

# Fast-Track and human rights

Advancing human rights in efforts to accelerate the response to HIV





# Contents

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Executive summary	<b>2</b>
Introduction	<b>4</b>
Integrating human rights principles in efforts to Fast-Track HIV services	<b>8</b>
Key human rights principles for HIV services	<b>9</b>
Principle 1: availability, accessibility, acceptability and good quality of services	<b>12</b>
Principle 2: equality and non-discrimination	<b>15</b>
Principle 3: privacy and confidentiality	<b>20</b>
Principle 4: respect for personal dignity and autonomy	<b>22</b>
Principle 5: meaningful participation and accountability	<b>26</b>
Scaling up human rights programmes alongside HIV prevention, testing and treatment services	<b>30</b>
Conclusion	<b>32</b>
Annex. Human rights checklists to Fast-Track HIV prevention, testing and treatment services	<b>34</b>
Checklist 1: HIV prevention services and human rights	<b>35</b>
Checklist 2: HIV testing services and human rights	<b>41</b>
Checklist 3: HIV treatment services and human rights	<b>47</b>
References	<b>54</b>

# Executive summary

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The global agenda for sustainable development includes a target of ending the AIDS epidemic by 2030. Experience to date shows the significant progress that can be achieved in the AIDS response through the mobilization of scientific knowledge, political will, financial resources and civil society.

To achieve this ambitious objective, UNAIDS has called on all countries to harness the next several years (until 2020) as a key window of opportunity for rapidly scaling up the HIV response in three main areas: HIV prevention, HIV testing and HIV treatment. This Fast-Track approach—endorsed by the United Nations (UN) General Assembly in the 2016 Political Declaration on Ending AIDS—requires maximizing existing tools in order to quicken the pace of progress to achieve specific targets and end the AIDS epidemic as a public health threat by 2030.

Despite this, it will not be possible to Fast-Track the HIV response and end the AIDS epidemic without addressing human rights. Gender inequality continues to undermine efforts to address HIV among women and girls around the world, and while many populations remain highly affected by HIV, they have inadequate access to effective quality prevention, testing and treatment services. These populations, which are being left behind by the response, include adolescents and young people (particularly adolescent girls and young women in eastern and southern Africa), indigenous communities, sex workers, prisoners, migrants, gay men and other men who have sex with men, transgender people and people who inject drugs. Human rights barriers—including stigma and discrimination, violence and other abuses, negative social attitudes and legal obstacles—contribute to vulnerability to HIV among these populations and limit their access to prevention, testing, treatment and care services.

As recognized by all UN Member States in the General Assembly resolutions on HIV,<sup>1</sup> the realization of human rights is an essential element of the HIV response. Yet for too long, legal, policy and human rights issues have been seen by some policy-makers, programme implementers and service providers as disconnected from (and at best parallel to) efforts to implement HIV prevention, testing or treatment programmes. Changing this situation should be a priority in efforts to Fast-Track the HIV response.

This document offers guidance on why and how efforts to Fast-Track HIV prevention, testing and treatment services can and should be grounded in human rights. Beyond being an imperative in themselves, human rights principles and approaches are critical to addressing barriers to HIV services and to achieving HIV targets. Human rights principles and approaches will help maximize the reach and impact of HIV prevention, testing and treatment programmes. They also will help address potential human rights challenges and prevent abuses that may occur in the context of urgent efforts to Fast-Track the achievement of HIV prevention, testing and treatment targets.

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<sup>1</sup> See the 2001 Declaration of Commitment on HIV/AIDS, the 2006 United Nations Political Declaration on HIV/AIDS, the 2011 Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS, and the 2016 Political Declaration on HIV and AIDS.

In particular, this document describes the key human rights principles, distilled from international legal standards, that should inform the scale-up of HIV services, and it briefly explains how these apply to HIV prevention, testing and treatment services. The following are the key human rights principles of most relevance:

- Availability, accessibility, acceptability and good quality of services.
- Non-discrimination and equality.
- Privacy and confidentiality.
- Respect for personal dignity and autonomy.
- Meaningful participation and accountability.

This document also summarizes the human rights programmes that should accompany and/or be integrated into HIV prevention, testing and treatment services. It provides three checklists to support and guide governments, donors, programme implementers (including direct service providers), civil society groups and other stakeholders when designing, monitoring and evaluating HIV prevention, testing and treatment services in order to ensure that the results are based on human rights principles and approaches, and that they leave no one behind. As the world intensifies actions to Fast-Track the HIV response, it is time for all key stakeholders involved in the HIV response to translate clear guidance on human rights into HIV-related prevention, testing and treatment programmes.

# Introduction

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*“We, Heads of State and Government and representatives of States and Governments assembled at the United Nations from 8 to 10 June 2016, reaffirm our commitment to end the AIDS epidemic by 2030 as our legacy to present and future generations”*

**2016 United Nations Political Declaration on Ending AIDS, para. 1.**

## **We can end the AIDS epidemic**

The countries of the world have committed to do just that by 2030 as part of the 2030 Agenda for Sustainable Development (1).

Experience to date shows the significant progress that can be achieved in the AIDS response through the mobilization of scientific knowledge, political will, financial resources and civil society. Between 2000 and 2015, annual new HIV infections fell by 35% worldwide (2). Meanwhile, annual AIDS-related deaths fell by 45%.

Scaling up treatment has been central to these gains. In 2000, less than 1% of people living with HIV in low- and middle-income countries had access to antiretroviral therapy (2). By 2015, however, the world had met and exceeded the goal of getting treatment to 15 million people globally, the great majority of them in low- and middle-income countries (3). These successes are among the greatest achievements in the history of global health.

## **But there is no ending AIDS without addressing human rights barriers and efforts to Fast-Track the response**

After a decade of significant progress, the AIDS response is at a critical juncture. At the end of 2015, only 46% of adults and 49% of children living with HIV globally were receiving antiretroviral therapy (4). Furthermore, roughly 1.1 million people died of AIDS-related illness in 2015 alone, and a further 2.1 million people were newly infected with HIV (2).

Gaps, blind spots, and the failure to scale up effective HIV prevention, treatment and care programmes for all are compromising our efforts against the epidemic. Many populations around the world remain highly affected by HIV but have inadequate access to effective, high-quality prevention, testing and treatment services. These populations—which include adolescents and young people (particularly adolescent girls and young women), sex workers, prisoners, migrants, gay men and other men who have sex with men and people who inject drugs—are being left behind by the response.<sup>2</sup>

Human rights barriers—including stigma, discrimination, violence and other abuses, negative social attitudes, and legal obstacles—contribute to the vulnerability to HIV among these populations. They also limit their access to prevention, testing, treatment and care services. In a recent report, UNAIDS stressed that human rights and gender-related vulnerabilities and barriers are among the reasons for the serious HIV prevention gap and the insufficient progress that has been made in reducing new HIV infections in many regions of the world (5).

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<sup>2</sup> The 2014 UNAIDS Gap report provides an overview of the issues and challenges faced by the populations left behind in the response. See UNAIDS, The gap report (Geneva: UNAIDS; 2014).

*“The AIDS response can only be Fast-Track<sup>3</sup>ed by protecting and promoting access [to] appropriate, high-quality, evidence-based HIV information, education and services without stigma and discrimination with full respect for rights to privacy, confidentiality and informed consent ...”*

**2016 United Nations Political Declaration on Ending AIDS**

To end the AIDS epidemic as a public health threat by 2030, these challenges must and can be overcome. UNAIDS has called on all countries to harness the next several years (until 2020) as a key window of opportunity to Fast-Track the HIV response around three main areas: HIV prevention, HIV testing and HIV treatment. This Fast-Track approach—endorsed by the United Nations (UN) General Assembly in the 2016 Political Declaration on Ending AIDS—requires maximizing existing effective tools to quicken the pace of progress to achieve the specific targets by 2030 in a manner that leaves no one behind.<sup>3</sup> Achieving this necessarily means paying specific attention to addressing human rights barriers such as stigma, discrimination, violence and other abuses, and the punitive laws and policies that embody or enable these infringements of fundamental human rights.

### **Human rights principles and approaches need to be part of efforts to Fast-Track the HIV response**

Ending AIDS is a matter of obligation for governments. By taking steps to prevent new HIV infections and ensure access to HIV prevention, testing and treatment for all, governments are acting on their obligation to fully realize over time the human rights to life and the highest attainable standard of physical and mental health. This, in turn, enables people to lead full and dignified lives. At the same time, protecting and promoting human rights—particularly those of people living with HIV and other populations most affected by the epidemic—also is a matter of necessity for ending AIDS. All UN Member States recognized the realization of human rights as an essential element of the HIV response in the 2001 Declaration of Commitment on HIV/AIDS, the 2006 Political Declaration on HIV/AIDS, the 2011 Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS, and the 2016 Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030 (6–9).

For too long, legal, policy and human rights issues have been seen—including by some policy-makers, programme implementers and service providers—as disconnected from (and at best parallel to) efforts to implement HIV prevention, testing or treatment programmes. Changing this situation should be a priority in efforts to scale up the HIV response.

Human rights principles and approaches operate at multiple levels and in various ways to strengthen the HIV response by creating a more enabling environment for prevention, testing and treatment services. These include the (a) individual level, (b) policy and programme level, and (c) population level.

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<sup>3</sup> By 2030, 95% of all people with HIV should know of their status, 95% of all those who know their HIV-positive status should receive treatment, and 95% of people receiving treatment should achieve sufficient viral suppression to preserve their immune system and significantly reduce onward transmission. For more on this, please see the following: UNAIDS, 90-90-90: an ambitious treatment target to help end the AIDS epidemic (Geneva: UNAIDS; 2014); UNAIDS, Fast-Track: ending the AIDS epidemic by 2030 (Geneva: UNAIDS; 2014); and the 2016 Political Declaration on HIV and AIDS.

*“Ending the AIDS epidemic will involve progress across the entire spectrum of rights: civil, cultural, economic, political, social, sexual and reproductive. Defending the rights of all people—including children, women, young people, men who have sex with men, people who use drugs, sex workers and clients, transgender people and migrants—is critical to ensuring access to life-saving services. Through the realization of their rights, people being left behind will move ahead, to the very forefront of the journey to end AIDS—informed and empowered, mobilized and engaged.”*

**UNAIDS 2016–2021 Strategy**

At the individual level, respecting and protecting human rights makes it possible for those at risk of acquiring HIV or those living with HIV to benefit from prevention, testing and treatment services. It also builds trust of health-care systems among individuals, which is essential to effective public health programmes. For example, awareness raising programmes for health care providers to reduce stigma and discrimination attitudes towards people living with HIV and key populations; protecting people against discrimination in health-care settings, ensuring respect for informed consent in testing and treatment, and protecting patient confidentiality all are mutually reinforcing measures that enable people to seek and access HIV services.

Applying human rights principles at the policy and programme level requires attention to the availability, accessibility, acceptability and quality of HIV services. (These key elements of the right to health are discussed in more detail below.) Human rights principles also help to focus attention on the most marginalized people who are facing the greatest barriers to access. These principles require and enable participation by affected communities in the design, implementation and evaluation of HIV services, thereby making them more effective.

At the population level, protecting and promoting human rights creates a legal, social and economic environment that is more enabling, thus improving access to (and uptake of) HIV prevention, testing, treatment, care and support services. Removing punitive laws and stigmatizing policies that affect specific populations at risk of HIV, and protecting them against violence and discrimination, makes it safer and easier for people within those populations to access HIV services, thereby protecting and promoting their health and that of others. Advancing human rights education—and promoting a culture of respect for human rights in law and more broadly in society—also helps to engage, empower and mobilize communities in protecting and realizing their rights, including the right to quality services.

Human rights principles and approaches are particularly relevant at a time when efforts are underway to scale up HIV services rapidly because they will help to maximize the reach and impact of such programmes, contributing to the realization of the right to health. They also will help to address potential human rights and gender equality challenges and prevent abuses that may occur in the context of urgent efforts to Fast-Track HIV prevention, testing and treatment services.

### **About this guidance**

This document offers guidance on why and how efforts to Fast-Track HIV prevention, testing and treatment services can and should be grounded in human rights. In particular, it shows that beyond being an imperative in themselves, human rights principles and approaches are critical to addressing barriers to HIV services and achieving HIV targets.

This document includes concrete examples that illustrate the importance of integrating human rights into HIV prevention, testing and treatment programmes. It also describes specific human rights programmes to eliminate stigma and discrimination and to advance access to justice as necessary, all of which are complementary elements of effective HIV responses.

In particular, it includes the following:

- A description of the key human rights principles that should inform the scale-up of HIV services, and how these apply to HIV prevention, testing and treatment services in particular.
- A short presentation of the key human rights programmes that should accompany and/or be integrated into HIV prevention, testing and treatment services.
- Three checklists (in the Annex) to support and guide governments, donors, programme implementers (including direct service providers), civil society groups and other stakeholders in designing, monitoring and evaluating HIV prevention, testing and treatment programmes to ensure that the results are based on human rights principles and approaches, and that they leave no one behind.

# Integrating human rights principles in efforts to Fast-Track HIV services

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*“The key is to do the right things at the right place, for the right people and in the right way.”*

**UNAIDS. AIDS by the numbers 2015. Geneva: UNAIDS, 2015.**

Ending the AIDS epidemic as a public health threat by 2030 is an ambitious goal. It requires rapid progress towards achieving key targets for HIV prevention, testing and treatment to be made by 2020. These targets include reducing new HIV infections to fewer than 500 000, reducing AIDS-related deaths to fewer than 500 000, and eliminating HIV-related stigma and discrimination (10, 11).

Achieving these targets will require focusing on countries, locations and populations that are bearing the worst brunt of the epidemic (4, 10, 12, 13). Rapidly scaling up HIV prevention, testing and treatment services is thus a human rights imperative as well as a public health necessity. We need to ensure, however, that while we are on the Fast-Track to ending AIDS, HIV services still respect, protect and fulfil human rights, including those of the populations particularly affected by HIV. These populations—who are particularly at risk of HIV infection and denial of HIV care in various contexts and ways—include the following:

- Adolescents and young people (particularly adolescent girls and young women).
- People living with HIV.
- Sex workers.
- Gay men and other men who have sex with men.
- Transgender people.
- People who use drugs.
- Prisoners and other detainees.

Among these groups, men who have sex with men, sex workers and their clients, transgender people, people who inject drugs, and prisoners and other detainees are considered key populations. These key populations often suffer from punitive laws or stigmatizing policies, and they are among those most likely to be exposed to HIV (14). Analysis of the data available to UNAIDS suggests that more than 90% of new HIV infections in central Asia, Europe, North America, the Middle East and North Africa in 2014 were among people from key populations and their sexual partners (13). In addition, ongoing pervasive gender inequality—including higher rates of poverty, restrictions on participation in public life, gender-based violence and harassment, and inadequate access to sexual and reproductive health services that are non-discriminatory and respectful of rights—also continue to undermine efforts to address HIV among women and girls.

*“The bedrock of the AIDS response is an absolute commitment to protecting human rights. Nothing other than zero discrimination is acceptable.”*

**UNAIDS. Fast-Track: ending the AIDS epidemic by 2030. Geneva: UNAIDS, 2014.**

Drawing from the extensive body of human rights standards, this section distils a set of key principles that should be integrated into the development and delivery of HIV prevention, testing and treatment services.

### **Key human rights principles for HIV services**

The following are the five most relevant key human rights principles when scaling up HIV prevention, testing and treatment services:

- Availability, accessibility, acceptability and good quality of services.
- Non-discrimination and equality.
- Privacy and confidentiality.
- Respect for personal dignity and autonomy.
- Meaningful participation and accountability

These key principles are derived from existing global and regional human rights treaties and instruments that impose obligations on states. Notably, these treaties include the core human rights instruments and treaties of the UN system,<sup>4</sup> as well as key human rights treaties and instruments adopted through various regional bodies.<sup>5</sup> The extent to which states have agreed to be bound by human rights treaties varies, but every UN Member State has ratified at least one of the core UN human rights treaties, and 80% of Member States have ratified four or more (15). Furthermore, the principles underlying the rights set out in these treaties often are part of countries’ domestic laws, from constitutions protecting certain fundamental rights to other laws and regulations that give effect to rights in various ways (e.g. laws protecting privacy, protecting against discrimination in various settings, or prohibiting sexual assault or other violence).

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<sup>4</sup> The foundational instruments of the modern international human rights system are the Universal Declaration of Human Rights (1948), the International Covenant on Civil and Political Rights (1966), and the International Covenant on Economic, Social and Cultural Rights (1966). The other core human rights treaties of the UN system are the International Convention on the Elimination of All Forms of Racial Discrimination (1965), the Convention on the Elimination of All Forms of Discrimination against Women (1979), the Convention Against Torture and Other Forms of Cruel, Inhuman or Degrading Treatment or Punishment (1984), the Convention on the Rights of Child (1989), the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families (1990), the International Convention for the Protection of All Persons from Enforced Disappearance (2006), and the Convention on the Rights of Persons with Disabilities (2006). For the complete list and full text of all core UN human rights treaties, see the webpage of the Office of the UN High Commissioner for Human Rights (OHCHR): <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CoreInstruments.aspx>. Other UN treaties also serve to protect human rights of various groups (such as refugees) or in specific contexts (e.g. education or work).

<sup>5</sup> Examples include the African Charter on Human and Peoples’ Rights (1981), the European Convention on Human Rights (1950), the revised European Social Charter (1996), the American Convention on Human Rights (1969) and the San Salvador Protocol to that convention (1988), and the Arab Charter on Human Rights (2004). The extent to which these treaties embody the same level of human rights protection as articulated in UN treaties varies significantly. As at the UN level, other treaties have been adopted in some regional systems that address in greater detail the rights of specific populations (women, children, prisoners, refugees, etc.) or specific human rights concerns (such as torture or labour rights).

International treaties give rise to firm, binding legal obligations on governments.<sup>6</sup> Aside from legally binding treaties, important human rights principles recognized by states also can be found, generally in nonbinding form, in declarations and resolutions of various sorts adopted by states, within the UN General Assembly or its subsidiary bodies such as the Human Rights Council.

Important guidance on human rights standards also may be found in the following sources:

- The various expert committees or working groups (known as “treaty bodies”) in the UN (or regional) systems that monitor the compliance of states with their human rights obligations under various treaties.
- The various special rapporteurs and other independent experts (known as “special procedures” in the UN system), who undertake analytical research and country missions, and conduct consultations with states, academic experts, civil society organizations, and UN and other intergovernmental organizations to help define and develop the content of international human rights norms.
- The UN specialized agencies and programmes established by states, which produce technical guidance in various formats that reflects human rights standards or helps define what policies, programmes and services should include in order to meet human rights standards. For example, UNAIDS and the OHCHR have produced the *International guidelines on HIV/AIDS and human rights*, which provides guidance to states in translating international human rights norms into practical observance in the context of HIV (16).

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### Sources of human rights standards, principles and guidance

- Treaties ratified by states at the UN or the regional level.
- Customary international law.
- Declarations and resolutions adopted by states.
- Comments, recommendations and findings of expert human rights committees.
- Human rights rapporteurs and other independent experts given a mandate by states.
- Technical guidance from specialized UN agencies and other international organizations.
- Domestic constitutions and other laws.

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<sup>6</sup> Furthermore, some fundamental human rights norms enjoy universal protection under what is known as customary international law across all countries—that is, the general practice of states is that these rights are accepted as reflecting their legal obligations. These obligations apply regardless of whether states have codified them in international treaties or domestic law.

Finally, other international organizations have taken steps to integrate human rights standards into HIV services and ensure accountability. For example, the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) has adopted minimum human rights standards that now form part of every grant agreement. Among other conditions, any programmes supported by funds from a Global Fund grant must ensure non-discriminatory access to services for all (including people in detention), and they must respect and protect informed consent, confidentiality and the right to privacy concerning prevention, testing, treatment or other health services rendered on HIV, tuberculosis and malaria.

In 2017, the Global Fund has published a Technical Brief on HIV, Human Rights and Gender Equality which supports applicants to include and scale up in their Global Fund grants programmes to remove human rights and gender-related barriers to HIV services, and to implement human rights-based and gender responsive approaches to HIV (17).

While it is important to understand that human rights standards are ultimately rooted in legal norms that governments have agreed to and repeatedly reaffirmed, there is no need for service providers to have a deep knowledge of all of these instruments and their legal sources. Indeed, this guidance attempts to synthesize the most important principles and considerations, and to apply them to the context of HIV prevention, testing and treatment services.

Human rights principles are interconnected and mutually reinforcing. For example, protecting the privacy of personal health information is important if services are to be accessible and acceptable; it also may be particularly important for young people, women and girls, and members of key populations, making it necessary for ensuring that there is equal access to services for everyone. Similarly, ensuring the accessibility of services requires that people do not experience discrimination when seeking or receiving them. Respecting personal autonomy in the delivery of HIV services is an essential aspect of those services being acceptable and of good quality, and that respect must apply equally to all service users. This overlap between the key principles in the context of HIV services illustrates that, as is recognized in international law, human rights are indivisible and interdependent—that is, the enjoyment of one right often depends on the ability to exercise other rights, and the improvement of one right often facilitates the enjoyment of others.

To help guide and monitor the effective inclusion of the five key human rights principles and approaches into efforts to Fast-Track HIV prevention, testing and treatment, the rest of this section will do the following:

- Introduce the content and relevance of these key interrelated principles in the design, implementation and evaluation of HIV services.
- Explain concretely what each principle requires for HIV prevention, testing and treatment services.

These principles are translated into checklists that can be found in the Annex to this guidance.

## **Principle 1: availability, accessibility, acceptability and good quality of HIV services**

*What is the principle?*

The right to the highest attainable standard of health requires that governments ensure that health goods, services and information are available, accessible, acceptable and of good quality (also known as the AAAQ requirements).<sup>7</sup>

- Availability means that “[f]unctioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity” (18).
- Accessibility means that “goods and services have to be accessible to everyone without discrimination,” and that includes physical and geographical accessibility as well as economic or financial accessibility (i.e. affordability) (18).
- Acceptability means that all “health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned” (18).
- Quality requirements include that “as well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality” (18).

*What does this mean for Fast-Tracking HIV prevention, testing and treatment?*

The following goods, services and information for combination prevention, HIV testing and treatment should be available, in line with WHO and UNAIDS recommendations:

- Condom and lubricant programming (including male and female condoms).
- Harm reduction services (including needle–syringe programs and opioid substitution therapy).
- Quality HIV testing services.
- Antiretroviral medicines for post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP).
- Antiretroviral medicines for treatment of people living with HIV and treatment for opportunistic infections.
- Voluntary medical male circumcision (VMMC).
- Access to sexually transmitted infection (STI) services.
- Social and behavioural programmes, including comprehensive sexuality education (12, 19, 20).

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<sup>7</sup> The right to health encompasses certain core minimum obligations of governments, including (a) ensuring access to health facilities, goods and services on a nondiscriminatory basis, especially for vulnerable or marginalized groups; (b) the provision of essential drugs, as defined from time to time by World Health Organization (WHO) guidance (i.e. the WHO’s Model List of Essential Medicines, updated periodically and available online at <http://www.who.int/medicines/publications/essentialmedicines/en/>); and (c) ensuring the equitable distribution of all health facilities, goods and services (18).

The above goods, services, and information should be available to everyone who needs them in the following ways:

- In sufficient quantity and coverage.
- At accessible locations, including urban and rural areas, and in locations that are easily accessible to everyone in need (including young people, women and girls, people living with disabilities, indigenous populations and key populations).
- In forms and modes that address the specific risks of those using them and are suitable to their needs.
- For free or at an affordable cost.
- Through commodities that are manufactured according to international standards and procedures that guarantee safety, quality and efficacy.

In addition, governments need to scale up the availability of HIV services by doing the following:

- Ensuring the equitable distribution of a sufficient number of health facilities, programmes, and adequately trained and paid health workers to deliver HIV services in a manner commensurate with local need.
- Integrating HIV services into other health services as another way of helping to scale up the availability of HIV programmes.

Governments need to accelerate efforts to make HIV services accessible for all by removing any legal, policy or practice barriers that hinder access directly or indirectly. Those barriers can include the following:

- Remove any requirement and eliminate any practice that requires a woman's spouse or partner to provide consent or be notified in order for the woman to receive HIV services (e.g. condoms, PEP, PrEP, testing or treatment). Similarly, remove any requirement and eliminate any practice that requires parental or guardian consent for adolescents seeking HIV services.<sup>8</sup>
- Take measures to eliminate physical and other barriers to access HIV services for people living with disabilities.
- Consider assigning responsibility for prison health services to ministries of health rather than the ministries responsible for prisons. This will improve access to HIV services for prisoners and ensure that they are equivalent to those available in the community.

Governments also need to promote accessibility and acceptability of HIV services, particularly for young people, women and girls, people living with disabilities, indigenous populations, and other key populations by taking measures to reduce

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<sup>8</sup> A recent review found that one of the major barriers to the uptake of HIV testing and counselling services among adolescents in sub-Saharan Africa is the requirement of parental or guardian consent for minors (21). Removing such barriers and adopting legal and policy frameworks that support independent access to HIV testing services for adolescents under the age of 18 is a necessary and important step for increasing accessibility to a key population affected by the epidemic (22).

barriers to access (such as fear of stigma, discrimination, criminalization and other abuses). Some examples of how to reduce these barriers include the following:

- Complementary programmes to protect against (and eventually eliminate) stigma, discrimination and unjust criminalization of people living with HIV and key populations (such as men who have sex with men, sex workers and people who use drugs). Such programmes will be necessary to ensuring accessibility and acceptability of HIV services among those who are concerned about the repercussions of being identified as HIV-positive and/or a member of a stigmatized and criminalized population.
- Sensitization and community involvement in HIV prevention and testing efforts, particularly for young people, women and girls, people living with disabilities, indigenous populations and members of key populations (such as men who have sex with men, sex workers and people who inject drugs).
- Programmes to enhance agency and the economic empowerment of women and girls and to address gender-based violence.

Governments also need to ensure the economic accessibility (i.e. affordability) of HIV prevention (e.g. condoms, sterile injection equipment, PEP, PrEP, VMMC kits), testing tools (e.g. test kits) and treatment (i.e. medicines). This can be accomplished by doing the following:

- Adopt and/or use laws, policies and initiatives that will increase affordability (e.g. regulating prices and preventing abusive pricing).
- Enact intellectual property and competition laws that facilitate competition between pharmaceutical manufacturers in order to reduce prices, and use flexibilities in those laws to this end.
- Lower or eliminate user fees that can be barriers to access to HIV prevention and testing services as well as for CD4 and viral load tests.

Ensuring the quality of HIV goods, services and information is essential to both their acceptability to users and their effectiveness. This requires the following:

- Services must be evidence-based.
- Commodities must meet product standards.
- Information must be accurate and accessible in various formats for a wide range of audiences with different levels of comprehension.
- Services must be provided in ways that meet human rights standards.
- Health-care providers must be trained on ethical and non-discriminatory attitudes and practices.
- Redress mechanisms must exist in case of human rights violations in health-care settings.

To ensure the acceptability of HIV services among all populations in need, it is important that governments, health institutions and providers follow technical guidance such as the WHO guidelines for HIV testing services—which include “the 5 Cs” (consent, confidentiality, counselling, correct test results and connection to care)—and the WHO guidelines on HIV treatment, including the recommendations tailored to specific populations (23). In particular, services should do the following:

- HIV testing programmes must not include coercive approaches. Furthermore, an integral element of a human rights-based approach to HIV testing services is ensuring informed consent to testing, which requires adequate pretest information that is accessible to, and understandable by, the person being tested.
- Programmes should ensure accuracy in diagnosis—such as by using good-quality diagnostic tests (e.g. rapid diagnostic tests prequalified by the WHO)—and implementing WHO-recommended testing strategies.<sup>9</sup>
- Programmes should undertake activities to improve prevention and treatment literacy, as this enhances the acceptability and feasibility of HIV prevention and treatment, especially when treatment is of long duration (as is the case with HIV) (24).

## **Principle 2: equality and non-discrimination**

*What is the principle?*

Equality and non-discrimination are key human rights principles that underpin the realization of all other human rights. As noted above, it is a core minimum obligation of states to ensure that health facilities, goods and services are equitably distributed, and to ensure access to those services on a non-discriminatory basis (18). Similarly, HIV prevention, testing and treatment services must be accessible without discrimination, including on the basis of socioeconomic status (that is, they must be affordable to all), and they must be acceptable (i.e. respect the culture and needs of specific populations).

The principles of non-discrimination and equality are reinforced extensively throughout a wide range of international human rights instruments and other guidance, including in relation to various populations disproportionately affected by HIV (including young people, women and girls, indigenous populations and key populations). Equality of men and women in the enjoyment of all human rights, including the right to health, is affirmed repeatedly in international law.<sup>10</sup> Similarly, various treaties, resolutions and declarations by states commit them to address particular concerns regarding discrimination and unequal access to health goods, services and information of various populations, such as racialized people, indigenous peoples, children and adolescents, older persons, some migrants, and prisoners and other detainees (25–40). The UN Committee on Economic, Social and Cultural Rights has outlined that the principle of non-discrimination must include addressing both formal discrimination (such as that in

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<sup>9</sup> For more on the problem of misdiagnosis and guidance for ensuring the quality of testing services, including human rights concerns raised by misdiagnosis, see Annexes 8, 9 and 14 of WHO’s Consolidated guidelines on HIV testing services (23).

<sup>10</sup> Examples include the following: Articles 2.2 and 3 of the International Covenant on Economic, Social and Cultural Rights; Articles 2.1 and 3 of the International Covenant on Civil and Political Rights; Articles 1, 3 and 12 of the Convention on the Elimination of all Forms of Discrimination Against Women; paragraph 1 of the General Recommendation No. 5: Women and HIV/AIDS (1990); and paragraphs 29 and 36 of the General Recommendation No. 24: Women and Health (1999).

laws or policies) and substantive discrimination (such as adopting special measures to overcome attitudes or conditions that perpetuate discrimination in practice) (41). Both direct and indirect discrimination are prohibited under international human rights law.<sup>11</sup>

*What does this mean for Fast-Tracking HIV prevention, testing and treatment?*

All people need some basic level of equitable access to services that can help prevent HIV transmission, such as basic prevention information and commodities that are accessible to them. They also need the opportunity to get tested for HIV should they be exposed to possible infection (be it through sexual activity, sharing of contaminated injection equipment, pregnancy or birth, and so on), while those who are diagnosed as HIV-positive need the opportunity to receive medical care (including antiretroviral therapy). Basic equality in the enjoyment of the right to health requires access for all.

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<sup>11</sup> Direct discrimination occurs when an individual is treated less favourably than another person in a similar situation for a reason related to a prohibited ground; e.g. where employment is denied to a people living with HIV because of their HIV status. Indirect discrimination refers to laws, policies or practices which appear neutral at face value, but have a disproportionate impact on the exercise of human rights. For instance, requiring a birth registration certificate for school enrolment may discriminate against ethnic minorities or non-nationals who do not possess, or have been denied, such certificates. See Committee on Economic, Social, and Cultural Rights. General Comment 20: Non-discrimination in Economic, Social and Cultural Rights (Article 2, para 2). E/C.12/GC/20, 10 June 2009.

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## **Reducing HIV-related stigma and discrimination among health-care workers in Thailand**

Although Thailand offers free HIV testing and treatment under its universal health-care scheme, data from treatment registration in 2012 indicated that half of people living with HIV started treatment late, when they had a CD4 count of less than 100. Health authorities recognized HIV-related stigma as a barrier to service uptake, and they set a target of reducing HIV-related stigma and discrimination in half by 2016.

To understand and address this situation, multistakeholder research—supported by the Ministry of Health—revealed that more than 80% of health-care workers surveyed had at least one negative attitude towards people living with HIV, while roughly 20% had observed colleagues who either were unwilling to provide services to people living with HIV or had provided them with substandard services. More than half of respondents used unnecessary personal protection measures—such as wearing two layers of surgical gloves—when interacting with people living with HIV. Among the people living with HIV who were surveyed, about one quarter reported avoiding seeking treatment at local health-care facilities due to fear of disclosure or poor treatment, and about one third reported having had their status disclosed without their consent. The survey also generated data on stigma against key populations.

The evidence triggered an acceleration of system-wide action. Thailand's Ministry of Public Health, in collaboration with civil society and international partners, developed initiatives to sensitize a broad range of health-care workers, including those in nonclinical work settings. Early results suggest that improving the attitude of health-care workers is not only key to providing better care to people living with HIV, but that it also has wider social benefits because health-care workers are highly regarded and seen as social role models. The pilot also confirmed that stigma and discrimination within health-care settings can be routinely measured, with the information gathered serving as the basis for planning and managing action and evaluating the results (4).

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The urgency of scaling up services cannot become an excuse for unjustified discrimination in selecting the populations for whom service scale-up is made a priority or the locations where it occurs. Decisions about how and where to scale up should be based on evidence, not on prejudicial assumptions or a discriminatory refusal to acknowledge which populations are most affected and in need of services. Indeed, entrenching discrimination in access to services—rather than being guided by evidence—will ultimately make it more difficult to achieve the universal access needed to end the AIDS epidemic.

The principles of non-discrimination and equality require the following for HIV prevention, testing and treatment services:

- HIV goods, services and information should be available for all. Services must be consciously designed and delivered with a view to reaching all the populations in need equitably, including young people, women and girls, people living with disabilities, indigenous populations and key populations. Those services must be delivered in nondiscriminatory ways in order to permit and encourage access by populations in need. Doing so requires policies and practices that clearly prohibit unjustified discrimination in service provision and provide a remedy when discrimination occurs based on sex, race, sexual orientation, gender identity or expression, HIV status, drug use or dependence, sex work, disability, incarceration, and other ground. For example, it is discriminatory to test women without informed consent because they are pregnant or to deny antiretroviral therapy to someone who uses illegal drugs (for instance, due to the prejudicial assumption that because they are a drug user, they will not adhere to or benefit from treatment). Similarly, it is discriminatory to segregate patients with HIV, to deny them medical procedures, or to charge them additional fees for services (42).
- Realizing equality in HIV prevention services and programmes also may require putting a specific emphasis on providing and scaling up services for populations that are disproportionately affected by HIV and are often left behind in the HIV response including prisoners, people with physical or other disabilities, sex workers, people who use drugs, gay men and other men who have sex with men, or transgender people, migrants, refugees and internally displaced people, and adolescents and young people, particularly adolescent girls and young women.
  - HIV prevention programmes are urgently needed to address the epidemic among prisoners; in some settings, HIV prevalence among people in prison may be up to 50 times higher than among the general population (13).
  - Positive measures need to be taken to ensure services are accessible to people with physical or other disabilities, because they represent one of the largest and most underserved populations (13).
  - It is discriminatory to refuse to develop and disseminate HIV prevention information and materials for sex workers, people who use drugs, gay men and other men who have sex with men, or transgender people due to the belief that doing so requires addressing their sexual practices, behaviours or gender identity in a factual way.
  - Similarly, it is discriminatory to underfund health services, including HIV services, for indigenous communities.
  - Migrants, refugees and internally displaced people are often underserved by HIV and health services.

- Adolescents and young people, particularly adolescent girls and young women in some regions such as eastern and southern Africa, are at heightened risk of HIV infection.
- In providing HIV-related treatment or other health services, care should be taken to avoid, or at least minimize, the risk of subsequent discrimination or other human rights violations (such as violence) against those who use these services (43). For example, respecting and protecting the right to privacy is important in order to respect the personal dignity and autonomy of people in disclosing their HIV status or other personal information, and it helps protect against other violations.
- Similarly, care should be taken to avoid HIV prevention, testing and treatment efforts that heighten stigma, discrimination or other human rights violations already experienced by people living with HIV, young people, women and girls, people living with disabilities, indigenous populations and key populations. For example, HIV prevention messages that may lead to scapegoating of certain populations as vectors of disease should be avoided, whether they are sex workers, people who use drugs, gay men or other men who have sex with men, transgender people, or those considered to be foreigners. Stigmatization decreases treatment adherence (44, 45).

Since higher HIV prevalence among key populations and their higher burden of AIDS is partly rooted in social, economic and legal inequalities, ensuring equitable, non-discriminatory access to services will require efforts to remove these barriers in the environment in which HIV services are to be delivered. For example, discriminatory laws, policies and practices that deny or restrict access to and uptake of HIV services for specific populations need to be abolished. This indicates the importance of various human rights programmes—such as Know Your Rights campaigns, access to legal services, law reform efforts and strategic litigation—to create a more enabling environment that supports uptake of HIV services. (See below on scaling up human rights programmes for more detail.)

To catalyze global and local actions to address discrimination in health care, UNAIDS and the WHO Global Health Workforce Alliance launched an Agenda for Zero Discrimination in Health Care on 1 March 2016. The Agenda aims to bring together relevant stakeholders for cohesive joint efforts towards a world where everyone, everywhere, is able to receive or provide health care with no discrimination. The Agenda prioritizes action to secure political leadership and commitment, scale-up implementation of what works to eliminate discrimination, and enhance accountability (42).

### Principle 3: privacy and confidentiality

*What is the principle?*

The right to privacy—and corresponding duty of service providers to protect confidentiality—is rooted in international human rights treaties (46, 47), as well as in various declarations and resolutions regarding obligations in health care that have been adopted by both states and international organizations of health professionals.<sup>12</sup> It also finds expression at the country level in domestic laws or regulations, and in frequently binding professional standards of practice for providers of health care and other services. International best practice guidance, including from specialized UN agencies, also insists on respecting privacy and confidentiality in the provision of HIV services (16,23).

Some limits on privacy and some disclosure of HIV status without the consent of the person may be permitted in limited circumstances for compelling reasons, but only if authorized by law. Furthermore, any such breach of confidentiality, including an infringement that is legally authorized or required, must be as limited as possible, thereby protecting the right to privacy to the greatest possible extent.<sup>13</sup>

*What does this mean for Fast-Tracking HIV prevention, testing and treatment?*

In the context of HIV prevention, testing and treatment, the right to privacy requires the following:

- People receiving services have a right to know what information is being collected about them by service providers delivering HIV prevention programmes, testing services or treatment (or related health care). Providers must answer service user questions about this and provide a copy of their records to the service user upon request.<sup>14</sup>

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<sup>12</sup> Some examples include the following: Article 9 of the Universal Declaration on Bioethics and Human Rights (2005); the World Medical Association (WMA) Declaration of Geneva (first adopted in 1948, most recently amended in 2006); the WMA International Code of Medical Ethics (first adopted in 1949, most recently amended in 2006); the WMA Declaration of Lisbon on the Rights of the Patient (first adopted in 1981, most recently affirmed as amended in 2015); and the WMA Statement on HIV/AIDS and the Medical Profession (2006). All documents are available online via <http://www.wma.net/en/20activities/10ethics/index.html>. Other examples include Nurses and Human Rights: International Council of Nurses Position Statement (2001), International Code of Ethics for Midwives from the International Confederation of Midwives (2008, most recently reviewed and adopted again in 2014), and the Madrid Declaration on Ethical Standards for Psychiatric Practice from World Psychiatric Association General Assembly (first adopted in 1996, most recently amended in 2002).

<sup>13</sup> Some human rights are absolute (e.g. the rights to life, freedom from medical experimentation without free consent, and freedom from torture or other cruel, inhuman or degrading treatment). These are nonderogable rights, meaning no government is ever permitted to breach or limit them under any circumstances. There are times, however, that limitations on some other rights may be justified, within certain narrow parameters, in order to achieve important, legitimate objectives. Key among these are the principles that any limitation on rights must use the least restrictive means required in order to achieve the purpose underlying the limitation, and that no limitation on a right can ever be arbitrary, unreasonable or imposed in a discriminatory manner. For more guidance, please see the following resources: United Nations, *Siracusa Principles of the Limitation and Derogation Provisions in the International Covenant on Civil and Political Rights* from the UN Economic and Social Council, E/CN.4/1985/4, 1985 (available from <http://hrlibrary.umn.edu/instreet/siracusapinciples.html>); and paragraphs 46–69 of *The Limburg Principles on the Implementation of the International Covenant on Economic, Social and Cultural Rights*, In: *Economic, social and cultural rights: handbook for national human rights institutions* (New York and Geneva: United Nations; 2005), pp. 125–35 (available from <http://www.ohchr.org/Documents/Publications/training12en.pdf>).

<sup>14</sup> To justify withholding such information, there must be some compelling justification related to the best interest of that particular service user or the necessity of protecting the legitimate rights of another person.

- The right to privacy must be respected, protected and fulfilled in all HIV services. This imposes a corresponding duty on service providers to ensure that all information about a person's access to HIV services, their serostatus and their treatment remains confidential.
  - Service providers should require no more than the personal information necessary to provide the service in question in accordance with standards of good, professional health-care practice.
  - To the maximum extent possible, HIV services should be situated and designed to facilitate access without people having to be identified as HIV-positive or as seeking HIV services. For example, highly visible signs marking a clinic as providing HIV services undermine privacy and create a barrier to access.
  - The physical set-up of health services should be such that it guarantees the confidentiality of direct service delivery (e.g. administering an HIV test) and communications between service users and service providers (e.g. private settings for pre- and post-test counselling, discussing the results of an HIV test or tests for monitoring viral load and drug resistance, discussing treatment options and effects, dispensing medications, and discussing related health concerns).
  - Policies and protocols in HIV services must guarantee at least confidentiality—and preferably anonymity, where practicable—to further reduce the risk of privacy violations. This includes practices for gathering and storing personal health information, and for protecting against unauthorized disclosure or misuse of that information. For example, patient files must not be visibly marked or stored in ways that communicate a person's HIV status to casual observers; information in patient files, whether paper or electronic, should only be accessible to authorized health personnel who are subject to clear, known and enforced rules regarding patient confidentiality; information should be reasonably protected against unauthorized access by others through physical safeguards (e.g. locked offices and storage units accessible only to authorized service providers) and/or digital ones in the case of electronic records (e.g. password protection and encryption).<sup>15</sup> Communities should be consulted in relation to techniques used for gathering and storing personal health and HIV data and their concerns relating to the protection of such data should be duly addressed.
  - The right to privacy should be ensured for all. It should be recognized that this is not always the case, particularly for women, mature adolescents and young people, people living with disabilities, prisoners, or members of key populations who also may be subject to unwarranted limitations on their medical confidentiality in various settings.

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<sup>15</sup> See UNAIDS/WHO Working Group, Guiding principles on ethical issues in HIV surveillance (Geneva: WHO; 2013) (available from <http://www.who.int/hiv/pub/surveillance/2013package/module2/en/>).

- The right to privacy in HIV services must extend beyond just preserving confidentiality of HIV status: it also must protect the confidentiality of other health or personal information obtained in the course of providing services. Disclosure of information may expose a person to stigma, discrimination, criminalization, violence or other abuse. Depending on the setting, this can include information about a person's sexual orientation or particular sexual practices, gender identity or expression, sex work, drug use or dependence (and treatment for drug dependence), ethnicity, migrant status, prior criminal record, socioeconomic status, and more.

*“Physicians must clearly explain the purpose of an HIV test, the reasons it is recommended and the implications of a positive test result. Before a test is administered, the physician should have an action plan in place in case of a positive test result. Informed consent must be obtained from the patient prior to testing...counselling and voluntary anonymous testing for HIV should be available to all persons who request it, along with adequate post-testing support mechanisms.”*

**World Medical Association.  
Statement on HIV Testing and the Medical Profession, 2006.**

#### **Principle 4: respect for personal dignity and autonomy**

*What is the principle?*

Respect for the dignity and autonomy of the individual is a foundational principle that is central to HIV services. To achieve the world's HIV prevention and treatment targets, the free and full cooperation of all people is required. Ensuring this requires ending coercive approaches or involuntary programmes that undermine trust in, and cooperation with, health services, thus frustrating efforts to end the epidemic. The principles of dignity, autonomy and self-determination are of particular concern to women, young people (especially girls), people living with disabilities, indigenous populations, and key populations, all of whom may experience societal norms, economic constraints or even legislation that limits their autonomous decision-making, including in the context of health.

Associations of health professionals have repeatedly reaffirmed the need to respect informed consent in the delivery of health services, including in the context of HIV.<sup>16</sup> The importance of respecting personal autonomy in the health context also has been underscored in relation to various populations whose rights have been violated or are at risk in health-care settings. For example, pregnant women have been the focus of intense programmes to increase HIV testing and connection to treatment in order to prevent mother-to-child HIV transmission. Studies suggest, however, that coercion and insufficient counselling lead to women being less likely to learn the result of their test; they consequently are less likely to initiate treatment to prevent mother-to-child HIV transmission and for their own health, or to adhere to such treatment (50, 51). It is thus important to remember that within all efforts to increase testing, informed consent and counselling is key to ensuring that the woman who is tested learns the results and acts on that knowledge.

<sup>16</sup> For an example, see World Medical Association, Statement on HIV/AIDS and the Medical Profession, October 2006 (available from <http://www.wma.net/en/30publications/10policies/a25/index.html>).

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### **Ten human rights, community engagement and gender equality considerations for validation of the elimination of mother-to-child HIV transmission**

Countries applying for validation of the elimination of mother-to-child HIV transmission must respect and comply with the following human rights, community engagement and gender equality principles:

1. Non-criminalization of mother-to-child transmission
2. No mandatory or coerced testing and treatment.
3. Informed consent.
4. No forced or coerced abortion, contraception or sterilization.
5. Confidentiality and privacy.
6. Equality and non-discrimination.
7. Availability, accessibility, acceptability and quality of services.
8. Accountability, participation and community engagement.
9. No gender-based violence.
10. Access to justice, remedies and redress.

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In the light of these human rights challenges, UNAIDS and WHO—together with the International Community of Women Living with HIV (ICW) and the Global Network of People Living with HIV (GNP+)—have developed a set of 10 considerations relating to human rights, gender equality and community engagement that are to be integrated in the process of country validation for the elimination of mother-to-child transmission of HIV (see ten considerations). This process marks the first time in public health history that human rights guarantees are considered a prerequisite to validating disease elimination (52).

*What does this mean for Fast-Tracking HIV prevention, testing and treatment?*

Reflecting the principle of respect for autonomy, UNAIDS and WHO have affirmed the importance of informed consent in HIV testing. If individuals or communities lose trust in health workers because they are fearful that health workers will subject their bodily material to an HIV test without consent, that lack of trust could have a chilling effect on access to health services more generally. Furthermore, the fact that women are disproportionately affected by coercive and involuntary approaches to HIV testing highlights the discriminatory, gendered impact of relaxing safeguards aimed at ensuring informed consent.

Ensuring that a patient provides specific, informed consent to an HIV test means that, before proceeding with a test, the testing provider must ensure that the individual patient has a solid understanding of at least certain key information. But this should not be misunderstood as requiring an onerous, uniform approach to every provider–patient encounter, which would represent an inefficient use of time and resources for both the patient and the health system. In the context of their interaction with an individual patient, testing providers can and should be able to gauge the degree to which the person requires more or less information in order to understand what having an HIV test would mean; this would allow them to adjust their approach accordingly.

Respecting, protecting and fulfilling personal dignity and autonomy in HIV services means the following:

- HIV testing must only be undertaken with voluntary, informed consent that (a) specifically addresses being tested for HIV and (b) is consistent with WHO guidelines on HIV testing services. As consent may not be presumed, service providers may routinely offer HIV testing, but they must receive affirmative, informed consent (“opting in”) before performing any test. Similarly, self-testing should be voluntary and should not be used to test another person without their consent.
- Mass testing campaigns (e.g. door-to-door or village-to-village Know Your Status initiatives) carry heightened risks of leading to testing that is not fully voluntary or based on informed consent. It also potentially does not provide adequate protection of confidentiality or guarantee quality testing. Any such initiatives should be approached with caution and incorporate concrete measures such as oversight and accountability to help ensure they do in fact deliver quality HIV counselling and testing that respect rights (including informed consent and confidentiality) (see below).

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## **Human rights concerns in mass HIV testing initiatives: lessons from Lesotho’s Know Your Status campaign**

In recent years, there has been a push, particularly in some high-prevalence countries in sub-Saharan Africa, to implement large-scale, community-based HIV testing initiatives. Interest in such approaches can be expected to increase in the context of efforts to scale up HIV prevention, testing and treatment services more rapidly in order to reach the Fast-Track Targets by 2020 and end the AIDS epidemic as a public health threat by 2030.

The experience of the implementation of the Know Your Status testing campaign in Lesotho in 2005 (and in other countries in sub-Saharan Africa) calls for caution regarding the design and implementation of such approaches. A report published by Human Rights Watch and the AIDS & Rights Alliance for Southern Africa (ARASA) after the implementation of the Lesotho campaign notes that “while these programs have real potential, their impact may be limited if they result in, or contribute to—intentionally or unintentionally—violations of basic human rights” (54). Researchers also found that the “campaign’s implementation was fraught with problems, resulting in poor training and supervision of counselors; poor linkages, at times, to other services after testing; and insufficient mechanisms to ensure respect for human rights and the accountability of government efforts. In places where the campaign was conducted most intensively, human rights protections, as well as the integrity of the counseling and testing provided, seemed most endangered.” (53)

In the drive to Fast-Track HIV prevention, testing and treatment, there are important lessons to be learned from such experiences, including addressing human rights risks and ensuring that those who test positive for HIV are linked to treatment and care. As the report by Human Rights Watch and ARASA stresses, these campaigns need careful planning, sufficient funding, good training, ample coordination, proper oversight, and the involvement of civil society, which can play a critical role in ensuring accountability and reporting potential human rights abuses. Without these elements, these programs risk failing to achieve their ambitious goals—as happened in Lesotho—or worse, damaging the cause they were intended to serve. (53)

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- No HIV treatment or other programmes (such as treatment for an STI or drug dependence) may be imposed without informed consent, nor is coercion into undergoing or continuing HIV treatment permissible. In cases where a service provider undertakes follow-up with patients to monitor compliance with treatment and maintain a connection to care—including after a missed appointment—no coercion into treatment is permissible, nor is it permissible to exclude a patient from HIV treatment if the patient does not consent to such ongoing tracing.<sup>17</sup>
- No service provider may treat a patient in a manner that constitutes torture or other cruel, inhuman or degrading treatment in the guise of treatment (for HIV, drug dependence or another health condition).
- No law may authorize—and no service provider should engage in—forced, coercive or otherwise involuntary sterilization of women, including on the basis of their HIV status (55).

## Principle 5: meaningful participation and accountability

*What is the principle?*

Decades ago, governments recognized the importance of meaningful participation in making decisions about health policy. According to the Declaration of Alma-Ata, people have the right and duty to participate individually and collectively in the planning and implementation of their health care (56). Allowing and encouraging participation is considered a core obligation of states with regards to their responsibility for the realization of the right to health (18). In the context of HIV, people living with HIV have highlighted the central importance of their involvement to make the response effective, and the principle of greater involvement of people living with HIV (GIPA) has been repeatedly endorsed by UN Member States, including in all four UN General Assembly resolutions on HIV adopted between 2001 and 2016.<sup>18</sup> The underlying rationale and principle apply equally with respect to the meaningful engagement of the populations particularly affected by HIV: if programmes are to be most effective, the intended beneficiaries must be meaningfully involved in their design.<sup>19</sup> Similarly, there must be accountability for how they are designed

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<sup>17</sup> A good example of defaulter tracing that respects human rights and is free from coercion is the experience of Médecins Sans Frontières in its clinics in the informal settlement of Kibera in Nairobi, Kenya. Patients are routinely contacted by a social worker via telephone, in-person visit, or both very soon after they miss an appointment. Patients, however, are asked whether they want to participate or not; they are not excluded from treatment if they do not consent to tracing. Results over three years showed that very few patients refused to provide contact information, and the number of patients lost to follow-up declined by nearly half while still respecting patient rights (54).

<sup>18</sup> An example of the GIPA principle can be found in The Denver Principles (1983) (available from [http://data.unaids.org/pub/ExternalDocument/2007/gipa1983denverprinciples\\_en.pdf](http://data.unaids.org/pub/ExternalDocument/2007/gipa1983denverprinciples_en.pdf))

<sup>19</sup> Examples include the following: Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute and International Network of People Who Use Drugs, Nothing about us without us—a manifesto by people who use illegal drugs (2008) (available from <http://www.aidslaw.ca/site/nothing-about-us-without-us-a-manifesto-by-people-who-use-illegal-drugs/?lang=en>); and Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute, Nothing about us without us—greater, meaningful involvement of people who use illegal drugs: a public health, ethical, and human rights imperative, International Edition (Toronto: Canadian HIV/AIDS Legal Network, International HIV/AIDS Alliance, Open Society Institute; 2008) (available from <http://www.aidslaw.ca/site/nothing-about-us-without-us-greater-meaningful-involvement-of-people-who-use-illegal-drugs-a-public-health-ethical-and-human-rights-imperative-international-edition/?lang=en>).

and implemented, and the monitoring and evaluation of such programmes need to include assessing how they reflect human rights standards. Here again, the meaningful involvement of the populations affected is essential.

*What does this mean for Fast-Tracking HIV prevention, testing and treatment?*

Meaningful participation is important for HIV services in various ways:

- HIV prevention, testing and treatment programmes necessarily raise culturally sensitive issues, such as sexuality and drug use. Involving communities in the design and implementation of programmes greatly reduces the risk of well-intended but inappropriate efforts, and it also increases opportunities for identifying potential social, cultural or legal barriers that will need to be addressed to facilitate access to services.
- Involving the populations most affected by HIV—including young people, women and girls, people living with disabilities, indigenous populations and key populations that need to be reached by HIV services—is essential to effective design and delivery of those services and ensuring they are available, accessible, acceptable and of good quality. Their involvement helps inform decisions about specific user-friendly prevention tools that are needed (e.g. which safer injection materials are needed and preferred or what information about age of consent and youth-sensitive approaches are needed to facilitate uptake of HIV services for adolescents and young people). The participation of these populations also helps identify potential human rights issues or other barriers to efficacy that need to be addressed, either within the service itself (e.g. improving the physical set-up of a clinic to maximize privacy) or in the environment in which it operates (e.g. police harassment and violence against particular communities, inadequate legal protection of privacy, barriers relating to age of consent, or stigma fuelled by criminalization).
- Similarly, participation is essential to achieving HIV treatment objectives. Antiretroviral therapy is lifelong, requiring ongoing engagement of people living with HIV. Successfully delivering other health services that support antiretroviral therapy adherence (such as opioid substitution therapy among some people who use drugs) also requires voluntary, ongoing engagement of those affected. Participation of communities and service-users can identify challenges for adherence to treatment that need to be addressed. These challenges can be related to the adverse effects of particular medication regimens, unnecessarily burdensome procedures or discrimination encountered within health services, or broader environmental barriers (such as difficulty maintaining privacy about health status to avoid stigma or discrimination). Experience shows that the inclusion of affected communities in the design and implementation of HIV treatment programs helps ensure that those programs are appropriate, and it contributes to changing social perceptions of HIV and people living with HIV (namely that they can be actively involved not just in designing HIV treatment programs, but also in implementing them) (57–60). In the context of efforts to scale up HIV services, community-based services delivery models are more crucial than ever (61). These models will need to be costed, resourced and included in national plans to scale up the response to HIV.

- Communities also have an important role in monitoring and evaluation: they can help to ensure that quality standards are met in HIV services, thereby contributing to greater trust of health services and prevention information and initiatives. Such trust and ongoing community engagement are necessary for achieving prevention and treatment targets (61).

Accountability is essential for the realization of human rights, and it will be essential to efforts to accelerate the achievement of the HIV prevention and treatment targets that must be reached if the world is to end the AIDS epidemic as a public health threat by 2030. This includes accountability for mobilizing the resources that are needed and for taking the necessary measures to protect and promote human rights if the targets are to be achieved. Similarly, governments must be held accountable for their obligations to respect rights by not interfering with or curtailing them, to protect individuals and groups against human rights abuses committed by others, and to fulfil human rights by taking positive steps to facilitate their enjoyment.

Effective accountability requires the following:

- Monitoring and evaluation to assess whether a country is progressing over time toward realizing the right to health through adequate data collection (which also captures whether key populations are enjoying equitable access to services).
- Mechanisms for holding states and others (such as providers of HIV services) accountable for complying with their human rights obligations.
- Awareness and capacity on the part of individuals and communities, both to participate in monitoring and evaluation and to use accountability mechanisms.

Effective accountability can be achieved through a variety of processes and institutions that will vary from setting to setting. This may include mechanisms at the level of a given program or service, or national, regional and even international mechanisms for holding governments accountable. Ensuring that accountability mechanisms are accessible, however, first requires that rights-holders be aware of their rights, which means that individuals need to know their rights and how to claim them. Thus providing information is one element of accessible, effective accountability. Individuals who suffer human rights violations also must have access to effective remedies in a timely manner. This is why some of the human rights programmes described below are so important, and why they must be supported and expanded as key complements to the rapid scale-up of HIV prevention, testing and treatment services in ways that reflect human rights principles.

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### **Ending stock-outs to support effective HIV responses: an accountability mechanism to make treatment work**

In 2013, six civil society organizations established a consortium, known as the Stop Stock Outs Project (SSP), to monitor the availability in the South African public sector of antiretroviral medicines for HIV, medicines for tuberculosis (TB), routine childhood vaccines and other essential medicines. The members of the consortium are the Rural Health Advocacy Project (RHAP), the Rural Doctors Association of Southern Africa (RuDaSa), the South African HIV Clinician's Society, SECTION27, Médecins Sans Frontières (MSF) and the Treatment Action Campaign (TAC).

Over the past four years, the SSP has established a hotline for patients and health-care workers to report stock-outs, and it has developed a reporting structure to communicate with the South African Department of Health when stock-outs occur. The SSP also collaborates with a variety of stakeholders to resolve stock-outs and shortages faced by patients and health-care workers in facilities across the country, and it advocates for policy change that will contribute to strengthening all levels of the supply chain. Over the past three years, the SSP has engaged local, provincial and national authorities in finding solutions to stock-outs, including through mechanisms to improve the supply chain management.

Similar initiatives to monitor and address stock-outs and increase access to HIV treatment exist in several other countries, where they are critical initiatives to support accountability in the HIV response. Expanding such programmes will be critical alongside efforts to Fast-Track the HIV response (62).

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# Scaling up key human rights programmes alongside HIV prevention, testing and treatment services

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*“Thirty years into the HIV epidemic, we still have major discrimination and stigma related to HIV, as well as laws and law enforcement that drive people away from HIV services. Such situations are undermining the HIV response across the world. This will only change if we make major investments in programmes to reduce such stigma and increase access to justice for those affected by HIV.”*

**Michel Sidibé, UNAIDS Executive Director, August 2011**

While efforts to address legal and human rights issues in HIV prevention, testing, and treatment programmes are necessary to end the AIDS epidemic as a public health threat by 2030, they are not sufficient. To accomplish that goal, they must be accompanied by deliberate commitments and actions to address the political, legal and social environments in which HIV responses take place. Broader issues—such as HIV-related stigma and discrimination, marginalization, social exclusion, violence and gender inequality—and their impact on the HIV epidemic should be confronted.

In order to protect people affected by HIV and support effective responses to HIV, UNAIDS recommends that every national HIV response include key programmes to reduce stigma, discrimination and other human rights violations, and to increase access to justice. These programmes not only help to realize basic human rights, but they also are critical enablers to the success of HIV prevention, testing and treatment programmes.

As outlined by UNAIDS, there are seven key human rights programmes needed in every HIV response.

1. Stigma and discrimination reduction programmes, such as the use of media campaigns to address discrimination, including in employment and educational settings, measuring stigma, and peer mobilization and support for and by people living with HIV.
2. HIV-related legal services, including legal information, advice and representation, alternative or community forms of dispute resolution, and strategic litigation.
3. Monitoring and reforming laws, regulations and policies relating to HIV, including reviewing the impact of laws and law enforcement on the HIV response, advocating and lobbying for law reform, engaging legislators, and promoting the enactment and implementation of laws, regulations and guidelines that prohibit discrimination and support access to HIV prevention, treatment, care and support.
4. Legal literacy (Know Your Rights) programmes, including awareness-raising campaigns, community mobilization and education, peer outreach, and telephone hotlines.
5. Sensitization of lawmakers and law enforcement agents on issues, including HIV and how it is and (is not) transmitted, the consequences of police activity on human rights

and the HIV response, training for prison personnel, and information and sensitization on HIV and its human rights aspects for legislators, prosecutors, lawyers, and traditional and religious leaders.

6. Training for health-care providers on human rights and medical ethics related to HIV, including training on ending discrimination in health-care settings for individual health-care providers, health-care administrators and health-care regulators.
7. Reducing discrimination against women in the context of HIV, including the following:
  - Programmes to strengthen the legal and policy environment to address gender inequality and violence.
  - Reforms of domestic violence laws and law enforcement to protect women and remove barriers to HIV services.
  - Reforms of property, inheritance and custody to ensure equal rights for women.
  - Programmes to reduce harmful gender norms and traditional practices that contribute to HIV risk.
  - Increased access to education and economic empowerment opportunities for women (63, 64).

Despite this—and despite the repeated recognition by states that addressing human rights is essential to an effective response to HIV—funding for such programmes, largely implemented by civil society organizations, remains insufficient and under threat, even though the world has agreed that it must rapidly scale up the HIV response in order to end the AIDS epidemic by 2030. As a 2015 study concluded,

*“little of the present annual funding for the global HIV response supports human rights programming ... UNAIDS estimates put the annual global spending for the human rights response to HIV at approximately US\$ 137 million. This is a fraction of the US\$ 19.1 billion that was spent in 2013 on the overall HIV response in low- and middle-income countries. Even though they are not directly comparable, these data are consistent with UNAIDS Global AIDS Response Progress Reporting (GARPR) data, which show that 0.13% of total AIDS spending reported to UNAIDS by low- and middle-income countries is allocated for human rights-related programming.” (65)*

In an effort to address this situation and advance Strategic Objective 3(c) of its Strategy 2017-2022 on removing barriers to services, the Global Fund has aligned with the seven key human rights programmes recommended by UNAIDS and introduced a module relating to them in its funding application. Additionally, the Global Fund has made catalytic funding available to 20 countries for scaling up the seven key programmes to reduce human rights barriers to HIV services (66).

# Conclusion

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There is no longer any doubt that HIV prevention and treatment are interrelated and mutually reinforcing. As noted by UNAIDS,

*“treatment supports the achievement of HIV prevention targets by reducing viral load and transmission of [HIV]. Prevention programmes support the achievement of the 90-90-90 [treatment] targets in various ways. Prevention communication enhances the demand for testing, while community-based prevention programmes can increasingly integrate demand generation for early [antiretroviral therapy] and adherence support for people living with HIV.” (67)*

The protection and promotion of human rights also must be recognized as an essential complement to HIV prevention, testing and treatment efforts, and it must be integrated with those efforts.

Ensuring access to the goods, services and information needed to prevent infection, receive a diagnosis and gain access to effective treatment is necessary to realizing the right to health. Ending discrimination and other social and legal barriers to prevention, testing and treatment services enhances the reach and impact of those services. This requires not only respecting and protecting human rights in the delivery of HIV prevention, testing and treatment programmes, but also addressing larger human rights barriers in the broader environment in which those services operate. Failing to address these human rights challenges in the response—and paying insufficient attention to the needs of all populations, including young people, women and girls, people living with disabilities, indigenous populations and key populations—is holding back efforts to end the epidemic. It simply will not be possible to Fast-Track the HIV response and end the AIDS epidemic without addressing human rights.

This guidance has outlined why efforts to scale up HIV prevention, testing and treatment must be grounded in human rights, but it also has shown how this can be done. As the world intensifies actions to Fast-Track the HIV response, it is time for all key stakeholders involved in the HIV response to use the approaches provided in this document.

## **Ending AIDS: a shared responsibility**

In recognizing the right to the highest attainable standard of health (and various other rights), Article 2 of the International Covenant on Economic, Social and Cultural Rights also provides that they each have a legal obligation of international assistance and cooperation to assist in fully realizing the right for all persons (68). More recent treaties, including the Convention on the Rights of the Child, affirm this shared responsibility (30). In the context of the right to health, this obligation of international assistance and cooperation requires countries to facilitate access to essential health facilities, goods and services in other countries, wherever possible, and to provide necessary aid when required, depending on the availability of resources (18).

There is no question that a sizeable, but feasible, financial investment is needed to achieve the world's prevention and treatment targets.<sup>20</sup> UNAIDS reports that low- and middle-income countries have answered the call for shared responsibility. In the past five years, domestic investment in the AIDS responses of these countries has increased by 46%, reaching US\$ 10.8 billion in 2015. A sizable investment gap remains, however. Reaching the Fast-Track Targets agreed by the United Nations General Assembly will require an additional US\$ 7 billion annually by 2020 (69). Reaching this level of investment (US\$ 26 billion) by 2020, and sustaining the required investments until 2030, and focusing them on delivering the most effective HIV services to the people in greatest need across the life cycle, will result in millions of additional lives saved and tens of millions of additional HIV infections averted.

Shared responsibility does not necessarily mean equal responsibility. Under international human rights law, there is a clear hierarchy of obligations under which the primary obligation to realize rights clearly rests with each sovereign state: it is a national obligation, and the complementary obligation lies with the international community. From a national perspective, the shared obligation related to HIV includes expending a maximum of available resources on HIV-related goods and services and requesting international cooperation and assistance (if required) to continue moving towards the full realization of the right to health. Correspondingly, the international community has the obligation to engage in international assistance and cooperation to expand the AIDS response to reach globally agreed upon targets for HIV, health and sustainable development.

The significant mobilization aimed at scaling up HIV prevention, testing and treatment has been globally unprecedented. Substantial resources have been marshalled and a multisectoral approach has been pursued that has involved public health officials, clinicians, politicians, affected communities, the armed forces, the law, and leaders in civil society, business and labour all working in concert to tackle the spread of HIV infection and reduce AIDS-related mortality (70). In particular, the scale-up of services in developing countries has been a manifestation of this principle of shared responsibility, and it remains central if the international community is to end the AIDS epidemic as a public health threat by 2030 through the achievement of the agreed upon prevention and treatment targets.

Mobilizing sufficient resources—both at the national and the international level—is and will remain a key challenge. Although the human rights principle of shared responsibility is valid for all elements of health (and other socioeconomic rights), the global AIDS response stands out as one of the most direct and sustained applications of the principle (71). That shared global investment in ending AIDS—in overcoming one of the world's greatest public health challenges—cannot ultimately succeed without ensuring that we respect, protect and fulfil human rights in our response.

Let's get serious about ending AIDS.

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<sup>20</sup> For resource estimates, see UNAIDS, *Fast-Track: update on investments needed in the AIDS response* (Geneva: UNAIDS; 2016) (available from [http://www.unaids.org/en/resources/documents/2016/unaids\\_fast-track\\_update\\_investments\\_needed](http://www.unaids.org/en/resources/documents/2016/unaids_fast-track_update_investments_needed)).

# Annex

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## **Human rights checklists to Fast-Track HIV prevention, testing and treatment services**

The human rights checklists to Fast-Track HIV prevention, testing and treatment services provide core questions to support national governments, HIV implementers, civil society and donors in ensuring that plans, programmes and activities to accelerate the response to HIV appropriately address human rights issues and considerations. They can be used in various contexts, including in the development and review of national HIV strategic plans, Fast-Track plans and HIV funding proposals to mechanisms such as the Global Fund to Fight HIV, TB and Malaria.

HIV prevention, testing and treatment services are part of a continuum of services; they are mutually reinforcing and should be integrated. At a time when the prevention benefits of HIV treatment have been demonstrated, there are further reasons for integrating HIV services. For clarity and expediency, however, the human rights issues, principles and considerations that are applicable in efforts to Fast-Track the response are described under three programmatic areas: HIV prevention, HIV testing and HIV treatment. Three human rights checklists are therefore provided that address those areas. While this presentation involves some repetition, the format does ensure that each checklist can be used as a standalone document.

The checklists should be used together with the Global Fund's Technical brief on HIV, human rights and gender equality which provides practical advice on how to implement and scale up the UNAIDS seven key programmes to reduce discrimination and increase access to justice in the context of HIV (17). The checklists may further be complemented with questions and information contained in the National Commitments and Policy Instrument (NCPI).<sup>21</sup>

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<sup>21</sup> The NCPI aims to measure progress in the development and implementation of policies, strategies and laws related to the HIV response, as well as promote consultation and dialogue on the HIV response between national stakeholders. It is a policy questionnaire consisting of two parts: Part A completed by national authorities and Part B completed by civil society and other non-governmental partners. The NCPI is submitted to UNAIDS by countries every two years as part of reporting on the global AIDS monitoring framework, and serves as a monitoring and accountability tool on the policy environment related to the HIV response. For further information on the global AIDS monitoring framework and the NCPI, see the 2017 Global AIDS Monitoring guidelines at [http://www.unaids.org/sites/default/files/media\\_asset/2017-Global-AIDS-Monitoring\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/2017-Global-AIDS-Monitoring_en.pdf).

## Checklist 1: HIV prevention services and human rights

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HIV prevention services involve the full package of biomedical, behavioural and structural programmes that together form combination prevention. These programmes include the following goods, services and information:

- Comprehensive condom and lubricant programming (including male and female condoms).
- Comprehensive harm reduction services (including needle–syringe programs, opioid substitution therapy, and so on).
- Social and behavioural programmes (including educational programmes).
- Post-exposure prophylaxis (PEP) and pre-exposure prophylaxis (PrEP).
- Access to sexually transmitted infection (STI) services, scheduled vaccines and other health care.
- Voluntary medical male circumcision (VMMC).
- Structural interventions, including removing laws, policies and practices that hinder access to prevention services, and supporting community empowerment. For women and girls, these structural interventions include programmes to enhance agency and address violence (e.g. cash transfers and keeping girls in schools) (12, 19, 20).

HIV testing services and the use of antiretroviral medicines as treatment by people diagnosed with HIV also are key elements of combination prevention. The application of human rights principles and standards to HIV testing services is dealt with in Checklist 2; their application to HIV treatment is covered in Checklist 3.

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### Availability, accessibility and acceptability of HIV prevention services

- Does the government have a national plan or programme for scaling up HIV prevention services? Has the plan been fully budgeted, and have funding sources been identified (including international sources, if necessary)?
- Does the scale-up plan aim to ensure that appropriate HIV prevention services are available and adequately distributed across the country, based on available data about the geographic distribution of HIV prevalence and incidence, and the populations most affected by the epidemic?
- Does the plan appropriately tailor HIV prevention services with the most suitable package of programmes to address each population group, including women and girls, adolescents and young people, indigenous communities, people living with

disabilities, people who inject drugs, sex workers, men who have sex with men, transgender people and prisoners?

- What measures are in place or are being implemented to ensure availability, accessibility and acceptability of HIV prevention services for all population groups, including women and girls, adolescents and young people, indigenous communities, people living with disabilities, people who inject drugs, sex workers, men who have sex with men, transgender people and prisoners? Important questions to consider include the following:
  - What steps is the government taking to ensure the adequate distribution of a sufficient number of facilities, programmes, and adequately trained and paid health workers and other community workers in order to deliver HIV prevention services that are commensurate with the local need in settings throughout the country?
  - Are the commodities, services and information needed for HIV prevention available for free? If payment of a fee is required for any of these, what measures are in place to ensure that these do not constitute a barrier to people or households without adequate resources to pay such fees?
  - What measures are in place to prevent and effectively respond to stock-outs of HIV prevention commodities?
  - What measures are being taken to improve awareness, knowledge and understanding of HIV, how it can be prevented, the availability of HIV prevention services, and the rights that people have in seeking and receiving those services?
  - Do HIV prevention services include sexuality education available to adolescents and young people?
  - Are knowledge and skills about HIV and HIV prevention options made available to them in ways that are understandable?
  - Are adolescents and young people able to have access to such knowledge, and to the commodities and services they need to reduce their risk of infection?
  - Can adolescents access commodities and services without requiring parental or guardian consent and with full protection for their privacy?
  - Is there outreach—including focused outreach to all the populations in need, such as young people, women and girls, people living with disabilities, indigenous communities and key populations—that provides accessible information about available HIV prevention services and how to gain access to them?
  - Are efforts being made to remove physical and other access barriers to HIV prevention services for people living with disabilities? Do people in prison (or those otherwise detained by the state) have access to HIV prevention information, commodities and services that are equivalent to the access enjoyed by people outside prison?

- Are migrants to the country (or those already within it) able to access HIV prevention services on the same basis as nationals of the country?
- What restrictions, if any, apply and to which categories of migrants are they applied? Are those restrictions in line with human rights standards and public health recommendations?<sup>22</sup>
- Are people who are known or believed to use illegal drugs able to get access to HIV prevention services without discrimination?
- Are there measures in place to ensure that people who provide, carry or use condoms, sterile injection equipment and other HIV prevention commodities are not harassed or subject to criminal prosecution?
- Is the government taking steps to end punitive laws, policies and practices against key populations that hinder their access to HIV prevention services? This should include laws that criminalize gay men and other men who have sex with men, transgender people, and sex workers (including their clients, workplaces and third parties). It also would include laws that criminalize the possession of substances for personal use, or those that allow for the involuntary detention of sex workers or people who use drugs (in so-called “rehab” centres or drug detention centres).

### **Equality and non-discrimination in services**

- Are there adequate measures in law to prevent and redress discrimination on various grounds in the provision of HIV prevention goods, services and information?
- Do the measures against discrimination adequately protect young people, women and girls, people living with disabilities, indigenous populations and key populations? If not, what actions and steps is the government taking to ensure non-discrimination in the context of efforts to scale up HIV services?
- Does government policy, including any Fast-Track plan, integrate a commitment to ensure that people can seek and receive HIV prevention services without discrimination?
- Are there adequate measures to ensure that health personnel and others involved in delivering HIV prevention services (e.g. community and outreach workers) are adequately trained about HIV and human rights?
- Does the training address the requirement of non-discrimination and the rights of all people—including young people, women and girls, people living with disabilities, indigenous populations, prisoners, and key populations—to have access to HIV prevention services?
- Do institutions providing health services have a commitment to ensure that people can seek and receive HIV prevention services without discrimination?

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<sup>22</sup> For more information, see UNAIDS, Report of the International Task Team on HIV-related travel restrictions: findings and recommendations (Geneva: UNAIDS; 2009) (available from [http://data.unaids.org/pub/Report/2009/jc1715\\_report\\_inter\\_task\\_team\\_hiv\\_en.pdf](http://data.unaids.org/pub/Report/2009/jc1715_report_inter_task_team_hiv_en.pdf)).

- Is this commitment to non-discrimination reflected in their policies?
- Does the institution have a patient charter of rights (or similar document) that specifically prohibits discrimination?
- What measures exist to ensure that there is no discrimination in the delivery of HIV prevention services?

### **Ensuring the quality of HIV prevention services**

- What measures are in place to ensure the quality of HIV prevention commodities that are being provided (e.g. male and female condoms and lubricants, injection equipment, and medicines used for PrEP, PEP or the treatment of other STIs) or of medical devices that are being used (such as those for VMMC)?
- Do these measures include establishing regulatory standards and bodies to ensure quality assurance of HIV prevention commodities and devices?
- Are there mechanisms to report and address challenges related to HIV prevention commodities and services that are of poor quality?
- Is there adequate training for health workers and other personnel (e.g. community and outreach workers) to ensure that they deliver evidence-informed and rights-based HIV prevention services?
- Does the training for health-care providers and other personnel (e.g. community and outreach workers) cover respecting and protecting human rights in the delivery of HIV prevention services (e.g. non-discrimination and maintaining confidentiality)?
- What measures—including review mechanisms that involve the input of people living with HIV and of other key populations—are in place or being implemented to ensure that HIV prevention materials and initiatives are crafted so as to avoid unintentionally stigmatizing these populations and communities and fueling discrimination or other human rights violations against them?

### **Privacy and confidentiality**

- Does any law or policy (including any Fast-Track plan) protect the right to privacy by guaranteeing the confidentiality of personal health information (including HIV status)?
- Does the protection of confidentiality apply to all health workers and other personnel (e.g. community and outreach workers) who may obtain such information about a person in the course of delivering HIV prevention services?
- Does any law or policy provide for exceptions to the protection of the confidentiality of personal health information (including HIV status)? Are those exceptions in compliance with human rights standards?<sup>23</sup>

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<sup>23</sup> Any limits to the protection of the right to privacy must be set out clearly in the law, and they cannot be arbitrary, unreasonable or imposed in a discriminatory manner. Furthermore, even if disclosure of a person's HIV test result may be allowed, privacy must still be protected to the greatest extent possible. Only the least invasive means possible of achieving a legitimate purpose is allowed.

- Do institutions that provide HIV prevention services have their own policies in place that guarantee the confidentiality of personal health information?
  - Do such policies explicitly prohibit the disclosure of a person's health information without the consent of that person?
  - What measures are in place to ensure discipline should this confidentiality be breached?
- Does the delivery of HIV prevention programmes ensure respect for, and protection of, the right to privacy in practice? In particular
  - Does the physical layout of the setting—such as the physician's office, health clinic, pharmacy or infirmary—ensure information can be communicated privately?
  - Is personal health information (whether paper-based or electronic) stored in ways that protect privacy by ensuring (a) only authorized health personnel have access to it (e.g. via physically restricted access or adequate password protection), and (b) that it cannot be seen by others (e.g. on the exterior of patient files or on a screen)?
  - Are there measures in place to ensure that personnel do not access, remove, use or disclose the personal health information of patients receiving the service?
  - Are those measures in line with human rights standards and recommendations?
  - Do the measures cover efforts to prevent and redress HIV-related breaches of confidentiality?
- If an HIV prevention service (such as STI testing and treatment, prescription of opioid substitution therapy, or use of antiretroviral medicines for PrEP and PEP ) includes follow-up or tracing efforts outside of a health facility, what policies and procedures are in place to do the following:
  - Ensure that a person is aware of this and gives informed consent to such follow-up before proceeding with the service?
  - Protect the privacy of a patient by keeping their health information (including HIV status) confidential in the course of tracing efforts?

### **Respect for personal dignity and autonomy**

- Do women face requirements in law or practice that limit their independent access to HIV prevention services, including spousal or partner consent or a requirement to notify a spouse or other party? If so, what steps is the government taking to address any such barrier to services for women?
- Do adolescents and young people face requirements in law or practice that limit their independent access to HIV prevention services, including parental or guardian consent or a requirement to notify parents, guardians or other parties?

- At what age are adolescents and young people recognized as being able to make independent decisions about their own health? Are mature minors recognized in law or practice as being able to make their own decisions about the receipt of health-care services?

### **Meaningful participation and accountability**

- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous populations and key populations involved in meaningful ways in any design, target setting, prioritization, delivery or monitoring of a national plan for scaling up HIV prevention policies and services? What forms does such participation take?
- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous populations and key populations engaged in the delivery of HIV prevention services, including through community-led programmes and other community delivery systems or approaches that are adequately funded and resourced?
- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous populations and key populations involved in mechanisms and efforts to monitor and evaluate the implementation of HIV prevention services and address challenges resulting from implementation?

## Checklist 2: HIV testing services and human rights

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For purposes of this checklist, HIV testing services are anchored in the “5Cs” recommended by WHO and UNAIDS (consent, confidentiality, counselling, correct results and connection), and the term refers to the full range of services that should be provided together with HIV testing. Those services include the following:

- counselling (pre-test information and post-test counselling);
  - linking people to appropriate HIV prevention, treatment and care services, along with other clinical and support services; and
  - coordinating laboratory services to support quality assurance and the delivery of correct results (23).
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### Availability, accessibility and acceptability of HIV testing

- Does the government have a national plan or programme for scaling up HIV testing services? Has it been fully budgeted, and have funding sources been identified (including international sources, if necessary)?
- Does the scale-up plan ensure that HIV testing services are available and equitably distributed across the country, based on available data about the geographic distribution of HIV prevalence, incidence, and the populations most affected by the epidemic?
- Does the plan include the most appropriate HIV testing options and approaches to address the needs of specific populations, including women and girls, adolescents and young people, indigenous communities, people living with disabilities, people who inject drugs, sex workers, men who have sex with men, transgender people and prisoners?
- What measures are being taken by the government and other stakeholders to ensure the availability, accessibility and acceptability of HIV testing services for all population groups, including young people, women and girls, people living with disabilities, indigenous populations and key populations?
- What measures are in place or are being taken to ensure the availability, accessibility and acceptability of HIV testing services for all populations in need, including young people, women and girls, people living with disabilities, indigenous populations and key populations? Important questions to consider include the following:
  - What steps is the government taking to ensure the adequate distribution of a sufficient number of facilities, programmes, and adequately trained and paid health workers and other community workers in order to deliver HIV testing services that are commensurate with the local need in settings across the country?

- Is HIV testing available for free? If payment of a fee is required for HIV testing services, what measures are in place to ensure that it do not constitute a barrier to people or households without adequate resources to pay such fees?
- What measures are in place to prevent and effectively respond to stock-outs of HIV testing commodities?
- What measures are being taken to improve awareness, knowledge and understanding of HIV, HIV testing options, and the rights of people to seek and receive HIV testing services?
- Are HIV testing services available to adolescents and young people?
- Is information about testing options made available to them in ways that are understandable?
- Are mature minors able to get tested for HIV without parental or guardian consent or notification, and are adolescents and young people without parents or guardians able to get tested?
- Are women able to give independent consent and make other independent decisions regarding HIV testing without barriers (such as requiring spousal or partner consent or notifying a spouse, partner or other party)?
- Is there outreach—including focused outreach to all the populations in need, such as young people, women and girls, people living with disabilities, indigenous communities and key populations—that provides accessible information about HIV testing options and how to gain access to them?
- Are efforts being made to remove physical and other access barriers to HIV testing services for people living with disabilities?
- Do people in prison (or those otherwise detained by the state) have access to quality, voluntary and confidential HIV testing services?
- Are migrants to the country (or those already within it) able to access HIV testing services on the same basis as nationals of the country?
- What restrictions, if any, apply and to which categories of migrants are they applied? Are those restrictions in line with human rights standards and public health recommendations?<sup>24</sup>
- Is access to HIV testing appropriately integrated in antenatal care services and programmes for tuberculosis and sexually transmitted infection?
- Is the government taking steps to end punitive laws, policies and practices against key populations that hinder their access to HIV testing services? This should include laws

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<sup>24</sup> Any limits to the protection of the right to privacy must be set out clearly in the law, and they cannot be arbitrary, unreasonable or imposed in a discriminatory manner. Furthermore, even if disclosure of a person's HIV test result may be allowed, privacy must still be protected to the greatest extent possible. Only the least invasive means possible of achieving a legitimate purpose is allowed.

that criminalize gay men and other men who have sex with men, transgender people, and sex workers (and their clients and workplaces). It also would include laws that criminalize the possession of substances for personal use, or those that allow for the involuntary detention of sex workers or people who use drugs (in so-called “rehab” centres or drug detention centres).

### **Equality and non-discrimination in HIV testing services**

- Are there adequate measures in law to prevent and redress discrimination on various grounds in the provision of health care (including HIV testing)?
- Do these measures against discrimination adequately protect young people, women and girls, people living with disabilities, indigenous people and key populations in the context of seeking and receiving HIV testing? If not, what actions and steps is the government taking to ensure non-discrimination in the context of efforts to scale up HIV services?
- Does government policy, including any Fast-Track plan, integrate a commitment to ensure that people can seek and receive HIV testing services without discrimination?
- What measures does the government take to ensure that health personnel are adequately trained about HIV and human rights, including the requirement of non-discrimination and the rights of all people to access HIV testing services (including young people, women and girls, people living with disabilities, indigenous people and key populations)?
- Are there adequate measures to ensure that health personnel and others involved in delivering HIV prevention services (e.g. community and outreach workers) are adequately trained about HIV and human rights, including in the context of HIV testing?
- Does the training for health personnel include the requirement of non-discrimination and the rights of all people—including young people, women and girls, people living with disabilities, indigenous people and key populations—to access HIV testing services?
  - Is this commitment to non-discrimination reflected in their policies?
  - Does the institution have a patient charter of rights or similar document that specifically prohibits discrimination?
  - What measures exist to ensure non-discrimination in the delivery of HIV testing services?

### **Ensuring quality of HIV testing services**

- What measures are in place to ensure that quality HIV testing services are provided?
  - Are health workers and other personnel adequately trained to deliver HIV testing services in accordance with quality standards (such as WHO guidelines)?

- Do these measures ensure that HIV testing policies, procedures and practices respect and protect human rights (e.g. do they ensure informed consent and protect confidentiality)?
- Are there mechanisms to report and address challenges related to HIV testing of poor quality?
- What measures are in place or being taken to ensure the quality of any medical devices (such as HIV test kits, reagents and laboratory equipment) that are being used in HIV testing services?
- What measures are in place or being taken to ensure the quality of laboratory services that perform HIV testing?
- What measures and procedures are in place to prevent and address cases of incorrect HIV diagnoses (whether false positive or false negative results)?

#### **Privacy and confidentiality**

- Does any law or policy (including the Fast-Track plan) protect the right to privacy by generally guaranteeing the confidentiality of personal health information, including whether a person has been tested for HIV and their test result?
- Does the protection of confidentiality apply to all health workers and other parties (such as community and outreach workers) who may obtain information about a person while delivering HIV testing services?
- Does any law or policy provide for exceptions to the protection of the confidentiality of personal health information (including HIV status)? Are those exceptions in compliance with human rights standards?<sup>25</sup>
- Do institutions providing HIV testing services have their own policies in place that guarantee the confidentiality of personal health information?
  - Do such policies explicitly prohibit the disclosure of a person's health information without the consent of that person?
  - What measures are in place to ensure discipline should this confidentiality be breached?
- Does the delivery of HIV testing services ensure the respect and protection of the right to privacy in practice? In particular:
  - Does the physical layout of the setting—such as the physician's office, health clinic, pharmacy or infirmary—ensure information can be communicated privately?
  - Is personal health information (whether paper-based or electronic) stored in ways that protect privacy by ensuring (a) only authorized health personnel have access to

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<sup>25</sup> Any limits to the protection of the right to privacy must be set out clearly in the law, and it cannot be arbitrary, unreasonable or imposed in a discriminatory manner. Furthermore, even if disclosure of a person's HIV test result may be allowed, privacy must still be protected to the greatest extent possible. Only the least invasive means possible of achieving a legitimate purpose is allowed.

it (e.g. via physically restricted access and adequate password protection), and (b) it cannot be seen by others (e.g. on the exterior of patient files or on a screen)?

- Are there measures in place to ensure personnel do not access, remove, use or disclose the personal health information of patients receiving services?
- Do the measures cover efforts to prevent and redress breaches of confidentiality?
- Do workers providing HIV testing services ensure they don't discuss individual patient information in front of or within hearing distance of others in the facility, or while outside the facility?
- If an HIV testing service includes follow-up or tracing efforts outside of a health facility, what policies and procedures are in place to do the following?
  - Ensure that a person is aware of this and gives informed consent to such follow-up before getting tested?
  - Protect the privacy of a patient by keeping their health information (including HIV status) confidential in the course of tracing efforts?

### **Respect for personal dignity and autonomy**

- What measures are in place to prohibit mandatory HIV testing and to ensure informed consent to HIV testing?
- Do women face requirements in law or practice that limit their independent access to HIV testing services, including spousal consent or a requirement to notify a spouse or other party? If so, what steps is the government taking to address any such barrier to services for women?
- Do adolescents and young people face requirements in law or practice that limit their independent access to HIV testing services, including parental or guardian consent or a requirement to notify parents, guardians or other parties?
- At what age are young people and adolescents able to make independent decisions about their own health, including getting tested for HIV?
- Are mature minors recognized in law or practice as being able to make their own decisions about HIV testing?
- Does the law provide that any medical programme, including HIV testing, may be done only with the specific, voluntary and informed consent of a person?
- Is the requirement for informed consent reflected in other government policy or the policies of institutions or organizations providing HIV testing?
- Are there regulatory standards for health workers and other testing providers that feature clear guidelines for respecting and protecting human rights, and that contain measures for discipline if those standards are not met (such as testing occurring without informed consent or confidentiality being breached)?

- What measures are being taken by government or service providers to ensure that health workers are aware of and respect patient autonomy when making informed decisions about whether or not to be tested for HIV?
- In cases where people may lack or have limited mental capacity for making informed decisions about HIV testing, does law or policy require the following? Are these steps being taken in practice?
  - Are people supported in making their informed wishes best known?
  - Is it ensured that any substitute decision-maker is acting in the best interests of those people in a way that is consistent with the person's informed wishes to the maximum extent possible?
- Are home testing and self-tests available options in the country? If yes, what measures have been taken to avoid the inappropriate use of home testing and self-testing (such as their use to test someone without their consent) and to ensure appropriate links to treatment, care and support services?

#### **Meaningful participation and accountability**

- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous populations and key populations involved in meaningful ways in the design, delivery or monitoring of a national plan for scaling up HIV testing, HIV testing policies, and related services? What forms does such involvement take?
- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous communities and key populations engaged in the delivery of HIV testing services, including through community-led programmes and other community delivery systems or approaches that are adequately funded and resourced?
- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous communities and key populations involved in mechanisms and efforts to monitor and evaluate the implementation of HIV testing services and to address challenges resulting from implementation?

### Checklist 3: HIV treatment services and human rights

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For purposes of this checklist, HIV treatment and treatment services mean the following (as appropriate in the context):

- Treatment information.
  - Antiretrovirals and other medicines.
  - Necessary medical devices.
  - Diagnostic tools needed for monitoring and guiding ongoing treatment.
  - Related health services, goods and information.
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#### Availability, accessibility and acceptability of HIV treatment

- Does the government have a national plan or programme for scaling up HIV treatment to reach the Fast-Track Targets? Has the plan been fully budgeted, and have funding sources been identified (including international sources, if necessary)?
- Do plans and measures to increase access to HIV treatment include efforts to take advantage of the flexibilities available under international intellectual property law in order to encourage competition and promote greater access to affordably priced medicines and other health technologies?
- Do plans and measures to increase access to HIV treatment include efforts to address anti-competitive practices and regulate the prices of medicines in order to prevent excessive pricing and improve affordability?
- Do government plans to accelerate access to HIV treatment include ensuring coverage of all HIV medicines listed for the treatment of adults and children on the most recent World Health Organization (WHO) Model List of Essential Medicines?<sup>26</sup> If not, what steps is the government taking to achieve such coverage for these medicines?
- Does the scale-up plan ensure that HIV treatment is available and equitably distributed across the country in accordance with available data about the geographic distribution of diagnosed HIV cases, AIDS-related illness and deaths, and populations most affected by the HIV epidemic? What measures are being taken by the government and other stakeholders to address inequitable geographic and population access (including for key populations)?

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<sup>26</sup> The list can be found online at <http://www.who.int/medicines/publications/essentialmedicines/en/>.

- What measures are in place or are being taken to ensure availability, accessibility and acceptability of HIV prevention services for all population groups, including women and girls, adolescents and young people, indigenous communities, people living with disabilities, people who inject drugs, sex workers, men who have sex with men, transgender people and prisoners? Important questions to consider include the following:
  - What steps is the government taking to ensure the equitable distribution of a sufficient number of facilities, programmes, and adequately trained and paid health workers and community workers in order to deliver HIV treatment that is commensurate with the local need in settings throughout the country?
  - Is treatment available for free? If payment of any fee is required for HIV treatment or related services, what measures are in place to ensure that these do not constitute a barrier to people or households without resources to pay such fees?
  - What measures are in place to prevent and effectively respond to stock-outs of HIV treatment commodities?
  - What measures are being taken to improve awareness, knowledge and understanding of HIV treatment, treatment options, and the rights people have in seeking and receiving HIV treatment (i.e. treatment and human rights literacy)?
  - Are safe, effective, and practicable paediatric formulations available to treat infants, children, adolescents and young people living with HIV?
  - Is information about such treatment and how to administer it made available to them and their caregivers in ways that are understandable?
  - Are mature minors able to get access to HIV treatment without parental or guardian consent, and are adolescents and young people without parents or guardians able to get access to treatment?
  - Are women able to give independent consent to treatment and make other decisions on their health without barriers such as spousal and partner consent or a requirement to notify a spouse or other party?
  - Is there outreach—including focused outreach to all the populations in need, such as young people, women and girls, people living with disabilities, indigenous communities and key populations—that provides accessible information about available HIV treatment options and how to gain access to them?
  - Do people in prison or those otherwise detained by the state have access to HIV treatment that is at least equivalent to that available to people outside of prison?
  - Are migrants to country (or those already within it) able to access HIV treatment and related health services on the same basis as nationals of the country? What restrictions, if any, apply and to which categories of migrants are they applied?

Are those restrictions in line with human rights standards and public health recommendations?<sup>27</sup>

- Are people who use drugs able to access HIV treatment without discrimination (including prejudicial assumptions that their use of other drugs means they will not adhere to or benefit from HIV treatment)?
- For people who may be dependent on other drugs, is HIV treatment coordinated with available voluntary access to other health services that can promote and protect their health (i.e. drug dependence treatment)? Does this include support with adhering to HIV treatment?
- Is the government taking steps to end punitive laws, policies and practices against key populations that hinder their access to HIV treatment? This should include laws that criminalize gay men and other men who have sex with men, transgender people, or sex workers (and their clients and workplaces). It also would include laws that criminalize the possession of substances for personal use, or those that allow for the involuntary detention of sex workers or people who use drugs (in so-called “rehab” centres or drug detention centres).
- To what extent is HIV treatment and care incorporated into other health services to provide reproductive health, maternal health and child health? Does this include any of the following?
  - Access to HIV testing as part of prenatal care?
  - Access to antiretroviral medicines and other programmes to prevent or reduce the risk of mother-to-child transmission during pregnancy and labour?
  - Access to antiretroviral therapy immediately upon delivery for infants born to HIV-positive mothers, continuing unless (or until) it can be determined that a child is HIV-negative?
  - Ongoing access to antiretroviral medicines for HIV-positive mothers?
  - Access to information, tools and support services regarding the best available options for feeding infants and children, whether through breastfeeding or formula feeding, depending on the mother’s circumstances?
- What steps are needed to ensure or improve access to safe formula and potable water to support women with avoiding breastfeeding if they would prefer to do so, thereby eliminating any risk of HIV transmission?

### **Equality and non-discrimination in treatment services**

- Are there adequate measures in law to prevent and redress discrimination on various grounds in the provision of HIV treatment?

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<sup>27</sup> For more information, see UNAIDS, Report of the International Task Team on HIV-related travel restrictions: findings and recommendations (Geneva: UNAIDS; 2009) (available from [http://data.unaids.org/pub/Report/2009/jc1715\\_report\\_inter\\_task\\_team\\_hiv\\_en.pdf](http://data.unaids.org/pub/Report/2009/jc1715_report_inter_task_team_hiv_en.pdf)).

- Do these measures against discrimination adequately protect the ability of women and girls, adolescents and young people, indigenous people and other key populations to access HIV treatment? If not, what actions and steps is the government taking to ensure non-discrimination in the context of efforts to scale up HIV treatment services?
- Does government policy, including any Fast-Track plan, integrate a commitment to ensure that people can seek and receive HIV treatment without discrimination?
- Are there adequate measures to ensure that health personnel and others involved in delivering HIV treatment (e.g. community and outreach workers) are adequately trained about HIV and human rights?
- Does training about HIV and health rights cover the requirement of non-discrimination and the rights of all people to access HIV treatment, including young people, women and girls, people living with disabilities, indigenous people and key populations?
- Do institutions providing HIV treatment have a commitment to ensure that people can seek and receive HIV prevention services without discrimination?
  - Is this commitment to non-discrimination reflected in their policies?
  - Does the institution have a patient charter of rights or similar document that specifically prohibits discrimination?
  - What measures exist to ensure the respect of non-discrimination in delivering HIV treatment?

### **Ensuring quality of HIV treatment**

- What measures are in place or are being taken to ensure that any medicines and medical devices being used to deliver HIV treatment are safe, effective and quality-assured?
  - Do these measures include establishing regulatory standards and bodies to ensure quality assurance of HIV medicines and related devices?
  - Are there mechanisms to report and address challenges relating to medicines and related devices of poor quality?
- What measures are available and being taken to address substandard or falsified medicines, or the promotion of unscientific substances or methods as treatment for HIV infection?
- Are different antiretroviral therapy regimens available and accessible for use in order to address drug resistance? Does this include, at a minimum, those using medicines listed on the most recent WHO Model List of Essential Medicines?<sup>28</sup>

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<sup>28</sup> The list can be found online at <http://www.who.int/medicines/publications/essentialmedicines/en/>.

- Is there adequate training for health-care providers and other personnel (e.g. community and outreach workers) on respecting and protecting human rights in the delivery of HIV treatment, such as the right to non-discrimination and confidentiality?

### **Privacy and confidentiality**

- Does any law or policy (including the Fast-Track plan) protect the right to privacy by generally guaranteeing the confidentiality of personal health information, including whether a person is receiving HIV treatment and the specific treatment they are receiving?
- Does the protection of confidentiality apply to all health workers and others who may obtain such information about a person in the course of delivering HIV treatment (e.g. outreach workers or persons administering coverage under any public or private health insurance plan)?
- Does any law or policy provide for exceptions to the protection of the confidentiality of personal health information, including HIV status? Are those exceptions in compliance with human rights standards?<sup>29</sup>
- Do institutions providing HIV treatment have their own policies in place guaranteeing the confidentiality of personal health information? Do such policies explicitly prohibit the disclosure of a person's health information to others without the consent of that person? What measures are in place to punish breach of confidentiality?
- Does the delivery of HIV treatment ensure the respect and protection of the right to privacy in practice? In particular:
  - Does the physical layout of the setting—such as a physician's office, health clinic, pharmacy or infirmary—ensure information can be communicated privately?
  - Is personal health information (whether paper-based or electronic) stored in ways that protect privacy by ensuring (a) only authorized health personnel have access to it (e.g. via physically restricted access and adequate password protection) and (b) it cannot be seen by others (e.g. on the exterior of patient files or on a screen)?
  - Are there measures in place to ensure that personnel do not access, remove, use or disclose the personal health information of patients receiving treatment?
  - Are those measures in line with human rights standards and recommendations?
  - Do workers providing treatment services ensure they do not discuss individual patient information in front of or within the hearing of other patients in the facility, or while outside of it?
- If an HIV treatment programme includes treatment follow-up efforts outside of a health facility, what policies and procedures are in place to do the following:

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<sup>29</sup> Any limits to the protection of the right to privacy must be set out clearly in the law, and they cannot be arbitrary, unreasonable or imposed in a discriminatory manner. Furthermore, even if disclosure of a person's HIV test result may be allowed, privacy must still be protected to the greatest extent possible. Only the least invasive means possible of achieving a legitimate purpose is allowed.

- Ensure that a patient is aware of this and gives informed consent to such follow-up before starting treatment?
- Protect the privacy of a patient by keeping their health information confidential in the course of making those efforts?
- Ensure those protections of privacy are in line with human rights standards and recommendations?

### **Respect for personal dignity and autonomy**

- Do women face requirements in law or practice that limit their independent access to HIV treatment, including spousal or partner consent or a requirement to notify a spouse, partner or other party? If so, what steps is the government taking to address any barriers to services for women?
- Do adolescents and young people face requirements in law or in practice that limit their independent access to HIV treatment, including parental or guardian consent or a requirement to notify parents, guardians, or other parties?
- At what age are adolescents and young people free to make their own medical decisions, including those regarding HIV treatment? Are mature minors recognized in law or practice as able to make their own decisions about HIV treatment?
- Does the law provide that any medical programme, including prescribing or continuing HIV treatment, may only be done with the voluntary, informed consent of a person?
- Is this requirement for informed consent reflected in other government policy or the policies of institutions or organizations providing HIV treatment?
- What measures are being taken by government or service providers to ensure that health workers are aware of, and respect, patient autonomy in making their own informed decisions about whether or not to start or continue HIV treatment?
- In cases where people may lack or have limited mental capacity for making informed decisions about HIV testing, does law or policy require the following? Are these steps being taken in practice?
  - Are people supported in making their informed wishes best known?
  - Is it ensured that any substitute decision-maker is acting in the best interests of those people in a way that is consistent with the person's informed wishes to the maximum extent possible?

### **Meaningful participation and accountability**

- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous communities and key populations involved in meaningful ways in the design, delivery or monitoring of a national HIV treatment plan and HIV treatment policies and services? What forms does such involvement take?
- Are people living with HIV and other members of key populations engaged in the delivery of HIV treatment, including through community-led programmes and other community delivery systems or approaches that are adequately funded and resourced?
- Are people living with HIV, young people, women and girls, people living with disabilities, indigenous communities and key populations involved in mechanisms and efforts to monitor and evaluate the implementation of HIV treatment and to address challenges resulting from implementation?

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