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GUIDANCE

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# Rights-based monitoring and evaluation of national HIV responses



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# Introduction

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## Human rights and the HIV response

Human rights are universal legal guarantees that protect individuals and groups against actions and omissions that interfere with fundamental freedoms, entitlements and human dignity (1). The Sustainable Development Goals (SDGs) feature a strong equity focus and a rights-based approach, putting non-discrimination and equality at the heart of sustainable development (2). Several of the SDG targets are relevant for a rights-based response to HIV, including SDG 3 (“Ensure healthy lives and promote well-being for all at all ages”), SDG 5 (“Achieve gender equality and empower all women and girls”), SDG 10 (“Reduce inequality within and among countries”) and SDG 16 (“Promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels”).

As recognized by all United Nations (UN) Member States in the General Assembly resolutions on HIV, the realization of human rights is an essential element of the HIV response.<sup>1</sup> It has long been recognized that access to human rights is an essential element to a successful HIV response, and that violations of human rights, including acts of discrimination, are major barriers to effective national responses to HIV. Through the 2016 Political Declaration on Ending AIDS, Member States recommitted to protecting the human rights of key and vulnerable populations in the context of HIV.

Many of the commitments within the 2016 Political Declaration on Ending AIDS relate directly to human rights and gender equality. The Declaration calls for eliminating gender inequalities and ending all forms of violence and discrimination against women and girls, people living with HIV and key populations. This includes HIV-related stigma and discrimination in health-care settings. The Declaration also focuses on empowering people living with, at risk of and affected by HIV to know their rights and to access justice and legal services to prevent and challenge violations of human rights. Other commitments in the Declaration require rights-based approaches in order to be effective.

The 2016 Political Declaration on Ending AIDS was endorsed and supported by global leaders, as was the requirement to report on national progress towards agreed upon and evolving targets via the Global AIDS Monitoring (GAM) framework. Global reporting requirements have evolved over time to include quantitative indicators of HIV-related discriminatory attitudes, discrimination experienced by people living with HIV in health-care settings and intimate partner violence. The GAM also includes questions on the legal and policy environment within the National Commitments and Policy Instrument (NCPI), which is composed of two parts: Part A is completed by national authorities, and Part B is completed by nongovernmental partners, including civil society (3).

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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 Ending AIDS.

In addition, funding agencies have increasingly aligned their funding guidelines and tools with human-rights related commitments made by countries. They have done this by placing increased emphasis on the need to demonstrate attention for human rights issues and the use of a rights-based approach in the national responses of recipients. One clear example is the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund), which committed to a four-year strategy in 2016 that includes protecting and promoting human rights as one of its strategic objectives. To achieve this, the Global Fund will increase efforts to implement and scale up programmes that address human rights barriers, which are the key programmes recommended by UNAIDS for reducing stigma, eliminating discrimination and increasing access to justice in national HIV responses (4).

The UNAIDS guidance document *Fast-Track and human rights* (2017) offers practical advice on why and how efforts to Fast-Track HIV services should be grounded in human rights principles and approaches, and why such efforts and responses should include the seven key programmes at a scale that can effect change (5). This guidance—*Rights-based monitoring and evaluation of national HIV responses*—builds upon that advice, elaborating on rights-based monitoring and evaluation of HIV services with the aim to achieve human rights and equity in the AIDS response and to Fast-Track the end of the AIDS epidemic as a public health threat.

## Objectives of this guidance

The objective of this guidance is to provide an overview of the key components of a framework for monitoring human rights programmes and protections in the context of HIV, and how that framework contributes to the broader monitoring of the HIV response. In particular, the guidance will provide information on the following:

1. How to monitor and evaluate key programmes designed to address HIV-related human rights commitments.
2. How to apply rights-based or rights-sensitive approaches to monitoring and evaluation of HIV programmes and activities.

## Guidance structure

The first section of this document—“Components of a human rights-sensitive monitoring and evaluation framework for the HIV response”—provides a brief overview of monitoring and evaluation principles and practices as they relate to human rights and HIV. It includes information on: (a) terminology; (b) indicators; (c) available sources for existing and validated indicators to help monitor interventions related to human rights and HIV; and (d) some principles and best practices for the design of a monitoring and evaluation framework for HIV and human rights programmes, and for the selection of indicators.

The first section also addresses the following questions:

- ▶ What is a monitoring and evaluation framework?
- ▶ Why do we need a monitoring and evaluation framework for human rights programmes and HIV?
- ▶ What are the baselines, benchmarks and targets related to human rights and HIV?
- ▶ What are possible data sources for monitoring and evaluating human rights programmes and HIV?

- ▶ How are indicators for human rights and the HIV response selected?
- ▶ What are the key components of a rights-based approach to monitoring and evaluation of the HIV response?

The second section of this guidance—“Monitoring and evaluation of the seven key human rights programmes within the national HIV response”—describes a framework for monitoring and evaluation of key programmes to eliminate stigma and discrimination and to increase access to justice. It includes examples of levels of change and the types of indicators that can be used to measure outputs and outcomes.

Finally, the third section—“A rights-based and rights-sensitive approach for monitoring and evaluation of national HIV programmes”—provides guidance for a rights-based and rights-sensitive approach to monitoring and evaluation. The aim of this section is to provide guidance on how to ensure that monitoring and evaluation systems themselves do no harm, and that they are implemented using human rights principles. This section addresses the following questions:

- ▶ How do we apply rights-based and rights-sensitive approaches in monitoring and evaluation planning?
- ▶ How do we apply rights-based and rights-sensitive approaches in data collection and storage?
- ▶ How do we apply rights-based and rights-sensitive approaches in data analysis?
- ▶ How do we apply rights-based and rights-sensitive approaches in data dissemination and use?

# Components of a human rights-sensitive monitoring and evaluation framework for the HIV response

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## What is a monitoring and evaluation framework?

A monitoring and evaluation framework identifies and illustrates: (a) the logic flow from programme inputs, activities, outputs, outcomes and impacts; (b) the indicators that will be used to measure the performance and results of the programme outputs, outcomes and impacts; and (c) how those indicators will be verified (i.e., the source of information for these measurements).

A results framework or a logframe is a management tool used in the design of a programme or project that correlates key strategic elements—including objectives, inputs, outputs, outcomes and impacts—with indicators and the assumptions and risks that may affect the implementation of the programme or project. Logframes are useful for planning, executing and evaluating programmes and projects (6).

## Important terminology in monitoring and evaluation

**Activities:** The actions taken or work performed through which inputs such as funds, technical assistance and other types of resources are mobilized to produce specific outputs (6).

**Data:** Specific quantitative and qualitative information or facts that are collected and analysed (7).

**Evaluation:** The systematic collection of information about the activities, characteristics and outcomes of a specific programme to determine its merit or worth. Evaluation provides credible information for improving programmes, identifying lessons learned and informing decisions about future resource allocation (7). Evaluation aims to investigate the achievement of a programme's results.

**Impacts:** The cumulative effect of programmes on what they ultimately aim to change over a longer period of time. Often, this effect will be a population-level health outcome, such as a change in HIV infection, morbidity and mortality. Impacts are rarely, if ever, attributable to a single programme, but a programme may, with other programmes, contribute to impacts on a population (6).

**Indicator:** A quantitative or qualitative variable that provides a valid and reliable way to measure achievement, assess performance or reflect change connected to an activity, project or programme (6).

**Inputs:** Used to perform activities, an input is a resource used in a programme, such as financial and human resources from a variety of sources. Also can include curricula, materials and other resources. Inputs can be outputs from other activities (6).

**Monitoring:** Routine tracking and reporting of priority information about a project or programme, such as its inputs, outputs, outcomes and impacts (7). Monitoring activities measure progress towards achieving programme objectives.

**Outcomes:** The intermediate changes that a programme effects on target audiences or populations, such as change in knowledge, attitudes, beliefs, skills, behaviours, service access, policies and environmental conditions (6).

**Outputs:** The immediate results of programme activities. This relates to the direct products or deliverables of programme activities, such as the number of counselling sessions completed, the number of people reached or the number of materials distributed (6).

**Target:** The specific performance goal tied to an indicator against which actual performance will be compared.

## **Why do we need a monitoring and evaluation framework for human rights programmes in the context of the HIV response?**

In order to effect positive change in the area of advancing human rights (or in any domain), it is crucial that appropriate mechanisms are in place to do the following:

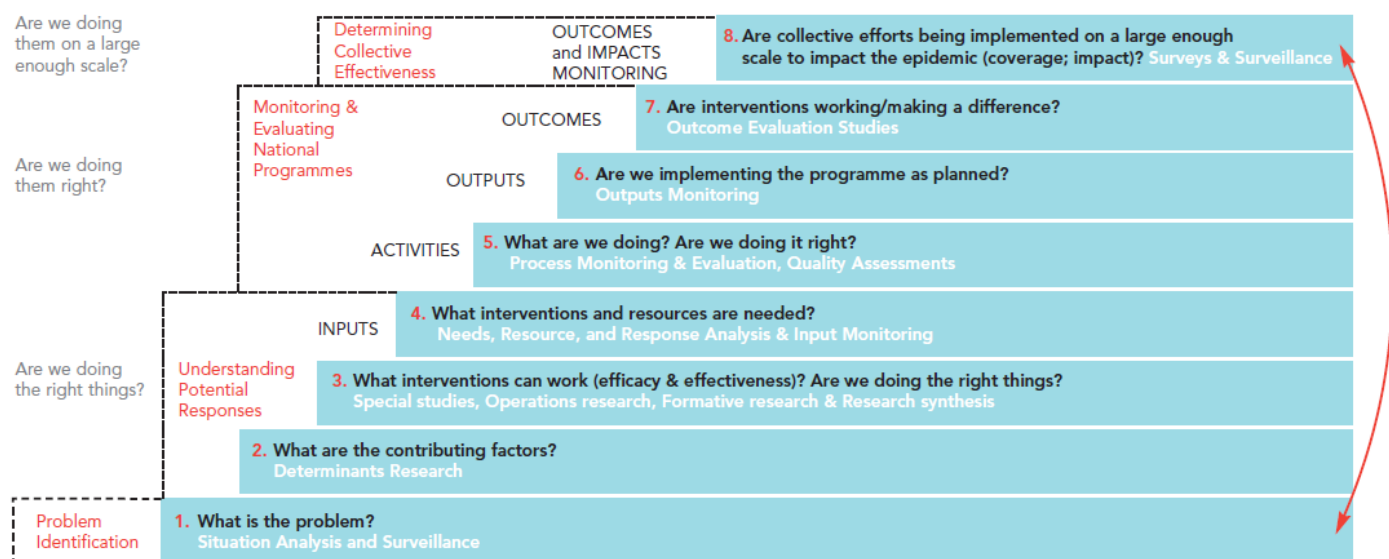
- ▶ Guide the planning, coordination and implementation of the programme.
- ▶ Assess the effectiveness of the programme.
- ▶ Identify areas for programme improvement.
- ▶ Ensure accountability to the people whose lives the programmes aim to improve.

A public health questions approach can be useful to identify pertinent questions that need to be addressed when planning a comprehensive national monitoring and evaluation system. These questions are presented in Figure 1, which also lists the main data collection methods that can be used to answer these questions. Table 1 provides an example of a generic logical framework that is based on the public health questions approach to addressing human rights issues related to the HIV response.



**Figure 1**

A public health questions approach to monitoring and evaluation



Sources: Organizing framework for a functional national HIV monitoring and evaluation system. Geneva: UNAIDS; 2008 ([http://www.unaids.org/sites/default/files/sub\\_landing/files/20080430\\_JC1769\\_Organizing\\_Framework\\_Functional\\_v2\\_en.pdf](http://www.unaids.org/sites/default/files/sub_landing/files/20080430_JC1769_Organizing_Framework_Functional_v2_en.pdf)); Rugg D, Carael M, Boerma T, Novak J. Global advances in monitoring and evaluation of HIV/AIDS: from AIDS case reporting to program improvement. *New Directions for Evaluation*. 2004;103:33-48.

**Table 1**

Generic logical framework showing example programme components that address human rights issues related to the HIV response and potential data sources from a public health questions perspective

Programme logic flow	Assessment and planning	Inputs (Resources)	Activities (Interventions, Services)	Outputs (immediate Effects)	Outcomes (Intermediate Effects)	Impacts (Long term Effects)
<b>Relationship clarifier questions</b>	What's the current situation? Who are the most affected/marginalized rights holders? What are the human rights barriers? Where do we aim to be? What do we need to do?	What resources do we need? Why do we need these inputs? So that we can deliver the following activities.	What do we need to do? Why do we need these activities? So that we can deliver the following outputs.	What will these activities yield? Why do we need these outputs? So that we can deliver the following immediate outcomes.	What are the outcomes of the activities and outputs? Why do we need these outcomes? So that we can have the following impacts.	
<b>Components within logic flow</b>	Situation analysis Response analysis Stakeholder capacity Gaps and needs Resource analysis Collaboration plans	Staff Funds Materials Facilities Supplies	Trainings Services Education Documentation Interventions	Output indicators: # Trained # Legal Literacy Materials Provided # Clients Served # Laws assessed	Outcome indicators: ▶ <b>Provider Behavior</b> ▶ <b>Risk/Resilience Behavior</b> ▶ <b>Service Use</b> ▶ <b>Percentage of cases of human rights violations where redress has been sought/resolved</b> ▶ <b>Clinical Outcomes</b> ▶ <b>Quality of Life</b>	Impact indicators: Social and legal norms, HIV incidence, STI Incidence, AIDS Mortality, Economic impact, Enjoyment of highest attainable standard of health
<b>Data sources</b>	<b>Programme Development</b>	<b>Programme-based Data</b>			<b>Population-based Biological, Behavioral &amp; Social Data</b>	<b>Population-based Biological, Behavioral &amp; Social Data, Modelling</b>

Source: Adapted from Basic terminology and frameworks for monitoring and evaluation. Geneva: UNAIDS; 2008 ([http://www.unaids.org/sites/default/files/sub\\_landing/files/7\\_1-Basic-Terminology-and-Frameworks-MEF.pdf](http://www.unaids.org/sites/default/files/sub_landing/files/7_1-Basic-Terminology-and-Frameworks-MEF.pdf), accessed 18 March 2019).

## What are the baselines, benchmarks and targets related to human rights and HIV?

A **baseline** is a point at the outset of an activity or programme that is used for comparison after that activity or programme has been implemented. It allows us to test if performance is really changing.

A **benchmark** is a point of reference or standard against which performance can be compared or assessed. It can include a value (or values) that has changed over time as progress is made towards the achievement of an ultimate target.

**Targets** are specific performance goals against which actual performance will be compared. They are the objective of a programme or intervention, expressed as a measurable value (that is, the desired value for an indicator at a particular point in time) (6). For human rights programmes, such targets could be derived based on the human rights standards in the core international human rights treaties, or in commitments made in relevant declarations or strategies (8–10). Some areas, such as nondiscrimination, are immediate human rights obligations; this means that the only possible target for them is zero (e.g., zero instances of discrimination experienced for any reason). For other areas related to advancing human rights, progressive realization and non-retrogression could guide target setting efforts.

The global commitments endorsed by Member States in the 2016 Political Declaration on Ending AIDS could guide target setting efforts at the national level and for specific human rights programmes within the national strategic documents on HIV. This includes national strategic plans, Fast-Track or acceleration planning, Global Fund concept notes, and any other relevant policies and plans.

## What are possible data sources for monitoring and evaluating human rights programmes in the context of the HIV response?

Monitoring and evaluation uses multiple types and sources of data, including routine programme (administrative) data, documentation of human rights violations or experiences of clients, public health surveillance data, statistical estimates (modelling), vital statistics and census data, participatory surveys and research studies, and mid-term and end-term evaluations.

A key component of a monitoring and evaluation framework are its indicators, which signal the state of a situation (6). As defined in *Human rights indicators: a guide to measurement and implementation* from the Office of the United Nations High Commissioner for Human Rights (OHCHR), a human rights indicator is “specific information on the state or condition of an object, event, activity or outcome that can be related to human rights norms and standards; that addresses and reflects human rights principles and concerns; and that can be used to assess and monitor the promotion and implementation of human rights” (11).

Indicators can be quantitative or qualitative (6). Quantitative indicators are those that use information in the form of counts, percentages, rankings or indices. This includes data on the time, cost and quantity for activities and their outputs. Qualitative indicators are those that use categorical information—a finite set of non-ordered values (such as a binary “yes/no” variable or some demographic characteristics such as sex) or ordered values (such as scales of the seriousness of violations of law)—or narrative information (such as case studies).

Human rights indicators can also be categorized as fact-based (objective, directly observed and verifiable by multiple observers) or judgement-based (subjective and based on the opinion, perceptions, attitudes and beliefs expressed by individuals). These types of indicators all have their uses and merits. Indicators that are fact-based and quantitative, for example, are more easily used in comparisons over time or across populations, demographic strata or geographic areas. Two important components of a rights-based or rights-sensitive approach to programme implementation and monitoring and evaluation, however, are questions of “how” and “why,” and qualitative approaches are very useful and important for addressing these.

Disaggregated data from other indicators that are not specifically human rights indicators can also be analyzed from a human rights perspective to assess which groups are being marginalized and left behind, and who is facing barriers in the availability, accessibility, acceptability and quality of services. Data that are regularly collected, such as by national statistics offices, could be useful to analyse and assess whether human rights are being respected, protected and promoted within the HIV response, even if the data go beyond the indicators included in the national HIV monitoring and evaluation plan.

Figure 2 shows the categories of indicators that can be used to monitor compliance with human rights standards.

**Figure 2**  
Categories of indicators used for human rights



Source: Human rights indicators: a guide to measurement and implementation. Office of the United Nations High Commissioner for Human Rights; 2012 ([http://www.ohchr.org/Documents/Publications/Human\\_rights\\_indicators\\_en.pdf](http://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf)).

## How should indicators for human rights and HIV be selected or developed?

It is now widely recognized that national governments should integrate human rights programmes and protections into their national HIV responses, and that they should demonstrate progress towards achieving national and global targets that focus on the reduction of HIV infections and deaths from AIDS-related illness and the elimination of stigma and discrimination.

The choice of indicators requires assessment across several criteria. The UNAIDS Indicator Standards provide a tool for use determining if proposed indicators meet a set of internationally agreed standards (12). Where possible, it is recommended to use existing indicators that have been tested rather than developing new indicators, particularly at outcome and impact levels. For output indicators, there may be relevant indicators that can be used as examples, but indicators specific to the programme of interest may need to be developed.

The following series of questions is used in the Indicator Standards to confirm that the essential components are included in an indicator (12).

- ▶ Does the indicator have a clearly stated title and definition?
- ▶ Does the indicator have a clearly stated purpose and rationale?
- ▶ Is the method of measurement for the indicator clearly defined, including the description of the numerator, denominator and calculation (where applicable)?
- ▶ Are the data collection methodology and data collection tools for the indicator data clearly stated?
- ▶ Is the data collection frequency clearly defined?
- ▶ Is any relevant data disaggregation clearly defined?
- ▶ Are there guidelines to interpret and use data from this indicator? For human rights indicators, this would include information on how the indicator measures compliance with human rights standards.
- ▶ What are the strengths and weaknesses of the indicator and the challenges in its use?
- ▶ Are relevant sources of additional information on the indicator cited?
- ▶ Has the indicator been field tested and shown to perform as designed?

There are additional indicator characteristics and methodological properties that can be considered when selecting human rights indicators.<sup>2</sup>

- ▶ SPICED (subjective, participatory, interpreted, cross-checked, empowering, diverse).
- ▶ RIGHTS (relevant and reliable; independent in its data collection methods from the subjects monitored; global and universally meaningful but also amenable to contextualization and disaggregation by prohibited grounds of discrimination; human-rights standards-centric; transparent in its methods, timely and timebound; simple and specific).

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<sup>2</sup> For more details, please see: Human rights indicators: a guide to measurement and implementation, Office of the United Nations High Commissioner for Human Rights; 2012 ([http://www.ohchr.org/Documents/Publications/Human\\_rights\\_indicators\\_en.pdf](http://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf)).

The Indicator Registry provides a comprehensive repository of indicators to track the AIDS epidemic and the national, regional and global responses. This includes indicators to monitor outcomes and impacts of programmes to reduce stigma and eliminate discrimination (such as in health facilities) and programmes to eradicate gender-based violence and intimate partner violence that comply with the indicator standards (13).

Examples of harmonized indicator sets that have been widely used and accepted in national and global monitoring of human rights in the context of HIV are the following:

- ▶ GAM indicators (formerly GARPR, UNGASS). These include indicators under the commitments of the 2016 Political Declaration on Ending AIDS (on eliminating gender inequalities and ending all forms of violence and discrimination against women and girls, people living with HIV and key populations) that measure discriminatory attitudes towards people living with HIV among the general population, discrimination experienced by people living with HIV in health-care settings, and intimate partner violence (3). The GAM also includes the NCPI, which aims to measure progress in the development and implementation of national HIV policies, strategies and laws. The NCPI contains questions that can serve to respond to qualitative and quantitative indicators of the existence of laws and policies that facilitate human rights or pose barriers to their achievement or protection.
- ▶ Set of six indicators on stigma and discrimination in health-care facilities that captures three programmatically actionable drivers of HIV-related stigma and discrimination: (a) fear of HIV infection among health facility staff; (b) stereotypes and prejudices related to people living with HIV or thought to be living with HIV; and (c) the policy and work environment. They also capture the manifestations of those drivers (observed, reported, and secondary stigma and discrimination) (14).

Other sets of indicators that may be applicable include those developed by agencies and initiatives such as the Global Fund and the United States President's Emergency Plan for AIDS Relief (PEPFAR).

Sources of data for relevant indicators include the following:

- ▶ The People Living with HIV Stigma Index, a tool to measure the forms and prevalence of stigma and discrimination experienced by people living with HIV and to document the settings where it occurs (15). The tool is implemented by and among people living with HIV in collaboration with academic institutions, governments, the UN and other partners.
- ▶ The standard questionnaire of the Demographic and Health Surveys includes questions used to construct three indicators that measure a driver and negative manifestations of HIV-related stigma and discrimination among the general population.
- ▶ Additional sources of programme data include administrative records of the Ministry of Health, hospitals, police, prisons and other institutions, or events-based data from national human rights institutions, courts and other legal mechanisms, service providers and nongovernmental organizations.
- ▶ Examples of indicators and questions included in the different data sources mentioned in this section are provided later in this document.

Community monitoring efforts can be an important data source: they recognize that the community is integral to the national response to HIV by actively engaging it in monitoring progress towards national, regional and global commitments. Community monitoring can provide real-time strategic information from the point-of-care to use at the national level on the coverage and quality of policies, services and programmes, and on the perspective of a diverse set of stakeholders. The People Living with HIV Stigma Index is an example of community monitoring.

## **What are the key components of a rights-based approach to monitoring and evaluation of the HIV response?**

A rights-based approach to monitoring and evaluation of the HIV response should consist of the following components:

- ▶ A framework for monitoring and evaluation of the national HIV epidemic and response that integrates human rights.
- ▶ A framework for monitoring and evaluating programmes that are aimed at reducing and eliminating stigma and discrimination related to HIV and at increasing access to justice (described in the section “Monitoring and evaluation of the seven key human rights programmes within the national HIV response”).
- ▶ Use of rights-based and rights-sensitive approaches in the monitoring and evaluation of national HIV programmes (described in the section “A rights-based and rights-sensitive approach for monitoring and evaluation of national HIV programmes”). Doing this ensures that the monitoring and evaluation system itself does no harm, and that it reflects the fundamental principles of participation, transparency, equality, non-discrimination and accountability.

# Monitoring and evaluation of the seven key human rights programmes within the national HIV response

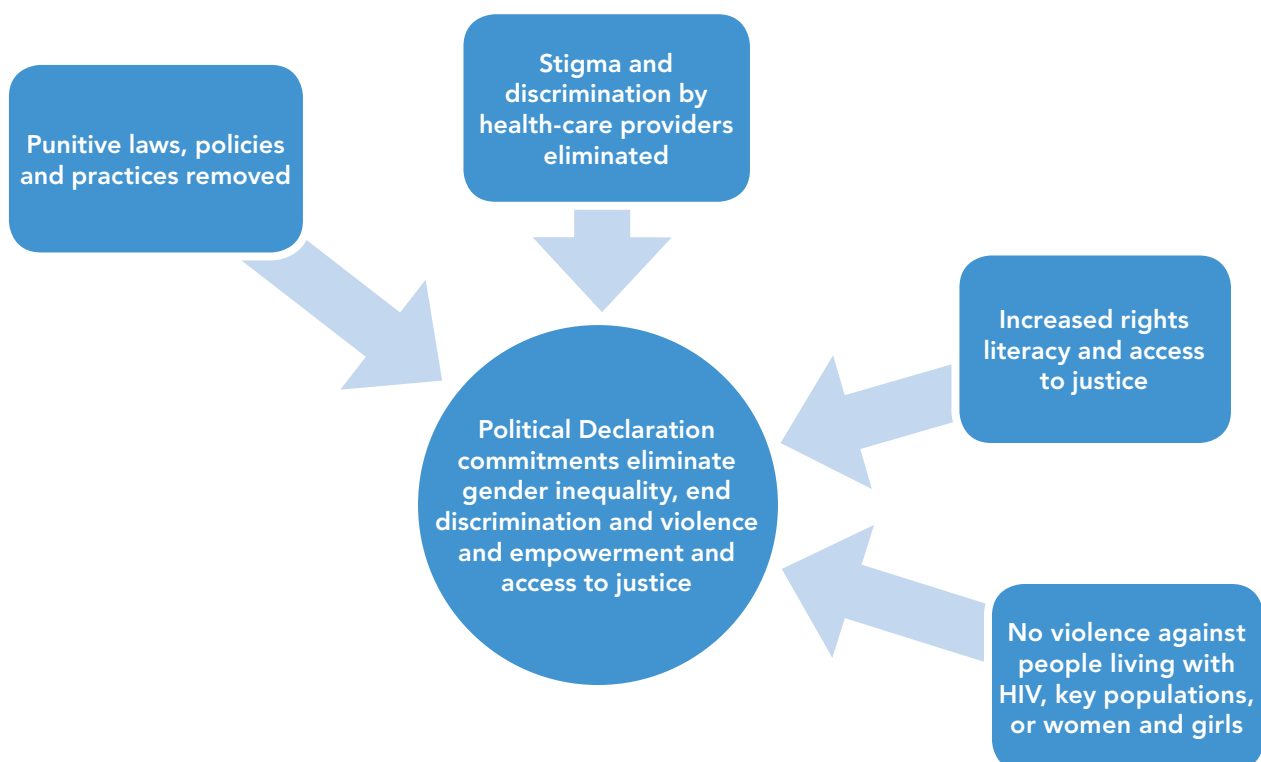
This section provides guidance on the monitoring and evaluation of the seven key programmes recommended by UNAIDS and global partners to reduce stigma and eliminate discrimination and to increase access to justice in national HIV responses (4). These key programs are aligned with the global vision of zero new infections, zero AIDS-related deaths and zero stigma and discrimination (5).

The seven key programmes are complementary: they include broad intervention strategies that reinforce each other and thus are not mutually exclusive. Multiple interventions may contribute to a single outcome indicator, and they may be repeated across programme areas.

Figure 3 shows the conceptual framework that links the objectives and goals of these programmes to the global HIV commitments.

**Figure 3**

Conceptual framework linking human rights programme objectives to global commitments in the 2016 Political Declaration on Ending AIDS



**Table 2**

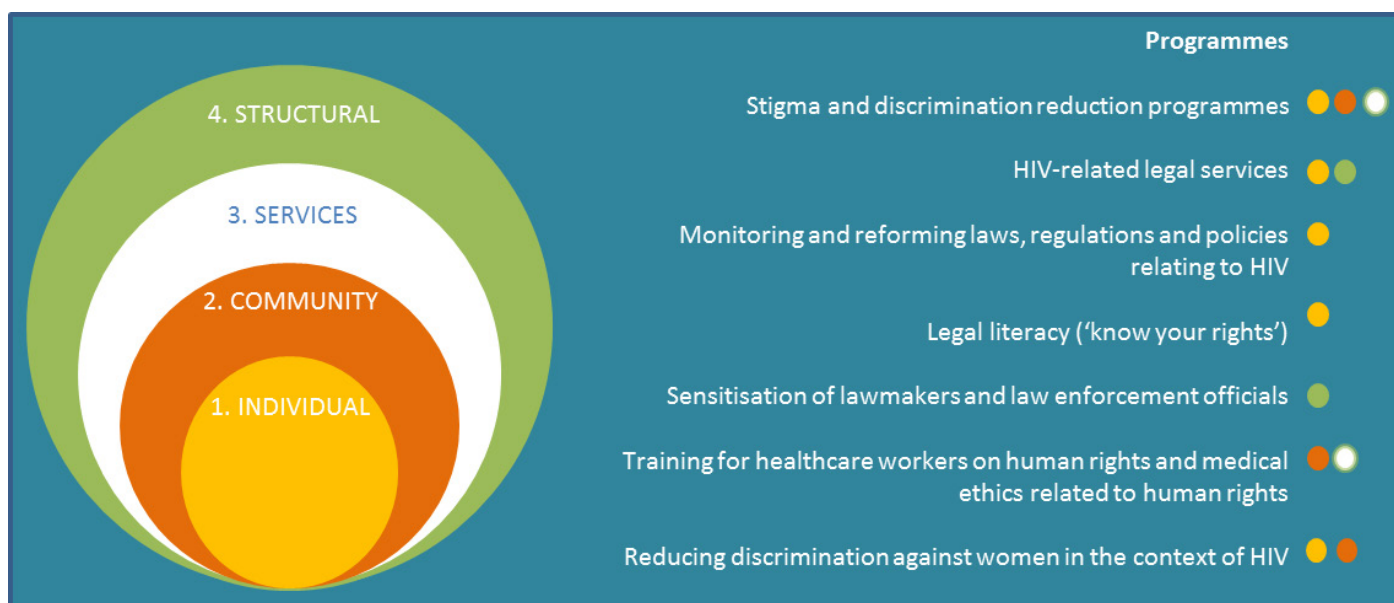
Summary of key human rights programmes to reduce stigma and eliminate discrimination and increase access to justice in the context of the HIV response

The programme	Why is it important?
Stigma and discrimination reduction	Addressing stigma and discrimination can positively influence a range of outcomes that are critical to the HIV response, including behaviours and uptake of HIV services and support services, all of which ultimately influence individual quality of life and HIV incidence and prevalence.
HIV-related legal services	HIV-related legal services can facilitate access to justice and redress in cases of HIV-related discrimination or other human rights violations.
Monitoring and reforming laws, regulations and policies relating to HIV	Laws, regulations and policies relating to HIV can negatively or positively impact a national HIV epidemic and the lives and human rights of those living with and affected by HIV. It is thus essential to monitor and reform laws, regulations and policies so that they protect and promote human rights, and support (rather than hinder) access to HIV and health services.
Legal literacy ("know your rights")	Legal literacy programmes teach those living with or affected by HIV about human rights and the national and local laws relevant to HIV. This knowledge enables them to organize around these rights and laws, to advocate for concrete needs within the context of HIV, and to seek remedies and redress if rights are violated.
Sensitization of lawmakers and law enforcement officials	These programmes seek to inform and sensitize those who make the laws (parliamentarians) and those who enforce them (e.g., Ministers of Interior and Justice, police, prosecutors, judges, lawyers, or traditional and religious leaders) about the important role of the law in the response to HIV.
Training for health-care workers on human rights and medical ethics related to human rights	Human rights and ethics training for health-care providers focuses on: (a) ensuring that health-care providers know about their own human rights to health and non-discrimination, as well as their human rights obligations in the context of HIV; (b) reducing stigmatizing attitudes in health-care settings; and (c) providing health-care providers with the skills and tools necessary to ensure the rights of patients to informed consent, confidentiality, treatment and non-discrimination.
Eliminating discrimination against women in the context of HIV	These programmes address gender inequality and gender-based violence, both as causes and as consequences of HIV infection.

The seven key programmes—which address necessary change at the individual, community, service and structural levels (see Table 2)—are seen as key to achieving universal access to HIV prevention, treatment, care and support. Figure 4 shows the key human rights programmes and the intervention levels that they affect.

**Figure 4**

Key HIV-related human rights programmes and their associated intervention levels



Source: HIV and human rights good practice guide. Hove (UK): International HIV/AIDS Alliance; May 2014 ([https://frontlineaids.org/wp-content/uploads/old\\_site/Alliance\\_GPG-HIV\\_and\\_human\\_rights\\_original.pdf?1407762153](https://frontlineaids.org/wp-content/uploads/old_site/Alliance_GPG-HIV_and_human_rights_original.pdf?1407762153)).



## Reducing stigma and eliminating discrimination

### Why is it important to monitor these programmes?

The consequences of stigma and discrimination are far-reaching. Prejudice directed towards people living with HIV creates a hostile environment that impacts not only on the quality of life of the individuals concerned, but that also has repercussions that go beyond the individual. They greatly reduce incentives to be tested for HIV, or if the test is positive, they decrease the likelihood that people will disclose their status to sexual partners or family, access HIV-related care and treatment, or seek out other forms of support. Stigma and discrimination manifestations can therefore influence a range of outcomes that are critical in the HIV response, including behaviours and uptake of HIV and support services, all of which ultimately influence the quality of life of individuals and HIV incidence and prevalence.

### Examples of activities

Six categories of approaches towards reducing stigma and eliminating discrimination have been described in the research (17).

1. **Information-based approaches.** Examples of this type of approach include documentation of cases of discrimination, information sessions, use of media (including social media), advertising campaigns, entertainment designed to educate and amuse (so-called “edutainment”), integration of nonstigmatizing messages into TV and radio shows, and engagement with religious and community leaders and celebrities.
2. **Skills-building.** Examples include participatory learning sessions to reduce negative attitudes, educational programmes (such as in schools) to explain how HIV is transmitted and clarify prevailing myths about modes of HIV transmission, and peer education programmes for specific segments of the population.
3. **Counselling and support.** Examples include peer mobilization and support developed for and by people living with HIV that is aimed at promoting health, well-being and human rights.
4. **Contact with affected groups.** Examples include community interaction and focus group discussions involving people living with HIV and members of populations that are vulnerable to HIV infection.
5. **Structural approaches.** In the context of HIV-related stigma, structural approaches encompass activities that address underlying power structures that enable stigmatization. Therefore, structural approaches are those aimed at removing, reducing or altering structural factors such as laws that criminalize HIV, hospital or workplace policies that institutionalize discrimination against people living with HIV (e.g., labelling of beds or mandatory HIV testing prior to employment), or a lack of the supplies that allow health-care workers to practice universal precautions. Structural approaches can also involve including non-discrimination as part of

institutional and workplace policies in employment and educational settings, or efforts to ensure that systems and legal support mechanisms are available for people living with HIV to seek justice in instances of discrimination.

6. **Biomedical approaches.** One example is normalizing HIV infection through activities such as opt-out informed consent-based HIV screening within general population settings (e.g., community-wide home-based testing or emergency room testing).

## What to measure?

The chosen monitoring indicators or evaluation methods should take into account the specific domains, target audiences and socio-ecological levels of the implemented interventions or programmes. For example, interventions or programmes can address one or several of the following domains (17).

- ▶ **Drivers** of stigma are individual-level factors that negatively influence the stigmatization process. These drivers include a lack of awareness of stigma and its harmful consequences, fear of HIV infection through casual contact with people living with HIV, fear of economic ramifications or social breakdown due to HIV-positive family and community members, and prejudice towards (and stereotypes about) people living with HIV and key populations at highest risk of HIV infection.
- ▶ **Manifestations** are the immediate results, mostly negative, of stigma being applied to individuals or groups. Some examples include anticipated stigma (fear of experiencing stigma if HIV status becomes known), perceived stigma (perceptions of how people living with HIV are treated in a given context), internalized stigma, shame, experienced or enacted stigma (experiencing stigmatizing behaviours outside the purview of the law), discrimination (experiencing stigmatizing behaviours within the purview of the law), and resilience (ability to overcome threats to health and development after stigma is experienced).
- ▶ **Facilitators** are societal-level factors that influence the stigmatization process. They include protective or punitive laws, availability of grievance redressal systems, awareness of rights, structural barriers at the public policy level, cultural and gender norms, existence of social support for people living with HIV, and power or powerlessness among people living with HIV to resist and overcome the manifestations of stigma.
- ▶ **Intersecting stigmas** are the multiple stigmas that people often face due to HIV status, gender, age, profession, migrant status, drug use, poverty, marital status, sexual and gender orientation, or any other ground.

Possible intervention audiences include youth, health-care workers, teachers, caregivers, family members, community members, journalists, workers/employees, police, community leaders, key populations affected by HIV, and people living with HIV. The prioritization of audiences should be conducted on the basis of existing country-specific or jurisdiction-specific evidence about the groups most affected by stigma and discrimination and the settings where it is most prevalent.

Interventions can be focused on one or multiple socio-ecological levels: (a) individual (knowledge, attitudes and skills); (b) interpersonal (family, friends and social networks); (c) organizational (organizations, social institutions and workplaces); (d) community (cultural values, norms and attitudes); and (e) public policy (national and local laws and policies).

## Examples of output indicators

Examples of some output indicators include the following:

- ▶ Number and coverage of programmes to train and sensitize health-care providers on non-discrimination, confidentiality and informed consent.
- ▶ Number and coverage of programmes to train and sensitize law enforcement officers on the human rights of people living with or affected by HIV, sex workers, gay men and other men who have sex with men, transgender people, and people who inject drugs in the context of HIV.
- ▶ Number and coverage of campaigns at the national and community levels to reduce HIV-related stigma and discrimination among the general population.
- ▶ Number and coverage of programmes at the national and community levels to inform and educate individuals about their rights within the context of HIV.

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Percentage of people with correct knowledge of how HIV is transmitted, disaggregated by age and sex (population-based surveys, integrated behavioural and biological surveillance surveys).
- ▶ Percentage of people reporting fear of HIV transmission through casual contact with people living with HIV (population-based surveys).
- ▶ Percentage of people reporting discriminatory attitudes towards people living with HIV, disaggregated by age and sex (population-based surveys).
- ▶ Percentage of people who report negative individual-level and population-level manifestations of HIV-related stigma (population-based surveys).
- ▶ Percentage of people living with HIV reporting discrimination in community settings, disaggregated by age and sex (People Living with HIV Stigma Index).
- ▶ Percentage of people living with HIV reporting discrimination in health-care settings, disaggregated by age and sex (People Living with HIV Stigma Index).
- ▶ Percentage of key populations reporting discriminatory attitudes towards people living with HIV, disaggregated by age and sex (integrated behavioural and biological surveillance surveys).
- ▶ Percentage of key populations citing fear of stigma as a reason to avoid seeking health care (integrated behavioural and biological surveillance surveys).

- ▶ Percentage of health-care staff reporting observed unjust treatment of patients living with HIV in their facility in the past 12 months (surveys among health-care staff).
- ▶ Percentage of key populations who reported physical violence in the last 12 months because someone believed they are members of a key population group (integrated behavioural and biological surveillance surveys).

## Legal literacy (“know your rights”)

### Why is it important to monitor these programmes?

Legal literacy programmes inform those living with or affected by HIV about their human rights and national and local laws relevant to HIV. This knowledge enables them to organize around these rights and laws and to advocate for concrete needs within the context of HIV. Thus, these programmes focus on both legal and rights knowledge and on strategies regarding how to use this knowledge to improve health and justice. The programmes may also provide information on different legal or human rights fora where one can advocate or seek redress, such as patients’ rights groups, ombudsperson offices and national human rights institutions.

### Examples of activities

Legal literacy programmes can form part of other HIV services (e.g., health care provision, prevention outreach, peer education, support groups or prison health services), or they can be stand-alone programmes involving a variety of activities:

- ▶ Awareness-raising campaigns that provide information about rights and laws related to HIV through media (e.g., TV, radio, print and Internet) and/or at health-care settings (e.g., leaflets and stickers).
- ▶ Community mobilization and education.
- ▶ Community monitoring of human rights violations.
- ▶ Community paralegal support and peer outreach.
- ▶ Telephone hotline service for information about HIV-related rights.

### What to measure?

Interventions or programmes may lead to the following desired changes:

- ▶ Change at the individual level: increased awareness, knowledge, skills, empowerment and participation. Affected populations know their rights and how to enforce them.
- ▶ Change at the community level: actions taken by communities around law and human rights issues.
- ▶ Change at the service level: people are increasingly able to access services without fear of discrimination.

## Examples of output indicators

Examples of some output indicators include the following:

- ▶ Number of persons reached through education sessions about HIV-related rights and laws.
- ▶ Amount of materials on rights and legal literacy distributed.
- ▶ Number of peer outreach sessions conducted.
- ▶ Number of community paralegals.
- ▶ Number of recipients of peer outreach activities.
- ▶ Number of hotline calls received and number of referrals made to legal services.
- ▶ Number of cases of HIV-related discrimination received.

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Knowledge of HIV-related rights among people living with HIV and key populations (programme data).
- ▶ Percentage of people living with HIV who sought redress when their rights were violated (People Living with HIV Stigma Index).

## HIV-related legal services

### Why is it important to monitor these programmes?

HIV-related legal services can facilitate access to justice and redress in cases of HIV-related discrimination or other human rights violations, promoting human rights and removing barriers to service access. Examples of instances where such legal services might be needed include:

- ▶ Breaches of privacy and confidentiality.
- ▶ Illegal action by the police.
- ▶ Discrimination in health care, employment, education, housing or social services.
- ▶ Denial of property and inheritance rights.

It is important to monitor legal service provision to see that it is geared to the needs of those most affected, is reaching all those in need, and is able to bring about change. Evaluating it to document its effectiveness beyond the individual cases resolved is also important.

### Examples of activities

HIV-related legal services may include the following activities:

- ▶ Training for people living with HIV and key populations on rights and available redresses under the law.

- ▶ Community paralegal support.
- ▶ Legal hotlines and Internet-based provision of advice.
- ▶ Legal information and referrals.
- ▶ Legal advice and representation, including through pro bono clinics.
- ▶ Alternative and community forms of dispute resolution.
- ▶ Engaging religious or traditional leaders and traditional legal systems (e.g., village courts) with a view to resolving disputes and changing harmful traditional norms.
- ▶ Strategic litigation.

## What to measure?

Interventions or programmes may lead to the following desired changes:

- ▶ Change at the individual level: increased awareness of rights, improved knowledge and greater empowerment to access justice.
- ▶ Change at the service level: increased knowledge, awareness and skills to provide legal support services, improved community outreach of legal services, and greater accountability from services (e.g., health services, police services and the employment sector) if violations are challenged.
- ▶ Change at the community and structural levels: this may occur where successful challenges bring about changes in law, policy, values and practices.

## Examples of output indicators

Examples of some output indicators include the following:

- ▶ Number of training sessions held.
- ▶ Number of individuals provided with training.
- ▶ Number of community paralegals providing services.
- ▶ Number of referrals for legal support or advice services for people living with HIV and other affected populations.
- ▶ Number of cases taken to judicial process.
- ▶ Number of people using legal support services.

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Knowledge among key populations of their rights and available redress (programme data).
- ▶ Number and percentage of referred cases satisfactorily resolved (programme data).
- ▶ Percentage of people living with HIV who sought redress when their rights were violated in the past 12 months (People Living with HIV Stigma Index).

## Monitoring and reforming laws, regulations and policies relating to HIV

### Why is it important to monitor these programmes?

Laws, regulations and policies relating to HIV can negatively or positively impact a national HIV epidemic and the lives and human rights of those living with and affected by HIV. It is thus essential to monitor and reform laws, regulations and policies so they support—rather than hinder—access to HIV and health services.

### Examples of activities

Monitoring and reforming laws, regulations and policies relating to HIV may involve the following activities:

- ▶ Legal environment assessments and monitoring of the impact of policies, laws and regulations in terms of uptake of (and retention on) HIV services.
- ▶ Assessment of legal provisions for access to justice for people living with or vulnerable to HIV.
- ▶ Advocacy and lobbying for law reform.
- ▶ Sensitizing religious and traditional leaders, parliamentarians and ministers of government departments (e.g., Justice, Interior, Corrections, Finance, Industry, Labour, Women's Affairs, Education, Immigration, Housing, Defence, Health and Trade).
- ▶ Reform of regulations and policies.
- ▶ Promotion of the enactment and implementation of laws, regulations and guidelines that prohibit discrimination and support access to HIV prevention, treatment, care and support.

### What to measure?

Interventions or programmes may lead to the following desired changes:

- ▶ Change at the service level: increased knowledge and understanding of the legal and regulatory framework and its impact on HIV among lawmakers, law enforcement officials and members of the judiciary.
- ▶ Changes at the individual and community levels: awareness, understanding and knowledge of laws, regulations and policies among people living with and affected by HIV.
- ▶ Changes at the structural level: whether recommendations were implemented.

### Examples of output indicators

Examples of some output indicators include the following:

- ▶ Legal environment assessment or legal audits and desk reviews completed and disseminated to key stakeholders.

- ▶ Access to justice assessment report completed and disseminated to key stakeholders.
- ▶ Number of engagements on relevant issues with parliamentarians and ministers of government departments.

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Existence of non-discrimination laws that specify protections for key populations and people living with and affected by HIV (legal and policy documents).
- ▶ Existence of laws and/or policies that present barriers to the delivery of HIV prevention, testing and treatment services or the accessibility of these services (legal and policy documents).
- ▶ Awareness of human rights standards and international guidelines among lawmakers, law enforcement agents and members of the judiciary (programme data).

## Sensitization of lawmakers and law enforcement agents

### Why is it important to monitor these programmes?

These programmes seek to inform and sensitize those who make the laws (parliamentarians) and those who enforce them (Ministers of Interior and Justice, police, prosecutors, judges, lawyers, and traditional and religious leaders) about the important role of the law in the response to HIV. This includes protecting those affected by HIV from discrimination and violence and supporting access to HIV prevention, treatment, care and support. Sensitization programmes aim to help ensure that individuals living with and vulnerable to HIV can access HIV services without fear of being targeted by law enforcement, and that they can lead full and dignified lives, free from discrimination, violence, extortion, harassment, and arbitrary arrest and detention.

### Examples of activities

Sensitization of lawmakers and law enforcement agents may involve the following activities:

- ▶ Sensitization of parliamentarians, personnel from the Ministries of Justice and Interior, judges, prosecutors, religious and traditional leaders, police, and prison personnel on the topics of HIV, the role of law and the enforcement of protective laws in the context of the HIV response.
- ▶ Development of HIV workplace policies and practices to protect lawmakers and police from HIV infection.
- ▶ Facilitated community dialogues or joint activities with people living with HIV and members of other key populations, including on law enforcement that undermines the HIV response.
- ▶ Efforts to improve prison policies and practices regarding access to HIV prevention, treatment and harm reduction.



- ▶ Facilitated discussions and negotiations among HIV service providers, those who access services, and police in order to address law enforcement practices that impede HIV prevention, treatment, care and support efforts.
- ▶ Training for prison personnel regarding the prevention, health-care needs and human rights of detainees living with or at risk of HIV infection.

## What to measure

Interventions or programmes may lead to the following desired changes:

- ▶ Change at the structural level: improved protection of the rights of people living with HIV and other key populations through laws, policies and judgments on HIV and AIDS that are compliant with international human rights standards.
- ▶ Change at the service level: improved access to justice for HIV-related human rights violations and increased awareness and understanding among law enforcers. This may lead to changes at the individual and community levels, with reduced stigma and discrimination, decreased human rights violations of people living with HIV and key populations, and increased access to justice.

## Examples of output indicators

Examples of some output indicators include the following:

- ▶ Number of sensitization sessions held on HIV and human rights in the past 12 months (disaggregated by target audience).

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Percentage of key populations reporting having experienced physical violence who identified police as the perpetrator(s) (integrated behavioural and biological surveillance surveys).
- ▶ Percentage of people living with HIV who sought redress when their rights were violated in the past 12 months (People Living with HIV Stigma Index).

## Training for health-care providers on human rights and medical ethics related to HIV

### Why is it important to monitor these programmes?

Human rights and ethics training for health-care providers focuses on two objectives. The first is eliminating discrimination against users of health services, reducing stigmatizing attitudes in health-care settings and providing health-care providers with the skills and tools necessary to ensure that the rights of patients to informed consent, confidentiality, treatment and non-discrimination are protected. The second objective is to ensure that health-care providers know about their own human rights in the context of HIV, including the rights to HIV prevention and treatment, universal precautions, compensation for work-related infection, and non-discrimination. This capacity-building is part of the comprehensive approach described in the *Agenda for zero discrimination*

*in health care*, occurring alongside the leadership and commitment of a broad range of stakeholders to multisectoral efforts to eliminate discrimination in health care, empower users of health services and produce stronger accountability (18, 19).

## Examples of activities

Human rights and ethics training should be conducted with the following groups:

- ▶ Individual health-care providers in order to raise awareness of the negative impact that stigma, breaches of confidentiality and neglect of informed consent in health-care settings can have on the lives of patients and their human rights. The fears and misconceptions that health-care providers have about HIV transmission also should be addressed, and human rights competencies, understanding, compassion and professionalism should be promoted.
- ▶ Health-care administrators to ensure that health-care institutions provide the information, supplies and equipment necessary to make sure health-care workers have access to HIV prevention and treatment (including the universal precautions needed for prevention of occupational transmission of HIV), and that they are protected against discrimination.
- ▶ Health-care regulators to ensure the enactment and implementation of policies that protect the safety and health of both patients and health-care workers, and those that prevent discrimination against people living with and vulnerable to HIV.

## What to measure?

Interventions or programmes may lead to the following desired changes:

- ▶ Change at the service level: increased awareness, knowledge and acceptance of human rights, improved services, and increased access to prevention, treatment, care and support. These changes will lead to change at the individual level for affected populations, including their ability to access health services free from stigma and discrimination, thus contributing to the highest attainable standard of health.

## Examples of output indicators

Examples of some output indicators include the following:

- ▶ Number of education sessions held and the number of health-care workers, administrators and educators reached.

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Mechanisms in place to record and address cases of HIV-related discrimination (NCPI).
- ▶ Percentage of health-care facilities with policies that protect the health and safety of patients, including people living with HIV and other key populations (surveys among health-care staff).
- ▶ Percentage of health-care facilities with policies that protect the health and safety of health-care workers (surveys among health-care staff).

- ▶ Percentage of health-care facilities with policies to prevent discrimination against people living with and vulnerable to HIV (surveys among health-care staff).
- ▶ Percentage of people living with HIV reporting having experienced discrimination in health care in the past 12 months (People Living with HIV Stigma Index).
- ▶ Percentage of key populations citing stigma as a reason for avoiding seeking health care (integrated behavioural and biological surveillance surveys).
- ▶ Percentage of health-care staff reporting observed unjust treatment of patients living with HIV in their facility in the past 12 months (surveys among health-care staff).

## Reducing discrimination against women in the context of HIV

### Why is it important to monitor these programmes?

While all other programmes are intended to apply gender-sensitive approaches, these programmes specifically address gender inequality and gender-based violence as both causes and consequences of HIV infection. They include programmes that address harmful gender norms and practices for women and girls, such as:

- ▶ Culturally accepted practices, such as cross-generational sex, concurrent partnerships, wife inheritance, early or forced marriage, female genital mutilation, and homophobia and transphobia.
- ▶ Inequality in sexual and reproductive decision-making.
- ▶ Gender barriers to health services.
- ▶ Discrimination in inheritance, property holding, marriage, divorce and custody.
- ▶ Sexual and other violence.
- ▶ Lack of equal access to educational and economic opportunity.
- ▶ Disproportionate burden of care and lack of support to caregivers in HIV-affected households.

Such programmes should be complemented by programmes focusing on men and boys that address harmful gender norms that make people—women and girls *and* men and boys—vulnerable to HIV infection.

### Examples of activities

These programmes can include:

- ▶ Activities to strengthen the legal and policy environment to ensure that laws protect women and girls from gender inequality and violence.
- ▶ Efforts to reform domestic relations, domestic violence laws, and law enforcement in instances where they fail to protect women sufficiently or where they create barriers to HIV prevention, treatment, care and support.
- ▶ Efforts to reform property, inheritance and custody laws to ensure equal rights for women, children and caregivers affected by HIV.
- ▶ Age-appropriate sexuality and life skills education programmes that also seek to reduce gender inequality and gender-based violence.

- ▶ Programmes to reduce harmful gender norms and traditional practices that put women and girls and men and boys at risk of HIV infection, including capacity-building of civil society groups working for women's rights and gender equality.
- ▶ Programmes to increase access to education and economic empowerment opportunities for women living with or vulnerable to HIV infection.
- ▶ Integrated health services with a well-functioning referral system, including post-rape care and post-exposure prophylaxis (PEP).

## What to measure?

Interventions or programmes may lead to the following desired changes:

- ▶ Change at the individual level: increased awareness and knowledge of women's rights, gender equality and life skills, and greater empowerment.
- ▶ Change at the community level: changes in norms and practices around gender equality and greater rights for women and girls, men and boys, transgender people and caregivers affected by HIV.
- ▶ Change at the structural level: protective laws to reduce gender inequalities and gender-based violence.

## Examples of output indicators

Examples of some output indicators include the following:

- ▶ Number of education sessions about women's rights and gender equality.
- ▶ Number of women reached by education sessions about women's rights and gender equality.
- ▶ Number of primary health-care facilities with functioning referral systems for survivors of gender-based violence.
- ▶ Number of capacity-building sessions held with civil society groups on the issue of women's rights and gender equality.

## Examples of outcome indicators

The following are some examples of outcome indicators (with potential data sources in parentheses):

- ▶ Existence of policies and laws relating to gender inequality and violence that impact HIV vulnerability for women and girls (policies and laws on early marriage, age of consent, girls' education, property and custody rights, marital rape, intimate partner violence, female genital mutilation and protection from forced sterilization).
- ▶ Percentage of ever-married or partnered women (aged 15–49 years) who experienced physical and/or sexual violence by a current or former intimate partner in the last 12 months (population-based surveys).
- ▶ Percentage of women (aged 15–49 years) who experienced sexual violence by persons other than an intimate partner since age 15 (population-based surveys).
- ▶ Percentage of girls (aged 15–19 years) who report experiencing forced sexual intercourse or any other forced sexual acts, by age at first incident of violence (population-based surveys).

# A rights-based and rights-sensitive approach for monitoring and evaluation of national HIV programmes

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Rights-based and rights-sensitive approaches to the monitoring and evaluation of HIV responses refers to the integration of human rights standards and principles into the monitoring and evaluation process. Beyond the issue of what is measured, human rights standards and principles also apply to how measurement is done, with the key human rights principles that are applicable to rights-based HIV programme planning and implementation also applicable to HIV programme monitoring and evaluation (5, 11, 20, 21).<sup>3</sup> These principles include the following:

- ▶ **Participation of people living with and affected by HIV.** All relevant stakeholders should be involved in HIV programme monitoring and evaluation, just as they should be involved in HIV programme implementation itself, such as through community monitoring.<sup>4</sup> This promotes the right to participation and gives stakeholders the power to bring about change in their own lives. Participation ensures that HIV programmes are designed, developed and implemented using a rights-based or rights-sensitive approach. Along with the direct benefits to the overall HIV programme, using such an approach signals a commitment at the level of the State to uphold and promote human rights, and such messages can be a powerful motivators to other government and nongovernment organizations. Full and equal participation means:
  - Involving a diverse range of people living with HIV and other key populations within the organizational structures and processes for monitoring and evaluation.
  - Involving a wide range of stakeholders, including community-based organizations of key populations and other affected communities, civil society organizations and faith-based organizations working for and with these communities, government institutions, traditional leaders, the private sector, donors and international organizations.
  - Ensuring that structures and processes are designed to promote the equal and full participation of all stakeholders.

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<sup>3</sup> In step with the 2030 Agenda for Sustainable Development and the SDGs, OHCHR has developed a guidance note that aims to provide general guidance and elements of a common understanding on a human rights-based approach to data, with a focus on issues of data collection and disaggregation. Such an approach will help to bring together relevant data stakeholders and develop communities of practice that improve the quality, relevance and use of data and statistics in way that is consistent with international human rights norms and principles. For more information, please see: A human rights-based approach to data. Leaving no one behind in the 2030 agenda for sustainable development. Geneva: OHCHR; 2018 (<http://www.ohchr.org/Documents/Issues/HRIndicators/GuidanceNoteonApproachtoData.pdf>).

<sup>4</sup> Article 25 of the International Covenant on Civil and Political Rights explicitly recognizes the right of citizens to participate in public affairs. This is supplemented by more general rights to participation, which can be found in treaties such as the International Covenant on Economic, Social and Cultural Rights (Articles 13.1 and 15.1), the Convention on the Elimination of All Forms of Discrimination Against Women (Article 7), the Convention on the Rights of the Child (Article 12) and the Convention on the Rights of Persons with Disabilities (Article 29). It also can be found in political declarations, including the Declaration on the Right to Development (Articles 1.1, 2 and 8.2), the Declaration on the Rights of Indigenous Peoples (Articles 5, 18, 19 and 41) and the Millennium Declaration (paragraph 25).

- Identifying capacity-building needs to promote the equal and full participation of stakeholders who lack experience and skills.
  - Identifying and addressing other barriers to equal and full participation for specific populations.
- ▶ **Empowerment.** This entails a combination of full stakeholder participation (as described above) and capacity-building of the stakeholders and the monitoring and evaluation implementers. It also includes accountability mechanisms for the purposes of oversight or redress. Empowerment, community monitoring and capacity-building help to ensure that key stakeholders are able to access and participate in the monitoring and evaluation processes, and that they can uphold the rights-based and rights-sensitive approaches in use. Since it educates monitoring and evaluation implementing organizations about their obligations, capacity-building can help to promote accountability, and it also informs participating stakeholders and informants about their rights and existing mechanisms so that they can take action when these are violated or unfulfilled.
  - ▶ **Equality and non-discrimination.** This includes valuing the people at the heart of the epidemic and the response, and ensuring that the systems in place as part of the response do no harm (e.g., they do not further stigmatize groups, do not discriminate against people and do not violate human rights). Furthermore, such an approach should ensure that data pertaining to all key and affected populations is available and used to guide programme design and funding.
  - ▶ **Transparency.** The right to freedom of expression explicitly includes “freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of [a person’s] choice.” (22) For this right to be realized in practice, relevant statistical information must be publicly available in a timely way and in an accessible format, taking into account considerations such as literacy levels, age, disability, language and cultural background (where applicable) (23).
  - ▶ **Accountability.** By setting out a framework by which monitoring and evaluation activities will be carried out using methods, mechanisms and processes that adhere to and promote human rights—and by establishing products that capture progress in realization of human rights—the national HIV programme promotes accountability for human rights violations and contributes to a reduction in rights violations. Oversight mechanisms guaranteeing the other human rights principles, such as participation of those affected in all stages of monitoring and evaluation, are also an important contributor to accountability.

Figure 5 demonstrates how these principles can be operationalized through a programme or project cycle.

**Figure 5**  
Programme or project cycle



Source: HIV and human rights good practice guide. Hove (UK): International HIV/AIDS Alliance; May 2014 ([https://frontlineaids.org/wp-content/uploads/old\\_site/Alliance\\_GPG-HIV\\_and\\_human\\_rights\\_original.pdf?1407762153](https://frontlineaids.org/wp-content/uploads/old_site/Alliance_GPG-HIV_and_human_rights_original.pdf?1407762153)).

## How do we apply rights-based and rights-sensitive approaches in monitoring and evaluation planning?

Just as national HIV strategic plans should include human rights-specific programmes and rights-based approaches, so should the national monitoring and evaluation plan. Rights-based or rights-sensitive monitoring and evaluation plans should include the following activities:

- ▶ A situational assessment or environmental scan of existing or past HIV programme monitoring and evaluation plans and mechanisms should be conducted in order to identify current strengths and challenges with respect to the collection of data on human rights indicators.
- ▶ Similarly, a scan should be conducted to identify strengths and gaps with respect to the processes used for the collection of these data. In particular, this scan should assess the extent to which rights-based or rights-sensitive approaches (that is, the principles of participation, empowerment, non-discrimination and accountability) were applied in the design of the monitoring and evaluation system and in the collection, analysis and use of monitoring and evaluation data. Necessarily, such

a scan should be planned and conducted in collaboration with people living with HIV, key populations and nongovernmental organizations that form part of the HIV response, and input should be solicited from these groups.

- ▶ Findings from these assessments and scans should be used as input in the updating or modification of the national monitoring and evaluation plan, and the monitoring and evaluation planning process itself should also incorporate a rights-based approach.
- ▶ Budgets of national strategic plans should include appropriate allocation of human and financial resources for the data collection to support the monitoring and evaluation plan, but they also should include resources for the application of a rights-based approach. This includes a budget for capacity-building on the subject of human rights and rights-based approaches for staff within the organizations that are implementing the monitoring and evaluation. Similarly, the budget should include resources for capacity-building of key stakeholders in order to enable their full participation in the monitoring and evaluation process. Resources required to support monitoring and evaluation-related activities to be conducted by key nongovernmental stakeholders must also be factored into the plan.
- ▶ An additional important factor to account for in the incorporation of a rights-based approach is the time required to use a participatory approach, which necessitates additional consultation and collaborative efforts not previously incorporated in monitoring and evaluation planning and implementation.

## **How do we apply rights-based and rights-sensitive approaches in data collection and storage?**

Monitoring and evaluation uses multiple types and sources of data, including routine programme (administrative) data, public health surveillance data, statistical estimates (modelling), vital statistics and census data, participatory surveys and research studies, and mid-term and end-term evaluations. The collection, processing and dissemination of statistical information have implications for the rights to information, privacy, data protection and confidentiality, and safety and security, and the process requires conforming to legal and institutional standards related to ethics, statistics and human rights. The principles of participation and self-identification also are important (11).

### **Participation**

Within the context of data collection and storage, participation involves:

- ▶ The inclusion of people living with HIV and key populations in the design of monitoring and evaluation data collection tools (e.g., questionnaires for surveys, reporting forms for public health surveillance, and evaluation questionnaires and information collection instruments).
- ▶ The inclusion of people living with HIV, key populations and nongovernmental organizations in data collection, such as programme data for ongoing programme monitoring and data collection in special studies (e.g., the collection of qualitative information to support process assessments and evaluation studies, participation on study teams for behavioural surveys, and research studies).



## Self-identification

The principle of self-identification requires that people should have the option of self-identifying when faced with a question seeking sensitive personal information (11). This is particularly relevant within the HIV response, as HIV disproportionately affects people who are vulnerable or exposed to HIV due to circumstances that may also make them vulnerable to discrimination on the grounds of their sex, gender identity, sexual orientation, race or ethnicity, sexual practices, occupation, or other social or physical attributes.

Furthermore, the use of rights-based principles dictates that the dimensions to be captured within data collection instruments should be developed jointly with the affected key populations in order to ensure that the information sought is relevant and non-discriminatory.

## Rights to information, privacy, data protection and confidentiality

The right to information is guaranteed by the Universal Declaration of Human Rights (Article 19) and the International Covenant on Civil and Political Rights (Article 19). The right to privacy, set out in the International Covenant on Civil and Political Rights (Article 17), relates to the principle of data protection, which requires that all data collection activities must respect robust guarantees to prevent the abuse of sensitive data.

Within the governing act in force within a state, the rights to information and privacy specify the conditions by which individuals can access records in the custody or under the control of public bodies. They also indicate the limits or controls in the manner in which public bodies collect personal information from individuals, and the protections against the unauthorized use or disclosure of personal information by public bodies.

Within the context of monitoring and evaluation of HIV programmes, the following are applicable:

- ▶ Staff within implementing organizations and participating stakeholders should all be cognizant of the relevant data needs and collect only what is necessary to the extent necessary, opting for non-personal data as much as possible.
- ▶ Data collection activities should be highly focused on collecting information at the finest level of disaggregation that is absolutely necessary, with a clear rationale for each data element collected.
- ▶ Implementing organizations and data holders should have clear policies in place relating to providing access to information and safeguarding the privacy of the individuals from whom information was collected.
- ▶ Data holdings should be subject to privacy impact assessments that aim to identify the risk posed to the individual and the organization if a privacy breach were to occur, and to determine the appropriate data security requirements for such data.
- ▶ The appropriate data security measures should be put in place within organizations that are involved in data collection and storage.

Policies should also be instituted to specify the conditions and requirements around data transmission and data sharing with other parties. Ordinarily, only nonpersonal data can be shared; informed consent should be sought for personal data information flows.

## Standards and ethics

Given the diverse possible data sources used for the monitoring and evaluation of HIV responses, it is to be expected that the guidance around standards and ethics applicable to the data sources is similarly diverse. In general, however, the following are relevant:

- ▶ Data collection methods and process should be subject to some form of ethical review. A good starting place is institutional research ethics boards or committees for implementing organizations or associated/affiliated accredited research facilities (e.g., universities).
- ▶ Data collection methods should safeguard the safety and security of respondents and interviewees, particularly when criminalized key populations are involved.
- ▶ The process of informed consent should be applied in all instances, including in the collection of administrative data. This ensures that individuals understand why they are being asked for specific information and that they understand how that data will be used. They should also have the freedom to refuse to provide information without fear of repercussion (such as reduced access to services or lower quality care).
- ▶ As much as possible, surveys should be conducted in a way that ensures the anonymity of participants (i.e., no personal identifiers should be collected as part of the survey). Alternatively, if identifying information is collected, efforts should be put in place to anonymize the data after collection (i.e., identifiers should be removed from the data sets completely or separated from the main data set).
- ▶ Survey responses should be grouped and person-specific identifiers should be stripped to protect the identity of respondents.
- ▶ Population data should be decentralized and the creation of a bridge file (e.g., where data are stored in another country outside the jurisdiction of local courts) should be encouraged, particularly in countries where the requisite institutions are weak and easy to influence.
- ▶ Clear harm mitigation strategies with assigned responsibilities, reporting obligations, access to remedies and compensation for data subjects should be in place in case of data leaks or other security breaches (24)

## How do we apply rights-based and rights-sensitive approaches in data analysis?

The indicators within a monitoring and evaluation framework form the basis of the data analysis plan. In addition to the application of the principles of participation, empowerment and non-discrimination described above, a rights-based and rights-sensitive approach to data analysis incorporates the following analysis methodologies:

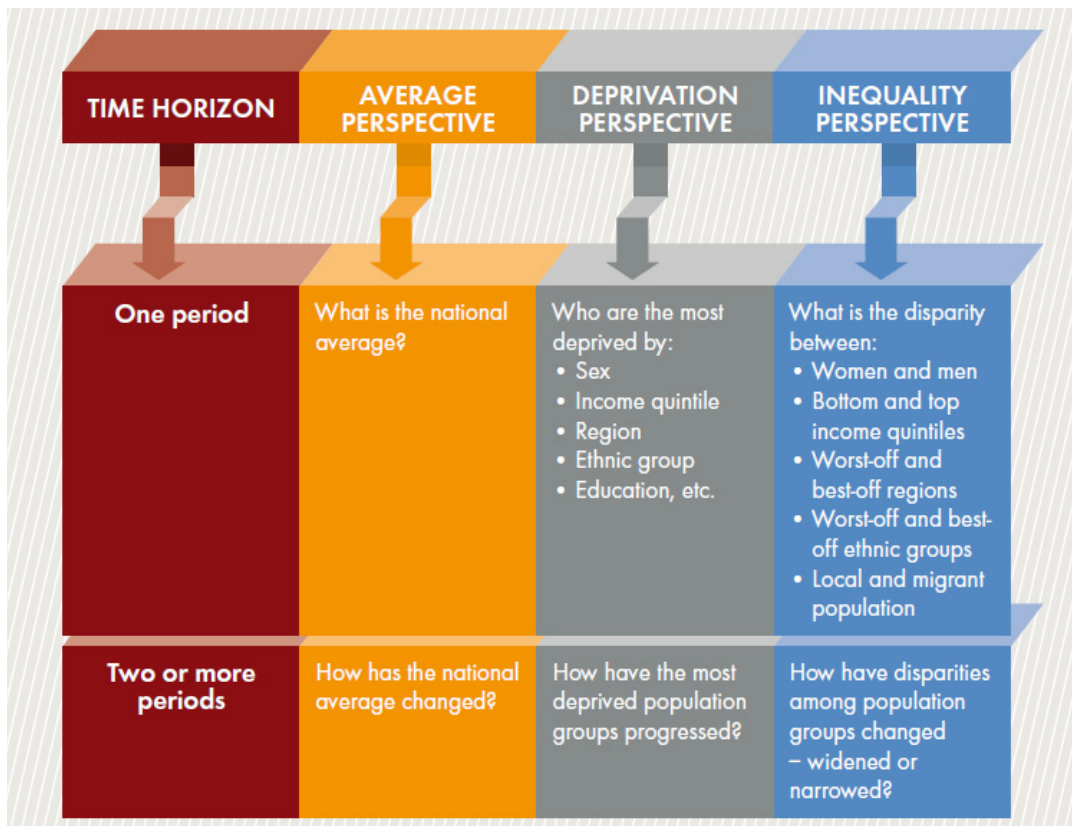
- ▶ In addition to national aggregates, indicators should be disaggregated to data for the smallest relevant group of individuals who are bound by common human rights characteristics. In the context of HIV, this corresponds to age- and gender-based analysis and disaggregation, as well as disaggregation by key populations affected most by the HIV epidemic (e.g., gay men and other men who have sex with men, people who inject drugs, sex workers, transgender people and prisoners) that are identified within the available epidemiological data.

- It is important to note that input from key informants, key populations, community-based organizations and other nongovernmental organizations active within a country's HIV response is crucial for identifying key populations for such disaggregation: the lack of data within epidemiological profiles may simply reflect a lack of the data collection mechanisms or specificity that is necessary to identify issues. For example, an issue with HIV transmission within a key population such as migrants may be missed if the existing surveillance systems do not collect information on citizenship or residency status.
- ▶ When indicators are readily available, an analysis and assessment combining three measurement perspectives can be systematically carried out, especially using outcome and process indicators: the "average perspective" shows the country's overall progress, the "deprivation perspective" shows the progress for its most deprived groups, and the "inequality perspective" shows progress in narrowing inequalities between its population groups or regions (see Figure 6).
- ▶ A policy on how to handle small cell sizes should be pre-established. Small cell sizes can occur when data sets with an overall small number of cases are disaggregated. The resulting small cell counts poses two problems: possible issues with poor data quality and possible risk of confidentiality breaches. For example, disaggregation of data on one indicator by geographic location, sex and sexual orientation—such as the count of gay men and other men who have sex with men in a particular location who have experienced a human rights violation (such physical abuse by police) in the past year—may result in fewer than five people. This is problematic for several reasons:
  - From a data quality perspective, it may be difficult to assess the importance of the indicator data or to assess trends across geographical areas because smaller numbers are associated with higher uncertainty or sampling error for the indicator value.
  - Analyses based on small samples also may lead to incorrect conclusions because the sample may be biased or not representative.
  - From the perspective of privacy and confidentiality, such small numbers may inadvertently reveal information about participants. Going back to the earlier example, the small numbers may reveal the sexual orientation of some men in a particular geographical location if it is generally known within their social circles that they experienced physical abuse from the police within the indicator time frame.
- ▶ Interpretation of data should be conducted in a sensitive and thoughtful manner in order to avoid further stigmatizing the implicated populations. Use of terminology like "drug abuse," "risky behaviour" or "promiscuous" should be avoided, as it ascribes blame to the people so described (25).
- ▶ The absence of information on relevant indicators can itself be an indicator of a lack of willingness and commitment on the part of key players within the HIV response to implement or monitor human rights.
  - An example might be when process indicators like the proportion of staff formally investigated for physical and nonphysical abuse are not compiled or disseminated, or when data on sexual orientation are not available in states where there are punitive laws targeting specific groups (e.g., laws criminalizing same-sex sexual behaviours).

- ▶ Quantitative data should not be used to make conclusions in isolation. Rather, these data should be used along with data from other quantitative indicators and with qualitative information; this will help in the interpretation and contextualization of the findings. It is important to remember that an indicator is merely a signal of a possible state, and that additional explanatory information is important to understand that state and to get to the “why” questions.
  - As an example, when a new indicator is introduced, the data on that indicator may suggest a low prevalence of a human rights violation. This may be the result of inadequate data collection mechanisms or low will to report on such data (perhaps due to perceived risks of reporting). Over time, data collection and reporting may improve, perhaps as a result of increased awareness of the importance of this human rights dimension, programmes that address risks of reporting, or data collection mechanisms and additional data sources. Within this scenario, a time trend analysis may show a significant rise in the prevalence of violations, whereas the contextual information would reveal that the rise is an artefact of these data collection and reporting changes.

**Figure 6**

Three perspectives for human rights assessments



Source: Human rights indicators: a guide to measurement and implementation. Office of the United Nations High Commissioner for Human Rights; 2012 ([http://www.ohchr.org/Documents/Publications/Human\\_rights\\_indicators\\_en.pdf](http://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf)).

## How do we apply rights-based and rights-sensitive approaches in data dissemination and use?

Human rights monitoring and evaluation requires access by all stakeholders, in particular the rights holders, to information on the realization of their rights. As such, a rights-sensitive monitoring and evaluation framework should include the following:

- ▶ A schedule for the dissemination of the information produced by the monitoring and evaluation activities. In partnership with key stakeholders, this publication and dissemination plan should take into account the various audiences, consumers and users of the information, and it should ensure that the method of dissemination is accessible (e.g., at the appropriate literacy level, using widely available media and in the locally prevalent language).
- ▶ For surveys focused on key populations, the principle of first access is a recommended approach: the key population from which the data were collected should be the first audience for the knowledge products produced.
- ▶ Knowledge products should be strategically designed and have a clear purpose, audience and dissemination plan. The principles of participation, empowerment, transparency and non-discrimination should also form part of the planning for each knowledge product.

### Summary

Throughout the monitoring and evaluation planning and implementation phases, the key questions outlined in Figure 7 can be used as a guide to assess if rights-based and rights-sensitive approaches have been used.

**Figure 7**

Checklist for right-based and rights-sensitive process assessment in monitoring and evaluation

- Were the beneficiaries involved in the needs assessment, monitoring and evaluation framework development, data collection, data analysis, and knowledge product development and dissemination?
- Does the monitoring and evaluation framework use the principles of rights-based approaches: participation, empowerment, non-discrimination and accountability?
- Does the monitoring and evaluation system respect basic rights to privacy, confidentiality and informed consent?
- Are the monitoring and evaluation system, process and outputs accessible and acceptable to all without discrimination?
- Does the monitoring and evaluation system collect information on the most vulnerable or most affected populations, both with respect to HIV and to human rights?

Source: Adapted from: HIV and human rights good practice guide. Hove (UK): International HIV/AIDS Alliance; May 2014 ([https://frontlineaids.org/wp-content/uploads/old\\_site/Alliance\\_GPG-HIV\\_and\\_human\\_rights\\_original.pdf?1407762153](https://frontlineaids.org/wp-content/uploads/old_site/Alliance_GPG-HIV_and_human_rights_original.pdf?1407762153), accessed 18 March 2019), p. 63.

# Conclusion

AIDS today is an epidemic of exclusion, discrimination and vulnerability. The science is clear, and there are tools to end AIDS as a public health threat. However, many populations across many countries continue to face human rights barriers in exercising their right to development and to accessing the best available science.

The 2030 Agenda for Sustainable Development has put equality and non-discrimination at the core of its shared framework for action. To end AIDS and achieve healthy lives for all as mandated by SDG 3, we need to work together to tackle the human rights barriers in order to ensure rights-based approaches that Fast-Track the response.

In its preamble, the 2016 Political Declaration on Ending AIDS explicitly states the importance of the “promotion, protection and fulfilment of all human rights and the dignity of all people living with, at risk of, and affected by HIV” as an objective and means of ending the AIDS epidemic. The Political Declaration on Ending AIDS has also mainstreamed human rights approaches: two out of the 10 Fast-Track commitments to end AIDS by 2030 include a dedicated focus to advancing human rights, empowerment, access to justice and the elimination of all forms of discrimination and violence.

In order to assess progress towards these commitments, it is important for national monitoring and evaluation systems to be rights-sensitive and to capture progress towards removing human rights barriers to effective AIDS responses.

This guidance on rights-based and right-sensitive monitoring and evaluation complements and builds upon the 2017 guidance document *Fast-Track and human rights*. In doing so, it aims to support national stakeholders to assess human rights barriers and develop, monitor and evaluate rights-based responses.

The time to act is now. The SDG monitoring framework places firm emphasis on leaving no one behind and on capturing progress towards eliminating discrimination. There are certain opportunities for human rights-based and rights-sensitive monitoring and evaluation. One of them is the Global Fund commitment to scale up key programmes to reduce and eliminate stigma and discrimination and to enhance access to justice through all its grants. To that end, it has made catalytic funding available for that purpose in 20 countries.

The world has committed to end AIDS, and it is working towards the vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths. If that vision is to become a reality, monitoring efforts need to support the commitment that no one will be left behind by the response.



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