THE
PEOPLE
LIVING
WITH HIV
**STIGMA
INDEX**

People Living with HIV
Stigma Index 2.0

GLOBAL REPORT 2023

HEAR US OUT: COMMUNITY MEASURING HIV-RELATED STIGMA AND DISCRIMINATION

THE
PEOPLE
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INDEX

ACKNOWLEDGEMENTS

This report was developed by the Global Network of People Living with HIV (GNP+) People Living with HIV Stigma Index (Stigma Index) team, with support from the International Community of Women Living with HIV (ICW), the Joint United Nations Programme on HIV and AIDS (UNAIDS), Johns Hopkins University (JHU) and Annette Gerritsen. We are grateful to the participants – people living with HIV - in all countries who contributed to this study by sharing their personal experiences and perceptions on the stigma that is attached to HIV in their country. GNP+ also extends its gratitude to the hard-working country teams who implemented Stigma Index 2.0. We also want to thank Jane Shepherd for the design of this report. With sincere thanks to UNAIDS for their technical and financial support for the Stigma Index programme.

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Contents

Foreword

All over the world, people living with HIV face persistent stigma and discrimination that continues to extensively affect our lives and how we access HIV prevention, treatment and care. Despite significant strides in medical advancements and global efforts to end AIDS, nine million people are still not on treatment and 630,000 people died from preventable AIDS-related causes in 2022. Social barriers like stigma and discrimination fuel inequalities in access to treatment.

The People Living with HIV Stigma Index (Stigma Index) is an evidence-gathering process for advocacy. While its main programme component focuses on community-led research to produce quality data, the overall programme goes beyond research and includes community mobilisation, capacity development and partnership building for targeted advocacy. This initiative stands as the most extensive and reliable tool for measuring the stigma and discrimination experienced by people living with HIV, providing important evidence that can contribute to the establishment of adequate policies and laws for creating a stigma- and discrimination-free environment for people living with HIV. Its genesis traces back to 2008, with the Stigma Index undergoing a transformation in 2018 with the advent of Stigma Index 2.0, followed by the launch of a standardised methodology in 2020.

While the Stigma Index has always been led by people living with HIV, the current methodology has strengthened the leadership role of people living with HIV across all stages of the implementation process. Additionally, due to strengthened technical support provided by GNP+ to national networks of people living with HIV leading the implementation at country level, they have taken on more technical roles in the process, thereby reducing the roles and responsibilities of the research partner.

This report emerges as a testament to the tireless dedication of countless people who have poured their hearts and souls into collecting and analysing data from the Stigma Index 2.0 studies conducted across 25 countries between 2020 and 2023.

In this report, we present the fruits of their labour – a tapestry woven from the experiences of over 30,000 individuals living with HIV. These stories, these numbers, paint a vivid picture of the current state of HIV-related stigma and discrimination worldwide. From the harsh glare of internalised stigma to the chilling winds of external discrimination, every facet of the struggle is meticulously examined.

Despite progress, many respondents continue to experience internalised stigma. Furthermore, to this day, a substantial number of people living with HIV experience high levels of stigma because of their HIV status. We hear the voices of those whose ability to find love or cope with stress is hampered, and we witness the disproportionate burden borne by key populations, where stigma and discrimination often cut deepest.

These findings, though disheartening, must motivate action for humanity. We are far from realising the vision set forth in the Global AIDS Strategy of reducing stigma and discrimination to below 10% by 2025. Young people, aged 18-24, and key populations are particularly vulnerable, demanding our immediate attention.

Policymakers, organisations and advocates must redouble their efforts in the fight against stigma and discrimination. It underscores the urgency of dismantling laws that target key populations: sex workers, people who use drugs and LGBTIQ+ people.

In this report, the stories of vulnerability and resilience offer inspiration to propel the HIV movement to keep their promise to end stigma and discrimination for all people living with HIV. It is the right thing to do.

Florence Riako Anam and Sbongile Nkosi
Co-Executive Directors
Global Network of People Living with HIV

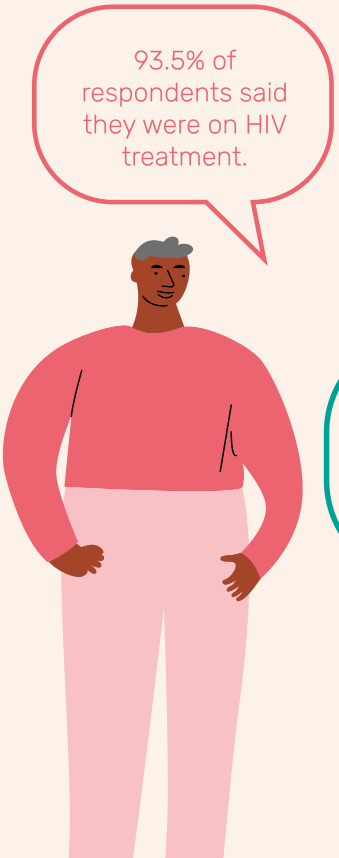
Key messages

In many countries, HIV-related stigma and discrimination, gender inequalities, and the criminalisation of drug use, sex work and same-sex sexual relationships continue to hamper access to services for people living with HIV. The People Living with HIV Stigma Index (Stigma Index) is led by people living with HIV and is the most widely used study to measure stigma and discrimination experienced by people living with HIV. In 2018, the questionnaire was updated (Stigma Index 2.0), and in 2020 a standardised methodology was launched. The aim of this report is to provide an overview of the current situation of HIV-related stigma and discrimination globally.

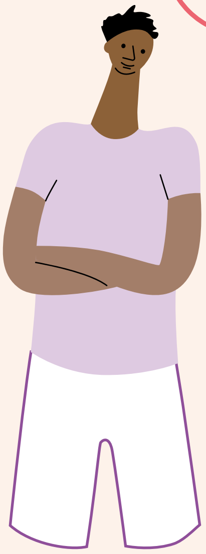
Data is drawn from Stigma Index 2.0 studies that used the standardised methodology and were conducted in 25 countries between 2020 and 2023. Participants were recruited using non-probability sampling, largely venue-based sampling and limited chain referral sampling. To be eligible, participants had to be adults and aware that they had been living with HIV for at least a year. Furthermore, gender and age diversity of the sample was ensured and at least a quarter of the sample was made up of people living with HIV from key populations (gay men and other men who have sex with men, sex workers of all genders, transgender people and people who use drugs of all genders).

The report presents results on a selection of indicators that cover the characteristics of people living with HIV; internalised HIV-related stigma; external HIV-related stigma and discrimination; and stigma and discrimination experienced by key populations.

The dataset includes the responses of 30,751 people living with HIV (average age 39 years, 53.9% assigned female at birth, 35.2% belonging to at least one key population group). The median time that respondents had known their HIV-positive status was six years, and 57.0% of all respondents indicated that at least one person knew their status, especially their (marital) partner or other family members. The vast majority (93.5%) of respondents said they were currently on HIV treatment or had ever been on treatment, and about a quarter of all respondents (26.9%) indicated that they had ever interrupted or stopped their HIV treatment.



Over a third of respondents felt ashamed to be HIV-positive.



INTERNALISED HIV-RELATED STIGMA

Overall, 84.8% of respondents agreed with one or more statements indicating internalised stigma. This figure stands at 37.6% for the Global AIDS Monitoring key indicator for internalised stigma, 'I am ashamed that I am HIV-positive'. Over a third (35.1%) of respondents living with HIV reported having adopted one or more of six behaviours during the past 12 months because of their HIV status. Of those behaviours, deciding not to have sex because of their HIV status was mentioned by the largest proportion of respondents (19.3%). Meanwhile, 20.6% of respondents indicated that the ability to meet one or more needs had been negatively affected by their HIV status over the past 12 months. The negative impact of one's HIV status on the ability to find love (24.6%) and to cope with stress (22.9%) was most frequently mentioned.

For all of the composite indicators as well as the key indicator for internalised stigma, the proportion decreased with increasing age and knowing one's HIV status for a longer time. The most common stigma-related reasons for interrupting or stopping treatment during the past 12 months were being worried that someone would find out their HIV status (34.6%) or not being ready to deal with their HIV infection (23.3%).

EXTERNAL HIV-RELATED STIGMA AND DISCRIMINATION

With respect to external HIV-related stigma and discrimination, particularly experiences in health care settings, **13.0% of all respondents reported having faced one or more experiences of stigma and discrimination due to their HIV status, perpetrated by health facility staff** working where they received their HIV care during the last 12 months. This proportion was almost double (24.9%) when looking at seeking care for non-HIV-related health needs (based on eight statements). For both types of services (HIV-specific health care and care for other health needs), being talked badly about or gossiped about (6.0% and 15.3%, respectively) and telling other people about the respondent's HIV status without consent (5.2% and 15.3%, respectively) were the most frequently mentioned experiences. Furthermore, among those who had ever stopped care or treatment for HIV at some point, 34.3% indicated that restarting was hampered due to their fear that health workers (doctors, nurses, staff) would treat them badly or disclose their status without their consent, and 16.5% indicated that it was because they had had a bad experience with a health worker previously.

In health care settings, the most frequent experience reported was being gossiped about.

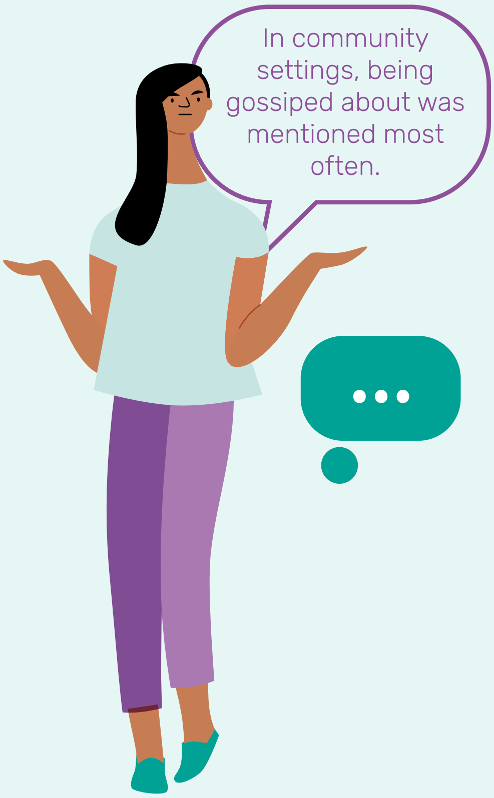
A quarter of respondents seeking non-HIV-related care faced stigma and discrimination.

HUMAN RIGHTS VIOLATIONS

Overall, 3.6% of all respondents indicated having been forced to get tested for HIV or disclose their HIV status for one or more of a list of five reasons during the past 12 months, most commonly in order to access health care services during the past 12 months (2.2%). In addition, 1.8% of respondents reported having experienced one or more of the other listed right abuses during the past 12 months, with having been forced to disclose their HIV status publicly or having had their status publicly disclosed without their consent being most frequently mentioned (0.9%). Among those who had experienced human rights abuses during the last 12 months, 73.0% had sought redress, most often filing a complaint (20.1%) or contacting a community organisation/network of persons living with HIV for support (19.8%).

73.0% of respondents sought redress after experiencing a human rights abuse.

Overall, 42.6% of respondents reported ever having taken some form of action to address external stigma, most commonly challenging or educating someone who was engaging in stigma and discrimination against other people living with HIV (32.3%) or towards the respondents themselves (26.5%).



STIGMA AND DISCRIMINATION IN COMMUNITY SETTINGS

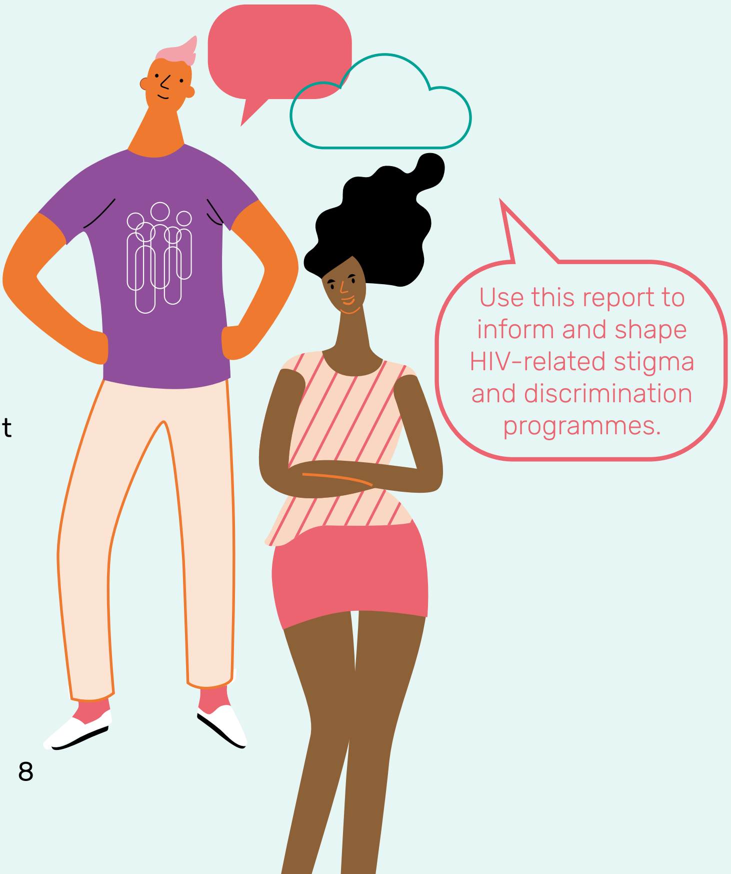
About a quarter of respondents (23.6%) reported that one or more experiences of stigma and discrimination due to their HIV status had occurred during the past 12 months, with being aware of people making discriminatory remarks or gossiping about them being mentioned most often (14.2% for 'other' people and 12.6% for family members).

STIGMA AND DISCRIMINATION AMONG KEY POPULATIONS LIVING WITH HIV

Reported incidents of one or more of seven experiences of stigma and discrimination that key populations faced due to reasons other than their HIV status during the past 12 months was highest among transgender people (49.4%), followed by gay men and other men who have sex with men (40.5%), and lowest among people who use drugs (27.0%) and sex workers (25.7%). Among all key population groups, these figures decreased with increasing age. The most frequently reported incidents were verbal harassment, being gossiped about by family members and being excluded from family activities. Reports of ever having had one or more of the listed experiences of stigma and discrimination were considerably higher compared to those occurring during the past 12 months.

CONCLUSION

In conclusion, the findings show that we are **far from achieving the Global AIDS Strategy goal of ensuring that by 2025**, less than 10% of people living with HIV experience stigma and discrimination. The results presented in this first global report on the Stigma Index can be used as a baseline for continued monitoring of HIV-related stigma and discrimination worldwide, to inform and shape policies at a global level and to influence organisations contributing to financing the HIV response. The findings show that continued programming is needed in countries to decrease both internalised and external HIV-related stigma and discrimination, with special attention to be given to interventions for key populations.



The People Living with HIV Stigma Index 2.0

In order for the world to get on track to end AIDS as a public health threat by 2030, the Global AIDS Strategy 2021-2026 sets out new targets to be reached by 2025. These can only be achieved in an environment where people living with HIV can use the services that will protect their health. However, in many countries, HIV-related stigma and discrimination; gender inequalities; and the criminalisation of drug use, sex work and same-sex sexual relationships continue to hamper access to these services. The Global AIDS Strategy requires that countries undertake reforms, so that by 2025:

- less than 10% of countries have legal and policy frameworks that lead to the denial or limitation of access to HIV-related services;
- less than 10% of people living with HIV and key populations experience stigma and discrimination; and
- less than 10% of women, girls, people living with HIV and key populations experience gender inequality and violence.

Source: UNAIDS (2020), Prevailing against pandemics by putting people at the centre.

To facilitate measuring and developing interventions to address HIV-related stigma, the People Living with HIV Stigma Index (Stigma Index) was developed in 2008 by GNP+, ICW, IPPF and UNAIDS. The Stigma Index is the most widely used study to measure stigma and discrimination experienced by people living with HIV. Advocacy is an essential part of the process. The aim is not just to understand the situation in a particular setting, it is also to inform and shape policies, practices and behaviour to remove stigma.

The Stigma Index is a continuous and systematic journey of activism to address HIV-related stigma and discrimination

Monitoring impact
Impact analysis to track progress on the quality of HIV services, legal environment, and financial investment in eliminating HIV-related stigma and discrimination

Stigma Index implementation
The Stigma Index is designed to be used by and for people living with HIV to collect evidence on HIV-related stigma and discrimination

Community mobilisation
The Stigma Index provides an opportunity to bring the community of people living with HIV together to collectively act on addressing HIV-related stigma and discrimination

Capacity development
The Stigma Index builds capacity in conducting community-led research

Partnership building
The Stigma Index fosters strategic partnerships between networks of people living with HIV and key stakeholders during the implementation and follow up activities

Advocacy
The Stigma Index strengthens community initiatives of evidence-based advocacy

The whole process – from planning and implementation of the study, to dissemination of the results and using the recommendations for advocacy work - is led by people living with HIV and guided by four key principles:

1. **Capacity building** – The lead network is expected to guide the entire implementation process, but is encouraged to work in collaboration with partners in country (such as research institutes), and technical assistance is available at every step of the way from the International Partnership.
2. **Accountability and ownership** – The Stigma Index centres around the GIPA principle, which calls for the Greater Involvement of People Living with HIV/AIDS. People living with HIV are not only the interviewers and the participants - the entire research design and implementation process is led by and for them.
3. **Embracing equality and diversity** – Whichever network takes the lead, all those involved in the implementation process should proactively work to ensure gender equality and to embrace the diversity that exists among the whole community of people living with HIV.
4. **Advocacy-oriented** – The data that is gathered through the Stigma Index enables a clear picture of stigma and discrimination to emerge. It also provides evidence for advocacy to shape policy and programmatic change, and to end HIV-related stigma and discrimination.

In 2016, the Population Council's Project SOAR and the International Partnership of the People Living with HIV Stigma Index (GNP+, ICW and UNAIDS; simply the International Partnership), undertook a process to update the Stigma Index to more fully capture the experiences of key populations living with HIV, as well as to respond to changes in global treatment guidelines and better understand the persistent barriers to HIV testing and treatment. The updated questionnaire – the Stigma Index 2.0 – was pilot tested in three countries (Cameroon, Senegal, Uganda), after which it was finalised in 2018.[1] In addition, in 2020, a standardised methodology was launched to ensure that the Stigma Index findings could be better compared over time and across different settings. By mid-2023, the standardised methodology had been used to implement the Stigma Index in 41 countries.

One of the benefits of a standardised approach is that it leads to a core set of indicators that are measured using a similar study design, enabling the combination of data from different countries. The aim of this report is to provide an overview of the current situation of HIV-related stigma and discrimination globally, and to shape the response to address HIV-related stigma and discrimination.

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[1] Throughout the report, Stigma Index relates to the latest Stigma Index 2.0 unless otherwise indicated.

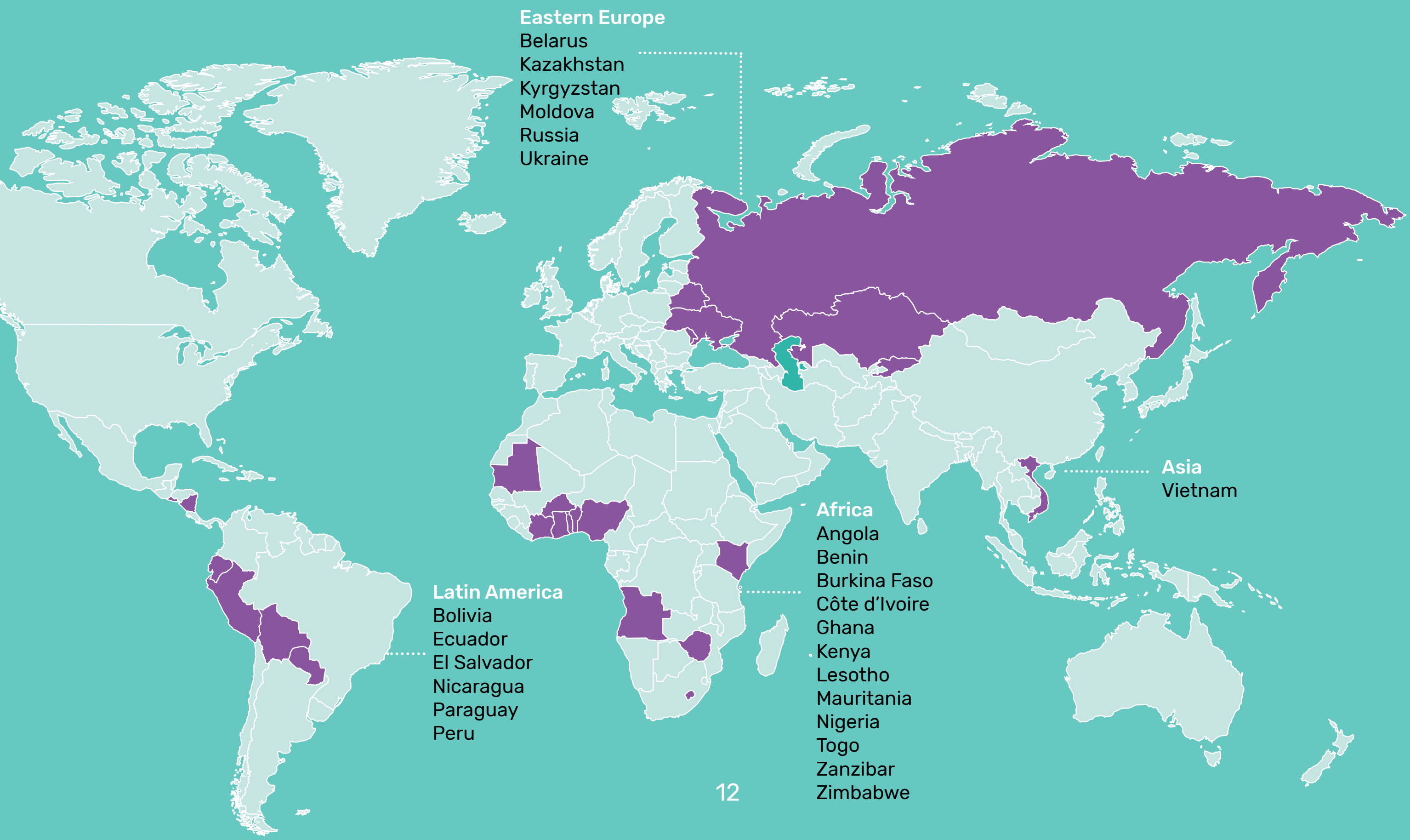
Standardised methodology

USING THE STANDARDISED METHODOLOGY

This report presents the data from Stigma Index 2.0 studies using the standardised methodology, conducted in 25 countries between 2020 and 2023. The studies all adhered to the six non-negotiable principles of the Stigma Index, namely that implementation:

1. must be led by networks of people living with HIV
2. must follow the 2020 standardised methodology
3. requires a sample that is inclusive of all sub-populations of people living with HIV
4. must comply with the International Partnership's review process on research protocol for quality assurance
5. must ensure that data is securely stored and shared with the International Partnership
6. must ensure that all presentations and reports produced from these analyses include authors from the implementing national network(s) of people living with HIV.

COUNTRIES CONTRIBUTING STIGMA INDEX 2.0 DATA IN THIS REPORT



Country data were included if the dataset was shared with the GNP+ Stigma Index team and cleaned by May 2023. Individual country reports can be accessed through www.stigmaindex.org.

Using the standardised methodology, participants were recruited using non-probability sampling. This included mainly venue-based sampling (e.g., at treatment facilities, community centres, association/network offices, hot spots, drop-in centres), as well as limited chain referral sampling (i.e., participants or community members used their networks to make people living with HIV aware of the study). The studies took place in selected sub-national areas in the country, which were chosen because at least 50% of the estimated number of people living with HIV in the country were living in these areas. Interviewers directly approached potential participants at venues or screened and selected those who were recruited by peers. To be eligible, participants had to be adults (18 years and older), aware that they were living with HIV for at least a year[2] and able to speak one of the languages being used for the questionnaire. Gender and age diversity of the sample had to be ensured, and at least a quarter of the sample had to be made up of people living with HIV from key populations (gay men and other men who have sex with men, sex workers of all genders, transgender people and people who use drugs of all genders).

Interviewers were people openly living with HIV in all their diversity, including people from key populations, young people and women. They were trained by the lead network (with support, where needed, from the research partner or International Partnership) to conduct the interviews and understand the background and overall goals of the Stigma Index. For each study, approval for implementation was obtained through the national ethical review board or equivalent body in its respective country. Everyone involved in the research - individuals and any service providers - were required to sign a confidentiality agreement. All participants provided informed consent before taking part in the study. The Stigma Index 2.0 was used in all studies, and included nearly 80 questions grouped into eight sections:

1. Sociodemographic information
2. Disclosure
3. Experiences of stigma and discrimination
4. Internalised stigma and resilience
5. Interactions with health care services
6. Human rights and affecting change
7. Stigma and discrimination experienced for reasons other than HIV status, and
8. A space for respondents to share anything else related to their experiences with stigma and discrimination.

The questionnaire was translated into local languages and pre-tested before use. This report is based on answers to a selection of about 50 of the included questions chosen by the International Partnership, with a key consideration being that the indicators were seen as being the most important across the different settings included.

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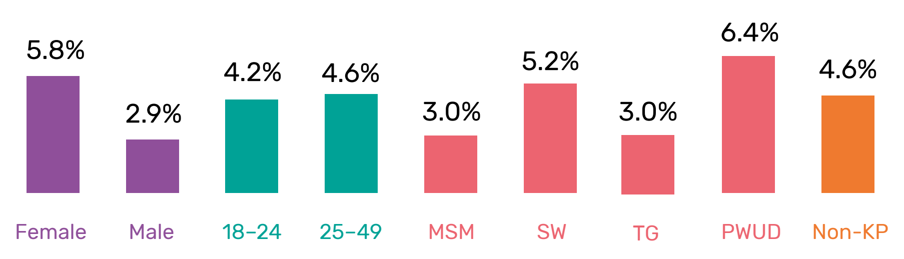
[2] Note that when receiving results from countries, it became clear that sometimes people who had known their HIV status for less than 1 year had also been included.

EXPLORING SRHR VIOLATIONS THROUGH THE STIGMA INDEX

The Stigma Index 2.0 standardised methodology captures key data about reported human rights violations experienced by people living with HIV while accessing sexual and reproductive health (SRH) services. Violations of sexual and reproductive health and rights (SRHR) pose significant challenges for the HIV response and represent an entrenched form of stigma and discrimination. To contextualise these experiences at the regional and country level, data on these experiences of human rights violations is explored more deeply in a parallel report, Confronting Coercion. This parallel research, led by ICW, combines qualitative research methods, a literature review, case studies and a focused gender analysis of recent data from available Stigma Index implementations to present the experiences of hundreds of people living with HIV around SRH services. The report explores experiences of SRHR violations and the ways that these violations are persistent, ongoing and structural, and provides recommendations for interventions to reduce and eliminate these experiences of discrimination. As there is a more comprehensive analysis available for this subject, we have limited the discussion of these findings in the current report and encourage readers to review the parallel report.

The figure below shows the experience of any human rights violations within SRH services during the last 12 months, disaggregated by sex, age and key population group (respondents aged 18-49 years).*



- Experiences of rights abuses in the context of SRHR have been reported in every Stigma Index Report.
- 4.2% of all respondents aged 18–24 years and 4.6% of respondents aged 25-49 years reported experiencing human rights violations in the context of SRH services.
- Among key populations, 5.2% of sex workers and 6.4% of people who use drugs experienced human rights violations in this context, compared to 4.6% who were not members of key populations.
- Twice as many females (5.8%) as males (2.9%) reported having experienced human rights violations in the context of SRH services within the last year.
- Women, including women from key populations, disproportionately experienced human rights violations in the context of SRHR.

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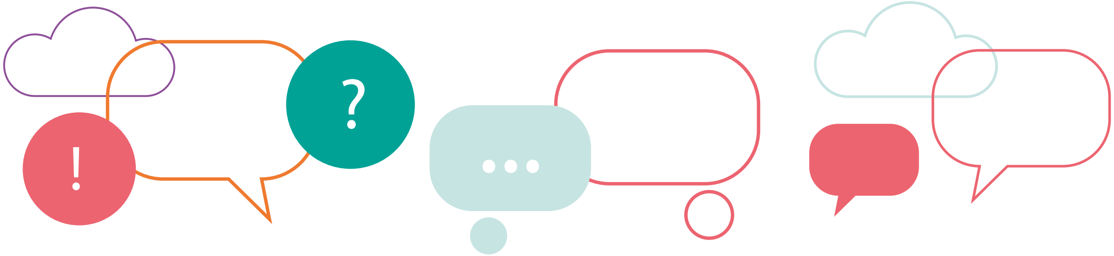
* MSM (gay men and other men who have sex with men, SW (sex workers), TG (transgender people), PWUD (people who use drugs), non-KP (people living with HIV who are not part of a key population group).

Digital data collection using tablets or mobile devices was recommended, although paper-based data collection or a combination of both were also used. For this global report, data quality control additional to what was conducted in country was implemented by having two or more reviewers inspect the data at various points in the data management process. Steps included cleaning individual country datasets utilising respective codebooks, evaluating the datasets with summative measures to ensure consistent coding of responses, troubleshooting when merging various datasets and assessment of the data in the case of unexpected findings during the analysis. Although countries used the standardised methodology, variations in implementation rigour led to differences in data quality that were later corrected – where possible – through the quality control process. Descriptive analyses, including frequency distributions (numbers and proportions) and measures of central tendency (mean and median), as well as cross-tabulation between variables were done in STATA and RStudio. Results were disaggregated across age groups[3], sex[4] and/or key population groups[5] where relevant, feasible and/or sufficiently powered (large enough sample). No significance testing was conducted.

In addition to presenting the quantitative data from the Stigma Index, the report includes data from ten interviews that were conducted with representatives from country networks, the International Partnership and key stakeholders. The aim of these interviews was to report on the technical assistance provided by the International Partnership for implementation of the Stigma Index, as well as on using the Stigma Index for monitoring and advocacy.

The findings presented in this report have undergone review by both the International Partnership as well as the networks of the countries included in the analyses.



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[3] Whenever there was a trend visible by age, analysis was also conducted by length of time that respondents had known their HIV status (less than 2 years, 2-<5 years, 5-<10 years and more than 10 years) to see if the trend was the same, as a statistically significant relationship was found between these two variables. Narrative results for the latter analysis are included in the text.

[4] Disaggregations are presented for sex assigned at birth, not gender, due to the limited number of respondents not identifying as cisgender and hence a lack of statistical power.

[5] For all analyses by key population group, the following criteria were used to categorise respondents: transgender people included respondents who identified as transgender, non-binary, or as people who were assigned a gender at birth that did not match their current gender identity; gay men and other men who have sex with men included respondents who identified as men who have sex with men, gay/homosexual or as having ever had sex with another man; sex workers included respondents who had ever had sex in exchange for money or goods or who identified as sex workers; and people who use drugs included respondents who had ever injected or habitually used drugs such as heroin, cocaine, or methamphetamines, or who identified as a person who uses (or used) drugs. The non-key population group comprised all other people living with HIV. However, it should be acknowledged that some respondents belonging to key population groups might not have disclosed this through the criteria questions, and hence were (incorrectly) included in the group of people living with HIV who were not part of a key population group. Nevertheless, since this was assumed to be a small number of respondents, disaggregation by key population group included the category 'non-KP'.

TECHNICAL ASSISTANCE FOR PLHIV-LED IMPLEMENTATION: COUNTRY AND REGIONAL CASE STUDIES

The International Partnership provides technical assistance to networks of people living with HIV throughout the Stigma Index implementation process, from the very first conversation about the possibility of conducting a Stigma Index study to the final report and advocacy.

The introduction of a standardised methodology led to an intensified need for technical assistance. This was not only because support was needed to ensure high quality implementation of the Stigma Index 2.0, but also because the number of countries implementing the study increased. Technical assistance provided by the International Partnership starts with supporting networks to begin the process and to ensure that implementation adheres to the six non-negotiable principles of the Stigma Index, followed by feedback on their protocols and reports. While some of the technical assistance provided is standardised across all studies, other aspects are tailored to the needs of the leading people living with HIV network(s) and the country context.

As more countries have gone through a first study round with the standardised approach, over time the focus of the support has shifted from the earlier phases in the process (preparation, planning, data collection) to data cleaning and analysis, prioritisation of indicators for reporting and the reporting format. John Hopkins University is currently working on a more detailed protocol template as well as clear guidance on how to clean, manage and analyse data. The expectation is that in the future, the focus of technical assistance will shift to the use of data for advocacy purposes and to support for qualitative aspects of the Stigma Index. Technical assistance beyond the aforementioned activities – such as support for writing a concept note (including budget) to obtain funding for the Stigma Index, sample size calculation and training of interviewers – is limited. Currently, almost all support is provided remotely through virtual trainings and meetings, support calls, emails and collaborative document review. Additional funding could make technical assistance more robust and enable more on-site support, which is especially important for building relationships with the networks.

In addition to the technical assistance described above, the Stigma Index Academy (a set of short courses) builds awareness among the community of people living with HIV on the need for the Stigma Index programme, its principles, the process of implementation and how the data can be used for advocacy. ICW also provides technical assistance to strengthen the engagement of networks of women living with HIV in Stigma Index processes. This includes support to obtain funding for Stigma Index implementation, support for equitable implementation and gender analysis of Stigma Index results and support to use the results to develop policies on gender-related issues.

With respect to supporting **gender analysis**, in September 2022, ICW conducted its Gender Equity in the Stigma Index (GESI) Workshop in Paraguay in partnership with Fundación Vencer, the lead implementing national network, and the regional coordinator of Stigma Index 2.0 implementation in the Latin American countries. The four-part GESI workshop series provides technical guidance to ensure gender equity in all aspects of the implementation process. This first workshop focused on developing a gender analysis framework and core tools for conducting the analysis. As a result, participants took key intersectional gender analysis tools into their collective data analysis work, ultimately including an intersectional gender analysis focusing on the experiences of women in the Latin American multi-country report.

Notably, the report disaggregated data by gender, allowing for a rich analysis of gendered experiences of stigma and discrimination. It drew from a diverse sample and highlighted key findings: cisgender women, particularly those living with HIV, face elevated unemployment rates and a higher likelihood of engaging in unpaid domestic work, which impacts their socio-economic well-being. Transgender women, on the other hand, experience even higher rates of HIV-related stigma in multiple settings, including health care and community settings. As a result, recommendations included strengthening the multisectoral response, implementing a gender-focused approach to education and providing scholarships to vulnerable populations, with a specific focus on cisgender and transgender women.

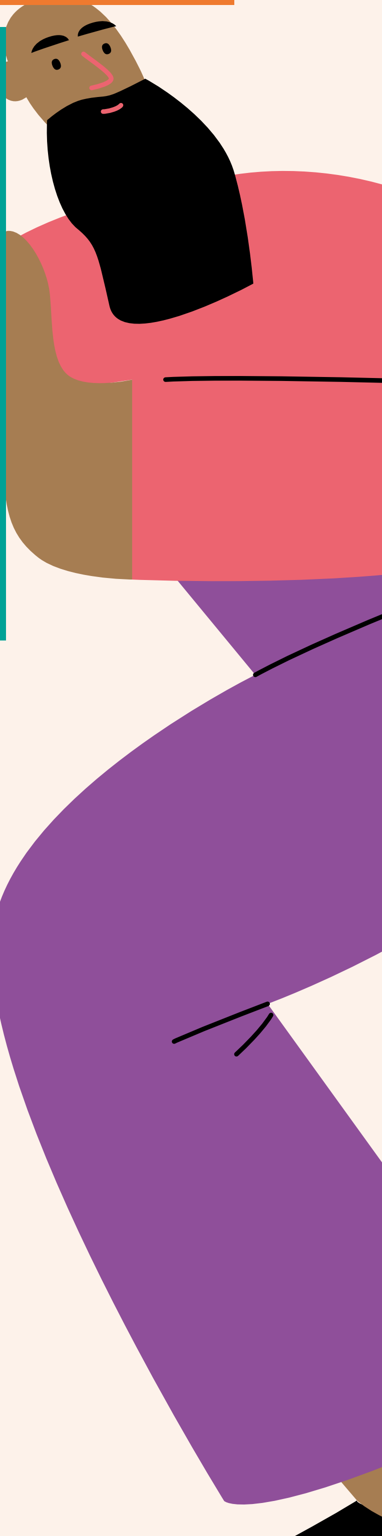
CASE STUDY: SUPPORTING PEOPLE LIVING WITH HIV LEADERSHIP IN MOROCCO

At the time of Stigma Index implementation (planned for 2019, but conducted in 2021-22 due to the COVID-19 pandemic), there was no active network of people living with HIV in Morocco. In order to do justice to the GIPA principle and at the same time acknowledge the country context, a people living with HIV committee was established to lead the implementation of the Stigma Index 2.0.

The International Partnership assisted with the terms of reference for the committee and the appointment of the country coordinator. Even though the committee is not a legally registered organisation, and the research institute therefore needed to receive the funding for the study, the Memorandum of Understanding ensured that the committee was in charge of the planning, budget and implementation. Implementation of the Stigma Index has now been finalised, but there are continued efforts to legally register the committee as a network of people living with HIV.

CASE STUDY: SOUTH-SOUTH LEARNING FOR REPORT WRITING IN LESOTHO

Staff of the Lesotho Network of People Living with HIV and AIDS (LENEPWHA), along with networks of other countries, received in-person training on the standardised approach at the beginning of 2020. In combination with remote support from the International Partnership during all phases of Stigma Index 2.0 implementation - completing the intake form, developing the protocol and budget, collecting data using REDCap and conducting data analysis - LENEPWHA successfully implemented the study in 2021 (with some delays due to COVID-19 lockdowns). When reviewing the draft report, the International Partnership identified a need for additional writing support and assisted with hiring a South African consultant to help the local consultant with data interpretation, language and formatting.



CASE STUDY: ON-SITE TRAINING OF IMPLEMENTING STAFF IN INDONESIA

The national network of people living with HIV in Indonesia, Jaringan Indonesia Positif (JIP), started writing their proposal for Stigma Index 2.0 implementation in November 2022. Besides several rounds of feedback on the protocol (both in writing as well as through discussions in virtual meetings), the International Partnership also assisted with the training of staff involved in implementing the study. Two staff members were invited by the network to provide on-site training to the research staff at the national level, the regional research field coordinators, data entry officers and around 50 interviewers. The training included general information on the purpose and methodology of the Stigma Index and how it could be used for advocacy, as well as specific content on data collection - for example, how to deal with sensitive information during data gathering and analysis. The researchers were also assisted with setting up the questionnaire in SurveyMonkey, and interviewers received two additional trainings, one of which was supported virtually by the International Partnership. The network greatly appreciated that one of the technical assistance providers knew the local context.

CASE STUDY: DEVELOPING A REGIONAL REPORT FOR LATIN AMERICA

In Latin America, five countries - Bolivia, Ecuador, Nicaragua, Paraguay and Peru - implemented the Stigma Index 2.0 around the same time. A regional coordinator was contracted to provide technical support to the national coordinators and oversee implementation of the entire project. Using the materials developed by the International Partnership (implementation guide, research protocol and report writing template), the five countries went through the implementation process together. The standardised approach made it possible to develop not only five country-specific reports, but also a regional report. The International Partnership provided guidance by sharing the West Africa regional report and lessons learned in its development, validated the different country datasets to ensure data consistency and reviewed the final Latin America regional report itself. One recommendation that followed from this process was to develop a standardised plan to assist countries in the analysis of their respective datasets.

Characteristics of people living with HIV

This section presents background information on the sociodemographics and characteristics of the people living with HIV included in this multi-country analysis. Data should not be understood as describing all people living with HIV, but rather should be read as a snapshot of respondents' characteristics and lived experiences. This information provides context that can be important when interpreting the experiences of stigma and discrimination discussed in the next sections. Note that the distribution of some of the characteristics is determined by the sampling strategy used. Some of these characteristics include, for example: minimum age, minimum duration of knowing their status, number of treatment naïve respondents, gender and age diversity, proportion of respondents with a key population background and distribution over the different key populations groups.

The dataset includes the responses of 30,751 people living with HIV (average age 39 years, 53.9% assigned female at birth, 35.2% belonging to at least one key population group). The median period of time that respondents had known their HIV-positive status was six years, and 57.0% of all respondents indicated that at least one person knew their status, especially their (marital) partner or other family members. The vast majority (93.5%) of respondents said they were currently on HIV treatment or had ever been on treatment, and about a quarter of all respondents (26.9%) indicated that they had ever interrupted or stopped their HIV treatment.

SOCIODEMOGRAPHICS

A total of 30,751 people living with HIV have been included in the analyses. The average age of respondents was 39 years, ranging from 18 to 100 years. Most respondents fell into the 25-49 age category (73.3%), followed by those aged 50+ years (17.7%) and those aged 18-24 years (9.0%).

Just over half of the respondents (53.9%) were assigned female at birth, while 46.1% were assigned male at birth. Respondents' self-identified gender is provided in **Figure 1**.

Of all respondents, 35.2% belonged to at least one key population group, with the distribution for the separate groups provided in **Figure 2**. Furthermore, 18.2% of respondents self-identified as members of a racial, ethnic or religious minority; 14.8% as part of an indigenous/aboriginal group; 6.6% as living with a disability; 5.8% as internally displaced persons; 5.8% as having been incarcerated/in prison; 3.2% as migrant workers; and 1.2% as refugees or asylum seekers.

Figure 1. Respondents' gender identity

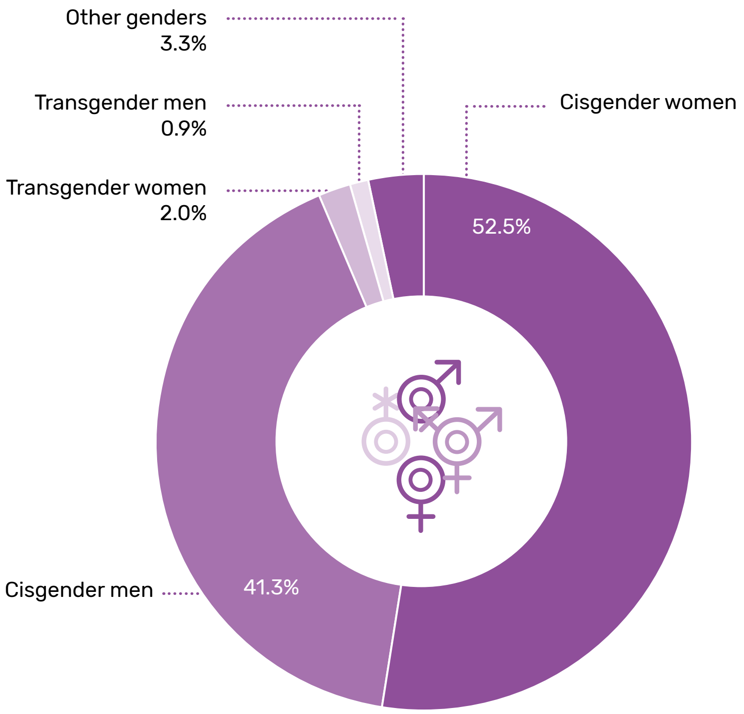
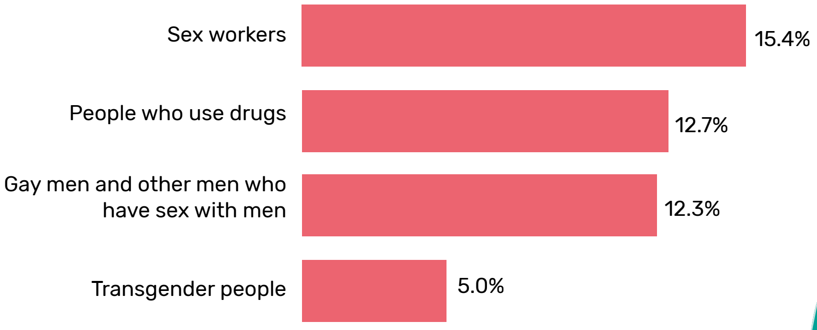


Figure 2. Proportion of respondents by key population*



* Respondents could be part of more than one key population.

Figure 3. Highest level of education completed by respondents

About a tenth (9.6%) of respondents reported currently pursuing any type of formal education. The highest level of education completed by respondents can be found in **Figure 3,** with just over a third indicating not having completed any formal education or only having completed primary education.

Respondents' employment status is presented in **Figure 4**, with a third being unemployed. About a quarter (24.1%) of respondents reported having been able to meet their basic needs (e.g., food, shelter or clothing) most of the time during the last 12 months, with a further 50.3% reporting that this was the case only some of the time.

Nearly a third (31.5%) of respondents said they were a member of a network or support group of people living with HIV, with **Figure 5** showing the proportions by sex, age, and key population group. Females were more often part of a network, as were older respondents (50+ years), those who had known their status for a longer time (5-<10 and especially 10+ years), sex workers and people living with HIV who did not belong to a key population.

Figure 4. Employment status of respondents

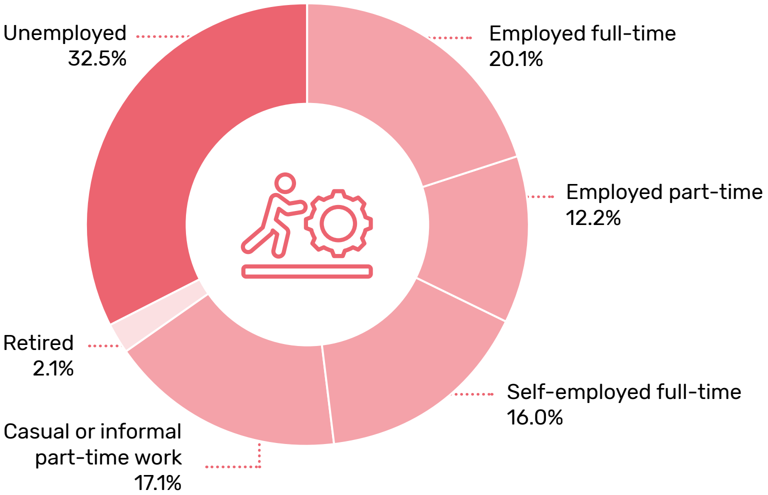
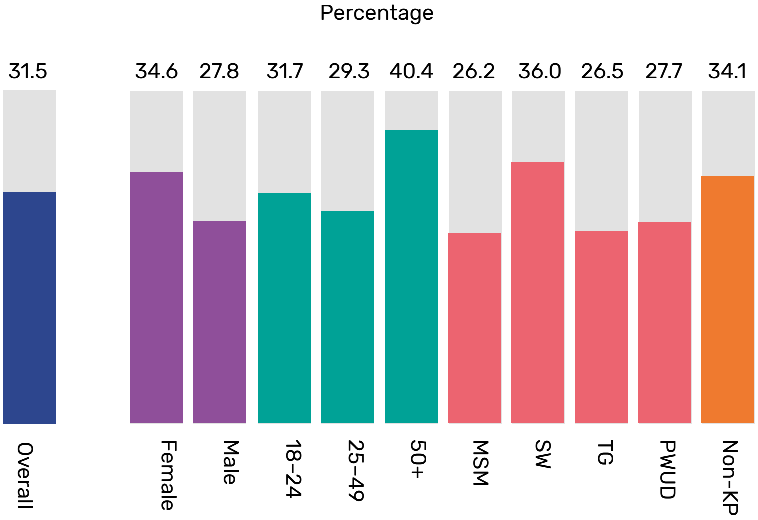


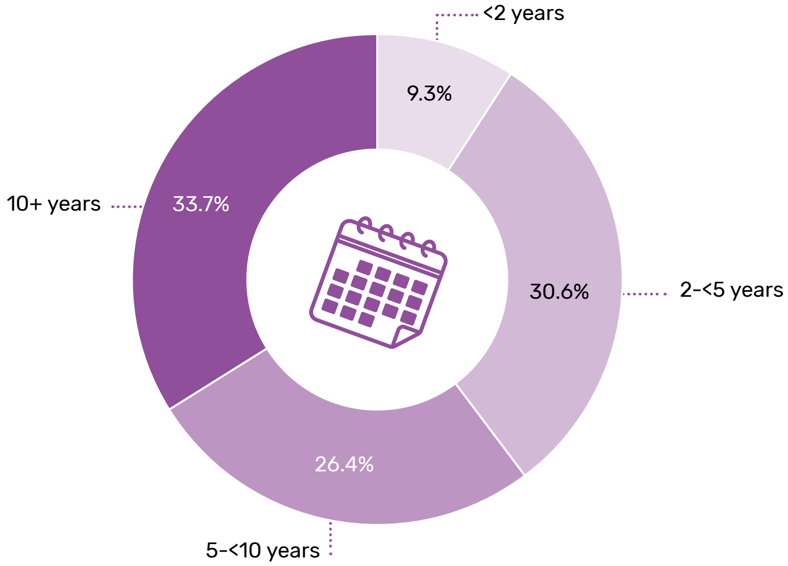
Figure 5. Membership of a network/support group of people living with HIV



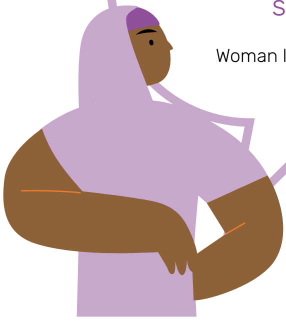
CHARACTERISTICS RELATED TO HIV STATUS

The median period of time that respondents had known their HIV-positive status was six years, ranging from less than a year to 40 years. The length of time that respondents had known their HIV status can be found in **Figure 6**. Over half (62.4%) of all respondents indicated that they were in an intimate/sexual relationship, with 47.6% of those respondents saying they had a partner(s) who was also living with HIV, 36.3% saying they had a seronegative partner(s) and 16.1% saying they were unsure of the status of their partner(s). Nearly two-thirds (63.6%) of all respondents were also taking care of children who lived in their household, with 26.7% of those respondents reporting having one child, 27.2% having two children and 46.1% having three or more.

Figure 6. Length of time that respondents had known their HIV status



> "I told my husband about my HIV… He didn't make a problem of it; on the contrary, he encouraged and supported me. Our relationship as a couple was strengthened."
>
> Woman living with HIV and disability, Burkina Faso



Over half (57.0%) of all respondents indicated that at least one of the persons listed in **Figure 7** knew their status, with the highest proportion indicating this to be their husband/wife/partner(s), followed by other family members, friends and children. Nearly half (49.8%) indicated that people they were close to (e.g., partner, family, close friends) were supportive when they first learned about their HIV status, compared to 18.8% for people they don't know very well. Nearly half (48.7%) also reported that disclosing their HIV status had become easier over time, and 45.8% indicated that disclosing

Figure 7. People who know respondent's HIV status

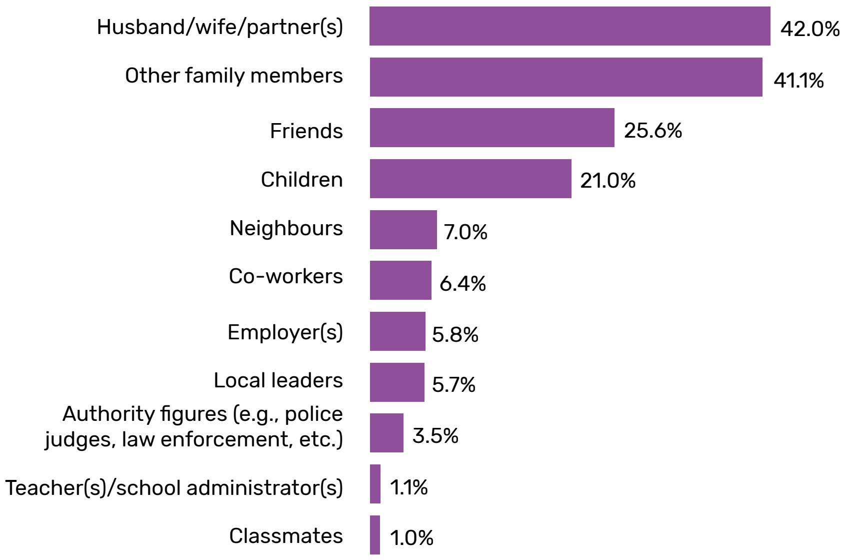
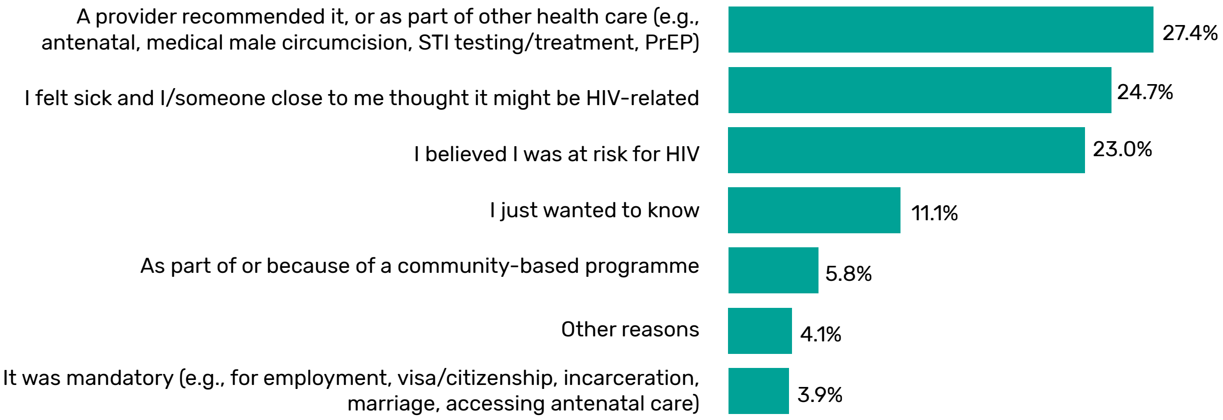


Figure 8. Main reasons for respondents to get tested for HIV

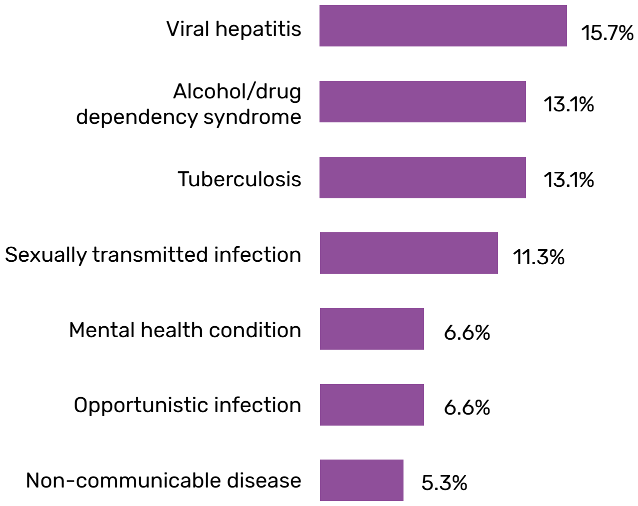


their HIV status to people they were close to had been a positive experience (compared to 18.6% for disclosing to people they didn't know very well). For those who had been living with HIV for ten years or more, a higher proportion agreed or somewhat agreed that disclosing their HIV status had become easier over time (61.1%), compared to those who had known their status for a shorter duration (50.3% 5-<10 years, 43.2% 2-<5 years and 42.7% less than 2 years).

Out of all respondents, 74.9% indicated that they had chosen to get tested for HIV themselves, 12.3% had been tested without their knowledge (and only found out after the test had been done), 9.1% had chosen to get tested but were pressured by others, 2.0% had been forced to take a test without their consent and 1.8% had been born with HIV or had acquired HIV in infancy/childhood. For those who had chosen to get tested, the main reasons were because it was recommended by a provider or as part of other health care provision, because the respondent was sick or because they believed themselves to be at risk of HIV (**Figure 8**). Over a third (38.8%) hesitated to get tested due to fearing other people's reactions to a positive test, with this fear being more prevalent among younger respondents compared to older respondents (45.5% among those aged 18-24 years, 39.5% among those aged 25-49 years and 32.8% among those aged 50+ years). This fear was also more prevalent among those who had known their HIV status for a shorter period of time (<10 years).

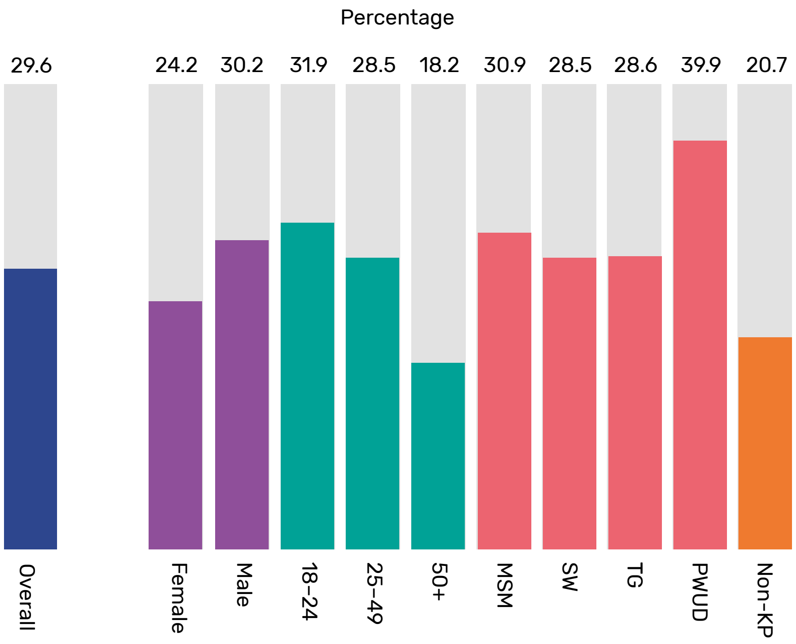
Over a third (39.5%) of respondents reported having been diagnosed with at least one condition that could be related to HIV or would be considered important by people living with HIV for their health. **Figure 9** shows the distribution for each of the diseases. Of those diagnosed, 40.8% indicated they had not been offered treatment for one or more of these conditions.

Figure 9. Respondents diagnosed with conditions other than HIV in the last 12 months



The vast majority (93.5%) of respondents said they were currently on HIV treatment or had ever been on treatment. About a quarter of all respondents (26.9%) indicated that they had ever interrupted or stopped their HIV treatment. Older people (50+ years) indicated this less often (with no difference based on how long they had known their HIV status), while males interrupted or stopped their HIV treatment more often (**Figure 10**). When looking at key population groups, reports of treatment interruptions were highest among people who use drugs and lowest among people living with HIV who do not belong to a key population group.

Figure 10. Respondents who ever interrupted or stopped HIV treatment



Internalised HIV-related stigma

People living with HIV hear and experience the same negative messages about HIV as people who are HIV-negative. This can lead to people judging, shaming or even hating themselves, and causes them to limit their own access to social, health, spiritual, family and other support systems out of fear of being judged or based on a belief that they don't deserve to be cared for. This is internalised stigma. It has also been linked to the refusal to accept antiretroviral therapy among newly diagnosed people living with HIV and to non-adherence among those on treatment. The Stigma Index focuses on internalised stigma in order to measure and monitor how these external messages, once internalised, limit the quality of life and access to and uptake of services for people living with HIV.

Overall, **84.8% of respondents agreed with one or more of six statements indicating internalised stigma.** This figure stands at 37.6% for the Global AIDS Monitoring key indicator for internalised stigma, 'I am ashamed that I am HIV-positive'. Over a third (35.1%) of respondents living with HIV had adopted one or more of six behaviours during the past 12 months because of their HIV status. Of those behaviours, deciding not to have sex because of their HIV status was mentioned by the largest proportion of respondents (19.3%).

Meanwhile, **20.6% of respondents indicated that the ability to meet one or more of ten needs was negatively affected by their HIV status over the past 12 months.** The negative impact of one's HIV status on the ability to find love (24.6%) and to cope with stress (22.9%) was most frequently mentioned. For all of the composite indicators as well as the key indicator for internalised stigma, the proportion decreased with increasing age (and knowing one's HIV status for a longer time).

About a quarter of all respondents (26.9%) indicated that they had ever interrupted or stopped their HIV treatment. The most common stigma-related reasons for interrupting or stopping treatment in the past 12 months were being worried someone would find out their HIV status (34.6%) or not being ready to deal with their HIV infection (23.3%).

"I couldn't tell anyone, because if I did, the stigma would be unbearable. I had to change my school, and my parents are still not aware of my status."

Young person living with HIV, Nigeria

Global AIDS Monitoring uses agreement with the statement 'I am ashamed that I am HIV-positive' as the key indicator to measure the percentage of people living with HIV who report internalised stigma. Based on that definition:

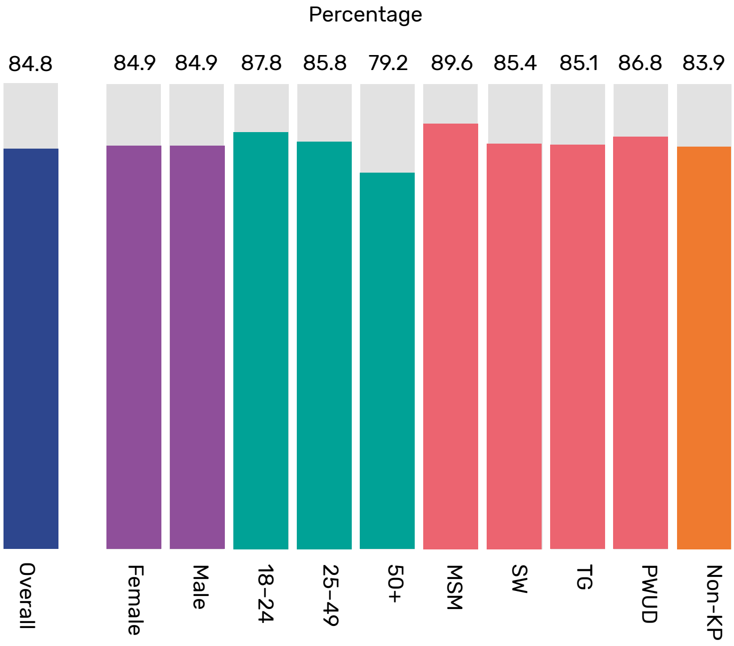
- More than a third (37.6%) of all respondents reported internalised stigma;
- This proportion decreased with increasing age - 44.5% among those aged 18-24, 38.5% among those aged 25-49 and 30.0% among those aged 50+ years – as well as with length of time for knowing one's HIV status;
- Over a third of female (38.6%) and male (36.4%) respondents reported internalised stigma;
- The proportion was higher among key population groups compared to other people living with HIV (33.4%): 40.2% among people who use drugs, 39.4% among transgender people, 39.3% among men who have sex with men and 39.1% among sex workers.

Data on agreement with all statements related to internalised stigma is presented in **Table 1.** The majority of respondents found it difficult to tell people that they were HIV-positive and reported hiding their status from others. Overall, 84.8% of respondents agreed with one or more of the six statements indicating internalised stigma, with the proportion by sex, age and key population group displayed in **Figure 11**. The proportion in agreement was lowest among those aged 50+ years (as well as among those who had known their status for ten or more years). Furthermore, of those who were part of a network or support group of people living with HIV, 80.2% agreed with one or more of six statements on internalised stigma, while this figure was 87.1% among those who were not part of a network or support group of people living with HIV.

Table 1. Agreement with statements on internalised stigma

	n	%
It is difficult to tell people that I am HIV-positive	21,749	70.8%
I hide my HIV status from others	20,742	67.6%
I am ashamed that I am HIV-positive	11,534	37.6%
I feel guilty that I am HIV-positive	11,225	36.6%
I sometimes feel worthless because I am HIV-positive	9,280	30.2%
Being HIV-positive makes me feel dirty	7,082	23.1%

Figure 11. Agreement with one or more of six statements on internalised stigma



Over the past 12 months, respondents reported adopting certain behaviours because of their HIV status (**Table 2**). Of those behaviours, deciding not to have sex because of their HIV status was mentioned by the largest proportion of respondents.

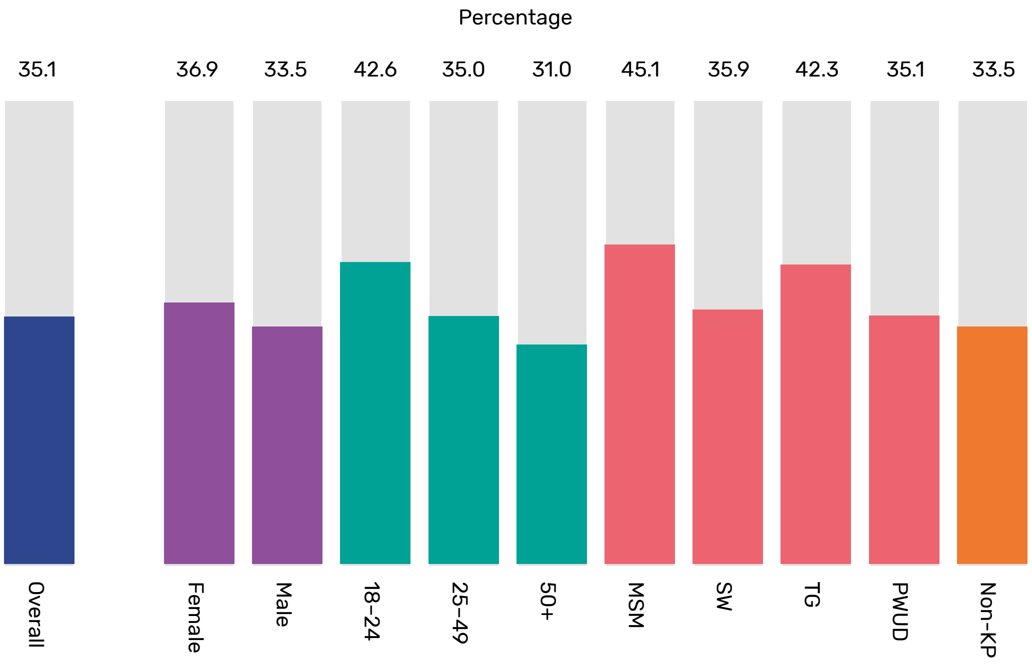
Over a third (35.1%) of respondents living with HIV adopted one or more of six behaviours in the past 12 months, and the proportion decreased with increasing age, as can be seen from **Figure 12**. This proportion was also lower for those who had known their status for five or more years. Results are displayed by sex, age and key population group.

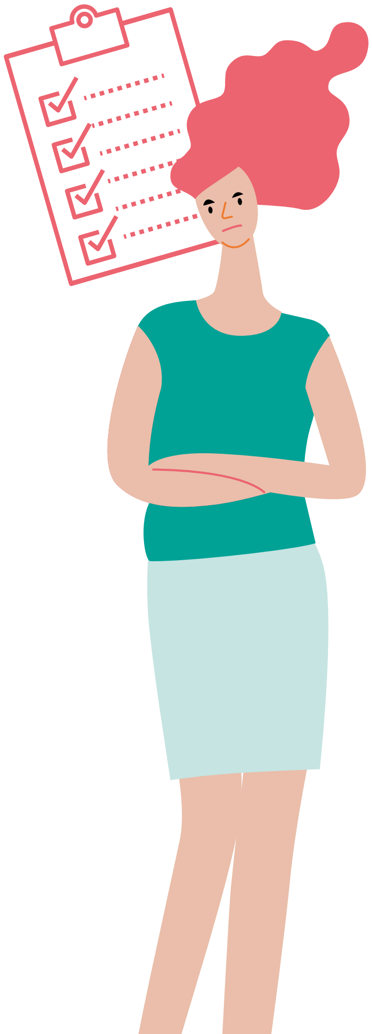
However, of those who were members of a network or support group of people living with HIV, 32.3% adopted one or more of six behaviours because of their HIV status, while this figure was 36.3% among those who were not members.

Table 2. Adoption of behaviours because of HIV status in the past 12 months

	n	%
I decided not to have sex	5,676	19.3%
I have isolated myself from family and/or friends	4,588	15.2%
I have chosen not to attend social gatherings	4,464	15.0%
I avoided going to a clinic or hospital when I needed to	4,017	13.3%
I have chosen not to seek social support	3,638	12.5%
I have chosen not to apply for job(s)	3,162	12.0%

Figure 12. Adoption of one or more of six behaviours because of HIV status in the past 12 months



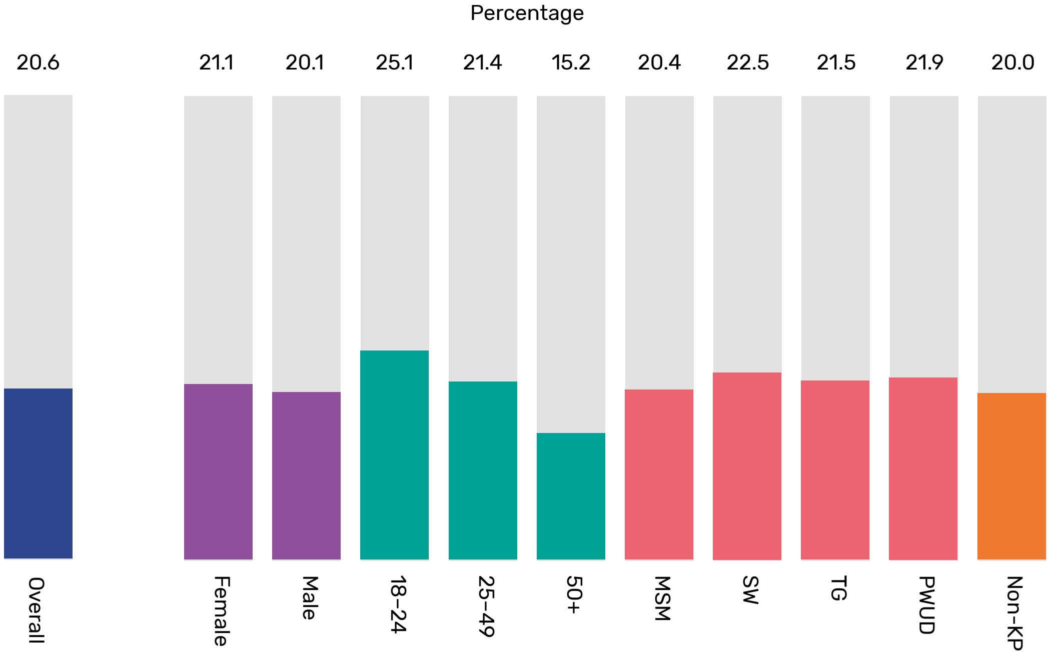


Furthermore, respondents indicated that their ability to meet several needs had been negatively affected by their HIV status over the past 12 months (**Table 3**). The negative impact of one's HIV status on the ability to find love and to cope with stress was most frequently mentioned. **Figure 13** reports on the proportion of respondents who indicated that the ability to meet one or more of ten needs was negatively affected by their HIV status over the past 12 months, with data disaggregated by sex, age and key population group. The proportion was lower among older respondents (50+ years) and decreased as the length of time of knowing one's HIV status increased (although differences were small). Overall, this was 20.6% of respondents living with HIV.

Table 3. Ability to meet needs negatively affected by HIV status over the past 12 months

	n	%
Ability to find love	6,874	24.6%
Ability to cope with stress	6,819	22.9%
Self-confidence	6,668	22.0%
Ability to have close and secure relationships with others	6,459	21.9%
Desire to have children	6,257	24.8%
Ability to achieve personal and/or professional goals	4,910	17.2%
Self-respect	4,668	15.7%
Ability to contribute to my community	3,090	11.1%
Ability to respect others	2,490	8.4%
My ability to practice a religion/ faith as I want to	2,245	8.3%

Figure 13. Ability to meet one or more of ten needs negatively affected by HIV status over the past 12 month



Study findings also showed that internalised stigma was the most frequent reason for non-adherence to treatment:

- Nearly a fifth (19.6%) of respondents indicated that fear of someone learning their HIV status had led to missing a dose of their HIV treatment. This decreased considerably with increasing age – 28.0% among those aged 18-24, 20.6% among those aged 25-49 and 12.2% among those aged 50+ years – and decreased a bit with increasing length of time of knowing one's HIV status. Among key populations, this figure was highest for sex workers (27.3%) and transgender people (25.9%), compared to 22.7% among people who use drugs and 21.0% among men who have sex with men, and 17.3% among people living with HIV who were not part of a key population group.
- The most common stigma-related reasons for interrupting or stopping treatment in the past 12 months were being worried someone would find out their HIV status (34.6%) or because they were not ready to deal with their HIV infection (23.3%).
- Among those who had ever stopped care or treatment for HIV, the most frequently mentioned reasons for making them hesitate, delay or prevent restarting were similar to those for why they interrupted or stopped in the first place: because they were worried that people would find out their status – particularly their partner(s), family or friends (46.0%) or other people (48.0%) – or because they were not ready to deal with their HIV infection (47.0%).

Respondents also indicated non-stigma related reasons for not currently being on HIV treatment or for ever having stopped in the past, mainly because:

- they could not tolerate the side effects of the medication (18.1%)
- medication was not available at the clinic (based on policy or stock outs) (13.8%)
- did not feel that treatment was needed (9.8%)
- were unable to collect medication at the clinic or pharmacy (9.5%)
- medication was not affordable for them (6.8%).

External HIV-related stigma and discrimination

Discrimination is a human rights violation and in the context of HIV refers to unjust treatment of an individual based on their HIV status. Stigma, the attribution of undesirable characteristics to an individual or group that reduces their status in the eyes of society, frequently drives experiences of discrimination. The health sector is one of the settings where people living with HIV experience discrimination, but they also experience it in the communities they live in. Measuring discrimination experienced by people living with HIV when seeking health care services as well as in the community offers valuable information on the programmatic responses needed to address this.

This section presents the experiences of stigma and discrimination that are directed towards people living with HIV by others. It covers experiences of discrimination related to health care settings, human rights violations and in community settings.

HEALTH CARE SETTINGS

Analysis of stigma- and discrimination-related experiences in health care settings shows that 13.0% of all respondents have faced one or more experiences of stigma and discrimination due to their HIV status, perpetrated by health facility staff working where they received their HIV care during the last 12 months. This proportion was almost double (24.9%) when looking at seeking care for non-HIV-related health needs (based on eight statements). For both types of services (HIV-specific health care and care for other health needs), being talked badly about or gossiped about (6.0% and 15.3%, respectively) and telling other people about the respondent's HIV status without consent (5.2% and 15.3%, respectively) were the most frequently mentioned experiences. Furthermore, among those who ever stopped care or treatment for HIV, 34.3% indicated that restarting was hampered due to their fear that health workers (doctors, nurses, staff) would treat them badly or disclose their status without their consent, and 16.5% indicated that it was because they had had a bad experience with a health worker previously.

> "The doctor disclosed my status during a ward round. After that, I had to be discharged from the hospital without treatment because of the negative attitudes towards me there."
>
> Person living with HIV, Belarus

Thirteen per cent of all respondents reported having faced one or more of seven experiences of stigma and discrimination due to their HIV status, perpetrated by the health facility staff who worked where they received their HIV care during the last 12 months. The proportion was much higher among key populations compared to other people living with HIV (**Figure 14**). **Table 4** presents the proportions for each of the experiences over the past 12 months. The most frequently mentioned incidents included being talked badly about or gossiped about by health facility staff; having their HIV status disclosed to other people without their consent; and health facility staff avoiding physical contact or taking extra precautions (e.g., wearing double gloves). Furthermore, 34.2% of respondents who had had one or more of seven experiences of stigma and discrimination when seeking HIV care also indicated that they had at some point interrupted or stopped their HIV treatment, while this figure was 24.7% for those who did not report any of these experiences.

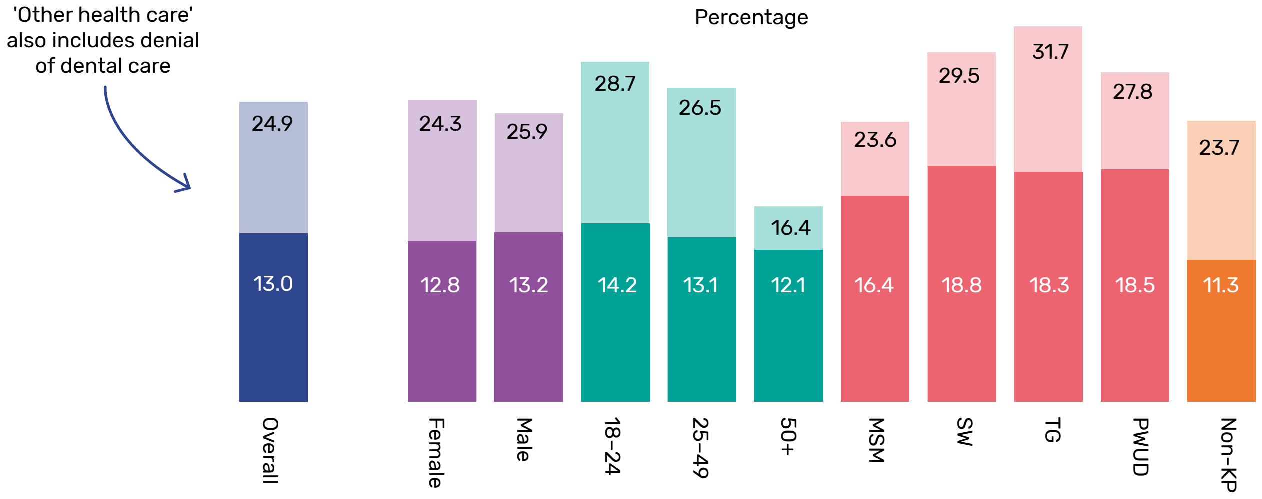
Table 4. Experiences due to HIV status when seeking HIV-specific and other health care during the past 12 months

	HIV specific health care		Care for non-HIV-related health needs	
	n	**%**	**n**	**%**
Being talked badly about or gossiped about	1,636	6.0%	2,148	15.3%
Telling other people about HIV status without consent	1,416	5.2%	1,612	15.3%
Avoidance of physical contact/taking extra precautions	1,317	4.9%	1,145	4.2%
Being advised not to have sex	1,213	4.5%	1,621	11.7%
Verbal abuse	1,084	4.1%	1,677	12.1%
Denial of health services	546	2.0%	1,713	12.1%
Physical abuse	316	1.2%	615	4.8%
Denial of dental care	-	-	1,674	11.9%

As was previously highlighted, internal stigma can hamper restarting treatment. However, external stigma also poses barriers for those who report having ever stopped care or treatment for HIV: 34.3% indicated that they were afraid that health workers (doctors, nurses, staff) would treat them badly or disclose their status without their consent, and 16.5% indicated that it was because they had had a bad experience with a health worker previously.

When seeking care for non-HIV-related health needs, 24.9% of respondents reported having had one or more negative experiences with health facility staff (based on eight statements) during the past 12 months due to their HIV status. This was almost twice as often, compared to when seeking HIV care. The proportion was lower among those aged 50+ years, compared to younger respondents (**Figure 14**), though there were no differences when looking at the length of time of knowing one's HIV status.

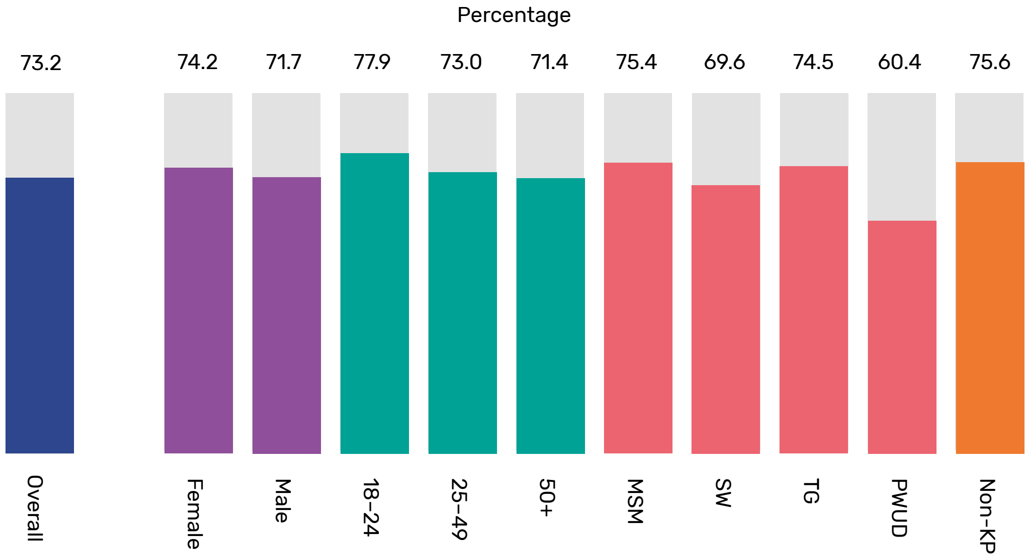
Figure 14. One or more experience due to HIV status when seeking HIV-specific (solid) and other health care (tinted) during the past 12 months



The most frequently mentioned experiences when seeking non-HIV-related health care were having their HIV status disclosed to other people without their consent and being talked badly about or gossiped about, followed by being verbally abused and facing denial of health services (**Table 4**). With the exception of avoidance of physical contact/taking extra precautions because of the respondent's HIV status, these incidents occurred more frequently in other health care settings than in HIV care and treatment facilities. In addition, nearly half (49.7%) of the respondents knew of a community-led facility that provides HIV prevention services and commodities.

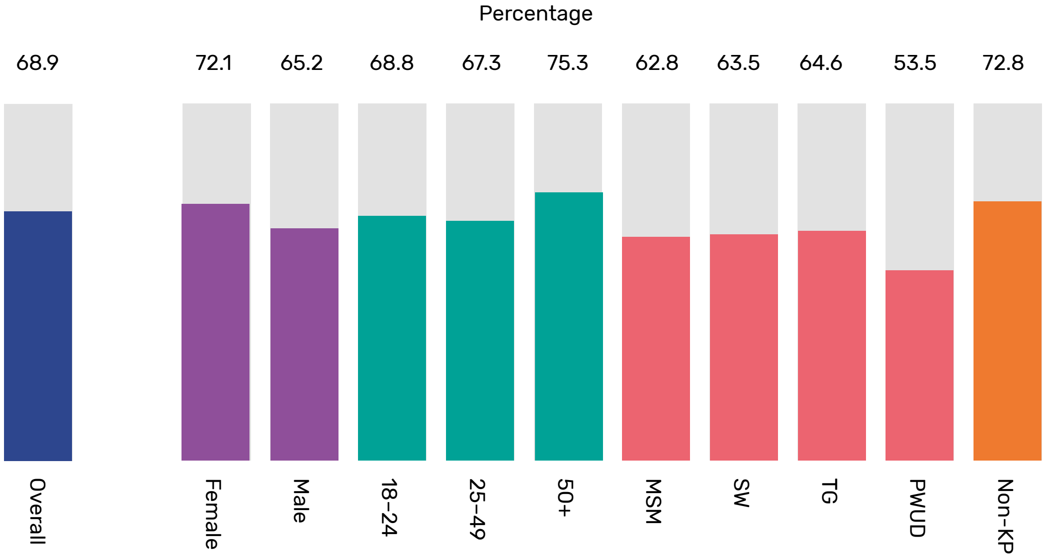
Almost three quarters of respondents (73.2%) reported not disclosing their HIV status when going outside the HIV clinic for general (non-HIV-related) health services. Differences by sex, age and population group were small, except for people who use drugs, in which case a smaller proportion indicated not disclosing (**Figure 15**).

Figure 15. Non-disclosure of HIV status when seeking general (non-HIV-related) health services



Only two thirds (68.9%) were sure that medical records relating to their HIV status were being kept confidential and would not be shared without their written informed consent. By contrast, about a quarter (26.9%) of respondents did not know, and 4.7% were sure that their medical records were not being kept confidential. The proportion of respondents who felt certain of confidentiality was higher among females compared to males; among older respondents (50+ years), which slightly increased with the length of time of knowing one's HIV status; and among people living with HIV who did not belong to a key population (**Figure 16**). This figure was much lower, however, among people who use drugs.

Figure 16. Respondents being sure that medical records relating to their HIV status are confidential



"I was threatened and hit by someone, and when I went to complain to the police, they beat and hit me."

Person who uses drugs, Mauritania

HUMAN RIGHTS VIOLATIONS

Out of all respondents, **3.6% indicated having been forced to get tested for HIV or disclose their HIV status** for one or more of five listed reasons during the past 12 months, most commonly in order to access health care services at some point during the past 12 months (2.2%). In addition, 1.8% of respondents reported having experienced one or more of the other five listed right abuses during the past 12 months, with having been forced to disclose their HIV status publicly or having had their status publicly disclosed without their consent being most frequently mentioned (0.9%). **Among those who had experienced human rights abuses during the last 12 months, 73.0% had sought redress**, most often filing a complaint (20.1%) or contacting a community organisation/network of persons living with HIV for support (19.8%). Overall, 42.6% of respondents reported ever having taken some form of action to address external stigma, most commonly challenging or educating someone who was engaging in stigma and discrimination against other people living with HIV (32.3%) or towards the respondents themselves (26.5%).

Out of all respondents, 2.2% reported that they had been forced to get tested for HIV or disclose their status in order to access health care services at some point during the past 12 months, and 4.7% of respondents reported having ever experienced this. Proportions for other reasons are listed in **Table 5**. Overall, 3.6% of respondents were forced to get tested for HIV or disclose their HIV status for one or more of these five reasons during the past 12 months, and 7.8% reported having ever experienced this.

Table 5. Forced to get tested for HIV or disclosure of status by reason, past 12 months and ever

	Past 12 months		Ever	
	n	**%**	**n**	**%**
Access health care services	640	2.2%	1,333	4.7%
Apply for a job or get a pension plan	297	1.1%	752	2.9%
Get medical insurance	231	0.8%	506	1.8%
Obtain a visa or apply for residency/ citizenship in a country	206	0.7%	547	1.9%
Attend an educational institution or get a scholarship	158	0.6%	402	1.4%

Respondents also reported other rights abuses: 0.9% indicated having been forced to disclose their HIV status publicly or had had their status publicly disclosed without their consent at some point during the past 12 months, and 2.8% of respondents reported having ever experienced this. Proportions for other abuses during the past 12 months and ever are provided in **Table 6**.

Table 6. Rights abuses experienced because of HIV status, past 12 months and ever

	Past 12 months		Ever	
	n	**%**	**n**	**%**
Forced to disclose my HIV status publicly or my status was publicly disclosed without my consent	270	0.9%	795	2.8%
Arrested or taken to court on a charge related to my HIV status	191	0.7%	369	1.3%
Detained or quarantined because of my HIV status	129	0.5%	331	1.2%
Denied a visa or permission to enter another country because of my HIV status	96	0.3%	306	1.1%
Denied residency or permission to stay in another country because of my HIV status	94	0.3%	318	1.1%

Overall, 1.8% of respondents reported having experienced one or more of these five rights abuses during the past 12 months, compared to 4.6% who had ever experienced this. Results are disaggregated by sex, age, and key population group in **Figure 17**.

Figure 17. Experienced one or more of five rights abuses during the past 12 months (solid) and ever (tinted)

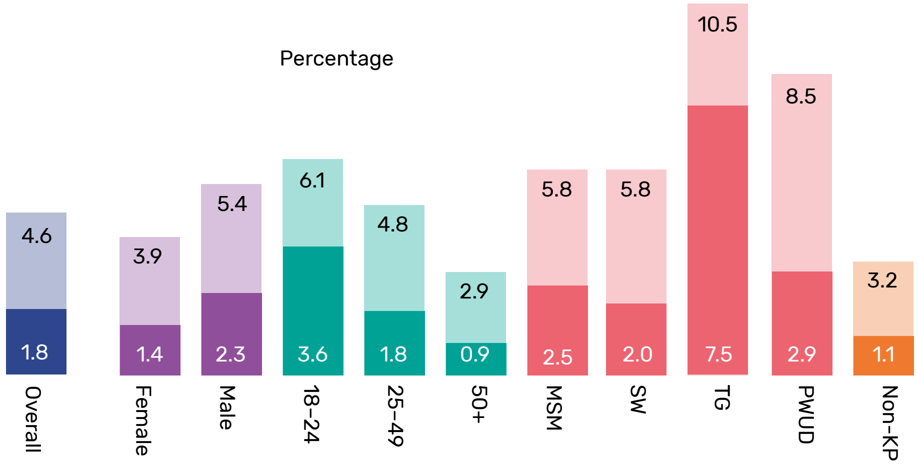
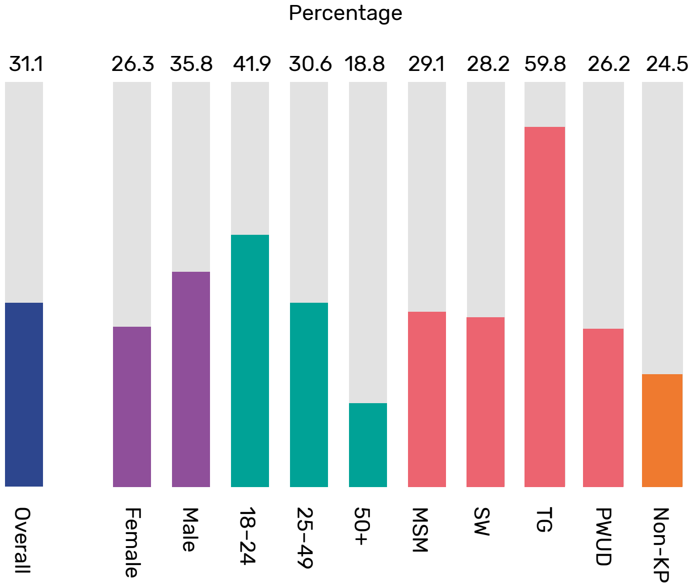
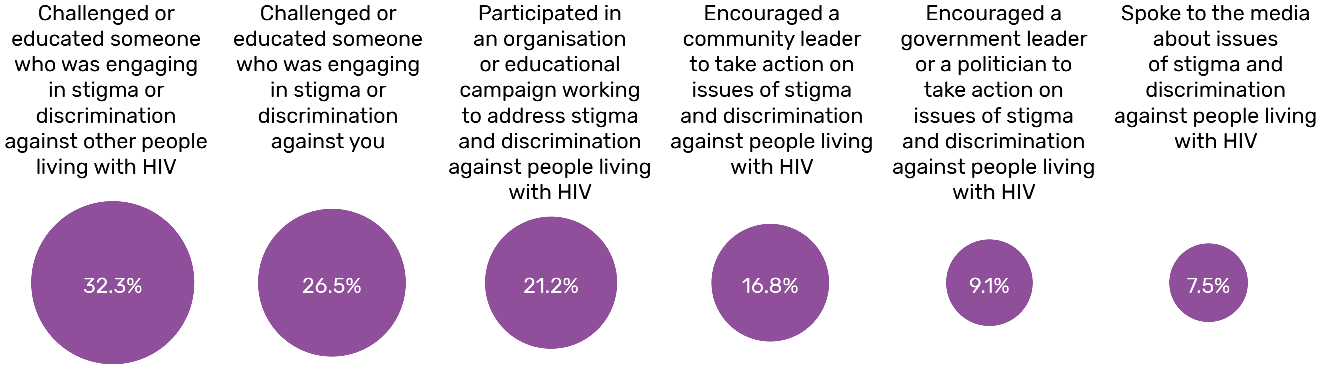


Figure 18. Seeking redress among participants who experienced human rights abuses during the last 12 months



Among those who had experienced human rights abuses during the last 12 months, 31.1% reported having sought redress, meaning they had filed a complaint (35.1%); contacted a community organisation/ network of persons living with HIV for support (34.4%); spoken out publicly (9.1%); contacted a government official or politician (5.1%); contacted a lawyer (1 participant); and/or taken action in another way (22.1%). **Figure 18** shows that younger people more frequently reported having sought redress, along with those who had known their HIV status for less than five years, males and transgender people. Furthermore, 33.0% of those who were members of a network or support group of people living with HIV reported having sought redress, compared to 30.0% of those who were not.

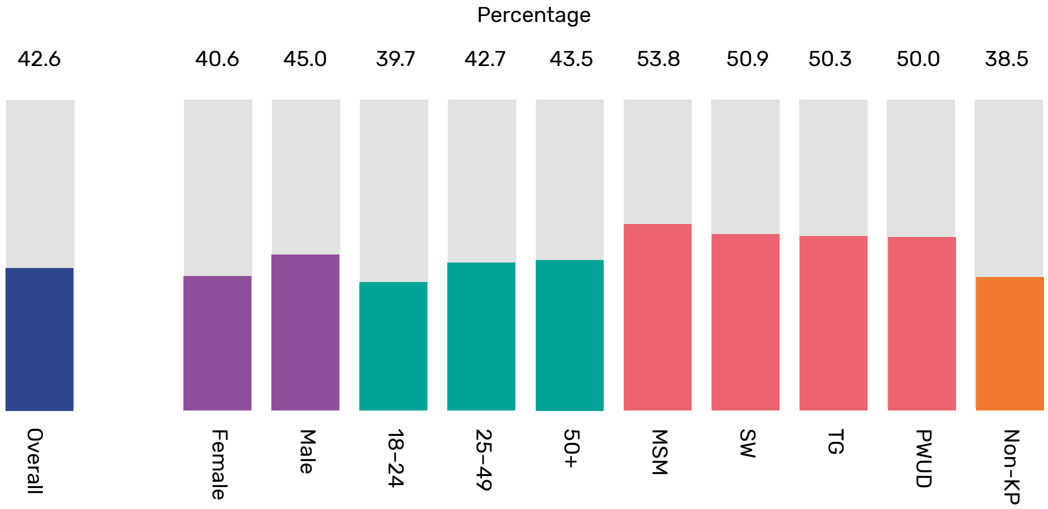
Figure 19. Actions ever taken to address external stigma



Overall, 42.6% of respondents reported having ever taken some form of action to address external stigma, most commonly challenging or educating someone who was engaging in stigma and discrimination against other people living with HIV (32.3%) or against the respondents themselves (26.5%) (**Figure 19**).

Looking at the results by sex, age and key population group, it can be seen that this proportion was lowest among people living with HIV who did not belong to a key population group (**Figure 20**). Meanwhile, 31.4% of all respondents said they had provided support (emotional, financial or other) to help someone living with HIV deal with stigma and/or discrimination.

Figure 20. One or more of six actions ever taken by respondents to address external stigma and discrimination



COMMUNITY SETTINGS

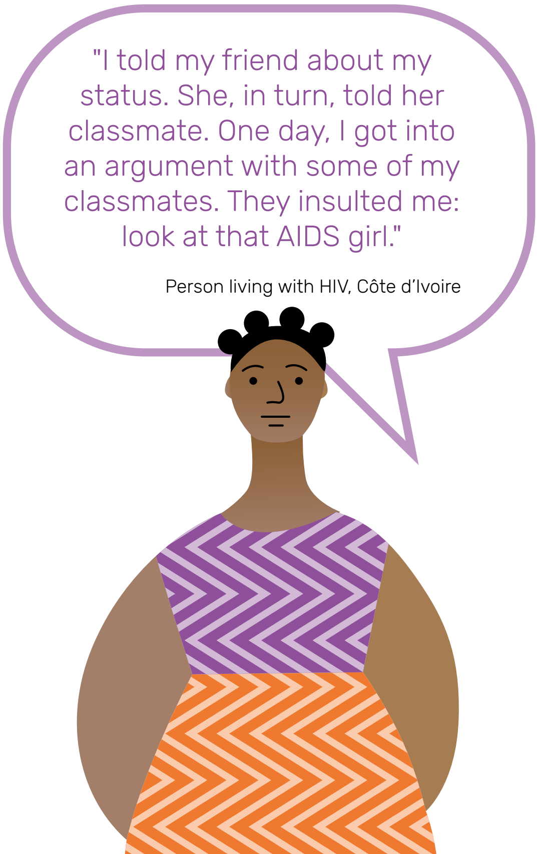
About a quarter of the respondents (23.6%) reported that one or more of the 11 statements related to experiences of stigma and discrimination because of their HIV status had happened to them during the past 12 months, with being aware of people making discriminatory remarks or gossiping about them being mentioned most often (14.2% for 'other' people and 12.6% for family members).

Respondents' agreement with each of the statements related to experiences of stigma and discrimination because of their HIV status during the past 12 months or ever is presented in **Table 7**. When looking at the past 12 months as well as ever, proportions were highest with respect to being aware of people making discriminatory remarks or gossiping about them (higher for 'other' people than for family members), followed by being verbally harassed because of their HIV status.

Overall, about a quarter of the respondents (23.6%) reported having faced one or more of the 11 experiences during the last 12 months, and 41.1% reported having ever faced one or more of

"I told my friend about my status. She, in turn, told her classmate. One day, I got into an argument with some of my classmates. They insulted me: look at that AIDS girl."

Person living with HIV, Côte d'Ivoire

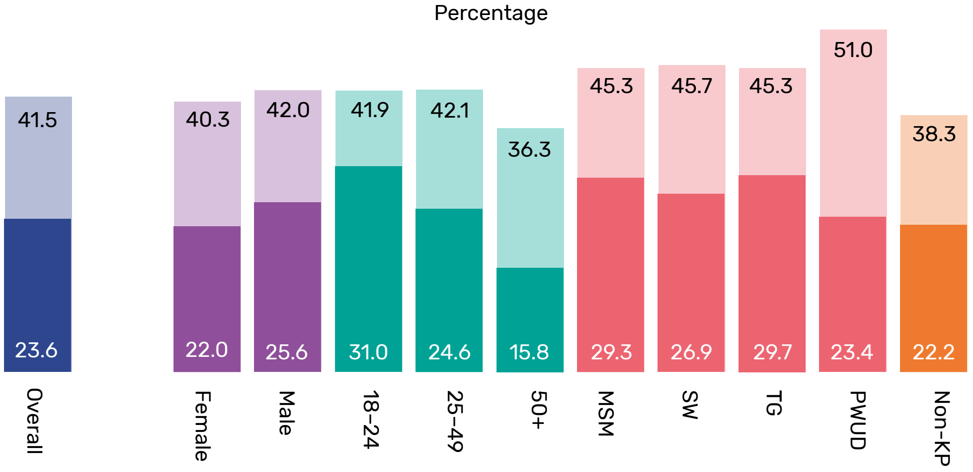


these experiences. **Figure 21** shows the proportions by age, sex and key population group. Proportions during the last 12 months were lowest among older respondents (50+ years). Meanwhile, for ever having had one or more of these 11 experiences, the proportion was lowest among people living with HIV who did not belong to a key population and highest among people who use drugs, as well as among those who had known their HIV status for ten or more years.

Table 7. Experiences of HIV-related stigma and discrimination in community settings during the past 12 months and ever

	Past 12 months		Ever	
	n	**%**	**n**	**%**
Aware of people (other than family members) making discriminatory remarks or gossiping about you	4,019	14.2%	7,869	27.8%
Aware of family members making discriminatory remarks or gossiping about you	3,637	12.6%	7,249	25.0%
Verbally harassed you	3,440	11.8%	6,305	21.6%
Blackmailed you	2,505	8.6%	3,734	12.8%
Wife/husband, partner(s) or child(ren) ever experienced discrimination	2,168	8.2%	3,428	13.4%
Excluded from family activities	2,260	7.8%	3,961	13.6%
Physically harassed or hurt you	2,219	7.6%	3,102	10.6%
Excluded from social gatherings or activities	2,143	7.5%	3,669	12.8%
Refused employment or lost a source of income or job	1,949	7.3%	3,207	12.0%
Job description or the nature of job changed, or denied a promotion	1,626	6.7%	2,295	9.4%
Excluded from religious activities or places of worship	1,717	6.3%	2,335	8.5%

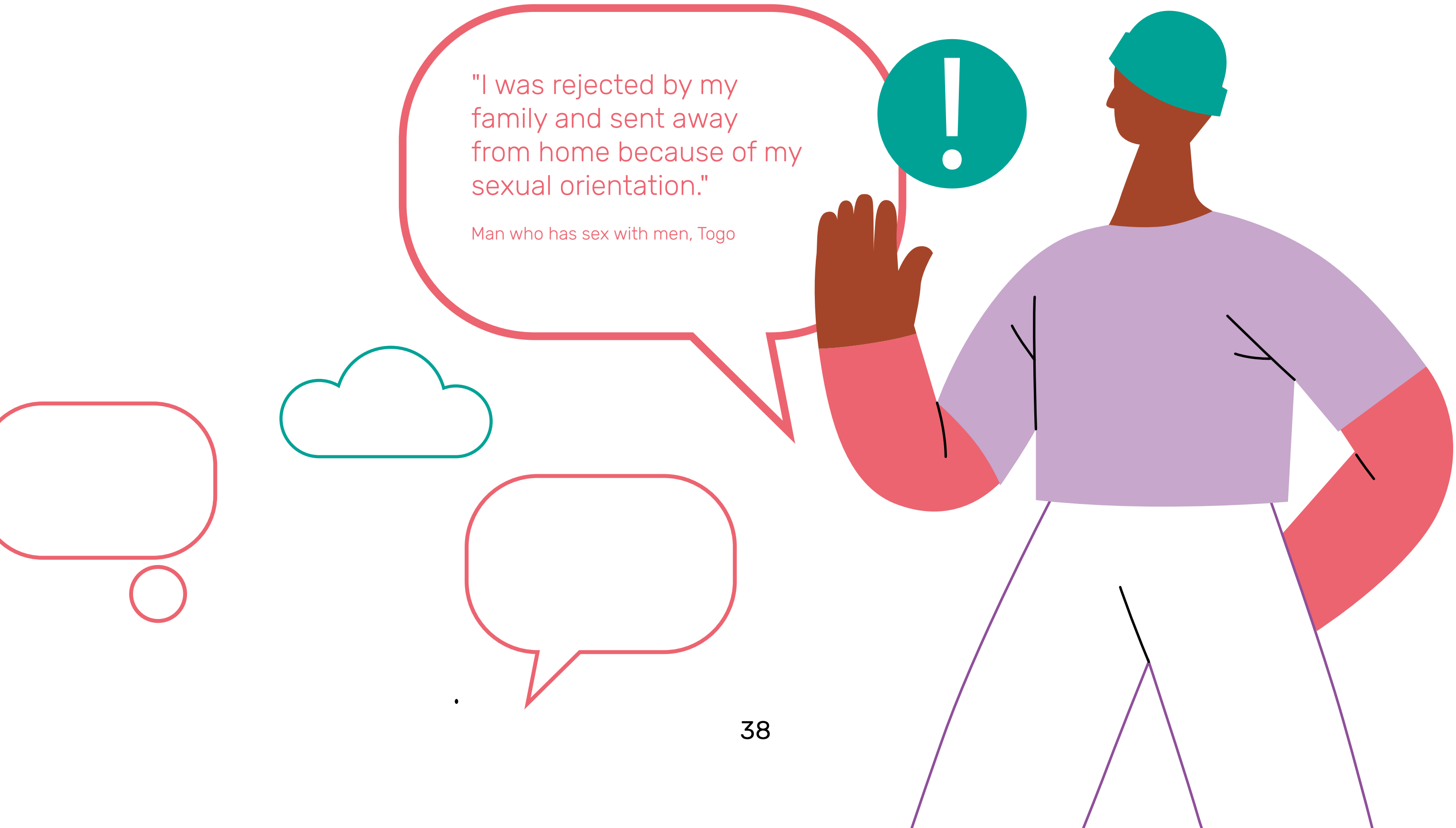
Figure 21. Facing one or more of 11 experiences of HIV-related stigma and discrimination in community settings during the past 12 months (solid) and ever (tinted)



Stigma and discrimination experienced by key populations

Key populations living with HIV not only experience stigma and discrimination due to their HIV status, but also because of being part of a key population group. This is due to negative and judgemental attitudes towards key populations; shame related to an individual's occupation, drug use, sexual orientation or gender identity; and social, cultural and gender norms. As a result, there is a lack of social acceptance, leading to reduced access to essential services and fuelling social inequalities. Knowledge about the stigma and discrimination experienced by sex workers, gay men and other men who have sex with men, people who use drugs and transgender people for reasons other than their HIV status is critical to putting interventions in place to reduce this, thereby improving their health outcomes.

Transgender people most frequently reported having faced one or more of the seven listed experiences of stigma and discrimination based on gender or behaviour (i.e., reasons other than their HIV status) during the past 12 months (49.4%). This was followed by gay men and other men who have sex with men (40.5%) and lowest among people who use drugs (27.0%) and sex workers (25.7%). **Among all key population groups, proportions decreased with increasing age.** Proportions were highest for experiencing verbal harassment, being gossiped about by family members and being excluded from family activities. Proportions for ever having had one or more of the listed experiences of stigma and discrimination were considerably higher than for those occurring during the past 12 months.



"I was rejected by my family and sent away from home because of my sexual orientation."

Man who has sex with men, Togo

This section presents stigma and discrimination experienced by key populations for reasons other than their HIV status.[6] Transgender people most frequently reported having faced one or more of the seven listed experiences of stigma and discrimination based on gender or behaviour during the past 12 months (49.4%). This was followed by gay men and other men who have sex with men (40.5%) and lowest among people who use drugs (27.0%) and sex workers (25.7%) (**Table 8**). The proportion was higher among females than males among sex workers (28.4% versus 21.2%) and people who use drugs (31.8% versus 24.6%).

Table 8. One or more experience of stigma and discrimination faced by key populations (last 12 months and ever)

	Gay men and other men who have sex with men	Sex workers	Transgender people	People who use drugs
	n (%)	**n (%)**	**n (%)**	**n (%)**
Last 12 months	1,228 (40.5%)	1,145 (25.7%)	730 (49.4%)	903 (27.0%)
Ever	1,954 (64.4%)	2,070 (46.4%)	1,084 (73.3%)	2,336 (69.9%)

Proportions were highest for experiencing verbal harassment (ranging from 14.7% to 25.4%), being gossiped about by family members (ranging from 11.9% to 22.7%) and being excluded from family activities (ranging from 8.4% to 19.1%) (**Table 9**).

Table 9. Stigma and discrimination experienced by key populations (last 12 months)

	Gay men and other men who have sex with men		Sex workers		Transgender people		People who use drugs	
	n (%)		**n (%)**		**n (%)**		**n (%)**	
	In last 12 mths	Ever	In last 12 mths	Ever	In last 12 mths	Ever	In last 12 mths	Ever
Being excluded from family activities	331 (12.1%)	714 (26.2%)	381 (8.4%)	872 (19.2%)	278 (19.1%)	549 (37.8%)	354 (10.7%)	1,292 (39.1%)
Being gossiped about by family members	592 (21.7%)	1,172 (43.0%)	540 (11.9%)	1,226 (27.0%)	330 (22.7%)	631 (43.4%)	565 (17.1%)	1,820 (55.2%)
Being afraid to seek health services	260 (9.5%)	575 (21.1%)	361 (7.9%)	853 (18.8%)	219 (15.1%)	456 (31.4%)	288 (8.7%)	1,088 (32.9%)
Avoiding seeking health services	210 (7.7%)	458 (16.8%)	334 (7.4%)	817 (18.0%)	187 (12.9%)	424 (29.2%)	265 (8.6%)	985 (32.1%)
Experiencing verbal harassment	532 (20.1%)	1,072 (40.5%)	668 (14.7%)	1,295 (28.5%)	369 (25.4%)	619 (42.6%)	607 (18.4%)	1,800 (54.6%)
Experiencing blackmail	242 (9.1%)	541 (20.3%)	405 (8.9%)	852 (18.8%)	202 (13.9%)	373 (25.6%)	222 (6.7%)	606 (18.3%)
Experiencing physical harassment	224 (8.4%)	552 (20.7%)	479 (10.6%)	973 (21.5%)	224 (15.7%)	401 (28.1%)	243 (7.3%)	849 (25.6%)

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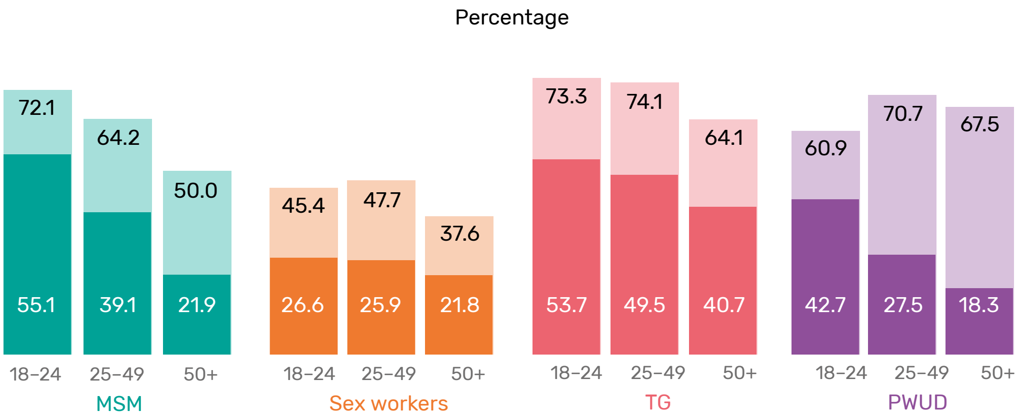
[6] This refers to experiences due to the respondent's gender identity (transgender people); being gay/homosexual/have sex with men; being a sex worker or sell (or sold) sex; and using (or having used) drugs.

Figure 22. One or more experience of stigma and discrimination faced by key populations in the last 12 months (solid) and ever (tinted), by age



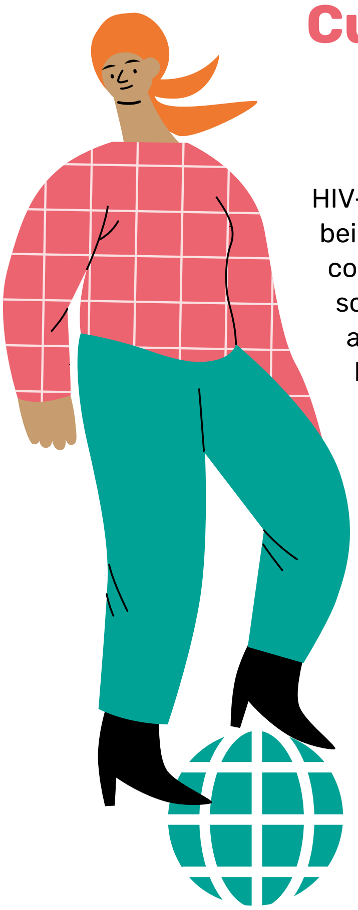
Proportions for having *ever* had one or more of the listed experiences of stigma and discrimination were considerably higher compared to those that had occurred during the past 12 months (**Table 8**). Patterns by sex were the same: 53.5% for female and 34.9% for male sex workers, 73.2% for female and 68.3% for male drug users.

Among all key population groups, proportions decreased with increasing age except among people who use drugs, where it was lowest among the youngest group (18-24 years) **(Figure 22**). For each of the experiences, proportions were considerably higher for ever having occurred versus occurring during the past 12 months, but the three most reported experiences remained the same: verbal harassment, gossip by family members and exclusion from family activities (**Table 10**).

Table 10. Stigma and discrimination experienced by key populations (ever)

	Gay men and other men who have sex with men	Sex workers	Transgender people	People who use drugs
	n (%)	**n (%)**	**n (%)**	**n (%)**
Being excluded from family activities	714 (26.2%)	872 (19.2%)	549 (37.8%)	1,292 (39.1%)
Being gossiped about by family members	1,172 (43.0%)	1,226 (27.0%)	631 (43.4%)	1,820 (55.2%)
Being afraid to seek health services	575 (21.1%)	853 (18.8%)	456 (31.4%)	1,088 (32.9%)
Avoiding seeking health services	458 (16.8%)	817 (18.0%)	424 (29.2%)	985 (32.1%)
Experiencing verbal harassment	1,072 (40.5%)	1,295 (28.5%)	619 (42.6%)	1,800 (54.6%)
Experiencing blackmail	541 (20.3%)	852 (18.8%)	373 (25.6%)	606 (18.3%)
Experiencing physical harassment	552 (20.7%)	973 (21.5%)	401 (28.1%)	849 (25.6%)

Current status and way forward



HIV-related stigma and discrimination significantly impact the health, lives and well-being of people living with or at risk of HIV. Since the beginning of the epidemic, the community of people living with HIV has been severely affected and stigmatised by society and its discriminatory practices, and we fully recognise the importance of addressing these systemic barriers to allow us to have meaningful and dignified lives as human beings. The Stigma Index was created as our way to systematically address this very challenging environment. This tool allows the community to collectively gather evidence regarding our experiences and use it to advocate for a better world for people living with HIV globally. Furthermore, the Stigma Index has been widely recognised and accepted as a tool for measuring progress against HIV-related stigma and discrimination, with the inclusion of indicators in UNAIDS' Global AIDS Monitoring (GAM), where they are used to measure progress towards the targets for societal enablers in the Global AIDS Strategy 2021–2026.

USING THE STIGMA INDEX DATA FOR GLOBAL AIDS MONITORING

Although the Stigma Index is primarily a data source for countries to improve their HIV programming, Stigma Index data is also used at the global level. Global AIDS Monitoring (GAM) is a set of indicators intended to inform national processes and improve national programming. In addition, it is used globally to monitor progress towards targets related to the Political Declaration on HIV and AIDS.

For indicators to be included in the GAM, they must be assessed by the UNAIDS Monitoring Technical Advisory Group (MTAG) against a set of criteria (e.g., reliability, feasibility). The standardisation of the Stigma Index ensured that the indicators derived from its questions scored well on these criteria.

GAM currently includes four indicators that can use the Stigma Index as a source:

1. Internalised stigma reported by people living with HIV
2. Stigma and discrimination experienced by people living with HIV in community settings
3. Experience of HIV-related discrimination in health care settings
4. People living with HIV seeking redress for violation of their rights.

Although the number of countries conducting the Stigma Index is increasing, not all data is reflected in the GAM. This is something that could be further improved in the future by creating a more supportive environment, including political and technical support from government and key stakeholders at national level.

CURRENT STATUS

According to UNAIDS estimates, of the 39 million people living with HIV globally, 86% knew their HIV status and 76% were receiving antiretroviral therapy in 2022.[7] Despite successes in expanding the availability of HIV testing and treatment, advanced HIV disease remains a major reason for the persistently high numbers of AIDS-related deaths: 630,000 in 2022. The most common causes of death among adults with advanced HIV disease were tuberculosis, cryptococcal meningitis and severe bacterial infections. There is growing concern about the prevalence of advanced HIV disease and mortality among people who started and then stopped HIV treatment but are now returning to HIV care. There is a need to remove the factors that make it more difficult to stay in care, which include stigma and discrimination, especially at health care facilities. Furthermore, as people living with HIV live longer, they also present with noncommunicable diseases, such as heart disease, cancer and diabetes, which can complicate HIV treatment and threaten people's health and lives. Service approaches might need to be adapted to provide the right clinical support to ageing people living with HIV.

The aim of this report was to provide an overview of the current situation of HIV-related stigma and discrimination globally. It shows that we are far from achieving the Global AIDS Strategy goal that by 2025, less than 10% of people living with HIV experience stigma and discrimination: 37.6% of respondents said they had experienced internalised stigma (i.e., being ashamed that they are HIV-positive), 24.9% said they had experienced HIV-related discrimination when seeking non-HIV-specific health services and 23.6% had experienced stigma and discrimination because of their health status in community settings during the past 12 months.

People living with HIV who belong to a key population group (gay men and other men who have sex with men, sex workers, transgender people and people who use drugs) experience even higher levels of HIV-related stigma and discrimination, most notably internalised stigma and experiences of stigma and discrimination in community settings. In addition to this, they experience high levels of stigma and discrimination because of their key population status (ranging from 25.7% to 49.4%). Looking at age, younger people living with HIV (aged 18-24 years) experience the highest levels of HIV-related stigma and discrimination (both internal and external, the latter especially in community settings). Proportions in general decrease with increasing age and often in conjunction with the length of time of knowing one's HIV status.

Aside from the limitations inherent to the Stigma Index 2.0 itself (e.g., cross-sectional design, sampling framework) as well as to the countries in the studies, it should be acknowledged that the methodology of the global report has some additional limitations. By combining data from different countries, possible context-specific variations in the responses to questions will not be visible. Consequently, this can hamper interpretation of the results. Only focusing on quantitative and not qualitative data has the same effect. Differences between sub-groups (in terms of age, sex, key population group) should be interpreted with caution, as no significance testing has been conducted. Furthermore, knowing that specific age or key population groups

[7] UNAIDS (2023), The path that ends AIDS: UNAIDS Global AIDS Update 2023.

experience more stigma and discrimination does not directly pinpoint the reason for this. As can be seen throughout the report, the finding that younger people often experience more stigma and discrimination could be related to a shorter length of time of knowing one's HIV status, as this is correlated with age, but trends are not always the same. Hence, there could also be other factors behind the age differences. More research is needed on this aspect.

In terms of the response at the international level, the **Global Partnership for Action to Eliminate all Forms of HIV-Related Stigma and Discrimination** (Global Partnership), of which GNP+ is a co-convener, aims to assist countries to take action to prevent and reduce HIV-related stigma and discrimination across six settings, including health care and individuals, households and communities and justice settings, making use of the latest evidence on best practices in each setting. It is supported by a technical working group comprising 10 United Nations agencies and 24 civil society organisations, and as of 15 September 2023, 36 countries had formally joined the Global Partnership as well. Countries are encouraged to plan and begin actual work to end HIV-related stigma, focusing on a few settings where they think they can make the greatest difference. Governments and civil society work together to choose the best interventions for each setting, with support and guidance from the partnership. GNP+ provides technical support to ensure that civil society and communities in all their diversity can fully participate in the coordination and implementation of the partnership at country level.

Another effort to address stigma and discrimination is the **Global Fund's Breaking Down Barriers initiative**, which provided financial and technical support to 20 countries to remove human rights and gender-related barriers to HIV, tuberculosis and malaria services for the period of 2017-2022. Midterm assessments of this work after 1.5 to 2.5 years showed that programmes implemented under this initiative featured many forms of raising community awareness of the harms of HIV-related stigma, as well as more targeted efforts such as eliminating stigma in health services. Training of and engagement with health workers on a range of human rights and ethics issues faced in HIV care were markedly expanded in most countries. In addition to stigma, programmes also focused on the confidentiality of medical records and HIV status as part of engagement with health workers.

While the community welcomes existing programmes and frameworks, it is important to recognise that there is a lack of dedicated funding and hence programming for reducing stigma and discrimination. The reality of interventions to address stigma and discrimination being paid for by different funding streams, such as HIV research, human rights programming and HIV treatment programmes, creates challenges in having a coordinated and systematic programme approach. The current design increases the risk for unbalanced investments: limited programming addressing internalised stigma on the one hand (while current results show the magnitude of this) and duplication of programmes covering external stigma on the other. The lack of one comprehensive results framework also complicates measuring the outcomes of stigma- and discrimination-related interventions. A conversation must be initiated among key stakeholders at all levels to create a dedicated funding stream to address HIV-related stigma and discrimination.

WAY FORWARD

The findings in this report solidify the importance of continuing efforts to address HIV-related stigma and discrimination in order to ensure that the 95-95-95 targets are reached in all populations, age groups and geographic areas by 2025. The current programme design must be revisited to foster innovation in combating all types of stigma and discrimination towards the community of people living with HIV, including intersectional stigma experienced by people living with HIV who belong to key populations. People living with HIV should have access to non-stigmatising health care for HIV and non-HIV-related needs, including sexual and reproductive health services. Furthermore, focused interventions to eliminate discriminatory policies, practices and criminalisation of people living with HIV need to be increased and expanded to address cross-cutting issues with other developmental sectors, such as gender equality, economic justice and intellectual property related to shared technology for better access to health commodities.

FURTHER ANALYSIS OF STIGMA INDEX DATA

Besides providing technical assistance, Johns Hopkins University (JHU) also plays a role in further analysing the data from Stigma Index studies. For example, data from individual country studies were combined and analysed for the West Africa regional report and for the current Global Report. This was made possible due to the standardised methodology, allowing comparisons between different settings and across time, and JHU contributed to the development of this approach.

Additional data analyses were also conducted, for example to assess associations between resilience and factors at the individual, interpersonal and structural levels. Some of this work has since been published in an academic journal. Currently, the team is also working on analyses of the impact of stigma on employment and violence, differences in the experiences of women living with HIV who do not belong to key populations compared to those who do, as well as looking into opportunities to compare the results from the Stigma Index with other population-based surveys that include people living with HIV.

In addition to documenting these findings in manuscripts, the results of these analyses have been presented at scientific conferences, e.g., at IAS 2023. Both manuscripts and presentations aim to contribute to the larger scientific literature on stigma while making quality data available for researchers, programme implementers, civil society and other relevant stakeholders. As a rule, all analyses and products are discussed, finalised with and approved by the International Partnership and relevant national networks.

The results presented in this first global report on the Stigma Index can be used as a baseline for continued monitoring of HIV-related stigma and discrimination worldwide while also serving as a starting point for a deep dive into some of the findings.

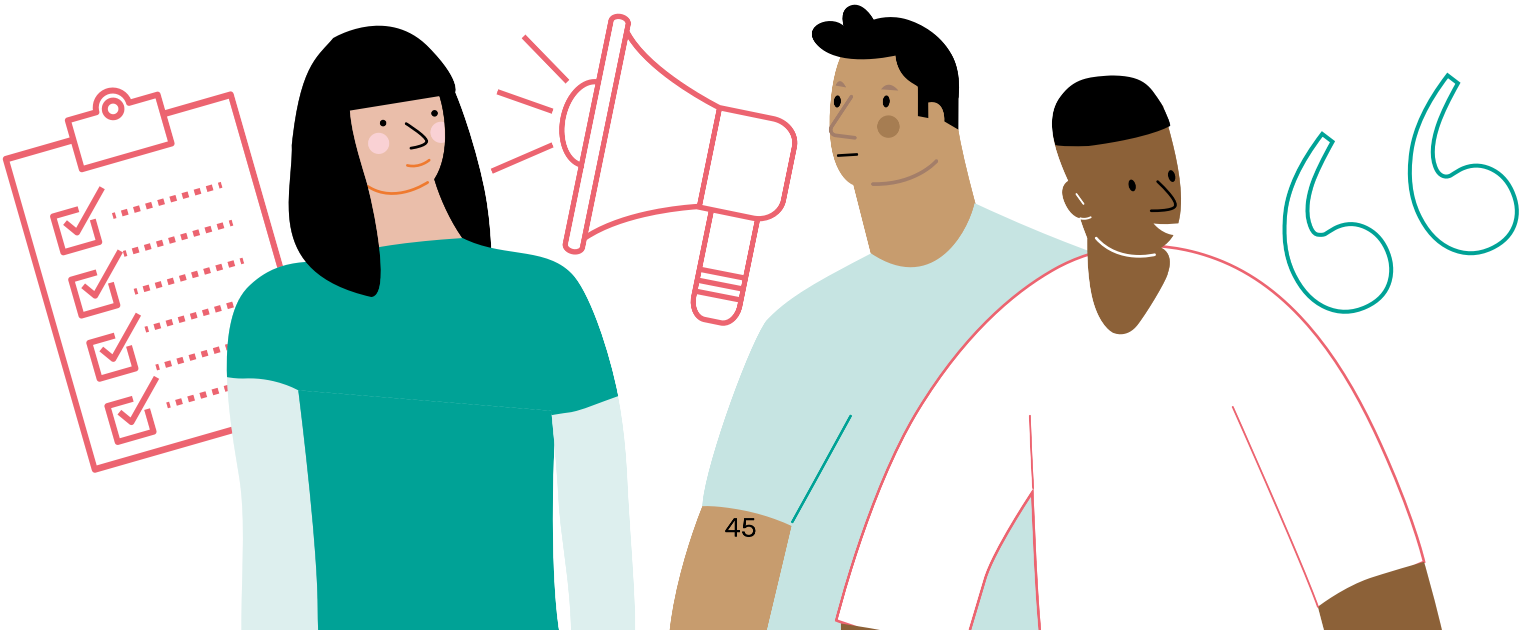
In addition, the results of this report can be used to inform and shape policies at the global level and can influence organisations contributing to financing the HIV response. At the country level, leading networks of people living with HIV should work with other relevant stakeholders to develop advocacy strategies (supported by the International Partnership's Advocacy Toolkit), including activities that are aimed at changing laws, policies and practices by influencing government officials and others in positions of power. Findings show that continued programming is needed in countries to decrease both internalised and external HIV-related stigma and discrimination, with special attention to be given to interventions for and with younger/more recently diagnosed people living with HIV and key populations.

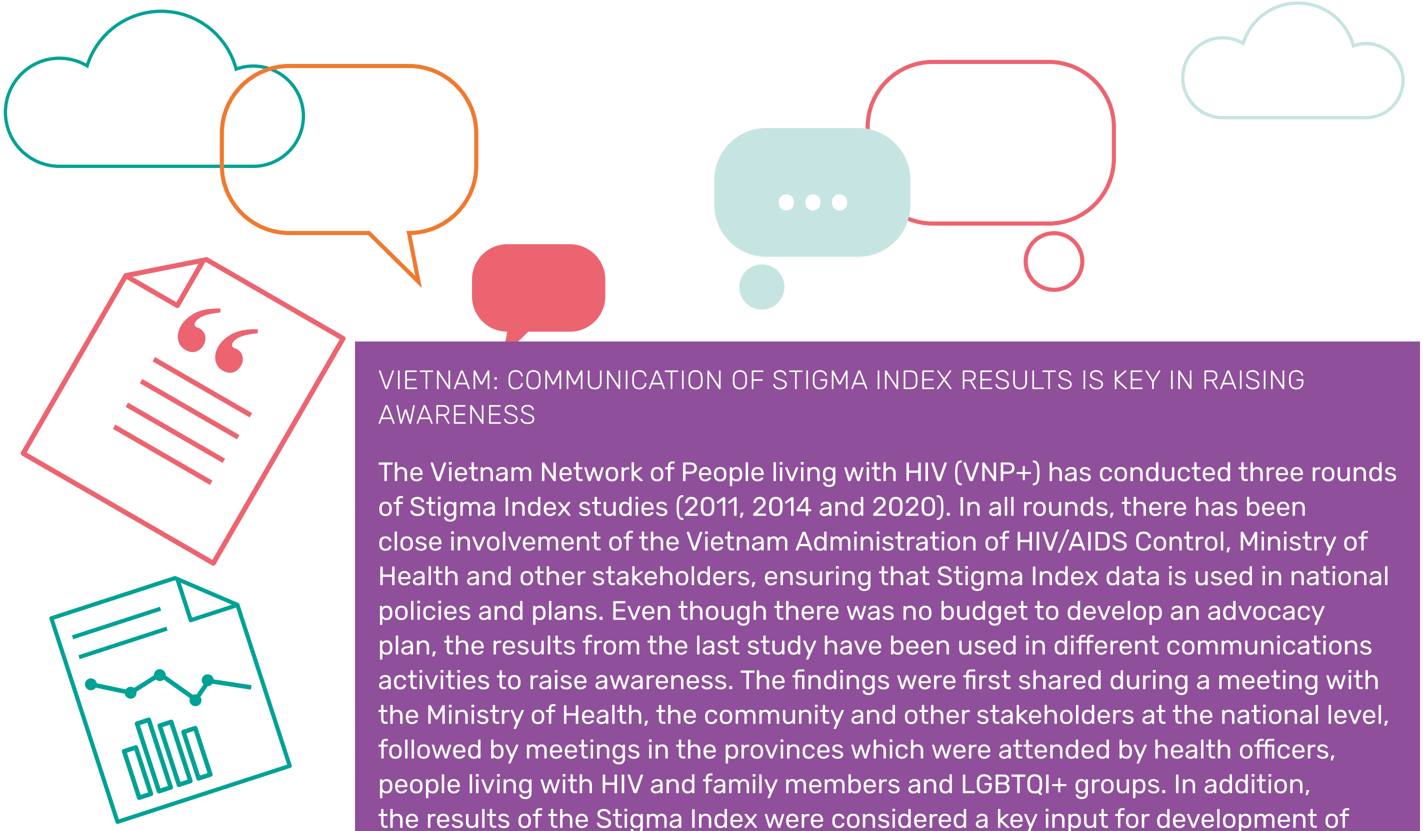
The continuity of support for the People Living with HIV Stigma Index programme beyond data gathering activities, including support for the community to use results, is critical to sustaining policy reform efforts. This is specifically important with regards to the criminalisation of same-sex relationships, gender expression, sex work and drug use, which receives insufficient investment despite overwhelming scientific evidence of the harmful effects of punitive approaches to public health. Finally, this report reflects our collective resilience as the community of people living with HIV - in all of our diversity – as well as our courage to continuously develop our capacity, reinvent our roles to adapt to the changing world and remain confident in achieving the goal of ending AIDS by 2030.

USING THE STIGMA INDEX FOR ADVOCACY: COUNTRY CASE STUDIES

BURKINA FASO NATIONAL PLAN TO COMBAT HIV-RELATED STIGMA AND DISCRIMINATION 2022-2025

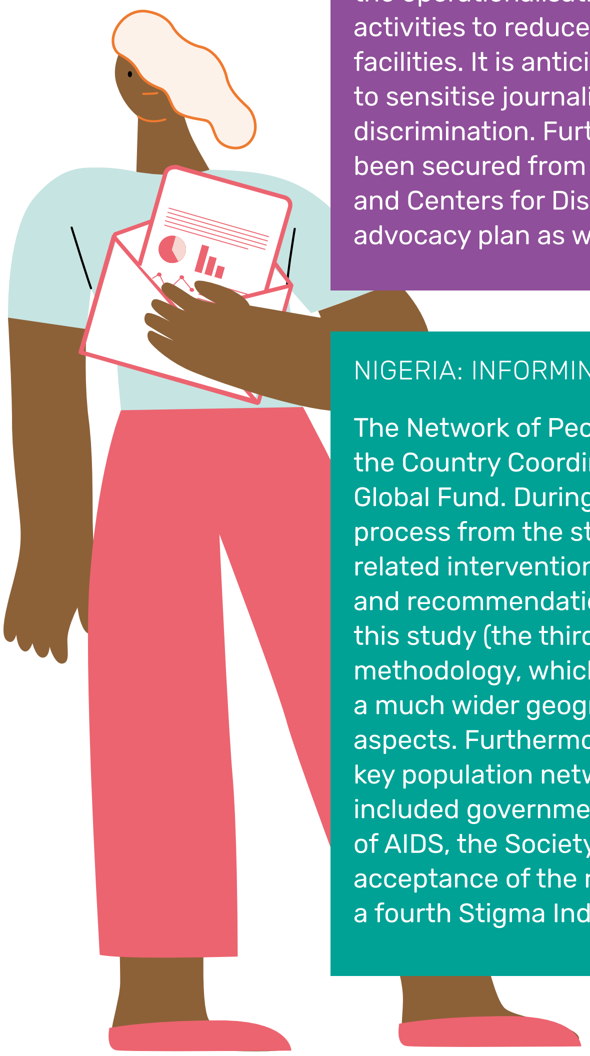
The National Network for Greater Involvement of People Infected and Affected by HIV/AIDS in Burkina Faso (REGIPIV/BF) released its Stigma Index 2.0 report in 2022. One of the report’s recommendations was to develop a national plan to promote and protect the rights of people living with HIV and key populations against discrimination by 2025. The network managed to obtain funding for hiring a consultant to draft the plan. This plan is currently being used by all national stakeholders in the response to HIV for advocacy purposes and to obtain funding for activities included in the related operational plan. Furthermore, a small grant was obtained through GNP+ to drive advocacy to amend Law 03/08/AN, which criminalises people living with HIV in articles 7, 20, 22 and 26. The required revisions have been documented, validated by the relevant committee and submitted for approval by the National Assembly.





VIETNAM: COMMUNICATION OF STIGMA INDEX RESULTS IS KEY IN RAISING AWARENESS

The Vietnam Network of People living with HIV (VNP+) has conducted three rounds of Stigma Index studies (2011, 2014 and 2020). In all rounds, there has been close involvement of the Vietnam Administration of HIV/AIDS Control, Ministry of Health and other stakeholders, ensuring that Stigma Index data is used in national policies and plans. Even though there was no budget to develop an advocacy plan, the results from the last study have been used in different communications activities to raise awareness. The findings were first shared during a meeting with the Ministry of Health, the community and other stakeholders at the national level, followed by meetings in the provinces which were attended by health officers, people living with HIV and family members and LGBTQI+ groups. In addition, the results of the Stigma Index were considered a key input for development of the operationalisation plan of Directive 10 – a policy focusing on strengthening activities to reduce stigma and discrimination related to HIV in health care facilities. It is anticipated that through a corporate fund, a grant can be obtained to sensitise journalists as well as medical students about HIV-related stigma and discrimination. Furthermore, for the next round of the Stigma Index, funding has been secured from the US President's Emergency Plan for AIDS Relief (PEPFAR) and Centers for Disease Control and Prevention (CDC) and this will include a clear advocacy plan as well.



NIGERIA: INFORMING THE GLOBAL FUND GRANT

The Network of People Living with HIV/AIDS in Nigeria (NEPWHAN) is part of the Country Coordinating Mechanism that submits funding applications to the Global Fund. During Grant Cycle 7, the network was involved in the grant writing process from the start for the very first time. The sections on human rights-related interventions in the funding request were fully informed by the results and recommendations of the 2021 Stigma Index study. This is largely because this study (the third in the country) was conducted using the standardised methodology, which is perceived as much more scientific and reliable. It also had a much wider geographic coverage and included both quantitative and qualitative aspects. Furthermore, it was coordinated by NEPWHAN in close collaboration with key population networks, and a wider range of stakeholders was involved. This included government (national and state), the National Agency for the Control of AIDS, the Society for Family Health, UNAIDS and FHI360, which increased acceptance of the results. The country is currently in the grant-making stage, and a fourth Stigma Index study is featured as one of the activities.

The People Living with HIV Stigma Index

www.stigmaindex.org