The global HIV response: lessons learned, new challenges, a moment of decision

The response to one of humanity’s greatest public health challenges is at a critical moment. The most recent Global AIDS Update from UNAIDS makes it clear that “all global targets for 2020 will be missed.” The choices made now, by the Joint Programme and by the international community as a whole, will determine whether it will be possible within the next decade to achieve the universally-agreed Sustainable Development Goal of ending AIDS as a public health threat by 2030. That effort is now beset and complicated by yet another public health crisis, with the emergence of COVID-19 threatening hard-won gains against HIV. This latest challenge underscores several key lessons from the last four decades of the HIV pandemic, which lessons should inform the next phase of the global AIDS response:

- **Political will to face the challenge is essential. It must be manifested both in the mobilization of the necessary human and financial resources, and in concrete actions creating an enabling environment for an effective, evidence-based response.** Where this political will, and these resources and this enabling environment, are present, the tide has begun to turn, reducing the rate of new infection and of deaths. Conversely, the absence of these key elements continues to frustrate and impede the AIDS response in too many settings, and will keep achievement of the SDG goal of ending AIDS, and other HIV-related SDGs, out of reach.

- **The protection and promotion of the full range of human rights, including gender equality, is an indispensable and central feature of this enabling environment.** This makes it all the more troubling that in recent years there has been, in many settings, a backlash against the protection and promotion of human rights, including of some of those communities and populations most affected by HIV – and hence all the more important that the Joint Programme have human rights as a central, animating principle and approach. UN Member States themselves have repeatedly declared in every Political Declaration on HIV and AIDS that the full realization of human rights for all “is an essential element in the global response to the HIV epidemic, including in the areas of prevention, treatment, care and support.” Experience in the HIV response has taught us that protecting and promoting human rights is practical, life-saving and economical. Preventing HIV, and
ensuring universal access to comprehensive care and treatment for those living with HIV, is a necessary part of states’ obligations to realize the right to the highest attainable standard of health for all, without discrimination. Furthermore, this effort to realize the health of individuals and the public cannot be divorced from the protection and promotion of other rights, such as freedom of expression and association, freedom from discrimination and the equal benefit and protection of the law, freedom from arbitrary detention and cruel or degrading treatment, privacy, security of the person (including freedom from violence by state and non-state actors), safety at work, education, social security in event of loss of livelihood, the benefits of scientific advancement, and participation.

- **Investments in the global HIV response must include adequate support for community-led responses and ensuring the engagement and involvement of affected communities at all levels.** The meaningful engagement of communities particularly affected by HIV makes the response stronger and more effective – and must include their integration into countries’ national AIDS plans, and their involvement in developing, delivering, monitoring and evaluating services, as well as in research and advocacy, public education, and community mobilization. It is also part and parcel of achieving the sustainable development goal of inclusive societies (SDG 16). In the UN General Assembly’s 2016 Political Declaration on Ending AIDS, Member States have recognized that communities play critical roles in the HIV response, and that community-based responses must be scaled up in order to meet the agreed-upon Fast-Track targets. Member States committed that by 2030, at least 30% of services would be community-led.

- **Investments in the HIV response have also yielded, and will yield, benefits beyond HIV.** They have strengthened responses to TB (which remains the opportunistic infection threatening those with HIV) and other sexually transmitted infections or blood-borne infections (including viral hepatitis). And as recent months have demonstrated, they have laid a foundation that in many settings is now being called upon to do yet more in responding to COVID-19 — another pandemic that demonstrates brutally the fault lines of social and economic inequities and thereby makes the case yet again for the urgent necessity of protecting and promoting human rights in order to respond effectively to a global public health threat.

**UNAIDS strategy beyond 2021: 10 key action points**

We have the scientific tools and evidence to achieve the goals of zero new HIV cases, zero AIDS deaths and zero discrimination. The new global AIDS strategy should lay out how the world can end AIDS as a public health threat by 2030. Key functions of the Joint Programme within that strategy include working with governments and civil society to generate the necessary political will, mobilize the necessary resources, create an enabling environment for an effective response, from the country level to the global, as well as monitor the epidemic and the response, to ensure that the ambitious goal is achieved. Keeping in mind the lessons learned over the last four decades, the UNAIDS Reference Group on HIV and Human Rights takes this opportunity to highlight for the UNAIDS Programme Coordinating Board, and for the international community more broadly, several key human rights challenges and priorities for action by the Joint Programme (including the UNAIDS Secretariat) and by the international community in achieving the HIV-related Sustainable Development Goals and ensuring that “no one is left behind.”
1. Human rights as the framework for defining, implementing and evaluating the response

The current UNAIDS strategy includes important commitments on human rights, including those of women and girls, and of key populations; this must be strengthened. The strategy for the Joint Programme beyond 2021 should explicitly adopt human rights as its framework, include concrete, specific human rights goals and ways to achieve those goals, combining the best available (and emerging) evidence with policies, programs and initiatives that protect and promote human rights, so as to maximize the benefits of our collective knowledge. A human rights framework for the HIV response reflects the binding obligations agreed to by states, including equality and non-discrimination as foundational, cross-cutting principles – which necessarily requires action to protect the rights of those most often left behind, including key populations, and to address gender inequalities. It offers key guidance for designing, implementing and evaluating services and also the legal and policy environment that will either enable, or impede, an effective response. It also mandates the participation of affected communities in the response. Widespread human rights abuses continue to fuel the epidemic; ignoring this reality will mean that the world fails to achieve the 2030 goal. Such a framework should guide not only the Joint Programme but the international community’s efforts as a whole, from country plans to the priorities and investments of donors and multilateral funding entities.

2. Universal, affordable access to health care, including ARVs for prevention and treatment

Achieving the Sustainable Development Goal of universal health coverage (Goal 3.8) must include access to HIV prevention and testing services targeted to various populations, and care and treatment for HIV and other co-morbidities threatening the health of people living with HIV. The Reference Group is keenly aware that many health services essential to an effective HIV response are already inadequately funded in many countries — and that this is especially the case for services that are needed by key populations who are particularly affected by HIV (and related concerns such as viral hepatitis and TB) but are often politically disfavoured and socially marginalized. In some countries reliant on international donor funding, these services needed by key populations are at even further risk if and when countries transition out of eligibility for funding, as domestic funding commitments may be insufficient or non-existent. User fees for health services also remain a major barrier for many, particularly in those countries where public health insurance coverage is limited. Finally, overly-stringent laws and policies on intellectual property, whether domestic or embedded in international trade and investment agreements, keep medicines and other health technologies unaffordable and inaccessible to too many.

According to the most recent Global AIDS Update, roughly one-third of people in need of life-saving ARVs still have no access and will die without it. The HIV epidemic, and the global mobilization in response to the urgent need for life-saving medicines to treat millions of people, have illustrated starkly the critical importance of ensuring countries have the ability to devise policies, including in the areas of intellectual property, investment, procurement, competition, and price regulation, to address public health needs. This effort will continue to be needed, with the same combination of urgency, human rights advocacy and political will that drove the first era of the HIV response.

The Reference Group therefore recommends that the new UNAIDS strategy include sustained attention to working with governments, civil society organizations and affected communities to:
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- track spending on HIV-related services, at the domestic and global levels, and their adequacy in light of estimated needs;
- mobilize sufficient domestic and global resources for HIV services, particularly for key populations;
- expand public insurance coverage of HIV-related services and abolish user fees; and
- maximize the flexibility of governments to ensure access to affordable medicines and other health technologies for all, including acting on the recommendations of the UN Secretary General’s High-Level Panel on Access to Medicines.

3. Stigma and discrimination against people living with HIV, key and vulnerable populations

Stigma and discrimination can and do kill. Governments may refuse to recognize the existence of key populations affected by HIV or to fund the evidence-based services needed to address HIV in those populations. Fear of discrimination, violence or other human rights violations is a barrier to people seeking health services, including HIV testing and treatment, and a challenge in maintaining connection to care and thereby achieving and sustaining viral suppression. The most recent Global AIDS Update 2020 has highlighted that “key populations and their sexual partners accounted for more than 60% of new adult HIV infections globally in 2019.” It is no coincidence that those key populations—namely, gay, bisexual and other men who have sex with (GBMSM), transgender people, people who use drugs, sex workers, people in prisons and other closed settings—are those often subjected to stigma and discrimination in a wide range of settings. People with disabilities are often overlooked and left out of HIV responses, despite often heightened vulnerability and additional barriers to services. The same realities face Indigenous communities in many parts of the world. Finally, migrants in many settings are at particular risk of being denied care and other services.

Ensuring access to HIV prevention measures, testing and treatment requires that UNAIDS, governments, the private sector and civil society tackle the stigma and discrimination faced by these populations; this must be central in the new UNAIDS strategy. In addition, the new strategy must include as a priority the full implementation of the Global Partnership for Action to Eliminate All Forms of HIV-related Stigma and Discrimination, including measures aimed at ending stigmatizing and discriminatory attitudes, practices and policies in health care and a range of other settings, supporting people living with HIV and key populations to know and defend their rights, and implementing laws and policies that protect effectively against discrimination.

4. Criminalization and other punitive laws, policies and practices

A “human rights approach” to HIV goes beyond ending stigma and discrimination. The criminalization of key populations and other punitive measures, including incarceration, arbitrary detention and abusive policing, remain central obstacles to overcoming AIDS (and other conditions such as tuberculosis and hepatitis C). As outlined in the Global AIDS Update 2020, the criminalization of people living with HIV and key populations such as sex workers, people who use drugs, transgender people and GBMSM is prevalent across the globe. Criminalization of key populations is often also accompanied, either directly or indirectly, by legal restrictions on distributing, accessing or possessing HIV prevention tools such as condoms or injection equipment, and the reality that such services are often woefully underfunded or
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accessible only by risking possible police attention or prosecution. In countries around the world, prisoners are routinely denied access to essential health services, and denied access to health services equivalent to those available outside of prisons, in direct contradiction of the UN Standard Minimum Rules on the Treatment of Prisoners (Mandela Rules). This has fuelled not only HIV in prisons, but also infections such as tuberculosis, viral hepatitis and now COVID-19. There is ample evidence of the need for ending criminalization and other punitive laws, policies and practices. There is also extensive guidance on how to instead create a legal and policy environment enabling effective HIV prevention and treatment interventions (e.g., International Guidelines on HIV and Human Rights, recommendations from the Global Commission on HIV and the Law, International Guidelines on Human Rights and Drug Policy, etc.)

The Reference Group is therefore of the view that the Joint Programme – the UNAIDS Secretariat and all relevant co-sponsors – has an essential role to play in abolishing such criminal and other punitive laws and policies, and their enforcement. In addition, there must be enhanced support, both political and financial, for interventions to protect the human rights of those subjected to such punitive laws, policies and approaches in the interim, as law reform efforts continue. Such a program of work should feature prominently in the UNAIDS strategy beyond 2021 if the goal of ending AIDS as a public health threat is to be achieved.

5. Human rights of women and girls, including access to education, economic empowerment and ending gender-based violence

Gender discrimination and inequality—including in severe forms such as gender-based violence—can put women and girls at greater risk of infection, and doubly disadvantage women and girls living with HIV, including impeding their access and adherence to treatment. The most recent Global AIDS Update reports what remains one of the most widespread and pernicious human rights crises on the planet: “Nearly one in three women worldwide have experienced physical or sexual violence by an intimate partner, non-partner sexual violence or both in their lifetime.” And young women, women belonging to ethnic and other minorities, transgender women, women who use drugs, sex workers and women with disabilities face heightened risk of violence. Finally, women living with HIV frequently report experiences of violence or the fear of violence from intimate partners and family members. Other coercive and abusive practices, rooted in harmful gender norms, also deny women and girls their bodily autonomy and dignity and can contribute to greater risk of HIV infection. Meanwhile, they also lead to inadequate and unequal access to education for many girls and women, with life-long effects on women’s employment opportunities, economic independence and risk of violence. Discriminatory laws and practices also deny or impede access to HIV-related health services for women. There is simply no way to end AIDS as a public health threat, when hundreds of millions of women are denied access to the information and means to protect their health, and do not enjoy the autonomy to use them. Achieving this Sustainable Development Goal is inextricably linked to the achievement of Goal 5, gender equality and the empowerment of women.

The Reference Group therefore recommends that the UNAIDS strategy beyond 2021 include an explicit commitment to, and programme of work for, eliminating harmful gender norms, discriminatory laws, and an end to gender-based violence.
6. Sexual and reproductive health rights

Universal access to sexual and reproductive health services is part of the Sustainable Development Goal of ensuring health lives and well-being (Goal 3), alongside the HIV-related goal; it is also a necessary component of achieving gender equality and women’s empowerment (Goal 5). Yet the Global AIDS Update 2020 highlights just how wide the gap remains between the current reality and universal access: “in much of the world, women continue to have insufficient access to high-quality sexual and reproductive health information, education and services—including family planning—all of which are central to realizing and protecting their sexual and reproductive rights and reducing HIV risk.” Furthermore, “[r]ural and urban poor, minority ethnic groups, adolescents and lesbian, gay, bisexual, transgender and intersex (LGBTI) people are particularly underserved.” Meanwhile, women living with HIV often face the double burden of HIV stigma and gender inequality, with many reporting experiencing discrimination and other mistreatment in health care settings, including breaches of confidentiality, forced or coerced sterilization or termination of pregnancy, or denial of sexual and reproductive health services. It is self-evident that sexual health services are essential to preventing the sexual acquisition and transmission of HIV as a sexually transmitted infection, and reproductive health care is essential to the prevention of vertical transmission. The full realization of the right to health, and the right to equality, for women, LGBTI people, sex workers and others, requires access to such services.

The Reference Group therefore recommends that the UNAIDS strategy beyond 2021 include an explicit commitment to, and programme of work for, advancing sexual and reproductive health and rights.

7. Ensuring human rights in the provision of all HIV services

Respecting and protecting human rights in all HIV and HIV-related health services is an ethical and legal obligation. It is also a pragmatic and necessary approach to sustained and effective engagement of those who need access to such services, which is essential to ultimately preventing and treating HIV and AIDS, so as to end the pandemic as a public health threat. Stigma, discrimination and other human rights breaches in the provision of services will mean that those in need, including key populations, will be unwilling or unable to access them, hobbling their effectiveness. For example, scaling up fully voluntary HIV testing and counselling, through multiple settings and modalities, is central to both prevention and treatment. But HIV testing policies and approaches that violate human rights are not the solution, nor are they necessary. UNAIDS has developed guidance on Fast-Track and human rights, outlining why and how HIV prevention, testing and treatment services can and should be grounded in human rights principles and approaches, thereby maximizing the reach and impact of such programmes.

The Reference Group recommends that the UNAIDS strategy beyond 2021 must include an explicit commitment to, and programme of work for, integrating human rights principles and approaches into all HIV and HIV-related health services.
8. Resourcing the human rights dimension of the AIDS response

Since 2016, the beginning of the current UNAIDS strategy, there has been an international consensus that we must “fast-track” the response if we are to achieve the SDG goal of ending AIDS as a public health threat by 2030. Yet Global AIDS Update 2020 has sounded the alarm on the stalling of overall global funding levels for the HIV response. Furthermore, within that envelope, funding to support programs that protect and advance human rights represent a troublingly small proportion, given that, as UN Member States have repeatedly, the protection and realization of human rights is “essential” to an effective HIV response. Important initiatives are underway in some quarters (e.g. the Global Fund to Fight AIDS, Tuberculosis and Malaria) to scale up funding for the implementation at country level of key human rights programmes recommended by UNAIDS. Despite such important efforts, there are few instances in the world where such programs have yet been taken to scale.

The Reference Group therefore recommends that the new UNAIDS strategy expressly identify the goal of ensuring, in collaboration with donors and other partners, enhanced investments in initiatives, by both government and civil society, to protect and promote gender equality and human rights, particularly of the key populations most affected by both HIV and by human rights violations that fuel the pandemic.

9. Concrete commitments to human rights defence and promotion within the Joint Programme’s strategy and action

When the right capacities are in place, including at country level, UNAIDS can help catalyze positive change, including on sensitive issues such as human rights. The UNAIDS Secretariat and country offices also play key roles in addressing urgent situations affecting HIV, be they imminent or ongoing human rights violations or humanitarian crises leading to interruptions in services and care. However, the Reference Group is concerned that, despite the centrality of human rights to an effective HIV response, the human rights capacity within the Joint Programme is limited. Both the UNAIDS Secretariat and the UN Development Programme (the co-sponsor with the broad lead on human rights) struggle with insufficient human and financial resources dedicated to human rights efforts in the HIV response. Resources within other Joint Programme co-sponsors for human rights are thin, as are resources within the Office of the UN High Commissioner for Human Rights (OHCHR) to address HIV-related human rights concerns. This capacity must be strengthened across the Joint Programme, both within headquarters and at country level, where UN staff have a key role to play in advancing human rights in the HIV response. There must also be accountability of UN staff within whose mandates such work falls; conversely, field staff who defend and advocate for human rights must be assured by their senior management that they will be protected by the UN for advancing this institutional mandate.

The International Guidelines on HIV and Human Rights, developed jointly by UNAIDS and the Office of the UN High Commissioner for Human Rights, provide detailed programmatic guidance for states on why and how to respect, protect and fulfil human rights in responding effectively to HIV. With the benefit of extensive global dialogues, the Global Commission on HIV and the Law has issued a series of
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evidence-based, human rights-based recommendations on how to create a more enabling legal and policy environment for an effective HIV response. The Joint Programme should also speak with one voice on issues such as the removal of punitive laws and policies, including in relation to drugs (in keeping with the UN system common position) and sex work (in keeping with longstanding UNAIDS guidance).

The Reference Group therefore urges that the new UNAIDS strategy should explicitly identify the protection and promotion of human rights as a core element of the Joint Programme’s mandate, including supporting countries, policymakers and service providers in implementing programmatic recommendations such as those identified above. The strategy should also commit to ensuring that there is adequate capacity and support within the Joint Programme (UNAIDS Secretariat and co-sponsors) to undertake this work.

10. Defending civic space and supporting community-based responses

The Reference Group is deeply concerned about the growing number of countries, including some of those heavily burdened by the HIV pandemic, in which civil society organizations representing and working with key populations affected by HIV, and organizations advocating for human rights, are being deliberately targeted by governments seeking to silence or otherwise impede their work. Such measures only undermine the HIV response—not only efforts to achieve zero discrimination and full respect for human rights, but also efforts to fast-track the achievement of HIV prevention and treatment targets and achieve the SDG goal of ending AIDS as a public health threat by 2030.

The Reference Group urges that any UNAIDS strategy beyond 2021 expressly commit the Joint Programme (UNAIDS Secretariat and co-sponsors) to defending and advancing civil space for community-led responses to HIV and related health concerns, including the work of organizations in defending and promoting human rights of women and of key populations.

Embedding human rights as foundational in the UNAIDS strategy beyond 2021

This cursory review of some key human rights challenges should underscore the reality that the “fast-track” approach will fail to achieve the internationally agreed targets for ending AIDS unless it attends to these and other human rights barriers to scaling up HIV prevention, testing and treatment. Human rights are “critical enablers” of an effective HIV response. The benefits of scientific advancement in the field of HIV—including the development of effective treatments that save lives and communities, and also boost prevention efforts—will go unrealized as long as people and communities do not know or cannot claim their rights, and as long as laws, policies and practices continue to deny or violate rights. This understanding should be a touchstone for the international community in striving to reach the SDG of ending AIDS as a public health threat by 2030 – and if the Joint Programme is to be fit for purpose, it must be a touchstone for the UNAIDS strategy beyond 2021.