

Making decisions and designing policies

The 2013 Guidelines emphasise the need to base decisions on and design policies to address the current national context. This includes promoting and fulfilling the human rights of underserved populations and reviewing punitive laws and practices.

Throughout the world, including in sub-Saharan Africa, HIV prevalence is substantially higher among key populations.¹ Yet in many countries key populations, including men who have sex with men, transgender people, sex workers and people who use drugs, are not receiving essential health services. And despite the evidence that punitive laws hamper an effective HIV response by denying services to people in greatest need, many countries continue to criminalise HIV transmission, sex work, drug use and homosexuality.

The 2013 Guidelines also recognise that different countries face different constraints, and that their respective HIV responses have strengths and weaknesses. Each country will need to decide on their priorities and the steps they must take in order for their HIV programme to reach the standard of care that the guidelines recommend. The 2013 Guidelines for the first time offer countries guidance on the decision-making process needed to prioritise the recommendations and design effective policies. There is also guidance on programme implementation and how to make efficient use of resources and monitor the outcomes of HIV programmes.

Most importantly, the 2013 Guidelines highlight the critical need of people living with HIV and HIV-affected communities, including key populations, to be meaningfully engaged and to have a say in the decisions that will affect their lives. Communities also need to advocate for key recommendations to be adopted into national programmes, and to hold the government and its partners accountable for their implementation.

What do the 2013 Guidelines say?

- ▶ Decisions regarding the implementation of the 2013 Guidelines should be made through a **transparent, open and informed process with broad stakeholder engagement, including meaningful participation from affected communities**, in policy, design, implementation, monitoring and evaluation.
- ▶ Decisions on how to adapt and implement the 2013 Guidelines should be based on an analysis of **epidemiological dynamics, programme performance, and the socioeconomic, policy and legal context**.
- ▶ Global and national commitments require providing HIV treatment and prevention to everyone in need, following the **human rights principles of non-discrimination, accountability and participation**. Key **ethical principles of fairness, equity and urgency** should also be observed in the process of reviewing and adapting the 2013 Guidelines.



In 78 countries, either adult same-sex sexual conduct is criminalised or lesbian, gay bisexual or transgender people have been criminally prosecuted under other laws on the basis of their sexual orientation.

Forward



Link

This module links to Chapter 10:

Guidance for programme managers, in the 2013 WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*. Available at: www.who.int/hiv/pub/guidelines/arv2013/progmanager/en/

¹. See Module A for a definition of key populations.

What does this mean for my country?

Setting priorities

The 2013 Guidelines come at a time when many countries are still to adapt their national guidelines and deliver care that is up to the standards recommended by the previous version of the guidelines. Given the realities of treatment programmes on the ground, with funding challenges, stock-outs and competing health priorities, providing wider and earlier access to a higher standard of treatment and prevention could seem particularly challenging. Some policymakers may argue they cannot afford to upgrade and further expand their programmes, while others may try to move forward by offering sub-standard care. Communities need to be vigilant throughout the decision-making process, gather evidence on the risks of such strategies, and put forward reasoned arguments to counter them.

In addition, programmes need to have a plan to *guarantee* that treatment of the most sick patients (those who are symptomatic or with a CD4 cell count of 350 or below) is prioritised. It is critical that the offer of treatment to healthier patients does not jeopardise the continued decentralisation and scale up of antiretroviral therapy (ART) to all areas, including remote, peripheral primary healthcare settings and to anyone for whom immediate access to ART could be life-saving.

Consulting widely

The 2013 Guidelines recommend setting up, if not already in place, a multidisciplinary working group, including people living with HIV and civil society, to consider and advise policymakers who are updating and implementing national guidelines. The role of this group would include reviewing the current context of the HIV and tuberculosis (TB) epidemics and the policy environment; assessing evidence related to the new recommendations and providing advice on how best to interpret them within the local context; identifying implementation issues such as costs, human resource and infrastructure needs; and providing advice on how to address these issues. Other effective mechanisms to influence policies, such as community advisory groups, should also be considered.

The 2013 Guidelines recommend an open, informed and transparent process so that all stakeholders are meaningfully involved. Networks of people living with HIV and community based organisations need to be aware of and engage with all available decision-making spaces and opportunities, including technical working groups, national AIDS councils, and Global Fund platforms such as the Country Coordinating Mechanism and country dialogues. As representatives of communities engage in these policymaking forums, they must consult, feed back and be accountable to the constituencies they speak on behalf of.

Following evidence

Communities will need to ensure that decisions are based on widely available evidence – not just about the nature of the epidemic, but also programme performance, gaps in coverage and the political, socioeconomic, legal and policy context. There is a need to generate and share better evidence on effective community-led services. We particularly need to highlight examples of initiatives that work to address the structural barriers that affect the ability and willingness of certain groups, including key populations, to access health services. There is also a need to advocate against the laws that criminalise key populations particularly sex workers, lesbian, gay and transgender people, and people who use drugs recently enacted in many countries.

Finally, while cost-effectiveness and impact of the new recommendations should guide decision-making and priority setting, communities will need to take a stronger stand to ensure that all decisions are based on the key principles of ethics, equity and human rights. For example, communities with allies such as human rights organisations or lawyers will need to monitor and respond to any moves to use the new recommendations as an excuse to

Engage!

People living with HIV and affected communities must actively engage in decision-making and priority setting to secure the most benefit from the 2013 Guidelines.



Advocate!

Advocate! Say no to laws and policies that criminalise key populations. Ensure the rights of all people living with HIV are respected.



coerce key populations in accepting early treatment, particularly in the context of concentrated epidemics. Evidence collected by communities that already monitor and report on human rights violations on a regular basis should be used to support advocacy efforts.

What is Positive Health Dignity and Prevention?²

Positive Health, Dignity and Prevention (PHDP) encompasses the full range of health and social justice issues for people living with HIV. It espouses the fundamental principles that responsibility for HIV prevention should be shared, and that policies and programmes for people living with HIV should be designed and implemented with the meaningful involvement of people living with HIV themselves.

Communities can use the PHDP framework to advocate for the key principles of creating a supportive and protective legal and policy environment; improving and maintaining the health and well-being of people living with HIV; promoting holistic health and wellness; addressing factors that undermine health and dignity; and responding to the needs of key populations. In contexts where advocating for human rights is risky and where key populations are criminalised, HIV and public health programmes can offer a platform to promote the universal right to health.

Operationalising PHDP does not involve creating new programmes, unless basic programmes do not currently exist. Rather, it focuses on creating linkages between existing programmes and improving their efficiency and responsiveness in meeting the needs of people living with HIV and their families in their communities. Individual programmatic elements will inevitably differ from setting to setting according to local contexts.

Programmatic components of PHDP fall under the following eight thematic areas:

1. Empowerment of people living with HIV and networks of people living with HIV
2. Health promotion and access
3. Gender equality
4. Human rights
5. Prevention of new infections
6. Sexual and reproductive health and rights
7. Social and economic support
8. Measuring impact.



Review!

Be vigilant! Make sure that human rights and the quality of treatment and care are not compromised in the rush to adapt guidelines or meet global goals.



2. UNAIDS, GNP+ (2013). *Positive Health, Dignity and Prevention: operational guidelines*. Available at: www.gnpplus.net/resources/positive-health-dignity-and-prevention-operational-guidelines/

Take stock! Take action!

- How close is your national programme to meeting the recommendations in the 2013 Guidelines? Where are the greatest gaps? What should be prioritised to improve access to the quality of care that people living with HIV receive and to save the most lives in your epidemic setting?
- Are the processes for discussing and making decisions related to the 2013 Guidelines transparent and open? Do all participants, including community representatives, have access to the evidence and information needed to inform their decision-making?
- Have representatives from all relevant stakeholders been involved? Do they include people living with HIV, women and youth groups, and representatives of key populations?
- Is the participation of people living with HIV and other key populations meaningful? What policy, legal or technical support can they be given so they can influence decision-making? Who can provide the support required?
- Are the decision-making criteria and rationale transparent? Are decisions made on the basis of scientific evidence, comparative cost-effectiveness of interventions, and principles of equity and human rights?
- Are the promotion, protection and fulfillment of human rights included in the national guidelines, and are the programmes rights based? Are Positive Health, Dignity and Prevention values being followed? Are there mechanisms at community and national levels to address, monitor and report violations of human rights?
- Has the decision-making taken into consideration:
 - HIV incidence and prevalence in specific population groups and regions
 - current coverage of programmes (e.g. testing, treatment, prevention of mother-to-child transmission) and their impact, such as viral suppression, drug resistance or mortality among people receiving treatment or new HIV infections in children
 - poverty, gender inequality, stigma and other factors affecting HIV vulnerability, access to services and the quality of life of people living with HIV
 - how punitive laws and practices related to HIV transmission, sex work, drug use and homosexuality may hinder access to services
 - ways to promote greater access to treatment and other services for people with least access, including key populations.
- Is there a risk mitigation strategy in place to ensure continued and assured service delivery, especially for those most in need?
- Is there a monitoring and evaluation plan with clear responsibilities for different stakeholders? Does it include the roles of communities as watchdogs to ensure effective implementation and promote equitable access and human rights? Are there mechanisms for community representatives involved in policymaking to consult and feed back to their constituencies?