ENSURING EFFORTS TO SCALE UP, STRENGTHEN AND SUSTAIN HIV RESPONSES

A Project of the Joep Lange Institute

July, 2018

AIDS 2018

This report represents an overview of and syntheses of results from seven consultations over an eight-month period from September 2017. It in turn is an abbreviated version of the main outcome of the process—a longer, comprehensive report that includes more extensive analysis and examples, as well as more detailed potential solutions and recommendations. That longer report is also available on the JLI website (www.joeplangeinstitute.org). Reports from each of the seven consultations can also be found on the JLI website.

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SUMMARY OF THIS REPORT

Driven by the UNAIDS Fast-Track initiative, the rapid scale-up of HIV treatment is transforming the lives of millions of people worldwide. But it is not sufficient on its own, no matter how many countries achieve the 90-90-90 targets or how quickly they get there. This report offers a broad framework for building on and expanding the Fast-Track successes so that the main goal can realistically be met: epidemic control, defined as eliminating new infections and ensuring all people living with the virus have access to the quality treatment and support services they need.

The information, analysis and observations in this report are based on seven consultations with a wide range of policy makers, scientists, advocates and service providers over a year through April 2017. The overall initiated was convened and supported by the Joep Lange Institute.

The report focuses primarily on identifying challenges, gaps, and weaknesses in the current response that must be confronted not only so that scale-up can continue, but so that overall approaches are strengthened, expanded and sustained in diverse contexts across an increasingly integrated health and development environment.

Key challenges and gaps

Challenges discussed in this report that could jeopardize efforts control the epidemic and to provide all people initiated on antiretroviral therapy (ART) with high-quality treatment and care include the following:

- stalled and declining funding for HIV responses
- rising rates of HIV drug resistance
- drug shortages and stock-outs
- overburdened health systems
- inadequate support for community systems
- lagging success in primary prevention
- failure to reach and support the most vulnerable, including key populations

Framework for the future

Potential solutions exist for all the challenges mentioned above. Each is likely to be needed, but none will be sufficient on their own to build, strengthen and sustain the kind of HIV responses ultimately needed. **This report proposes that most challenges and solutions be considered through the lens of four themes or pillars that should guide future work: differentiated service delivery (DSD), strengthened community systems, integration, and innovative and sustainable financing approaches**. All four are approaches through which fundamental changes can be made that collectively create a framework that could turn the tide everywhere, for everyone.

Recommendations

There is no magic bullet in this report, or anywhere else, that will solve all the current barriers described to ensure the quality of HIV treatment, prevention and care services that reach all in need and can reasonably be sustained. However, there are many steps that can be taken to lay the groundwork for achieving the kind of thorough, quality-centered framework required for ultimate success. **In Section 4, this report presents a series of specific, targeted actions and decisions that should be taken within the recommended priority challenge areas below**:

- reinvigorating primary HIV prevention
- improving data collection on HIV incidence and population size, to better target prevention spending and interventions
- preventing a resurgence of HIV in middle-income countries (MICs)
- scaling up resources for community-based responses
- strongly and quickly confronting HIV drug resistance
- realizing the promise of new and mobile technology
- developing HIV-inclusive universal health coverage (UHC) platforms and schemes

1. INTRODUCTION AND OVERVIEW

1. INTRODUCTION AND OVERVIEW

1.1 The perils within progress: what treatment scale-up cannot deliver

Snapshot from a year in the global HIV epidemic
The estimated number of people living with HIV topped 100 million for the first time as the year came to an end. HIV estimates have become increasingly unreliable due to challenges with measuring incidence and prevalence, especially in key populations. The majority of those newly infected do not know their status and have little incentive to find out because no viable treatment options exist: HIV strains resistant to most available drugs predominate, and effective new antiretroviral combinations are years away from development and availability.

Annual deaths from AIDS have risen steadily for a decade, surpassing 4 million the previous year. Pervasive AIDS-related fear, prejudice, intolerance and bigotry likely mean, however, that far more people died from HIV-related causes that were hidden or obscured.

The estimate for new infections for the past year—also thought to be highly imprecise—was that about 5 million people were newly infected. Pre-exposure prophylaxis (PrEP) long ago became useless in the era of blanket drug-resistance. Requesting or using a condom is rarely a practice, given renewed emphasis on abstinence and shaming of people with sexually transmitted infections and unwanted pregnancies. Prevention of mother-to-child transmission (PMTCT) efforts are increasingly failing, reversing trends in which several countries had claimed elimination of vertical transmission: Last year an estimated 500,000 babies were born with HIV. Among adolescents, HIV is by far the most important killer.

In a growing number of countries, uncontrolled HIV epidemics have led officials to resort to laws and policies to criminalize behaviors that risk transmitting HIV. People living with HIV and others assumed to be highly vulnerable and at risk, including members of key populations, are prohibited from having sex outside of marriage. Several nations now have laws and policies mandating that people identified as (or accused of being) gay or transgender must be arrested and put to death.

Most are denied access to health services of any kind, although in many middle- and lower-income countries health options are limited even for those not living with HIV or subject to official discrimination (excluding the small minority who can afford private care).

The snapshot above is from the year 2030. Or rather, it could be. Such a doomsday scenario, which evokes the early years of the HIV response, may seem implausible or overly pessimistic given recent successes. But some version is not so far-fetched if those successes are not built upon and maintained.[0]

Phenomenal progress in the global HIV response over the past decade has transformed the lives and hopes of millions of people. Globally, annual AIDS deaths were estimated at 1 million in 2016, a decline of 48% from a peak in 2005.[1] More than half of the world's 37 million people living with HIV have been initiated on antiretroviral therapy (ART).[2] The roll-out and prioritization of prevention of mother-to-child transmission (PMTCT) services have averted an estimated 2 million new infections in children since 2000—1.6 million of them since 2010 alone.[3] According to a recently released Global Burden of Disease Study, years of life affected by disease or early death fell by 44% for HIV/AIDS between 2006 and 2016.[4]

The rapid scale-up of ART in recent years is a main reason for these successes, and a key factor behind this rapid scale-up are the so-called 90-90-90 targets introduced in 2014 by the Joint United Nations Programme on HIV/AIDS (UNAIDS) as part of its Fast-Track initiative.[5] With aggressive programs to increase HIV testing and treatment initiation, some countries—including several low-income ones with high HIV burdens—have achieved, or are close to achieving, one or more of the 90-90-90 treatment targets.[6]

Such successes are worth recalling to put in perspective both what has been gained and what could be lost if progress does not continue and further accelerate. The benefits of target-motivated treatment scale-up to both individuals and the public health are enormous. An important concern, though, is that countries are using these core targets as the sole or primary gauge of the scope and effectiveness of their overall epidemic responses.

Treatment initiation is a means, not an end. Despite the powerful, proven value of treatment as a way to prevent HIV transmission, treatment on its own will not be able to lower HIV incidence to the levels needed for epidemic control, however 'control' is defined.[7] Some 2 million new infections every year worldwide[8] underscore the weakness of prevention programs overall. According to findings from one study in Zimbabwe, 465,000 of the estimated 1.15 million people living with HIV in the country are not virally suppressed.[9]

Meeting the 90-90-90 targets is not the end of AIDS. The millions who are on treatment must take quality ART consistently for the rest of their lives, which in most cases should mean multiple decades. Given current trends and trajectories in new infections and ART scale-up, a world in which 40 million people or more are on HIV treatment until at least the year 2075 is not far off. Planning now is needed for long-term, sustainable solutions to maintaining treatment effectiveness and improving prevention efforts.

1.2 The rationale and goals of this report: above and beyond Fast-Track

Under the guidance and influence of the 2030 Agenda for Sustainable Development and its wide-ranging Sustainable Development Goals (SDGs), the world today is at a critical point in the nexus of HIV, health and broader development. With the current focus on integration and universal health coverage (UHC), countries, donors and international institutions must determine where, how and to what extent HIV can be integrated into the future health and development architecture.

In response to this increasingly urgent planning and policy-making need, the Joep Lange Institute (JLI) convened a series of seven consultations between September 2017 and April 2018 under the guidance of Chairs Mark Dybul, Nduku Kilonzo and Lillian Mworeko.[10] The consultations aimed to support the development of effective and sustainable HIV response frameworks. They focused primarily on identifying challenges, gaps, and weaknesses in the current response that must be confronted for continued scale-up and sustained success and on offering suggested approaches to address these gaps. Consultation participants included leaders in the field from policy makers, program implementers, service providers, researchers, donors, UN agencies, civil society groups and advocates.

This report starts from the premise that the Fast-Track initiative is not sufficient on its own to guide and direct the kind of comprehensive responses needed to avoid even a tiny echo of the doomsday 2030 scenario above. One reason is that the initiative is only being implemented selectively in many countries, with important prevention, human rights and social support targets ignored or forgotten as emphasis focuses on treatment progress. Another reason is that target-based approaches set at a global level suggest that 'one size fits all' strategies are appropriate for every context. Countries must have programmatic and financial space to look beyond, including more deeply into what is driving their epidemics and how the specific factors and conditions can be addressed more directly, effectively and equitably. A third reason is that rapid scale-up is widening an already precarious imbalance between what countries are promising their citizens living with and at risk for HIV and what they can confidently assume they can deliver.

The goal of controlling the HIV epidemic by 2030 is laudable and potentially achievable, at least when defined as eliminating new infections and ensuring all people living with the virus have access to the quality treatment and support services they need. However, this goal will be difficult to reach if there are insufficient resources available and/or if programs do not have the capacity to adequately scale up health and support services to tens of millions more people over the coming years. The intention of this report is not to dispute the Fast-Track goals. Rather, it is to encourage critical analysis of their impact and feasibility as more information is gathered, with responses to that information influencing the development and implementation of improved strategies for increased effectiveness.

Nduku Kilonzo
Executive Director, National Aids Control Council of Kenya
& Chair Joep Lange Preconference AIDS2018

"We are not on track of ending AIDS by 2030. This report really begins to ask: what do we need to do differently and how do we get there?"

2. CHALLENGES TO A SUSTAINABLE AND EFFECTIVE GLOBAL HIV RESPONSE

BELGIUM

NIGERIA

HEALTH ECONOMISTS

AUSTRALIA

ZAMBIA

ARGENTINA

ACTIVISTS

RESEARCHERS

2. CHALLENGES TO A SUSTAINABLE AND EFFECTIVE GLOBAL HIV RESPONSE

2.1 The stalled and volatile state of HIV financing

No realistic scenario for future HIV responses can ignore the constraining impact of funding shortfalls. To meet the Fast-Track goals, UNAIDS estimated in 2014 that investment in HIV programs in low- and middle-income countries (LMICs) would need to increase by about one third, from approximately $19.2 billion available in 2014 to $26.2 billion by 2020.[11] This overall escalation would require more external and domestic funding, including total annual international donor assistance for the HIV response that would be at least $2.8 billion higher in 2020 compared with 2014 levels. In 2015, however, donor investments for the HIV effort were $1 billion *lower* than the previous year, the first time in five years that such levels declined.[12]

This external financing plateau was underscored in a landmark global health financing report released in April 2018 by the Institute for Health Metrics and Evaluation (IHME).[13] Among its findings were that prevention spending continues to lag, never yet having come close to the minimum 25% share of all HIV resources that UNAIDS has stated should be the minimum level.[14] Another finding was that recent declines in development assistance for health, including for HIV, leave the most vulnerable people even more exposed because this source currently constitutes the majority of HIV spending each year in low-income countries and countries with extremely high HIV prevalence.

But it is not just people in lower-income countries who should be worried. People living with, affected by and vulnerable to HIV in many wealthier countries, particularly those classified as middle-income by the World Bank, also should be apprehensive about the future. The Global Fund and many bilateral donors are pulling out of many middle-income countries (MICs) as they shift HIV spending priorities to lower-income ones. However, more than half of the world's people living on less than $2 per day and a full 70% of the world's people living with HIV live in these 'middle-income' contexts.

Many MICs' health systems lack sufficient funding and programming to reach key and vulnerable populations with quality HIV prevention, treatment, and care. In many of those countries, community-based organizations (CBOs) and other local civil society groups have been central to efforts to provide essential HIV services to the most vulnerable and marginalized. Most them receive a large share of their financial support, if not all their support, from the Global Fund and other external partners. By greatly reducing or eliminating such groups' main sources of funding, reduction of Global Fund and other international support for HIV programs in MICs has had a negative impact on quality of HIV services and engagement of key and vulnerable populations in health.[15] The result has been slower progress and reversals in efforts to diagnose and treat people and prevent new infections.

2.2 The quality of HIV treatment delivery is under-prioritized and under threat

The constrained decision-making parameters necessitated by inadequate financing are important underlying factors in the numerous other challenges discussed in this report. Perhaps the biggest overall potential threat that links all components of HIV responses, especially as rapid scale-up continues, is the need to ensure continued quality of services. Speed and progress toward meeting scale-up targets are important priorities as well, but for many—including people already on ART, those who will be initiated as scale-up continues, and those at relatively high risk of infection—ensuring the quality of services is a matter of life or death. One overarching concern about quality is that it can erode slowly over time as pressures on health systems increase. The outcomes of eroding service-delivery quality may not be noticed until the harm has been done. Some of the

many quality-related issues that are challenges to sustainable and effective HIV responses are summarized below:

Consistency of drug supply. Stock-outs of antiretroviral drugs (ARVs) and other HIV service commodities are regularly reported around the world. Stock-outs are often the result of badly designed or poorly functioning supply chains, particularly at the lowest level—the 'last mile' before the drugs and other commodities are in the hands of clients. The magnitude of the problem is evident in numerous reports—many of which are prepared by community groups monitoring stock-outs—about shortages in diverse settings worldwide. Stock-outs have been reported in recent years in many countries, including those as diverse as the Democratic Republic of Congo (DRC),[16] South Africa,[17] India,[18] Ukraine[19] and Argentina.

HIV drug resistance (HIVDR). WHO's HIV Drug Resistance Report 2017 documents steadily increasing drug resistance since 2001 in low- and middle-income countries among individuals starting first-line ART.[20] Pre-treatment drug resistance (PDR) levels exceeding 10% to WHO-recommended first-line ARVs have been reported in 6 of 11 countries in Eastern and Southern Africa as per recent national surveys.[21]

In 2017, WHO launched its Global Action Plan (GAP) on HIV Resistance 2017–2021, which provides the most comprehensive strategic response to HIVDR to date.[22] The leadership of WHO on this issue is to be commended. Yet although welcome and undeniably beneficial, the GAP does not (and perhaps cannot) provide useful suggestions for individual clients who are making personal treatment decisions, including whether to go on ART or to switch regimens. More guidance on such issues would be of great assistance not only for those clients but also for facility-based health care workers involved in clients' care and community-based groups supporting them.

Most HIV drug resistance stems from inconsistent adherence to ART regimens, with resistant strains then often transmitted to others. Therefore, closer attention and consideration should be given to treatment initiation advice and options. There is no question that earlier ART initiation, regardless of CD4 cell count, is beneficial both for a client's long-term HIV prognosis and as a prevention intervention. But it might not always be the wisest decision, given the underuse and lack of adherence services coupled with gaps in the drug supply chain in many contexts.

It can be reasonably assumed that drug resistance will decline due to proposed plans—including a July 2017 WHO recommendation—to replace efavirenz (EFV) with dolutegravir (DTG) in first-line regimens, as clinical trial data have indicated that DTG is a 'better' drug in that it has fewer side effects and a higher threshold to development of resistance. However, in May 2018, the US Food and Drug Administration (FDA) and the European Medicines Association (EMA) both issued alerts regarding the development of serious birth defects associated with DTG use in Botswana.[23] More information is needed about the drug's overall safety and to determine if and how the Botswana findings will affect the use of DTG-containing regimens as the standard first-line treatment.

Overburdened health systems and underfunded support systems. The success of the ongoing treatment scale-up has also led to increasing reports about overburdened health care systems and workers, with consequences including extended wait times and limited ability to provide the client-centered care needed to ensure treatment effectiveness.[24]

In 2013, according to a WHO survey, there were 17.4 million fewer health workers worldwide than were needed to provide essential primary health care services, with the most acute health workforce shortages occurring in Africa and South East Asia.[25] Task-shifting, which includes moving tasks traditionally conducted by physicians to nurses and community health workers (CHWs) and peer-based service providers, has helped to alleviate the burden on physicians and build additional client capacity in many health programs. But, many of these nurses and other workers are now also overwhelmed with the numbers of people and tasks for which they are responsible.

In addition, **the emphasis on rapid scale-up of treatment initiation has come at the cost of reductions in the delivery of critical enabling support services, which for many are as important as pills for maintaining good health and quality of life.** Ensuring the quality of HIV care and treatment has become much harder as a result.

Critical enabling services are strategies, activities and approaches that aim to overcome the full range of major barriers to uptake of HIV services, including the myriad ones outside of the health system. Critical enablers might include, for example, advocacy and policy work to decriminalize activities such as sex work; remove or reform age of consent policies for HIV testing, ART initiation, and access to sexual and reproductive health services; and reduce stigma, discrimination and violence by sensitizing health care workers, law enforcement personnel, and parliamentarians, among others. Critical enablers also include provision of support services for adherence, treatment literacy, transportation, food security, and mental health.

Many critical enabling services are provided by CBOs, including those led by people living with HIV. The work of these organizations remains underfunded and under-prioritized. To achieve the 90-90-90 targets, UNAIDS estimates that funding community-delivered services will need to increase about four-fold during the next five years.[26] However, there is little to no data of aggregated funding levels going towards critical enabling services. Meanwhile, community-based organizations report decreased funding levels in most regions. Further, leading global measures of human rights have reported worsening rights-related situations in every region of the world, and HIV programs serving key and vulnerable populations routinely report rights violations as a barrier for people to access services.[27,28,29]

2.3 Lagging success in HIV primary prevention

Some success has been achieved in preventing HIV transmissions. The estimated number of new adult HIV infections declined by more than 20% in 57 countries between 2000 and 2015, and the number of new infections stabilized in 20 countries. However, more than 2 million people worldwide were newly infected with HIV last year. As a result, the core 2020 Fast-Track prevention target—to lower annual new infections to 500,000 that year—is off track by a wide margin.

Coverage with proven prevention tools, services and effective interventions remains low. For example, the number of condoms available in Africa covers only about half the current need;[30] almost half (43%) of countries with injecting drug use do not have any needle/syringe programs;[31] and only about 38% of people living with HIV are virally suppressed,[32] well below the level needed for the prevention effect of treatment to have an impact on HIV incidence.

Key populations remain at much higher risk of HIV infection.[33] A UNAIDS report from 2016 noted the following: "Recent studies suggest that people who inject drugs are 24 times more likely to acquire HIV than adults in the general population, sex workers are 10 times more likely to acquire HIV and gay men and other MSM are 24 times more likely to acquire HIV. In addition, transgender people are 49 times more likely to be living with HIV and prisoners are five times more likely to be living with HIV than adults in the general population."[34]

Adolescents and young people, especially women and girls, also are disproportionately vulnerable to HIV. Globally in 2016, new infections among young women aged 15–24 were 44% higher than men their age.[35] Another important consideration is that although adolescent boys and young men face lower levels of risk and vulnerability compared with their female counterparts, at least in sub-Saharan Africa, they are less likely to know their HIV status. This points to prevention and information failures specific to both young males and females at a time when countries can afford it the least from long-term perspectives. Africa as a continent is the youngest on average in the world, with the majority of people in some countries younger than 20. According to one projection, the number of Africans between 15 and 24 years of age could reach 450 million by 2050, compared with about 200 million in 2010.[36]

Responding to the full suite of challenges faced by key populations, young people and others in micro-epidemic 'hotspots' is made more difficult by the lack of targeted funding for prevention and of reliable data and information about many of these groups. The data gaps are particularly large regarding key population sizes and HIV incidence. Because they expose trends and higher-risk areas and populations, comprehensive HIV incidence estimates are central to efforts to identify who is 'missing' in HIV responses. In the absence of improved incidence measurement at sub-national levels, it will remain difficult to effectively target HIV prevention and testing services. Efforts to do so for key and vulnerable populations is especially problematic if not impossible when it is not clear where they are, their population size, or their specific risk factors.

3. GUIDING PILLARS OF A FRAMEWORK FOR IMPROVED, LONG-TERM RESULTS

THAILAND

VIETNAM

UKRAINE

RESEARCHERS

AUSTRIA

POLICY MAKERS

BRAZIL

NURSES

3. GUIDING PILLARS OF A FRAMEWORK FOR IMPROVED, LONG-TERM RESULTS

Potential solutions exist for all the challenges mentioned above. Each is likely to be needed (and many are presented as recommendations in Section 4), but none will be sufficient on their own to build, strengthen and sustain the kind of HIV responses ultimately needed. This report proposes that most challenges and solutions be considered through the lens of four themes or pillars that should guide future work: differentiated service delivery (DSD), strengthened community systems, integration, and innovative and sustainable financing approaches. All four are approaches through which fundamental changes can be made that collectively create a framework that could turn the tide everywhere, for everyone. The progress required to reach such goals relies on there being more of all four of them: more DSD in programming, more engagement and leadership of communities, more integration and more financing for HIV.

The four pillars are distinct, yet also interdependent, overlapping and mutually reinforcing. One example of the chain of connections: More integration within HIV responses and externally—e.g., HIV integration with broader health and development—could lead to more funding being allocated for HIV, including from development areas and resources associated with education, labor and youth, among others. More funding on HIV-relevant programming and interventions in turn should lead to more money being available for and allocated to communities for their essential work. Increased financial space and capacity for communities would make DSD more effective and sustainable because communities must be extensively involved if DSD approaches are to be successful.

Differentiated service delivery. Differentiated service delivery (DSD) is a high-profile approach to program design that is intended to improve the coverage, quality and impact of HIV service delivery. It is based on the underlying idea of meeting clients' preferences and expectations at different stages of their HIV 'journey' in as simplified a way as possible, and ideally while reducing unnecessary burdens on the health system.[37]

Most of the initial differentiated ART (DART) models are based on the observation that clients who are stable and doing well on treatment do not need—and often do not want—intensive monitoring or frequent visits to health facilities. Instead, DSD offers a more tailored approach, Many DART models therefore divide clients into 'stable' and 'unstable' categories, based on variables such as extent of immunosuppression (CD4 count), presence/absence of viral suppression, treatment adherence history, comorbid health conditions, age (e.g., adolescent vs. adult) and presence/absence of pregnancy.

Most DART programs focus on reducing the number of clinic visits and simplification of drug delivery. Providing less intensive services and/or moving services to community-based locations as opposed to health facilities should not be equated with providing inferior care. Improved linkage between community and facility services is required, and peer-based linkage support, treatment literacy, transportation and child care, nutritional support, counselling and mental health, substitution therapy, and legal services also should be available to those who need them in order to achieve treatment success even where DSD models are operational.

The concept of differentiated services is also relevant for HIV primary prevention. To be more effective globally and in more contexts, primary prevention must ensure access to a full a range of interventions with proven benefits. But not all people will want or need all these interventions. Nearly all individuals in both high and low prevalence settings can benefit from a basic package of services that includes information, condoms and HIV testing, for example. But only some—and often only a small number—will at any given time need or benefit from other services such as syringe exchange, PrEP or mental health care. The simplicity is in the basic services being widely and

easily available, while the complexity lies in the availability of targeted, discrete interventions to the specific populations and individuals who need them wherever they may be and regardless of how few will take them up.

Ensuring Efforts to Scale up, Strengthen and Sustain HIV Responses

Despite the promise of DSD, there are many challenges and concerns about how to appropriately incorporate DSD into health systems. A major concern is handling the complexities and complications that inevitably result from having multiple ways of managing clients. Health care staff must understand different models and properly facilitate care and support across them. DSD can also create challenges for routine monitoring and adequate, timely tracking of client records and oversight. Another key question is whether DSD actually cuts costs and increases efficiencies.

Community engagement. Communities have long been central to the HIV response, and community-based responses continue to affect every aspect of the HIV response. They create the demand for services, implement prevention, testing, linkage to care, treatment literacy and adherence support services, and provide the critical enabling social services and advocacy without which health services cannot be effective. Without strong and well-resourced community systems, the promise of DSD approaches cannot be realized, targets for zero discrimination cannot be met, and the promise to 'leave no one behind' cannot be fulfilled. AIDS cannot be ended without affected communities serving as the foundation to the HIV response.

The term 'community-based' can refer to two different yet often linked or complementary concepts and interventions: activity driven by communities, which typically refers to independent CBOs and networks, and delivery within communities, which can be undertaken by such independent entities as well as others (including from the health system). Community-driven activity in particular can be critical for reaching the most vulnerable and marginalized. A robust community-based response of both kinds is required to address each of the challenges described earlier in this report, from reaching people 'missing' from HIV responses to controlling drug resistance to stopping drug stock-outs and shortages.

Despite the importance of the role that community-based efforts play in effective HIV responses, the CBOs and other independent entities continue to face funding challenges in nearly every context, with many organizations forced to reduce operations or shut their doors completely over the past few years. UNAIDS acknowledges the importance of substantial increases in resources allocated towards community-based efforts, concluding that investments in community mobilization and services must increase *more than threefold* between 2015 and 2020." to reach current targets[38] According to the UNAIDS Strategy 2016–2021, the increase should be even greater through 2030, moving from a global average of 5% in 2013 to cover at least 30% of all service delivery by 2030.[39]

Few donors are ready and willing either to pay for advocacy work. That challenge constrains the scope of networks of people living with HIV and key populations to undertake some of their most important and potentially influential efforts, such as advocating for legal and policy reform. Funding for human rights advocacy has always been far below the estimated needs and has been cut even further in the past few years.[40]

External donors could make a big difference by relaxing strict policies on what financial assistance can be used for, setting aside more funds for community-based responses, and more actively seeking new and diverse recipients through calls for proposals. Additional funding from governments could be facilitated through broader introduction of social contracting mechanisms, in which governments formally link with civil society groups in HIV responses through contractual arrangements for the provision of HIV prevention, treatment and other services. Development of standardized reporting mechanisms for community-based services is another important approach to both encouraging government support and building CBO capacity.

Integration. Although some specialized HIV services are still critical for responses, HIV treatment, prevention and support services have been and will continue to be integrated within broader health, development, financing, and social systems. Changes in the political landscape and the priorities of both donor and implementing countries—as seen, for example, through the launch in

2015 of the 2030 Agenda for Sustainable Development—make continued consolidation of more integrated approaches to HIV responses inevitable.

Ensuring Efforts to Scale up, Strengthen and Sustain HIV Responses

There several ways of thinking about HIV-relevant integration, including integration of HIV within primary care and other health care services (e.g., for TB and sexual and reproductive health); integration of HIV services within other areas of development and social welfare (e.g., schools); and integration of HIV within broader funding and structural mechanisms for health and development. Areas in which integration of HIV-related concerns could produce more effective and efficient outcomes might include improved health outcomes through integrated service delivery; integration of HIV services within all platforms, structures and systems designed to deliver universal health coverage (UHC); and integration of HIV-relevant services across all government ministries and agencies.

Discussions around integration and HIV should proceed with caution, however, regardless of the promises and opportunities. There is limited data about the effectiveness of comprehensive and extensive integrated strategies involving HIV services, and some major risks must be considered—such as the possibility of decreased HIV program quality and impact. To help recognize and avoid such risks, more attention and resources should be directed toward evaluation and implementation science research on HIV-relevant integration.

Financing. Establishing a sustainable financing framework for the HIV response is a key priority for quality scale-up. Direct budget support and taxation policies are the most efficient and effective sources of additional domestic funds for national HIV responses. For political and other reasons, such as competing demands for the use of relatively modest budgets, they are not always a realistic option.

National health insurance schemes are one example of a financing mechanism and instrument that several countries have been using in recent years to move closer to achieving UHC. What can and has been done regarding integrating HIV services into such schemes depends on factors including epidemiological burden, income and other economic conditions, and political will and support. Evidence to date in many countries indicates that many of the ambitious efforts to develop national health insurance programs to reach UHC goals have encountered challenges associated with the schemes' structural and financial stability and expansion of coverage, with HIV services proving to be particularly difficult to support directly. One option some countries might consider is to run external donor support for HIV services through national health insurance programs, which could help to stabilize such programs and better prepare countries for transitions away from donor support.

Risk pool development can also be useful. People living with HIV and other high-cost conditions could be covered separately from the general insured population with specialized funds, thereby easing pressure on the main insurance scheme. Risk pools of this sort, which can be funded through mobile payment mechanisms, are likely to be most useful in countries with relatively high HIV burdens.

Other tools within the broad area of innovative financing have also been raised as a way to identify effective service delivery approaches as well as scale up and sustain those approaches. These include *pay-for-performance contracts* and *social impact bonds, vouchers, sustainability bridge funding,* and *compulsory licensing for generic drug manufacturing.* Each of these is described in greater detail in the full report at **www.joeplangeinstitute.org.**

SENEGAL

4. CONCLUSION AND RECOMMENDATIONS

DONORS

COMMUNITY REPRESENTATIVES

GERMANY

ADVOCATES

SCIENTISTS

INDONESIA

LAWYERS

IVORY COAST

4. CONCLUSION AND RECOMMENDATIONS

There is no magic bullet in this report, or anywhere else, that will solve all the current barriers described to ensure the quality of HIV treatment, prevention and care services that reach all in need and can reasonably be sustained. Many of the ideas offered here have been described previously, some since the beginning of the epidemic. This goes beyond pills and condoms, as important as they are, to include real human rights protection; recognition of the value that communities play in improving engagement in health; and an acknowledgment that everyone everywhere has a right to good health and safety regardless of where they live, who they love, or their age, gender or economic status. Perhaps the greatest challenge to ending AIDS is that it depends primarily on one precondition that has often been lacking: ongoing political will to fully fund and implement the tools, programs and policies that are proven effective.

The framework of solutions proposed here also is meant to address a longer-term view of a sustainable HIV response. While the Fast-Track targets are extremely useful in setting and achieving milestones, the HIV global response must now be centered on development of long-term and sustainable approaches based on the decades of commitment required to reach and maintain control of the epidemic and secure the lives of people living with HIV for decades to come. For these ideal outcomes to be achieved, UNAIDS and its partner agencies, donors, civil society and implementing countries must develop more sophisticated country-specific strategies based on realistic trajectories and evidenced-based approaches for decreasing HIV incidence; implement comprehensive treatment delivery that includes critical enabling support services; and exhibit a true commitment to human rights that addresses gender inequity and violence and discrimination and criminalization of key populations.

The overarching priority of acting on evidence is worth re-emphasizing, as it is relevant for all actions and strategies moving forward. For example, more research and analysis are needed to answer some of the important questions around community-based services, DSD, incidence measurement, and integration. Evidence and data can help to better determine, for example, the strengths and weaknesses of specific HIV interventions provided by CBOs in a range of settings; which DSD models work best; how best to target prevention funding; and the effect of integration of HIV into primary care on the quality of HIV services. Results from more extensive and comprehensive research in such areas should influence decision-making and advocacy.

There are many steps that can be taken to lay the groundwork for achieving the kind of thorough, quality-centered framework required for ultimate success. A sampling of those actions and decisions are presented as suggestions to address the recommended priority challenge areas below. Based on the main themes and gaps arising from the consultation process for this report, they are proposed to help guide future work by all stakeholders in HIV responses in coordinated, collaborative and integrated ways. Additional recommendations can be found in the main, comprehensive report from which this document is derived and in the reports from the seven consultative meetings that informed the final main report. All these documents are available on the Joep Lange Institute website at www.joeplangeinstitute.org.

(1) Reinvigorate primary HIV prevention

A significant increase in funding for HIV prevention is required. In addition:

- **Governments**, in an effort to meet public health and human rights goals, should eliminate laws and policies that discriminate and/or criminalize consensual sexual behavior, drug use and eliminate bans on effective prevention activities such are syringe exchange and substitution therapy.
- The potential of pre-exposure prophylaxis (PrEP) to prevent transmission among those most vulnerable is a particularly compelling, yet underutilized. As a core component of their HIV prevention efforts, **governments** should seek to rapidly scale up PrEP access that is accompanied with quality support services and diagnostic testing.
- The **Global Fund, PEPFAR and other donors** should develop ways to more successfully incentivize countries to focus more on primary prevention—and to do so using evidence-informed, targeted ways to have the most impact. Thus, for example, support would end for abstinence programs and would be scaled up for PrEP, condom availability and harm reduction. The **Global Fund** should seek to boost prevention funding in its grants, perhaps by setting strict minimum targets both for proposals and signed agreements.
- **Research and academic institutions** have key roles to play in conducting research to better understand where and how to engage people in prevention interventions, which interventions are most effective and cost-effective, and how to measure success.

(2) To better target prevention spending and interventions, improve data collection on HIV incidence and population size

Improved, targeted data on HIV incidence and key population sizes, disaggregated by sex, age and demographics, are needed to identify micro-epidemics and 'hotspots' at national and sub-national levels.

- **Governments** should commit to gathering such data consistently and making the results publicly available, including through their progress reporting to the United Nations.
- **UNAIDS, WHO and other UN agencies**, in conjunction with **research institutions,** should more proactively encourage and support such efforts, offering technical support and advice and facilitating referrals for expertise and funding.
- **Community-based groups** should be involved in data-gathering processes, as they are likely to have deeper knowledge about and closer links with affected communities. The involvement of communities also lends legitimacy to data-collecting efforts and increases the likelihood that governments will be held accountable if they do not respond responsibly or effectively to the findings.
- **Donors**, such as the Global Fund, should prioritize funding proposals based on a country's presentation of sufficient data about population sizes and incidence measurement at sub-national levels, including that of key populations

(3) Prevent a resurgence of HIV in middle-income countries (MICs)

- **The UN**, in consultation with international financial institutions, should develop transparent measurements of progress on sustainable development that go beyond per capita income. These should recognize poverty in all of its forms and dimensions and the economic, social and environmental dimensions of domestic output and structural gaps at all levels. Additional criteria to be considered could include fiscal space, economic growth, health spending, inequality, willingness to pay, debt to gross domestic product (GDP) ratio, etc.
- **Governments** in both MICs and lower-income countries should not assume that external financing will always be available and thus they should begin transition planning as soon as possible. As they reduce dependency on external donors, they should prioritize efforts to allocate adequate levels of domestic funding to address HIV and other health needs, including those of key populations.
- **The Global Fund and other donors** should develop bridge funding mechanisms for MICs facing transition as one option. But the concept of 'bridge' might not be sufficient in places where the other end of the metaphorical bridge, domestic financing and support, is uncertain or unlikely. The funding and support strategies and approaches implemented should be designed to be used and prioritized for as long as the gaps exist, regardless of how long that might take.
- **Donors** also should jointly agree on strategies to support CBOs and other civil society groups in such countries not only to sustain what was started by the Global Fund and others, but to preserve progress made to date and expand and strengthen it. Such funding should include support for advocacy to encourage transition planning and implementation.

(4) Scale up resources for community-based responses

- **Governments** should support community-based services for HIV treatment, prevention and support through funding, capacity building and technical support to CBOs and other independent entities engaged in HIV work. Such services should work in partnership with health systems. Social impact bonds tied to performance-based funding are one method to be explored to finance and expand community-driven work.
- **Governments** should also review and update existing laws and regulations in order to provide social contracting mechanisms and to broaden the role that civil society can play in health services delivery, including drug dispensary and HIV testing and counselling.
- **The Global Fund and other donors** should develop and support funding mechanisms for CBOs working at national, regional and global levels to advocate for human rights protections and provide technical support to local community-based service providers. Community-driven grants programs, such as the Robert Carr civil society Networks Fund, are a useful method to support these activities. They deserve and require greater investment.
- **CBOs and civil society groups** must ensure that they establish the systems and procedures necessary to show how, why and where they are using increased funding, with extra effort made to develop impact indicators that highlight both priority quantitative and qualitative issues that collectively provide a full picture of the scope and breadth of their work. In most contexts, the development of such indicators should be done in collaboration with government agencies to which CBOs are reporting.

(5) Confront HIV drug resistance (HIVDR)

- **WHO** should take the lead in developing simplified messaging regarding HIVDR to help those outside of the research community understand its relevance and importance, including all donors, government health officials and policy makers, CBOs and other civil society groups.
- **Governments** should (a) invest in increased laboratory capacity to better detect drug resistance and expand access to viral load testing; (b) invest in community-based, mobile technology-based and other adherence support services; and (c) ensure that supply chains can provide ARVs consistently without stock-outs or shortages at clinics. Better data management is one potentially useful approach to strengthening supply chains. And, governments and donors must commit to ensuring access to second- and third line regimens so that treatment options are available for people with HIVDR.
- **CBOs and other civil society groups** should make it a priority to provide information to communities on the risks of HIVDR as well as help to monitor it, including among those only recently initiated on treatment. Communities also have a key role to play in monitoring and reporting on drug stock-outs and shortages. CBOs should prioritize increasing their capacity to provide treatment literacy and adherence support services.
- **WHO, UNAIDS, governments and researchers** should initiate a rapid, comprehensive analysis of DTG to give a more thorough understanding of its risks and opportunities, including for treatment-naïve individuals.
- **Research institutions and industry** should prioritize the development of new and more affordable technologies for drug resistance monitoring.

(6) Realize the promise of new and mobile technology

- **WHO** should develop guidelines for using mobile phones and other digital solutions and be transparent at all stages, thereby helping promote crowd-sourced solutions. For example, WHO indicators for quality of care by providers could be supplemented with a new set of mobile phone-based early warning indicators (EWIs) that are used by clients and communities to report on quality of care in a geo-targeted and real-time manner. Heat maps and benchmarks of community-supported quality of care could be constructed, using centralized data depots at WHO.
- **Governments and donors** should set up and strengthen links with private-sector partners with expertise and experience in digital technologies that are acceptable and adaptable in specific contexts, including resource-constrained ones. In particular, linkage to mobile phone providers will allow for using new sets of data that can help target HIV treatment and prevention efforts and identify vulnerable populations as well as potential hotspots of HIV. Companies such as Safaricom in Kenya have had great success innovating and expanding mobile-payment systems, for example.

- Part of these efforts may require greater upfront and future rewards. **Governments, donors and other external partners (e.g., foundations),** also should establish and prioritize incentive-based programs that reward new and promising digital solutions targeted toward improving overall HIV responses and the experiences of the most vulnerable and key populations in particular. Models that might prove promising include work done by Unitaid and others to promote new point-of-care (POC) diagnostic options.
- **Entrepreneurs** in **mobile technologies** should be stimulated to come up with digital solutions that support HIV prevention, ART supply chain management, HIV treatment and care and empower individuals as well as communities in monitoring and securing determinants of quality of care. Innovative digital pooling of public and private funds through mobile healthcare exchange platforms (such as M-TIBA in Kenya[41]) can potentially strengthen HIV responses and leverage total amount of money in the system.

(7) Develop HIV-inclusive UHC platforms and schemes

All partners involved in UHC development and financing must make this a priority.

- HIV treatment and prevention should be included in UHC-driven insurance schemes as quickly as feasible.
- The **Global Fund, World Bank and other donors** should consider funding all aspects of comprehensive HIV care through UHC schemes to allow those schemes to stabilize as they grow.
- UHC must include more than access to health and treatment services, as coverage for prevention interventions is vital.
- Any UHC scheme must include key and marginalized populations if it is to succeed and be truly universal.
- High drug prices in middle-income countries could undermine the stability of UHC schemes. Access to generic medications and/or reduced pricing should be extended to MICs if their UHC goals are to be met.
- Community advocates should be involved in all aspects of UHC program development, implementation and monitoring.

Mark Dybul
Professor, Joep Lange Chair and Fellows Program

“What we really need is people who are willing to see and hear the world in a fundamentally different way”

DOCTORS

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ENDNOTES

RUSSIA

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Lillian Mworeko
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"Global goals will only be achieved when investments are put in community responses and structures"

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This report is an outcome of a collaboration between a special group of experts from across the globe.

The Joep Lange Institute aims to make health markets work for the poor. Digital technology can revolutionize healthcare, connecting those who are currently excluded to better quality care and more equitable finance. We identify and accelerate innovative (digital) solutions and advocate to scale those that have real impact. Ultimately, we believe that the question isn't whether or not inclusive healthcare is possible. It's whether there is enough political will to make it happen.

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