



**THE PEOPLE LIVING
WITH HIV STIGMA
INDEX 2.0 IN SIX
DISTRICTS OF SOUTH
AFRICA 2020 – 2021**
Report



science & innovation

Department:
Science and Innovation
REPUBLIC OF SOUTH AFRICA

THE PEOPLE LIVING WITH HIV STIGMA INDEX 2.0 IN SIX DISTRICTS OF SOUTH AFRICA 2020 – 2021 *Report*



POSITIVE
WOMEN'S NETWORK
FOR WOMEN LIVING WITH HIV/AIDS



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RESEARCH REPORT

The People Living with HIV Stigma Index 2.0 in Six Districts of South Africa 2020 – 2021

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FOREWORD

The 2020 – 2021 People living with the Human Immunodeficiency Virus (HIV) (PLHIV) Stigma Index 2.0 Survey, conducted by the PLHIV, the lesbian, gay, bisexual, transgender and intersex (LGBTI), the Disability, and the Sex Worker sectors in partnership with the Human Sciences Research Council (HSRC) across six districts – two each in the provinces of Kwazulu-Natal, Mpumalanga and the Free State – reveals that people living with HIV are still reporting both internalised and experienced stigma. PLHIV Networks, together with human rights activists, must respond to the findings from the survey by establishing community legal support services for PLHIV. These advocacy strategies must include efforts to repeal or reform harmful HIV criminalisation laws, as well as strengthen legal frameworks that protect the rights of PLHIV. Legal aid on its own will not change the situation or protect the rights of PLHIV. A twin-track approach of providing support while getting to the heart of stigma is, therefore, a more effective and long-lasting solution.

The PLHIV Stigma Index 2.0 was designed to capture the intersectional stigma and discrimination faced by sex workers, LGBTI people, and people who use drugs. It is also known that PLHIV experience stigma and discrimination because of the groups they belong to, the ways they self-identify, and the behaviours that they engage in. Prejudices such as racism, sexism, homophobia, and transphobia are often intertwined, and all of these play a role in the HIV epidemic. The ground-breaking findings that are presented in this report should therefore be used to develop advocacy tools and inform the design of new interventions while supporting existing stigma reduction interventions.

Civil society must focus on advocacy activities that are specifically aimed at changing laws, policies and practices, by influencing government officials and those in positions of power. To achieve this, a range of familiar strategies may be needed. These strategies could include things such as collaborating with the media, building networks with like-minded formations, awareness-raising, holding demonstrations to highlight the plight of affected communities, and reframing the existing harmful narratives to shift public opinion. These efforts should be accompanied by targeted approaches such as engaging directly with parliamentarians and government officials, participating in policymaking bodies, and submitting evidence to public consultations and national human rights bodies. For this to be successful, a PLHIV Stigma Index advocacy strategy must aim to educate communities about HIV-related stigma, and directly address discrimination by and within political, economic and social institutions, while seeking to reduce stigma within the community.

Experience has taught us that advocacy requires both education and action. To be effective, advocacy needs to be based on good evidence, and those in power need to be educated about ways they can bring about the changes that are needed. The PLHIV Stigma Index 2.0 Study Report provides the material for the first stage in this process, and helps the sector and key stakeholders identify what needs to change to address HIV-related stigma and discrimination. The second phase of the response will entail the identification of catalysts for change. To achieve this, the sector will need to join with development partners who can provide financial support for advocacy activities aimed at achieving the goal of having stigma- and discrimination-free societies.

South Africa must expand the implementation of the Stigma Index 2.0 Survey to other districts so that we can have a national picture of the extent of stigma and discrimination. The expansion of the Stigma Index 2.0 into the remaining districts must be led and managed by the PLHIV sector. The government, the private sector, policymakers, politicians, and civil society must be united in striving towards a society with zero stigmas and discrimination.

Mr Mluleki Zazini

National Director

National Association of People Living with HIV and AIDS (NAPWA), South Africa

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CONTRIBUTORS

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Name	Role	Responsibilities
Dr Allanise Cloete, PhD	Principal Investigator	Provided overall management to the project team to ensure that the objectives of the research project were achieved. Managed the overall work plan, timelines, budget, project design, and survey implementation. Provided oversight for data collection and data analysis. Led the conceptualisation, reporting, and dissemination of research findings.
Prof Khangelani Zuma, PhD	Senior Technical Advisor	Led the technical design and supported the implementation of activities. Served as an analyst and technical specialist and participated in the selection of, and coordination of the work of, short-term Analysts, Researchers, and other Technical Specialists.
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Centers for Disease Control and Prevention (CDC)

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ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral treatment
CBO	Community-based organisation
CDC	Centers for Disease Control and Prevention
COVID-19	Coronavirus disease 2019
CSO	Civil society organisation
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	The Global Network of People Living with HIV/AIDS
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
LGBTI+	Lesbian, Gay, Bisexual, Transgender, Intersex+
MSM	Men who have sex with men
NAPWA	National Association for People Living with HIV and AIDS
NDOH	National Department of Health
NGO	Non-governmental organisation
NSP	National Strategic Plan
PAC	Positive Action Campaign
PCA	Provincial Council on AIDS
PEPFAR	The United States President's Emergency Fund for AIDS Relief
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PWID	People who inject drugs
PWN	Positive Women's Network
PWUD	People who use drugs
SANAC	South African National AIDS Council
SANERELA+	South African Network of Religious Leaders Living with or Personally Affected by HIV or AIDS
SOGI	Social Orientation and Gender Identity
STI	Sexually transmitted infections
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America

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This study surveyed people living with HIV (PLHIV) in six districts of South Africa. The successful completion of this study required not only the technical knowledge and skills of those involved, but also their commitment to and passion for the elimination of HIV-related stigma and discrimination. We acknowledge and thank the PLHIV who consented to take part in this study. Without their voluntary participation, this study would not have been possible. They shared with us their time, personal information, and experiences despite many still experiencing stigmatisation and discrimination. The information provided will assist in advocating for the implementation of stigma mitigation campaigns in South Africa.

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DEFINITIONS USED IN THIS STUDY

Civil society comprises various organisations that work together in the interest of fellow citizens.

Coronavirus disease 2019 (COVID-19)-related stigma refers to any negative associations made to people who have been diagnosed with, or have recovered from COVID-19.

Discrimination is any form of arbitrary distinction, exclusion, or restriction affecting a person, usually (but not only) because of an inherent personal characteristic or perceived membership of a particular group, which can rise to the level of a human rights violation. Discrimination, as defined under international human rights law, is any distinction, exclusion, or restriction based indirectly or directly on grounds prohibited under international law, which has the effect or intent of nullifying the recognition, enjoyment, or exercise on an equal basis of others of all human rights and fundamental freedoms, in the political, economic, social, cultural, civil or any other field.

Experienced stigma occurs when people living with HIV are insulted, rejected, avoided, verbally or physically abused, stereotyped, or discriminated against because of their HIV or key population status.¹

HIV-related stigma generally relates to negative beliefs, feelings, and attitudes towards PLHIV, groups associated with PLHIV, or their families and friends. HIV-related stigma can also affect other key populations at higher risk of HIV infection, such as people who use drugs (PWUD), people who inject drugs (PWID), sex workers, men who have sex with men (MSM), and transgender people.

Internalised stigma occurs when an individual believes that negative attitudes and perceptions about people living with HIV like shame and guilt are true, and applies these perceptions to themselves.²

Resilience among PLHIV is a dynamic process encompassing positive adaptation in the context of living with HIV. Positive adaptation implies an improvement in one's ability to meet a range of physiological and social needs.

Stigma refers to beliefs and/or attitudes. Stigma can be described as a dynamic process of devaluation that significantly discredits an individual in the eyes of others. When stigma is acted upon, the result is often discrimination.

Tuberculosis (TB)-related stigma refers to attitudes or actions, which include gossiping, verbal, social and family exclusion, avoidance and physical harassment aimed at people diagnosed with TB.

SUMMARY

Background: Stigma and discrimination against PLHIV remain some of the key barriers to the effective prevention and management of HIV in Africa. Similarly, the outbreak of Coronavirus disease 2019 (COVID-19) is expected to put key and vulnerable groups – including PLHIV – at heightened risk, given that containment measures to slow the pandemic including lockdowns and disruption of basic services are already being seen to exacerbate existing economic and social inequalities. Moreover, with the onset of the COVID-19 pandemic, fear of infection also increases social exclusion and stigmatisation. The Stigma Index was developed by various international organisations to assess different forms of stigma and discrimination experienced by PLHIV. For the first time in South Africa, this study made use of the Stigma Index 2.0 – an updated version of the Stigma Index that reflects shifts in the HIV epidemic and the global response to HIV.

Aims: Making use of the Stigma Index 2.0, we aimed to measure the levels of stigma and discrimination experienced by PLHIV, as well as stigma and discrimination attached to TB, COVID-19, disability, sex work, sexual orientation and gender identity (SOGI), and cyberbullying.

Study design: This Stigma Index 2.0 was implemented in six districts across the provinces of KwaZulu-Natal, Mpumalanga, and the Free State. The districts selected were identified based on the need to have both urban and rural districts included in the study. For each of the provinces, one urban and one rural district were purposefully selected.

This study included PLHIV aged 15 years and older who were linked to an organisation, including those attending primary healthcare centres, home-based care organisations, community-based organisations (CBOs), and non-governmental organisations (NGOs), to access support or care related to HIV. Stratified purposeful sampling (by district) with equal allocation was used in each province to enable reporting at the district level. The Stigma Index 2.0 responses and consent were recorded on tablets. Data collection was conducted using side-by-side interviewing. An overall final sample of 3 716 participants self-reported as living with HIV; 73.4% (n=2 677) were female and 26.6% (n=972) were male.

Data analysis: Basic descriptive analysis of stigma (by sex, age, educational attainment, etc.) and graphical displays were used to summarise both experienced and internalised stigma, as well as discrimination by background characteristics of study participants.

Study findings: Both HIV- and TB-related experiences and internalised stigma varied from low to moderate levels across the three provinces and the six districts. Experienced stigma ranged from 10% to 27% (n/N: 61/607 – 182/664) across the six districts. Endorsement of internalised stigma ranged from 14% to 31.5% (n/N: 82/578 – 206/655) across the six districts. The 15–24 year age group experienced the highest levels of internalised stigma and a greater propensity to experience cyberbullying. Higher levels of internalised stigma were also found among key and vulnerable populations, specifically people with disabilities, sexual and gender minorities, and sex workers.

Conclusions: Low to moderate levels of both HIV- and TB-related experiences and internalised stigma were found. Of concern were low levels of reported resilience within the context of living with HIV. Consequently, internalised stigma reduction campaigns or programmes need to be intensified and community stigma reduction interventions may also help to address issues of internalised stigma in the three provinces of KwaZulu-Natal, Free State, and Mpumalanga.

Introduction

Context and background

Key and vulnerable populations, including PLHIV, continue to experience stigma and discrimination that can affect their quality of life and well-being.³ HIV-related stigma undermines the emotional, mental, social, and physical well-being of PLHIV.⁴ HIV-related stigma reduces the uptake of HIV testing, disclosure, engagement in care, and uptake of and adherence to HIV treatment, and therefore remains a key barrier to effective prevention and management of HIV in Africa.⁴⁻⁶ In addition, stigma and discrimination prevent key and vulnerable populations, including PLHIV, from having access to decent employment, social support, integrated services, and sometimes education, which contributes greatly to the reduction in their quality of life and the opportunities to improve socioeconomic conditions.⁷ HIV-related stigma cannot be understood without considering social conditions such as poverty, gender-based violence, social and gender inequality, and local norms and attitudes.⁸

Intersecting stigma

Intersectional stigma is a concept that has emerged to characterise the convergence of multiple stigmatised identities within a person or group, and to address their joint effects on health and wellbeing.⁹ However, more recent work has expanded the concept beyond the individual to include underlying structural inequalities. For example, Jackson-Best and Edward (2018) note that “at its foundation, stigma is about social inequality and social control, which create a hierarchy that devalues stigmatised people”.¹⁰ Intersectional stigma examines social support and/or relational and collective resilience, including collective empowerment, resistance, solidarity, and community mobilisation and transformation.¹¹

In the South African context, intersectional HIV-related stigma often involves ‘othering’ through stigmatising already oppressed groups, such as ‘black’ Africans and ‘black’ African women specifically, and blaming them for the transmission of HIV. The history of stigma and discrimination in South Africa is most evident in the *apartheid* system of legislated segregation.¹² Seminal research conducted by Campbell and colleagues (2005) suggests that despite the abolishment of apartheid legislation: “at the symbolic level, the close link that several informants made in their study between HIV and ‘black’ African people both draws on and feeds back into negative stereotypes of ‘black’ people that have a long history in South Africa”.¹³ Thus, with the onset of the HIV epidemic, a discourse of ‘othering’ that mediates cultural and racial positionings concerning those deemed responsible for transmitting HIV emerged in South Africa.¹³ This accentuates both the exclusion and devaluation of PLHIV leading to double or multiple stigmas (i.e., ‘super-stigmatisation’).^{14,15}

Due to existing discrimination against women in various societies, attitudes towards women living with HIV are often less accommodating compared to the attitudes towards men in the same situation. Women living with HIV are often blamed for infecting their husbands and unborn children and spreading the virus,^{8,16} and are described in stigmatising terms such as ‘vectors’, ‘diseased’ and ‘prostitutes’ – terms which are rarely, if at all, used when describing men living with HIV.¹⁶ For couples, stigmatisation against women living with HIV can lead to violence against women from their male partners, or exclusion from the household.⁸

Internalised stigma

Data collected from 1 068 PLHIV from Cape Town in South Africa, 1 090 PLHIV from eSwatini, and 239 PLHIV from Atlanta in the United States of America (USA), showed that internalised stigma was positively correlated with higher depression scores in all three countries, and that higher internalised stigma scores were related to greater depression symptoms.¹⁷ For participants in both Cape Town and Atlanta, individuals who indicated that they have been treated differently since disclosing their HIV status, had a greater internalised stigma.¹⁷ For all three sites, individuals who reported not having disclosed their HIV status, also experienced greater internalised HIV-related stigma.¹⁷ In a study conducted among 92 MSM living with HIV in Cape Town, South Africa, internalised stigma was high among all who took part in the study, with 56% of men reporting that they concealed their HIV status from others.¹⁸ MSM living with HIV reported experiencing greater social isolation and discrimination resulting from being HIV-positive, including the loss of housing or employment due to their HIV status.¹⁸

Stigma in healthcare

Stigma is a well-documented barrier to health-seeking behaviour, engagement in care, and adherence to treatment across a range of health conditions globally.¹ HIV-related stigma often manifests in healthcare settings in the form of denial of services, and being subjected to negative health worker attitudes when accessing healthcare services. According to the findings of the Stigma Index 2014 study, 7.4% of female participants self-reported forced sterilisation.³ It remains a concern that 13.5% did not receive ART during pregnancy despite national policy availing it free of charge to all HIV-positive pregnant women.³ Also concerning is that almost one-tenth (9.6%) of the participants reported that they did not know that such treatment existed.³

TB-related stigma

Due to the high co-morbidity of tuberculosis (TB) and HIV in South Africa,¹⁹ TB-related stigma was also measured in the Stigma Index 2014 study. It was found that two-thirds of participants (66.3%) reported having disclosed their TB diagnosis to people outside the household, whereas the remainder of about one-third (33.7%) had not done so.³ PLHIV may not have disclosed their TB status because of fears of experiencing stigma and discrimination. Over a third (36.3%) of participants reported being teased, insulted, or sworn at because of their TB status, and 41.4% reported being gossiped about because of their TB status.³ Internalised feelings of TB-related stigma were found to be moderately high, as just over a quarter of the participants (26.8%) indicated feeling unclean or dirty.³

The human rights response in South Africa

South Africa is characterised by an inclusive, anti-discrimination, and rights-based approach at the national level. For instance, under Section 9 of the South African Constitution, discrimination on the grounds of sexual orientation is unconstitutional. The ‘equality clause’ – the first of its kind in the world – in the South African 1996 Constitution prohibits discrimination based on sexual orientation and provides for the protection of the rights of lesbian, gay, bisexual, trans, and/or intersex people.

The current National Strategic Plan (NSP) on HIV, sexually transmitted infections (STIs) and TB 2017–2022 (2017) is the country’s master plan that outlines the country’s response to the prevention and treatment of HIV and AIDS, TB and STIs over five years. Goal 5 aims to ground the response to HIV, TB and STIs in human rights principles and approaches, to reduce stigma and discrimination, to ensure equal treatment for all, and to increase access to justice in the context of HIV, TB and STIs for all key and vulnerable populations. *The Three-Year National Implementation Plan for a Comprehensive Response to Human Rights-Related Barriers to HIV and TB Services and Gender Inequality in South Africa* aims to strengthen, scale up, and improve coordination of a comprehensive response to human rights-related barriers and gender inequality.²⁰

The two most recent NSPs on HIV, STIs and TB, namely, the South African NSP on HIV, STIs and TB 2012–2016 (2012)²¹ and NSP on HIV, STIs and TB 2017–2022 (2017)²² reaffirm that “Nobody should be left behind”, and outline concrete objectives to curb the epidemic among key and vulnerable populations. In what has been hailed as a world-first, the SANAC launched the country’s national LGBTI+ HIV plan in 2017. The plan aimed to be inclusive and address the needs of the LGBTI+ community.¹⁶

Similarly, the *South African National Sex Worker HIV Plan (2016–2019)* includes service delivery models that meet the needs of different contexts and outlines a core package of services.²³ The aims of the South African National Sex Worker HIV Plan are to: (i) reduce HIV, STI and TB incidence among sex workers; (ii) reduce HIV, STI and TB-related mortality among sex workers; and (iii) reduce human rights violations experienced by sex workers.²³

The history of the Stigma Index

The Stigma Index collects information about the experiences of PLHIV related to stigma, discrimination, and human rights (see www.stigmaindex.org/about-stigma-index).²⁴ The PLHIV Stigma Index (Stigma Index) was developed in 2008 by the Global Network of PLHIV (GNP+), the International Community of Women Living with HIV (ICW), International Planned Parenthood Foundation, and UNAIDS to facilitate the measurement and development of interventions to address HIV-related stigma.²⁴ According to Friedland and colleagues (2020), the Stigma Index is the most widely used survey measuring stigma and discrimination experienced by PLHIV from their perspective.²⁵ Concerning the use of the term ‘index’, Friedland *et al* (2020) clarifies that although the term ‘index’ is often used to describe a compound measure that aggregates multiple indicators, in this case, it describes a survey with nearly 100 questions assessing different types of stigma and related phenomena.^{25,26} The Stigma Index operationalises the GIPA principle (greater involvement of people living with HIV and AIDS) in that PLHIV leads the research, which includes data collection and dissemination.^{25,26} According to the GNP+, the Stigma Index has now been updated and strengthened by the Stigma Index 2.0 study, which reflects shifts in the HIV epidemic and the global response.²⁴ This study made use of the Stigma Index 2.0 that was adapted to fit the South African context and included the following modules:

- New questions focused on specific populations to better understand how different groups of PLHIV and key populations are affected by stigma and discrimination.
- An expanded healthcare section to look at the impact of stigma on health and access to healthcare services across the whole continuum of care, and not just HIV services.
- A new questionnaire that is streamlined and easier to use, using digital data collection (see www.stigmaindex.org/about-stigma-index).²⁴

In addition to the aforementioned items, the Steering Committee together with the research team recommended including measures on:

- TB-related stigma
- COVID-19 stigma and access to healthcare during lockdown
- Cyberbullying.

Previous studies using the Stigma Index in South Africa

In South Africa, the Stigma Index was implemented in the OR Tambo District of the Eastern Cape province between October 2011 and August 2012 among a sample of 799 PLHIV.²⁷ The study was conducted in three local municipalities: King Sabatha Dalindyebo, Nyandeni, and Ngquza local municipalities.²⁷ Following the 2011–2012 study, the Stigma Index was implemented in 10 Foundation for Professional Development-supported clinics in the four provinces of Gauteng, North West, Mpumalanga, and Limpopo among a total of 486 PLHIV.²⁸

The SANAC commissioned the HSRC to conduct the first national Stigma Index study in South Africa in 2014. The study was conducted to address the key priority area of reducing HIV-related stigma and discrimination as outlined in the NSP on HIV, STIs and TB 2012–2016 (2012). Information for this study was gathered from PLHIV in 18 districts (two districts per province), across all nine provinces of South Africa. A total of 10 473 PLHIV were included in the study, thus making it the world’s largest study ever undertaken using the Stigma Index survey.

The main findings of the study were as follows:³

- a) Experienced stigma was more likely to be reported by:
 - female participants
 - youth aged 15–24 years
 - participants who had lived with an HIV-positive diagnosis for 2–4 years
 - participants who were married or cohabiting, but the spouse/partner was temporarily not living in the same household
 - participants who had completed secondary education
 - participants living in small towns and villages
 - participants who often or rarely went without enough food to eat
 - participants who were employed, and
 - participants who live in Free State, KwaZulu-Natal, and Mpumalanga provinces.
- b) There was evidence of moderate levels of internalised stigma, with substantial minorities of participants of roughly between 19–30% 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 other older family members and children in the household. In the workplace, however, most employers and bosses were not aware of the HIV-positive status of participants. In the healthcare setting, participants felt that confidentiality of their HIV-positive status was also maintained.
- d) Over a third (36.3%) of participants who were co-infected with TB, reported being teased, insulted, or sworn at because of their TB status, and 41.4% reported being gossiped about because of their TB status.

Overall aim of the study

The study aimed to make use of the Stigma Index 2.0 to measure the levels of stigma and discrimination experienced by PLHIV. In addition, we also investigated the stigma and discrimination experienced by PLHIV attached to TB, COVID-19, disability, SOGI, as well as the stigma experienced because of someone's HIV status, COVID-19 status, and stigma experienced and perpetrated through cyberbullying.

Overall purpose

The overall purpose of this study was to measure self-reported stigma and discrimination experienced by PLHIV in six districts of the three South African provinces of KwaZulu-Natal, Free State, and Mpumalanga. This will ultimately inform the development and implementation of national policies and programmes to protect the health and rights of PLHIV, as well as HIV prevention programmes.

Objectives of the study

- a) To measure the levels of stigma and discrimination experienced by PLHIV in six districts of the South African provinces of Kwazulu-Natal, Free State, and Mpumalanga.
- b) To inform the development and implementation of national policies that protect the rights of PLHIV.
- c) To inform programmatic interventions on HIV/TB-related stigma and discrimination.
- d) To assess the impact of COVID-19 on access to HIV care, treatment, counselling, and other health services for PLHIV.
- e) To assess the extent to which PLHIV experiences COVID-19 stigma.
- f) To assess whether PLHIV experiences other intersecting forms of stigma and discrimination (i.e., SOGI, disability, sex work).
- g) To assess whether cyberbullying is a medium used through which HIV-related stigma and discrimination are perpetrated.
- h) To inform programmatic interventions, including advocacy tailored for PLHIV during and beyond the COVID-19 pandemic.

Intended use of the study findings

We hope that the index will foster change within communities as it is being used, as well as be a tool to advocate for the broader changes needed according to the index data. Ultimately, we hope that the index will be a powerful advocacy tool that acts to support the collective goal of governments, CBOs, activists, and PLHIV alike in order to reduce the stigma and discrimination linked to HIV. In addition, lessons learned on conducting research during COVID-19, while staying true to the Stigma Index key principles, will provide useful guidance for future implementation of the Stigma Index.

How the study was done

The benefits of the Stigma Index, particularly for those conducting it, go further than just collecting this much-needed evidence. The index is a project that has been developed and implemented by and for PLHIV,²⁴ hence a key principle is that its planning and implementation are led and owned by PLHIV.²⁹ Thus, the study was implemented within a context that not only emphasised the empowerment of PLHIV but also their networks and local communities – with the leadership of the SANAC PLHIV sector, the LGBTI+, Disability and Sex Worker sectors of SANAC, as well as the SANAC.

Ensuring the greater involvement of PLHIV in the Stigma Index 2.0 project

Planning and conceptualisation of the study

Representatives of the five organisations that are collectively known as the SANAC PLHIV sector, as well as the LGBTI+, Disability and Sex Worker sectors of SANAC, SANAC, and a representative of the National Department of Health (NDoH), served as members of the Steering Committee. Steering Committee members conceptualised key elements of the research study: advising on how to recruit PLHIV, selecting the sampling methodology, defining the eligibility criteria, and finalising the cultural adaptation of the Stigma Index 2.0. The adaptation of the Stigma Index 2.0 training manual was led by a member of the Steering Committee representing the SANAC PLHIV sector.

Steering Committee meetings were held before the implementation of each phase of the study to ensure ownership of the study. The Steering Committee also guided the research team in the selection of districts. The role of the HSRC was to provide technical support in terms of protocol development and oversee survey implementation by the fieldwork team led by two project managers that represented organisations of the SANAC PLHIV sector.

Members of the Steering Committee, primarily those representing the participating civil society sectors, suggested potential candidates who could be selected as project managers, supervisors, and interviewers. Suitable candidates were encouraged to apply via the HSRC Human Resources process, and those who were shortlisted were interviewed for the aforementioned project staff positions.

Training of Stigma Index 2.0 project staff

Project management staff and interviewers were trained in a five-day workshop (see Appendix 1). Training on the administration of the Stigma Index 2.0 project, using the Stigma Index Training Manual developed by GNP+ and adapted to our local context, was facilitated by a Steering Committee member, and a representative of the PLHIV sector, as well as HSRC researchers working on the project.

Data collection

Participant recruitment was done with the assistance of the five partner organisations in the SANAC PLHIV sector (i.e., NAPWA, TAC, INERELA+ Positive Faith in Action, PWN, and the Positive Action Campaign), as well as the LGBTI+, Disability and Sex Worker sectors of SANAC. These organisations compiled a district-level list of institutions that provide services to PLHIV. This list included networks of people living with HIV, and CBOs or NGOs that provide any kind of support to PLHIV. All the organisations were contacted and invited to introduce the study to their programme beneficiaries. Where needed, project supervisors presented the study to the potential participants. Those who indicated an interest in participating in the study were then taken through the informed consent process, before completing the survey.

Individuals were eligible to participate in the Stigma Index 2.0 project if they were living with HIV, were aged 15 years or older, were accessing services from any one of the purposefully sampled institutions across all six districts, and verbally consented to participate in the study. Study participants were recruited from six districts across the three provinces of the Free State, KwaZulu-Natal, and Mpumalanga. These provinces were selected because the previous Stigma Index implemented in 2014 showed that experienced and internalised stigma was the highest.

The six districts in the study included the following:

- Free State: the Thabo Mofutsanyane and Mangaung district municipalities
- KwaZulu-Natal: the uMgungundlovu district municipality and the eThekweni metropolitan municipality
- Mpumalanga: the Ehlanzeni and Gert Sibande district municipalities.

The districts selected were based on a need to include both urban and rural districts in the study. For each province, one urban and one rural district was purposefully selected. Using purposeful sampling, the five partner organisations in the SANAC PLHIV sector provided the research team with lists of institutions that serve PLHIV. These lists included networks of PLHIV and CBOs or NGOs that provide any kind of support to PLHIV in the selected provinces and districts. With the guidance of the project managers, each district team developed a work plan based on the lists that included initial contact with facilities and/or organisations. This often required brief face-to-face presentations on the study criteria and sharing information with local organisation leads and potential participants – who then indicated their interest to participate in the study – after which dates and venue information for the actual data collection was set.

Data collection took place only after obtaining informed consent/assent. Informed consent/assent was read out to all research participants. The consent statements contained all the information the participants needed to make an informed decision about whether to participate in the survey including all elements of informed consent as required by 45 Code of Federal Regulations (CFR) 46.116; 21 CFR 50.25(a)(b). All consent/assent forms and questionnaires were translated from English into seSotho, siSwati, xiTsonga, isiNdebele, Afrikaans, and isiZulu.

Potential participants were informed of the following:

- a) Participation in the Stigma Index 2.0 is voluntary, and participants may withdraw at any time.
- b) Withdrawal from the study will not affect their access to health services outside of the survey.
- c) Participants were informed that they do not have to answer questions that make them uncomfortable.
- d) Any information that they disclose during the study will be considered confidential (i.e., no personal identifiers will be used in any reports or publications; only aggregate data will be reported).
- e) The potential risks and benefits of the study were also explained to potential participants.
- f) After the consent form was read, potential participants were invited to ask questions about any aspect of the Stigma Index 2.0 study and their participation. If they agreed to participate in the study, participants provided verbal consent indicating that they understood and agreed to all items contained in the consent/assent form.

The Stigma Index 2.0 study was completed at the site of the selected institution, or an appointment was made for the interview to be completed at a time and location most suitable for the participant. Efforts were made to schedule interviews on a day when potential participants attended the selected CBO/NGO. Even though the protocol allowed for virtual interviews through either phone, WhatsApp, Zoom, or similar platforms, each consenting participant in this study was interviewed face-to-face by one of the project interviewers, as this was the preferred approach by the Steering Committee when the COVID-19 lockdown conditions were permitting. All COVID-19 regulations were strictly followed during these interviews.

Data management

Data were collected electronically through the REDCap system using tablets, and paper questionnaires were made available for backup in case there was a fault with the electronic devices or the system. In cases where the information was collected on paper (due to tablet malfunction), the interviewer who collected the data on paper was responsible for capturing the information into the system as soon as a tablet became available or the system was up and running.

The confidentiality of study participants was upheld throughout the data collection process. Tablets were password protected. Once data was uploaded to the HSRC backup system, the data was deleted from tablets to reduce the risk of a confidentiality breach if a tablet was lost or stolen. Data flow was in real-time, and the data manager and analyst assessed the completeness of the questionnaire, the average time it took to complete certain sections, as well as the whole questionnaire. All electronic files were backed up weekly with daily incremental backups.

As part of quality control processes, data validation tools were built into the tablet data collection system to minimise data entry errors and encourage proper form completion. These included restrictions on the type of data that was entered, such as predefined values (code sets) for categorical data, range restrictions for numeric data, and logic checks. Some key data entry fields were flagged as compulsory fields to ensure completeness, and skip patterns were used to prevent erroneous data entry and encourage proper survey completion. Error messages and caution notices were triggered when survey staff entered faulty data so that they were aware and were able to correct the problem.

Supervisors used tracking sheets to record the total number of interviews conducted daily by interviewers. They also verified that information captured in the REDCap system correlated with the information from the tracking sheets. Inconsistencies (missing demographics or incomplete records of interviews having no information but incorrectly submitted to REDCap) were reported to the data manager who ensured that missing information was corrected, and incorrect/incomplete records were removed. When the weekly analysis was performed, the manager also ensured that there was a correlation between information in the tracking sheets and interview records in REDCap.

The REDCap-SQL data management system was used and the HSRC hosted the server to store the data. The data was stored in the REDCap database. A routine and adequate backup was provided to the electronically stored data using the HSRC backup system. Records in the dataset did not contain any personally identifiable information. Thus, records in the dataset were linked through a uniquely generated identification number. Access to the data was limited to authorised personnel, and each user of the system had an individual account.

Measures

Key indicators of stigma used in this report are outlined in detail in the questionnaire domains of the Stigma Index 2.0. These include disclosure, the experience of stigma and discrimination, internalised stigma, resilience, and experiences of TB-related stigma, COVID-19 stigma, cyberbullying, interaction with healthcare facilities, and human rights and effecting change.

Experience of stigma and discrimination (11 items):

- Have you ever been excluded from (a) social gatherings or activities, (b) religious activities or places of worship, and (c) family activities because of your HIV status?
- Have you ever been aware of (d) family members, (e) other people (other than family members) making discriminatory remarks or gossiping about you because of your HIV status?
- Has someone ever (f) verbally harassed you, (g) blackmailed you, (h) physically harassed (or hurt you) because of your HIV status?
- Have you ever been (i) refused employment or lost a source of income or job because of your HIV status?
- Has (j) 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?
- Has (k) your wife/husband, partner(s), or child(ren) ever experienced discrimination because of your HIV status?

One response for each question. (Yes, within the last 12 months=1, Yes, but not in the last 12 months=2, No=3, N/A =4).

Internalised stigma (6 items):

- Please tell me if, in general, you agree or disagree with the following statements (a) It is difficult to tell people that I am HIV positive, (b) Being HIV positive makes me feel dirty, (c) I feel guilty that I am HIV positive, (d) I am ashamed that I am HIV positive, (e) I sometimes feel worthless because I am HIV positive (f) I hide my HIV status from others.

(Agree/Yes=1 or Disagree/No=2)

PLHIV Resilience Scale(10 items):

- Please answer whether your ability to meet your needs in the last 12 months has been positively affected, not affected, or negatively affected by your HIV status: (a) my self-confidence, (b) my self-respect, (c) my ability to respect others, (d) my ability to cope with stress, (e) my ability to have close and secure relationships with others, (f) my ability to find love, (g) my desire to have children, (h) my ability to achieve personal and/or professional goals, (i) my ability to contribute to my community, (j) my ability to practice a religion/faith as I want to over the past 12 months has been positively affected=1, not affected=2, or negatively affected=3 by your HIV status.

Select one response for each item.

Experience of TB-related stigma (4 items):

- Since you fell sick with TB, have you (a) been teased, insulted, or sworn at, (b) been gossiped about, (c) felt unclean or dirty because of your TB, (d) told anyone outside your household about your TB diagnosis?

(Yes=1 or No=2)

COVID-19 stigma (9 items):

If you indicated that you were personally diagnosed with COVID-19: Thinking of the time that you were diagnosed with COVID-19, did any of the following happen?

- Became (a) aware of family members making discriminatory remarks or gossiping about you because of your COVID-19 status, (b) became aware of other people (other than family members) making discriminatory remarks or gossiping about you because of your COVID-19 status, (c) being verbally harassed (e.g., yelled at, scolded at, or otherwise verbally abused) because of your COVID-19 status, (d) being physically harassed or hurt (e.g., pushed, hit, or otherwise physically abused) because of your COVID-19 status, (e) lost a source of income or job because of your COVID-19 status or you were diagnosed with COVID-19, (f) your wife/husband, partner(s) or child(ren), and other family members have experienced discrimination because of your COVID-19 status, (g) a healthcare facility denied you care because of your COVID-19 status (includes healthcare worker leaving you unattended or refusing to attend to you), (h) experienced discrimination from healthcare workers because of your COVID-19 status, (i) when seeking healthcare, you were treated worse compared to other patients because of your HIV status that was coupled with the COVID-19 diagnosis.

Select one response for each item. (Yes=1, No=2, N/A=3)

Cyberbullying (11 items):

- Someone (a) threatened to disclose my HIV status online, (b) someone disclosed my HIV status online, (c) have been cyberbullied, (d) someone posted mean or hurtful comments about me online, (e) someone posted a mean or hurtful picture of me online, (f) someone posted a mean or hurtful video of me online, (g) someone created a mean or hurtful web page about me, (h) someone spread rumours about me online, (i) someone threatened to hurt me through a cell phone text message, (j) someone threatened to hurt me online, (k) someone pretended to be me online and acted in a way that was mean or hurtful.

Select one response for each item. (Yes=1, No=2, N/A=3)

Interaction with healthcare facilities (5 items):

This measure focused on the sexual and reproductive health domain based on the following question: In the last 12 months, has a healthcare professional done any of the following solely because of your HIV status (a) advised you not to mother/father a child, (b) pressured or incentivised you to get sterilised, (c) sterilised you without your knowledge or consent, (d) denied you contraception/family planning services, (e) told you that you had to use (a specific method of) contraception to get your HIV antiretroviral treatment?

Select one response for each item. (Yes=1, No=2, N/A=3, Prefer not to answer=4)

Human rights and effecting change (3 items):

- Do you know if there are any laws in South Africa to protect people living with HIV from discrimination?

Yes, there are laws=1, No, there are no laws=2, I don't know if there are laws=3.

- Do you know of any organisations or groups that you can go to for help if you experience stigma or discrimination?

Yes, I know of organisations or groups that I can go to for help if I experience stigma or discrimination=1, No, there are no organisations or groups that I know of that can help me if I experience stigma or discrimination=2.

- Do you know of any national HIV anti-stigma campaign that was launched in the last 12 months?

Yes, I know of a national HIV anti-stigma campaign that was launched in the last 12 months=1, No, I do not know of any national HIV anti-stigma campaign that was launched in the last 12 months=2, No, I have never heard of any national HIV anti-stigma campaign=3.

Data analysis

All data were analysed using Stata Statistical Software version 15.0 (College Station, TX: StataCorp). Descriptive statistics (frequencies and percentages) and crosstabulations of demographic characteristics (sex, age, and district) were used to summarise key measures of disclosure, experienced stigma and internalised stigma including measures of TB-related stigma, COVID-19 stigma, cyberbullying, interaction with healthcare facilities for sexual and reproductive health, as well as human rights and effecting change. Microsoft Excel 2016 was used to visually display summary tables and figures.

Ethical considerations

The protocol and research instruments together with consent forms were submitted to the HSRC Research Ethics Committee (REC), the Provincial RECs in the provinces of KwaZulu-Natal, Mpumalanga, and the Free State through the National Health Research Database (NHRD), the US CDC's Division of Global HIV and TB, and Centre for Global Health for ethical review before implementation of the survey. This project was reviewed following CDC human research protection procedures, but CDC investigators did not interact with human subjects, nor did they have access to identifiable data or specimens for research purposes.

Participation of minors

PLHIV, especially minors, might not have disclosed their status to anyone else including parents/guardians except people in their support groups. Hence, in our study, the minor (between the ages of 15 and 17 years old) decided whether to participate and thus assent (i.e., express their will), and we did not seek any verbal consent from their parents/guardians. This decision was supported by the following:

- Section 129(2) of the Children's Act stipulates that "a child can consent to medical treatment, without the consent of his/her parent or caregiver, at the age of 12 years and if the child possesses the maturity and mental capacity to understand the benefits, risks, social and other implications of the treatment".
- Section 10 of the same Act, states that "every child that is of such an age, maturity and stage of development that they can participate in decision-making is entitled to express their view regarding such a decision and these views must be given due consideration".
- Section 14(1) of the National Health Act states that: "all information concerning a service user, including information related to health status, treatment or stay at an establishment is confidential".

Study findings

SECTION 1: Description of sample who took part in the study

Of the PLHIV who were approached to take part in the study, 93.7% agreed to participate. Altogether, a final sample of 3 716 participants self-reported as living with HIV, 73.4% ($n=2\ 677$) were female, and 26.6% ($n=972$) were male. Participants were almost equally distributed across the six study districts (see Table 1).

Table 1: Sample distribution: The Stigma Index 2.0 in Six Districts of South Africa 2020–2021 (n=3 716)

Provinces	Districts	<i>n</i>	%
KwaZulu-Natal	eThekweni	675	18.2
	uMgungundlovu	583	15.7
Free State	Mangaung	606	16.3
	Thabo Mofutsanyane	611	16.4
Mpumalanga	Ehlanzeni	596	16.0
	Gert Sibande	645	17.4

Age and race

Table 2 shows the age distribution of study participants. A higher proportion of study participants were aged 30–34 years at 15.4% followed by those 50 years and older at 14.8%. Fewer participants were aged 20–24 years at 9.5%, and 15–19 years at 8.3%. Almost all the participants were ‘black’ African (98.5%).

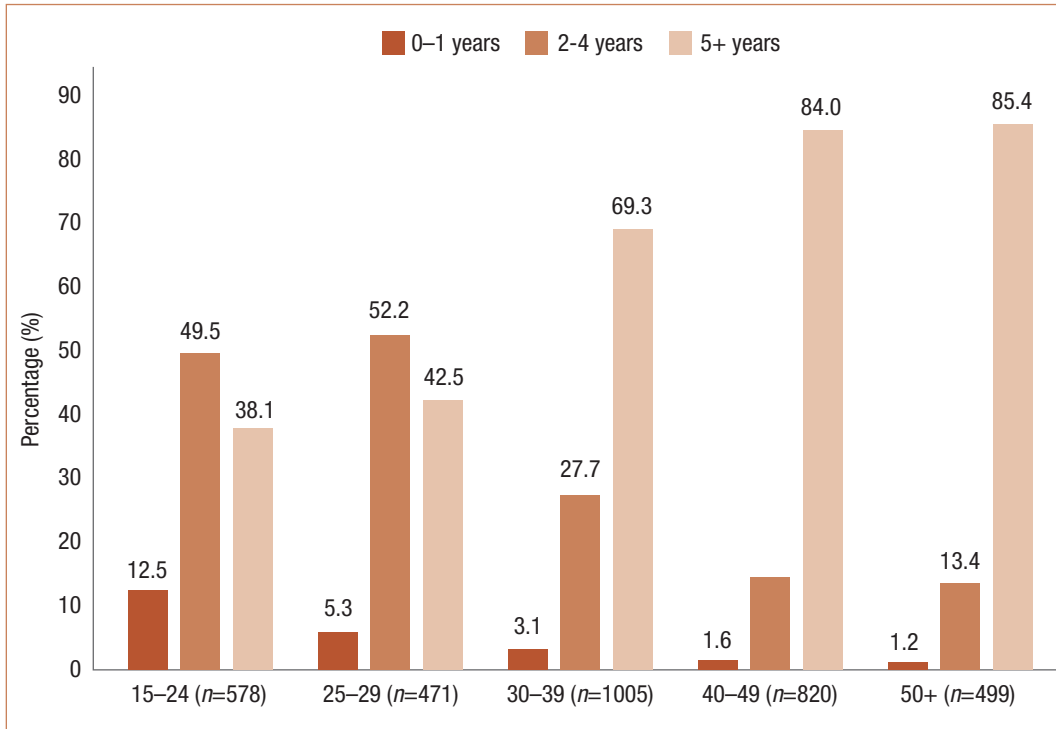
Table 2. Age distribution: The Stigma Index 2.0 in Six Districts of South Africa 2020–2021 (n=3 716)

Age groups (years)	<i>n</i>	%
15–19	310	8.3
20–24	351	9.5
25–29	520	14.0
30–34	572	15.4
35–39	533	14.3
40–44	509	13.7
45–49	372	10.0
50+	549	14.8

Years living with HIV by age

The majority of those aged 50 years and older (85.4%), followed by those aged 40–49 years (84.0%), and those 30–39 years (69.3%), reported living with HIV for five years and more. Almost half of those aged 15–24 years (49.5%) and 25–29 years (52.2%) reported living with HIV for 2–4 years. (see Figure 1).

Figure 1. Length of time living with HIV by age: The Stigma Index 2.0 in Six Districts of South Africa 2020–2021



Being on ART, treatment interruptions, and self-reported viral load

Of those who reported having ever received ART, 99.6% (3 406/3 421) were currently receiving ART. Almost ninety percent (85.6%) (2 929/3 422) reported that they have never stopped or interrupted taking ART. Nearly two-thirds (63.3%) (2 118/3 347) reported having an undetectable viral load from their most recent viral load test in the last 12 months.

Relationship status

Two-thirds (67.2%) (2 483/3 697) of the participants reported that they were currently in an intimate/sexual relationship. Of those who were in any type of relationship, 61.5% (1 530/2 488) indicated that their partner was also HIV positive.

Education

Of 3 712 participants, 69.6% reported that they had completed secondary school, while 12.6% completed primary school, and 5.7% had no formal education. Only 8.4% completed university/tertiary level education, and 3.7% had completed trade/vocational school.

Employment status

Just over half (52.0%) of the participants were unemployed, 25.0% reported being either full-time or part-time employed, 12.1% reported being currently a student, and 4.0% reported doing casual or informal part-time work (self-employed or paid work for others). Only 3.0% reported being self-employed full-time (business owner, etc.).

Key populations

Among males who responded to the question on identity ($n=611$), 11.5% identified as gay/homosexual men, and 4.4% reported having sex with other men. Among females ($n=1 293$), 2.6% identified as lesbian or gay, and 0.6% identified as bisexual. Participants were also asked if they were transgender and of 3 656 respondents, 2.1% identified as transgender whilst 0.7% identified as neither female nor male (i.e., non-binary) or transgender.

Of 3 410 participants who responded to the question on transactional sex, 14.0% reported that they had sex in exchange for money or goods, and 7.2% identified as sex workers.

On self-reported disability, only 9.9% of 3 698 respondents reported having a disability of any kind, including vision, hearing, or mobility. Participants were also asked about imprisonment and 4.0% of 3 671 reported a history of incarceration.

Basic needs (food, shelter, and clothing)

Participants ($n=3 665$) were asked if they were able to meet basic needs (e.g., food, shelter, or clothing) in the last 12 months. Half (50.6%) of the participants reported never having gone without basic needs in the last 12 months, while 41.0% reported that they had sometimes gone without basic needs in the last 12 months, and 8.0% reported that they had gone without basic needs most of the time in the last 12 months.

SECTION 2: Experiences of stigma and discrimination from other people

Experiences of external stigma

Table 2.1 shows that overall, 15.4% of participants reported experiences of stigma. Reported experiences of stigma was higher among females than males, and among those aged 25–29 than 15–24 years. Proportionally, a higher number of participants from the eThekweni district reported experiencing stigma when compared to other districts.

Table 2.1: Experiences of stigma by socio-demographic characteristics

Socio-demographic characteristic	No experiences of external stigma		Experienced external stigma		Total
	<i>n</i>	%	<i>n</i>	%	
Total	3 057	84.6	557	15.4	3 614
Sex of respondent					
Male	819	86.3	130	13.7	949
Female	2 192	84.1	415	15.9	2 607
Age groups (years)					
15–24	560	90.5	59	9.5	619
25–29	411	80.6	99	19.4	510
30–39	899	82.7	188	17.3	1 087
40–49	725	84.3	135	15.7	860
50+	462	85.9	76	14.1	538
Districts					
eThekweni	482	72.6	182	27.4	664
uMgungundlovu	505	87.4	73	12.6	578
Mangaung	500	85.0	88	15.0	588
Thabo Mofutsanyane	546	90.0	61	10.0	607
Ehlanzeni	494	85.9	81	14.1	575
Gert Sibande	530	88.0	72	12.0	602

Table 2.2 shows that 5.3% of participants reported being excluded from social gatherings, 9.5% reported that family members made discriminatory remarks toward them regarding their HIV-positive status, and 9.9% reported that other people made discriminatory remarks towards them regarding their HIV-positive status. Regarding employment, 1.2% were refused employment as a result of their HIV-positive status, whilst 0.9% had their job description or nature of job changed as a result of their HIV status.

Table 2.2: Experiences of stigma and discrimination involving social situations

Social situation	Yes, n (%)	No n (%)	N/A n (%)	Total
Excluded from religious activities	134 (3.7)	3 450 (94.1)	81 (2.2)	3 665
Excluded from social gatherings	194 (5.3)	3 404 (93.9)	65 (1.8)	3 663
Excluded from family activities	195 (5.4)	3 397 (92.8)	67 (1.8)	3 659
Family making discriminatory remarks	347 (9.5)	3 242 (88.7)	66 (1.8)	3 655
Other people making discriminatory remarks	360 (9.9)	3 219 (88.3)	66 (1.8)	3 645
Verbal harassment	196 (5.4)	3 381 (92.9)	63 (1.7)	3 640
Blackmail	72 (2.0)	3 500 (96.1)	70 (1.9)	3 642
Physical harassment or hurt you	80 (2.2)	3 476 (95.8)	73 (2.0)	3 629
Refused employment or lost a source of income	43 (1.2)	3 458 (95.5)	120 (3.3)	3 621
Job description or the nature of the job has been changed	32 (0.9)	3 410 (94.5)	165 (4.6)	3 607
Wife/husband or partner or children experienced discrimination because of your HIV status	63 (2.8)	3 411 (94.8)	124 (3.4)	3 598

N/A – not applicable

SECTION 3: Disclosure

Table 3.1 shows that 62.8% of participants reported that disclosing their HIV status to people to whom they are close has been a positive experience. A similar proportion (61.9%) also reported that people with whom they are close were supportive when they first learned about the participant's HIV status. Nearly half (45.9%) of the participants reported a positive experience after disclosing their HIV status to people whom they do not know very well. Similarly, 45.2% of participants reported that people whom they do not know very well were supportive when they first learned about the participant's HIV status. Over half (57.5%) reported that disclosing their HIV status has become easier over time.

Table 3.1: Experiences of disclosing the HIV status among people living with HIV

Disclosure	Agree n (%)	Somewhat agree n (%)	Disagree n (%)	N/A n (%)	Total
Disclosing your HIV status to people you are close to has been a positive experience.	2 283 (62.8)	674 (18.6)	601 (6.5)	75 (2.1)	3 633
People you are close to were supportive when they first learned about your HIV status.	2 250 (61.9)	723 (19.9)	576 (15.8)	86 (2.4)	3 635
Disclosing your HIV status to people you do not know very well has been a positive experience.	1 666 (45.9)	750 (20.6)	974 (26.8)	242 (6.7)	3 632
People you do not know very well were supportive when they first learned about your HIV status.	1 643 (45.2)	760 (20.9)	962 (26.5)	268 (7.4)	3 633
Disclosing your HIV status has become easier over time.	2 086 (57.5)	620 (17.1)	833 (23.0)	86 (2.4)	3 625

N/A – not applicable

SECTION 4: Internalised stigma and resilience

Table 4.1 shows that overall, 49.7% of participants endorsed measures of internalised stigma. Endorsement of internalised stigma was higher among males than females, and among participants aged 15–24 than those aged >25 years. Compared with those from other districts, proportionally more participants from the eThekweni district, and proportionally fewer participants from the uMgungundlovu district, endorsed measures of internalised stigma.

Table 4.1: Reported endorsement of internalised stigma by socio-demographic characteristics

Socio-demographic characteristics	Did not Endorse internalised stigma		Endorsed internalised stigma		Total
	<i>n</i>	%	<i>n</i>	%	
Total	1 844	50.3	1 824	49.7	3 668
Sex of respondent					
Male	454	47.1	509	52.9	963
Female	1 366	51.7	1 278	48.3	2 644
Age groups (years)					
15–24	235	35.9	420	64.1	655
25–29	212	41.2	302	58.8	514
30–39	536	49.0	557	51.0	1 093
40–49	521	60.2	345	39.8	866
50+	340	63.0	200	37.0	540
Districts					
eThekweni	148	22.2	519	77.8	667
uMgungundlovu	399	68.8	181	31.2	580
Mangaung	385	65.4	204	34.6	589
Thabo Mofutsanyane	253	41.7	354	58.3	607
Ehlanzeni	390	66.2	199	33.8	589
Gert Sibande	269	42.3	367	57.7	636

Table 4.1.1 shows that among people with disabilities, 43.5% endorsed measures of internalised stigma. The endorsement was 77.5% among participants who reported a history of incarceration. Endorsement of internalised stigma was higher among males who identified as bisexual (27.3%), followed by males who reported having sex with other men (51.9%), and participants who identified as sex workers (65.5%).

Table 4.1.1: Endorsement of internalised stigma among marginalised and key populations

	Did not endorse internalised stigma		Endorsed internalised stigma		Total
	<i>n</i>	%	<i>n</i>	%	
Marginalised groups					
People with disabilities	204	56.5	157	43.5	361
Participants who reported a history of incarceration	20	22.5	69	77.5	89
Key populations					
Males who reported having sex with other men in the last 12 months	13	48.1	14	51.9	27
Males who identified as bisexual	8	72.7	3	27.3	11
Participants who identified as sex workers	119	75.8	127	65.5	246

Table 4.1.2 shows participants' endorsement of specific measures of internalised stigma in the last 12 months. While less than 20.0% of participants reported experiences of internalised stigma, 40.9% reported that it was difficult to tell people that they are HIV positive.

Table 4.1.2: Reported experiences of internalised stigma

Items	Agree/Yes <i>n</i> (%)	Disagree/No <i>n</i> (%)	Total
It is difficult to tell people that I am HIV positive	1 497 (40.9)	2 166 (59.1)	3 663
Being HIV-positive makes me feel dirty	441 (12.0)	3 223 (88.0)	3 664
I feel guilty that I am HIV positive	677 (18.5)	2 987 (81.5)	3 664
I am ashamed that I am HIV positive	605 (16.6)	3 047 (83.4)	3 652
I sometimes feel worthless because I am HIV positive	506 (13.9)	3 144 (86.1)	3 650
I hide my HIV status from others	1 034 (28.4)	2 603 (71.6)	3 637

Table 4.2: Reported resilience among people living with HIV in the last 12 months

Items	Has been positively affected by HIV status <i>n</i> (%)	Has been negatively affected by HIV status <i>n</i> (%)	Has not been affected by HIV status <i>n</i> (%)	N/A <i>n</i> (%)	Total
Self-confidence	600 (16.4)	591 (16.2)	2 428 (66.4)	40 (1.1)	3 659
Self-respect	584 (15.9)	378 (10.3)	2 661 (72.7)	39 (1.1)	3 662
Ability to respect others	567 (15.5)	201 (5.5)	2 855 (78.0)	36 (1.0)	3 659
Ability to cope with stress	553 (15.1)	448 (12.2)	2 610 (71.4)	47 (1.3)	3 658
Ability to have close and secure relationships with others	491 (13.4)	332 (9.1)	2 754 (75.3)	82 (2.2)	3 659
Ability to find love	474 (13.0)	339 (9.3)	2 708 (74.3)	126 (3.5)	3 647
Desire to have children	422 (11.6)	370 (10.2)	2 637 (72.5)	208 (5.7)	3 637
Ability to achieve personal and/or professional goals	452 (12.5)	229 (6.3)	2 852 (78.7)	91 (2.5)	3 624
Ability to contribute to my community	450 (12.4)	194 (5.4)	2 847 (78.6)	130 (3.6)	3 621
Ability to practice a religion/faith as I want to	447 (12.4)	184 (5.1)	2 880 (79.9)	95 (2.6)	3 606

N/A – not applicable

Table 4.2.1 shows the mean composite score of each of the PLHIV resilience scale items. The items were coded as (-1= negatively affected; 0 = not affected; 1=positively affected). Mean scores less than zero show more negatively affected than positively. Females had higher individual mean scores compared to males. Study participants aged 40-49 years had a higher resilience mean score while those aged 15-24 years had the lowest. Lower levels of resilience were reported by study participants in the Ehlanzeni district, while the highest levels were reported by participants in the Gert Sibande district.

Table 4.2.1: Reported resilience among people living with HIV in the last 12 months by socio-demographic characteristics

Socio-demographic characteristics	<i>n</i>	Mean*	SD
Total	3 638	0.5	4.2
Sex of respondent			
Male	955	0.3	4.1
Female	2 625	0.6	4.2
Age groups (years)			
15-24	640	0.1	4.6
25-29	513	0.5	4.3
30-39	1 089	0.6	4.1
40-49	862	0.8	4.2
50+	534	0.4	3.6
Districts			
Mangaung	589	-0.4	3.4
Thabo Mofutsanya	607	-0.1	2.3
eThekwini	655	1.1	4.9
uMgungundlovu	578	-0.3	2.5
Ehlanzeni	583	-1.1	3.6
Gert Sibande	626	3.7	5.3

**Based on the PLHIV resilience 10 item scale coded as (-1=negatively affected; 0=not affected; 1=positively affected) and used to calculate a composite resilience mean score*

Table 4.2.2 shows the mean resilience composite score for marginalised and key populations living with HIV. Participants who identified as sex workers reported higher levels of resilience, while males who reported having sex with other men had lower resilience levels.

Table 4.2.2: Reported experiences of resilience among marginalised and key populations living with HIV in the last 12 months

Socio-demographic characteristics	<i>n</i>	Mean*	SD
Marginalised groups			
People with disabilities	358	0.2	4.5
Participants who reported a history of incarceration	89	0.2	5.0
Key populations			
Males who reported having sex with other men in the last 12 months	26	-0.5	2.0
Males who identified as bisexual	2	0.0	0.0
Participants who identified as sex workers	245	0.9	5.5

**Based on the PLHIV resilience 10 item scale coded as (-1=negatively affected; 0=not affected; 1=positively affected) and used to calculate a composite resilience mean score*

SECTION 5: Experiences of TB-related stigma

Table 5.1 shows that overall, 46.1% of participants reported experiences of TB-related stigma. Reported TB-related stigma was higher among males than females, and among participants aged 25–29 years than those in other age groups. Proportionally more participants from the Mofutsanyane district, followed by residents of the eThekweni district, reported experiences of TB-related stigma. Compared with all other districts, proportionally fewer participants from the uMgungundlovu district reported experiences of TB-related stigma.

Table 5.1: Experiences of TB-related stigma in the last 12 months by socio-demographic characteristics

Socio-demographic characteristics	No experiences of TB-related stigma		Experienced TB-related stigma		Total
	<i>n</i>	%	<i>n</i>	%	
Total	261	53.9	223	46.1	484
Sex of respondent					
Male	78	50.0	78	50.0	156
Female	177	56.0	139	44.0	316
Age groups (years)					
15–24	34	63.0	20	37.0	54
25–29	14	43.8	18	56.3	32
30–39	74	58.3	53	41.7	127
40–49	81	49.4	83	50.6	164
50+	58	54.2	49	45.8	107
Districts					
eThekweni	43	43.4	56	56.6	99
uMgungundlovu	46	74.2	16	25.8	62
Mangaung	61	60.4	40	39.6	101
Thabo Mofutsanyane	32	36.8	55	63.2	87
Ehlanzeni	25	54.3	21	45.7	46

Table 5.2 shows that of 482 participants who reported having been diagnosed with TB, 37.8% disclosed their TB diagnosis to people outside their household, 19.8% reported being teased, insulted or sworn at because of their TB status, 25.3% reported being gossiped about because of their TB status, and 14.6% reported feelings of uncleanness or feeling dirty because of their TB status.

Table 5.2: Experiences of TB-related stigma among people living with HIV

Items	Yes	No	Total
	<i>n</i> (%)	<i>n</i> (%)	
Have you been diagnosed with TB?	482 (14.3)	2 895 (85.7)	3 377
Since you fell sick with TB, have you been teased, insulted, or sworn at?	95 (19.8)	385 (80.2)	480
Since you fell sick with TB, have you been gossiped about?	121 (25.3)	358 (74.7)	479
Since you were diagnosed with TB, have you felt unclean or dirty because of your TB status?	70 (14.6)	410 (85.4)	480
Have you told anyone outside of your household about your TB diagnosis?	181 (37.8)	298 (62.2)	479

SECTION 6: COVID-19 stigma

Table 6.1 shows that overall, 50.0% of participants who had ever tested positive for COVID-19 reported that they had experienced COVID-19 stigma. Variation of COVID-19 stigma by sex, age group, and the district is unclear because few participants reported ever testing positive for COVID-19.

Table 6.1: Experiences of COVID-19-related stigma by socio-demographic characteristics

Socio-demographic characteristic	No experiences of COVID-19 stigma		Experienced COVID-19 stigma		Total
	<i>n</i>	%	<i>n</i>	%	<i>n</i>
Total	28	50.0	28	50.0	56
Sex of respondent					
Male	7	50.0	7	50.0	14
Female	20	48.8	21	51.2	41
Age groups (years)					
15–24	0	0.0	3	100.0	3
25–29	1	33.3	2	66.7	3
30–39	7	58.3	5	41.7	12
40–49	14	51.9	13	48.1	27
50+	6	54.5	5	45.5	11
Districts					
eThekweni	12	66.7	6	33.3	18
uMgungundlovu	4	50.0	4	50.0	8
Mangaung	2	20.0	8	80.0	10
Thabo Mofutsanyane	5	55.6	4	44.4	9
Ehlanzeni	3	42.9	4	57.1	7
Gert Sibande	2	50.0	2	50.0	4

Table 6.2 shows that of the participants who have ever been diagnosed with COVID-19, 1.5% reported having been diagnosed and recovered from COVID-19, 26.8% reported being aware that family members made discriminatory remarks or gossiped about their COVID-19 status, 41.1% reported that discriminatory remarks were made about their COVID-19 status.

Table 6.2: Experiences of COVID-19 stigma among PLHIV because of their COVID-19 status

Items	Yes	No	N/A	Total
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Ever been diagnosed with COVID-19?	56 (6.6)	795 (93.4)	–	851
Became aware of family members making discriminatory remarks.	15 (26.8)	41 (73.2)	0	56
Became aware of other people (other than family members) making discriminatory remarks.	23 (41.1)	32 (57.1)	1 (1.8)	56
Being verbally harassed (e.g., yelled at, scolded, or other verbal abuse).	6 (10.7)	50 (89.3)	0	56
Being physically harassed or hurt (e.g., pushed, hit, or other physical abuse).	0	55 (100.0)	0	55
Lost a source of income or job because of your COVID-19 status or because you were diagnosed with COVID-19.	8 (14.3)	46 (82.1)	2 (3.6)	56
Your wife/husband/partner(s) or child(ren) and other family members have experienced discrimination because of your COVID-19 status.	9 (16.1)	43 (76.8)	4 (7.1)	56
A healthcare facility denied you care because of your COVID-19 status.	3 (5.4)	53 (94.6)	0	56
Experienced discrimination from healthcare workers because of your COVID-19 status.	9 (16.1)	47 (83.9)	0	56
When seeking health care, you were treated worse compared to other patients because of your HIV status which was coupled with the COVID-19 diagnosis.	5 (9.1)	50 (90.9)	0	55

Table 6.3, which presents results on stigma experienced due to a diagnosis and recovery from COVID-19, indicates that 41.1% of the participants reported being excluded from social gatherings or activities even though they had recovered from COVID-19. Furthermore, 26.8% reported being excluded from family activities even though they had recovered from COVID-19. In addition, 25% reported they were avoided by family members even though they had recovered from COVID-19. With regards to the stigma experienced outside the family, 38.2% of participants reported being avoided by people outside their family even though they had recovered. In total 14.5% of participants reported losing a source of income or job because of their COVID-19 status.

Table 6.3: Stigma experienced due to diagnosis and recovery from COVID-19

Items	<i>n</i>	%
Thinking of the time that you were diagnosed with COVID-19, did any of the following happen?		
Lost a source of income or job because of your COVID-19 status or because you were diagnosed with COVID-19.		
No	47	85.5
Yes	8	14.5
Thinking of the time since you recovered from COVID-19, did any of the following happen?		
I was excluded from social gatherings or activities (e.g. as per COVID-19 regulations for weddings, funerals and parties) even though I recovered from COVID-19.		
No	33	58.9
Yes	23	41.1
I was excluded from family activities even though I have recovered from COVID-19.		
No	41	73.2
Yes	15	26.8
People outside my family continue to avoid me (do not want to associate with me) even though I have recovered from COVID-19.		
No	34	61.8
Yes	21	38.2
My family members avoid me (meaning they do not want to associate with me) even though I have recovered from COVID-19.		
No	42	75.0
Yes	14	25.0

Section 7: Cyberbullying

Table 7.1 shows that overall, 5.9% of the participants had experienced cyberbullying. Experiences of cyberbullying were higher among participants aged 25–29 years followed by those aged 15–24 years, and least among those 50 years and older. Compared with all other districts, proportionally more participants from eThekweni, and proportionally fewer participants from Thabo Mofutsanyane, had experienced cyberbullying.

Table 7.1: Experiences of cyberbullying related stigma by socio-demographic characteristics

Socio-demographic characteristics	No experience of cyberbullying-related stigma		Experienced cyberbullying-related stigma		Total
	<i>n</i>	%	<i>n</i>	%	
Total	3 413	94.1	214	5.9	3 627
Sex of respondent					
Male	889	93.4	63	6.6	952
Female	2 471	94.5	144	5.5	2 615
Age groups (years)					
15–24	590	90.6	61	9.4	651
25–29	460	89.8	52	10.2	512
30–39	1 015	93.8	67	6.2	1 082
40–49	826	96.8	27	3.2	853
50+	522	98.7	7	1.3	529
Districts					
eThekweni	573	87.5	82	12.5	655
uMgungundlovu	554	95.4	27	4.6	581
Mangaung	546	94.5	32	5.5	578
Thabo Mofutsanyane	593	97.7	14	2.3	607
Ehlanzeni	552	94.5	32	5.5	584
Gert Sibande	595	95.7	27	4.3	622

Table 7.2 shows that of the participants that responded to questions on cyberbullying, 2.4% reported that someone had threatened to disclose their HIV status online, and 3.9% reported that they have been cyberbullied. In addition, 2.2% reported that someone had spread rumours about them online, while 2.4% reported that someone threatened to hurt them using a cell phone text message.

Table 7.2: Experiences of cyberbullying among people living with HIV

Items	Yes	No	Total
	<i>n</i> (%)	<i>n</i> (%)	
Someone threatened to disclose my HIV status.	87 (2.4)	3 536 (97.6)	3 623
Someone disclosed my HIV status online.	55 (1.5)	3 567 (98.5)	3 622
I have been cyberbullied.	140 (3.9)	3 482 (96.1)	3 622
Someone posted mean or hurtful comments about me online.	100 (2.8)	3 517 (97.2)	3 617
Someone posted a mean or hurtful picture of me online.	60 (1.7)	3 557 (98.3)	3 617
Someone posted a mean or hurtful video of me online.	19 (0.5)	3 592 (99.5)	3 611
Someone created a mean or hurtful web page about me.	17 (0.5)	3 583 (99.5)	3 600
Someone spread rumours about me online.	79 (2.2)	3 512 (97.8)	3 591
Someone threatened to hurt me using a cell phone text message.	85 (2.4)	3 496 (97.6)	3 581
Someone threatened to hurt me online.	42 (1.2)	3 534 (98.8)	3 576
Someone pretended to be me online and acted in a way that was mean or hurtful.	26 (0.7)	3 539 (99.3)	3 565

Section 8: Interaction with healthcare facilities

Sexual and reproductive health choices

Table 8.1 shows that overall, 6.4% of participants reported experiences of stigma from a healthcare professional in the last 12 months solely because of their HIV status. The reported experience of stigma from a healthcare professional was higher among females compared to males, and among participants aged 25–49 than those aged ≥ 50 years. Compared with participants from other districts, a higher proportion of participants from Gert Sibande, uMgungundlovu, and eThekwini districts reported experiences of stigma from healthcare professionals.

Table 8.1: Experiences of stigma from a healthcare professional because of HIV status in the last 12 months

Socio-demographic characteristics	No experiences of stigma from a healthcare professional		Experienced stigma from a healthcare professional		Total
	<i>n</i>	%	<i>n</i>	%	
Total	2 853	93.6	196	6.4	3 049
Sex of respondent					
Male	729	98.5	11	1.5	740
Female	2 088	92.2	177	7.8	2 265
Age groups (years)					
15–24	482	95.8	21	4.2	503
25–29	415	93.0	31	7.0	446
30–39	887	92.0	77	8.0	964
40–49	694	93.0	52	7.0	746
50+	375	96.2	15	3.8	390
Districts					
eThekwini	548	90.9	55	9.1	603
uMgungundlovu	420	89.9	47	10.1	467
Mangaung	405	96.9	13	3.1	418
Thabo Mofutsanyane	590	98.3	10	1.7	600
Ehlanzeni	465	98.7	6	1.3	471
Gert Sibande	425	86.7	65	13.3	490

Table 8.2 shows reported stigmatising advice received from healthcare professionals in the last 12 months because of their HIV status. Few (1.3%) participants reported being incentivised to get sterilised or being denied contraception/family planning services.

Table 8.2: Advice given by healthcare professionals because of HIV status for males and females living with HIV in the last 12 months

Items	Yes	No	Prefer not to answer	N/A	Total
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	
Advised you not to mother/father a child.	148 (4.2)	2 850 (81.1)	67 (1.9)	451 (12.8)	3 516
Incentivised you to get sterilised.	46 (1.3)	2 894 (82.2)	78 (2.2)	503 (14.3)	3 521
Sterilised you without your knowledge or consent.	6 (0.2)	2 922 (83.1)	76 (2.2)	511 (14.5)	3 515
Denied you contraception/family planning services.	19 (0.5)	2 913 (82.9)	71 (2.0)	512 (14.6)	3 515
Told you that you had to use (a specific method of) contraception to get antiretrovirals.	45 (1.3)	2 882 (82.2)	72 (2.1)	505 (14.4)	3 504

N/A – not applicable

Table 8.3 shows perceived pressure received from healthcare professionals to female participants in the last 12 months because of their HIV status. Few participants (2.8–2.9%) reported feeling pressured to use a specific type of contraceptive method or to use particular infant feeding practices.

Table 8.3: Pressure by healthcare professionals on women living with HIV accessing healthcare in the last 12 months

Items	Yes	No	Prefer not to answer	N/A	Total
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Advised you to terminate a pregnancy.	49 (2.0)	2 161 (86.3)	26 (1.0)	267 (10.7)	2 503
Pressured you to use a specific type of contraceptive method.	73 (2.9)	2 174 (86.6)	23 (0.9)	241 (9.6)	2 511
Pressured you to use a particular method of giving birth/delivery option.	49 (2.0)	2 183 (87.3)	24 (1.0)	246 (9.8)	2 502
Pressured you to use particular infant feeding practices because of HIV status.	71 (2.8)	2 162 (86.5)	24 (1.0)	243 (9.7)	2 500
Please change to: Pressured you to take HIV (antiretroviral) treatment during pregnancy.	67 (2.7)	2 155 (86.6)	23 (0.9)	243 (9.8)	2 488

N/A – not applicable

In addition, less than one percent (0.6%) of 2 932 participants reported that they obtained ART conditional on the use of certain contraceptives because of their HIV-positive status.

Confidentiality of medical records

Table 8.4 shows that 74.4% of participants believed that their medical records were kept confidential and would not be shared without their written consent, 8% believed that their medical records were not kept confidential, and 18% did not know if their medical records were kept confidential.

Table 8.4: Confidentiality of medical records relating to HIV status

Confidentiality of records	<i>n</i>	%
I am sure that my medical records will be kept confidential and will not be shared without my written informed consent.	2 652	74.4
I don't know if my medical records are kept confidential.	628	17.6
It is clear to me that my medical records are not being kept confidential.	285	8.0

Access to healthcare during the COVID-19 pandemic

Almost one-third (29.9%) of 3 574 participants reported that they needed a healthcare provider due to illness or injury since the start of the COVID-19 pandemic. About a quarter (23.1%) of 3 575 participants reported that the pandemic affected their ability to access a healthcare facility, and 13.1% of 3 359 participants reported that they were unable to obtain their medication (i.e., ART or any other medications) because of the COVID-19 pandemic.

SECTION 9: Human rights and effecting change

Knowledge of laws in South Africa protecting PLHIV from discrimination

Table 9.1 shows that 54.1% of participants reported being aware of laws that protect PLHIV from discrimination. Of these, 10.8% reported that there were no laws that protect PLHIV from discrimination.

Table 9.1 Knowledge of any laws in South Africa to protect people living with HIV from discrimination

Knowledge of laws	<i>n</i>	%
Yes, there are laws.	1 955	54.1
No, there are no laws.	390	10.8
I don't know if there are laws.	1 268	35.1

Knowledge of organisations or groups protecting PLHIV from discrimination

Table 9.2 shows that more than half (56.0%) of participants reported being aware of organisations or groups that can help PLHIV.

Table 9.2 Knowledge of organisations or groups protecting people living with HIV from discrimination

Knowledge of organisations	<i>n</i>	%
Yes, I know of organisations or groups that you can go to for help if you experience stigma or discrimination.	2 010	56.0
No, there are no organisations or groups that can help me if I experience stigma or discrimination.	1 579	44.0

Effecting change

Table 9.3 shows that of 3 617 participants that responded to the question on effecting change, a third (34.8%) reported that they had challenged or educated someone who engaged in stigma or discrimination against PLHIV. Almost a fourth (38.1%) challenged or educated someone who was engaged in stigma or discriminated against by other PLHIV, and a third (34.8%) provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination.

Almost a third (28.5%) were part of an organisation or educational campaign to address stigma and discrimination against PLHIV.

Less than a quarter (18.9%) of participants reported that they encouraged a community leader to act on issues of stigma and discrimination against PLHIV, while 14.2% reported that they encouraged a government leader or a politician to act on issues of stigma and discrimination against PLHIV, and 11.9% reported to have spoken to the media about issues of stigma and discrimination against PLHIV.

Table 9.3: Effecting change among people who engaged in stigma or discrimination against people living with HIV

Items	Yes	No	Total
	n (%)	n (%)	
Challenged or educated someone who was engaging in stigma or discrimination against you.	1 259 (34.8)	2 358 (65.2)	3 617
Challenged or educated someone who was engaging in stigma or discrimination against other PLHIV.	1 381 (38.1)	2 239 (61.9)	3 620
Provided emotional, financial, or other support to help someone living with HIV deal with stigma and/or discrimination.	1 259 (34.8)	2 361 (65.2)	3 620
Participated in an organisation or educational campaign working to address stigma and discrimination against PLHIV.	1 028 (28.5)	2 584 (71.5)	3 612
Encouraged a community leader to take action about issues of stigma and discrimination against PLHIV.	682 (18.9)	2 926 (81.1)	3 608
Encouraged a government leader or a politician to take action about issues of stigma and discrimination against PLHIV.	510 (14.2)	3 094 (85.8)	3 604
Spoke to the media about issues of stigma and discrimination against PLHIV.	428 (11.9)	3 161 (88.1)	3 589

Key findings

This study addressed levels of stigma and discrimination as experienced by HIV-positive, key, and vulnerable populations. This was the first time that the Stigma Index 2.0 was used to assess levels of stigma and discrimination in South Africa. Overall, this study found evidence of high levels of internalised stigma and low levels of resilience reported among the study population.

Main study findings

The main findings of the study were as follows:

1. **Access to basic needs:** Almost half of the study sample reported sometimes or most of the time going without basic needs in the last 12 months. Given that most participants in the study are currently on ART, this might have dire consequences on the overall health and well-being of those who took part in the study. The NSP highlights that poverty, inequality, inadequate access to education, and poor nutrition increase vulnerability to HIV, TB and STIs, deter individuals from seeking needed services early, and interfere with the ability of individuals to receive services and to adhere to prescribed regimens.
2. **Experienced stigma:** Varied from low to moderate levels across the three provinces and six districts. Experienced stigma ranged from 10–27% across the six districts. In these districts, HIV-related stigma was higher in urban areas compared to rural areas.
3. **Disclosure:** Almost two-thirds (62.8%) of participants reported that disclosure of their HIV status to people to whom they are close has been a positive experience; whilst almost half of the study sample reported that disclosure of their HIV status to people they do not know very well, was a positive experience. Over half (57.5%) of the study sample reported that disclosure of their HIV status became easier over time.
4. **Internalised stigma:** Between 31.2% – 77.8% of participants reported internalised stigma across the six districts. 77.8% of participants reported experiencing internalised stigma in the eThekweni district in KwaZulu-Natal. This is of particular concern given that internalised stigma is associated with lower retention in care and reluctance to access health care when needed. The 15–24-year age group experienced the highest levels of internalised stigma and cyberbullying. Higher levels of internalised stigma were also found for key and vulnerable populations, specifically people who reported previous incarceration and those who identified as sex workers. Bisexual men also had higher levels of internalised stigma than men who reported having sex with other men. Given the levels of internalised stigma among key and vulnerable populations, punitive laws and practices targeting key and vulnerable populations must be taken into consideration because these serve as human rights barriers to effective HIV programming. For example, the Provisions of the Sexual Offences and Related Matters Amendment Act (Act 32 of 2007) indicates that any person who participates in the solicitation of indecent exposure and knowingly living from the proceeds of sex work is guilty of a crime and subject to penalty.²⁰ These laws drive a wide range of violent and abusive practices against them by law enforcement, which contributes to lower uptake of sexual and reproductive health services including HIV care, which in turn increases their risk for HIV treatment interruption.²⁰

5. **Resilience:** Most of the study participants who reported any resilience (i.e. that HIV had positively affected their ability to meet their needs), reported low levels of resilience, suggesting that interventions may be needed to support resiliency among PLHIV.
6. **TB-related stigma:** PLHIV may not have disclosed their TB status due to fears of experiencing stigma and discrimination. Of the 482 participants who reported having been diagnosed with TB, about 20% reported being teased insulted or sworn at whilst 25% reported being gossiped about because of their TB status.
7. **Stigma experiences during interaction with healthcare facilities:** A small proportion of female participants were advised not to have children, were denied contraception/family planning, or were coerced by a healthcare professional to be sterilised.

It is of grave concern that some participants believed that healthcare professionals had breached confidentiality or believed that their records would not be kept completely confidential.

The fear of COVID-19 infection increases social exclusion and stigmatisation.³⁰ In the Stigma Index 2.0 study, equitable access to healthcare in general, access to sexual and reproductive health services, and access to healthcare during the COVID-19 pandemic, were assessed. A very small proportion of the study sample reported experiencing challenges during the COVID-19 pandemic when accessing health care.

According to the UNAIDS (2020) report in May 2020, of the 16 countries included in their review, 10 reported having experienced disruptions of HIV prevention and treatment services.³¹ Moreover, there were multiple reports of PLHIV not having enough ART for a lockdown period of more than 60 days, as well as reports of people having abandoned their HIV treatment due to a lack of food.³²

8. **The ‘Know Your Rights campaigns’** rolled out by SANAC aimed to increase awareness of local and national legislation and rights to enable key and vulnerable groups to challenge civil rights and gender equity violations, particularly discrimination in the healthcare environment. The findings of the Stigma Index 2.0 provide an important indication of the impact of the ‘Know Your Rights campaigns’ in the three provinces included in this study. Results suggest that over half of the study sample were aware of policies protecting PLHIV as well as organisations that provide support to PLHIV. Similarly, 34.8% of the study sample challenged or educated someone who engaged in stigma or discrimination. It should be noted that most participants were recruited from local NGOs and PLHIV support groups. Hence participants of our study sample might have had access to information and knowledge that PLHIV who do not belong to NGOs and support groups might not necessarily have. Thus, in future studies, recruitment should aim to include other PLHIV who do not regularly access NGO services.

Study limitations

In the absence of a national sampling frame for all marginalised groups living with HIV, studies like ours must use a purposive sample. This sampling method has limitations and a major one is that the selection of participants is not a probability one. Chances of bias and difficulties in selecting a truly representative sample are inherent, even though all efforts are made to ensure that the sample is as diverse as possible. The final sample was biased towards PLHIV belonging to support groups. Consequently, the findings are not generalisable to all PLHIV in the country. Therefore, there is a possibility that the study findings do not reflect the experiences of all PLHIV in the country.

While this is a convenient and recommended way of recruiting participants belonging to marginalised groups, not all PLHIV are members of support groups. In addition, there is also no guarantee that the individuals accessing PLHIV support groups represent the whole population of PLHIV.

Another limitation introduced by purposive sampling is that one must select participants who have specific knowledge and belong to the population of interest. In the case of HIV, they have to be living openly with HIV and are known to be approachable to participate in the study. In our case, the participants were a special group in that they were aware of their HIV-positive status, and because of this, were more likely to have accepted their HIV status due to their participation in support group activities, which may increase knowledge of one's rights, promote disclosure, acceptance and positive living. Hence, there is a possibility that such individuals may have different experiences of certain forms of stigma when compared to those who did not attend support groups, have not disclosed their status, or are not living openly with HIV.

A small proportion of the study sample identified themselves as key populations. This considerably limits our understanding of the level of stigma and discrimination experienced by key populations. Future studies should include a specific recruitment strategy to engage members of key population groups and not rely on a general recruitment process.

It is also important to note that most of our participants were receiving ART, and this may have contributed to their experiences of certain forms of stigma. Literature on stigma has shown that people who have certain physical attributes that are devalued by society, can be stigmatised and rejected socially.³³ The advent of ART has reduced the stigma of social rejection of a person living with HIV and contributed to normalising HIV and its social construction as a chronic disease.³⁴

The study was also implemented during the COVID-19 pandemic, and this affected data collection to some extent. Challenges included restricted movements, concerns about staff and participants' safety, fear and risk of infections, and an inability to change the data collection method to an online survey to reduce face-to-face interactions. All these factors may have biased the sample and influenced who agreed to be interviewed for the study.

The study for the first time included COVID-19 questions to measure past diagnosis with COVID-19 and related stigma. At the time of the survey, there were no validated measures and the research team developed measures using previous HIV scales and questions that had been used in other countries. The current measures should be validated in this population before future use. Also, very few participants reported that they had been infected with COVID-19, underscoring the uncertainty in our findings on COVID-19 stigma. Lastly, the study relied on self-reported information. Self-reported declarations may be affected by recall and social desirability biases.

Study implementation lessons

The following implementation and administrative challenges were encountered during the Stigma Index 2.0 study.

Training

- a) A more intensive cultural adaptation of the training and fieldwork manual is needed to allow for translation and adaptation of all training and fieldwork materials before training.
- b) More time should be allocated for project staff to get to know each other in smaller groups during the training. This includes planning field activities as a team.
- c) More time should be allocated to the different sections of the Stigma Index 2.0 – so that field staff can become familiar with the different sections of the tool.
- d) More time should be allocated for interviewers to become familiar with digital data collection during the training.
- e) Training should include more intensive training with project managers and supervisors on managing project funds and other administrative duties.

Implementation

- a) Implementation of the study was conducted in two phases. The first part of the study was implemented in 2020 (November–December). Fieldwork resumed after the December holidays and commenced in early January 2021. This resulted in a break in momentum.
- b) Even though restrictions were lifted to allow face-to-face interviews, the HSRC project staff were not able to travel and support the teams for quality assurance purposes as much as would have been possible pre-COVID-19. COVID-19 restrictions also affected the administrative processes of the HSRC, as the turnaround time was two to three times longer.
- c) Furthermore, the limited presence of researchers onsite also meant that teams were not regularly debriefed, and the lack of mental health support caused some unintended distress for interviewers and supervisors. For future studies making use of the Stigma Index, we recommend that greater effort is put into having regular team debriefing sessions to provide project staff with better coping skills, and where needed, provide further mental health services.

- d) Information Technology (IT) staff capacity to do continuous onsite training across the three participating provinces was lacking/limited.
- e) Stigma Index project staff across the districts were widely dispersed, which resulted in supervisors spending long hours driving.
- f) One of the main challenges was fieldwork logistics, especially for the Free State and Mpumalanga provinces. There were delays in advances (i.e., money used for participant reimbursements, fuel and airtime, etc.) and sleep-outs for travelling, which impacted the planning and implementation of the study.
- g) Delay in obtaining approval from the NDoH to implement the study in public healthcare facilities in the three provinces meant that we were unable to recruit PLHIV from public healthcare facilities in all districts except the eThekweni district in KwaZulu-Natal.
- h) Recruitment of key populations was challenging, and the involvement of the Sex Worker, Disability and LGBTI+ sectors in the Stigma Index 2.0 study was minimal during the implementation of the study.

Capacity development of civil society partners

- a) The Stigma Index is grounded on the GIPA principles that advocate for the rights of PLHIV to actively participate in decision-making processes related to HIV research policy and programming adopted in the country. As such, the Stigma Index 2.0 study found that PLHIV (not only the sector leads but the field staff) should play a greater role in data handling and dissemination.
- b) To this end, the Stigma Index 2.0 study made a special effort to capacitate civil society sector leads, project managers, and supervisors with Policy Brief writing and dissemination skills at a three-day Policy Brief writing workshop. Workshop participants indicated that the skills they acquired during the workshop helped them understand the importance of using empirical data to inform their advocacy agenda.
- c) Nonetheless, future Stigma Index studies should find more innovative ways in which to capacitate civil society partners with various project management, implementation, writing, dissemination, and administrative skills.

During the implementation of the Stigma Index 2.0 study, lessons were learned that might be useful for the future implementation of the Stigma Index study in South Africa. In the first instance, the importance of reaching and maintaining good relationships with activists and leaders of the different SANAC civil society sectors was integral to the success of the study. Maintaining good relationships with these gatekeepers was formally constituted through the establishment of the Steering Committee. Thus, a fully representative Steering Committee was the first step in building rapport and connecting with PLHIV. Through the establishment of meaningful connections with the leaders of the PLHIV SANAC Sector in South Africa, we ensured that the study was conducted within a social justice paradigm. The Steering Committee was not duplicitous in its role; members took meaningful decisions during the study. However, more active participation and commitment from all the civil society partners will greatly improve future Stigma Index study implementation.

Next steps for consideration

Based on the main findings, the following action points should be considered by SANAC:

1. The findings of this study are to be disseminated by SANAC to the Provincial Council on AIDS (PCAs) and provincial departments of health officials in the three provinces of KwaZulu-Natal, Free State, Mpumalanga, as well as at the district level in order to inform the development of tailored stigma mitigation campaigns.
2. Considering that stigma levels were high in the eThekweni district of KwaZulu-Natal, further efforts to address stigma through the implementation of district-specific anti-stigma campaigns may help.
3. Social and economic inequality is seen as a human rights barrier in the NSP's current programmes, and policies could be reviewed that aim to provide social relief to PLHIV.
4. Following the study findings, consideration must be made for developing a specially tailored campaign targeting youth and young adults aged 15–24 years living with HIV. Given that 64% of student participants endorsed measures of internalised stigma, psychological support interventions for this age group should be prioritised. Moreover, psycho-social support to increase resilience and reduce the internalised stigma that is tailored for key and vulnerable populations should also be considered.
5. The quality of healthcare for PLHIV – particularly interactions between healthcare workers and key populations – should be improved through education and training for healthcare staff and in collaboration with networks of PLHIV. Monitoring of human rights-related barriers to HIV services by implementers and key and vulnerable groups themselves should be considered. In addition, we suggest that the National and provincial Departments of Health monitor stigma and discrimination in healthcare facilities (as per the implementation of the Patients' Rights Charter).
6. Lessons learned from the Stigma Index 2.0 project conducted in South Africa could be incorporated into future Stigma Index studies. Specifically, more research is needed to further refine the national understanding of stigma and discrimination among key and vulnerable populations. Moreover, taking into consideration the high burden of HIV/TB co-infection in South Africa, the next Stigma Index 2.0 should consider expanding to issues beyond feelings of dirtiness or uncleanliness with regard to TB measures. For example, did clients experience internalised feelings of shame, isolation from society, and fear of discriminatory practices because of their TB status? More importantly, was there greater stigma experienced by persons with DR-TB, and finally, did TB-related stigma impact a client's willingness to interface with the healthcare system?

Conclusions

In conclusion, low to moderate levels of both HIV- and TB-related experienced stigma were observed in our study population. In addition, low levels of resilience linked to living with HIV were also reported. However, a substantial proportion of participants in the Stigma Index 2.0 project reported experiencing internalised stigma when compared to experienced stigma across the three provinces and districts. Important next steps for consideration made in the Stigma Index 2014 study included the need for interventions and programmes addressing internalised stigma.³ Internalised stigma reduction campaigns or programmes may also help to improve resilience in the three provinces of KwaZulu-Natal, Free State, and Mpumalanga, and improve HIV outcomes.

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ANNEXURE I

#	Name	Surname	Province	District	Position
1	Pamela	Myeni	Durban Office	KZN and Gert Sibande	Project Manager
2	Kagisho	Mile	Pretoria Office	Free State and Ehlanzeni	Project Manager
3	Nthabiseng	Taba	Free State	Mangaung	Supervisor
4	Nontozanele	Ntlakana	Free State	Mangaung	Interviewer
5	Moqebelo	Khumalo	Free State	Mangaung	Interviewer
6	Nompumelelo	Semudi	Free State	Mangaung	Interviewer
7	Dumisani	Ngwenya	Free State	Thabo Mofutsanyane	Supervisor
8	Sibongile	Chaka	Free State	Thabo Mofutsanyane	Interviewer
9	Lebohang	Simela	Free State	Thabo Mofutsanyane	Interviewer
10	Stephen	Litaole	Free State	Thabo Mofutsanyane	Interviewer
11	Pulane	Kutoane	Free State	Thabo Mofutsanyane	Interviewer
12	Nkeletso	Choenyane	Mpumalanga	Ehlanzeni	Supervisor
13	Nokuthula	Mashego	Mpumalanga	Ehlanzeni	Interviewer
14	Bongiwe	Ndlovu	Mpumalanga	Ehlanzeni	Interviewer
15	Nonhlanhla	Khumalo	Mpumalanga	Ehlanzeni	Interviewer
16	Coeth	Sithole	Mpumalanga	Ehlanzeni	Interviewer
17	Nolubabalo	Mkhangazi	Mpumalanga	Ehlanzeni	Interviewer
18	Nomasonto	Hlatshwayo	Mpumalanga	Gert Sibande	Supervisor
19	Maria	Shongwe	Mpumalanga	Gert Sibande	Interviewer
20	Ntombifuthi	Shongwe	Mpumalanga	Gert Sibande	Interviewer
21	Christabel	Mahlaba	Mpumalanga	Gert Sibande	Interviewer
22	Nomusa	Khumalo	Mpumalanga	Gert Sibande	Interviewer
23	Nomkhosi	Sinqaba	Mpumalanga	Gert Sibande	Interviewer
24	Thembelihle	Mtambo	KZN	EThekwini	Supervisor
25	Nondumiso	Mchunu	KZN	EThekwini	Interviewer
26	Ngitheni	Makhathini	KZN	EThekwini	Interviewer
27	Silindile	Zulu	KZN	EThekwini	Interviewer
28	Xolisile	Zwane	KZN	EThekwini	Interviewer
29	Promise	Makhanya	KZN	UMgungundlovu	Supervisor
30	Nokubonga	Zuma	KZN	UMgungundlovu	Interviewer
31	Sibusiso	Buthelezi	KZN	UMgungundlovu	Interviewer
32	Caswell	Mokuoane	KZN	UMgungundlovu	Interviewer
33	Skhumbuzo	Ngcobo	KZN	UMgungundlovu	Interviewer



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