

## Developing summary measure(s) of HIV-related stigma and discrimination

### Concept note

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The 2030 Agenda for Sustainable Development includes a target to end the AIDS epidemic by 2030. The path to achieving this ambitious target was set by the Political Declaration on Ending AIDS at the UN General Assembly High Level Meeting in June 2016.<sup>1</sup> How to measure whether individual countries are moving towards the 2030 target was the subject of a meeting of experts convened by the UNAIDS Science Panel on 4-6 October 2017 in Glion, Switzerland. That meeting focused specifically on proposed definitions and measures for the term “epidemic control”. Participants of the “Glion meeting” agreed that a new summary metric of impact indicators (e.g. new HIV infections and morbidity and mortality among people living with HIV) should be packaged with improved measures of HIV-related stigma and discrimination and a “policy cascade” that measures whether an enabling legal and policy environment is in place for efforts to eliminate stigma and discrimination.<sup>2</sup>

Various survey questions, indicators and scales have been developed to measure stigma across various context and populations. Data availability varies across these different measures. The number and variety of measures allow to understand diverse manifestations of stigma and discrimination. Individual measures however may not allow to understand in a more comprehensive way what the situation of stigma and discrimination is and how they manifest in the various aspects of a persons’ life, for comparison over time and across contexts. Due to the complexity of the drivers and manifestations of HIV-related stigma and discrimination, no single, globally adopted measure of stigma and discrimination has emerged, making it difficult to arrive at an estimate of prevalence. Summary measure(s) of HIV-related stigma and discrimination would allow countries and global partners to track the status of HIV-related stigma and discrimination, including the legal and policy environment, over time and monitor progress towards the goal of eliminating HIV-related stigma and discrimination, guiding action and measuring if actions are leading to improvements for people affected.

### Defining stigma and discrimination

Stigma refers to beliefs and/or attitudes and can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others, such as when certain attributes are seized upon within particular cultures or settings and defined as discreditable or unworthy. When stigma is acted upon, the result is discrimination.

Discrimination refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group. It is a human rights violation. In the case of HIV, this can be a person’s confirmed or suspected HIV-positive status, irrespective of whether or not there is any justification for these measures. The terms stigmatization and discrimination have been accepted in everyday speech and writing, and they may be treated as plural.<sup>3</sup>

Non-discrimination is one of the basic principles of international human rights law. Thus, discrimination is a human rights violation and is prohibited by international human rights law and

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<sup>1</sup> [https://www.unaids.org/sites/default/files/media\\_asset/2016-political-declaration-HIV-AIDS\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2016-political-declaration-HIV-AIDS_en.pdf)

<sup>2</sup> A summary of the Glion meeting deliberations and recommendations is available at [http://www.unaids.org/sites/default/files/media\\_asset/glion\\_oct2017\\_meeting\\_report\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/glion_oct2017_meeting_report_en.pdf).

<sup>3</sup> UNAIDS 2015 Terminology Guidelines ([https://www.unaids.org/sites/default/files/media\\_asset/2015\\_terminology\\_guidelines\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2015_terminology_guidelines_en.pdf)).

most national constitutions. The Commission on Human Rights (now the Human Rights Council) and the Committee on Economic, Social and Cultural Rights have elaborated on the principle of non-discrimination and have explicitly recognized HIV status as a prohibited ground of discrimination. Based on existing human rights standards and international commitments a definition of HIV-related discrimination is provided as follows:

*a)* Discrimination in the context of HIV refers to unfair or unjust treatment (an act or omission) of an individual based on his or her real or perceived HIV status. Discrimination in the context of HIV also includes unfair or unjust treatment which increases vulnerability to HIV infection or to the impact of HIV.

In addition to people living with HIV and depending on the social and legal context, key populations that may suffer from discrimination relevant to HIV vulnerability and impact include women, children, young people, migrants, refugees and internally displaced people, sex workers, people who use drugs, men who have sex with men, transgender people and people in prisons and other closed settings.

*b)* HIV-related discrimination is closely linked to stigma, i.e. negative beliefs, feelings and attitudes towards people living with HIV and/or associated with HIV. However, it is important to note that even if a person feels stigma towards another, s/he can decide not to act in a way that is unfair or discriminatory. Conversely, a person may discriminate against another without personally holding stigmatizing beliefs, for example, where discrimination is mandated by law or policy.

*c)* HIV-related discrimination may also be closely related to gender inequalities. Power imbalances in society and individual relationships, harmful social norms, violence and marginalization may limit the ability of those affected to avoid HIV infection and/or to mitigate its impact.

*d)* HIV-related discrimination may occur in families, workplaces, health-care facilities, prisons and other closed settings, schools, the uniformed services, places of worship, and in the context of social networks, housing, insurance, social support, travel, migration, asylum and refugee resettlement.

Discrimination can be institutionalized through laws, policies and practices that negatively target people living with HIV and marginalized groups. Omission can also be a form of discrimination when, for example, the level of resources directed towards certain populations are not commensurate with the level of epidemic among them, and/or when HIV surveillance fails to track infections among these populations. The manifestations of HIV-related discrimination often cut across different sectors of society. However, its effects are felt by individuals where they live, work, access health care, go to school, and seek justice. Thus, it is important to devise specific strategies that will be effective for tackling HIV-related discrimination in those sectors.<sup>4</sup>

### **What has been done so far?**

Among the follow-up actions to the Glion meeting, UNAIDS asked civil society leaders and expert researchers to join a multi-stakeholder task team for the development of summary measures on stigma, discrimination and an enabling policy environment for effective AIDS responses.

The task team was invited to meet at UNAIDS headquarters in Geneva, Switzerland, to develop a set of consensus recommendations to UNAIDS on the establishment of a country-level summary

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<sup>4</sup> UNAIDS Programme Coordinating Board, Background note for the Thematic Segment: Non-discrimination, 31<sup>st</sup> Meeting, 11-13 December 2012 ([http://files.unaids.org/en/media/unaids/contentassets/documents/pcb/2012/20121111\\_PCB%2031\\_Non%20Discrimination\\_final\\_newcoverpage\\_en.pdf](http://files.unaids.org/en/media/unaids/contentassets/documents/pcb/2012/20121111_PCB%2031_Non%20Discrimination_final_newcoverpage_en.pdf)).

measure of stigma and discrimination faced by people living with HIV and key populations at high risk of HIV infection and the legal and policy environment for the protection of the fundamental rights of these individuals, including their ability to access health and HIV services. The task team was urged to use existing indicators that are periodically measured by countries and facilitate tracking of in-country trends and comparison among countries.

For the development of recommendations to integrate in a meaningful way people living with HIV, key populations and others particularly affected by HIV-related stigma and discrimination, meeting participants agreed to revise the process into two tracks:

- The short-term development of an interim indicator set to be used by UNAIDS as it analysed end-2017 country data and delivered its global progress report ahead of the AIDS 2018 conference;
- A longer-term process for the development of the final summary measure(s), linked to the development of the *Global Partnership to End All Forms of HIV related Stigma and Discrimination*.

An interim framework and indicator set were published in the UNAIDS 2018 *Miles to Go* report.<sup>5</sup>

### Challenges and limitations

The following important challenges and limitations around developing summary measure(s) of HIV-related stigma and discrimination have been noted:

- Data availability, including of survey data collected every 3-5 years;
- How to create a composite measure that balances reflecting how stigma and discrimination affect certain populations or how they manifest in specific settings while also focusing on a set of indicators that allow to see important patterns in HIV-related stigma and discrimination;
- How to properly weight different forms/frequency of stigma and discrimination in a composite measure;
- Measures should include data from community monitoring sources, in addition to data reported by governments.

### Existing frameworks and measures of HIV-related stigma and discrimination

*STRIVE Technical Brief on Measuring HIV stigma and discrimination, July 2017*

A technical brief on measuring stigma and discrimination was developed by STRIVE, a research consortium investigating the social norms and inequalities that drive HIV. The STRIVE framework organizes stigma and discrimination into the following:

1. *Drivers and facilitators of stigma and discrimination* which include as key conceptual domains for measurement fear of infection through casual contact with people living with HIV, social judgement including shame, blame, prejudice and stereotypes, and the legal and policy environment;
2. *Stigma 'marking'*;
3. *Manifestations of stigma* which include as key conceptual domains for measurement anticipated, perceived, internalized and experienced stigma, discrimination and resilience;
4. *Stigma and discrimination outcomes*; and,
5. *Stigma and discrimination impacts*.

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<sup>5</sup> UNAIDS 2018, Miles to Go: Closing gaps, breaking barriers, righting injustices ([https://www.unaids.org/sites/default/files/media\\_asset/miles-to-go\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/miles-to-go_en.pdf)).

The STRIVE framework notes that the drivers, facilitators and manifestations of stigma and discrimination can be measured from the different perspectives of people living with HIV, the general population and healthcare workers. For example, acts of discrimination can be measured through the behaviours of the general population or health-care workers, as well as the reported experiences of people living with HIV and key populations at higher risk of HIV infection.

#### *The Health Stigma and Discrimination Framework, 2019*

Building on the HIV stigma and discrimination framework published by STRIVE in 2017 and other existing conceptualizations of health-related stigmas, a new framework was developed by Anne Stangl et al that can be applied to various health conditions in addition to HIV, including leprosy, mental health and obesity/overweight. It proposes the following domains across which the stigmatization process can be broken down: drivers and facilitators, stigma 'marking, and stigma manifestations.<sup>6</sup>

#### *Rights-based indicators for HIV epidemic transition, 2018*

Joseph Amon et al propose a rights-based indicator framework for assessing epidemic transition, that includes five categories of indicators<sup>7</sup>:

- levels of coverage of key evidence-based prevention and treatment interventions;
- HIV incidence and prevalence;
- AIDS-related or all-cause mortality among people living with HIV;
- stigma and discrimination; and
- the legal and policy environment.

Meaningful involvement of people living with and affected by HIV are noted as key to these efforts.

#### *People Living with HIV Stigma Index*

The People Living with HIV Stigma Index<sup>8</sup> is a survey of people living with HIV conducted by people living with HIV, following the principle of GIPA (the greater involvement of people living with HIV), where the research process is as important as the survey results. The Stigma Index produces quantitative data on stigma and discrimination experienced by people living with HIV in health-care settings, the workplace, schools, the community and family settings. It also measures the impact of experienced and/or fear of stigma, including access to services. Since its launch in 2008, more than 1,600 people living with HIV have been trained as interviewers, and 100,000 people living with HIV in over 100 countries have been interviewed.

A revised Stigma Index 2.0 was launched in 2017. The tool was revised to reflect changes in both the epidemic and the response, to improve the collection of information on sub-groups of people living with HIV, to refine individual questions and to update the sampling methodology of the survey. These changes aim to make data collection and analysis more consistent, to reduce administration time, to incorporate existing validated response scales (e.g. on mental health) and to reduce the number of open-ended questions.

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<sup>6</sup> Stangl, A., et al, The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas, BMC Medicine 2019 (<https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-019-1271-3>).

<sup>7</sup> Amon, JJ., et al, Defining rights-based indicators for HIV epidemic transition, PLOS Medicine, December 21, 2018 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6303010/pdf/pmed.1002720.pdf>).

<sup>8</sup> <http://www.stigmaindex.org/>

### *Population-based surveys and Integrated Bio-Behavioural Surveys*

Population-based surveys, such as the Demographic and Health Survey<sup>9</sup> and the Multiple Indicator Cluster Survey<sup>10</sup>, are household surveys with large sample sizes that aim to produce results that are representative of national and sub-national populations. Respondents are asked a range of questions, including questions regarding HIV-related knowledge, attitudes, beliefs and behaviours. HIV status may also be measured through blood sampling.

Integrated bio-behavioural surveillance (IBBS) surveys are focused on key populations at higher risk for HIV infection. They often use respondent-driven sampling to reach populations of sex workers, people who inject drugs, men who have sex with men and other key populations to measure HIV-related behaviours (e.g. sexual risk behaviour, access and utilization of services) and HIV status through blood sampling. Module 29 of the IBBS, focuses on shame, stigma, harassment and discrimination. Questions related to stigma and discrimination are also included in other modules.<sup>11</sup> Biobehavioural surveys are needed alongside programme data to provide representative information about people who access services and people who do not access services.

### *Measuring stigma and discrimination in Global AIDS Monitoring*

UNAIDS has the mandate to support countries to report on global commitments in the AIDS response. Through the Global AIDS Monitoring process, previously UNGASS and GARPR, UNAIDS provides guidance to national AIDS programmes and countries on indicators to measure and report on the country epidemic and response. Countries have been submitting reports on their epidemic and response to UNAIDS every two years since 2003 and annually since 2013.

Policy questions on stigma and discrimination have been included in the Global AIDS Monitoring framework since 2004, through the National Composite Policy Index questionnaire, now the National Commitments and Policy Instrument (NCPI). The NCPI is an integral component of GAM that consists of two parts: Part A is to be completed by national authorities, and Part B is to be completed by civil society and other non-governmental partners in the national AIDS response. The full NCPI is included in GAM every two years. A subset of questions from Part A are included in GAM during interim years.

GAM, including the NCPI, has evolved over time to include additional indicators and questions on stigma and discrimination. The 2019 GAM<sup>12</sup> included seven indicators related to stigma and discrimination collected through population-based surveys, integrated bio-behavioural surveillance (IBBS) surveys and the People Living with HIV Stigma Index

- Indicator 4.1. Discriminatory attitudes towards people living with HIV;
- Indicators 4.2A-D. Avoidance of health care among key populations because of stigma and discrimination (four sub-indicators, one each for sex workers, men who have sex with men, people who inject drugs and transgender people)<sup>7</sup>
- Indicator 4.3. Prevalence of recent intimate partner violence; and,
- Indicator 4.4 Experience of HIV-related discrimination in health-care settings.

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<sup>9</sup> <https://dhsprogram.com/>

<sup>10</sup> <http://mics.unicef.org/>

<sup>11</sup> <https://www.who.int/hiv/pub/guidelines/biobehavioral-hiv-survey/en/>

<sup>12</sup> UNAIDS 2019 Global AIDS Monitoring ([https://www.unaids.org/sites/default/files/media\\_asset/global-aids-monitoring\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/global-aids-monitoring_en.pdf)).

In follow-up to regional commitments towards zero discrimination, three additional indicators on stigma and discrimination are included in GAM for countries in Latin America and the Caribbean, for which data are collected through special studies and from national human rights observatory, national redress mechanism, or equivalent national entity records<sup>13</sup>:

- LAC 2.3.1b (A-E). Percentage of people from key and vulnerable populations who experienced discrimination in health services in the last 12 months (five sub-indicators, one each for sex workers, men who have sex with men, people who inject drugs, transgender people, a vulnerable population);
- LAC 4.1.1.1. Number of acts of violence against lesbian, gay, bisexual, transgender and intersex (LGBTI) persons reported in the past 12 months; and,
- LAC 5.1.1. Human rights violations towards people living with HIV and key populations.

### Related initiatives

#### *Agenda for Zero Discrimination in Health Care*

UNAIDS and the World Health Organization's Global Health Workforce Alliance launched the Agenda for Zero Discrimination in Health Care on 1 March 2016. The Agenda brings together all stakeholders for joint efforts towards a world where everyone, everywhere, is able to receive the health care they need with no discrimination. This includes by removing punitive laws, policies and practices that undermine people living with HIV, key populations and other vulnerable groups, or block their access to good quality healthcare services, and by empowering them to exercise their rights. It is also important to ensure that healthcare workers enjoy their labour rights free from stigma and discrimination.<sup>1415</sup>

#### *Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination*

During the 41st meeting of the UNAIDS Programme Coordinating Board (PCB) in December 2017, the NGO Delegation of the UNAIDS Programme Coordinating Board (PCB) called on the UNAIDS Joint Programme to take coordinated, concerted and accelerated action at country level to end HIV-related stigma and discrimination by establishing a *Global Partnership to End All Forms of HIV related Stigma and Discrimination*. The Global Partnership is co-convened by UNAIDS, UN Women, UNDP and the Global Network of People Living with HIV (GNP+), with leadership and support from the NGO delegation to the UNAIDS PCB. The initiative aims to support UN Member States to fulfill the human rights obligations to end HIV-related stigma and discrimination previously made at global, regional and national levels; establish and strengthen partnerships among stakeholders to implement and scale-up programmes to address HIV-related stigma and discrimination; and strengthen measurement and accountability towards the elimination of HIV-related stigma and discrimination.

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<sup>13</sup> [https://www.unaids.org/sites/default/files/media\\_asset/gam-lac-progress-zero-discrimination\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/gam-lac-progress-zero-discrimination_en.pdf)

<sup>14</sup> Agenda for Zero Discrimination in Healthcare ([https://www.unaids.org/sites/default/files/media\\_asset/Agenda-zero-discrimination-healthcare\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/Agenda-zero-discrimination-healthcare_en.pdf)).

<sup>15</sup> UNAIDS Background Note – Zero Discrimination in Healthcare Settings, 41<sup>st</sup> Programme Coordinating Board meeting, 12-14 December 2017 ([https://www.unaids.org/sites/default/files/media\\_asset/20171129\\_UNAIDS\\_PCB41\\_Zero\\_discrimination-health-care-settings\\_17.27\\_EN.pdf](https://www.unaids.org/sites/default/files/media_asset/20171129_UNAIDS_PCB41_Zero_discrimination-health-care-settings_17.27_EN.pdf)).

Recognizing that HIV-related stigma and discrimination can be found in every aspect of a persons' life, the Partnership will focus on six settings: individual, household and community; healthcare; education; workplace; justice system; and, humanitarian and emergency settings.<sup>16</sup>

The results of this work to develop summary measures of HIV-related stigma and discrimination will be aligned with the work of the Global Partnership. Summary measure(s) will focus on the situation or status of HIV-related stigma and discrimination and stigma and discrimination experienced by key populations. The monitoring framework to be developed and recommended by the Global Partnership will focus on the response, and monitoring implementation and results of the recommended programmes by settings to be proposed by the Global Partnership.

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<sup>16</sup> UNAIDS, 2018, Global Partnership for Action to Eliminate All Forms of HIV-Related Stigma and Discrimination ([https://www.unaids.org/sites/default/files/media\\_asset/global-partnership-hiv-stigma-discrimination\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/global-partnership-hiv-stigma-discrimination_en.pdf)).

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