



UNAIDS Reference Group on HIV and Human Rights

Rights, Readiness and Response:

Written comments on the working draft of the WHO convention, agreement or other international instrument on pandemic prevention, preparedness response and recovery

by the UNAIDS Reference Group on HIV and Human Rights 15 September 2022

The UNAIDS Reference Group on HIV and Human Rights was established in 2002 to advise the Joint United Nations Programme on HIV/AIDS on all matters relating to HIV and human rights. The Reference Group speaks with an independent voice; thus, its views do not necessarily reflect the views of the UNAIDS Secretariat or any of the UNAIDS Cosponsors.

INTRODUCTION

Public health emergencies such as pandemics implicate human rights – not just the right to health, but the rights to life, benefit from scientific progress, privacy, liberty, freedom of movement, freedom of arbitrary detention, non-discrimination, employment, safety at work, education, freedom of assembly and expression, and freedom of information. These rights are inalienable, universal, interdependent and indivisible.

Yet the COVID-19 pandemic, like the ongoing HIV pandemic, has revealed that failure to respect, protect and fulfil human rights also undermines an effective response to such public health challenges. The failure of wealthy countries to ensure equity, including in access to health goods, has led to preventable disease, suffering and death, on a massive scale, in low- and middle-income countries, and has been detrimental to public health globally. Likewise, at the national level, many countries failed to adequately recognize the impact of traditional public health responses on human rights, particularly of their most marginalized people, and to mitigate those proactively.

Moreover, some countries have used the pandemic as an excuse to consolidate legal and political power, failing to safeguard human rights, as required by international, regional and national law, when invoking emergency powers in the name of public health. Too often, the emphasis has been on coercive, punitive approaches rather than approaches that enable and support individuals, households and communities to follow best public health practice for preventing further transmission and to gain access to vaccines, treatment and other necessary health care.

The negative effects of pandemics such as HIV and COVID-19, and the burden of measures adopted in response (some necessary, others unjustified), fall most heavily upon ~~key~~ certain populations and communities, often those already marginalized. In the case of both HIV and COVID, these include sex workers; men who have sex with men, transgender people and LGBTQ+ communities more generally; people who use drugs; people of colour; migrants, including refugees; people living with HIV, tuberculosis, viral hepatitis and other chronic diseases; those in prison and other closed settings; and those experiencing economic precarity and homelessness. The marginalization experienced by these populations under “normal” conditions – because of stigmatization, discriminatory laws, criminalization and violence – was exacerbated by the emergency measures imposed in most countries after the onset of the COVID-19 pandemic.



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Gender inequalities have also contributed to both HIV and COVID-19, and have been exacerbated by them (e.g., greater burdens of care, loss of livelihoods as a result of pandemic response measures, greater exposure to intimate partner violence during lockdowns, etc.) Finally, COVID-19, and the measures adopted in response, also had disproportionate impact on the elderly, who have experienced a higher burden of serious illness and death, as well as, in some countries, the harms of strict isolation measures, often in facilities with inadequate infection prevention and control measures.

We, the members of the [UNAIDS Reference Group on HIV and Human Rights](#), are people from the HIV and human rights community, including advocates, jurists, ethicists, people living with HIV, people working in the NGO and community sector, people working in the government sector, and academics. Decades of experience with HIV have demonstrated yet again that measures to prevent, prepare for and respond to pandemics – whether at global or national levels – can be effective only if grounded in respect for universal human rights. **All measures taken must be equitable, proportionate, and centre the participation of affected communities, taking particular care to ensure vulnerable and marginalized populations are supported to participate, and maintain existing essential services for the health and social protection of these populations.**

We call upon the Intergovernmental Negotiating Body (INB) to ensure that the text of the WHO convention, agreement or other international instrument on pandemic prevention, preparedness, response and recovery (PPRR) contains explicit, enforceable and actionable commitments to respect, protect and fulfil human rights, including of marginalized and affected populations. Several aspects warrant special attention in any instrument.

EQUITY IS FUNDAMENTAL

Health and other inequities experienced during the COVID-19 pandemic have echoed those of the HIV pandemic. People in low-income countries – and marginalized populations in all countries – have suffered from unequal access to diagnostics, therapeutics and vaccines. Simply put, the protection of intellectual property – and of corporate profits – has taken precedence over the protection of life and the right of all to benefit from scientific knowledge. Such long-standing barriers to greater production capacity, including in particular in developing countries, have contributed to an inadequate supply of diagnostics, treatment and vaccines.

Hoarding of vaccines and other products from this limited supply has further exacerbated inequities in access. This both violates human rights and continues to damage global public health by prolonging the pandemic, facilitating further spread and the emergence of new, more transmissible variants. To realize the human rights principle of equity, including equal access to health care, and ensuring measures taken do not disproportionately impact on vulnerable and marginalised communities, any new instrument must:

- Provide mechanisms for the equitable sharing of knowledge and technologies related to pandemic prevention, preparedness and response (PPRR)



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- Impose a binding obligation on pharmaceutical companies to license diagnostics, therapeutics and vaccines, in order to ensure equity of access, going beyond the voluntary commitments of the [UN Guiding Principles on Business and Human Rights](#)
- Establish guidelines to address global-level funding gaps for low-income countries, and to direct adequate resources at the national level to key and marginalized populations
- Direct countries to implement measures for pandemic prevention, preparedness and response based on scientific and medical evidence, not on political expediency
- Insist on the importance of community-led organisations voluntarily participating in governments' PRR efforts, with adequate funding to do so and including helping to inform policy and practice
- Collect and analyse disaggregated data to understand the pandemic's effects upon key and marginalized populations – while ensuring that data collection, analysis and storage safeguards the right of all people to privacy and anonymity.

EMERGENCY MEASURES MUST BE NECESSARY AND PROPORTIONATE

Pandemics are complex crises; governments' responses will need to be multi-faceted and dynamic, evolving with new evidence and circumstances. But throughout, governments must take care to respect, protect and fulfil human rights in accordance with their international (and domestic) legal obligations. International human rights law recognizes that certain restrictions on civil liberties and other human rights may sometimes be justified, including to respond to infectious diseases, but within certain safeguards and parameters.

The [Siracusa Principles](#) adopted by the UN Commission on Human Rights identify the accepted standards that governments must respect when adopting measures that limit human rights, including in the name of public health. In essence, any measures that limit rights must be: necessary to achieve a legitimate, pressing objective; the least intrusive and restrictive means of achieving that objective; neither arbitrary nor discriminatory in application; of limited duration; and subject to review and appeal. Furthermore, the needs of the most vulnerable must be considered. Satisfying these criteria obviously requires that any measure limiting rights be rooted in evidence. **These principles should be reflected in any international instrument on pandemic PRR, as both a matter of law and of good public health policy.**

Many governments failed to respect these principles in their emergency response to the COVID-19 pandemic. This flawed approach, which disproportionately affected marginalized populations, must not become a template for future pandemic responses. Any new instrument on PRR should make clear that:

- Any limitation or derogation of rights must be legitimate, necessary, proportionate, time-bound, and neither arbitrary nor discriminatory.
- Punitive measures for pandemic control should never be used as a first step unless absolutely necessary.
- Emergency and other powers must not be misused to further marginalize people, especially via contact tracing or other non-anonymous data collection.



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- Legislation, administrative laws or regulations discriminating, in intent or effect, against key and marginalized populations should not be introduced or expanded under cover of pandemic response measures.
- All laws and policies introduced during a pandemic must be reviewable by a court of law.

PARTICIPATION MEANS CENTERING THE EXPERIENCE OF AFFECTED POPULATIONS

The gains made in the fight against the HIV pandemic have demonstrated the value and necessity of the meaningful participation of civil society and communities, including most affected or key populations and other marginalized populations and the organisation and networks lead by them. Furthermore, international human rights law recognizes the principle of participation in the conduct of public affairs, including the protection and promotion of human rights. This includes those rights affected by pandemics and the response to them. We call for any new instrument on PPRR to reflect this lesson. This means that:

- Community-led (and women-led) organizations and networks of key and marginalized populations (“communities”) must be meaningfully engaged and participate without restrictions, in decision-making on the PPRR instrument, with opportunities for engagement designed to enable their participation.
- Any international instrument on PPRR must respect and enable country ownership and leadership and acknowledge the disproportionate impact of pandemics on communities in formerly colonised and lower-income countries.
- National governments must meaningfully engage civil society and communities in the design, implementation and accountability measures of the PPRR instrument.
- Civil society and communities must be meaningfully involved in decision-making, monitoring and oversight of funds under the PPRR instrument or Financial Intermediary Fund (FIF), to help ensure transparency and accountability.

EFFORTS TO ADDRESS PERSISTENT MARGINALIZATION MUST NOT BE NEGLECTED

COVID-19 emergency measures had devastating effects upon marginalized populations who have an ongoing need for health and social protection services. Examples include the availability of sexual and reproductive health services, particularly emergency maternal health services; services for migrants, who were sometimes subject to detention or deportation; people experiencing homelessness, who were sometimes relocated and lost access to community-led services; harm reduction and other services for people who use drugs (particularly when such services were not considered ‘essential’); loss of access to shelters or other support for individuals who were in danger of violence within the home; and criminalized groups such as sex workers, who suffered a loss of livelihood, harassment and sometimes violence, but were often not eligible for public financial support programs.

In some countries, especially those with overburdened or precarious health systems, health facilities and personnel were redeployed to cater for COVID19, leaving vulnerable communities without



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access to sexual and reproductive services, mental health services and other essential health care. In many contexts, donors were unwilling to repurpose funding to provide urgently needed assistance such as shelter and food.

The COVID response failed to reflect a key lesson from four decades of responding to HIV: the needs of key and marginalized populations, including women and girls, must be front and centre in pandemic response. Any new PPRR instrument must therefore direct countries to:

- Be aligned with and build upon WHO's [operational guidelines](#) on maintaining essential health services and systems in the COVID-19 context. This means that access to services for sexual and reproductive health, HIV, harm reduction and mental health must be maintained by governments, private-sector providers and donors.
- Ensure that pandemic responses do not impact on access to essential services and infrastructure .
- Provide livelihood support, including for workers in the formal and informal or gig economies (which include sex workers in many contexts).

People in prisons and other closed settings are particularly marginalized in all aspects of pandemic response and are at especially high risk of infection because of overcrowding and limited access to medical services, including diagnostics, therapeutics and vaccines. Any PPRR instrument must reinforce that:

- Governments should adopt measures to reduce prison populations by using pre-trial detention and incarceration following conviction as a last resort. In addition, governments should reduce prison populations by acting on their obligations under international human rights law to decriminalize drug use and possession for personal consumption, same-sex sexual activity, and sex work.
- WHO-designated essential services apply to prisoners and those in other forms of detention
- Detention should not be used to criminalise and punish people who fail to adhere to pandemic restrictions, since this simply increases vulnerability to infection and onward transmission of disease.
- The state should not misuse a pandemic emergency as an excuse to further criminalize and/or detain, or further limit the rights of key and marginalized populations.

PREPAREDNESS AND RESILIENT SYSTEMS ARE KEY

There is a need for resilient systems before a pandemic strikes. In a pandemic emergency, already weak infrastructure and service delivery mechanisms are liable to collapse. COVID has illustrated again the consequences of underinvestment in health and community systems and in failing to treat healthcare as a public good. At the same time, the reallocation of resources in response can exacerbate inequalities, leaving at-risk populations even more vulnerable than before. The COVID-19 pandemic, for example, had a disproportionate impact on women and girls across a wide range of factors, including greater burdens of care for children at home and sick relatives, loss of employment and income, increased rates of domestic violence and lack of access to sexual and reproductive health services.



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Both HIV and COVID experiences have shown that strong social protection mechanisms, health services and other infrastructure that impacts on the social determinants of health are critical to preparedness and an equitable and effective response. In addition, communities are central to effective pandemic response. Community-based health workers are essential to local surveillance and service delivery. Key populations themselves have often been at the forefront of the last-mile response, ensuring that services are brought to those most in need – sometimes despite the risk to their own health, and under threat of discrimination and legal sanction. As an essential part of PPRR, any new instrument must include commitments by Member States to:

- Take proactive measures toward achieving universal health coverage, as part of realizing the right to the highest attainable standard of health for all, in keeping with obligations under the *International Covenant on Economic, Social and Cultural Rights*.
- Guide countries on effectively improving health and social-protection systems and ensure they are both universal and gender transformative.
- Emphasize support for community health workers, especially peer workers from key and marginalized populations, and the importance of integrating them into the pandemic response, and protecting them from discrimination and harassment.
- Specify that the financial resources allocated to strengthen countries' PPRR should not compromise other important policies for health, well-being and social justice.
- Putting in place measures that ensures there is reduced wastage, leakage and corruption of resources directed towards addressing the pandemic.

Finally, we note that the current draft instrument does not refer to the HIV pandemic, a pandemic which, to date, has claimed over 40 million lives, and from which we have drawn invaluable lessons and experience on the importance of a human rights approach to health. We urge the drafters to include reference to the HIV response and lessons learned, particularly on the importance of meaningful engagement of community-led organisations and networks at all stages of design, implementation monitoring and evaluation, and of actionable, implementable human rights obligations.