwide HIV strategy. More granular data was needed to track viral load and to make sure that no one was excluded from treatment and prevention services. In particular, the continuing gaps in information about whether PEPFAR, the Global Fund, and other programs were reaching enough women and young girls had become an urgent problem.

It became clear that, to ensure progress county by county and country by country, PEPFAR had to collect more age- and sex-disaggregated data. It also needed to develop and implement community-level surveys. PEPFAR responded by starting a revolution in accountability and impact, powered by granular data paired with GPS coordinates and more transparency. This change has transformed global health and U.S. foreign assistance forever.

> *“If we look back, [PEPFAR] has taught us monitoring and evaluation. It has taught us better planning. It has told us to find the gap when we didn’t reach our targets.”*
>
> *— Dr. Anges Binagwaho*
>
> *Former Minister of Health of Rwanda, The Lazarus Effect, 15 Years Later, 2018*

Data Drives Change

PEPFAR has refined this approach every year. By using data to allow managers of PEPFAR programs to drive the performance of implementers and partners, it has improved the quality of services and increased access for all clients – including those in the most rural and the most urban areas – and pushed policy changes at the national level. These are some of the major advances:

- From the beginning, PEPFAR was careful to make a distinction between direct (originally called downstream) results, which counted only those unique individuals served at sites funded directly by the program, and indirect (or upstream) results. President Bush was committed to ensuring the full participation of women in PEPFAR’s activities, and the program set the goal that all implementing partners should report treatment data for both men and women.
- In 2004, PEPFAR began funding and providing training for nationwide, population-based AIDS Indicator Surveys and included testing for HIV in large-scale Demographic and Health Surveys, both of which collected blood samples to establish a more accurate picture of the overall prevalence of HIV and the number of new infections that were occurring each year (called incidence).
- In 2005, PEPFAR introduced Geographic Information Systems (GIS) mapping and geospatial modeling to follow changes in the epidemic and plot the rollout of services.
- In 2006, PEPFAR rolled out the first of many data-quality tools designed to improve the accuracy of its reporting of results.
- In 2007, PEPFAR started to assist national governments in mapping the location of sites that provided treatment and care for HIV.
- In 2012, PEPFAR introduced analyses of its expenditures linked to results and shared the data with national governments to help them understand the cost of HIV services.
- In 2014, PEPFAR began requiring sex-specific data from all sites, which allowed the program’s managers to see clearly how much men were underserved in treatment and women in prevention. This spurred additional innovation to increase access to testing and treatment services for men and

create new ways to keep women and girls safe.

- In 2015, PEPFAR started tracking data disaggregated by age band. This showed that children, especially between the ages of 10 and 18, were also severely underserved in both treatment and prevention.
- In 2015, PEPFAR created the first multicountry analyses of HIV prevalence, incidence, and behavioral findings, called Population-Based HIV Assessment Surveys (PHIAs). They provided greater insight into trends at the household and community level and were faster than traditional methods. Funded serially through 2025 through the Centers for Disease Control and Prevention and implemented by ICAP at Columbia University, the PHIAs have clarified who PEPFAR is serving and who the program is missing. Most importantly, the PHIAs showed that most people under 25 did not know their HIV status, and that most who were HIV-positive were not receiving treatment.
- In 2016, PEPFAR required all its partners to provide geolocation data for the specific sites where they were working.
- In 2016, PEPFAR streamlined and increased reporting to a quarterly schedule, with monthly reporting from sites that were significantly underperforming.
- In 2017, PEPFAR began to publish all disaggregated site-level data in a transparent format freely available on PEPFAR.gov.

The product of this evolution was granular age- and sex-disaggregated data, matched with local demographic and geographic information, that showed communities, governments, and PEPFAR the gaps in their collective programming. Despite more than a decade of funding from PEPFAR and the Global Fund, it took the combination of these data sources to finally reveal the communities, key populations, and ages without access to services. The data enabled real-time course corrections and continuous programmatic improvements and provided the evidence to advocate for changes to country-specific policies that were creating structural barriers to access or hindering a comprehensive response to the HIV pandemic. The site-level disaggregated data allowed partners and communities to hold the program accountable for quality services executed in a cost-effective manner and focus on improving the health of the clients they were serving. The data also identified both high-performing and low-performing sites, from laboratories to clinics, and facilitated the sharing of best practices across them. This created local ownership and pride in improving outcomes for their clients.

The refined surveys and sophisticated collection and analysis of data reshaped PEPFAR's funding decisions. The program became laser-focused on ensuring that those in the greatest need were receiving prevention and treatment and reoriented allocations so that every dollar spent resulted in the outcomes and impact needed to fulfill the new global HIV strategy published by UNAIDS. PEPFAR realigned funding within and across countries based on need or equity and invested in specific new initiatives to address the clear gaps in services that were now visible in the data. Although PEPFAR's budget had been flat or declining since 2009, the Office of the U.S. Global AIDS Coordinator created financial flexibility to pay for these new efforts through increasing efficiencies and eliminating any duplication with the Global Fund.

The new initiatives targeted populations that PEPFAR's data showed had been missed or underserved by all HIV/AIDS programs. These efforts saved hundreds of thousands of additional lives without sacrificing quality or coverage for PEPFAR's core beneficiaries during its first 10 years – adult and pregnant women:

- Beginning in 2011, PEPFAR greatly expanded access to voluntary medical circumcision as part of the comprehensive set of interventions to protect young men from acquiring HIV.
- In 2014, PEPFAR launched Accelerating Children's Treatment to bring ARVs to more youngsters.
- In 2015, PEPFAR created the DREAMS (Determined, Resilient, Empowered, AIDS-Free, Mentored, and Safe) program focused on preventing HIV infection in girls and young women ages 10 to 22.

- In 2015, PEPFAR adopted the “test and start” policy to ensure everyone had access to HIV testing and immediate access to lifelong HIV treatment.
- In 2016, PEPFAR started MENSTAR to address the gap in male HIV diagnosis and access to treatment. This public-private partnership conducted focus groups to understand the unique challenges men had with health care; participants asked for greater protections for their anonymity and for clinics to open early and close late to allow them to stop in on the way to and from work.

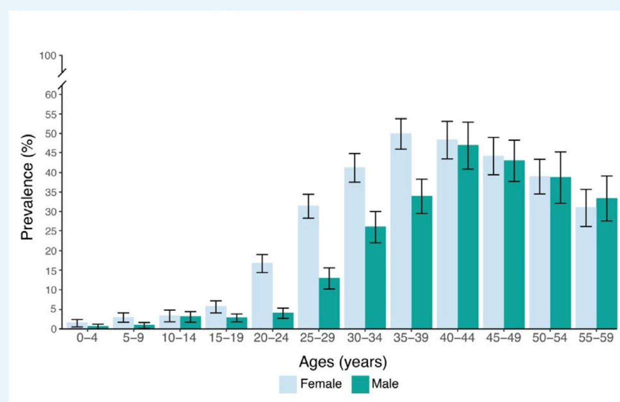
In a virtuous cycle, PEPFAR collected data on its new initiatives and then improved them. The results showed remarkable innovation on the ground could be expanded within countries and immediately transferred to others.

Lesotho Case Study

A great example is what happened in the Kingdom of Lesotho. To address the gaps in male treatment, the government started male testing-and-treatment clinics in storefronts that opened early and closed late; the facilities employed male nurses and physicians to address the concerns men had raised. The Ministry of Health also launched age-specific services to create peer support. At the same time, granular site-level and survey measurements anchored the program in a client-centered approach to ensure access independent of location or risk group. In 2018 and 2019, the Ministry of Health, PEPFAR, and their partners used the data and recommendations from the community to drive access to better HIV drugs and modify services to make testing, treatment, and compliance easier. Most effective was the introduction of multimonth prescribing to decrease the number of visits to clinics for stable clients.

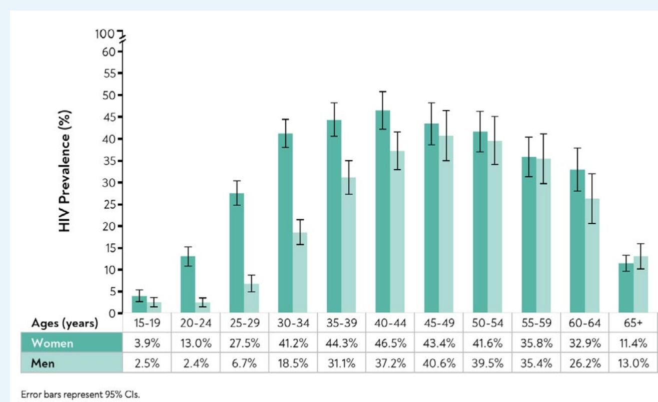
The results of this approach are clear. The combined use of data, policy changes to lower barriers to access, and a constant drive to heighten programmatic quality produced significant improvements in outcomes for clients and impact at the country level. These changes occurred across PEPFAR’s programs from HIV awareness to HIV testing to HIV treatment and continuous access to HIV drugs to maintain suppression of the virus in patients. A series of surveys from Lesotho in 2016 and 2017 and repeated in 2020 and 2021 showed a decrease in HIV prevalence in the younger age bands, with fewer new HIV infections and stable or increased HIV prevalence in the older age bands as clients survived despite HIV infection (Figure 1, Panels A and B). The survey also illustrated HIV prevalence by geography, with regions and potential requirements to adjust investments highlighted (Figure 2, Panels A and B).

Figure 1, Panel A: HIV prevalence by age and sex, 2016-2017



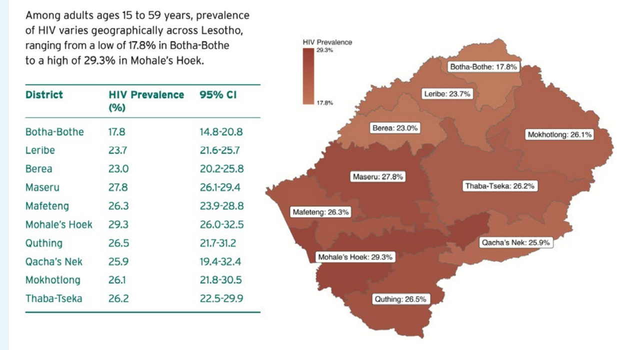
Source: Lesotho Population-Based HIV Impact Assessment, 2016-2017

Figure 1, Panel B: HIV prevalence by age and sex, 2020-2021



Source: Lesotho Population-Based HIV Impact Assessment, 2020

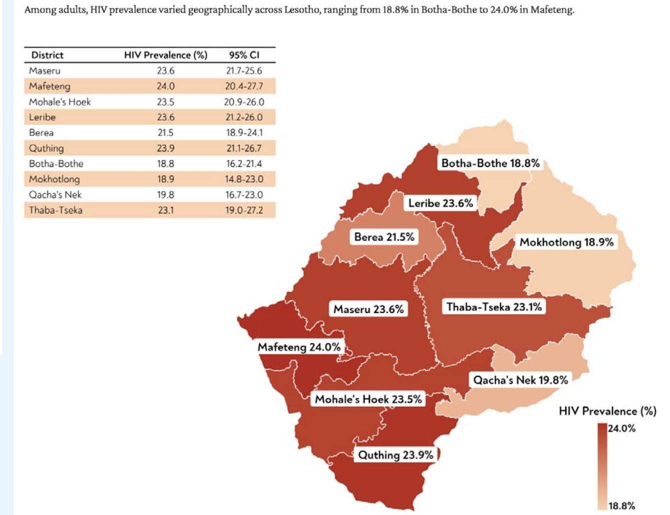
Figure 2, Panel A: HIV prevalence among adults by district, 2016-2017



District	HIV Prevalence (%)	95% CI
Botha-Bothe	17.8	14.8-20.8
Leribe	23.7	21.6-25.7
Berea	23.0	20.2-25.8
Maseru	27.8	26.1-29.4
Mafeteng	26.3	23.9-28.8
Mohale's Hoek	29.3	26.0-32.5
Quthing	26.5	21.7-31.2
Qacha's Nek	25.9	19.4-32.4
Mokhotlong	26.1	21.8-30.5
Thaba-Tseka	26.2	22.5-29.9

Source: Lesotho Population-Based HIV Impact Assessment Summary Sheet, 2016-2017

Figure 2, Panel B: HIV prevalence among adults by district, 2020-2021

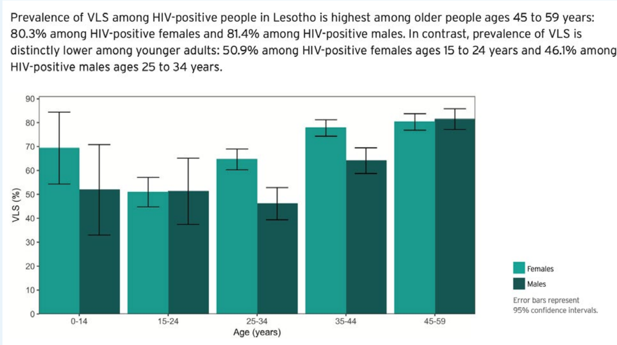


District	HIV Prevalence (%)	95% CI
Maseru	23.6	21.7-25.6
Mafeteng	24.0	20.4-27.7
Mohale's Hoek	23.5	20.9-26.0
Leribe	23.6	21.2-26.0
Berea	21.5	18.9-24.1
Quthing	23.9	21.1-26.7
Botha-Bothe	18.8	16.2-21.4
Mokhotlong	18.9	14.8-23.0
Qacha's Nek	19.8	16.7-23.0
Thaba-Tseka	23.1	19.0-27.2

Source: Lesotho Population-Based HIV Impact Assessment Summary Sheet, 2020

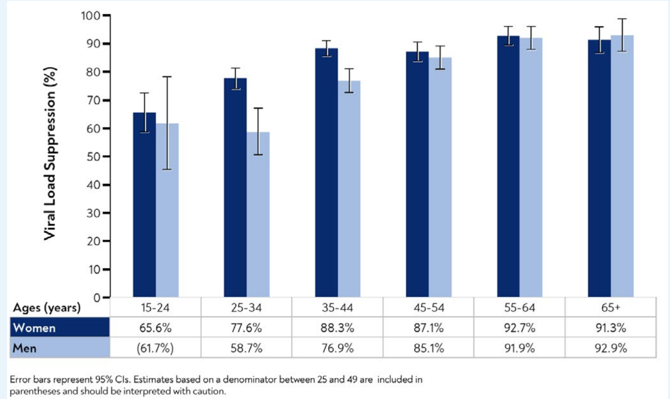
Panel A (2016-2017) and Panel B (2020-2021) of Figure 3 show age- and sex-specific improvements in access to lifesaving treatment and effective viral-load suppression across age groups, including a dramatic increase across all males and especially in young men and young women. These data streams, analysis, and focus on the quality and ease of services were critical to ensuring access to continuous treatment in Lesotho despite the COVID-19 pandemic.

Figure 3, Panel A: Viral load suppression among people living with HIV by age and sex, 2016-2017



Source: Lesotho Population-Based HIV Impact Assessment Summary Sheet, 2016-2017

Figure 3, Panel B: Viral load suppression among adults living with HIV by age and sex, 2020-2021



Ages (years)	15-24	25-34	35-44	45-54	55-64	65+
Women	65.6%	77.6%	88.3%	87.1%	92.7%	91.3%
Men	(61.7%)	58.7%	76.9%	85.1%	91.9%	92.9%

Source: Lesotho Population-Based HIV Impact Assessment, 2020

Conclusion

PEPFAR's achievements owe much to its decision-making and implementing architecture – responsibility for meeting ambitious targets coupled with the necessary authority to do so and clear lines of accountability with results measured in actual human lives, rather than process.

The goals of PEPFAR today are the same as when President Bush announced it: No matter where you live or what community you're from in PEPFAR's partner countries, the program wants to ensure you have access to quality prevention and treatment services. PEPFAR and its partners in government and at the community level are using data to calibrate interventions to the right places at the right time, to see who they are missing, and to perform immediate corrective actions. The same improvement in the HIV pandemic seen in Lesotho is visible almost everywhere PEPFAR is working, country by country, ageband by ageband, and across sexes. Data allow the program to find the sites that are high performers and learn from them and to spot the ones that are underperforming so they can correct shortcomings. Data let PEPFAR see clients at each delivery site to ensure everyone who needs services is receiving them; to expand access to people it has never reached; to locate those who have dropped out of treatment; and to correct the financial, physical, and cultural barriers to services.

Changing the course of pandemics requires strong leadership combined with the localized collection and analysis of consistent data. It also requires the use of this information in real time to save lives with high-quality, effective medical care, to prevent new infections with high-quality interventions, and to improve the overall impact of taxpayers' investments. U.S. government health and foreign-assistance programs can and should adopt PEPFAR's approach to data. Collecting data without continuous programmatic improvement and adjustment is a bad use of money and time and a betrayal of the people these programs aim to serve.

Recommendations

The United States should learn from PEPFAR's use of data and data analytics in the following ways to improve domestic health care and the U.S. government's assistance overseas:

Congress:

Congress should require that recipients of U.S. foreign-assistance funds that are working to support individual service-delivery sites collect geospatial coordinates for each site location.

The U.S. Department of Health and Human Services (HHS):

HHS should cross-analyze all available data sets at HHS Operating Divisions to identify who is missing from critical prevention and treatment services for our domestic pandemics, from opioids to COVID-19 to obesity.

All U.S. government departments and agencies that implement foreign assistance:

These departments and agencies should regularly and consistently collect validated data broken down by gender and age group across all sites. Each site should be matched with geospatial coordinates and the data should be continuously used to improve programs and increase impact.

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