Letter from the Executive Director

Hope, Hype and Revolutions: The realities of data in the 21st century

Big Data. What do these words mean to you? Chances are, if all the *AVAC Report* readers got together in a room (which we would love) and arranged themselves by their understanding of the term, we would be all over the place. It hasn't seized the attention of many people working on the front lines of the HIV response. Nevertheless, the concept and its applications are starting to shape the landscape of countries with persistent epidemics.

What about *prevention data*? What do these words mean to you? Is it the measure of new cases of HIV? Is it coverage of HIV testing? Is it the percentage of people on antiretroviral therapy (ART) who have achieved virologic suppression? Chances are, *AVAC Report* readers would name these types of information and many others, too. We would also be largely in agreement about the enormous gaps in data regarding the size, needs and best approaches for reaching many key groups including adolescent girls and young women, gay men and other men who have sex with men, transwomen—and others.

In this Report, we take a look ahead at both Big Data and prevention data. Big Data is a term on the horizon—a bigger deal in the broader development sphere than in the HIV response. We are looking at how this concept relates to HIV because HIV and global health as a whole can do much better at keeping up with broader development trends. At the same time, we are focusing in on HIV prevention data because it is not possible to end the epidemic without doing much better as soon as possible.

Let's take each of these topics separately. First, Big Data. The term refers to extremely large data sets that can't be analyzed or processed by traditional systems. Big Data refers to both the quantity of information and the techniques that have evolved to turn this information into insights.

There are three reasons why Big Data are relevant to HIV.

1 **Big Data are a big part of the conversation about how to track progress towards and even meet the Sustainable Development Goals (SDGs)[1]—and the success of the HIV response**

[1] UN. 2015. *Sustainable Development Goals. www.un.org/sustainabledevelopment/sustainable-development-goals/.*

depends on its integration into this effort. As the UN Data Revolution Group wrote in its 2014 report on Big Data, *A World That Counts*,[2] achieving the SDGs will require "a significant increase in the data and information that are available to individuals, governments, civil society, companies and international organizations to plan, monitor and be held accountable for their actions." Funders focused on development progress are making big grants to high-tech companies specializing in bottom-up data collection. What these will yield remains to be seen, but the success of development programs will almost certainly be measured using Big Data—so advocates need to understand what's being counted and by whom.

2 **Big Data, in the most traditional and literal sense, are fueling new discoveries in HIV vaccinology and related fields.** Advocates have to understand why these matter in order to keep up the demand for sufficient funding for basic science research.

3 **"Big Data" is the rallying cry and rationale for geographic, population- and individual-level targeting of HIV/AIDS resources by funders and implementers.** This isn't necessarily Big Data but rather highly detailed data on rates of new HIV diagnoses, clinic performance, who lives in households, income, education and more. These data help guide decisions and funding, but they're only as good as the systems used to collect them and those systems are still very weak. So advocates need to understand the strengths and weaknesses of data-driven decision-making that's shaping our world.

Prevention data, which are the primary focus of the Report, are essential to meaningful changes in the epidemic. Yet everywhere we look, whether it is reports from countries, PEPFAR or GFATM, the data are sorely lacking. The power of Big Data—new approaches, massive data sets—won't matter if basic questions about who is receiving what sorts of prevention services and with what levels of impact remain unanswered.

TABLE 1 **HIV Prevention Research Status Report (July 2016)**

Strategy	Status
Antibodies	• Passive immunization trials are looking at safety and efficacy of the VRC01 antibody in Africa and the Americas. • Other antibodies and trials to follow.
HC/HIV risk	• ECHO trial of DMPA (Depo Provera), copper IUD and Jadelle implant launched Q4 2015.
Long-acting injectable ARV	• Two Phase III trials of cabotegravir are planned to start over the next 12 months.
Multipurpose prevention technologies	• 60- and 90-day contraceptive+dapivirine and 60-day contraceptive+tenofovir vaginal rings are furthest ahead in development. • More formulations (e.g., films, inserts) are in development.
Oral PrEP	• Tenofovir-based daily PrEP is safe and effective and is rolling out in many countries. • WHO recommends it for all at substantial risk, September 2015.
Preventive vaccines	• The efficacy trial HVTN 702 builds on previous success—planned launch in Nov 2016. • Janssen Ad26/mosaic candidate—possible efficacy trial in 2017. • Other candidates are in development.
Rectal gel	• First Phase II completed. Reduced glycerin tenofovir gel is safe, well-tolerated. Mixed feedback on applicator and ease of use. • Other candidates and delivery systems are in development.
Vaginal gel	• Tenofovir gel is not being pursued based on data from trials to date. • Other candidates and delivery systems are in development.
Vaginal ring	• Two trials show modest protection with dapivirine ring; key differences among age groups. Open-label extension trials planned/underway. • Other rings for prevention of HIV and/or pregnancy and other STIs are in development.

[2] UN Independent Expert Advisory Group on a Data Revolution for Sustainable Development. 2014. *A World That Counts: Mobilising the Data Revolution for Sustainable Development. www.undatarevolution.org/report/.*

Four Problems with Data Points for HIV Prevention*

1. The data are not sufficiently broken down.
2. Data are missing for many of the people most in need of prevention.
3. The data aren't there to measure prevention progress.
4. Data driving basic science to new breakthroughs need sustained funding.

For possible solutions, see Executive Summary, page 6.

Unfortunately, as *AVAC Report* was being finalized, we received a painful reminder of the consequences of these gaps. The *UNAIDS Global AIDS Update*[3] on the state of the epidemic found that there was no decline in new cases of HIV for the 2010–2015 time period. The current UNAIDS "Fast-Track" goal calls for a reduction to no more than 500,000 new annual diagnoses by 2020. With these trends, that's absolutely not going to happen.

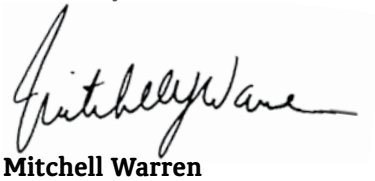
Could data have predicted this? Why yes, they could. During the time period in question, annual numbers of voluntary medical male circumcisions remained relatively constant—and then dipped in 2015, an alarming trend that is way off pace for current global goals.[4] Viral load access crept ahead, but in some places where this diagnostic was available, there were still low rates of virologic suppression, which is key for maximizing treatment's prevention benefit. Also during this time period, rates of funding for civil society and rights-focused organizations plummeted,[5] criminalization of gay people and people living with HIV intensified in many parts of the world, and the promise of PrEP for some individuals at high risk was all but ignored.

So there's actually no surprise in the findings—rather, there's a warning. We as advocates and activists need to make sure that everyone and everything that counts is counted. The world needs to act on the gaps, whether that is a gap in information, e.g., data on adolescent girls and young women or gay men and other men who have sex with men, or a gap demonstrated by information, e.g., the challenges with retention in Option B+ programs.

In mid-July, days before the International AIDS Conference, UNAIDS issued its first *Prevention Gap Report* detailing the gaps and challenges in current non-ART prevention.[6] This is needed and overdue leadership and AVAC looks to continued action from UNAIDS and other stakeholders.

For the past 30 years, HIV/AIDS activists have been at the forefront of understanding data, demanding action and seeking to safeguard ethics and human rights throughout. In many ways there's nowhere else that we should be other than on the front lines of a data revolution, ensuring that facts and bytes and floods of information are "ground-truthed"—confirmed by the lived realities of the people in question and turned into good questions and strategic actions owned by people on the front lines.

That's why our report theme is *Big Data, Real People*—because there's no success via information if that information isn't connected to, and informed and owned by individuals who can question it, act on it and who will, at the end of the day, be the revolution.



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[3] UNAIDS. 2016. *Global AIDS Update 2016. www.unaids.org/en/resources/documents/2016/Global-AIDS-update-2016.*
[4] WHO. 2016. *WHO Progress Brief: Voluntary Medical Male Circumcision for HIV Prevention in 14 Priority Countries in East and Southern Africa. www.who.int/hiv/pub/malecircumcision/brief2016/en/.*
[5] UNAIDS. 2015. *Sustaining the Human Rights Response to HIV: Funding Landscape and Community Voices. www.unaids.org/sites/default/files/media_asset/JC2769_humanrights_en.pdf.*
[6] UNAIDS. 2016. *Prevention Gap Report. www.unaids.org/en/resources/documents/2016/prevention-gap.*