THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0
SOUTH AFRICA, 2024

COMMUNITY LEADING, COMMUNITY IN ACTION

THE PEOPLE LIVING WITH HIV STIGMA INDEX

REPUBLIC OF SOUTH AFRICA

SANERELA+

NAPWA

TAC

HSRC Human Sciences Research Council

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SOUTH AFRICA, 2024

Stigma Index 2.0 Implementing Organisations

National Association for People Living with HIV and AIDS

Positive Women's Network

Treatment Action Campaign

South African Network of Religious Leaders Living with and Affected by HIV and AIDS

South African National AIDS Council

Human Sciences Research Council

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FOREWORD

The People Living with HIV (PLHIV) Stigma Index 2.0 study comes at a critical moment in South Africa's public health landscape, following the nation's recovery from the COVID-19 pandemic. The detrimental effects of COVID-19 have disproportionately impacted the people living with HIV community, exacerbating existing vulnerabilities and deepening inequalities in healthcare access, economic stability, and social support. Many people living with HIV faced disruptions in their treatment regimens, increased isolation, and heightened stigma as health systems prioritised COVID-19 responses. The insights gained from this study will be instrumental in assessing the compounded impact of stigma in the post-pandemic era while also evaluating progress made since the 2014 National Stigma Index Study.

This Stigma Index 2.0 study holds particular significance as the first people living with HIV-led initiative of its kind in South Africa, aligning with the principles set forth by the International Partnership of the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), and the Joint United Nations Programme on HIV/AIDS (UNAIDS), with support from Johns Hopkins University. It represents a major milestone in ensuring that the voices and lived experiences of PLHIV remain at the centre of research, advocacy, and policy development. Furthermore, this study is globally groundbreaking as it is the first Stigma Index 2.0 to include adolescents aged 15–17, recognising the country's high HIV prevalence among young people and the urgent need to address stigma in this demographic. By incorporating their perspectives, the study broadens its impact and strengthens strategies to protect and support young people living with HIV.

The people living with HIV sector remains a key partner in supporting South Africa's National Strategic Plan (NSP) 2023–2028, which outlines the country's roadmap towards ending HIV as a public health threat by 2030. Stigma remains one of the most significant barriers to achieving this goal, affecting treatment uptake, retention in care, and adherence to antiretroviral therapy (ART). The findings of this study will serve as a foundation for targeted interventions aimed at eliminating stigma, ultimately improving health outcomes and enhancing the quality of life for people living with HIV.

The Stigma Index 2.0 study provides South Africa with an opportunity to identify and implement concrete interventions that address stigma and discrimination in healthcare settings, households, communities, educational institutions, workplaces, and the justice system. Its findings will inform evidence-based advocacy, ensuring that stigma reduction efforts are data-driven and responsive to the evolving challenges faced by people living with HIV.

The role of the South African National AIDS Council (SANAC) remains pivotal in driving the country's national HIV response, and the PLHIV-led Stigma Index 2.0 will contribute to shaping scientific and advocacy-based interventions that directly combat stigma. By leveraging the study's findings, SANAC, together with PLHIV networks and other stakeholders, can work collaboratively to reduce stigma and discrimination, foster inclusive healthcare environments, and strengthen the overall response to HIV in South Africa. This study reaffirms the collective commitment to a stigma-free society where every person living with HIV can access care, support, and opportunities without fear of prejudice or exclusion.

The Human Rights Technical Task Team remains steadfast in its commitment to ensuring that the recommendations from the Stigma Index 2.0 study are effectively implemented, recognising that stigma and discrimination continue to be significant barriers to accessing HIV prevention, treatment, care, and support services.

Mr. Andries Carl Nel
Minister of the Department of Justice and Constitutional Development
Co-Chair of the Law and Human Rights Technical Task Team

Mr Thabo Majuja
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Co-Chair of the Law and Human Rights Technical Task Team

PREFACE

Stigma and discrimination against people living with HIV remain significant barriers to effective HIV prevention, treatment, care, and support services in South Africa, where HIV prevalence is among the highest in the world. These barriers manifest in various ways, including social exclusion, fear of disclosure, workplace discrimination, and unequal access to healthcare services. As a result, many individuals hesitate to seek healthcare interventions such as testing or treatment due to concerns about how they will be perceived by their families, communities, and employers. This reluctance not only affects their health outcomes but also contributes to the continued spread of HIV, as undiagnosed or untreated individuals are more likely to transmit the virus.

Addressing HIV-related stigma is essential for strengthening the national response to HIV, improving health outcomes, and promoting equitable access to services. A stigma-free environment encourages people to come forward for testing and treatment, enhances adherence to medication, and ultimately reduces HIV-related morbidity and mortality. Efforts to combat stigma require a multifaceted approach, including public education campaigns, policy reforms, and community engagement initiatives that challenge discriminatory attitudes and promote understanding. Healthcare workers play a crucial role in this effort by providing compassionate, non-judgmental care and ensuring that PLHIV feel safe and respected in medical settings.

The PLHIV sector extends its heartfelt gratitude to all stakeholders who played a crucial role in the successful implementation of the People Living with HIV Stigma Index 2.0 study. This landmark initiative would not have been possible without the collective efforts of the many partners dedicated to advancing the rights and well-being of people living with HIV.

A special acknowledgement goes to the Stigma Index 2.0 Global Partners and the Human Sciences Research Council (HSRC) for their invaluable technical guidance, which ensured that the study adhered to rigorous research standards and produced reliable, evidence-based findings. The South African National AIDS Council also deserves recognition for its steadfast technical support, which helped streamline the study's processes and reinforced its alignment with national HIV response strategies.

Deep appreciation is extended to the Steering Committee for its strategic direction and oversight, which ensured that the study remained focused on its objectives and upheld the integrity of its methodology. The active involvement and leadership of people living with HIV organisations were instrumental in the successful implementation of this study, ensuring that it remained true to the principles of the People Living with HIV Stigma Index 2.0 non-negotiables. Their commitment to community-driven research and advocacy has helped amplify the voices of those directly affected by HIV-related stigma and discrimination.

This study was made possible through the generous financial support of the Global Fund, whose investment in stigma-reduction initiatives underscores the importance of creating an inclusive, stigma-free environment for people living with HIV. The funding enabled data collection, analysis, and dissemination, ensuring that the study's findings contribute meaningfully to policy and programme development.

The study was led by the National Association of People Living with HIV and AIDS. The success of the People Living with HIV Stigma Index 2.0 study reflects the power of collaboration and the shared commitment of all stakeholders to eliminating stigma and discrimination. Moving forward, the insights gained from this study will be instrumental in shaping evidence-based interventions, fostering supportive policies, and strengthening advocacy efforts to create a more just and equitable society for people living with HIV.

Mluleki Zazini – **SANAC People Living with HIV Sector Chairperson**

Thandi Maluka – **Chairperson of the Steering Committee for the People Living with HIV Stigma Index.**

ACKNOWLEDGEMENTS

The PLHIV Stigma Index 2.0 study, led by the National Association of People Living with HIV and AIDS (NAPWA) on behalf of the people living with HIV sector, was conducted across 18 districts in South Africa, capturing diverse experiences and providing a comprehensive understanding of HIV-related stigma and discrimination at the community level. The successful completion of this large-scale study required not only the technical expertise and methodological rigour of those involved, but also their unwavering dedication, resilience, and passion for the elimination of HIV-related stigma and discrimination.

Conducting research of this magnitude involved extensive planning, coordination, and collaboration across multiple sectors to ensure that the study remained inclusive, ethical, and representative of the realities faced by people living with HIV. From protocol development to study implementation and report writing, every stage of the study was driven by a shared commitment to amplifying the voices of those affected and translating their lived experiences into meaningful action.

We extend our deepest gratitude to all individuals who contributed to the success of this study. This includes members of the Steering Committee, the South African National AIDS Council (SANAC) secretariat, the HSRC, the Stigma Index 2.0 International Partnership, fieldworkers, and technical advisors, whose expertise ensured the study's credibility and impact. We also recognise the contributions of the SANAC Civil Society Forum Sectors for mobilising communities, facilitating participation, and upholding the principles of the meaningful involvement of people living with HIV. Their leadership was instrumental in ensuring that the study remained community-driven and reflective of real-life challenges.

We further extend our gratitude to the SANAC CEO for making the highly skilled and dedicated SANAC team available from the project's inception through to the dissemination of the study results. The study would not have been successful without them. We also recognise the support from the National Department of Health Director-General, Dr Sandile Buthelezi, as well as provincial and district health directors. We also appreciate the Provincial Heads of Secretariat and provincial ethics committees for granting field access. Most importantly, we sincerely thank the PLHIV who bravely shared their experiences, contributing valuable insights that will drive efforts to reduce stigma in South Africa. Their participation is central to the study's success.

The funding of this study for the people living with HIV sector was made possible through the generous support of the Global Fund grants, which played a crucial role in enabling this important research. The funding was channelled through the AIDS Foundation of South Africa as the Principal Recipient, which in turn granted SANAC, as a Sub-Recipient, support for the implementation of this critical activity. This financial support ensured the effective execution of the Stigma Index 2.0 study, allowing for the collection of vital data to inform stigma-reduction interventions and advocacy efforts.

The people living with HIV sector extends its gratitude to the UN family, the National Department of Health, the Department of Social Development, and the International Partnership of GNP+, ICW, and UNAIDS, with support from Johns Hopkins University, for providing technical support and guidance for this study. The people living with HIV sector is at one of its proudest moments, as this Stigma Index was sector-led, and extends its gratitude to NAPWA for leading the study, along with the following individuals: Mr Mluleki Zazini, Duncan Khothatso Moeketse, Ms Amukelani Nghonyama, Mr Themba Radebe, and Mr Godfrey Lepono, as well as the nine supervisors and 54 interviewers (their details are acknowledged in Appendix 1). We also extend our sincere appreciation to the training facilitators, Mr Pholokgolo Ramothwala and Ms Mpho Lekghetho, as well as to the administration and finance management team, Ms Sizakhele Mbhele and Ms Busisiwe Bhebhe, for their invaluable support during the implementation of the survey.

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Human Sciences Research Council for their technical support and skills transfer provided through the research and administration teams.

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We thank Ms Yolande Shean and Ms Sinazo Ndiki for providing a capacity enhancement workshop to the project managers, finance and administrative staff at NAPWA.

South African National AIDS Council:

Dr Thembisile Xulu, Dr Rogerio Phili, Mr Pholokgolo Ramothwala, Ms Sewele Dlamini, Dr Mlungisi Ntshangase, Mr Kulani Mabasa, Ms Thandekile Mbele, Ms Monica Ravele.

Lastly, we sincerely thank the Steering Committee members listed below for their oversight, support, and guidance from inception to the completion of the People Living with HIV Stigma Index 2.0 in South Africa.

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This study represents a collective effort to advance human rights, improve health outcomes, and foster a society free from stigma and discrimination. The dedication and passion demonstrated by all involved provide a strong foundation for future interventions aimed at promoting dignity, equality, and justice for people living with HIV.

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CDC	Centres for Disease Control and Prevention
EEA	Employment Equity Act
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	The Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICW	International Community of Women Living with HIV
IOM	International Organisation for Migration
IT	Information Technology
KPs	Key Populations
LGBTI	Lesbian, Gay, Bisexual, Transgender, Intersex
MSM	Men Who Have Sex with Men
NAPWA	National Association of People Living with HIV and AIDS
NGO	Non-Governmental Organisation
NSP	National Strategic Plan
PAC	Positive Action Campaign
PEPFAR	United States President's Emergency Fund for AIDS Relief
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
PrEP	Pre-Exposure Prophylaxis
PWN	Positive Women's Network
PWUD	People Who Use Drugs
REDCap	Research Electronic Data Capture
SABSSM	South African HIV Behavioural Sero-Status and Media Impact Survey
SANAC	South African National AIDS Council
SANERELA+	International Network of Religious Leaders Living with or Personally Affected by HIV or AIDS
SW	Sex Workers
TAC	Treatment Action Campaign
TG	Transgender
U=U	Undetectable = Untransmittable
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organisation

DEFINITIONS OF KEY TERMS

Discrimination	An arbitrary distinction, exclusion, or restriction that affects a person with the effect or intent of nullifying the recognition, enjoyment, or exercise of their human rights and fundamental freedoms in all aspects of life.
HIV-related discrimination	The unfair or unjust treatment (act or omission) of an individual based on their real or perceived HIV status. Discrimination in the context of HIV also includes key populations and other vulnerable groups.
HIV-related stigma	Negative beliefs, feelings, and attitudes towards people living with HIV, groups associated with people living with HIV, and key populations at higher risk of HIV infection.
Key populations	The 2023–2028 South African National Strategic Plan (NSP) prioritises the following key populations due to their elevated vulnerability to HIV, TB, and STIs, as well as their likelihood of experiencing stigma and discrimination: sex workers and their clients; trans and gender-diverse people; gay men and men who have sex with men (MSM); people who use drugs; and people in prisons and other closed settings.
Vulnerable groups	The 2023–2028 South African NSP prioritises adolescents and young people, as well as people with disabilities, due to the risk of HIV, STI, and TB transmission, and the challenges they face in accessing services. In this study, adolescents referred to as people living with HIV, aged 15 to 17 years, were included.

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EXECUTIVE SUMMARY

Introduction

The People Living with HIV (PLHIV) Stigma Index 2.0 is a global research initiative designed to measure and document the stigma, discrimination, and rights violations experienced by people living with HIV. The 2024 South Africa report, led by the National Association of People Living with HIV and AIDS (NAPWA) in collaboration with other stakeholders, provides a comprehensive assessment of HIV-related stigma and discrimination in South Africa since the implementation of the first Stigma Index study in 2014.

Methodology

The study followed a standardised methodology, with adaptations to include adolescents aged 15–17, in line with South African legislative frameworks. Key aspects of the methodology include:

Geographical scope: The study covered all nine provinces in South Africa, with 18 districts selected to include both urban and rural areas.

Study Participants: The study included people living with HIV aged 15 and older, with a focus on key populations, such as men who have sex with men, sex workers of all genders, transgender people, and people who use drugs.

Sampling and recruitment

Venue-based sampling: Participants were recruited from healthcare facilities and through networks of organisations providing support to PLHIV from five partner organisations affiliated with the South African National AIDS Council PLHIV sector, including NAPWA, Treatment Action Campaign (TAC), SANERELA+, Positive Women's Network, the Positive Action Campaign, LGBTI+, Disability, and Sex Worker sectors.

Limited chain-referral sampling: Used to recruit hard-to-reach populations, including adolescents and key populations. Participants were given contact cards to recruit other people living with HIV whom they knew.

Research instrument: A standardised quantitative Stigma Index 2.0 questionnaire was used, covering areas such as HIV disclosure, experiences of stigma, interactions with healthcare services, and human rights. Additional country-specific questions addressed TB-related stigma, disability-related stigma, and cyberbullying.

Ethical review: The study received ethical clearance from the Human Sciences Research Council (HSRC) and provincial ethics committees. Informed consent was obtained from all participants, with special provisions for minors aged 15–17.

Data collection and management: Data were collected electronically using the Research Electronic Data Capture (REDCap) system and analysed using Stata version 18.0. Descriptive statistics were used to summarise the data, with a focus on participants' socio-demographic characteristics and experiences of stigma.

Characteristics of Participants (aged 18 years and older)

The study included 5 065 participants from all nine provinces of South Africa, focusing on 18 districts (both urban and rural). Key demographic characteristics of the participants include:

Age: Most participants (69.7%) were aged 25–49 years, 11.8% were aged 18–24 years, and 18.4% were 50 years or older.

Sex assigned at birth and gender identity: Most participants (63.6%) were assigned female at birth, and 36.4% were assigned male at birth. In terms of gender identity, 62.1% identified as female, 33.0% as male, 2.8% as transgender, and 1.5% did not identify as female, male, or transgender.

Key populations: About 28.5% of participants belonged to at least one key population group, including sex workers (14%), people who use drugs (10%), men who have sex with men (5.7%), and transgender individuals (5.4%).

Education and employment: Most participants (58.7%) had completed secondary or high school education, 17.1% had no formal education, and 57.4% were unemployed.

Household composition: Most participants (43.2%) were living with 1–2 children, while 18.7% were not caring for any children.

Key Findings

HIV Disclosure

Voluntary disclosure: Figure 1 shows that over half of the participants voluntarily disclosed their HIV status, primarily to family members (73.2%), followed by friends (52.6%) and partners (51.2%). Voluntary disclosure was low in professional settings (9.3% to employers) and in educational settings (1.5% to teachers and 1.0% to classmates).

Positive experiences: About 65.5% of participants reported positive experiences when disclosing to close contacts, while only 40.8% reported positive experiences when disclosing to people they did not know well.

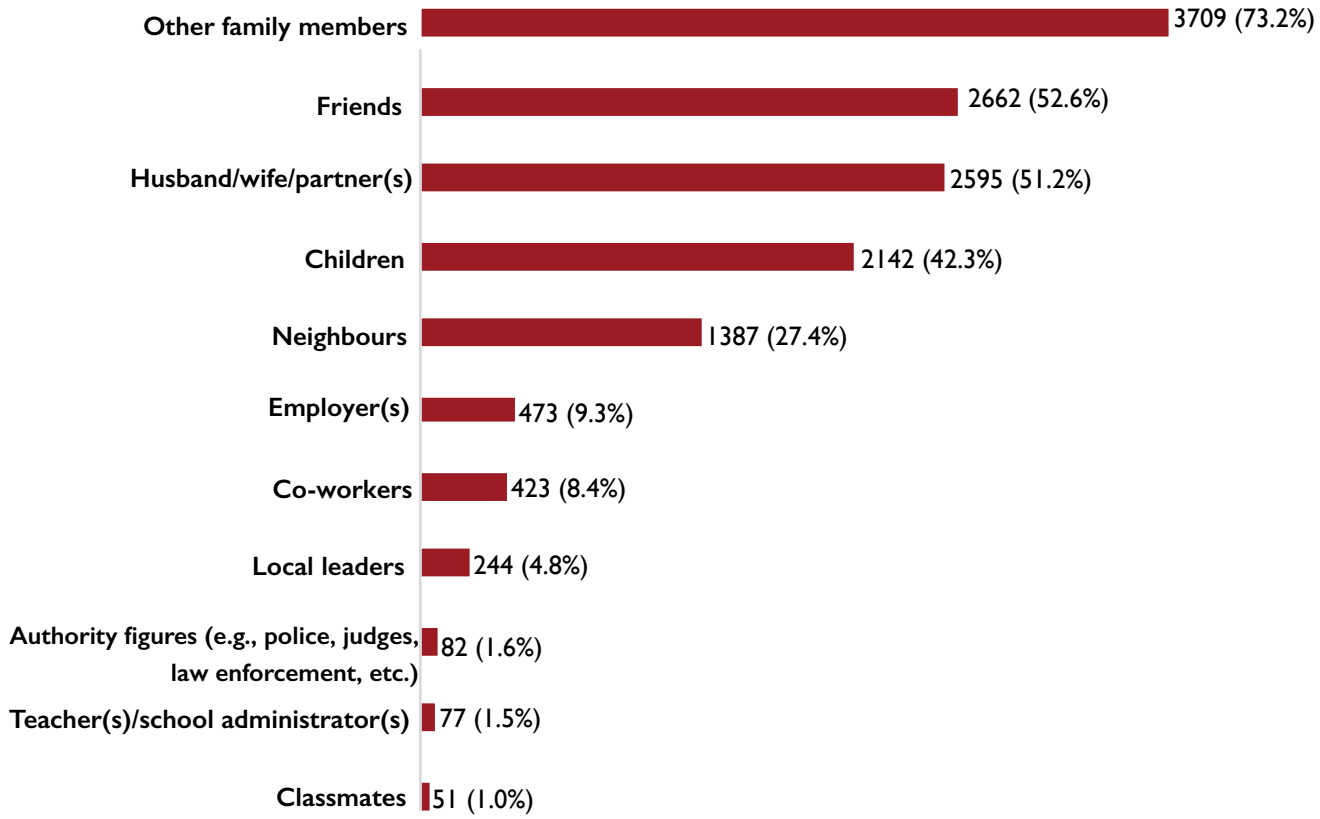

Figure 1. Disclosure of HIV status to various people or groups

Unintended disclosure: A few participants (3.3%) reported that their HIV status was disclosed without their consent, primarily by family members.

External stigma and discrimination

Experiences of stigma: Approximately 6.1% of participants reported experiencing external stigma in the last 12 months, a decrease from 14.3% in previous years. Common forms included discriminatory remarks (4.9%) and verbal harassment (3.6%).

Internalised stigma

Impact on well-being: Internalised stigma negatively affected self-confidence (12.9%), relationships (11.4%), and self-respect (9.9%). Younger individuals (18–24 years) and key populations, such as people who use drugs and sex workers, reported higher levels of internalised stigma.

Feelings of shame and guilt: About half of the participants (48.6%) found it difficult to disclose their HIV status, and 17.3% felt guilty about their status.

Healthcare interactions

Stigma in healthcare settings: About 7.8% of participants experienced stigma when seeking HIV-specific healthcare, 3.2% were advised not to have sex, and 3.1% were gossiped about.

Treatment hesitancy: About 32.1% of participants delayed starting treatment due to fear of stigma, and 12.6% reported interrupting their treatment.

Key populations

Multiple layers of stigma: Key populations, including men who have sex with men, transgender individuals, and people who use drugs, faced additional stigma due to their identities. For example, 23% of people who use drugs reported exclusion from family activities, and 15.8% of transgender individuals experienced verbal harassment.

Disclosure and support: Key populations were more likely to disclose their identities to others within their communities; however, they faced higher levels of discrimination in broader social settings.

TB-related stigma

Experiences of stigma: Among all people living with HIV, 16.8% of participants had been diagnosed with TB, and 37.9% reported being gossiped about due to their TB status. TB-related stigma remains a significant concern, particularly among people who use drugs and sex workers.

Cyberbullying

Experiences of cyberbullying: Less than 4% of participants reported experiencing cyberbullying across 11 individual items, with threats to disclose their HIV status online being the most common form (3%). Key populations, particularly young people (18–24 years), were more likely to experience cyberbullying.

Awareness of support and campaigns

Support groups: Only 38% of participants were members of HIV-support groups, with higher participation among transgender individuals (50%) and lower among people who use drugs (36.6%).

Awareness of campaigns: Less than half of participants (48.3%) were aware of the Undetectable = Untransmittable (U=U) campaign, with most learning about it through local clinics (1 726 participants; 71.9%).

Recommendations

Disclosure: Strengthen community-based partner and social network referral programmes that promote voluntary testing, informed consent, and supported disclosure. Provide resources such as counselling, peer-led support groups, and community workshops to ensure confidentiality and psychosocial support.

External stigma: Increase community awareness through evidence-based anti-stigma campaigns and develop gender-sensitive, culturally appropriate policies to address stigma in healthcare and community settings. Ensure multisectoral collaboration and monitoring frameworks. Stakeholders: the Department of Health, the Department of Social Development, the Department of Education, PLHIV networks, traditional leaders, non-governmental organisations (NGOs), and community organisations.

Internalised stigma: Implement mental health and peer-led support programmes that promote psychological well-being, reduce self-blame, and empower people living with HIV through storytelling, education, and the promotion of positive messaging such as U=U. Stakeholders: people living with HIV networks, mental health advocacy groups, the Department of Health, and the South African National AIDS Council (SANAC).

Healthcare facilities: Train healthcare workers on reducing stigma, patient rights, and providing gender-responsive care. Establish independent and confidential systems to monitor and address stigma, discrimination, and rights violations within health facilities. Stakeholders: the Department of Health, healthcare training institutions, professional councils, people-living-with-HIV-led organisations, and human rights bodies.

Human rights: Increase awareness of laws protecting people living with HIV through rights education, and support access to justice by providing legal assistance and advocacy services. Promote rights-based, migrant-friendly services and build partnerships to strengthen accountability. Stakeholders: the Department of Justice and Constitutional Development, Legal Aid South Africa, the Department of Home Affairs, the Department of Social Development, the Department of Education, and PLHIV networks.

Key populations: Develop targeted, culturally sensitive interventions for key populations, including people who use drugs, sex workers, and transgender individuals, with active involvement from people living with HIV-led networks. Stakeholders: people living with HIV-led networks, NGOs, the Department of Health, and academic institutions.

Women, adolescent girls and boys: people living with HIV networks, especially those led by women living with HIV, should lead education and training initiatives focused on rights, policies, and health access for women and adolescents living with HIV across all age groups. Stakeholders: women-led people living with HIV networks, the Department of Women, Youth and Persons with Disabilities, the Department of Health, and educational institutions.

Closing

The 2024 People Living with HIV Stigma Index 2.0 highlights the ongoing challenges of stigma and discrimination faced by PLHIV in South Africa, particularly among key populations and young people living with HIV. While progress has been made since the 2014 study, substantial work remains to reduce stigma, improve healthcare experiences, and support the mental well-being of people living with HIV. The findings emphasise the need for targeted interventions, greater awareness, and stronger support networks to create a more inclusive and stigma-free society for people living with HIV.

1. INTRODUCTION

1.1 The People Living with HIV Stigma Index

The People Living with HIV (PLHIV) Stigma Index 2.0 is a global research programme that uses a standardised methodology and instrument to collect information on stigma, discrimination, and the rights of PLHIV to support advocacy efforts aimed at influencing policy and interventions. The Stigma Index is conducted by and for PLHIV and is supported by several organisations. This approach embodies the Greater Involvement of People Living with HIV and AIDS (GIPA) Principle, empowering PLHIV networks at the country level to lead the study's full implementation.

The current Stigma Index International Partnership comprises the International Community of Women Living with HIV (ICW), the Global Network of People Living with HIV/AIDS (GNP+), and the Joint United Nations Programme on HIV/AIDS (UNAIDS), with technical support provided by Johns Hopkins University. This International Partnership offers technical assistance to people living with HIV networks worldwide, supporting them in implementing the People Living with HIV Stigma Index 2.0 methodology and using the results for targeted advocacy.

The People Living with HIV Stigma Index was first launched in 2008 and was revised in 2018 to reflect shifts in the HIV epidemic and the global response. Along with this update, a standardised methodology was introduced in 2020, creating the PLHIV Stigma Index 2.0.[1] The 2024 PLHIV Stigma Index 2.0 study in South Africa was led by non-governmental organisations (NGOs) from the South African National AIDS Council (SANAC) PLHIV sector, namely the National Association of People Living with HIV and AIDS (NAPWA), the Treatment Action Campaign (TAC), the South African Network of Religious Leaders Living with and Affected by HIV and AIDS (SANARELA+), the Positive Women's Network (PWN), and the Positive Action Campaign. In addition, three other SANAC sectors, i.e. the Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI+) sector, as well as the Disability and Sex Worker sectors. The study was implemented alongside the Human Sciences Research Council (HSRC) and SANAC in selected districts across all provinces in South Africa.

1.2 Study background

1.2.1 HIV context in South Africa

South Africa faces one of the highest HIV prevalence rates in the world.[2] Although HIV prevalence declined from 14.0% in 2017 to 12.7% in 2022, it remains a significant public health concern.[3] Nationally, an estimated 7.7 million people were living with HIV in 2023.[4] The burden of the epidemic is among adolescents and adults aged 15 years and older (approximately 7.5 million). Females (4.9 million) continue to be disproportionately affected compared to males (2.6 million), and adolescent girls and young women (8.4%) are more affected than adolescent boys and young men (3.8%).[4] Similarly, among South Africa's nine provinces, HIV prevalence in 2022 ranged from 17.4% to 7.4%, with the highest prevalence observed in Mpumalanga (17%) and KwaZulu-Natal (16%), and the lowest in the Western Cape (7.4%).

Key population groups, including sex workers and their clients, transgender individuals and gender-diverse people, gay men , men who have sex with men, people who use drugs, and people in prisons and other closed settings, are recognised as priority groups in the 2023–2028 South African National Strategic Plan (NSP).[5] This designation reflects their elevated vulnerability to HIV, TB and STIs, as well as their increased likelihood of experiencing stigma and discrimination.[5] Small-scale studies provide further insight into HIV prevalence among these groups. The 2019 South African Men's Health Monitoring Survey (SAMHMS-II) reported HIV prevalence among men who have sex with men ranging from 44.3% (316 participants, Johannesburg) to 26.8% (274 participants, Cape Town) and 16.7% (159 participants, Mahikeng). The Sibanye Methods for Prevention Packages Programme (MP3), conducted in Cape Town and Port Elizabeth, reported an overall HIV prevalence of 43% among 292 men who have sex with men and transgender women.[7] According to the Botshelo Ba Trans study conducted by the HSRC in 2019, HIV prevalence among the transgender population was 58%. Among 3 005 female sex workers enrolled in a sex worker programme across twelve districts in South Africa, HIV prevalence was 62.1%.[8]

The 2023–2028 NSP recognises people with disabilities as a priority population due to their heightened risk of HIV, STI and TB transmission.[5] They also face socio-economic and structural barriers that limit access to education, employment, and healthcare.[9-11] These challenges are even more pronounced for individuals with both a disability and living with HIV.

A 2019 study on HIV status, knowledge, attitudes, and behaviour among persons with and without disabilities found that the prevalence of HIV was 16.7% among individuals with disabilities. The rate was even higher among specific groups: 23.0% among those with visual, hearing, or speech disabilities and 31.6% among those with hearing disabilities.[12]

Persons with disabilities and HIV face compounded challenges arising from intersecting factors such as gender, socio-economic vulnerability, social exclusion, and the double stigma associated with both HIV status and disability.[13,11] In South Africa, evidence suggests that these vulnerabilities affect both men and women, with their particularly affected. For example, maternal HIV and disability have been linked to an increased risk of premature child mortality,[14] while women with disabilities and living with HIV report higher rates of intimate partner violence compared to HIV-negative women without disabilities.[15] The dual stigma of HIV and disability intensifies exclusion within healthcare systems and communities, limiting access to essential care and support and contributing to poor mental health outcomes, including anxiety, depression, and post-traumatic stress disorder.[16]

Sex workers and people who use drugs remain priority populations in the 2023–2028 NSP.[5] In 2019, a survey among female sex workers in South Africa linked to sex worker programmes found an HIV prevalence of 62.1% among 2 999 participants with available HIV test results. The estimated HIV incidence was approximately 4.6 new infections per 100 person-years, based on recency-of-infection biomarker testing.[17] Similarly, high HIV incidence was observed among people who use drugs accessing harm-reduction services in four South African provinces, with 283 (11.8%) of 2 402 participants acquiring HIV during the follow-up period (2019–2022), which covered over 2 306 person-years.[18]

Systematic discrimination and stigma against people who use drugs and sex workers in South Africa continue to pose major obstacles to effectively addressing the HIV epidemic. The criminalisation of drug use and sex work, combined with deeply rooted social stigma, limits these groups' access to HIV prevention, care, and treatment. For people who use drugs, fear of police harassment and legal consequences discourages them from accessing services such as HIV testing, opioid substitution therapy, and needle-exchange programmes. Within healthcare settings, they are often labelled as criminals rather than patients, resulting in poor treatment, denial of services, and breaches of confidentiality. These factors severely hinder their ability to receive adequate HIV care and increase their risk of both contracting and transmitting the virus. Sex workers face similar structural and societal barriers. The criminalisation of sex work exposes them to violence, police abuse, and extortion, deterring them from seeking legal protection or healthcare.

Stigma within healthcare environments often results in the denial of HIV testing and treatment, further increasing vulnerability to infection. Both people who use drugs and sex workers experience social exclusion, including family rejection, homelessness, and economic hardship, which limits their access to essential health services. This marginalisation also negatively affects their mental health and undermines adherence to HIV treatment. Among individuals from already marginalised racial, gender, or socio-economic backgrounds, intersectional stigma, such as gender-based violence or racial discrimination, further intensifies their vulnerability to HIV and creates additional barriers to care and support.

Numerous biological, structural, environmental, and socio-behavioural factors have been linked to South Africa's high HIV prevalence.[19,20] Inequalities in socio-economic level, multiple sexual partners, unprotected sex, detrimental gender norms, sexual violence, alcohol and drug usage, and age differences in partnerships between young men and women are all examples of this.[21-23] Crucially, new research has also identified stigma as a contributing factor to high HIV prevalence.[6]

1.2.2 HIV-related stigma in South Africa

HIV-related stigma manifests in several forms, including enacted, anticipated, internalised (self-stigma), and perceived (community) stigma. Enacted stigma refers to discrimination or prejudice experienced by individuals because of their HIV status. Anticipated stigma involves the fear of negative treatment if one's HIV status is disclosed. Internalised stigma, or self-stigma, occurs when individuals adopt a negative self-perception due to living with HIV. Perceived stigma, also known as community stigma, reflects an awareness of negative societal attitudes towards people living with HIV.[24,25] Evidence suggests that stigma is linked to the concealment of HIV status and the avoidance of healthcare services due to fear of identification and discrimination.[26] Consequently, HIV-related stigma remains a significant barrier to effective HIV management and prevention.[v]

In South Africa, the prevalence of HIV-related stigma among people living with HIV varies widely, with estimates ranging from 43.5% to 88%.[28, 19] Anticipated stigma affects approximately 24.4% to 43% of people living with HIV, while internalised stigma has been reported in 22% to 41% of cases.[28] Among adults living with HIV, 85% reported experiencing anticipated stigma.[29] Adolescents and youth appear particularly vulnerable to enacted stigma, with over 90% of adolescents reporting that someone else was aware of their HIV status.[2] Effective healthcare and social integration remain significantly hampered by the stigma associated with women and young girls living with HIV. Adolescents and young people living with HIV have reported mistreatment due to their HIV-positive status, with more than a two-fold increase in the likelihood of experiencing enacted stigma when their HIV status was disclosed to non-family members, such as friends, teachers, or sexual partners.[30] Similarly, HIV-positive young women who were pregnant or had recently given birth reported keeping their HIV status a secret due to fear of external stigma from community members, including peers. Selective disclosure is uncommon among peers, even though it may provide emotional and adherence support.[31] Ultimately, these experiences negatively affect mental well-being, reinforced by social exclusion and both internalised and enacted stigma.

The Human Sciences Research Council, through the five series of the South African National HIV Prevalence, Incidence and Behaviour Surveys (SABSSM), conducted between 2002 and 2017, show that external stigma has declined over time. For instance, in the 2002 SABSSM survey, 26% of participants reported that they would not be willing to share a meal with a person living with AIDS, 18% expressed unwillingness to sleep in the same room with someone with AIDS, and 6% stated that they would not speak to a person known to have AIDS.[2] By 2005, the second series of the SABSSM survey showed that most participants were willing to care for a family member with AIDS.[29] However, varying proportions of participants continued to exhibit some degree of negative attitudes and perceptions toward people living with HIV. Participants indicated some hesitation about marrying a person living with HIV, with less than half (46.5%) stating that they would consider doing so. In the fourth SABSSM survey conducted in 2012, most participants showed positive attitudes towards five of the six stigma questions (range: 79.0%–91.6%), with the question "Would you be willing to care for a family member with AIDS?" receiving the highest level of support.[27] However, participants demonstrated ambivalence regarding a particular stigma-related statement, specifically, "Would you want to keep the HIV-positive status of a family member a secret?".[32] Fifty per cent of the participants concurred with this statement.[32] Overall, the attitudes assessed were predominantly positive and demonstrated improvement over the course of the previous three surveys.[32-33] Multiple predictors of external stigma, including race, educational attainment, self-perceived risk of HIV, and HIV knowledge, were identified from the 2012 survey.[34] These positive trends persisted in the 2017 SABSSM series, wherein five of the six stigma-related questions indicated that most participants (ranging from 85.8% to 91.7%) held positive attitudes toward people living with HIV. The question concerning the willingness to care for a family member with AIDS again received the highest proportion of favourable responses.[35]

Beyond the SABSSM surveys, research has documented secondary stigma faced by older female caregivers of family members living with HIV in South Africa.[35] This stigma manifested in various forms, including verbal stigma, such as finger-pointing and gossip, social stigma, such as social isolation; and physical stigma, including separation from family members.[35] Efforts to combat stigma have involved community-based interventions that promote accurate HIV information and aim to change cultural attitudes.[35] When these initiatives are adapted to local contexts and supported by community stakeholders, they effectively reduce stigma.[28,36] Achieving sustained stigma reduction requires educational programmes, challenging deeply rooted beliefs, and implementing inclusive legislation.[37]

1.2.3 TB-related stigma in South Africa

Similar to HIV, TB remains a significant public health challenge in South Africa, which is among the 30 countries with the highest TB burden globally.[38] The first South African national TB prevalence survey (2017–2019) estimated a prevalence of 852 cases per 100 000 population, with higher rates among men than women. The survey further identified a disproportionate burden of undiagnosed TB among adolescents and young people aged 15–24 years, as well as those 65 years and older. For people living with HIV, model-based estimates indicated a TB prevalence of approximately 1 734 cases per 100,000 population.[39] South Africa continues to experience the dual burden of TB-HIV co-infection, which further complicates efforts to control both epidemics.[40]

TB-related stigma, like HIV stigma, presents a barrier to timely access to healthcare, diagnosis, treatment adherence, and disclosure.[41] Various dimensions of TB-related anticipated, internalised, and enacted stigma and discrimination were observed, all shaped by socio-cultural and structural factors. A recent study conducted across 93 communities (urban, peri-urban, and rural) in a South African district found that community-level TB stigma was consistently associated with HIV-related stigma, an association especially pronounced in urban and rural communities.[42]

In healthcare settings, the syndemic interaction between TB and HIV has led to overlapping forms of stigma. HIV-related stigma is often projected onto individuals with TB, reinforcing dual or layered stigma.[43] Manifestations include segregated queues for TB and HIV services, which may compromise patient confidentiality and contribute to experiences of internalised and external stigma and discrimination. Moreover, the strong social association between TB and HIV contributes to internalised stigma among co-infected individuals, further discouraging care-seeking and disclosure.[44]

1.2.4 Cyberbullying

The rapid expansion of digital platforms has created new avenues for harassment, stigma, and the dissemination of harmful content. Cyberbullying has emerged as a growing concern that violates fundamental human rights, including the rights to dignity, privacy, and equality.[45] For people living with HIV, these online attacks often reinforce existing experiences of HIV-related stigma and discrimination. A study conducted among people living with HIV across six districts in South Africa found that 3.9% of the 3 622 participants had experienced cyberbullying, with 2.4% reporting threats of having their HIV status disclosed online. These incidents were reported more frequently among men and individuals aged 15 to 29 years.[46] Similarly, young people living with HIV who experienced cyberbullying were found to miss clinic appointments and demonstrate poor adherence to antiretroviral therapy, primarily due to fear of involuntary HIV status disclosure.[47] These experiences also increase the risk of mental health challenges, including depression, anxiety, and suicidality.[48,49]

1.2.5 South Africa's policies protecting the rights of people living with HIV

The South African Human Rights Commission (SAHRC) plays a critical role in advocating for the rights of people living with HIV, primarily through legal interventions that address individual cases of discrimination.[50] However, its focus tends to be on specific instances of discrimination. While this approach is valuable, it may not fully address the broader societal stigma associated with HIV. To effectively combat HIV-related systemic stigma, a more comprehensive strategy that integrates legal action with proactive education and awareness initiatives is required. Such initiatives, implemented collaboratively with civil society and relevant community-based organisations, could challenge and change societal attitudes and misconceptions underpinning stigma, fostering a more inclusive and supportive environment for people living with HIV.

South Africa has made significant strides, guided by the Constitution as an overarching framework for the protection of human rights, including those of people living with HIV. The Constitution of the Republic of South Africa, 1996,[51] explicitly prohibits unfair discrimination, stating that no person, including the state or private entities, may discriminate directly or indirectly against anyone on any grounds. In particular, individuals cannot be unjustly discriminated against due to their HIV status. Section 10 of the Constitution guarantees the right to privacy for all individuals, including protection of communications from unauthorised disclosure. This means that no one, whether an employer, healthcare provider, family member, partner, or friend, can disclose a person's HIV status without their consent. This protection extends to the employment sphere, where potential or current employees are safeguarded against discrimination based on their HIV-positive status.

Additionally, the Protection of Personal Information Act 4 of 2013, further safeguards individuals' personal and health information, ensuring confidentiality.[52] The implementation of legal frameworks, such as the Employment Equity Act (EEA) 55 of 1998, now amended to the Employment Equity Amendment Act 4 of 2022, and the Promotion of Equality and Prevention of Unfair Discrimination Act (PEPUDA) 4 of 2000, also ensures the protection of rights for all, including in the workplace.[53-55] For example, Section 6(1) of the EEA 55 of 1998 states that no one may unjustly discriminate against an employee, either directly or indirectly, in any employment policy or practice based on one or more grounds, including, but not limited to, an individual's HIV status.

HIV testing and other medical testing of employees are prohibited by Section 7 of the EEA unless authorised by legislation and supported by medical facts, employment requirements, or social policy. In particular, HIV testing requires permission from the Labour Court, which evaluates the request according to stringent standards. Without the court's consent, employers are not permitted to use vague or indirect questionnaires to ascertain employees' medical status. If consent is granted, the court may mandate counselling before and after the test and ensure information confidentiality. Although the EEA primarily addresses workplace discrimination, it does not extend to stigma or discrimination that may arise between peer employees. These limitations might lead to isolation, bullying and exclusion of colleagues living with HIV, creating an uncomfortable and hostile environment for those affected by the epidemic.

The PEPUDA Act of 2000 was enacted to prevent and prohibit unfair discrimination, harassment, and hate speech, thereby promoting equality across various sectors, including healthcare. Initially, the Act addressed discrimination based on race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language, and birth. However, it did not explicitly include HIV/AIDS status as a protected ground. In 2017, Section 1(a) of PEPUDA was amended to explicitly prohibit discrimination on the grounds of HIV/AIDS status. This amendment was a significant step toward addressing HIV-related discrimination within the legal framework.

1.3 Rationale for implementing the People Living with HIV Stigma Index 2.0 in South Africa in 2024

In 2014, the SANAC commissioned the HSRC to conduct the country's first national People Living with HIV Stigma Index study. The study was designed to address the key priority areas of reducing HIV-related stigma and discrimination, as outlined in the National Strategic Plan on HIV and AIDS (2012–2016). Information for the study was gathered from people living with HIV in 18 districts (two per province) across all nine provinces of South Africa. A total of 10 473 people living with HIV were included, making it the largest study ever undertaken using the Stigma Index globally. The main findings of the study were:[56]

a. Experiences of external stigma were more likely to be reported by females, youth aged 15–24 years, those who had lived 2–4 years with an HIV-positive diagnosis, those who were married or cohabiting but whose spouse/partner was temporarily not living in the same household, those who had completed secondary education, those living in small towns and villages, those who often or rarely went without enough food, those who were employed, and those living in Free State, KwaZulu-Natal, and Mpumalanga provinces.

b. There was evidence of moderate levels of internalised stigma, with substantial minorities of participants (roughly 20–30%) indicating that they felt ashamed (28.7%), guilty (28.0%), blamed themselves (30.5%), blamed others (19.1%), or had low self-esteem (22.2%).

c. Disclosure of HIV-positive status to spouses and partners was found to be very high, as was disclosure to older family members and children in the household. In the workplace, however, most employers were not aware of participants' HIV-positive status. In healthcare settings, participants generally felt that the confidentiality of their HIV-positive status was maintained.

d. Finally, over a third (36.3%) of participants living with both HIV and TB reported being teased, insulted, or sworn at because of their TB status, and 41.4% reported being gossiped about due to their TB status.

The 2024 People Living with HIV Stigma Index 2.0 study was a follow-up to the study commissioned by SANAC and conducted by the HSRC in 2014. It used a standardised methodology and instrument. Due to the evolving nature of the epidemic and shifts in the socio-political landscape, an updated assessment was necessary to inform evidence-based interventions addressing stigma in the current context. The overall purpose of the study was to document and understand the stigma and discrimination experienced by people living with HIV in various settings, including healthcare, workplaces, and social spaces, and to assess self-reported stigma and discrimination among people living with HIV in South Africa. Conducting this follow-up study was crucial for identifying the most pressing barriers faced by people living with HIV, including those faced by key and vulnerable populations.

In addition, the 2024 People Living with HIV Stigma Index 2.0 aimed to empower people living with HIV and their networks to conduct the study in line with the GIPA Principle. This report provides updated data to support advocacy and inform policies aimed at protecting the health and rights of people living with HIV and improving their quality of life.

1.4 Aim and objectives of implementing the Stigma Index 2.0

The study aimed to document and assess the levels of stigma and discrimination experienced by people living with HIV in the general population and among key and vulnerable populations.

1.4.1 Objectives of the study

a. To document and assess levels of HIV-related stigma and discrimination experienced by people living with HIV in 18 districts across the South African provinces of Gauteng, Western Cape, Northern Cape, Eastern Cape, North West, KwaZulu-Natal, Mpumalanga, Free State, and Limpopo.

b. To inform the development and implementation of national policies that protect the rights of people living with HIV.

c. To inform programmatic interventions on HIV-related stigma and discrimination.

The People Living with HIV Stigma Index 2.0 follows a standardised methodology, which typically only allows participants aged 18 and above to be enrolled in the study. This restriction is intended to protect the confidentiality of minor participants and mitigate potential power imbalances arising from the requirement for parental consent. However, given that South Africa has the largest population of people living with HIV globally, the rising transmission among younger people remains a concern. National legislative frameworks, such as the Children's Act and the National Health Act, allow minors aged 15–17 to provide assent without parental consent to participate in research. It was agreed with the International Partnership for the Stigma Index 2.0 that the 2024 South African People Living with HIV Stigma Index would be an exception and could include minor participants. Consequently, the study included people living with HIV aged 15 years and older.

2. METHODOLOGY

2.1 Geographical scope of the study

The study covered all nine provinces in South Africa. However, only 18 districts, two from each province, were selected, namely Gauteng, Western Cape, Northern Cape, Eastern Cape, North West, KwaZulu-Natal, Mpumalanga, Free State and Limpopo. The selection of districts was guided by the need to include both urban and rural areas. In each province, one urban and one rural district were purposefully selected.

2.2 Study participants

Participants were selected from a diverse population of people living with HIV in South Africa. The study included people living with HIV aged 15 years and older, as well as key and priority populations (people living with HIV, lesbian, gay, bisexual, transgender, queer or questioning, intersex, and asexual, men who have sex with men, sex workers, people who use drugs and persons with disabilities). The following inclusion and exclusion criteria were applied:

Inclusion criteria

a. Aged 15 years and older.

b. Knew they had been living with HIV for at least 12 months.

c. Able to provide informed consent and understand all elements of the study.

d. Resided in one of the selected nine provinces and 18 districts.

e. Fluent in one of the following languages: English, Sesotho, Sepedi, Setswana, siSwati, isiXhosa, Xitsonga, Tshivenda, Afrikaans, or isiZulu.

Exclusion criteria

a. Unable to understand or provide informed consent.

b. Had already participated in the current study.

c. Key population members not living with HIV.

d. Exhibited violent behaviour or signs of severe mental illness that would prevent the interviewer from obtaining informed consent at the time of the interview.

e. Under the visible influence of drugs or alcohol at the time of the interview.

2.3 Sampling and recruitment

The Stigma Index sample size calculator (https://www.stigmaindex.org/library/sample-size-calculator) was used to estimate the minimum sample required in South Africa. Based on data on the average reported avoidance of clinics and hospitals due to HIV in the 2014 Stigma Index report, and accounting for potential underreporting, an adjusted estimated stigma prevalence of 8.2% was used to calculate the sample size. Using a target precision of 1.5% and a 95% confidence interval, the required sample size for people living with HIV adults aged 18 years and older, was 5 144. An additional 5.3% was added to recruit adolescents aged 15–17 years, bringing the total sample size to 5 401. A total of 300 people living with HIV were targeted for recruitment in each of the selected districts.

Recruitment approach

The recruitment of study participants was based on two purposive sampling techniques: venue-based and limited chain-referral sampling.

Venue-based purposive sampling was implemented in healthcare facilities, with the assistance of six partner organisations in the SANAC people living with HIV sector (NAPWA, TAC, SANERELA+, PWN, and the Positive Action Campaign), as well as the LGBTI+, disability, and sex worker sectors of SANAC. A list of institutions providing services to people living with HIV was compiled, including networks of people living with HIV and community-based organisations or NGOs offering any form of support to people living with HIV in the selected provinces and districts.

Limited chain referrals sampling was used to recruit participants who were less likely to be reached through the venue-based approach, such as those who were lost to follow-up, not in care, aged 15– 17 years, or part of key populations. Approximately 25% of the sample (1 350 out of 5 401) were recruited via this method. Each participant was given three cards containing the contact details of the project coordinator and asked to provide them to people they knew were living with HIV, especially those from key populations and those aged 15–17 years.

2.4 Research instrument

The research instrument used in this study was the standardised PLHIV Stigma Index 2.0 quantitative questionnaire, which was loaded into the Research Electronic Data Capture (REDCap) system on tablets for data collection. The questionnaire collected data on HIV-related stigma and discrimination experienced by people living with HIV, covering the following areas:

- Disclosure of HIV status
- Experiences of stigma and discrimination
- Internal stigma and resilience
- Interaction with healthcare services
- Human rights and affecting change
- Stigma and discrimination experienced for reasons other than HIV
- Personal experience of stigma and discrimination.

In addition, country-specific questions addressed areas with a compounding impact on people living with HIV:

- Disability-related stigma
- TB-related stigma
- Experiences of cyberbullying
- Awareness of various HIV national campaigns and support groups, to determine the level of support received by people living with HIV.

2.5 Ethical review

The protocol and research instruments, along with the information sheets and consent forms, were approved by the HSRC Research Ethics Committee (REC: 1/20/11/19). Additional approval was obtained from the provincial RECs in Gauteng, the Western Cape, Northern Cape, Eastern Cape, North West, KwaZulu-Natal, Mpumalanga, Free State, and Limpopo through the National Health Research Database. Permission to conduct the study was also secured from the relevant provincial districts prior to the survey's implementation.

2.6 Implementation

The data collection approach varied depending on the type of site. After obtaining permission to conduct the study from provincial and district authorities, as well as all relevant stakeholders at the identified sites, the team supervisor arranged and scheduled appointments for data collection at times and dates convenient for the sites. During each visit, the supervisor assessed the feasibility of conducting interviews, ensuring that confidentiality was maintained. Private spaces were identified where potential participants, including walk-ins, would feel most comfortable for interviews. All participants were offered R50 as a token of appreciation for their time and their contribution to improving policies related to stigma. They were also provided with a list of available support resources, including counselling and paralegal services where applicable, to ensure access to support if the interview triggered emotional distress or if participants requested assistance that interviewers could not provide.

Field staff training: To ensure the study was conducted to the highest ethical standards, interviewers were provided with training manuals and received training in research ethics, ethical protection of participants, and confidentiality. Field staff received training on both the contents of the data collection instruments and the use of the interview tools, including RedCap. Specific training was given on managing participants aged 15–17 years. All staff signed confidentiality agreements. Training lasted five days and included role-playing various survey processes.

Informed consent process: Once selected, potential participants received copies of the information sheet and consent forms in one of the nine official languages, which they reviewed with the data collector. The data collectors read the information sheet verbatim to participants. Participants provided verbal consent, indicating that they understood and agreed to all the items in the consent form, thereby enrolling them in the study. The participants were informed that participation was voluntary and that they could withdraw at any time without penalty. Withdrawal did not affect participants' access to health services outside the survey. Participants were also informed that they did not have to answer any questions that made them uncomfortable and that any information disclosed during the survey would remain confidential. No personal identifiers would be used in reports or publications; only aggregate data would be reported. The potential risks and benefits of participation were also explained to the participants.

Collection and processing of data in the field: Data were collected and managed electronically using the REDCap system. The data processing coordinator/manager for the survey was trained on data processing to ensure that no personally identifiable data were collected from participants. Survey data were protected with a password, and access was restricted to the survey investigators. Interview data were entered directly into tablets during the interview and backed up daily. Data collectors also had printed copies of the English and translated versions of the information sheets, consent forms, and questionnaire (translated into the languages spoken in the sampled districts, e.g. Sesotho, Sepedi, Setswana, siSwati, Xitsonga, isiXhosa, Tshivenda, Afrikaans and isiZulu).

2.7 Data management and analysis

REDCap, a web-based secure data management platform, was used to export and download data to a statistical package. The data management team, which supported and monitored the collected data, included a Data Manager, a Data Quality Assurance Officer/Analyst, and three Data Monitors. The team was responsible for monitoring the flow of real-time data and ensuring the completeness of questionnaires. Access to the survey database and dataset was restricted, with survey investigators granted access according to their roles. Non-electronic data from this study are stored for five years in accordance with the study protocol.

Basic descriptive analyses, including frequencies and percentages, were used to summarise the data. External and internalised stigma were summarised by the socio-demographic characteristics of participants, including age, sex, gender, relationship status, educational level, employment status, and region/district, as well as economic situation. All analyses were performed using Stata version 18.0 (StataCorp, College Station, Texas, USA).

3. RESULTS

3.1 Characteristics of study participants

Table 1 presents the socio-demographic characteristics of study participants aged 18 years and older. The study sample was fairly distributed across all nine provinces, with a higher proportion of participants from KwaZulu-Natal (12.7%) and a lower proportion from the Eastern Cape (10.0%). Most participants (69.7%) were aged 25–49 years, while 11.8% were aged 18–24 years, and 18.4% were aged 50 years or older. The mean age of participants was 38.4 years. Among participants, 63.6% were assigned female and 36.4% were assigned male. In terms of self-reported gender identity, 62.1% identified as female, 33.0% as male, 2.8% as transgender, and 1.5% did not identify with any of the listed categories.

Table 1. Socio-demographic characteristics of participants (n = 5 065)

Variables	n*	%
Province		
Western Cape	551	10.9
Eastern Cape	506	10.0
Northern Cape	568	11.2
Free State	565	11.1
KwaZulu-Natal	643	12.7
North West	557	11.0
Gauteng	571	11.3
Mpumalanga	578	11.4
Limpopo	531	10.5
Age groups		
18–24	599	11.8
25–49	3 531	69.7
50+	934	18.4
Sex assigned at birth		
Female	3 217	63.6
Male	1 845	36.4
Gender identity		
Female	3 089	62.1
Male	1 641	2.8
Transgender	138	2.7
I do not identify as female, male, or transgender	75	1.5
I prefer not to answer	28	0.6

** Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 2 shows the breakdown of the participants' gender identity, based on a combination of sex assigned at birth and self-reported gender identity. Among the 4 941 participants who answered both questions, most participants (61.7%) were cisgender women, meaning they were assigned female at birth and self-identify as women. A further 32.9% were cisgender men, meaning they were assigned male at birth and self-identify as men. Other identities accounted for less than 3%, and 1.5% did not conform to any of the listed categories.

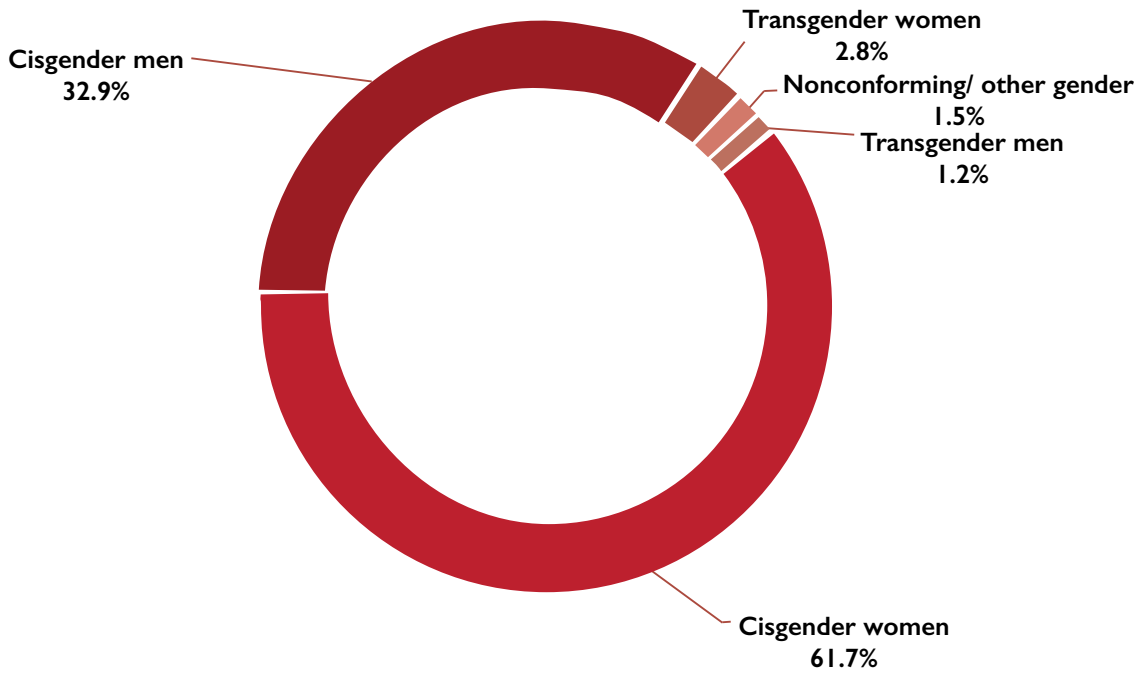

Figure 2. Gender identity of participants (assigned at birth and self-reported)

Of the 5 065 participants, 28.5% belonged to at least one key population group, while 71.5% belonged to the general population. Figure 3 shows the proportions of the different key population groups. The largest proportion of key population members were sex workers (14.0%) and people who use drugs (10.0%). There were almost equal proportions of men who have sex with men and transgender individuals.

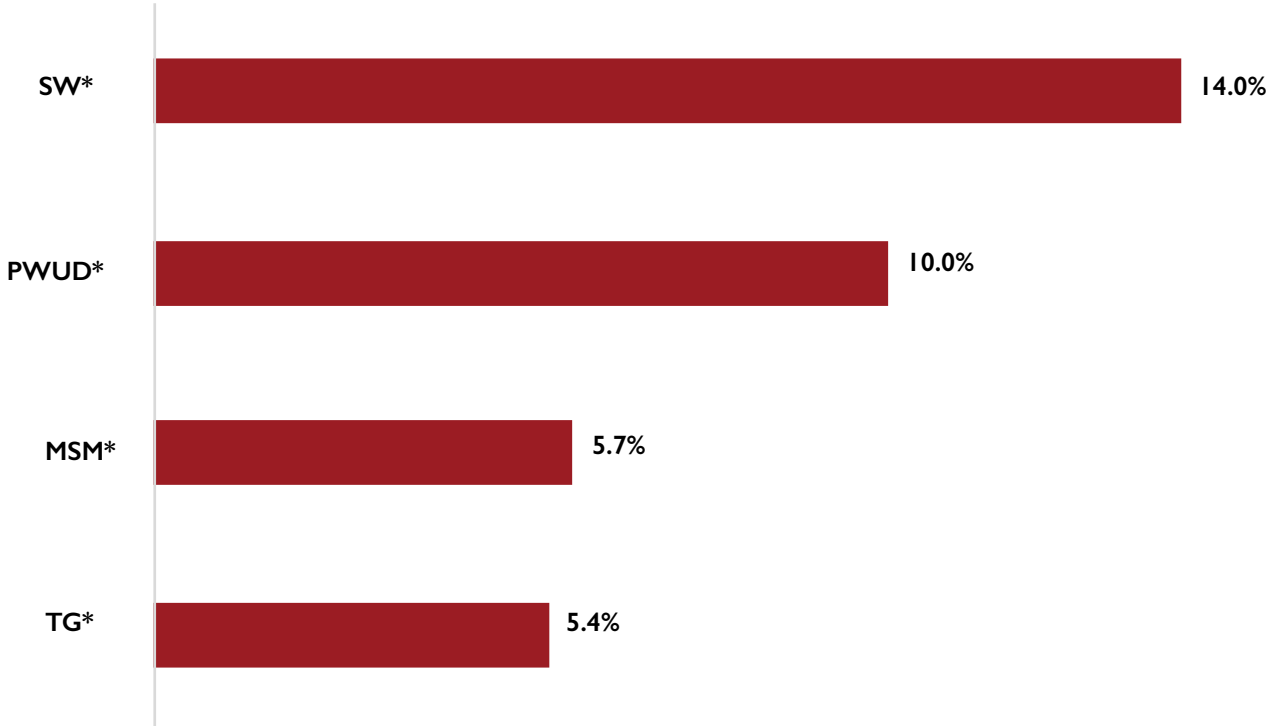

Figure 3. Proportion of key populations

**Note: Participants can belong to more than one group*

Figure 4 shows that, among the 5 042 participants who responded to the question on belonging to a racial, ethnic or religious minority, 20.1% (n = 1 011) reported belonging to such a group. Of the 5 043 participants who responded to the question about disability, 6.9% (n=350) reported having a disability. Among the 5 042 participants who responded to the question on belonging to indigenous or aboriginal groups, 6.0% (n = 300) reported that they were members of such a group. Among those who responded to the questions on migration, 1.2% (n = 60) reported being migrant workers, 0.9% (n = 44) were refugees or asylum seekers, 0.6% (n = 32) were internally displaced persons, and 0.9% (n = 45) were incarcerated or in prison.

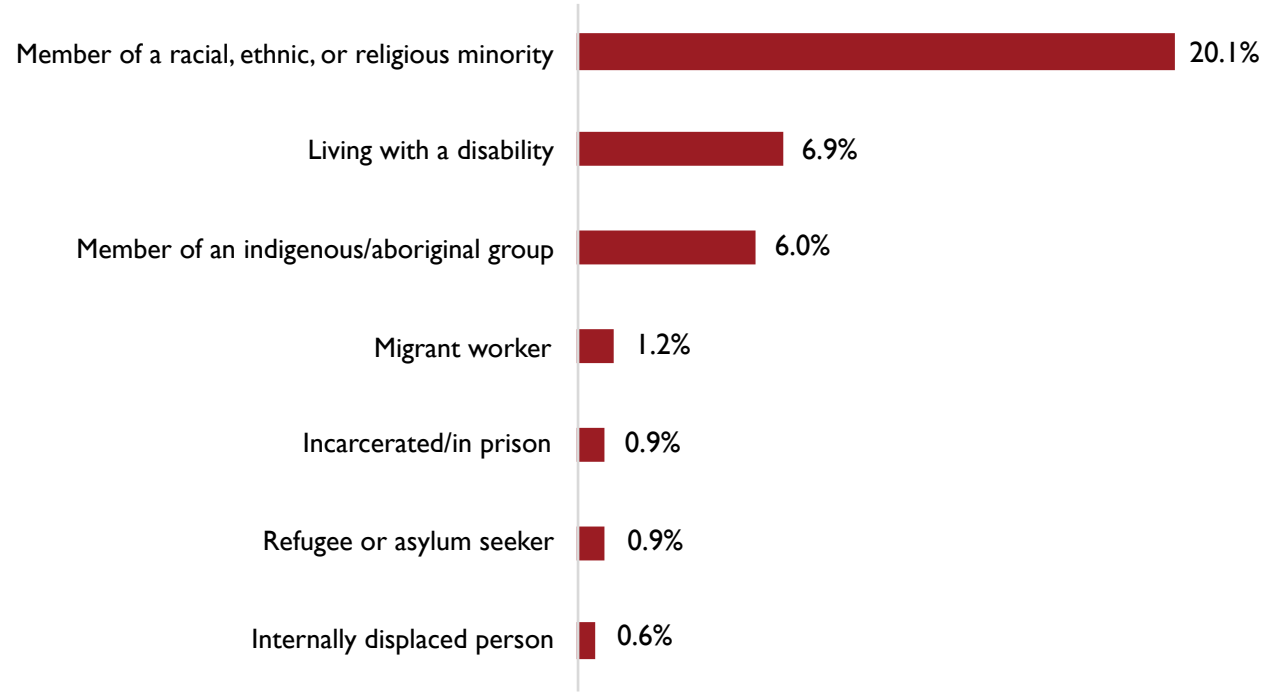

Figure 4. Membership or affiliation with various groups

Table 2 shows that most participants (58.7%) had completed secondary or high school education, while 17.1% had no formal education. In addition, most participants were unemployed, with only 14.6% in full-time employment and a small proportion (4.1%) retired.

Table 2. Education table levels and current work status

Variables	n*	%
Highest level of formal education		
No formal education	865	17.1
Primary/elementary/local equivalent	486	9.6
Secondary/high school/local equivalent	2 959	58.7
Trade/vocational school	170	3.4
University/tertiary education	565	11.2
Current work status		
In full-time work (as an employee)	737	14.6
In part-time work (as an employee)	691	13.7
Working full-time, but not as an employee (self-employed or business owner)	178	3.5
Doing casual or informal part-time work (self-employed or paid work for others)	343	6.8
Retired/on pension	208	4.1
Unemployed	2 904	57.4

**Subtotals do not equal the overall total due to questionnaire item non-response*

Table 3 shows that most of the participants (64.2%) were currently in an intimate or sexual relationship. Among those in an intimate or sexual relationship, 56.2% reported that their partner was also living with HIV, while 22.3% were not sure of their partner's HIV status.

Table 3. Relationship status and partner HIV status

Variables	n*	%
Currently in an intimate/sexual relationship (whether married or unmarried)		
Yes	3 239	64.2
No	1 806	35.8
Partner is also living with HIV		
Yes	1 816	56.2
No	695	21.5
Not sure	721	22.3

**Subtotals do not equal the overall total due to questionnaire item non-response*

Table 4 shows that a higher proportion of participants (43.2%) were living with one to two children in their households, while 10.5% reported caring for five or more children. Just under a fifth (18.7%) indicated that they were not caring for any children.

Table 4. Household composition

Number of children living in your household that you take care	n*	%
0	932	18.7
1–2	2 155	43.2
3–4	1 381	27.7
5+	526	10.5

**Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 5 shows participants' responses on how often they had been unable to meet basic needs such as food, shelter, or clothing in the past 12 months. Of the 5 058 participants who responded to the question, a few (12.3%, n = 621) indicated that they were unable to meet their basic needs most of the time. About half of the participants (47.4%, n = 3 396) indicated that they had never failed to meet their basic needs.

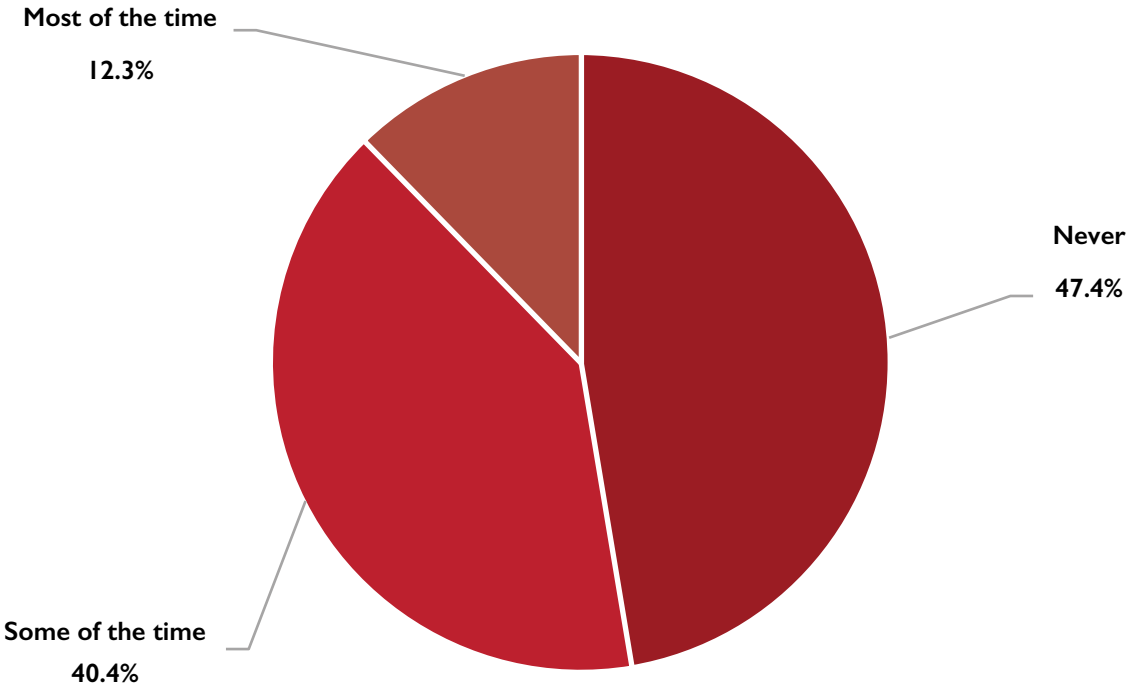

Figure 5. Inability to meet basic needs in the past 12 months

Table 5 shows participants' responses to questions about their inability to meet basic needs in the past 12 months, stratified by age, sex, and key populations. A higher proportion of participants aged 50 years and older reported being unable to meet their basic needs some of the time (41.6%) or most of the time (13.6%) compared with other age groups. In addition, a higher proportion of females indicated that they were unable to meet their basic needs some of the time (42.3%), while a higher proportion of males reported being unable to meet their basic needs most of the time (13.1%). Among key populations, sex workers had the highest proportion of those who reported being unable to meet their basic needs some of the time (46.0%), followed by people who use drugs (45.1%). People who use drugs reported the highest proportion of being unable to meet their basic needs most of the time (19.0%).

Table 5. Inability to meet basic needs, by demographic group

Variables	n*	Never (%)	Some of the time (%)	Most of the time (%)
Total	5 058	47.4	40.4	12.3
Age groups				
18–24	599	53.4	36.7	9.8
25–49	3 527	47.0	40.7	12.3
50+	931	44.8	41.6	13.6
Sex assigned at birth				
Female	3 212	47.0	41.3	11.8
Male	1 843	48.1	38.8	13.1
Key population groups**				
MSM	291	54.5	32.1	13.4
Sex workers	707	41.7	46.0	12.3
People who use drugs	503	35.8	45.1	19.0
Transgender people	270	54.2	36.9	8.9
Non-key population	3 605	49.0	39.6	11.4

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

The average number of years participants (n = 4 660) had known their HIV status was 8.4 years. Figure 6 shows that a higher proportion of participants (37%, n = 1 722) had known their HIV status for 10 years or more, while a small proportion of participants (4.5%, n = 211) had known their HIV status for less than two years.

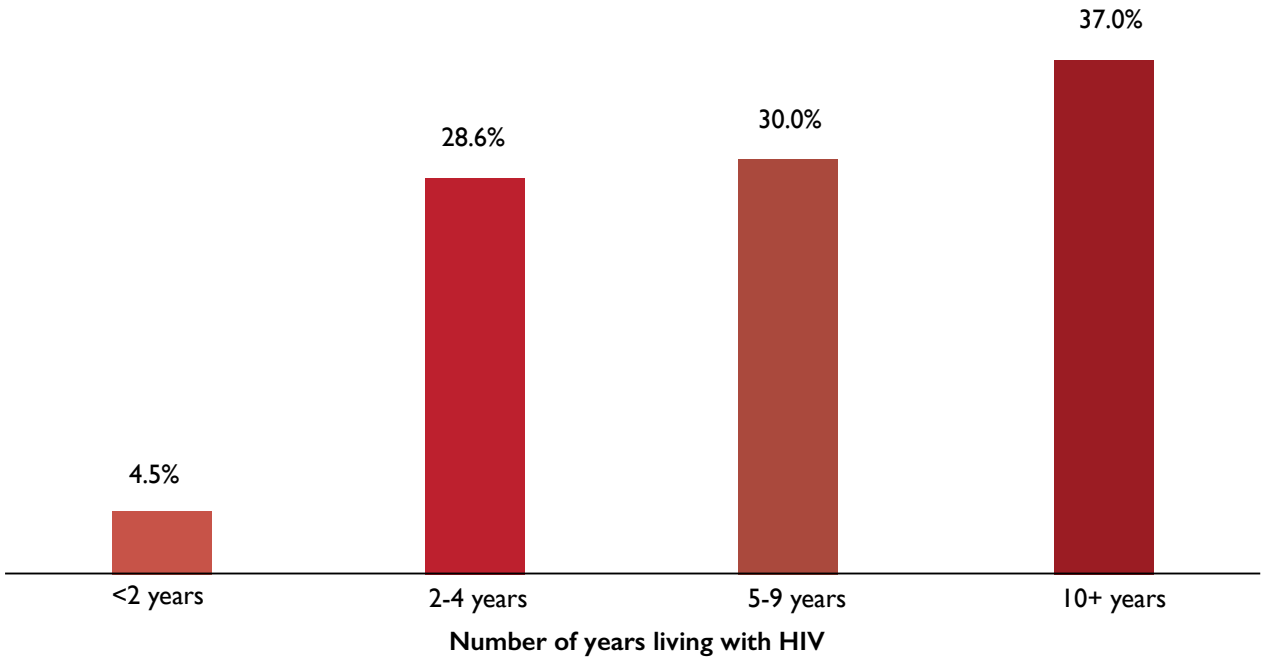

Figure 6. Length of time participants have known their HIV status

Figure 7 shows that, overall, a lower proportion of people living with HIV (38%) reported being members of support groups. Membership varied slightly across sex, age groups, and key populations. A higher proportion of females (39.8%) than of males (34.9%), and participants aged 50 years and older (40.9%) were members of support groups compared with their counterparts. Among key populations, transgender people (50%) and men who have sex with men (48.1%) had the highest proportion of those who were members compared with other groups.

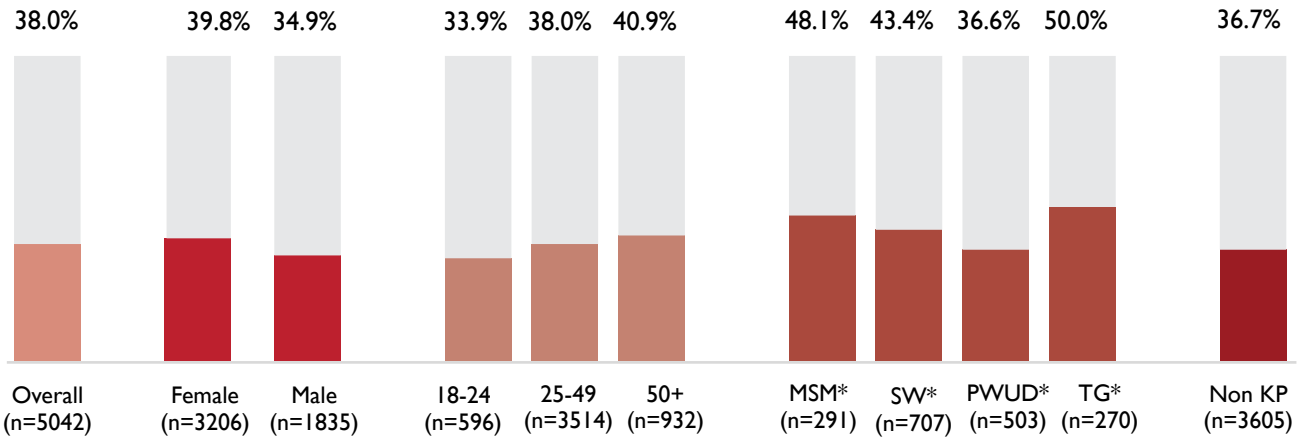

Figure 7. Membership of support groups for people living with HIV, by sex, gender, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

3.2 Disclosure

3.2.1 HIV status disclosure

The participants were asked to indicate whether various people or groups knew their HIV status. Figure 8 shows that most participants disclosed their HIV status to family members (73.2%). Many participants also disclosed their HIV status to friends (52.6%) and husbands, wives, or partners (51.2%). Fewer participants indicated that groups such as employers, co-workers, teachers, classmates or local leaders or authorities knew their HIV status.

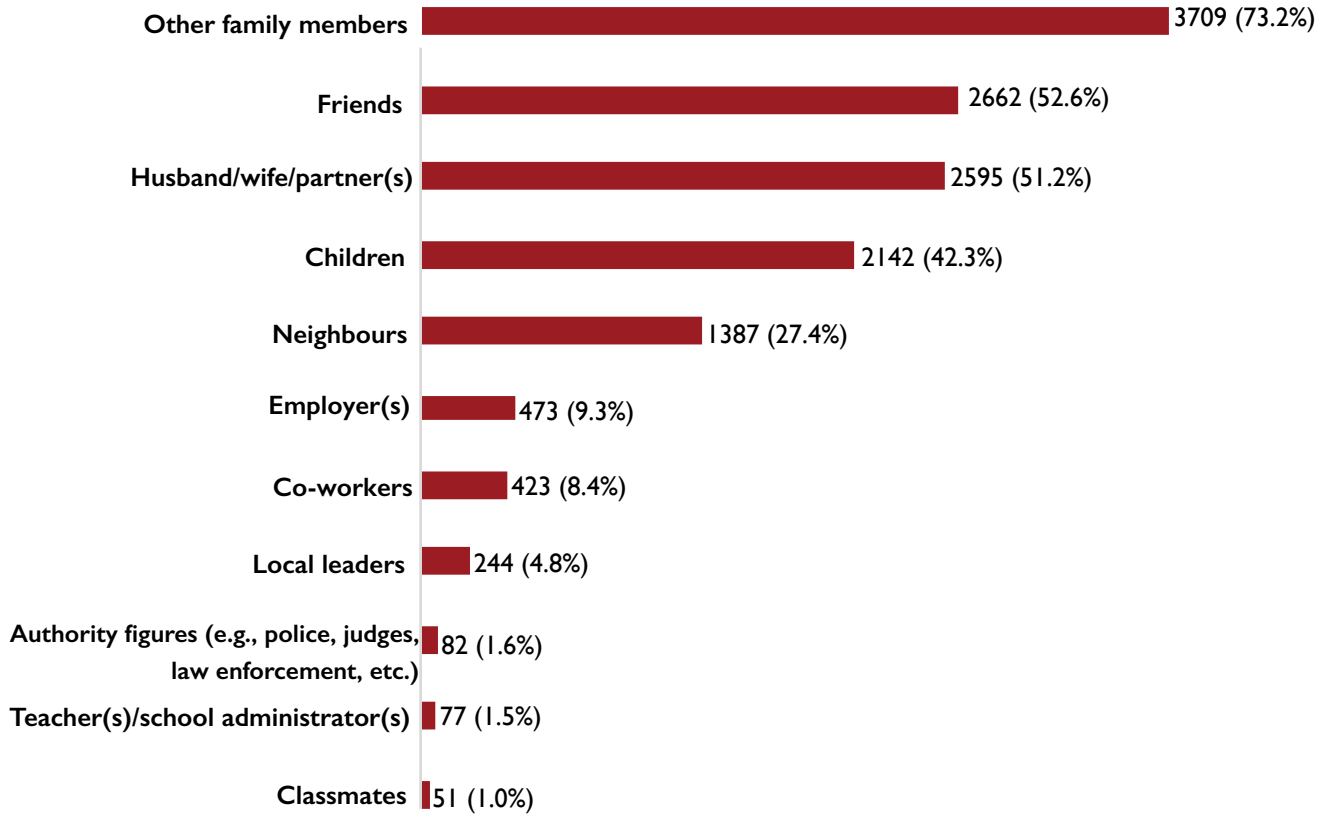

Figure 8. Disclosure of HIV status to various people or groups

The participants were asked whether their status had ever been disclosed to at least one person or group without their consent. Overall, among the 5 065 participants, instances of non-consensual disclosure were rare (Table 6). The results show that 3.3% (n = 169) of participants reported that other family members knew their status without consent, 3.0% (n = 152) reported that friends had known their HIV status without consent, and only 1.5% (n = 77) of participants indicated that their partners had known their status without consent.

Table 6. Disclosure of HIV status without consent (n = 5 065)

Variables	n*	%
Your husband/wife/partner(s)	77	1.5
Your children	73	1.4
Other family members	169	3.3
Your friends	152	3.0
Your neighbours	133	2.6
Your employer(s)	21	0.4
Your co-workers	38	0.8
Your teacher(s)/school administrator(s)	9	0.2
Your classmates	10	0.2
Local leaders	13	0.3
Authority figures (e.g. police, judges, law enforcement, etc.)	10	0.2

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.2.2 Disclosure experience

Table 7 shows that a higher proportion of participants (66.5%) reported having a positive experience when disclosing their HIV status to people close to them, such as partners, family members, and close friends. In addition, 64.8% of participants indicated that those close to them were supportive when they first learned about their HIV status. However, a smaller proportion (38.8%) of participants agreed that disclosing their HIV status to people they do not know well had been a positive experience. Most participants felt that disclosing their HIV status had become easier over time, with 53.1% agreeing and 14.9% somewhat agreeing with the statement.

Table 7. Experiences of disclosing HIV status

Variables	n*	Disagree (%)	Somewhat agree (%)	Agree (%)
Disclosing your HIV status to people you are close to (e.g. partner, family, close friends) has been a positive experience	5 019	19.1	14.4	66.5
People you are close to were supportive when they first learned about your HIV status	5 018	19.9	15.2	64.8
Disclosing your HIV status to people you don't know very well has been a positive experience	4 888	40.5	18.8	40.8
People you don't know very well were supportive when they first learned about your HIV status	4 853	43.0	18.2	38.8
Disclosing your HIV status has become easier over time	5 006	32.0	14.9	53.1

**Subtotals do not equal the overall total due to questionnaire item non-response*

Participants who felt that disclosing their HIV status had become easier over time were stratified by sex, age, key population status, and length of time living with HIV (Figure 9). Overall, a high proportion of participants felt that disclosing their HIV status had become easier over time. A higher proportion of females (69.0%), participants aged 50 years and older (71.4%), sex workers (69.3%), and those who had lived with HIV for 10 years or more (73.9%) reported that disclosing their HIV status had become easier over time compared to their counterparts. However, the proportion of those who felt that disclosing their HIV status had become easier over time was lower among key populations than among non-key populations.

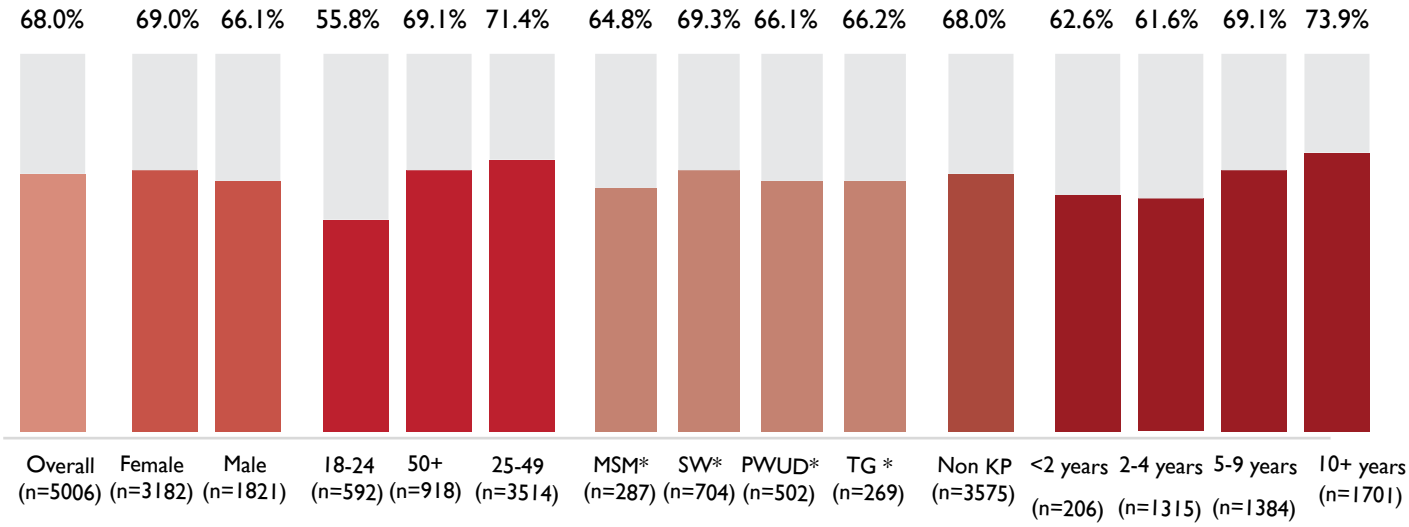

Figure 9. Agreement that disclosing HIV status has become easier over time, by sex, age, key population type, and length of time living with HIV

**In the key population category, individuals may* have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may *overlap*

3.3 Experience of HIV-related stigma and discrimination

3.3.1 External HIV-related stigma and discrimination

Table 8 presents the different forms of stigma and discrimination experienced by people living with HIV in the past 12 months and the 12 months prior. The results show that experiences of stigma and discrimination have decreased overall, as the proportions of participants reporting specific forms are generally lower in the past 12 months compared to the previous period. The most frequently reported forms of stigma and discrimination in thve past 12 months (compared with the 12 months prior) included other people (excluding family members) making discriminatory remarks or gossiping about them (5.0% versus 6.9%), family members making discriminatory remarks or gossiping about them (4.9% versus 7.8%) and being verbally harassed because of their HIV status (3.6% versus 3.8%). Some participants also reported being excluded from social gatherings or activities (2.8% versus 5.4%), family activities (2.4% versus 5.1%), and religious activities or places of worship (2.2% versus 3.3%).

Table 8. Stigma and discrimination experienced by people living with HIV

Variables	n*	Yes, within the past 12 months (%)	Yes, but not within the past 12 months** (%)	No (%)
Have you ever been excluded from social gatherings or activities (e.g. weddings, funerals, parties, clubs) because of your HIV status?	5 036	2.8	5.4	91.8
Have you ever been excluded from religious activities or places of worship because of your HIV status?	5 001	2.2	3.3	94.5
Have you ever been excluded from family activities because of your HIV status?	5 041	2.4	5.1	92.4
Have you ever been aware of family members making discriminatory remarks or gossiping about you because of your HIV status?	5 037	4.9	7.8	87.2
Have you ever been aware of other people (other than family members) making discriminatory remarks or gossiping about you because of your HIV status?	5 038	5.0	6.9	88.1
Has someone ever verbally harassed you (e.g. yelled, scolded, or was otherwise verbally abusive) because of your HIV status?	5 039	3.6	3.8	92.6
Has someone ever blackmailed you because of your HIV status?	5 039	2.0	1.5	96.4
Has someone ever physically harassed or hurt you (e.g. pushed, hit, or was otherwise physically abusive) because of your HIV status?	5 038	1.4	1.3	97.2
Have you ever been refused employment or lost a source of income or job because of your HIV status?	4 981	1.1	1.0	97.9
Has your job description or the nature of your job ever been changed, or have you ever been denied a promotion, because of your HIV status?	4 940	1.0	0.9	98.2
Has your wife/husband, partner(s) or child(ren) ever experienced discrimination because of your HIV status?	4 960	1.6	1.9	96.5

**Subtotals do not equal the overall total due to questionnaire item non-response*
***12 months prior*

Figure 10 shows the experiences of at least one form of stigma and discrimination among people living with HIV in the past 12 months compared to more than 12 months prior, disaggregated by sex, age, key populations, and non-key populations. Consistent with previous findings, the results indicate that experiences of stigma and discrimination have decreased overall, as the proportions of participants reporting such experiences were generally lower in the last 12 months compared to the earlier period. Overall, 6.1% of participants reported experiencing at least one form of stigma and discrimination in the past 12 months, compared to 14.3% more than 12 months prior. The prevalence of stigma and discrimination was higher among females (7% versus 14.3%), participants aged 18–24 years (6.5% versus 16.9%), sex workers (10.3% versus 20.1%), and transgender people (7.0% versus 21.0%). The experience of at least one form of stigma and discrimination in the past 12 months was lower among non-key populations compared to key populations.

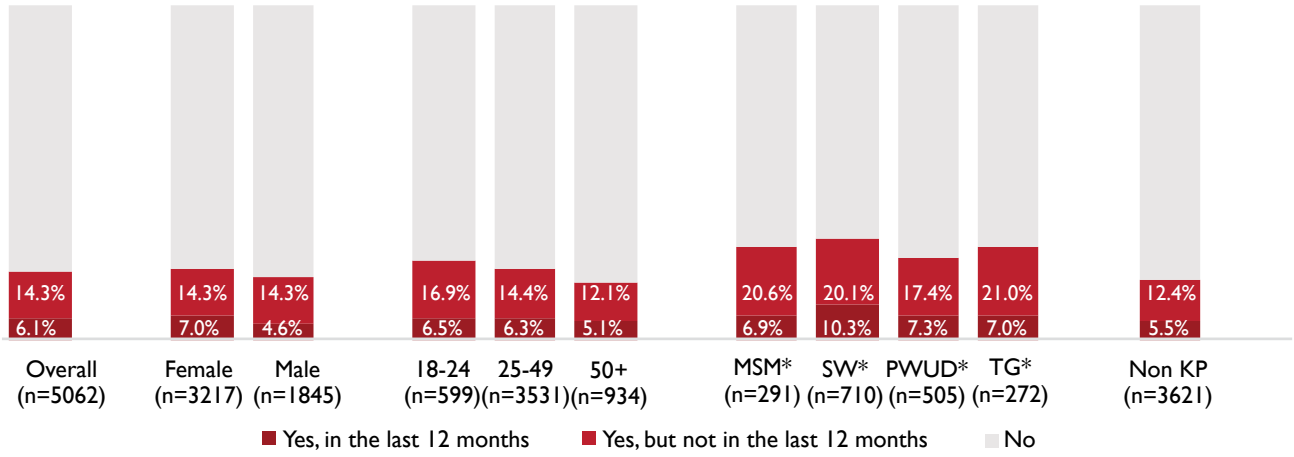

Figure 10. Experience of at least one form of stigma or discrimination, by sex, age, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs) so totals may overlap*

3.3.2 Internalised HIV-related Stigma

Participants were asked whether their ability to meet specific needs over the past 12 months had been negatively, positively, or not affected. Table 9 shows that a higher proportion (12.9%) of participants reported that their HIV status negatively affected their self-confidence, followed by their ability to find love (11.8%), their ability to cope with stress (11.5%), and their ability to have close and secure relationships with others (11.4%).

Table 9. Effect of HIV status on the ability to meet specific needs

Variables	n*	Negatively affected (%)	Positively affected (%)	Not affected (%)
My self-confidence	5 047	12.9	16.4	70.7
My self-respect	5 043	9.9	13.4	76.7
My ability to respect others	5 040	6.8	12.1	81.1
My ability to cope with stress	5 041	11.5	16.5	72.0
My ability to have close and secure relationships with others	5 041	11.4	12.2	76.4
My ability to find love	5 014	11.8	13.0	75.3
My desire to have children	4 990	10.7	12.4	76.9
My ability to achieve personal and/or professional goals	4 893	8.5	11.7	79.8
My ability to contribute to my community	4 992	8.8	11.5	79.7
My ability to practice a religion/faith as I want to	4 966	7.7	10.5	81.8

**Subtotals do not equal the overall total due to questionnaire item non-response*

The ability to meet one or more of the ten needs negatively affected by HIV status over the past 12 months was stratified by sex, age, key populations, and non-key populations. Figure 11 shows that overall, 20.2% of participants were negatively affected by their HIV status over the past 12 months. A higher proportion of females (20.8%), those aged 18–24 years (25.5%), sex workers (25.6%), and people who use drugs (25.7%) were negatively affected compared with their counterparts. A lower proportion of non-key populations were negatively affected by their HIV status compared to key populations.

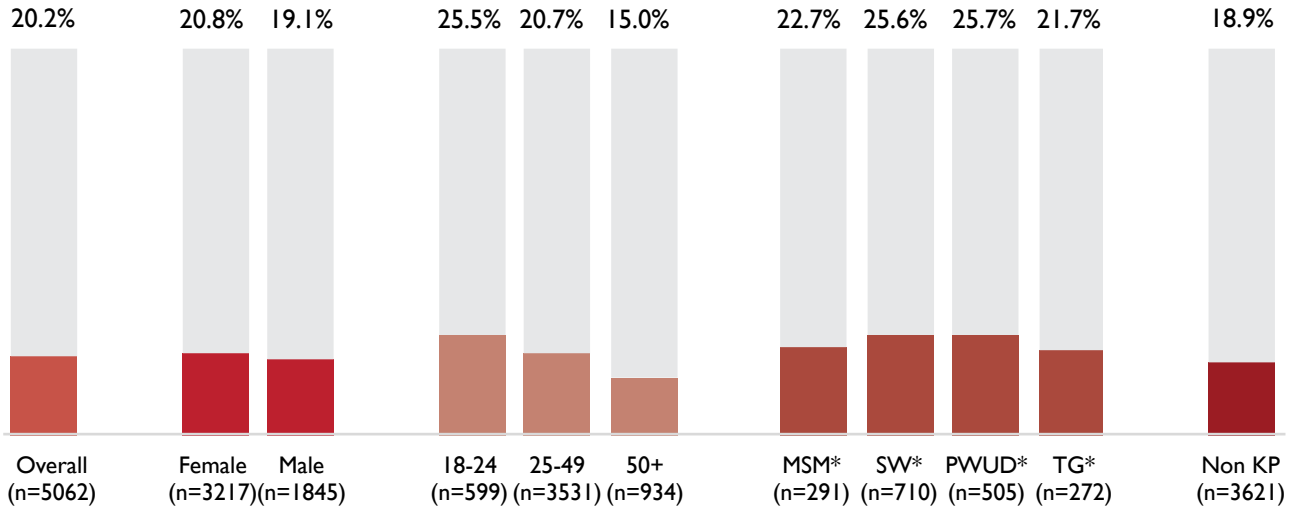

Figure 11. Ability to meet one or more of ten needs negatively affected by HIV status over the past 12 months, by sex, age, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

A follow-up question asked participants whether their HIV status had affected their ability to meet their needs for the better, about the same, or for the worse over the past 12 months. Table 10 shows that a higher proportion of males (4.3%), participants aged 50 years and older (4.3%), and sex workers (4.0%) reported that their HIV status had negatively affected their ability to meet specific needs compared with the previous 12 months.

Table 10. Change in the effect of HIV status on the ability to meet at least one specific need in the previous 12 months

Variables	n*	About the same (%)	Worse (%)	Better (%)
Total	4 889	26.0	3.5	70.5
Sex assigned at birth				
Female	3 116	23.6	3.0	73.4
Male	1 770	30.2	4.3	65.5
Age groups				
18–24	576	27.6	2.4	70.0
25–49	3 410	26.2	3.5	70.4
50+	902	24.2	4.3	71.5
Key population groups**				
MSM	277	32.9	1.8	65.3
Sex worker	694	27.7	4.0	68.3
People who use drugs	490	33.7	3.1	63.3
Transgender people	254	35.0	2.0	63.0
Non-key population	3495	24.2	3.5	72.2

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Probing how participants felt due to their HIV status (Table 11), a high proportion (48.6%) reported that it was difficult to disclose their HIV status to others, while 26.7% indicated that they hid their HIV status from others.

Table 11. Feelings of shame and guilt due to HIV status

Variables	n*	%
It is difficult to tell people that I am HIV positive	5 057	48.6
Being HIV positive makes me feel dirty	5 059	10.2
I feel guilty that I am HIV positive	5 058	17.3
I am ashamed that I am HIV positive	5 059	15.4
I sometimes feel worthless because I am HIV positive	5 060	14.2
I hide my HIV status from others	5 050	26.7

**Subtotals do not equal the overall total due to questionnaire item non-response*

Responses to agreement with one or more of the six statements on internalised stigma were stratified by sex, age, key populations, and non-key populations. Figure 12 shows that overall, 54.6% of participants agreed with one or more of the six statements on internalised stigma. A higher proportion of males (57.3%) and participants aged 18–24 years (68.6%) agreed with one or more of the statements of internalised stigma compared to their counterparts. Among key populations, a higher proportion of people who use drugs (65.0%) agreed with one or more of the six statements on internalised stigma compared to other groups. Non-key populations had lower percentages of participants who agreed with one or more of the six statements on internalised stigma compared to key populations.

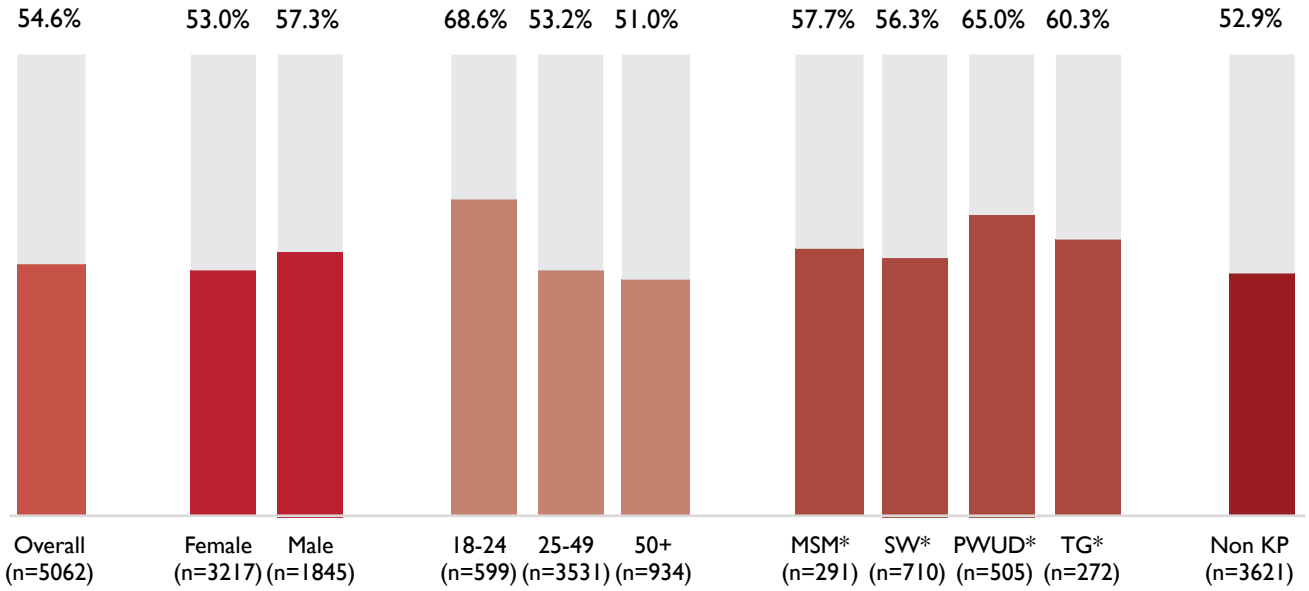

Figure 12. Agreement with one or more of six statements on internalised stigma, by sex, age, and key population type
**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Participants were asked about various avoidance behaviours adopted in the past 12 months that may be related to internalised stigma or fear of discrimination (Table 12). A higher proportion reported choosing not to attend social gatherings (6.4%), followed by those who decided not to have sex (5.5%), those who isolated themselves from family and friends (5.4%), and those who chose not to seek healthcare (4.8%).

Table 12. Avoidance behaviours due to internalised stigma or fear of discrimination (past 12 months)

Variables	n*	Yes (%)	No (%)
I have chosen not to attend social gatherings	5 042	6.4	93.6
I have chosen not to seek health care	5 049	4.8	95.2
I have chosen not to apply for a job(s)	4 973	2.2	97.8
I have chosen not to seek social support	5 024	4.5	95.5
I have isolated myself from family and/or friends	5 042	5.4	94.6
I decided not to have sex	4 994	5.5	94.5

**Subtotals do not equal the overall total due to questionnaire item non-response*

The adoption of at least one avoidance behaviour in the past 12 months that may be related to internalised stigma or fear of discrimination was stratified by sex, age, key populations, and non-key populations. Figure 13 shows that overall, 12.6% of participants had adopted at least one avoidance behaviour because of their HIV status in the past 12 months. A higher proportion of males (13.5%), those aged 18–24 years (19.9%), sex workers (20.7%), and people who use drugs (21.2%) had adopted at least one avoidance behaviour compared to their counterparts. A lower proportion of the non-key population group had adopted at least one of these avoidance behaviours compared to key populations.

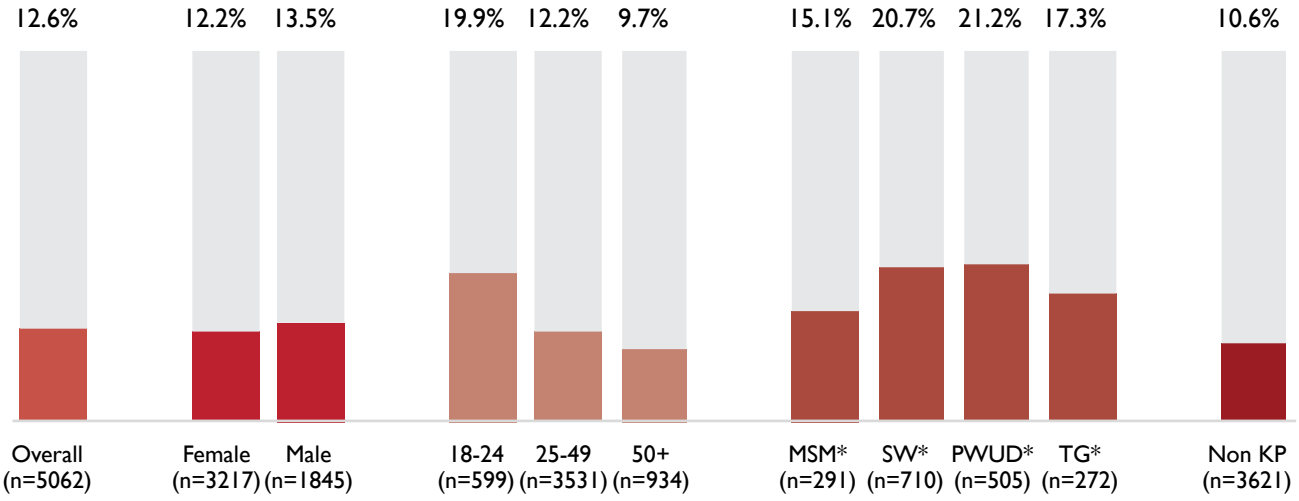

Figure 13. Adoption of at least one avoidance behaviour due to HIV status in the past 12 months, by sex, age, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

3.4 Interaction with healthcare services

3.4.1 HIV testing, care, and treatment

Table 13 shows that overall, most participants (84.1%) reported that it was their choice to be tested for HIV. Ten percent reported that they were pressured by others to get tested, 1.8% reported that they were tested without their knowledge and only found out afterwards, 0.8% reported being forced to take an HIV test without their consent, and 3.2% reported that they were born with HIV or acquired it in infancy/childhood and were not aware they had been tested.

Variations in HIV testing experiences were observed by age, sex, and key population groups. A larger proportion of participants aged 18–24 years reported that they were born with HIV or acquired it in infancy/childhood. Among key populations, 11.7% of sex workers and 18.0% of people who use drugs reported being pressured by others to get tested, compared with other key populations.

Table 13. Choosing to be tested for HIV, by demographic group

Variables	n*	Yes, it was my choice (%)	Yes, but I was pressured by others (%)	No, I was tested without my knowledge and only found out after the test had been done (%)	No, I was forced to take an HIV test without my consent (%)	No, I was born with HIV or acquired HIV in infancy/ childhood and was not aware I had been tested (%)
Total	5 063	84.1	10.0	1.8	0.8	3.2
Age groups						
18–24	599	67.9	8.0	2.0	0.8	21.2
25–49	3 529	86.8	10.0	1.5	0.8	0.9
50+	934	84.5	11.5	3.0	1.0	0.1
Sex assigned at birth						
Female	3 216	85.4	9.3	2.0	0.8	2.5
Male	1 844	81.9	11.3	1.6	0.9	4.3
Key population groups**						
MSM	1 671	85.2	8.9	0.7	1.7	3.4
Sex worker	4 808	83.8	11.7	1.7	1.1	1.7
People who use drugs	4 837	76.6	18.0	1.2	1.0	3.2
Transgender people	4 941	89.0	6.6	1.5	0.4	2.6
Non-key population	5 063	84.5	9.3	2.0	0.8	3.4

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Table 14 shows the main reasons participants decided to take an HIV test. Overall, the highest proportion (27.6%) reported testing because they were feeling sick and thought it might be HIV-related, followed by wanting to know their HIV status (25.9%) and believing they were at risk for HIV (22.2%). The reasons for taking an HIV test varied across age, sex, and key population groups. Most HIV tests were taken by those who felt sick, believed they were at risk, or were advised by a service provider as part of other healthcare seeking.

Table 14. Main reason for getting tested for HIV, by demographic group

Variables	n*	A provider (%) recommended it, or as part of other healthcare (e.g. antenatal, medical male circumcision, STI testing/ treatment, PrEP)	I believed I was at risk for HIV (%)	I felt sick and I/ someone close to me thought it might be HIV-related (%)	As part of or because of a community-based programme (%)	It was mandatory (e.g. for employment, visa/ citizenship, incarceration, marriage, to access antenatal care) (%)	I just wanted to know (%)	Other reason(s) (%)
Total	4 757	16.1	22.2	27.6	2.6	1.4	25.9	4.3
Age groups								
18-24	455	22.2	18.2	22.3	4.0	2.2	27.9	3.3
25-49	3 408	16.1	22.9	25.5	2.7	1.3	27.1	4.4
50+	894	12.8	21.9	38.1	1.2	1.2	20.4	4.4
Sex assigned at birth								
Female	3 039	17.6	21.5	26.2	1.6	1.8	25.7	5.6
Male	1 715	13.4	23.6	30.0	4.2	0.6	26.2	2.0
Key population groups**								
MSM	271	10.7	26.9	21.8	6.3	0.4	31.7	2.2
Sex worker	677	16.0	21.9	22.3	3.1	1.5	31.2	4.1
People who use drugs	476	14.3	23.5	30.3	3.6	1.1	24.6	2.7
Transgender people	2 560	18.1	24.6	21.9	4.2	0.0	30.0	1.2
Non-key population	3 388	16.8	21.8	28.8	2.0	1.5	24.2	4.8

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Table 15 shows the time between first considering an HIV test and taking the first test. Overall, most participants (61.7%) reported deciding to take an HIV test within six months or less of first considering it. These were mainly youth aged 18–24 years (72.7%) and men who have sex with men (67.0%). A higher proportion of sex workers (18.0%) and people who use drugs (20.6%) waited more than two years before getting tested compared to other demographic groups.

Table 15. Time between considering and taking the first HIV test, by demographic group

Variables	n*	6 months or less	More than 6 months to 2 years (%)	More than 2 years (%)	I don't know/can't remember (%)
Total	4761	61.7	16.5	9.8	11.9
Age groups					
18–24	454	72.7	13.4	5.3	8.6
25–49	3 413	60.9	17.4	10.0	11.7
50+	894	59.4	14.5	11.4	14.7
Sex assigned at birth					
Female	3 041	62.1	16.1	10.0	11.7
Male	1 717	61.2	17.1	9.4	12.3
Key population groups**					
MSM	273	67.0	13.2	6.6	13.2
Sex worker	678	62.1	18.0	11.2	8.7
People who use drugs	476	61.6	20.6	8.0	9.9
Transgender people	260	64.2	16.9	8.1	10.8
Non-key population	3 391	61.0	16.2	10.1	12.7

**Subtotals do not equal the overall total due to questionnaire item non-response*

*** In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Table 16 summarises participants' reports on whether fears about how others would respond if they tested positive for HIV influenced their decision to get tested. Overall, 41.7% of participants reported such fears, which made them hesitant to take their first HIV test. This fear was more common among youth aged 18–24 years (53.3%), transgender individuals (53.8%), sex workers (50.9%) and people who use drugs (48.8%).

Table 16. Fear of others' responses and participants' hesitation to test for HIV, by demographic group

Variables	n*	Yes (%)	No (%)
Total	4 758	41.7	58.3
Age groups			
18–24	453	53.3	46.7
25–49	3 411	40.8	59.2
50+	894	39.3	60.7
Sex assigned at birth			
Female	3 039	40.4	59.6
Male	1 716	43.9	56.1
Key population groups**			
MSM	273	37.0	63.0
Sex worker	677	50.8	49.2
People who use drugs	477	48.8	51.2
Transgender people	260	53.8	46.2
Non-key population	3 388	39.6	60.4

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Participants were asked if they were currently or had ever been on HIV treatment. Table 17 shows that the majority (97.6%) of participants reported being currently on or having ever been on HIV treatment, with high proportions observed across all selected demographic characteristics.

Table 17. Currently or ever been on HIV treatment, by demographic group

Variables	n*	Yes (%)	No(%)
Total	5 055	97.6	2.4
Age groups			
18–24	598	94.6	5.4
25–49	3 526	97.7	2.3
50+	930	99.0	1.0
Sex assigned at birth	3 211	98.1	1.9
Female	3 211	98.1	1.9
Male	1 841	96.7	3.3
Key population groups**			
Men who have sex with men	288	95.5	4.5
Sex worker	709	96.8	3.2
People who use drugs	503	94.2	5.8
Transgender people	271	97.8	2.2
Non-key population	3 614	98.2	1.8

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Participants were asked whether it was their choice to start HIV treatment or if they were pressured or forced by anyone. Table 18 shows that most participants (81.7%) reported being informed of the benefits and choosing to start treatment as soon as it was offered. Some participants (13.9%) reported that they chose to wait and start treatment at a later time.

Table 18. Reasons for starting HIV (antiretroviral) treatment

Variables	n*	%
I was told the benefits and chose to start as soon as it was offered to me	4 028	81.7
When treatment was offered to me, I took the decision to wait and started at a later time	686	13.9
I felt pressured or forced to start by the health care staff	115	2.3
Other reason(s)	102	2.1

**Subtotals do not equal the overall total due to questionnaire item non-response*

Participants were asked how long it took them to start treatment after being diagnosed with HIV. Table 19 shows that overall, most participants (61.2%) reported starting treatment immediately or on the same day they were diagnosed. This proportion was consistently above 60% across all demographics, except for those aged 50 years and older (56.9%) and those who identified as transgender (55.1%). Some participants (18.4%) reported starting treatment within 1–30 days after diagnosis; this pattern was consistent across all demographics and was higher among males (19.5%) and those who identified as transgender (22.3%).

Table 19. Time from HIV diagnosis to starting treatment

Variables	n*	Immediately, or the same day I was diagnosed (%)	>1 day to 1 month (30 days) after being diagnosed (%)	>1 month to 6 months after being diagnosed (%)	>6 months to 2 years after being diagnosed (%)	>2 years after being diagnosed (%)	I can't remember (%)
Total	4 932	61.2	18.4	8.2	3.6	1.8	6.8
Age groups							
18–24	566	64.0	16.3	4.9	1.1	0.2	13.6
25–49	3 444	61.8	18.7	8.2	4.0	1.9	5.3
50+	921	56.9	18.6	9.9	4.0	2.1	8.6
Sex assigned at birth							
Female	3 149	63.3	17.8	7.1	3.5	2.0	6.2
Male	1 780	57.3	19.5	10.0	3.9	1.4	7.9
Key population groups**							
MSM	1 610	61.8	16.4	10.2	2.2	2.2	7.3
Sex worker	4 685	63.0	15.9	10.2	5.1	2.6	3.2
People who use drugs	4 707	65.8	15.0	9.3	4.0	1.7	4.2
Transgender people	4 811	55.1	22.3	8.3	6.4	3.4	4.5

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Participants were asked to indicate reasons that made them hesitate, delay, or prevent them from initiating HIV care or treatment. Table 20 shows that the most commonly cited reason was not feeling ready to deal with their HIV infection (32.1%), followed by concern that other people (not family or friends) would find out about their status (30.9%), and worry that their partner, family, or friends would learn their status (28.2%).

Table 20. Reasons for delaying or avoiding HIV care or treatment

Variables	n*	Yes (%)	No (%)
I was worried that my partner, family or friends would find out my status	5 054	28.2	71.8
I was worried other people (not family or friends) would find out my status	5 055	30.9	69.1
I was not ready to deal with my HIV infection	5 056	32.1	67.9
I was afraid health workers (doctors, nurses, staff) would treat me badly	5 059	13.0	87.0
I had a bad experience with a health worker previously	5 051	7.8	92.2

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.4.2 Treatment interruptions

Participants were asked if they had ever interrupted or stopped taking their HIV (antiretroviral) treatment. Figure 14 shows that overall, 12.6% of participants reported ever interrupting or stopping their HIV treatment. A higher proportion of males (13.9%), those aged 25–49 years (13.9%), and PWUD (29.0%) reported ever interrupting or stopping treatment compared with their counterparts. Treatment interruption or stopping was lower among key populations compared to non-key populations.

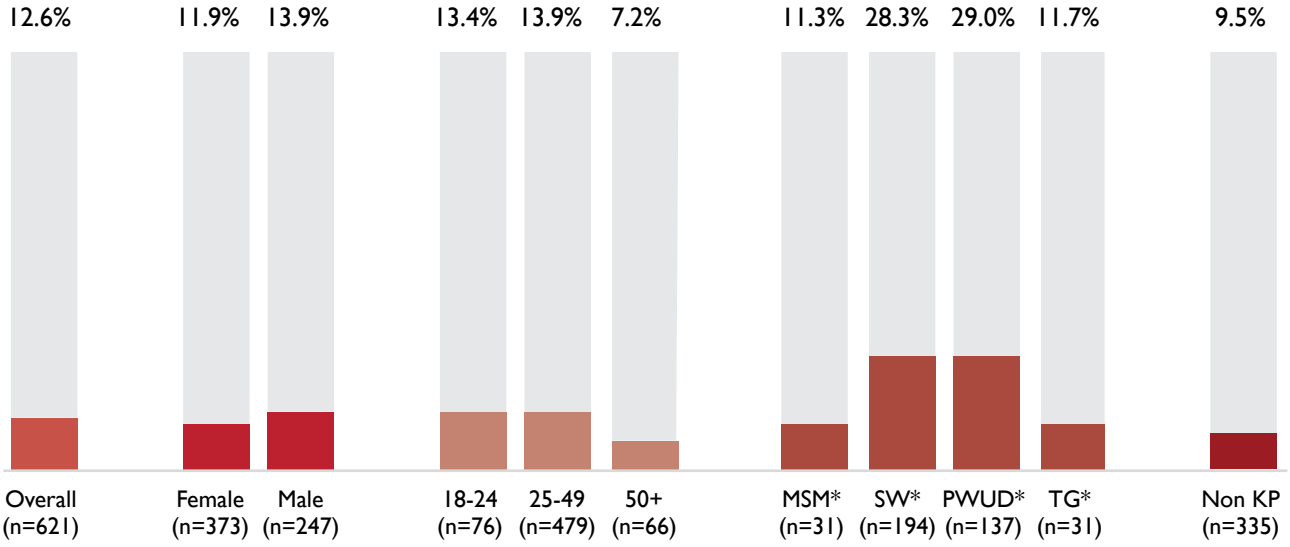

Figure 14. Participants who have ever interrupted or stopped HIV treatment, by age, sex, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Participants who had ever stopped treatment at any time in the past 12 months were asked to indicate their reasons from a list of stigma-related factors. Table 21 shows that the most common reason participants reported was being worried that someone would find out their HIV status (25.1%), followed by not being ready to deal with their infection (17.3%).

Table 21. Stigma-related reasons for stopping HIV (antiretroviral) treatment in the past 12 months (n = 577)

Variables	n*	%
I am worried that someone would find out my HIV status	145	25.1
I am not ready to deal with my HIV infection	100	17.3
I am worried the healthcare workers would treat me badly or disclose my HIV status without my consent	27	4.7
I was denied HIV treatment due to currently using drugs	31	5.4
Other reason (please specify)	274	47.5

**Subtotals do not equal the overall total due to questionnaire item non-response*

Participants who had ever stopped HIV care or treatment were asked what factors made them hesitate, delay, or prevent them from restarting care or treatment for HIV. Table 22 shows that the most reported reason was not being ready to deal with their HIV infection (36.5%), followed by worry that a partner, family, or friends would find out their status (35.4%), and worry that other people (not family or friends) would find out their status (34.3%).

Table 22. Reasons for hesitating or delaying HIV care or treatment restart among those who had previously stopped

Variables	n*	Yes (%)	No (%)
I was worried that my partner, family, or friends would find out my status	615	35.4	64.6
I was worried other people (not family or friends) would find out my status	618	34.3	65.7
I was not ready to deal with my HIV infection	617	36.5	63.5
I was afraid health workers (doctors, nurses, staff) would treat me badly	618	19.3	80.7
I had a bad experience with a health worker previously	615	15.8	84.2

**Subtotals do not equal the overall total due to questionnaire item non-response*

Participants were asked the main non-stigma-related reason for not currently taking, or having ever stopped, HIV treatment. Table 23 shows that the most commonly reported reason was not feeling that treatment was needed (16.3%), followed by inability to tolerate medication side effects (15.4%). Some participants reported that medication was not available at the clinic (11.5%).

Table 23. Non-stigma-related reasons for stopping or not taking HIV treatment (n = 435)

Variables	(%)
Medication not available at the clinic (due to policy or stock-outs)	11.5
Medication not affordable	0.7
Unable to collect medications at the clinic or pharmacy	11.5
Cannot tolerate medication side effects	15.4
Do not feel treatment is needed	16.3
Was in prison or detention, and treatment was not available	1.4
Other reasons (please specify)	43.2

Participants (n = 4 124) were asked whether their most recent viral load test in the past 12 months showed an undetectable viral load. Over two-thirds (n = 3 276, 79.4%) reported an undetectable viral load. For 381 participants (9.2%), the virus was detectable and not virally suppressed, while 467 participants (11.3%) were awaiting their results and therefore did not know their status.

3.4.3 General health status

Most participants reported that their health was good at the time (85%). Only a few participants (1.9%) felt their health was poor, while 13.1% reported it was fair.

Figure 15 shows the conditions other than HIV that participants were diagnosed with in the past 12 months. Overall, 11.4% reported a tuberculosis diagnosis, 8.6% reported sexually transmitted infections, and 6.6% reported mental health conditions. Some participants also reported alcohol or drug dependency syndrome (5.9%), non-communicable diseases (3.2%), and opportunistic infections (2.2%).

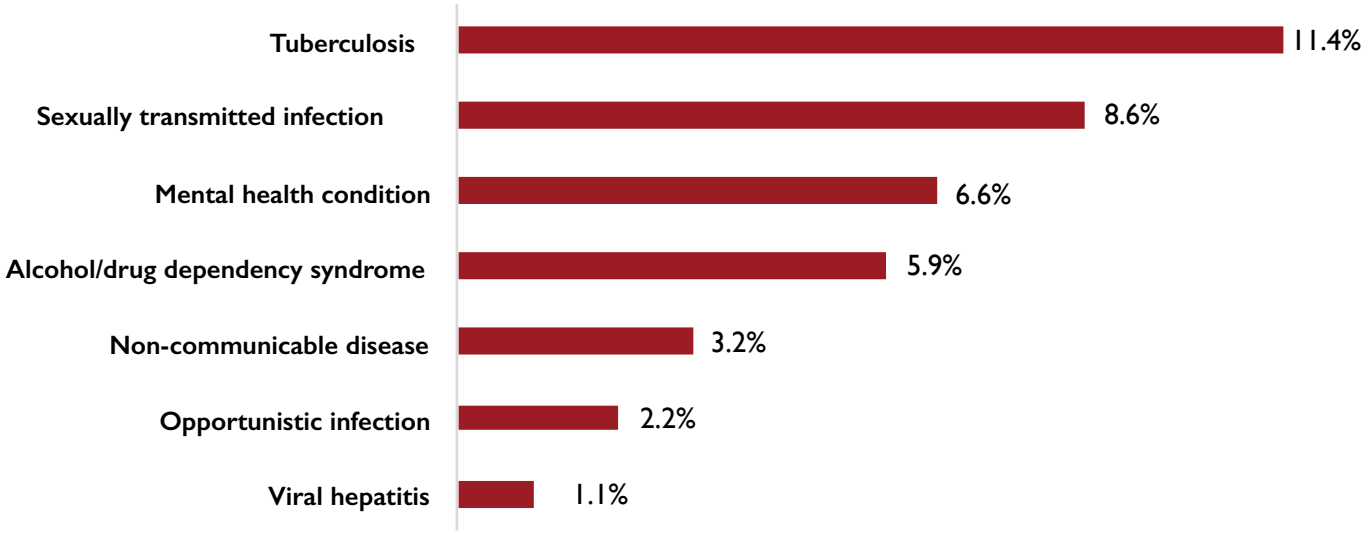

Figure 15. Diagnoses of non-HIV conditions in the past 12 months (n = 1 207)

Most participants (85%) reported being offered treatment for all the conditions for which they had been diagnosed.

3.4.4 Service delivery experiences

Table 24 shows where participants receive regular HIV care and treatment. Most participants reported receiving care and treatment from a government or public clinic or facility (89.1%), while a smaller proportion used private or NGO facilities. Community-led care, such as drop-in centres run by key population groups, accounted for a smaller share (2.8%).

Table 24. Main source of HIV care and treatment (n = 5 061)

Variables	n*	%
Government or public clinic or facility	4 511	89.1
Private clinic, hospital or doctor's office	192	3.8
Non-governmental clinic or facility	122	2.4
Community-led care (e.g. drop-in centres run by key population groups)	140	2.8
Multiple places	46	0.9
N/A - I am not currently receiving HIV care or treatment	50	1.0

**Subtotals do not equal the overall total due to questionnaire item non-response*

Participants were asked whether they were aware of a clinic offering community-led HIV services that they could access. Table 25 shows that 44.2% of participants were aware of such a clinic and could access care there. A quarter of participants knew of such a clinic but did not access care there, while 25.8% of participants were not aware of any such clinic.

Table 25. Knowledge of community-led clinics offering HIV services (n = 5 008)

Variables	n*	%
Yes, there is, but I don't access my HIV care there	1 256	25.1
Yes, there is, and I access my HIV care there	2 212	44.2
No, there is not	249	5.0
I don't know	1 291	25.8

**Subtotals do not equal the overall total due to questionnaire item non-response*

Participants were asked to select from a list of HIV-related services available at community-led facilities. Table 26 shows that the majority of participants identified HIV information (81.9%) and HIV treatment services (61.0%) as the main services they could access. Many participants also mentioned adherence counselling (55.3%), HIV care and testing services (53.5%), and peer group support (46.5%).

Table 26. HIV services accessed at community-led facilities by participants (n = 3 468)

Variables	%
HIV information	81.9
Peer group support	46.5
Adherence counselling	55.3
Prevention services and commodities	36.8
HIV treatment services	61.0
Case management	29.4
HIV care and testing services	53.5

Table 27 summarises participants' experiences at health facilities in the past 12 months when seeking HIV-specific care. A small proportion reported being advised not to have sex (3.2%), being gossiped about (3.1%), or being denied health services because of their HIV status (2.0%).

Table 27. Experiences with facility staff when seeking HIV-specific health care in the past 12 months

Variables	n*	%
Denial of health services because of your HIV status	4 998	2.0
Being advised not to have sex because of your HIV status	5 006	3.2
Being talked badly about or gossiped about because of your HIV status	5 008	3.1
Verbal abuse (yelling, scolding, name-calling, or being otherwise verbally abused) because of your HIV status	5 008	2.0
Physical abuse (pushing, hitting, or being otherwise physically abused) because of your HIV status	5 006	0.9
Avoidance of physical contact with you/taking extra precautions (e.g., wearing double gloves) because of your HIV status	5 005	0.7
Telling other people about your HIV status without your consent	4 992	1.9

**Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 16 shows that overall, 7.8% of the participants reported experiencing one or more forms of stigma or discrimination from healthcare workers due to their HIV status at the facilities where they sought HIV treatment in the past 12 months. Experiences were higher among females (8.3%), youth aged 18–24 years (9.4%), and sex workers (13.5%) compared with their counterparts, and were higher among key populations than non-key populations.

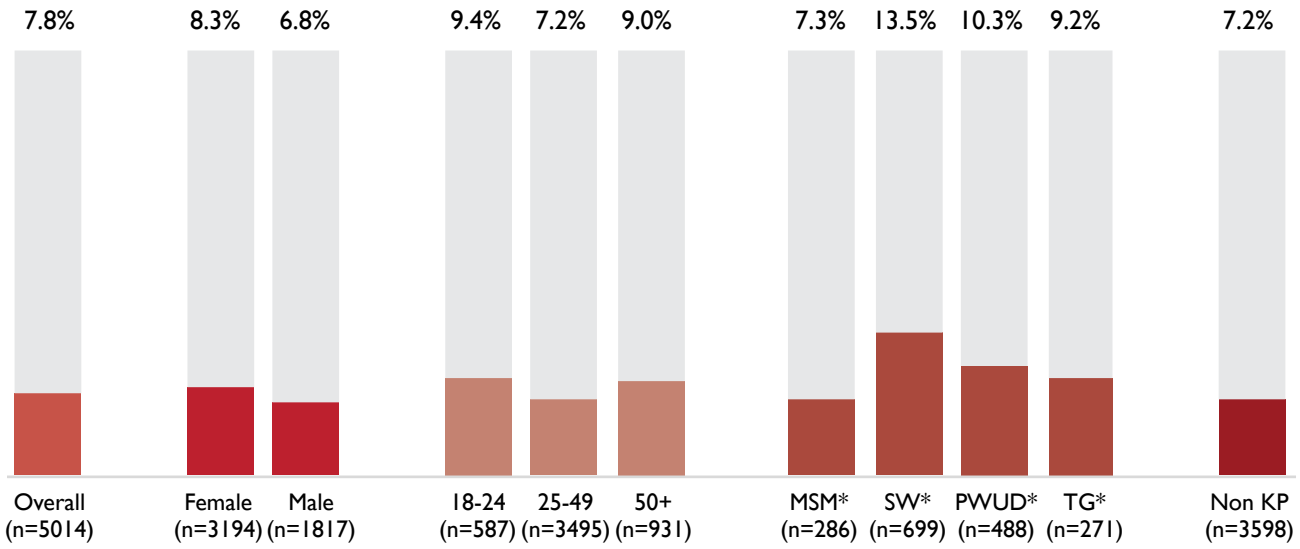

Figure 16. Experiences of stigma or discrimination from healthcare workers when accessing HIV care in the past 12 months, by sex, age, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Table 28 shows participants' experiences with health facility staff in the past 12 months when seeking care for non-HIV-related needs. Common experiences included being advised not to have sex (8.0%), being gossiped about or spoken badly about (5.5%), and being verbally abused (5.2%).

Table 28. Experiences with facility staff when seeking non-HIV care in the past 12 months (n = 1 107)

Variables	n*	%
Denial of health services because of your HIV status	1 105	4.3
Denial of dental care because of your HIV status	1 105	3.8
Being advised not to have sex because of your HIV status	1 104	8.0
Being talked badly about or gossiped about because of your HIV status	1 106	5.5
Verbal abuse (yelling, scolding, name-calling, or being otherwise verbally abused) because of your HIV status	1 106	5.2
Physical abuse (pushing, hitting, or being otherwise physically abused) because of your HIV status	1 105	3.2
Avoidance of physical contact with you/taking extra precautions (e.g., wearing double gloves) because of your HIV status	1 105	3.0
Telling other people about your HIV status without your consent	1 103	4.3

**Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 17 shows that overall, 13.1% of participants reported experiencing at least one negative interaction with healthcare staff in the past 12 months when seeking care for non-HIV-related health needs due to their HIV status. The experiences were higher among females (14.0%), youth aged 18–24 years (13.7%), and men who have sex with men (22.4%) compared with their counterparts and were generally higher among key populations than non-key populations.

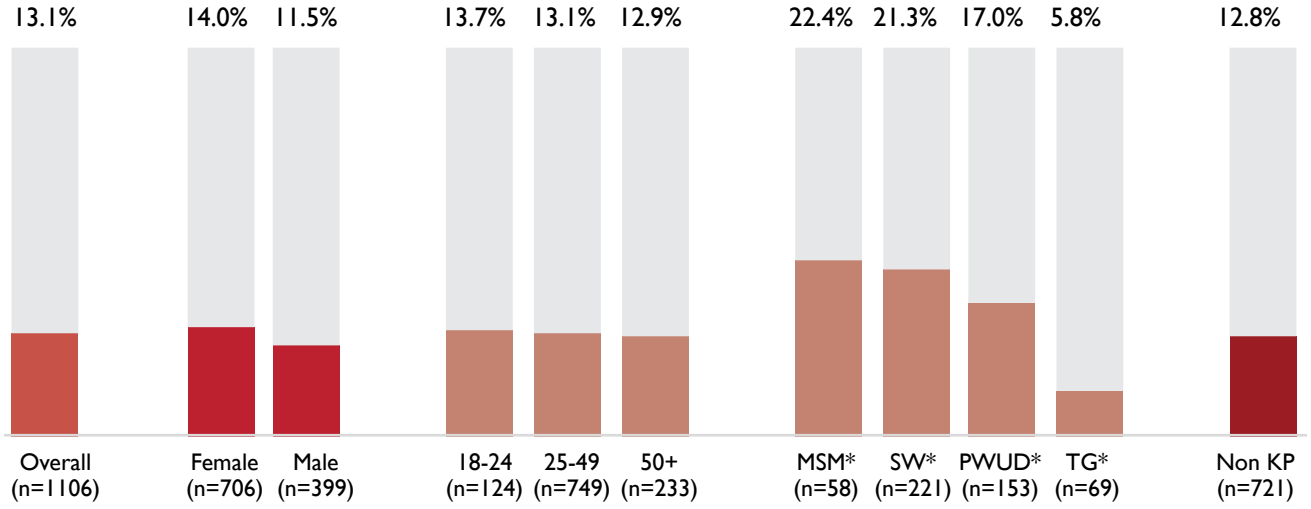

Figure 17. Stigma or discrimination from healthcare workers when seeking non-HIV care in the past 12 months, by sex, age, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Participants were asked who they usually disclose their HIV status to when seeking general (non-HIV-related) health services outside the HIV clinic. Figure 18 shows that 40.3% of participants reported that they usually disclose their HIV status in such settings.

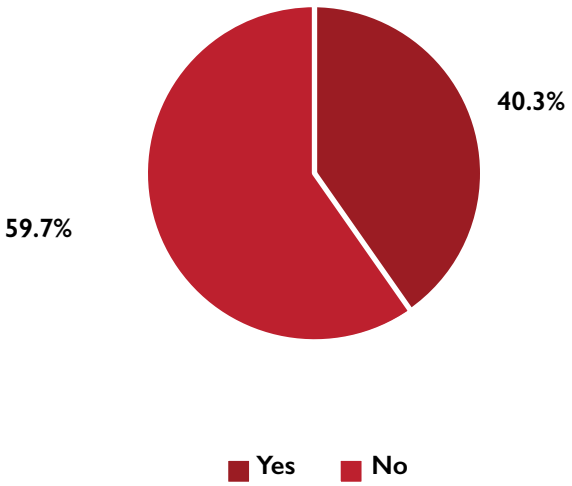

Figure 18. Participants' disclosure of HIV status when seeking general health services outside HIV clinics

Participants (n = 5 062) were asked whether they thought their medical records related to their HIV status were kept confidential. Most participants (77.9%, n = 3 942) reported being confident that their records were kept confidential and would not be shared without their written informed consent. Some participants (20.3%, n = 1 030) were uncertain about the confidentiality of their records, while a few (1.8%, n = 80) believed their records were not kept confidential.

3.4.5 Sexual and reproductive health

Participants were asked about treatment they received from healthcare professionals solely because of their HIV status. Table 29 shows that a small proportion of participants reported experiencing discriminatory practices, including being advised not to have children (1.1%) and being told to use a specific method of contraception to receive HIV treatment (1.3%).

Table 29. Treatment received from healthcare professionals due to HIV status

Variables	n*	Yes (%)	No (%)
Advised not to mother/father a child	4 686	1.1	98.9
Pressured or incentivised to get sterilised	4 478	0.6	99.4
Sterilised without knowledge or consent	4 453	0.4	99.6
Denied contraception or family planning services	4 463	0.8	99.2
Told to use a specific method of contraception to receive HIV treatment	4 477	1.3	98.7

**Subtotals do not equal the overall total due to questionnaire item non-response*

Table 30 presents the results on treatment received from healthcare professionals by participants assigned female at birth. A few participants reported being advised to terminate a pregnancy. Some were pressured to use a specific contraceptive method, a particular method of giving birth or delivery option, or a specific infant feeding practice. Others were pressured to take HIV (antiretroviral) treatment during pregnancy.

Table 30. Treatment received by females (as assigned at birth) from healthcare professionals solely because of their HIV status

Variables	n*	Yes, within the past 12 months (%)	Yes, but not within the past 12 months (%)	No (%)
Advised to terminate a pregnancy	3 076	0.2	0.8	99.0
Pressured to use a specific type of contraceptive method	3 112	1.2	1.3	97.6
Pressured to use a particular method of delivery	3 096	1.2	1.9	96.9
Pressured to use a particular infant feeding practice	3 080	1.5	2.3	96.2
Pressured to take HIV (antiretroviral) treatment during pregnancy	3 079	2.1	3.4	94.4

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.5 Human rights and affecting change

Participants were asked about their experiences of human rights violations (Table 31). Although the proportions were relatively small, the reported violations related to HIV status were severe. Specifically, 0.6% were forced to undergo testing or disclose their status to obtain a visa or residency, 0.3% to apply for a job or pension plan, and 0.2% to attend an educational institution. Additionally, 0.4% were forced to disclose their status to access healthcare services, and 0.3% to obtain medical insurance. Some participants also experienced more severe violations, including arrest or detention (0.1%–0.2%), denial of visa or entry (0.1%), public disclosure of their status (0.2%), and forced sex (0.4%).

Table 31. Experiences of human rights violations

Variables	n*	Yes, within the past 12 months (%)	Yes, but not within the past 12 months (%)	No (%)
Forced to obtain a visa or apply for residency or citizenship	5 055	0.6	0.6	98.8
Forced to apply for a job or pension plan	5 057	0.3	0.7	99.1
Forced to attend an educational institution or receive a scholarship	5 057	0.2	0.4	99.3
Forced to access health care services	5 056	0.4	1.3	98.3
Forced to obtain medical insurance	5 055	0.3	0.3	99.4
Arrested or taken to court due to HIV status	5 045	0.1	0.2	99.7
Detained or quarantined due to HIV status	5 053	0.2	0.2	99.6
Denied visa or entry due to HIV status	5 046	0.1	0.2	99.7
Denied residency or permission to stay due to HIV status	5 048	0.1	0.2	99.7
Forced public disclosure of HIV status	5 043	0.2	0.3	99.5
Forced to have sex against their will	5 035	0.4	0.8	98.8

**Subtotals do not equal the overall total due to questionnaire item non-response*

Among participants who experienced rights violations in the past 12 months, 44.0% (n = 22) reported trying to take action, while 56.0% (n = 28) did not. Participants (n = 5 041) were also asked whether they knew of any laws in the country protecting people living with HIV from discrimination. About two-thirds (65.4%, n = 3 297) of participants were aware of such laws, 3.6% (n = 172) believed no such laws exist, and 31.0% (n = 1 565) were unsure.

Table 32 shows that participants engaged in various actions to address stigma and discrimination. Common actions included challenging or educating someone engaging in stigma or discrimination against them (16.7%) or other people living with HIV (16.0%). Others (15.4%) reported providing emotional, financial, or other support to help someone living with HIV cope with stigma or discrimination, while 11.1% participated in an organisation or campaign addressing stigma and discrimination against people living with HIV.

Table 32. Actions to effect change

Variables	n*	Yes, within the past 12 months (%)	Yes, but not within the past 12 months (%)	No (%)
Challenged or educated someone engaging in stigma or discrimination against you	5 060	16.0	10.9	73.1
Challenged or educated someone engaging in stigma or discrimination against other people living with HIV	5 062	16.7	9.7	73.6
Provided emotional, financial, or other support to help someone living with HIV cope with stigma or discrimination	5 057	15.4	7.8	76.8
Participated in an organisation or educational campaign addressing stigma and discrimination against people living with HIV	5 058	11.1	5.8	83.1
Encouraged a community leader to take action on issues of stigma and discrimination against people living with HIV	5 048	7.9	4.2	87.9
Encouraged a government leader or politician to take action on issues of stigma and discrimination against people living with HIV	5 054	6.3	3.6	90.2
Spoke to the media about issues of stigma and discrimination against people living with HIV	5 047	4.5	3.0	92.5

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.6 Non-HIV-related stigma, status disclosure and support group membership

This section presents results on non-HIV-related stigma and discrimination experienced by participants due to their group membership, such as being transgender or non-binary, gay/homosexual/men who have sex with men, lesbian/women who have sex with women, sex workers, or people who use drugs. Participants were also asked about their awareness of their group status and participation in related networks or support groups.

3.6.1 Non-HIV-related stigma and discrimination experienced by key populations

Table 33 presents stigma and discrimination experienced by key populations due to their gender identity, being sex workers, or being people who use drugs in the past 12 months. The most common experiences reported were exclusion from family activities, family members making discriminatory remarks or gossiping, and verbal harassment. Persons who use drugs experienced higher levels of discrimination across many items, while bisexual participants and men who have sex with men were less likely to report stigma and discrimination.

Table 33. Stigma and discrimination experienced by key populations

Variables	Transgender* (n = 197)(%)	MSM* (n = 291) (%)	Lesbian* (n = 262) (%)	Bisexual* (n = 109) (%)	Sex worker* (n = 710) (%)	PWUD* (n = 504) (%)
Felt excluded from family activities	7.4	8.3	11.8	5.6	13.8	23.0
Family members made discriminatory remarks or gossiped	15.8	7.6	15.6	13.8	15.4	23.0
Felt afraid to seek health services	7.9	6.6	9.2	8.3	10.2	13.7
Avoided health services due to fear someone might learn of identity	5.8	4.1	9.9	6.4	9.9	12.0
Verbally harassed	14.8	8.7	15.4	11.0	15.0	19.6
Blackmailed	6.8	4.8	11.1	7.3	10.0	9.4
Physically harassed or hurt	5.3	5.2	9.7	5.6	10.2	12.9

**Individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Among gay/homosexual/men who have sex with men participants, the most frequent experiences were verbal harassment (8.7%), exclusion from family activities (8.3%), and family members making discriminatory remarks or gossiping (7.6%). Lesbian/gay/women who have sex with women most reported discriminatory remarks or gossip (15.6%), verbal harassment (15.4%), and exclusion from family activities (11.8%), with a higher proportion reporting blackmail (11.1%) than other groups.

Table 34 shows the most common forms of stigma and discrimination experienced by participants due to their gender identity or sexual orientation. Across the groups, the most frequently reported experiences included family members making discriminatory remarks or gossiping (15.6%), exclusion from family activities (11.8%), and being blackmailed (11.1%).

Lesbian/gay/women who have sex with women most often reported being blackmailed compared to the other groups. Bisexual participants, or those who have sex with both men and women, commonly reported discriminatory remarks or gossip from family members (13.8%) and verbal harassment (11.1%). Sex workers frequently experienced discriminatory remarks or gossip from family members (15.4%), verbal harassment (15.0%), and exclusion from family activities (13.8%).

People who use drugs reported high levels of stigma and discrimination, including family members making discriminatory remarks or gossiping (23.0%), exclusion from family activities (23.0%), and verbal harassment (19.6%). This group reported higher proportions across six of the seven forms of stigma and discrimination (see Table 34).

Table 34. Stigma and discrimination due to identity

Variables	Transgender* (n = 197)(%)	MSM* (n = 291) (%)	Lesbian * (n = 262) (%)	Bisexual* (n = 109) (%)	Sex worker* (n = 710)	PWUD * (n = 504)
Felt excluded from family activities	7.4	8.3	11.8	5.6	13.8	23.0
Family members made discriminatory remarks or gossiped about you	15.8	7.6	15.6	13.8	15.4	23.0
Felt afraid to seek health services because of identity	7.9	6.6	9.2	8.3	10.2	13.7
Avoided seeking health services due to fear someone might learn of their identity	5.8	4.1	9.9	6.4	9.9	12.0
Verbally harassed because of identity	14.8	8.7	15.4	11.0	15.0	19.6
Blackmailed because of identity	6.8	4.8	11.1	7.3	10.0	9.4
Physically harassed or hurt because of identity	5.3	5.2	9.7	5.6	10.2	12.9

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.6.2 Disclosure of non-HIV-related status

Table 35 shows the groups to whom the participants disclosed their identities. A higher proportion of all key populations disclosed their identities to people with the same identities. In contrast, a lower proportion disclosed to other people in their community. In addition, sex workers had lower rates of disclosure across all groups compared with other key populations.

Table 35. Disclosure of identity by key populations

Variables	Transgender* (n = 197)	MSM* (n = 291)	Lesbians* (n = 262)	Bisexual* (n = 109)	Sex worker* (n = 710)	PWUD* (n = 504)
Other people with the same identity	83.7	86.6	80.5	72.5	59.6	82.1
Family or friends	82.6	83.2	77.0	66.1	43.1	70.9
Other people in their community	81.9	69.7	71.6	59.3	37.5	67.0

**Individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

3.6.3 Membership of networks and support groups by key population

Figure 19 shows membership of networks or support groups among different key populations. A higher proportion (57.9%) of men who have sex with men reported being members of such networks or support groups compared to other key populations. In contrast, people who use drugs were the least likely to belong to such networks or support groups (29.1%).

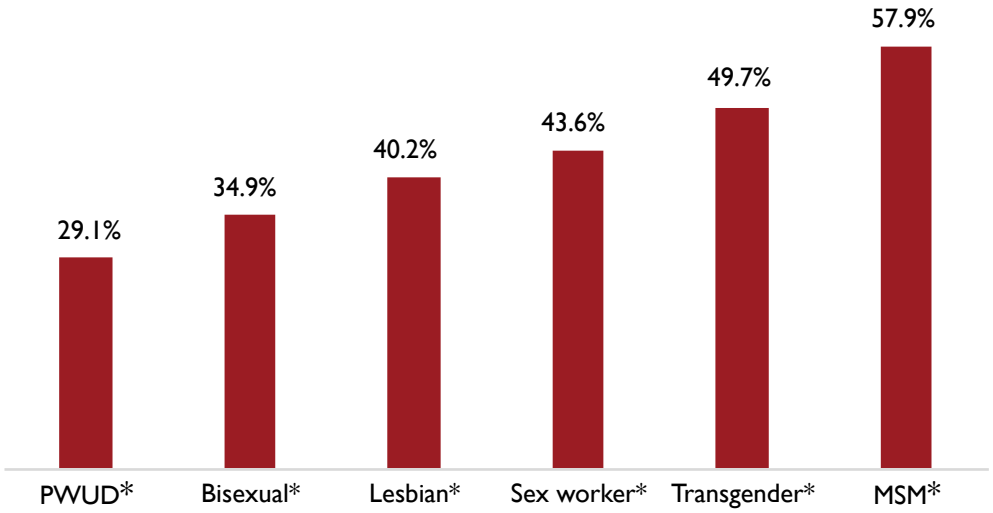

Figure 19. Membership of support networks, by key population

**Individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

3.7 South African specific modules and results

The sample (n = 5 357) for the South African additional questions section included adolescents aged 15–17 years (Table 36). Most participants were from KwaZulu-Natal (12.4%), aged 25–49 years (66.0%), assigned female at birth (63.2%), and self-identified as female (61.7%). The majority were black African (97.4%) and South African citizens (98.4%). Furthermore, 62% were currently in an intimate or sexual relationship, 55% reported that their partner was also living with HIV, 59.4% had completed secondary or high school education, and 59.5% were unemployed.

Table 36. Socio-demographic characteristics of the South African sample, which includes adolescents aged 15-17 years (n = 5 352)

Province	n*	%
Western Cape	613	11.5
Eastern Cape	544	10.2
Northern Cape	569	10.6
Free State	587	11.0
KwaZulu-Natal	661	12.4
North West	618	11.5
Gauteng	591	11.0
Mpumalanga	593	11.1
Limpopo	576	10.8
Age group		
15–17	282	5.3
18–24	599	11.2
25–49	3 531	66.0
50+	934	17.5
Sex assigned at birth		
Female	3 378	63.2
Male	1 966	36.8
Gender identity		
Female	3 240	61.7
Male	1 749	33.3
Transgender	149	2.8
I do not identify as female, male, or transgender	85	1.6
I prefer not to answer	28	0.5
Population group		
Black African	4 835	97.1
Coloured	133	2.7
Indian/Other	5	0.1
White	5	0.1
Citizenship status		
South Africa citizen	4 890	98.4
Non-South African citizen	77	1.6
Currently in an intimate/sexual relationship (married or unmarried)		
Yes	3 313	62.2
No	2 014	37.8

Partner also living with HIV		
Yes	1 835	55.3
No	716	21.6
Not sure	769	23.2
Highest level of formal education		
No formal education	882	16.6
Primary/elementary/local equivalent	531	10.0
Secondary/high school/local equivalent	3 166	59.4
Trade/vocational school	179	3.4
University/tertiary education	569	10.7
Current work status		
In full-time work (as an employee)	739	13.8
In part-time work (as an employee)	695	13.0
Working full-time, but not as an employee (self-employed or business owner)	178	3.3
Doing casual or informal part-time work (self-employed or paid work for others)	343	6.4
Retired/on pension	209	3.9
Unemployed	3 178	59.5

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.7.1 Stigma and discrimination due to disability status

Of the 4 957 participants who responded to the South Africa-specific questions, 10.9% (n = 538) reported living with a disability. Table 37 presents the forms of stigma and discrimination experienced by people with disabilities due to their disability status. The most common forms of stigma and discrimination included family members making discriminatory remarks or gossiping about them (23.0%), being excluded from family activities (19.0%), experiencing verbal harassment (12.8%), and feeling afraid to seek health services (12.1%).

Table 37. Stigma and discrimination due to disability status (n = 473)

Variables	n*	%
Have you ever felt excluded from family activities	102	19.0
Have you ever felt that family members have made discriminatory remarks or gossiped about you	124	23.0
Have you ever felt afraid to seek health services	65	12.1
Have you ever avoided seeking health services because you were worried someone may learn you are living with a disability	47	8.7
Has someone ever verbally harassed you	69	12.8
Has someone ever blackmailed you	27	5.0
Has someone ever physically harassed or hurt you	21	3.9
Has someone approached you for sex and expressed that they hope your condition will help improve or cure their HIV-positive status	18	3.3

**Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 20 shows that overall, 9.5% of people with a disability experienced at least one form of stigma or discrimination within the past 12 months. A higher proportion of females (11.6%), adolescents aged 15–17 years, and transgender persons (33.3%) experienced at least one form of stigma or discrimination due to their disability status compared with their counterparts. In addition, people with a disability who belong to key populations were more likely to have experienced at least one form of stigma or discrimination compared with those belonging to non-key populations.

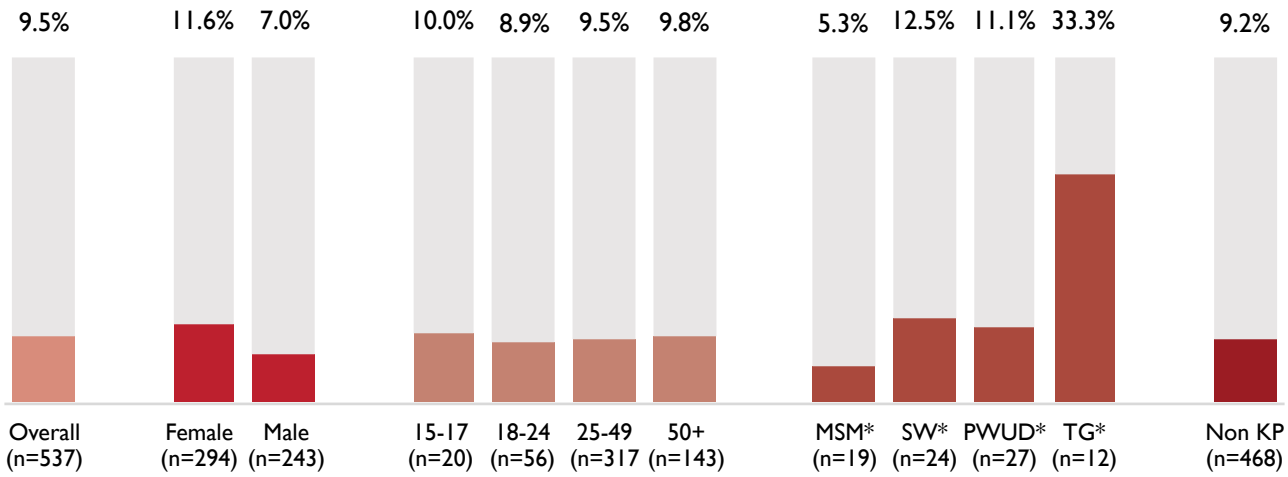

Figure 20. Experiences of at least one form of stigma and discrimination due to disability, by sex, age, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

3.7.2 TB-related stigma and discrimination

Table 38 presents participants who reported that having ever been diagnosed with TB, by selected demographic characteristics. The proportion of participants who had ever been diagnosed with TB was higher among those aged 50 years and older (26.9%), males (19.1%), people who use drugs (23.1%), and sex workers (20.5%).

Table 38. Participants ever diagnosed with TB, by demographic group

Variables	n*	Yes (%)	No (%)
Total	4972	16.8	83.2
Age group			
15–17	263	12.5	87.5
18–24	568	9.3	90.7
25–49	3276	15.8	84.2
50+	854	26.9	73.1
Sex assigned at birth			
Female	3099	15.4	84.6
Male	1861	19.1	80.9
Key population group**			
MSM	291	10.9	89.1
Sex worker	710	20.5	79.5
People who use drugs	505	23.1	76.9
Transgender	288	16.3	83.7
Non-key population	3621	16.3	83.7

**Subtotals do not equal the overall total due to questionnaire item non-response*

***In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Table 39 presents findings for the 834 participants who indicated that they had ever been diagnosed with TB. The most frequently reported form of stigma and discrimination was being gossiped about (37.9%).

Table 39. Stigma and discrimination among participants ever diagnosed with TB (n = 834)

Variables	Yes (%)	No (%)
Been teased, insulted or sworn at	23.5	67.5
Been gossiped about	37.9	62.1
Felt unclean or dirty because of your TB	23.1	67.9

Participants were also asked whether they had told anyone outside their household about their TB diagnosis, and 37.9% indicated that they had.

3.7.3 Experiences of cyberbullying due to HIV status

Table 40 shows that some participants experienced cyberbullying due to their HIV status. The most common forms were threats to disclose HIV status online (3.0%), being cyberbullied (2.2%), and having someone post mean or hurtful comments online (1.8%). In addition, a small number reported that someone had actually disclosed their HIV status online (1.5%).

Table 40. Experiences of cyberbullying due to HIV status

Variables	n*	(%)
Someone threatened to disclose my HIV status online	149	3.0
Someone disclosed my HIV status online	76	1.5
I have been cyberbullied	110	2.2
Someone posted mean or hurtful comments about me online	88	1.8
Someone posted a mean or hurtful picture of me online	50	1.0
Someone posted a mean or hurtful video of me online	26	0.5
Someone created a mean or hurtful web page about me	26	0.5
Someone spread rumours about me online	79	1.6
Someone threatened to hurt me through a cell phone text message	77	1.6
Someone threatened to hurt me online	52	1.1
Someone pretended to be me online and acted in a way that was mean or hurtful	44	0.9

**Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 21 shows that overall, 4.7% of participants experienced at least one form of cyberbullying due to their HIV status. A higher proportion of males (5.0%), youth aged 18–24 years (5.5%), and sex workers (10.0%) experienced at least one form of cyberbullying compared with their counterparts. Participants belonging to key populations also reported higher levels of cyberbullying than those in non-key populations.

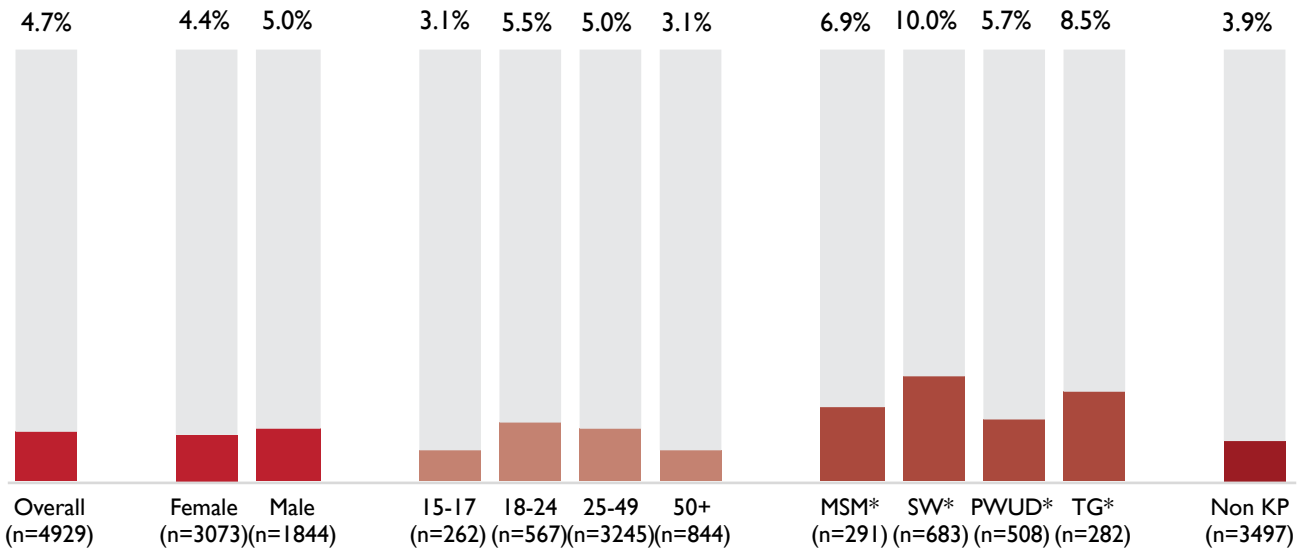

Figure 21. Proportion of participants experiencing at least one form of cyberbullying due to HIV status, by age, sex, and key population type

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

A small proportion of participants self-reported engaging in cyberbullying against other people living with HIV. Table 41 shows that the three most common activities were threatening to disclose someone's HIV status (0.6%), cyberbullying (0.4%), and posting mean or hurtful comments about someone (0.4%).

Table 41. Cyberbullying among people living with HIV

Variables	n*	%
I threatened to disclose someone's HIV status online	32	0.6
I disclosed someone's HIV status online	11	0.2
I have cyberbullied others	21	0.4
I posted mean or hurtful comments about someone online	22	0.4
I posted a mean or hurtful picture of someone online	10	0.2
I posted a mean or hurtful video of someone online	5	0.1
I created a mean or hurtful web page about someone	5	0.1
I spread rumours about someone online	13	0.3
I threatened to hurt someone through a cell phone text message	12	0.2
I threatened to hurt someone online	4	0.1
I pretended to be someone else online and acted in a way that was mean or hurtful	7	0.1

**Subtotals do not equal the overall total due to questionnaire item non-response*

3.7.4 Awareness of various HIV national campaigns and support groups

Table 42 shows participants' awareness of the 'Undetectable = Untransmittable' (U=U) campaign and their sources of information. Less than half of the participants (48.3%) had heard of the U=U campaign. The main source of information was local clinics (71.9%).

Table 42. Awareness of the U=U campaign

Variables	n*	%
Heard of the U=U campaign	2 399	48.3
Sources of information on U=U		
Local clinic	1 726	71.9
Event	456	19.0
NGO	861	35.9
Media (television, radio, social media)	602	25.1
Other	165	6.9

**Subtotals do not equal the overall total due to questionnaire item non-response*

Figure 22 presents participants' knowledge of organisations or groups that people living with HIV can approach for help if they experience stigma or discrimination, by sex, age and key populations. Overall, less than half of the participants (44.2%) were aware of any organisation they could turn to for assistance. Awareness was higher among females (44.7%), those aged 25–49 years (46.0%), and transgender persons (58.0%) compared with their counterparts. Participants belonging to key populations were also more likely to be aware of organisations they could approach than those in non-key populations.

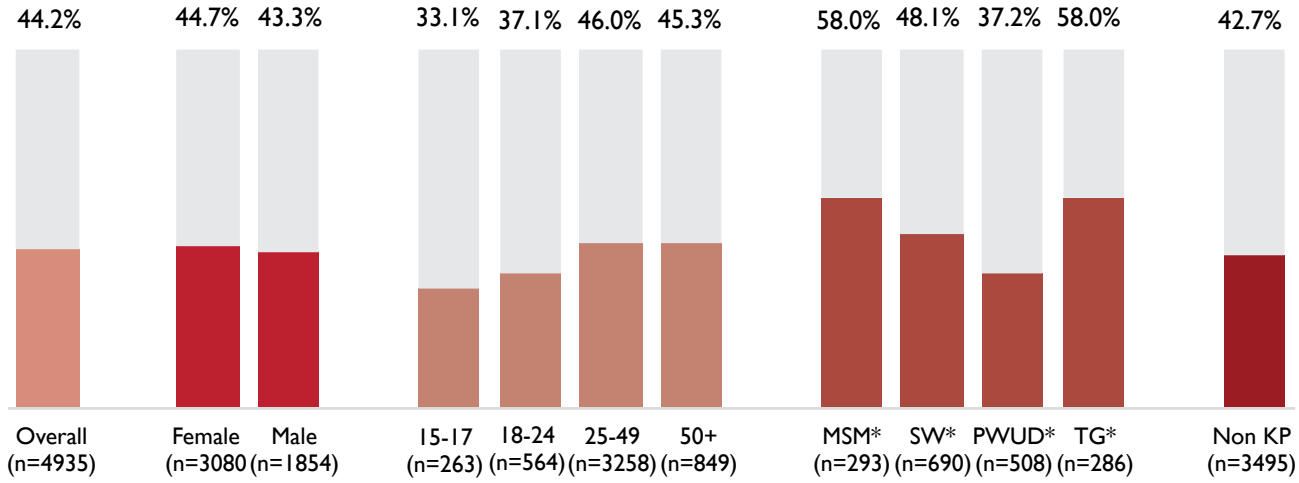

Figure 22. Participants' awareness of organisations or groups to approach for help if they experience stigma or discrimination

**In the key population category, individuals may have multiple identities (e.g. a sex worker may also be transgender and/or a person who uses drugs), so totals may overlap*

Among the 2 094 participants who knew of organisations or groups to approach for help with stigma and discrimination, the most frequently mentioned were people living with HIV support groups (78.7%), networks of people living with HIV (50.5%), local non-governmental organisations (37.6%), the AIDS helpline (26.2%), and human rights organisations (21.5%).

Table 43. Knowledge of organisations or groups that people living with HIV can approach for help if they experience stigma or discrimination (n = 2 094)

Organisation or group	%
People living with HIV support group	78.7
Network of people living with HIV	50.5
Local non-governmental organisation	37.6
Faith-based organisation	14.0
A legal practice	11.1
A human rights organisation	21.5
National non-governmental organisation	13.3
National AIDS council or committee	18.9
International non-governmental organisation	6.9
UN organisation	6.2
AIDS Helpline	26.2
Legal Aid South Africa	12.0
Workplace	5.2
School	2.4
Other	1.8

Figure 23 shows that a small proportion of participants (19.3%) were aware of a national campaign launched within the past 12 months. Among those aware of the anti-stigma campaign, most participants (83.6%) reported learning about it through radio or television.

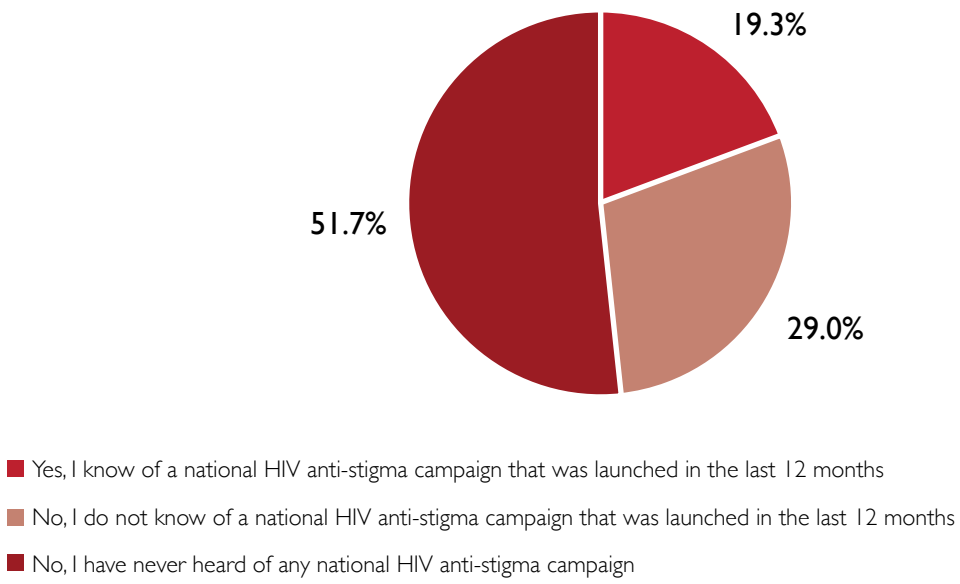

Figure 23. Knowledge of any national HIV anti-stigma campaign launched in the past 12 months

3.7.5 COVID-19-related stigma and discrimination

A small proportion of participants (4.9%, n = 245) reported being diagnosed with COVID-19 between 2020 and 2021. Of these, 22.0% indicated that they had been treated worse than other patients when seeking healthcare due to their HIV status in combination with the COVID-19 diagnosis.

4. DISCUSSION

The 2024 People Living with HIV Stigma Index 2.0 in South Africa is the second follow-up to the 2014 People Living with HIV Stigma Index study. The 2024 People Living with HIV Stigma Index 2.0 employed standardised methodology and instruments to document and assess the levels of stigma and discrimination experienced by people living with HIV in the general population and among key populations in South Africa.

Overall, compared with the 2014 findings, the 2024 results indicate that disclosure patterns have remained largely unchanged, with a significant number of people living with HIV continuing to experience challenges in disclosing their HIV status. These challenges are closely associated with increased levels of internalised stigma, which were higher in this survey (54%) than in 2014 (43%). They may also help explain the lower reported levels of external stigma (10%) in 2024 compared with 2014 (36%). Rather than reflecting a genuine decline in stigma from others, these lower levels may be influenced by anticipated and internalised stigma among people living with HIV.

A marked decline was observed in reports of coerced sterilisation, with only 0.6% (18 participants) indicating that they had been coerced in 2024, compared with 7% (625 participants) in the 2014 Stigma Index.

This section discusses the main findings emerging from the study.

4.1 HIV disclosure

The 2024 Stigma Index findings suggest that more than half of the participants had disclosed their HIV-positive status to people closest to them, rather than in professional and educational settings. Similar disclosure patterns were reported in the 2014 Stigma Index, suggesting that professional and educational environments may not always be perceived as safe or protective. Fear of HIV-related stigma and discrimination in these settings may discourage disclosure. Additionally, disclosure in the workplace is not obligatory under South African law, as outlined in the Employment Equity Act and the 2023 HIV, TB and STI Management Policy for the Public Service.[53,54,57]

The study also shows that a significant proportion of participants had not disclosed their HIV-positive status. This finding highlights that, despite the implementation of initiatives such as Test and Treat, anti-stigma campaigns, and community-based support groups, including ART adherence clubs, disclosure remains a major barrier.

Notably, only 38% of people living with HIV surveyed reported affiliation with a support group. These groups play a crucial role in providing psychosocial support and facilitating disclosure when individuals feel ready.[58,59] The low level of participation suggests that adequate support systems for coping with HIV are not consistently accessible to all people living with HIV, which may contribute to the ongoing difficulties surrounding disclosure.

Given the changing and challenging global funding climate, which has traditionally supported such organisations, it is important for the people living with HIV sector and the South African government, through a coordinated response, to identify lessons from existing groups and explore ways to scale up and sustain these benefits. Similarly, the findings highlight the need for targeted interventions to address internalised and anticipated HIV-related stigma.

4.2 Experiences of HIV-related stigma and discrimination

4.2.1 External stigma and discrimination

Fewer than 10% of people living with HIV reported experiencing external stigma. The most common forms, each reported by fewer than 5% of participants, included discriminatory remarks or gossip among family members, as well as verbal harassment by healthcare workers, friends and others. More severe forms of stigma and discrimination, reported by fewer than 3% of participants, included physical harassment or assault, blackmail, refusal of employment opportunities, loss of income, or denial of promotion.

Experiences of external stigma were similar across settings, including healthcare facilities and family environments. The 2024 findings show an overall decline in these experiences compared with the 2014 report, in which 36% of participants reported external stigma.

This decline may be due to several factors, including reduced disclosure to avoid external stigma, increased resilience among people living with HIV, and the impact of ongoing advocacy and support programmes that promote awareness and acceptance of HIV within communities. Nevertheless, there remains a need to strengthen programmes that educate and provide support for people living with HIV at the community level, including within public health facilities.

4.3 Internalised stigma and discrimination

Internalised stigma remains a serious concern affecting the mental and emotional well-being of people living with HIV in South Africa. The 2024 Stigma Index 2.0 findings show that internalised stigma among people living with HIV increased to 54%, compared with 43% in the 2014 Stigma Index. This rise may partly explain the persistent challenges with disclosure reported by many participants and highlights a growing threat to the mental and emotional health of people living with HIV in South Africa.

The increase is particularly concerning given the number of initiatives introduced by both governmental and non-governmental organisations to address HIV-related stigma. These include the Integrated Chronic Disease Management (ICDM) model,[60] the 2023–2028 NSP for HIV, TB and STIs, and the HIV Counselling and Testing campaign.[61] These initiatives are coordinated through SANAC, which provides a multi-sectoral platform to align and strengthen the national HIV response.[5,61]

Non-governmental organisations such as the Anova Health Institute, LoveLife, and the South African Depression and Anxiety Group (SADAG) have also played important roles in promoting mental health awareness and community dialogue to reduce HIV-related stigma.[62-65] However, the continued rise in internal stigma in South Africa suggests that interventions addressing the mental health of people living with HIV need to be strengthened and adapted to be more effective.

Recognising the persistent challenge of internalised stigma, SANAC has also sought to address the societal attitudes that perpetuate discrimination. One such initiative was the launch of a national communication campaign, "I Can't Change My HIV Status, But You Can Change Your Attitude," on World AIDS Day 2014. The campaign aimed to foster ongoing national dialogue on HIV stigma and discrimination. Given the increase in internalised stigma and the continuing difficulties with HIV disclosure, it remains critical to monitor and evaluate the effectiveness of such initiatives in improving the overall well-being and quality of life of people living with HIV.

A plausible contributing factor to the high levels of internalised stigma observed in this study is the low participation of people living with HIV in HIV support groups. Evidence consistently shows that participation in support groups protects against internalised and anticipated HIV-related stigma.[66] However, several barriers continue to limit participation. In many communities, such groups are unavailable or inaccessible. Even when they do exist, logistical challenges such as inconvenient meeting times and a lack of transport often prevent attendance. In addition, fear of unintended HIV status disclosure due to concerns about confidentiality breaches discourages many from joining. This fear of exposure and possible social rejection reinforces the very internalised stigma that support groups are designed to address.[67]

4.4 Experience of stigma and discrimination by healthcare workers

A proportion of people living with HIV reported negative experiences when interacting with healthcare facilities. The most common forms of stigma reported by fewer than 4% of participants included being advised not to have sex because of their HIV status, being talked about or gossiped about, and being denied healthcare services.

While 7% (625 participants) of participants reported being coerced into sterilisation in the 2014 Stigma Index, this number declined significantly in 2024, with only 18 participants (0.6%) reporting such experiences. Following the 2014 survey, South Africa introduced several guidelines that have contributed to this decline. One key development was the National Guideline for the Prevention of Mother-to-Child Transmission (PMTCT) of Communicable Infections, updated in 2019, which promotes the integration of sexual and reproductive health services for women living with HIV. The guideline provides comprehensive strategies for reducing vertical HIV transmission and explicitly discourages coerced reproductive health procedures. It also emphasises preventing primary HIV infection, avoiding unintended pregnancies, and supporting maternal viral suppression.[68]

Despite this progress, reports of coerced sterilisation and other negative healthcare experiences remain concerning, as they may discourage people living with HIV from seeking care. Interventions that prioritise stigma-reduction training and the enforcement of policies upholding confidentiality, informed consent, and respectful treatment within healthcare settings remain essential to improving the healthcare experiences of people living with HIV.

4.4.1 Delay and hesitancy to start treatment

Overall, nearly one-third (32.1%) of survey participants reported hesitating or delaying initiation of antiretroviral therapy (ART) because they felt unprepared to deal with their HIV diagnosis and were concerned that people close to them, though not necessarily family and friends, would find out. In addition, some participants delayed and hesitated to start treatment due to fear (19.3%) and negative experiences with healthcare workers (15.8%). These findings highlight the significant influence of anticipated HIV stigma and discrimination on healthcare engagement. As observed above, disclosure beyond immediate circles was limited in this survey. Fear of others discovering one's HIV status likely reflects internalised stigma and anxiety about possible judgment or mistreatment due to HIV-positive status.

The South African National Consolidated Guidelines for the Management of HIV in Adults, Adolescents, Children and Infants and Prevention of Mother-to-Child Transmission provide direction for healthcare professionals to support ART initiation and address barriers such as stigma and patient hesitancy.[69] The guidelines emphasise a patient-centred approach, promoting care that acknowledges individual concerns, educates patients about the benefits of early treatment, and creates safe, non-judgemental environments to reduce fears related to disclosure and discrimination.[69]

4.5 Stigma and discrimination experienced by key populations

Key population groups experience multiple and intersecting forms of stigma and discrimination, stemming from both their HIV-positive status and their social or personal identities. Understanding how these layers of stigma overlap and reinforce one another is essential for designing effective and inclusive interventions in South Africa.

4.5.1 Non-HIV-related stigma and discrimination

Gender Identity

The 2024 Stigma Index 2.0 findings show that among key population groups, people who use drugs and sex workers experience high levels of identity-related stigma. Such stigma was found to be particularly prevalent within family settings. Drug use and sex work are both highly stigmatised in South Africa. The heightened discrimination within families toward people who use drugs may stem from societal perceptions of people who use drugs as "addicts" struggling with addiction, a perception that can impose psychological and emotional strain on family members. At the community level, stigma and discrimination may be reinforced by mistrust and negative stereotypes related to the perceived illegality of drug use. Consequently, people who use drugs often experience diminished social status, including beliefs that they "deserve" mistreatment, abuse, or violence, and are unworthy of respect and fair treatment.[70-72]

Similarly, sex work remains criminalised in South Africa and is often viewed by society as immoral or unlawful. However, efforts are underway to reform this legal framework. The government has initiated a process to decriminalise sex work, including a constitutional challenge led by sex worker activists against laws criminalising the profession. The Sex Work Decriminalisation Bill is currently under review.

Disclosure of non-HIV-related status

Overall, most participants reported having disclosed their identity to others, including those with the same identity, friends, family members, and others within their community. Across all groups, key groups were more likely to disclose to other people with the same identity compared to family, friends, and other people in their communities. The prevalence of disclosure to others within the same identity might indicate the presence of community support networks, where shared experiences create a safer and more understanding environment for disclosure.

Disclosure was most common among transgender participants, of whom over 80% had shared details about their identity. Men who have sex with men were the most likely to disclose their identity overall, with 86.6% participants reporting that others within the same identity group were aware of their status. This may be attributed to strong support networks within the men who have sex with men community, where shared experiences and an understanding of the challenges faced encourage openness and mutual support.

In contrast, sex workers were the least likely to disclose their identity, with only 59.6% reporting that people with the same identity were aware of their status. This suggests that sex workers may continue to face significant stigma and discrimination in both personal and professional contexts. Fear of judgment may contribute to reluctance to disclose their identity, particularly within broader community settings.

The lowest levels of disclosure across all key populations were observed when sharing identity with the broader community. This pattern was particularly pronounced among sex workers (37.5%) and people who use drugs (67.0%), indicating that wider communities remain less accepting and more stigmatising. These low disclosure rates are concerning, as they suggest the existence of persistent barriers to acceptance. Fear of discrimination, exclusion, or even violence likely continues to discourage disclosure beyond immediate support networks.

Family members and close friends also represented an important group for disclosure, though at lower levels than peers within the same identity groups.

4.6 Membership in relevant networks or support groups

The 2024 findings highlighted that 57.9% of men who have sex with men were members of networks or support groups, a significantly higher proportion compared with other key populations. This suggests that men who have sex with men benefit from well-established community networks that provide safe spaces for socialising, sharing experiences, and accessing resources.

In contrast, people who use drugs had the lowest membership in networks or support groups, with only 29.1% reporting involvement in such groups. This relatively low participation may reflect the stigma and discrimination frequently faced by people who use drugs. The lower membership levels among other key populations suggest the need for targeted outreach, education, and the development of more accessible and non-judgmental support networks tailored to the specific needs of people who use drugs.

Men who have sex with men who were actively engaged in networks or support groups were also more likely to disclose their identity to others within the same identity group. This highlights the crucial role that such networks play in promoting a sense of belonging, trust, and empowerment, which in turn can foster openness and reduce stigma. Expanding the availability and accessibility of support networks for other key populations could similarly encourage disclosure and improve overall well-being.

Participants identifying as transgender experienced considerable discrimination based on their gender identity. These experiences were particularly pronounced in family settings, including discriminatory remarks, gossip, exclusion from family activities, and verbal harassment. For some individuals, such experiences have increased in the past 12 months, partly due to fear of seeking help.

Overall, experiences of discrimination were most prevalent among people who use drugs, transgender individuals, lesbians, women who have sex with other women and gay individuals. While levels varied across different forms of stigma, exclusion from family activities and verbal harassment were the most frequently reported experiences across key population groups.

Main findings from the South African-specific questions

Findings from the 2024 Stigma Index study showed that adolescents and young people aged 15–24 living with HIV experienced higher levels of stigma and discrimination compared with older people living with HIV in South Africa. Adolescents aged 15–19 are considered a priority group in the national HIV response, with an HIV prevalence of 4.3% reported in the 2022 national HIV prevalence survey conducted by the HSRC.[3]

In addition to HIV-related stigma, the study also documented experiences of disability-related stigma, TB-related stigma and cyberbullying among people living with HIV. Similar to HIV stigma, TB-related stigma and discrimination can create barriers to accessing healthcare services and contribute to social isolation.[41-42] Cyberbullying has become an increasing concern in South Africa, driven by the rise in online harassment and intimidation.[45-47] Given these challenges, documenting experiences of cyberbullying among people living with HIV was an important component of this study.

4.7 TB-related stigma and discrimination

People living with HIV experienced both external and internalised stigma related to having ever been diagnosed with TB. Overall, 16.8% of participants living with HIV reported a history of TB. More than a third (37.9%) reported being gossiped about due to their TB diagnosis, a slight decline from 41% in the 2014 report. Additionally, nearly a quarter (23.5%) reported being teased, insulted, or sworn at, compared with 36% in 2014.

Internalised stigma, reflected in feelings of being unclean or dirty because of their diagnosis, was reported by 23.1% of participants in 2024, compared with 27% in 2014. Although these figures show some decline, TB-related external and internalised stigma and discrimination remain a concern.

Experiences of TB-related stigma were more prevalent among people who use drugs (23.1%), sex workers (20.5%), and males (19.1%). Targeted studies measuring both external and internalised TB-related stigma continue to be crucial in South Africa to guide interventions for those diagnosed and to inform healthcare practices and community-based programmes.

4.8 Stigma and discrimination due to disability status

A proportion of people living with HIV and individuals with disabilities reported experiencing various forms of stigma and discrimination related to their disability. The most common forms included discriminatory remarks from family members (23.0%), exclusion from family activities (19.0%), verbal harassment (12.8%), and fear of seeking health services (12.1%). Stigma and discrimination extended beyond social interactions, with 8.7% of participants avoiding healthcare services out of concern that others would learn about their disability. These findings highlight the profound impact of disability-related stigma on both social participation and access to healthcare.

Gender differences were observed, with 15.3% of females with disabilities reporting stigma and discrimination compared with 11.9% of males, suggesting that women may face compounded discrimination due to both gender and disability. Age also influenced experiences, as younger individuals aged 15–17 reported lower levels of stigma.

The prevalence of verbal harassment and family exclusion highlights the psychological toll, potentially contributing to internalised stigma and feelings of isolation. Notably, 3.3% of participants reported being propositioned for sexual relations under the misconception that engaging with a person with a disability could cure HIV, illustrating the intersection of multiple stigmas and dangerous myths.

These multifaceted challenges highlight the need for targeted interventions addressing the unique vulnerabilities of people living with HIV with disabilities. South Africa's NSP for HIV, TB, and STIs (2023–2028) emphasises a people-centred, inclusive approach to healthcare, aiming to eliminate these illnesses as public health hazards by 2030.[5] The NSP also stresses equitable access to services and the importance of addressing social and structural drivers, including stigma and discrimination. Monitoring the implementation of these strategies remains critical to ensure their effectiveness.

4.9 Cyberbullying due to HV status

Although cyberbullying is a growing concern in South Africa, fewer than 4% of participants in this study reported experiencing it. While this prevalence is lower than that reported in other population groups, it remains concerning given the potential psychological impact.[73-75] For people living with HIV, cyberbullying may exacerbate existing experiences of stigma and discrimination. Follow-up studies are needed to better understand the extent and consequences of cyberbullying among people living with HIV.

4.10 Awareness of HIV national campaigns and support groups

Less than half of participants (48.3%) were aware of campaigns such as the U=U campaign. Among those aware, most (71.9%) had heard about it through local clinics, while 35.9% learned about it via NGOs. Similarly, fewer than half of participants (44.2%) knew of organisations they could approach for support if they experienced stigma or discrimination. Among those aware of existing support organisations, the most recognised sources of support were people living with HIV support groups (78.7%), people living with HIV networks (50.5%), and local NGOs (37.6%).

Support groups for people living with HIV offer important benefits by fostering a sense of community and providing strategies to cope with the multiple layers of stigma and discrimination experienced in various settings. Such challenges can affect access to justice, human rights, and essential services, often intersecting with HIV status, race, gender identity, and socio-economic background. The emotional and informational support offered by these groups can help individuals adhere to treatment, reduce internalised stigma, disclose their status without fear, and navigate life with HIV while managing broader socio-economic challenges, including gender-based violence, which affects many in South Africa.

Ultimately, support from these groups, along with family and societal acceptance, is essential for the mental well-being and overall thriving of people living with HIV. Investing in and revitalising these support networks is crucial to ensure that all PLHIV remain connected and have reliable sources of support across South Africa.

5. RECOMMENDATIONS AND ADVOCACY PLAN

Disclosure

- The National Department of Health and provincial health departments should advocate for community-based partner and social network referral programmes that encourage voluntary HIV testing among sexual partners and close contacts of people living with HIV. These programmes should target people living with HIV and key populations, adolescent girls, young women, and young men, while ensuring informed consent, confidentiality, and psychological support throughout the disclosure process. The National HIV Testing: Policy and Guidelines (2016) should be reviewed to strengthen alignment with ethical, rights-based approaches that support voluntary disclosure, reduce stigma, and facilitate coping mechanisms for both people living with HIV and their partners.
- People living with HIV networks and community-led organisations, including women-led initiatives, should actively design, lead and implement community-based workshops that promote voluntary and supported HIV status disclosure. These workshops should emphasise confidentiality, mutual support and empowerment. In line with the NSP for HIV, TB, and STIs, such interventions should prioritise engagement with key populations and women across all age groups, aiming to build supportive environments that promote testing, treatment adherence, and shared responsibility in HIV management.
- The National Department of Health and provincial health departments should collaborate with key stakeholders, including the Department of Social Development, the Department of Women, Youth and Persons with Disabilities, and civil society, to provide resources for disclosure support. This should include counselling, peer-led support groups, and awareness programmes tailored to the needs of people living with HIV, particularly women and adolescent girls, as outlined in the National Health Act (2003) and aligned with the principles of the NSP for HIV, TB and STIs (2023–2028).
- The Department of Health should ensure that community healthcare workers are comprehensively trained to provide empathetic, supportive and non-judgmental disclosure services to all patients, including people living with HIV. Training should equip healthcare workers with the skills to navigate sensitive conversations in an ethical and respectful manner, in line with the principles of dignity, confidentiality, and non-discrimination outlined in the South African Medical Association (SAMA) *Code of Ethics*.

External Stigma

- People living with HIV networks should take the lead, in collaboration with community-based organisations, NGOs, traditional leaders, and youth groups, to strengthen education and support mechanisms within community and public health facilities to reduce external stigma among people living with HIV and key populations, particularly women and adolescent girls. This aligns with community-led, rights-based strategies outlined in SANAC's NSP for HIV, TB and STIs (2023–2028), which emphasises the meaningful involvement of people living with HIV in stigma reduction and community mobilisation.
- The National Department of Health, together with provincial health departments and in partnership with other departments such as the Department of Social Development, Department of Education, and Department of Justice and Constitutional Development, should develop or implement inclusive, gender-sensitive, and culturally appropriate policies and guidelines to prevent and address external stigma in healthcare settings and communities. These policies should include clear indicators for tracking progress, accountability, and continuous improvement in line with the NSP for HIV, TB and STIs (2023–2028) and the National Health Act (2003).
- The National Department of Health, in partnership with provincial health departments, Basic Education, Social Development, and local municipalities, should design and implement evidence-based, culturally sensitive awareness programmes and anti-stigma campaigns. These initiatives should be aligned with the NSP for HIV, TB and STIs (2023–2028) and the National Health Act (2003) to promote social behaviour change and eliminate HIV-related stigma and discrimination through multisectoral collaboration.

Internalised Stigma

- People living with HIV networks, in partnership with community-based organisations and mental health advocacy groups, should develop and lead evidence-informed advocacy and peer-led campaigns to address internalised stigma, promote mental health awareness, and reduce stigma around mental illness. These initiatives should empower people living with HIV through storytelling, psychological support, and the right education. A monitoring and evaluation framework should be integrated into these campaigns to assess their reach, effectiveness, and psychological outcomes among key populations, particularly women and adolescents.
- The Department of Health, in collaboration with SANAC, should design, fund, and promote positive messaging and national awareness campaigns to reduce HIV-related stigma and enhance the mental well-being of people living with HIV. These campaigns should address psychological distress, low self-esteem, reluctance to seek care, and internalised blame. Aligned with the UNAIDS *Mental Health and HIV Technical Brief* (2018), campaigns should be evaluated through periodic surveys, qualitative studies, and community feedback loops to ensure continued relevance and impact.
- The National Department of Health, together with SANAC, people living with HIV networks, and other relevant departments, should strengthen the U=U campaign by promoting consistent, evidence-based messaging through healthcare providers, schools, and public media. Communication should be culturally appropriate and accessible, and healthcare workers must be trained to deliver accurate U=U information. The campaign should be widely disseminated and include robust monitoring and evaluation to track its impact, in line with the NSP for HIV, TB and STIs (2023–2028), while empowering people living with HIV as active participants in their own health.

Healthcare Facilities

- The National Department of Health and provincial health departments, in collaboration with people living with HIV networks, professional health councils, and NGOs, should strengthen the capacity of healthcare workers to provide care for people living with HIV and key populations, including women and adolescent girls, through training and sensitisation programmes. These programmes should address intersectional stigma, patient rights, and gender-responsive care, and be integrated into ongoing professional development structures to align with the National Health Act (2003). Capacity-building initiatives should be evaluated through pre- and post-training assessments, periodic knowledge reviews, and feedback from people living with HIV. These actions, consistent with the National Health Act (2003) and the NSP for HIV, TB and STIs (2023–2028), must actively involve people living with HIV as co-facilitators and evaluators to ensure relevance and accountability.
- Healthcare providers, in partnership with people-living-with-HIV-led organisations and training institutions, should design and deliver culturally sensitive, community-informed training modules and sensitisation programmes that reflect the lived realities of people living with HIV and key populations. Training should prioritise the needs of women, adolescent girls, sex workers, and LGBTQI individuals, guided by the World Health Organisation (WHO) key population guidelines (2013; 2014). A monitoring framework should be developed to assess changes in healthcare worker attitudes, service delivery quality, and patient satisfaction through regular surveys, case reviews, and mystery client evaluations.
- Healthcare providers and facility managers, working with the Department of Health and human rights bodies, should establish independent, confidential monitoring systems to identify stigma, discrimination, and rights violations in healthcare facilities. These systems must include clear complaint procedures, referral pathways, and mechanisms for resolution and redress. Monitoring tools such as anonymous feedback channels, periodic audits, and stigma indicators should be institutionalised and reviewed regularly by a multisectoral oversight team, including people living with HIV networks and legal support organisations, in alignment with the WHO's (2014) and the UNAIDS (2017) rights-based guidance.
- The National Department of Health and provincial health departments should promote and institutionalise people-centred, rights-based approaches that prioritise the needs, dignity, preferences, and holistic well-being of people living with HIV and key populations. These approaches should be informed by continuous feedback and implemented through respectful care protocols, inclusive facility designs, and supportive staff attitudes. Monitoring and evaluation activities should include routine tracking of patient satisfaction, retention in care, and service quality through both quantitative and qualitative methods.

Human Rights and Access to Justice

- The Department of Health and donors should mobilise resources for people living with HIV networks and organisations to implement stigma reduction programs, as emphasised in the UNAIDS "Guidelines on HIV and Human Rights" (2017) and the South African NSP for HIV, TB and STIs (2023–2028). This should include tracking resource flows, programme implementation rates, and stigma-related outcomes using baseline and follow-up surveys, qualitative feedback from beneficiaries, and stigma indicators.
- The government, in collaboration with people living with HIV, especially women living with HIV, and key populations networks, should increase awareness and promote anti-discrimination campaigns to address stigma and discrimination against people living with HIV and key populations, in line with the WHO "Framework on integrated people-centred health services" (2016) and the South African Promotion of Equality and Prevention of Unfair Discrimination Act (2000). These efforts should be monitored through regular assessments of public attitudes via community surveys, social media sentiment analysis, and tracking the reach and effectiveness of campaigns using media metrics and pre- and post-campaign knowledge assessments.
- People living with HIV networks, led by women living with HIV, should provide education and training on rights, policies, and regulations related to women living with HIV across all age groups and key populations, as outlined in the WHO "Framework on integrated people-centred health services" (2016) and the South African NSP for HIV, TB and STIs (2023–2028).
- The Department of Justice and Constitutional Development, Legal Aid South Africa, and people living with HIV network should collaborate to support access to justice for people living with HIV and key populations, including providing legal assistance and advocacy services, as recommended by the UNAIDS "Guidelines on HIV and human rights" (2017) and the South African Constitution (1996). Monitoring mechanisms should track the number and outcomes of legal cases, user satisfaction with legal services, and identify systemic legal barriers faced by people living with HIV. Regular reviews of legal aid utilisation, case follow-up rates, and community legal awareness indicators should be included.
- All stakeholders should establish partnerships with community-based organisations to promote human rights and access to justice for people living with HIV, in line with the WHO "Framework on integrated people-centred health services" (2016) and the NSP for HIV, TB and STIs (2023–2028). To monitor progress, there should be mapping and evaluation of partnerships, assessment of the reach and impact of joint initiatives, and annual stakeholder feedback sessions to improve coordination and accountability.
- The National Department of Health, provincial health departments and healthcare providers should ensure that HIV services are migrant-friendly and accessible to migrant populations, including providing language interpretation services and addressing cultural barriers, as recommended by the International Organisation for Migration (IOM) "HIV and Migration" (2019) and the South African National Health Act (2003). Given the multifaceted nature of migration and health, a multisectoral approach is important. The Department of Home Affairs should facilitate the regularisation of migrants' legal status to ensure access to healthcare, while the Department of Education can support language and cultural orientation programmes. In addition, the Department of Social Development and the National Treasury should allocate resources and develop integrated policies that support health equity for migrant populations.

6. STRENGTHS AND LIMITATIONS OF THE STUDY

The strength of the 2024 Stigma Index 2.0 lies in its participatory approach, with people living with HIV leading data collection and being involved in all aspects of the implementation. The inclusion of diverse Participants, including key population groups, allowed for meaningful disaggregation and ensured that the study aligned with the global Stigma Index 2.0 framework. However, the study had several limitations that should be considered when interpreting the findings. The purposive recruitment of participants through healthcare services, support groups, or chain referrals limits the generalisability of the findings to all people living with HIV in the country. The study encountered challenges reaching some key population groups, especially sex workers who are still heavily stigmatised. Furthermore, while self-reporting is a common method for data collection in the Stigma Index 2.0, it is important to acknowledge that self-reported data can be susceptible to biases, including recall and social desirability bias. Additionally, the Stigma Index 2.0 may not capture the full spectrum of stigma experienced by all individuals, particularly those who are not aware of their HIV status or are not part of the sampled populations. Despite these limitations, the findings offer valuable data to inform advocacy efforts and policies aimed at protecting the health and rights of people living with HIV and improving their quality of life.

Recommendations for future studies

In future studies, the following should be considered:

- Work closely with organisations that have already established partnerships with community-based organisations that work with key population groups and involve these organisations in the study's design and implementation.
- Provide a safe and confidential environment that ensures that Participants from key population groups feel protected and respected when taking part in the study.
- Be mindful of power dynamics at play when engaging with key population groups and take steps to address these dynamics. This may include using peer-led recruitment strategies or involving key population groups in the design and implementation of the study.
- Take into account the broader political context in which the study is being conducted and take steps to mitigate potential risks or challenges.
- Future studies should consider documenting the experiences of key population groups living with HIV in their interactions with law enforcement officers. Law enforcement officers have been reported as sources of stigma, discrimination and abuse against key populations. Such prejudice may negatively affect their access to health and other essential services, including justice.
- Strengthen the study instruments by sharing lessons learned across countries and identifying areas for improvement in the questionnaire flow, skip logic, missing sections and the use of probes.
- To reduce missing data, implementers should provide stronger support and closely monitor data collectors' performance. This includes tracking trends and the volume of incomplete questions and sections per data collector, which may indicate a need for retraining or checking whether the data collector is comfortable discussing certain topics, such as gender, same-sex relationships, key populations, and drug use.

CONCLUSION

The findings of the 2024 People Living with HIV Stigma Index 2.0 study provide important insights into the current state of HIV-related stigma and discrimination in South Africa. While the study confirms that stigma and discrimination persist, it also highlights improvements from the past. This progress is a testament to the coordinated efforts of government, civil society organisations, and individuals who continue to work tirelessly to address these challenges.

Despite these gains, the study also underlines the need for sustained efforts to address stigma and discrimination. The findings of this study highlight that key populations living with HIV, such as sex workers, men who have sex with men, and people who use drugs, continue to be affected by multi-layered levels of stigma and discrimination at both the healthcare facilities and in communities. Young people living with HIV also require targeted support to address their unique needs and concerns. Similarly, internalised stigma remains a serious challenge, pointing to the need for mental health support to be integrated into the services offered to people living with HIV.

To build on the progress South Africa has made, it is important to intensify the efforts that have already been made by building on the multi-faceted and well-coordinated approach that involves government, people living with HIV networks, civil society organisations, communities and individuals to create a supportive and inclusive environment that promotes dignity, well-being, and human rights for all people living with HIV.

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Appendix 1: List of the 2024 Stigma Index Data Collection Team

Name	Surname	Name	Surname
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Vuyolwethu Aaron	Zazela	Bongeka	Mdlalo
Yanga	Mata	Maria Khungeka	Lindani
Phumza	Zinyane	Melikhaya Thomas	Gonintebe
Bongiwe	Poyo	Nana Maseti	Ngqoleka
Sibulele	Dlokova	Busisiwe	Makinana
Lindani Joseph	Saliwe	Nokuthula Agnes	Ndlovu
Nandipha Mirriam	Pitso	Sithabile Siphelele	Mpanza
Dineo	Motloang	Bayanda Perfect	Mthethwa
Lerato	Nkoata	Lungile Precious	Ngubane
Nomthandazo	Nhlapho	Promise	Memela
Sibongile	Gaba	Nosipho	Mncwabe
Maria Ntombi	Pege	Vuyani	Macotha
Jan Mohau	Mthethwa	Sephendu Justice	Solo
Lindiwe Betty	Nkosi	Neo	Marumo
Kelebogile Given	Selepe	Mvula	Mnisi
Nteboheng	Mokoena	Isaac Boitumelo	Tsame
Lebohang Pamela	Sefatsa	Tshepiso Felicia	Louw
Busisiwe Prudence	Shongwe	Jacqualine	Magano
Nokuthula Sweetness	Mlotshwa	Phumla	Mkhuba
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Refilwe	Mokgoro	Ndivhudzannyi Goodness	Tshavhumbya
Queen	Kwetla	Ndivhudzannyi Goodness	Tshavhumbya
Mpho	Nathane	Violet Koko	Mmupani
Kopano	Lekalakala	Lawrence Mashamba	Sengwane
Boitumelo	Botlhoko	Phumudzo Juliet	Nethomboni
Priscilla	Moji	Mpho	Netshiongolwe
Nozuko Denise	Manong	Livhuwani Sheilagh	Ravhuwani
Sanelizwi	Mema	Ndivhudzannyi Goodness	Tshavhumbya
Patricia Sinethemba	Renene	Violet Koko	Mmupani
Bahenyi	Mogotsi		
Oratile Pearl	Kutiri		

NOTES

THE PEOPLE LIVING WITH HIV STIGMA INDEX

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