Align high-impact strategies with human rights and realities

Today there is a vast amount of scientific literature about how to treat and prevent HIV effectively, including many articles focused specifically on what it will take to end the epidemic. But the realm of peer-reviewed papers isn’t reality. And there is a real danger that some or all of the potential benefits of today’s strategies will be lost because of an unbridged gap between the science- and human rights-based agendas for the global AIDS response. That’s why one of our top recommendations and priorities for 2015 is: Align high-impact strategies with human rights and realities.

More than thirty years ago, AIDS activists redefined the way that people living with a disease related to doctors and researchers. People living with HIV—who insisted on this term, with its dignity and agency, rather than “AIDS victims” or “sufferers”—became experts on the science of virus. They and their doctors, nurses, friends and allies, including many researchers, mastered pathogenesis, immunology and drug development.

In the absence of drugs—or even, at the outset, a name for the pathogen—human rights and HIV were closely

Global ART Coverage (2014)

Here is the current view of global ART coverage. To close the gaps and have a high impact, it’s key to have high-quality services, better, simpler regimens and a comprehensive, rights-based approach that puts informed choice and civil society leadership at the center. This approach isn’t in place of or in addition to the scientific evidence. It is evidence-based, with extensive reports showing that ART succeeds with community-based models of delivery and support.

connected. In the early years of the epidemic in the United States, the government did little to provide accurate information or fund research. The majority of HIV cases were in gay men, and their lives, it seemed, did not matter. In that context, investment in research, acceleration of trials and other forms of scientific work were a human right. At the same time, rampant stigma and mistrust of the government meant that traditional epidemic control measures like routine testing and contact tracing were rejected by many in the LGBT community—contentious decisions whose public health impact is felt to this day.

Today these same issues have been reconfigured again. In many contexts there is a growing gap between scientific and rights-based discourses about the AIDS epidemic. And that’s within the world of HIV. There is an even bigger gap between the HIV response and the broader agendas put forward by LGBT individuals, women and girls and other “key populations” (see box, at right, about how this term is used and misused today).

There are many reasons for the ways that human rights- and science-based agendas for HIV have parted ways—and why there’s a growing focus on bringing these agendas back together. The GFATM now has human rights as one of the pillars of its five-year strategy. As Treatment Action Campaign co-founder Mark Heywood noted in an essay published in 2014, an increased emphasis from UNAIDS on country government leadership—regardless of national policies and politics, and sometimes at the expense of the agendas articulated by affected communities—is one contributing factor. “Inter-governmental, governmental and donor agencies are now retreating from human rights commitments—and have been doing so since 2010.”

This retreat from human rights has come at the same time as a series of groundbreaking scientific advances. With

Language Watch: Defining Key Populations

What’s in a name? A lot, as it turns out. Right now, the terminology for “key populations” is, well, key to many conversations about effective AIDS programming. But the term isn’t used precisely. Sometimes it’s a euphemism for gay men and other men who have sex with men (MSM) and transgender women. Sometimes it refers to these groups and sex workers. Sometimes it’s used to refer to adolescent girls. Euphemisms don’t have a place in effective public health. Fortunately, this fuzziness is a problem that can be addressed by good data collection and forthright discussions of who is actually at risk and/or in need. Key populations are groups that have a disproportionate burden of disease and lack of access to services—in any epidemic and in any context. The determination of key populations is a data-driven question that can be answered by reviewing country-level data, provided that there’s an active effort to measure HIV incidence and prevalence in marginalized and criminalized groups. In many situations, women and girls are key populations. Targets and planning documents that tackle “key pops” (meaning gay men, MSM, transwomen and sex workers) on the one hand and women and adolescents on the other needlessly muddy the waters. Clarity is key.

new biomedical tools come new demands for public health programs, which face human-resource shortages, infrastructure challenges and restrictive policy environments. These tools also bring new demands for stakeholders to envision innovative, even radical, new approaches to delivery that dismantle the barriers between the biomedical, behavioral and structural drivers of HIV risk and individual behavior. After all, oral PrEP is a behavioral intervention—it has to be used correctly and consistently to have a benefit, just like ART. Right now, there are big dreams for radical new approaches to HIV prevention using biomedical tools. But, with the possible exception of VMMC (see page 12) there’s not much of a prevention revolution happening on the ground. Advocates who doubt that biomedical advances will be rolled out with a rights-based approach are entitled to their skepticism, but what’s also needed, from all stakeholders, is a commitment to working together over the next few years to ensure that there’s funding, innovation and category-busting implementation of truly effective prevention.

The problem, of course, is that many of the activists needed to help make this happen are now struggling to keep themselves and their organizations afloat. Funding for human rights-based work among civil society organizations has faltered (see graphic, at right). HIV-focused civil society is better funded than sectors like women’s rights or LGBT—but that prosperity is relative, and all are inadequately supported.

What’s needed today is a fundamental shift in the conceptualization and implementation of components of a biomedically oriented approach to ending the epidemic. As the science advances, more money needs to flow to civil society groups—not less. And the programs that deliver these combination packages need to be deeply embedded with, informed and led by people living with and at risk of HIV. Without these close connections, the programs will not reach the people most in need. Shifting funding and program design to include civil society, and particularly people living with and most at risk of HIV, should improve accountability for all involved. Civil society groups need to commit to and deliver on results tied to impact, defined in terms that all agree upon. In addition, here are three more key recommendations:

- **Pursue high levels of ART coverage, while addressing issues of choice and coercion.** Having the option to choose to start ART—including at high CD4 cell counts and in order to preserve health and reduce risk of onward transmission—ought to be the reality for every person living with HIV. And in an ideal world, ART expansion would happen in a climate of informed choice. But there are concerns that, as Option B-Plus and other “test and treat” programs that initiate ART regardless of CD4 cell count are introduced, the conditions that allow someone to make an informed choice about whether to start ART and to remain adherent when they do will be overlooked. Will proposed programs that aim to diagnose individuals and initiate ART on the same day be able to provide the type of counseling and peer-to-peer support that will surely
be needed to navigate disclosure, adherence and acceptance of one's diagnosis all at once? They should, but in a climate of scarce resources and diminishing funding for civil society groups there's no guarantee that they will.

Revise the “rights versus HIV” rhetoric and reality that’s splitting LGBT groups and other key potential allies from those on the frontlines of the fight against HIV. “Biomedical interventions shift the locus of control towards the medical,” said Chris Beyrer from Johns Hopkins University and the current president of the International AIDS Society, in a plenary at the 2014 HIV Research for Prevention Conference (HIV R4P). He noted that the sites of medical treatment are often closely aligned with repression, abuse and discrimination for people who are persecuted by the state for their sexual orientation, drug use, sex work, migrant status or any other reason. Programs that target individuals who are disproportionately living with and/or at risk of HIV acquisition can only succeed in a rights-based environment. The funders and implementers of biomedically oriented programs must work in solidarity with efforts to roll back repressive legislation. By the same token, rights-focused groups need informed agendas about biomedical tools.

Remember that culture and community views often can’t be modeled—but they can’t be ignored, either. Whether it is determining the appropriate age range for delivering VMMC or developing efficiency-oriented approaches to treatment delivery, there are models that suggest the right way to proceed. But these models are only as good as the data that go into them. And there are still limited data on a range of key structural and social issues that affect the uptake of services and long-term adherence to strategies, be they PrEP, ART or—someday—a vaginal or rectal microbicide. Stakeholders need to acknowledge that what is modeled isn’t necessarily what is possible if cultural, economic and social norms run counter to programmatic goals. Programs won’t fail if this complexity is part of the planning; instead, they’ll be even more likely to succeed.