

# Data Watch: Closing a Persistent Gap in the **AIDS** Response

A new approach to tracking data to guide the AIDS response

An update on the *Action Agenda to End AIDS*

**An Action Agenda to End AIDS**, launched by amfAR and AVAC at the 2012 International AIDS Conference, outlined key actions that need to be taken in 2012–2016 to lay the foundation to end the AIDS pandemic. In launching the *Action Agenda*, amfAR and AVAC pledged to use the framework as a monitoring mechanism to enhance accountability in the AIDS response.

It is clearer than ever that we have the means to prepare for the pandemic’s “end game.” However, extinguishing the pandemic will not happen on its own. The tools at our disposal will only hasten the end of the pandemic if we use them effectively, at sufficient scale and focused on those most in need. Across the AIDS response, diverse stakeholders need to

redouble efforts to maximize the strategic impact of finite resources.

In this update, amfAR and AVAC take stock of global progress towards ending the AIDS epidemic and lay out an agenda for improving accountability through better data collection. As we sought to track progress, we realized that the lack of timely data for decision-makers represents a major obstacle to a more strategic and effective response. Hence, amfAR and AVAC are launching *Data Watch* to identify the types of core information needed, assess whether existing data systems are meeting essential data needs, and recommend ways to ensure that critical information is effectively marshaled to maximize public health impact.

There are signs of important gains in the response:

**Progress in bringing core interventions to scale continues.** As the figure on page 6 illustrates, as of December 2013, the world appeared to be on track to meet the interim targets outlined in the *Action Agenda*. These gains are having impact—increasing access to antiretroviral therapy, scaling up other core interventions and reducing AIDS-related deaths.

**Scale-up of voluntary medical male circumcision accelerates.** As of December 2013, PEPFAR-funded programs reached their initial target of supporting circumcision services for at least 4.7 million men in priority countries in Africa.<sup>1</sup> Globally, an estimated 5.8 million men have been circumcised in priority countries since WHO and UNAIDS first endorsed voluntary medical male circumcision for HIV prevention in 2007.<sup>2</sup> Although no estimate currently exists for the number of new infections averted by scale-up to date, follow-up studies in Kenya, South Africa and Uganda have found that the prevention benefits of circumcision are sustained after more than five years and appear to increase over time.<sup>3</sup>

**New scientific evidence underscores the need for faster scale-up of high-quality HIV treatment and prevention.** Having already averted 1.5 million deaths and halved HIV incidence through its national treatment program, South Africa could virtually eliminate AIDS-related deaths and further lower HIV incidence by 50% by 2020 through more frequent HIV testing in high-prevalence settings and universal, early treatment access. The greatest gains come from implementation of treatment as part of combination prevention—and supplemented by programs that support adherence and virologic suppression.

**There are emerging signs of high impact programming.** At least 30 low- and middle-income countries are currently developing national investment cases. Countries that have completed the exercise have prioritized scale-up of core interventions, focusing service delivery on geographic “hotspots,” and scaling up programming for key populations.<sup>4</sup> Putting these plans into action will have tremendous impact. Modelers from the US Centers for Disease Control and Prevention estimate that a serodiscordant heterosexual couple that combines HIV treatment, circumcision and condom use has only a 0.2% chance of HIV transmission over 10 years.<sup>5</sup>

## AN ACTION AGENDA TO END AIDS: PRIORITY ACTIONS

- Prioritize rapid, comprehensive scale-up of core interventions (e.g., HIV testing, HIV treatment, voluntary medical male circumcision, prevention of mother-to-child transmission)
- Mobilize sufficient, sustainable resources
- Clarify roles and responsibilities and ensure accountability in the response
- Ensure accountability and transparency of funders and implementers
- Build the evidence base to end AIDS
- Improve the efficiency and effectiveness of programs

## Despite this progress, there continue to be several challenges:

### **Inadequate knowledge of HIV status prevents full realization of the potential of HIV treatment.**

UNAIDS estimates that less than half of all people living with HIV in sub-Saharan Africa know their HIV status.<sup>6</sup> This is extremely concerning because lack of awareness of HIV infection exposes individuals to risks of severe HIV-related illness or even death. In addition, data convincingly show that HIV transmission is more likely to occur among undiagnosed HIV-positive individuals than people who know that they are HIV-positive.

### **Children are being left behind in the scale-up of HIV treatment.**

Children living with HIV are substantially less likely than treatment-eligible adults to receive antiretroviral therapy<sup>6</sup>, in part due to the fact that only 42% of children born to HIV-positive mothers received early infant diagnostic services in 2013.<sup>7</sup> These gaps have life-and-death consequences, as children living with HIV face 50% odds of dying before age two if they receive no HIV treatment,<sup>8</sup> with peak mortality risk occurring at 2–3 months.

### **There is considerable variation in coverage of core interventions.**

Even as progress in scaling up core interventions in sub-Saharan Africa continues to inspire the world, gains are not evenly

distributed. While at least six countries in Africa were providing antiretroviral medicines to at least 90% of pregnant women as of December 2013, only 27% of pregnant women living with HIV in Nigeria and 33% in the Democratic Republic of Congo received antiretrovirals; together, Nigeria and DRC were home to more than 200,000 pregnant women living with HIV last year.<sup>6</sup>

### **The AIDS response continues to fail key populations.**

Although key populations defined by UNAIDS as men who have sex with men, people in prison, people who inject drugs, sex workers and transgender people are most in need of core interventions due to their much higher than average risk of HIV infection, they confront substantial barriers to health care access, including punitive laws, stigmatizing attitudes among health care workers, and inaccessible services. For instance, according to a global survey of men who have sex with men, only 14% of respondents in low-income countries reported having access to HIV treatment in 2012.<sup>9</sup> It will be impossible to end AIDS if populations at elevated risk continue to be left behind. Addressing the health and human rights of key populations must become a priority at the global and national levels.

**The world's capacity to end AIDS is jeopardized by uncertainties regarding AIDS financing.** Total funding for HIV programs in low- and middle-income countries appears to have plateaued, with \$19.1 billion available in 2013.<sup>6</sup> Global capacity to sustain and strengthen these gains is undermined

by a pullback of international donors from HIV assistance.<sup>10</sup> The 2013 WHO antiretroviral guidelines, which nearly doubled the number of people eligible for HIV treatment, will require incremental funding of up to 10% above the 2015 resource target of \$22-24 billion.<sup>11</sup>

## DATA WATCH: CLOSING A PERSISTENT GAP IN THE AIDS RESPONSE

Imprecise or outdated data also undermine the response. Pivotal questions remain unanswered by the primary repositories of global HIV-related strategic information: What proportion of people living with HIV have been diagnosed, and what proportion have achieved viral suppression? What is current treatment coverage for key populations? Do resource allocations reflect a more strategic approach, with a greater emphasis on the core interventions capable of reversing the global epidemic? Moreover, even where strategic information is available, it is usually measuring progress that was made more than a year ago, preventing the use of current data to adapt policies and programmatic approaches as needed.

AVAC and amfAR are launching *Data Watch* to help advocates track progress—and to hold the key sources of global HIV information accountable for timely, accurate reports. As we launch this project, we identify the strengths and weaknesses of the key sources of information in the global AIDS response: the Global Fund, PEPFAR and UNAIDS.

### KEY GLOBAL AGENCIES: DATA FOR ACCOUNTABILITY

In the last several years, major global players have announced key initiatives to improve the strategic impact of the AIDS response: the PEPFAR Blueprint, the Global Fund's New Funding Model, and the UNAIDS investment approach. Having announced these welcome initiatives to enhance the efficiency and effectiveness of finite HIV funding, these global AIDS leaders have the responsibility to deliver and to let diverse stakeholders know whether they have done so.

The clearest way to demonstrate whether these initiatives are achieving their intended results is to *follow the money*. Are funding patterns changing to prioritize high-value, high-impact core interventions? The inability to discern from existing data whether resource patterns are changing to increase strategic impact makes it impossible to hold funders accountable for their commitments.

If strategic data described later in this report are to be effectively used to accelerate progress towards ending AIDS, the collective data systems will need substantial improvements. Based on the analysis below, our top-line recommendations are:

*The Global Fund and PEPFAR should transparently disclose all strategic data.*

Both organizations need to provide easy-to-access, easy-to-use online portals to allow diverse stakeholders to obtain raw or analyzed, easily digestible strategic data. For each agency, it is also critical that there is full and timely disclosure of how funds are spent, and how the expenditures are linked to results. In addition to providing meaningful access to donor-specific information, the Global Fund and PEPFAR should collaborate with national partners, UNAIDS, WHO and other key stakeholders to combine program data into a single, validated, non-duplicated reporting stream.<sup>12</sup>

*UNAIDS should aggressively implement its plan to move to six-month reporting of results.* UNAIDS plans to implement twice-yearly reporting for coverage of certain core interventions, with details still to be determined. Extensive training and capacity building will be required to build the infrastructure for twice-yearly reporting, but more frequent and timely availability of results is essential to increase the flexibility and adaptability of the response. A move to twice-yearly reporting should also be accompanied by efforts to improve the accuracy of the reported data.

*The Global Fund, PEPFAR and UNAIDS should routinely report a single set of outcomes at each stage of the HIV treatment continuum.* The impact of ART for treatment and prevention depends on virologic suppression. Through a combination of scaled-up program reporting and modeling, estimates should also be generated for rates of linkage to care, retention in care, and viral suppression. Countries also need to improve their estimates of the numbers of undiagnosed people living with HIV.

*Reports on HIV treatment coverage need to be disaggregated by age.* Separate coverage figures are needed for adults, adolescents and children, with a common agreement on age segments.

*UNAIDS should use its convening power to assemble a consultation of key stakeholders and technical experts to develop meaningful strategies to measure access to and utilization of core interventions by key populations.*

## DATA UPDATE: WHAT WE SAID WOULD HAPPEN IN 2012 VS. WHAT ACTUALLY HAPPENED

IF WE DO THIS...

- Make hard choices by prioritizing rapid and comprehensive scale-up of core interventions along with specific, rights-based approaches to reach populations at greatest risk.
- Mobilize sufficient, sustainable resources to ensure the rapid and comprehensive scale-up of core interventions.
- Agree on clear roles and responsibilities and hold one another accountable for results through agreed timelines, target outcomes, transparent reporting and real-time assessment of results.
- Build the evidence base to end AIDS by prioritizing implementation research and the search for a preventative vaccine and a cure.
- Use every resource as effectively as possible by lowering the unit costs of core interventions, improving program management and strategically targeting services.

In 2012, we projected the numbers needed in order to be on the path to ending AIDS. Here we show what really happened.

The following years, 2014 and beyond, represent what needs to happen in order to continue on the path to ending AIDS.

WE CAN ACHIEVE THIS...

	2012	2013	2014	2015
	9 million people on ART Actual: 9.7 million ✓	11 million people on ART Actual: 12.9 million ✓	At least 13 million people on ART	At least 15 million people on ART
	No more than 1.9 million new HIV infections Actual: 2.3 million ✗	No more than 1.3 million new HIV infections—a tipping point, as the number of new ART slots surpasses the number of new infections for the first time. Actual: 2.1 million <sup>1</sup> ✓		No more than 1.0 million new HIV infections
	No more than 280,000 new infections in children and 65% PMTCT coverage Actual: 260,000 infections; 62% coverage ✓	No more than 200,000 new infections in children and 75% PMTCT coverage Actual: 240,000 infections; 67% coverage ✗	No more than 100,000 new infections in children and 85% PMTCT coverage	At least 90% PMTCT coverage
	No more than 1.6 million AIDS deaths and 9% fewer TB deaths than in 2010 Actual: 1.6 million AIDS deaths; 20% fewer TB deaths ✓	No more than 1.5 million AIDS deaths and 30% fewer TB deaths than in 2010 Actual: 1.5 million AIDS deaths ✓	No more than 1.4 million AIDS deaths and 40% fewer TB deaths than in 2010	No more than 1.4 million AIDS deaths and 40% fewer TB deaths than in 2010
	At least 4.7 million voluntary medical male circumcisions (VMMC) supported by PEPFAR. Actual: 4.7 million circumcisions ✓		At least 60% coverage of VMMC in 14 priority countries	80% coverage of VMMC in priority countries is within immediate reach
	20% of African countries achieve Abuja Declaration Actual: 11% ✗	40% of African countries achieve Abuja Declaration ?	60% of African countries achieve Abuja Declaration	100% of African countries achieve Abuja Declaration
	At least 10 countries pledge to increase funding to the Global Fund ?	At least \$18 billion available for HIV programs, with at least 10 additional countries pledging to increase funding to Global Fund Actual: \$19 billion ✓	At least \$20 billion available for HIV programs	At least \$24 billion available for HIV programs, including \$4.7 billion from the domestic public sector in sub-Saharan Africa

✓ Actual data met target ✗ Did not meet target ? Data not available ✓ Actual data partially met target

1. Due to faster-than-expected treatment scale-up, the tipping point was reached despite the number of new infections exceeding 1.3 million.

*Donors and international technical agencies should prioritize efforts to strengthen routine reporting, data collection and analytic capacity at the national and sub-national levels.* There is often considerable delay in the reporting of clean service utilization and outcome data from program sites to

health authorities, as well as delays in the transfer of aggregated data from sub-national to national levels. Donors should prioritize funding to build robust and sustainable data collection and analytic capacity – an outcome whose benefits will extend far beyond the AIDS response.

## WHAT DATA MATTER MOST?

- **Coverage of core interventions** including HIV testing, antiretroviral therapy, voluntary medical male circumcision, prevention of vertical transmission, male and female condom availability, and harm reduction programs.
- **Disaggregated information** by gender, age, key population status, and other key factors. Overall numbers are insufficient.
- **Indicators of service quality** including percentage of people on ART with undetectable viral load tests, retention in care data and more.
- **Impact data on incidence, HIV prevalence and AIDS-related deaths** are the ultimate indicators of success.
- **Results-linked expenditure data** shed light on where programs are achieving results and on how reallocation of resources could improve program impact.

## ESSENTIAL CHARACTERISTICS OF STRATEGIC DATA FOR ACTION

**To drive strategic action and accelerate progress toward ending AIDS, the field needs data that answer key questions and meet the needs of diverse stakeholders.**

**Strategic data are timely.** Jim Kim, World Bank President and former head of the WHO HIV program, has cited the six-month data reporting window used by the ‘3 by 5’ initiative as an important reason why treatment scale-up was so successful.

**Strategic data are reliable.** Decision-makers at all levels need confidence that they can base their decisions on the information they receive.

**Strategic data are pertinent.** Having too many monitoring indicators can be as harmful as having too few. It is especially critical that indicators are in place to answer key questions (see box).

**Strategic data are easily accessible.** Data should be easily accessible on the web, including on mobile devices. Data should be provided in a user-friendly format, i.e., something other than spreadsheets with raw data.

**Strategic data are effectively used.** Evidence needs to drive action. This requires analytical capacity to understand the import of key data, targeted investments to scale up civil society capacity to ensure that the meaning of strategic data is effectively communicated to key decision-makers, and political commitment by decision-makers to follow the evidence.

**Strategic data consider the data needs of service providers.** While national health ministries and international agencies take the lead on assembling, analyzing and disseminating aggregate data, program data are, first and foremost, useful to program implementers themselves as a continuous feedback loop for monitoring and improving program performance. Accordingly, data collection strategies need to take account of the needs of on-the-ground implementers. In addition to building the capacity of service providers to collect and use program data for continuous quality improvement, national and global agencies need to simplify and streamline data gathering, entry and reporting to the greatest extent possible.

**Strategic data must disclose its basis.** Due to weaknesses and gaps in data reporting systems, models that leverage available data are used to develop estimates for the denominators and numerators of coverage figures. Use of modeling is both inevitable and useful, but reports of strategic data need to clearly differentiate *real* data (e.g., directly measured service utilization) from modeled data, including an explicit explanation of the assumptions on which models are based.

## HOW KEY DATA SOURCES MEASURE UP

At the global level, there are three key sources of strategic data on the AIDS response: the Global Fund, PEPFAR, and UNAIDS.

### Global Fund

The Global Fund is the largest multilateral funder for HIV programs, accounting for 20% of all international HIV assistance in 2012.<sup>13</sup> Through its New Funding Model, which is now being fully implemented, the Global Fund aims to enhance its strategic impact by supporting high-impact interventions in resource-limited settings and targeting services to areas in greatest need.

#### Global Fund's strategic data.

The Global Fund makes strategic information available to stakeholders through two means. First, via an expanded web portal launched in October 2013, the Global Fund enables stakeholders to obtain extensive information about specific grants. Second, each year the Global Fund summarizes key results in a publication (available on the web).

#### Strengths of Global Fund's strategic data.

The Global Fund's web portal provides access to extensive information on specific grants, indicator results by geographic area, funding flows, and the like. The annual results publication provides aggregate data and analyses, including the number of people reached by key

services supported by the Global Fund, trends in service uptake, and estimates of the public health impact of Global Fund grants. The annual publication also summarizes Global Fund financing, including funding for the Global Fund's three priority diseases, regional funding breakdowns and total amounts devoted to particular categories of interventions (e.g., prevention, treatment, health systems strengthening, etc.). Tables and graphs in the annual publication make results readily accessible to diverse audiences.

#### Potential limitations of Global Fund's strategic data.

**Timeliness.** In May 2014, the latest results available were as of December 2012. Work is needed to provide results on a more current and ongoing basis.

**Pertinence.** Although it includes extraordinary detail about specific grants and countries, the Global Fund's website is not especially useful for answering key strategic questions. For example, it is unclear from raw data how one would generate a reliable estimate of the Global Fund's total funding for core interventions or discern funding trends for specific interventions over time. (The need to

understand trends in funding will be especially important under the Global Fund's New Funding Model, which aims to enhance the strategic focus and impact of Global Fund grants.) The annual results publication provides greater detail on funding but only with respect to broad service categories (e.g., treatment, prevention) rather than for specific interventions (e.g., voluntary medical male circumcision, prevention of mother-to-child transmission, prevention programs for key populations, etc.).

It is also difficult, if not impossible, to ascertain from information made publicly available by the Global Fund whether all populations are benefiting equitably from grant-supported programs. Only an overall figure is provided for HIV treatment access, with no differentiation between adults, adolescents and children. While the most recent annual results publication summarizes estimated funding for people who inject drugs, such information is not readily available for other key populations. Although it has been possible to obtain insights on funding for key populations through an exhaustive review of Global Fund proposals, such efforts confront two key challenges: first, submission of a proposal was traditionally merely the first stage in a lengthy process that often results in funding disbursements that differ substantially from what was originally proposed; and second, the traditional process of proposal development and submission in

competitive rounds has been replaced by the New Funding Model, which has its own unique procedures and will require new monitoring methods.<sup>14</sup> Perhaps most importantly, the Global Fund only reports on approved funding—i.e., on how grants are intended to be spent—and does not routinely report how funds are expended or on how or whether the expenditures are linked to results.

## TRANSPARENCY AND ACCOUNTABILITY IN THE PHILANTHROPIC ARENA

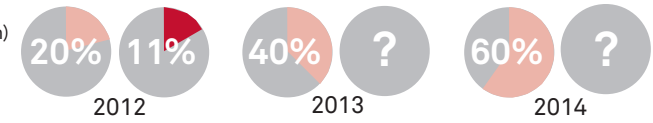
The Bill & Melinda Gates Foundation, one of the most influential philanthropic agencies in the AIDS response (and indeed in much of global health), also needs to be accountable and transparent in the targets it sets for its investments and the performance data that are gathered throughout the lifespan of a project. The Foundation, which has long been criticized for its opacity, joined the International Aid Transparency Initiative at the end of 2013 and has made a commitment to improve its performance in this arena. We look to the Foundation to align the frequency and quality of its reporting, targets and impact measures with the other major stakeholders working in the prevention and treatment arenas, and suggest an annual report and web-based information portal focused specifically on its HIV portfolio.

# ENDING AIDS: WHERE WE ARE TODAY

## Global progress towards key indicators in the fight against HIV/AIDS

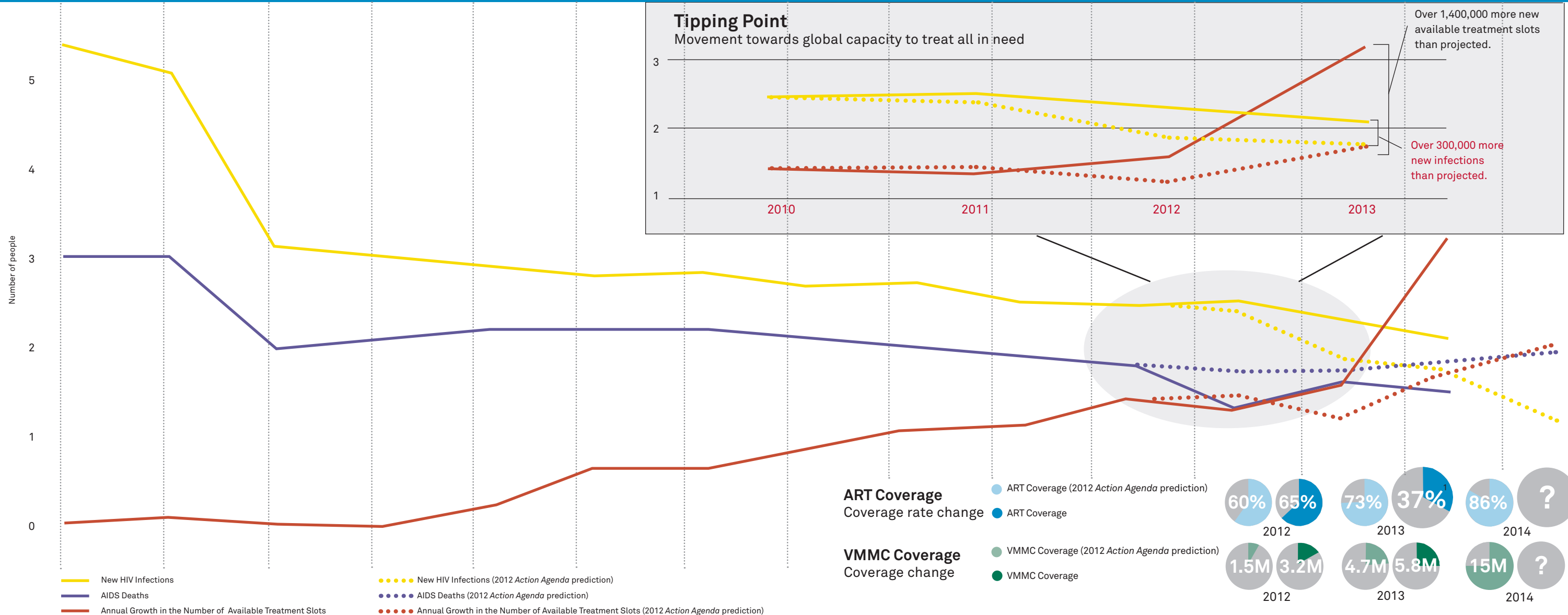
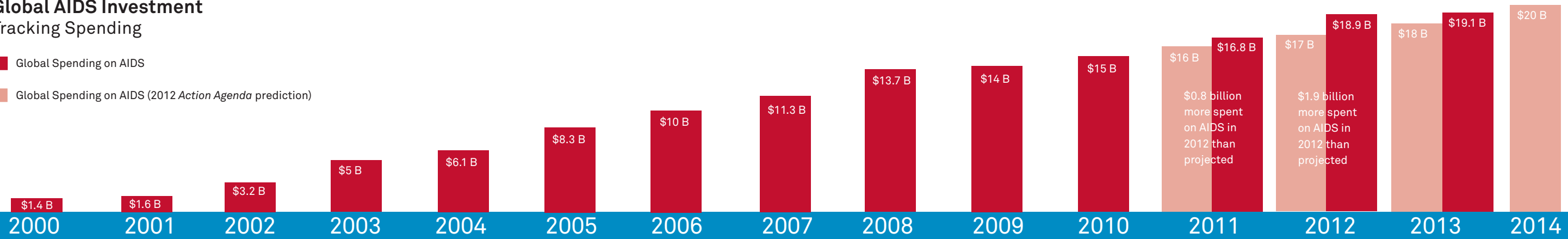
**Abuja Declaration Target Progress**

- % of countries meeting target (2012 Action Agenda prediction)
- % of countries meeting target



### Global AIDS Investment Tracking Spending

- Global Spending on AIDS
- Global Spending on AIDS (2012 Action Agenda prediction)



1. Total number of people eligible for ART expanded after WHO changed its treatment guidelines in 2013

Reported results also do not provide meaningful information on service quality; thus, while the number of people enrolled in HIV treatment is reported, results are not disclosed with respect to retention in care. Similarly, although the Global Fund reports data on the number of HIV testing sessions supported with its grants, no information is provided on rates of linkage to care for people who test HIV-positive.

**Accessibility.** To answer the strategic questions raised by the *Action Agenda*—specifically with respect to funding, uptake and outcomes associated with core interventions—a professional research team or consulting firm would likely be needed. This complicates efforts by civil society to function effectively as watchdog. Aidsplan plays a helpful role in this regard, providing up-to-date information on Global Fund activities and helping organize civil society monitoring efforts in regions and countries.

**Recent developments regarding Global Fund's strategic data.** The Global Fund has recognized that it needs to strengthen its data collection, management and analytical systems, and is reportedly planning to sharpen these systems. However, persons knowledgeable about the Global Fund emphasize that the organization's data management system remains far from what will be needed to deliver strategic information consistent with transparency and accountability.

## **PEPFAR**

PEPFAR is the largest single source of funding for the HIV response, accounting in 2012 for 49% of all international HIV assistance and 23% of all HIV funding.<sup>1</sup> Through its *PEPFAR Blueprint: Creating an AIDS-free Generation*, PEPFAR has pledged to enhance its strategic impact through support for core interventions, including attention to the access needs of key populations. Under its authorizing legislation, PEPFAR is required to use at least 50% of its funding for HIV treatment programming.

**PEPFAR's strategic data.** PEPFAR uses three primary mechanisms to make strategic information available. 1) At least once annually, PEPFAR produces updated results from its programming, making this information available online. PEPFAR officially reports to the U.S. Congress annually on its activities and impact. 2) Details regarding PEPFAR activities and funding are available in detailed supplemental budget justification documents provided to Congressional appropriations committees. And 3) Country Operational Plans (COPs), also available on the PEPFAR website, provide extensive detail regarding PEPFAR budgeting and programming in each of the countries that receive PEPFAR assistance. However, in the versions of the COPs made publicly available, some information is typically redacted, limiting comprehension of activities.

## **Strengths of PEPFAR's strategic data.**

PEPFAR reports on outcomes for each of the core interventions prioritized in the *Action Agenda*. Of all major global HIV data sources at the global level, PEPFAR data are the most timely; whereas in May 2014, Global Fund and UNAIDS were providing data as of December 2012, PEPFAR was providing results as of September 2013.

PEPFAR's budget document permits tracking of budgeted amounts for core interventions over time in countries where PEPFAR provides assistance. (For example, information available online demonstrates that PEPFAR funding for voluntary medical male circumcision in Uganda rose from \$2.9 million in 2009 to \$31.1 million in 2012.) Budget documents disaggregate amounts budgeted by PEPFAR for HIV treatment by age, with separate funding figures reported for adults and children.

Extensive detail is available through the COPs for individual countries. The COPs describe how funding within each country is allocated among PEPFAR agencies, service categories and implementing agencies. Each COP also discloses target indicators across service categories, including (in some countries) the number of members of key populations that PEPFAR-supported programs will reach.

PEPFAR also prioritizes the use of data in its planning and implementation.<sup>15</sup> Each year, PEPFAR country programs undergo an evidence-driven planning process, in collaboration with national governments, to develop intricate interagency plans to respond to national needs.

## **Potential limitations of PEPFAR's strategic data.**

**Timeliness.** Although PEPFAR results are published in a more timely manner than most other global-level HIV strategic data, COPs are typically made publicly available online only after the relevant programming has been completed.<sup>15</sup>

**Reliability.** As PEPFAR has pursued its country ownership agenda, transitioning in a number of PEPFAR countries from direct service provision to technical support, questions have been raised about whether it is appropriate for PEPFAR to claim service numbers (e.g., number of people on HIV treatment, etc.) where the program did not actually pay for the services delivered.<sup>16</sup> In particular, the favorable numbers cited as PEPFAR results may obscure the considerable systemic challenges and hardship to clients experienced in places where this transition to country ownership is most advanced.<sup>16</sup>

**Pertinence.** Although funding figures and indicator targets are available for individual country programs through the COPs, PEPFAR's success in reaching key populations with a range of essential services, including HIV treatment, is unclear from available information. PEPFAR results disclose only a single number of people receiving HIV treatment, making it difficult to compare PEPFAR outcomes for children with those for adults. In addition, the single overall



treatment coverage number fails to address issues of service quality, including the proportion of people receiving PEPFAR-supported HIV treatment who achieve durable viral suppression.

**Accessibility.** Among global health and development donors, PEPFAR ranks low (50th out of 67 agencies) with respect to data transparency, according to a leading international watchdog group, which found that “PEPFAR does not disclose information on contracts to prime partners and sub-partners in a machine-readable and open format consistent with the US Open Data Policy.”<sup>17</sup> In addition, COPs, when published, typically include substantial redactions, and the presentation of information in the COPs makes it difficult for external stakeholders to interpret them.

**Recent developments regarding PEPFAR’s strategic data.** PEPFAR’s new leader, US Global AIDS Coordinator Dr. Deborah Birx, has announced a new initiative to improve the transparency of PEPFAR data. PEPFAR is implementing an Expenditure Analysis Initiative program-wide, with the aim of generating clear data on funding for specific program categories. These data describe how and where PEPFAR funds are actually spent, and the specific results from such spending; however, this information is not made public.

PEPFAR has begun to make certain budget data more accessible with the

recent launch of its *Planned Budget Dashboard*. Designed as an online portal linked to ForeignAssistance.gov, the Dashboard allows users to access and visualize planned budget data extracted from country and regional operational plans. Data can be presented by country/region, year, program area, and implementing agency, and then further broken down by budget code. Though the Dashboard represents a significant and welcome move toward increased accessibility of key budget data, it does not permit downloading data for individual countries or program areas, and the information discloses only budgeted allocations rather than actual amounts spent.

The Dashboard includes an important new feature that permits year-by-year assessment of results achieved through PEPFAR. In some cases, additional detail is needed, such as the distribution among key populations of those reached by PEPFAR-supported prevention services and the reach of different types of interventions for key populations.

## **UNAIDS**

Unlike the Global Fund and PEPFAR, UNAIDS focuses on catalytic advocacy, coordination, normative guidance, and strategic information rather than funding for direct service provision (although certain components of UNAIDS, such as UNICEF, UNFPA, the UN High

Commissioner on Refugees, and the World Food Program, do provide direct services). UNAIDS is the primary global-level repository for strategic information on HIV.

**UNAIDS’ strategic data.** UNAIDS has developed modeling tools to help countries estimate HIV prevalence, HIV incidence, need for HIV treatment, number of pregnant women living with HIV, and other key epidemiological variables.<sup>15</sup> (Due to the weaknesses of many national public health surveillance systems, the modeling tools use limited data that can be extrapolated to generate broader estimates about national epidemics.)

UNAIDS releases comprehensive data on core indicators (with outcomes provided at global, regional and country levels) annually prior to World AIDS Day. Data are available online (through the AIDSInfo system) and in the electronically accessible *Global Report on the AIDS Epidemic*. The core indicators focus on 10 priority targets articulated in the 2011 *Political Declaration on HIV and AIDS*. Information against these core indicators is submitted annually by countries through the Global AIDS Response Progress Reporting (GARPR) system.<sup>20</sup>

Every other year, countries submit responses to the National Commitments and Policy Instrument (NCPI). The NCPI is an extensive questionnaire that seeks information from countries regarding the methods by which national responses are planned and implemented, the nature and

extent of services, national achievements and gaps, and the human rights environment. There are two components of NCPI—one for the national government, and the other for non-governmental respondents.

For the purposes of UNAIDS’ own accountability, UNAIDS each year publishes a performance monitoring report, which is submitted to the UNAIDS Program Coordinating Board (the UNAIDS governing body) and made available online. The annual performance monitoring report publishes UNAIDS results against indicators set forth in the UNAIDS Unified Budget, Results and Accountability Framework, with results provided for the organization as a whole, in individual thematic areas, for individual Cosponsors and the Secretariat.

### **Strengths of UNAIDS’ strategic data.**

**Timeliness.** Whereas countries previously submitted national progress reports every two years, GARPR reporting is now conducted annually. Performance monitoring results for UNAIDS are typically made public roughly six months after the end of the calendar year in question.

**Reliability.** UNAIDS undertakes an extensive, multi-step process to validate data submitted by countries, involving UNAIDS Cosponsors (e.g., WHO, UNICEF) and key partners (e.g., Global Fund, PEPFAR). If methodological

questions arise, countries are required to respond to UNAIDS data inquiries. Several years ago, UNAIDS revised its epidemiological modeling methodology to move beyond sole reliance on sentinel HIV surveillance in prenatal settings, which had overestimated HIV prevalence and incidence in many countries. This revision is believed to have made UNAIDS estimates closer to actual experience in countries.

**Pertinence.** UNAIDS annually reports data on each of the core interventions in the *Action Agenda*. HIV treatment coverage is disaggregated by age and sex, and information is also provided on key populations' use of HIV testing and basic prevention services. UNAIDS (in collaboration with the Henry J. Kaiser Family Foundation) is also the recognized source of critical information on annual HIV resource flows, with important strides made in recent years to provide additional detail on funding for particular types of interventions.

**Accessibility.** Strategic data generated by UNAIDS are provided in analyzed form, with accompanying graphics and tables. Country-specific data are available through the user-friendly AIDSInfo portal on the UNAIDS website.

**Use of Data.** UNAIDS has increasingly prioritized the use of strategic data to inform and strengthen decision-making by partners. Through assistance to countries to develop national investment

cases, UNAIDS helps countries leverage epidemiological, cost-effectiveness and modeling data to enhance the strategic focus and sustainability of national programs.<sup>21</sup> In addition, UNAIDS serves as the primary resource for strategic and technical information to inform planning by PEPFAR and grant decisions by the Global Fund.

#### ***Potential limitations of UNAIDS' strategic data.***

**Timeliness.** By the time UNAIDS reports epidemiological and indicator data, the information is already nearly one year old. At the time a new report emerges, the data on which the AIDS field has been relying is nearly two years old. At this stage of the response, with a widening array of priority tools available to alter the epidemic's trajectory, more timely release of critical data is needed.

**Methodology.** Questions have been raised regarding the methodology used by UNAIDS to estimate new HIV infections, HIV prevalence and AIDS-related deaths. In July 2014, researchers associated with the Global Burden of Disease study estimated in a Lancet article that 19% fewer people are living with HIV worldwide than estimated by UNAIDS<sup>22</sup>. The Global Burden of Disease researchers, who use a different methodology than UNAIDS for making estimates, determined that UNAIDS had also overestimated HIV incidence and AIDS-related deaths. Routine

publication by UNAIDS of its estimates in peer-reviewed journals could improve the reliability of UNAIDS estimates.

**Reliability.** The reliability and utility of NCPI results are uncertain. The primary portion of the NCPI survey is completed by national governments, which have a vested interest in reporting the most favorable perspective possible on the national response. Although Part B of the NCPI is completed by "non-governmental sources," representatives of UN agencies and bilateral donors frequently comprise a large share (sometimes a majority) of Part B respondents. As a result, NCPI reporting often fails to generate a genuine civil society response to governmental responses to the NCPI survey.

Although UNAIDS deserves credit for attempting to systematically collect strategic data on key populations, the methodology used is questionable. Countries are advised, but not required, to use civil society organizations to conduct surveys of key populations. Because such surveys are typically limited to capital cities, they are not nationally representative of the key population surveyed. As little guidance is provided regarding methods for identifying survey participants, surveys may focus on members of key populations who are easiest to reach rather than all those in need. Moreover, for men who have sex with men, the survey uses as a proxy for access to HIV prevention whether survey participants know where to get an HIV

test and whether they have been given a condom in the last year from any source—criteria that fall well shy of meaningful prevention access. UNAIDS survey results regarding prevention access for key populations have substantially exceeded access findings derived from civil society surveys.<sup>9</sup>

**Pertinence.** Although UNAIDS monitors key populations' access to HIV testing and prevention services, information generated by UNAIDS does not permit an understanding of treatment access among these populations. UNAIDS' methodology for generating regional and global estimates of outcomes across the HIV treatment continuum continues to evolve, highlighting the need for more systematic collection and analysis of strategic data to allow estimation of results at each stage of the cascade. Although UNAIDS annually provides breakdowns in HIV financing by broad categories (e.g., prevention, treatment, management and administration), additional detail and transparency are needed to allow monitoring of funding for all core interventions.

Core indicators on HIV testing—which monitor the number of tests performed and the percentage of particular populations that report having been tested in the last 12 months—are useful for identifying broad trends in testing. However, these indicators provide limited information regarding the proportion of people living with HIV who are

undiagnosed—a key piece of information required for monitoring the HIV treatment continuum.

### **Recent developments regarding UNAIDS’ strategic data.**

To improve the timeliness of strategic data, UNAIDS has announced plans to move to six-month reporting for key indicators. UNAIDS has also moved to annual reporting by countries of a core set of key indicators, replacing an earlier system that provided for biennial reporting.

Although most GARPR indicators in 2014 remain the same as those used in previous years, some have been revised. In particular, to estimate HIV treatment coverage, countries will no longer use the total number of treatment-eligible people as its denominator but instead will take account of all people living with HIV. This change acknowledges the clear trend towards earlier initiation of HIV treatment, as reflected in the 2013 *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* from WHO.

In addition to the specific challenges outlined above, UNAIDS’ capacity to generate strategic data has been undermined by substantial reductions in the number of strategic information and monitoring staff over the last 12–18 months. Undertaken as part of a broader restructuring of the UNAIDS Secretariat, these cutbacks have substantially

weakened UNAIDS’ capacity to analyze strategic data and to respond to stakeholders’ data requests.

In addition, UNAIDS has created the *Treatment Situation Room*, which uses a model derived from scale-up trends over the last 24 months to estimate up-to-the-minute treatment coverage. With service data now reported twice yearly to UNAIDS, the treatment scale-up model is adjusted every six months. The interactive *Treatment Situation Room* also allows users to assess not only national progress but also sub-national trends in a number of countries, with plans to expand sub-national data to additional high-burden countries. The sub-national analyses have the potential to assist decision-makers in identifying geographic and population “hotspots” where intensified scale-up efforts are needed. The *Treatment Situation Room* also tracks national HIV treatment policies and guidelines on an ongoing basis.

## **CONCLUSION**

Since release of *An Action Agenda to End AIDS* in 2012, a broad global consensus has developed that the tools and strategies now exist to end the AIDS epidemic. In light of persistent gaps in access to high-value, high-impact core interventions, it is clear that we will need to be smarter

and more strategic to lay the foundation to end AIDS. Collecting and using the best, most timely and strategic data will be central to future success. Much has been accomplished in building the data systems needed to support an effective AIDS response, but much more will need to be done in order to maximize the impact of finite funding.

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