



Executive Summary

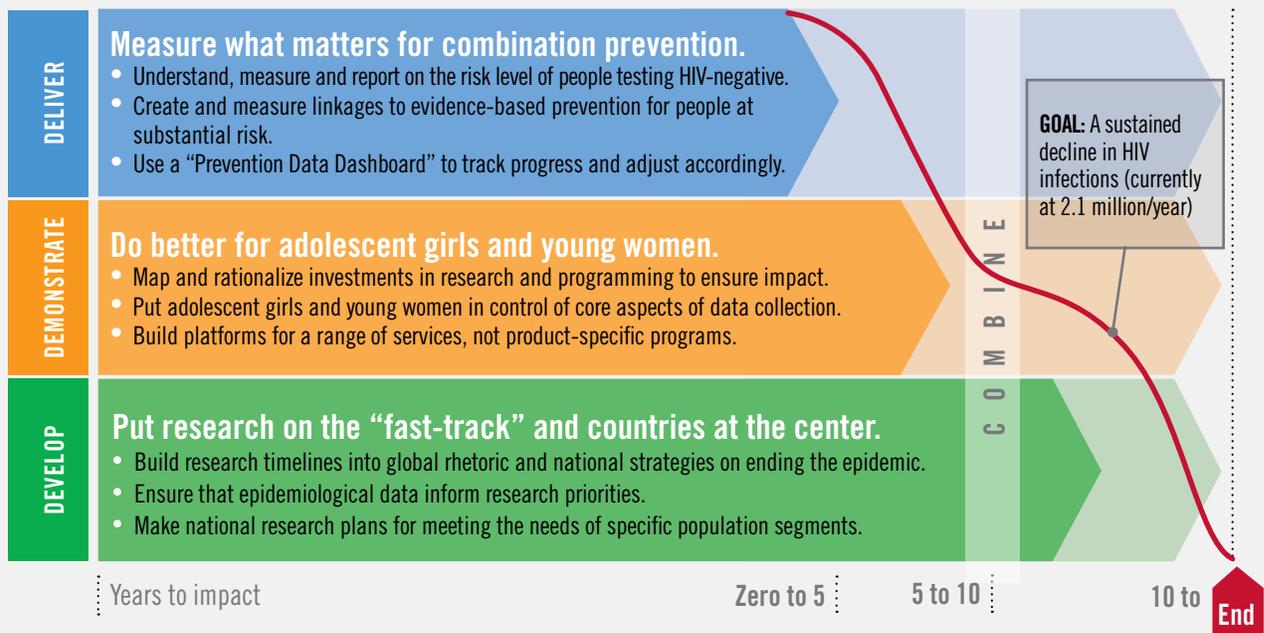
Big Data Real People

This year's AVAC Report takes on one of the most urgent issues facing biomedical HIV prevention today: gaps in the type and quality of data collected on prevention for HIV-negative people. Globally, the number of new HIV infections is not declining. In the places where gains have been made, continued progress is not guaranteed. Fixing core problems with how prevention data are collected and reported is key to slowing the rate of new cases of HIV.

Data points in HIV prevention correspond to real people with specific needs that change over time. *AVAC Report 2016* argues that today's prevention data don't reflect these real people in nearly enough detail. Much of the data on services offered to people who test HIV-negative is inadequate. Countries, funders and implementers report on "people reached" with referrals and condoms, yet data on who is being reached—particularly among key populations—are inadequate. And in the era of strategies such as VMMC (voluntary male medical circumcision) and PrEP (pre-exposure prophylaxis) that have direct impact on HIV risk, reports on referral rates are unacceptable. The new prevention data paradigm should provide detailed information on who is being reached and track linkages to evidence-based tools.

Changing the approach to HIV prevention data means assessing and adapting relevant "Big Data" approaches that analyze enormous data sets to identify new correlations. It also means adapting systems that have existed for decades to reflect new prevention tools and goals.

AVAC Report 2016: Top-line recommendations



How to Fix the Four Major Problems with Data for HIV Prevention

<p>1 The data are not sufficiently broken down.</p>	<ul style="list-style-type: none"> ✓ Countries need to be resourced and supported to collect and report data on services financed/implemented by age, gender, income status, key population status and more. Donors can support this with resources and requirements for such data. ✓ Civil society must work across agendas (e.g., women and girls, key populations) to develop specific, actionable demands of all stakeholders that lead to collection and presentation of actionable, high-quality, disaggregated data.
<p>2 Data are missing for many of the people most in need of prevention.</p>	<ul style="list-style-type: none"> ✓ GFATM and PEPFAR have pledged to improve the quantity, quality and consistency of data gathered on key populations. These promises need to be kept, with fast-paced information-sharing and action taken in countries that are not prioritizing resources based on the data. ✓ Funding cuts to civil society groups need to be reversed and the potential for “Big Data”-based systems (e.g., using data delivered by cell phone or collected by lay people) should be explored as part of supporting these groups to document their communities.
<p>3 The data aren’t there to measure prevention progress.</p>	<ul style="list-style-type: none"> ✓ Global and national stakeholders must implement a coordinated overhaul of prevention indicators and analyses such that linkages, uptake and adherence are all captured, and prevention measures consisting solely of “people reached” are abandoned. ✓ “Prevention Data Dashboards” at the country and funder levels must be realized to help ensure accountability and accuracy in tracking progress on incidence reductions.
<p>4 Data driving basic science to new breakthroughs need sustained funding.</p>	<ul style="list-style-type: none"> ✓ Maintain funding for basic science so that there are resources for innovation, including data-driven approaches that look across large data sets for clues to guide vaccine design. ✓ Map and engage in the ethical and methodological issues impacting the demand for and design of future HIV prevention trials. Countries will need additional tools to bring the epidemic to an end—and they must be at the center of decision-making.

TOP PRIORITY HIV Prevention Data Dashboards

In 2016, there is no justification for prevention data to be as patchy and mysterious as they are. HIV testing is not, in and of itself, a prevention service. However, HIV testing linked to impactful services is. Comprehensive prevention is not just condoms, referrals for STI treatment and possible counseling about voluntary medical male circumcision (VMMC) or PrEP. It includes male and female condoms, condom-compatible lubricant, STI treatment and documented linkages to the most appropriate and needed services, including VMMC, ART for partners living with HIV, PrEP, opportunities to build social capital, financial support, harm reduction and much more. The global rhetoric agrees, but the reporting system tells a different story. Linkages aren’t documented and program components aren’t well-defined. Some indicators, such as “people reached with prevention messages”, exist unchanged from what they were 20 years ago.

Let’s link rhetoric and reporting through the piloting and widespread adoption of HIV Prevention Data Dashboards that reorganize existing indicators into “cascade”-style readouts of the services obtained by people testing HIV-negative. Of eligible men testing negative, how many are getting circumcised? Of individuals at substantial risk, how many receive a PrEP prescription, refills and repeated HIV-negative tests?

A dashboard is a visual display of the critical information needed to achieve objectives; consolidated and arranged so that the information can be easily monitored. To see what a Prevention Data Dashboard could look like, turn the page.

FIGURE

1 Prevention Data Dashboards: A key tool for impact on the epidemic

There is increasing emphasis on measuring the testing “yield” of new HIV positive diagnoses and linkages to ART. But there is no comparable approach to the “prevention yield”—the number of eligible HIV-negative people linked to evidence-based strategies. “Prevention Dashboards” could change this. Many relevant data are already available; they just aren’t systematically collected and clearly presented. Some elements, like reliable indicators of risk status for subsets of some populations, need to be defined. Elements that are not as easily quantified, like legal, social and structural factors, need to be addressed in separate tracking systems as well. Still, piloting dashboards will illuminate gaps, uses and further needs. UNAIDS has changed the conversation about ART for PLHIV by publicizing broad targets, emphasizing new indicators, securing global and national buy-in and reporting out on progress. If UNAIDS could do for other forms of prevention what it has done for ART for PLHIV, it would be an enormous contribution. If not, other stakeholders will need to step in. ***The global community, governments and funders all need these dashboards or equivalent shifts in their conceptualization of HIV prevention programming and evaluation.***

Note: Data in charts are for illustrative purposes only.

