



# **The People Living With HIV Stigma Index: South Africa 2014**

## **SUMMARY REPORT**

**MAY 2015**

**Full report submitted by the Human Sciences Research Council  
(HSRC) to the South African National AIDS Council (SANAC)**



**in collaboration with the SANAC PLHIV Sector**



**Additional funders:**



## TABLE OF CONTENTS

FOREWORD .....	1
PREFACE .....	3
LIST OF CONTRIBUTORS.....	4
ACKNOWLEDGEMENTS.....	5
LIST OF ACRONYMS AND ABBREVIATIONS .....	7
INTRODUCTION .....	9
OVERALL AIM OF THE STUDY .....	10
WHY THIS STUDY WAS DONE .....	10
HOW THE STUDY WAS DONE.....	10
RESULTS .....	11
SECTION 1: WHO TOOK PART IN THE STUDY.....	11
SECTION 2: EXPERIENCES OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE.....	13
SECTION 3: EXPERIENCES OF TB-RELATED STIGMA.....	15
SECTION 4: SEXUAL REPRODUCTIVE HEALTH .....	16
SECTION 5: ACCESS TO WORK, HEALTH AND EDUCATION SERVICES.....	17
SECTION 6: INTERNALIZED STIGMA .....	18
SECTION 7: DISCLOSURE AND CONFIDENTIALITY .....	21
SECTION 8: HIV TESTING AND TREATMENT .....	23
RECOMMENDATIONS .....	25
CONCLUSIONS .....	26

## FOREWORD

Democratic South Africa is founded on the highest ideals of a constitution that accords an equal status to the dignity and rights of all citizens as it does to all of our rights to economic freedom and access to a full and comprehensive package of public services including health, education and social support.

The letter of the Constitution obliges the state to fulfil its multitudinous responsibilities. The spirit of the Constitution enjoins communities, families and individuals to play their part in ensuring that we all live free of prejudice, fear and discrimination.

The HIV epidemic has challenged both state and community when it comes to how we have responded and one of the areas where we have come up short since the start of the epidemic has been the ubiquitous stigma and discrimination that we have seen since the beginning of the epidemic three decades ago.

Thankfully, through the efforts of the Department of Health and SANAC (representing government, NGOs and the private sector), we have seen a major improvement in the overall management of the HIV epidemic. This report shows that similar progress has been made to reduce stigma and discrimination. It also shows that there is still much room for improvement. Only if we are armed with an objective measure of the levels of remaining stigma will we be able to further tackle this problem.

The SANAC Human Rights Technical Task Team which we jointly chair has the oversight role of ensuring all forms of HIV related discrimination as well as stigma is roundly addressed as part of the National Strategic Plan. We are pleased to see this report from the SANAC Secretariat done jointly with the HSRC, Departments of Justice, Social Development and Health, the PLHIV sector and donors so that it truly captures the multi-sectoral approach of SANAC.

THE PEOPLE LIVING WITH HIV STIGMA INDEX: SOUTH AFRICA  
2014

Now that we have a good baseline of information we will be encouraging SANAC to take up the recommendations of the report with a view to embarking on a major national campaign to tackle all forms of stigma and discrimination.

Mr John Jeffery

Deputy Minister of Justice and Correctional Services

Ms Janet Love

Co-Chair of the Human Rights Technical Task Team (TTT), SANAC

## PREFACE

When the National Strategic Plan was being written, activists of the people living with HIV (PLHIV) sector wisely demanded that the reduction of stigma and discrimination becomes one of the five main goals of the HIV response. This report shows that they were right.

South Africa has made good progress in dealing with HIV related stigma and the levels of stigma are relatively low when analysing instances of stigma independently of each other. When composite scores of external and internal scores are analysed the report shows that there is still a moderate level of stigma affecting about one-third of PLHIV who took part in the study.

Unsurprisingly, the report shows that internalized stigma is still a major challenge in South Africa with more than 40% of PLHIV expressing feelings of internalized stigma.

For many years, subjective views have dominated the discourse on the levels of stigma and discrimination in the country. This report provides an objective view that will serve as a baseline for future comparisons.

The report recommends that the South African National AIDS Council (SANAC) needs to work with all partners in government, civil society and the private sector to defeat the epidemic of stigma that remains a constant barrier to successfully winning the war against HIV and TB.

We would like to thank the team of the Human Sciences Research Council (HSRC) that conducted the survey, the PLHIV organisations that played a central role in this study, the SANAC Human Rights Technical Task Team (TTT), the Departments of Justice, Social Development and Health and Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) and the The University of Witwatersrand Reproductive Health and HIV Institute (WRHI) who co-funded this study.

Fareed Abdullah  
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## ACKNOWLEDGEMENTS

This study surveyed PLHIV in 18 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.

First, 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 stigmatization and discrimination. The information provided will assist in advocating for the implementation of stigma mitigation campaigns in South Africa.

The People Living with HIV (PLHIV) Stigma Index was commissioned by the South African National AIDS Council (SANAC) under the leadership of the SANAC's Human Rights Technical Task Team (TTT). No research study can be successfully implemented without financial support and therefore we thank both SANAC and The University of Witwatersrand Reproductive Health and HIV Institute (WRHI). Part of the funding obtained through SANAC was contributed by the Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) while all the funding provided by WRHI was provided to it by the United States President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID).

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We would like to extend our gratitude to the members of the Steering Committee which consisted of the following representatives: Rentia Agenbag (SANAC), Maren Lieberum (GIZ), Mluleki Zazini (The National Association of People Living with HIV and AIDS, NAPWA), Nkhensani Mathabathe and Eric Verscheuren (both from UNAIDS), Rob Hamilton (PATH), Andrew Mosane (Treatment Action Campaign, TAC), Busi Tshabalala (Positive Women's Network, PWN now with the National Education Health and Allied Workers' Union, NEHAWU), Pholokgolo Ramothwala (Positive Convention), Leslie Inso (Network of African People Living with HIV and AIDS, NAPSAR); Pelisa Dana (Eastern Cape

AIDS Council, ECAC) and lastly both Pierre Brouard and Rakgadi Mohlahlane (Centre for the Study of AIDS, University of Pretoria).

We wish to thank the three trainers of the Stigma Index: namely Rob Hamilton, Pholokgolo Ramothwala as well as Busi Tshabalala for a job well done. We would not have been able to complete the study successfully without the daily efforts of the fieldwork staff, hence we would like to acknowledge the - provincial coordinators, supervisors, and interviewers who spent months in the field, often away from their families and loved ones. We would also like to thank the Data Capturing Unit (DCU) in the Research Methodology and Data Centre (RMDC) of the HSRC under the leadership of Mr Joel Makhubela.

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## LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ARV	Antiretroviral treatment
CI	Confidence Interval
CPD	Continuing Professional Development
CSPRO	Census Survey Processing software
DENOSA	Democratic Nursing Organisation of South Africa
DOH	Department of Health
DOJ	Department of Justice
DPSA	Department of Public Service and Administration
ECAC	Eastern Cape AIDS Council
EFA	Exploratory factor analysis
GIPA	Greater Involvement of People Living with HIV and AIDS
GIZ	Deutsche Gesellschaft für Internationale Zusammenarbeit
GNP+	Global Network of People Living with HIV
HAST	HIV, STIs and TB research programme
HCT	HIV Counselling and Testing
HIV	Human immunodeficiency virus
HRC	Human Rights Commission
HSRC	Human Sciences Research Council
ICW	International Community of Women Living with HIV
IDUs	Injecting Drug Users
IPPF	International Planned Parenthood Federation
MSM	Men who have sex with men
NAPSAR	Network of African People Living with HIV and AIDS,
NAPTOSA	National Professional Teacher's Organisation of South Africa
NAPWA	National Association of People Living with HIV and AIDS
NEHAWU	National Education Health and Allied Workers' Union

## THE PEOPLE LIVING WITH HIV STIGMA INDEX: SOUTH AFRICA 2014

NGO	Non-governmental organization
NHI	National Health Insurance
NSP	National Strategic Plan on HIV, STIs and TB
ORs	Odds ratios
PEPFAR	United States President's Emergency Plan for AIDS Relief
PEPUDA	Promotion of Equality and Prevention of Unfair Discrimination Act
PLHIV	People Living with HIV
PWN	Positive Women's Network
REC	Research Ethics Committee
RMDC	Research Methodology and Data Centre
SABCOHA	The SA Business Coalition on HIV
SADTU	South African Democratic Teachers Union
SAMA	South African Medical Association
SANAC	South African National AIDS Council
SAS	Statistical Analysis System
SPSS	Statistical Package for the Social Sciences
SRH	Sexual, Reproductive Health
TAC	Treatment Action Campaign
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV
USAID	United States Agency for International Development
WRHI	Wits Reproductive Health and HIV Institute

## INTRODUCTION

### What is stigma and discrimination

Stigma and discrimination towards people living with HIV (PLHIV) are widely recognized as barriers to prevention, the provision of adequate health care, adequate psychological and social support, and appropriate medical treatments in South Africa. Stigma refers to the process of devaluing or discrediting individuals in the eyes of others.

Different types of stigma have been identified, such as: external stigma; internalized stigma; anticipated stigma and “courtesy stigma”.

Stigma cannot be understood without considering the following factors: poverty, gender-based violence, social inequality, local norms and attitudes.

Discrimination, follows stigma, and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status.

### The different types of stigma

**External stigma** is done by others to PLHIV. It is displayed through attitudes or actions aimed at PLHIV including insults, rejection, avoidance, intolerance, stereotyping, discrimination, and physical violence.

**Internalized stigma** happens when PLHIV begin to believe the negative things that those around them say or think. It can also be seen as thoughts and behaviours resulting from the person's own negative thoughts about him/herself based on his/her HIV status.

**Anticipated stigma** is the anticipation or expectation that one will be treated differently or poorly because of the stigmatized identity of PLHIV as a group. Lastly, “**courtesy stigma**” is the stigmatization a person perceives or experiences due to their association with a stigmatized individual or group.

### Stigma on top of stigma

HIV-related stigma often happens together with other forms of social stigmatization as a result of race, gender, and class-based inequalities, engaging in sex work, having non-normative gender identities or

sexualities, religious persecution, xenophobia, drug use, mental and/or physical disability, disease, and so forth. This increases both the exclusion and devaluation of PLHIV leading to double or multiple stigma (i.e., "super-stigmatization").

### **TB-related stigma**

The Steering Committee of the project made a decision to include items that relate to TB-related stigma in South Africa because TB often affects people with HIV. Indeed, South Africa has the third-highest absolute TB burden in the world. To our knowledge this is the first national study to include TB-related stigma items in the PLHIV Stigma Index.

### **OVERALL AIM OF THE STUDY**

- To measure the levels of stigma and discrimination experienced by PLHIV in the general population of South Africa
- To explore how this information could be used to strengthen programmes and service delivery
- To measure the levels of TB-related stigma experienced by PLHIV in South Africa

### **WHY THIS STUDY WAS DONE**

SANAC has acknowledged that stigma and discrimination of PLHIV needs to be addressed. SANAC noted that although there has been tremendous progress made over the last 3-4 years in respect of this, it was a very difficult task to undertake because of the high levels of violence towards women and sexual minorities in South Africa. As a result of these concerns, SANAC commissioned the implementation of this national PLHIV Stigma Index study. This study was conducted to address the key priority area of reducing HIV – related stigma and discrimination.

### **HOW THE STUDY WAS DONE**

Information for this study was gathered from PLHIV in 18 districts (two per province) of South Africa, one of which is a pilot district for National Health Insurance (NHI). The interviews took place from September to December 2014. The survey involved interviewing PLHIV who were 15 years of age and older using the PLHIV Stigma Index. The majority of respondents were recruited through their participation in the support group networks of National Association of People Living with HIV and AIDS (NAPWA), Treatment Action Campaign (TAC), and Positive

Women's Network (PWN). Others were recruited through health facilities or NGOs where they were accessing HIV support or care. Some PLHIV affiliated with the three organisations were recruited and trained as either team supervisors or interviewers.

## RESULTS

### SECTION 1: WHO TOOK PART IN THE STUDY

A total of 10 473 people were included in the study. All respondents were HIV-positive.

#### Province and locality type

- 49% of respondents were from small towns or villages
- 31% were from rural areas
- 20% were from large towns or cities

#### Sex and age

- 65% of respondents were female
- The largest proportion of male and female respondents were between the ages of 30 to 39 years
- Fewer youth (10%) aged 15 to 24 years and older adults aged 50 years or older (11%) made up the sample

#### Years living with a HIV diagnosis by age

- 50% of respondents reported living with a HIV diagnosis for five years and more
- 12% reported 1 year and less of living with HIV
- 36% of the youth aged 15 to 24 years reported living with HIV for one year and less
- 16% of youth reported living with HIV for five years and more
- 71% of the older respondents aged 40 to 49 years and 69% of those aged 50 years and older reported living with HIV for five years or more

### Relationship status

- 40% of respondents reported having been in a relationship but not living together
- 24% were married or cohabiting and currently living with their husband/wife/partner in a household
- 21% of respondents reported a single relationship status

### Sexual activity

- 82% of the respondents reported that they were currently sexually active (i.e. at the time of the survey)
- 18% reported no sexual activity

### Key populations

- 2% each reported that they identified with the following categories: gay/lesbian, prisoner and migrant worker
- 1% each identified with transgender and sex worker

### Physical disability

- 94% of respondents reported to having no physical disability (not including general ill health related to HIV)

### Education

- 66% reported having completed secondary school
- 11% reported to have completed technical college/university
- 18% had only completed primary school
- 5% had no formal education

### Employment

- 61% had no form of employment and indicated that they were not looking for work
- 8% indicated that they were currently a student
- 32% reported that they were either full-time or part-time employed

Of those engaged in some form of employment:

- 21% reported being employed in the private for profit sector
- 19% in the not for profit (NGO) sector
- 14% reported being employed by government



- 14% reported the informal industry as a place of employment
- 10% of respondents were employed in either the agriculture; industrial and other service sectors

### Socio-economic status

- 50% of the respondents reported that their household did not have enough money for basic things like food and clothes
- 39% reported that there was money for food and clothes, but they were short on many other things
- 9% reported that they had most of the important things, but few luxury goods
- 2% reported that they had money for extra things such as holidays and luxury goods

### Food security

- 54% reported that they have “often” (12%), “sometimes” (36%) and “rarely” (6%) gone without food during the last 12 months

## SECTION 2: EXPERIENCES OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

### Experiences of exclusion from social activities

An overwhelming majority of respondents (90-97%) reported never having been excluded from social gatherings. However, for those that did report having been excluded, between 29-44% reported that the main reason for this exclusion was their HIV status (see table below).

Type of social activity	% reported exclusion	% of those who reported exclusion that said it was due to their HIV status
Social gatherings	10%	44%
Family activities	8%	44%
Workplace activities	5%	28%
Religious activities	4%	29%
School/university activities	3%	34%

**Experiences of stigma and discrimination involving exclusions from social situations reported by respondents and reasons reported for this**

### Experiences of being gossiped about, verbal assaults and physical harassments

The majority of the respondents reported never being gossiped about (69%); verbally assaulted and harassed (84%); physically harassed (91%) and never having been physically assaulted (92%) in the last 12 months. The majority of respondents reported having never experienced discrimination (78%); never being physically assaulted by their wife/husband or partner (90%) or ever having experienced psychological violence (92%) in the last 12 months.

The percentage of respondents who reported their HIV status as the reason why they experienced stigma and discrimination from other people can be seen in the table below.

Social situation	% of those who reported stigma and discrimination that said it was due to their HIV status
Being gossiped about	42%
Discrimination	37%
Verbal assault and harassment	35%
Physical harassment and assault	27%
Physical assault	26%

#### Respondents who reported their HIV status as the reason why they experienced stigma and discrimination from other people

Of the 8% of respondents who reported having been assaulted, 41% reported that a person outside the household who is known to them assaulted them; with 32% of the respondents indicating that a husband/wife/partner physically assaulted them.

Those who have experienced stigma and discrimination because of any reason other than their HIV status reported that it was because of their TB status (35%), with 9% indicating having experienced stigma and discrimination because of their sexual orientation.

When asked to report the reasons for overall HIV-related stigma and/or discrimination in the last 12 months, 26% of the respondents indicated that they believed that people did not understand how HIV is transmitted and were afraid, while 18% indicated that people were afraid that they would be infected with HIV.

### Overall experience of external stigma

Overall, it was found that 36% of the respondents experienced some external stigma.

#### Who is more likely to experience external stigma

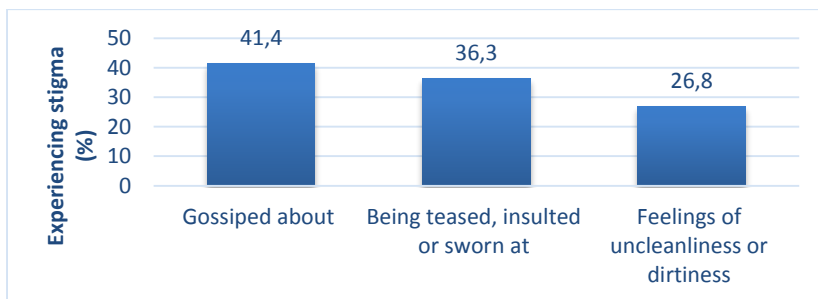
When looking at the links between experiences of external stigma and various socio-demographic variables, the following experienced more external stigma:

- female respondents
- respondents in the youngest age group of 15-24 years
- respondents who have lived with a HIV-positive diagnosis for 2-4 years
- respondents who were married or cohabiting with a partner but partner temporarily not living in the same house
- respondents who had completed secondary school education
- respondents who did not have money for basic things like food and clothes or had money for food and clothes, but short on many other things
- respondents living in small towns or villages and large towns or cities
- respondents who often, sometimes or rarely went without enough food to eat
- respondents who were employed
- respondents from Free State, KwaZulu-Natal and Mpumalanga (which have the highest HIV prevalence)

### SECTION 3: EXPERIENCES OF TB-RELATED STIGMA

It was found that 66% of respondents indicated having had disclosed their TB diagnosis to people outside the household whereas the remainder 34% actually had not done so which is concerning. PLHIV may not have disclosed their TB status due to fears of experiencing stigma and discrimination. Over a third (36%) of respondents reported being teased, insulted or sworn at because of their TB status and 41% reported being gossiped about because of their TB status. Internalized feelings of stigma as related to a TB diagnosis, measured by feelings of uncleanness or dirtiness, were found to be moderately high as 27% of respondents indicated feeling unclean or dirty (figure below).

## THE PEOPLE LIVING WITH HIV STIGMA INDEX: SOUTH AFRICA 2014



Experiences of TB-related stigma and disclosure reported by respondents in the study

### SECTION 4: SEXUAL REPRODUCTIVE HEALTH

The large majority of the respondents (80%) reported having children. The majority of the respondents (70%) reported that they had received counselling about their reproductive options. This means that 30% of the respondents had not received such counselling. This is concerning.

The overwhelming majority of the respondents (87%) indicated that health care professionals never discouraged them from having children. Of concern is that 7% of respondents reported that they were forced to be sterilized. In addition, 37% of the respondents said that access to ARV treatment was conditional on use of contraceptives. The overwhelming majority (95%) of women reported not being coerced to terminate a pregnancy or about the type of delivery method (86%) while a large majority also said the same for infant feeding practices (77%).

The overwhelming majority of the respondents (95%) reported that they received information about PMTCT and 87% reported that they received ARV treatment during pregnancy. It remains a concern that 14% did not receive ARV treatment during pregnancy despite national policy dictating it be made available free to all HIV-positive pregnant women.

**Reproductive health issues in the 12 months**

Reproductive health issue	%
Coerced by health care professional on choice of infant feeding practices because of HIV status	23%
Coerced by health care professional about which method of giving birth to use because of HIV status	14%
Not given information about healthy pregnancy and motherhood as part of the PMTCT programme	5%
Coerced by health care professional to terminate pregnancy (have an abortion) because of HIV status	5%
Did not have access to ARV treatment for PMTCT during pregnancy	3%
Were refused ARV treatment for PMTCT during pregnancy	1%

**SECTION 5: ACCESS TO WORK, HEALTH AND EDUCATION SERVICES**

It was reassuring that an overwhelming majority of respondents (95%) were never refused accommodation because of their HIV-positive status. Of the 5% of respondents who did report having had to change their place of residence, 49% indicated that their HIV-positive status was the reason, or part thereof, for this.

The overwhelming majority of the respondents indicated that they were never refused employment (92%), had their job descriptions altered (92%), or lost a job or source of income (89%) because of their HIV-positive status. Of respondents, who had lost a job, nearly 40% indicated that their HIV-positive status was either directly or indirectly responsible for this during the preceding 12 months. In addition, about 24% felt that discrimination because of their HIV-positive status by an employer or co-workers contributed to them losing a job or a source of income and 44% attributed their job loss to their own poor or failing health, which could be interpreted as likely a result of their HIV-positive status.

Almost all respondents indicated that they were never personally refused access to an educational institution (98%) and neither had their children been dismissed, suspended or prevented from attending a school (99%) because of their HIV-positive status.

Most respondents indicated that they were never denied general health services (97%) or sexual and reproductive health services (94%). A possible cause for concern is that HIV-related stigma is still present where

HIV-positive persons want to access family planning services, as 8% of the respondents indicated that they were denied these services during the preceding 12 months.

## SECTION 6: INTERNALIZED STIGMA

Internalized stigma may lead to reduced self-confidence, loss of motivation, withdrawal from social contact, avoidance of work-and health-based interactions, and abandonment of planning for the future.

### Feelings of internalized stigma by respondents

Overall, 43% of the respondents reported having experienced feelings of internalized stigma.

#### Feelings of internalized stigma

The table below presents the results of self-reported feelings of internalized stigma. With regards to internalized stigma, 29% felt ashamed, 28% had feelings of guilt, 31% blamed themselves, and 19% blamed others and had low self-esteem (22%). Hence there is evidence of internal stigma experienced by a sizeable proportion of PLHIV who took part in the study. Of note is that experiences of internal stigma were found to be higher than experiences of external stigma reported by respondents in the last 12 months. Of concern, one in ten of the respondents felt that they should be punished as a result of their HIV-positive status (11%) and one in ten felt suicidal in the last 12 months (11%).

#### Self-reported internal stigma among respondents in the survey

Feelings experienced	%
Ashamed	29%
Guilt	28%
Blaming oneself	31%
Blaming others	19%
Having low self-esteem	22%
Should be punished	11%
Suicidal	11%

### Who is more likely to experience internalized stigma

When looking at the links between experiences of internalized stigma and various socio-demographic variables, the following experienced more internalized stigma:

- respondents in the youngest age group of 15-24 years
- respondents who were living with HIV for 0-1 year
- respondents who were married or cohabiting but the husband/wife/partner is temporarily living/working away and divorce/separated
- respondents who had no formal education and those with technical college/university level education
- respondents who had money for extra things such as holidays and luxury goods
- respondents living in rural areas
- respondents who often went without enough food to eat
- respondents from Mpumalanga, KwaZulu-Natal and Free State (which have the highest HIV prevalence)

### Avoidance behaviour due to internalized stigma

Overall, it was found that 41.9% of the respondents engaged in some avoidance behaviours due to internalized stigma.

### Avoidance behaviours due to internalized stigma

When asked which avoidance behaviours they had done during the last 12 months because of their HIV status, 4% decided to stop working, 5% decided not to apply for a job/work or promotion or training, 4% withdrew from education/training or not take up education/training opportunity, 5% avoided going to local clinics when they needed to, and 3% avoided going to hospitals when they needed to (which is of concern). Although still a minority, slightly more respondents chose not to attend social gathering(s) (12%), isolated themselves from family and/or friends (10%), decided not to get married (15%), and decided not to have sex (14%) due to their HIV status. Most importantly, almost 32% of respondents decided not to have (more) children because of their HIV status.

**Things respondents had done during the previous 12 months due to their HIV status**

Top 5 things done in last 12 months	%
Decided not to have (more) children	32%
Decided not to get married	15%
Decided not to have sex	14%
Chose not to attend social gathering(s)	12%
Isolated oneself from family and/or friends	10%

**Who is more likely to engage in avoidance behaviours due to internalized stigma**

When looking at the links between engaging in avoidance behaviours due to internalized stigma and various socio-demographic variables, the following engaged in more avoidance behaviours:

- female respondents
- respondents in the oldest age group of 50 years and older
- respondents who had lived with a HIV-positive diagnosis for five years and more
- respondents who were divorced/separated and widow/widower
- respondents who had no formal education
- respondents who did not have money for basic things like food and clothes and those who had just enough money for food and clothes but for no other things
- respondents who often or rarely went without enough food to eat
- respondents from the Free State

**Fear of potential stigma**

Overall 39% of the respondents in the study reported that they had experienced some fear of potential stigma.

**Fear of potential stigma**

A substantial proportion of the respondents reported fearing, in descending order, being gossiped about (29%), that someone would not want to be sexually intimate with them because of their HIV-positive status (21%), being verbally insulted, harassed and/or threatened (17%), being physically harassed and/or threatened (13%), and being physically assaulted (12%) in the past 12 months.



## THE PEOPLE LIVING WITH HIV STIGMA INDEX: SOUTH AFRICA 2014

**Fear of things happening in the last 12 months whether they actually happened before or not**

Things respondents were fearful of happening to them	%
Being gossiped about	29%
Afraid that someone would not want to be sexually intimate with them because of their HIV-positive status	21%
Being verbally insulted, harassed and/or threatened	17%
Being physically harassed and/or threatened	13%
Being physically assaulted	12%

### **Who is more likely to experience fear of potential stigma**

When looking at the links between fear of potential stigma and various socio-demographic variables, the following experienced more fear:

- respondents in the youngest age group of 15-24 years
- respondents who lived for 0-1 year with a HIV-positive diagnosis
- respondents who were married or cohabiting but the husband/wife/partner is temporarily living/working away and divorced/separated
- respondents who had no formal education or technical college/university education
- respondents who had money for basic things like food and clothes but short on many other things
- respondents living in small towns or villages
- respondents who often were without enough food to eat
- respondents who were employed
- respondents from KwaZulu-Natal, Gauteng and Free State

## **SECTION 7: DISCLOSURE AND CONFIDENTIALITY**

### **Disclosure to different groups of people**

Respondents were asked about how the different groups of people that they interact with were first informed about their HIV-positive status. The majority (89%) of respondents indicated that they had disclosed their HIV status to their husband/wife/partner, 4% of respondents did not know, and 3% reported that their spouses/partners saw the results first.

Similar patterns were observed when PLHIV disclosed to other adult family members and other PLHIV. Most (68%) disclosed their HIV-positive status to the children in their family, 21% said that their children did not know of their status, and 8% reported that their children were informed

by someone else with their consent. A third (33%) of employers/bosses did not know the HIV positive status of respondents.

In relation to disclosure to others, 63% indicated that community leaders did not know of their status, 49% who had reported previous engagement in sex work indicated that their clients did not know about their status, and 49% of the respondents indicated that they had informed PLHIV of their status.

### **Pressure placed on respondents by others to disclose their HIV status**

The overwhelming majority of respondents often felt pressured by both individuals who are living with HIV (90%) and those who are not living with HIV (91%) to disclose.

### **Disclosure of HIV status to other people without their consent by a health care professional**

The majority of respondents (72%) indicated that their status was not disclosed without their consent. Of some concern was the fact that 4% believed that they had their status disclosed previously without their consent by others, whereas 24% reported that they were unsure. Similar findings were found when respondents were asked about how confidential they thought that their medical records were concerning their HIV status with 65% expressing confidence that their medical records will be kept completely confidential. However, 5% indicated that it was clear to them that their medical records were not being kept confidential while 30% indicated that they did not know if their medical records were kept confidential.

### **Reactions of other people towards respondents after disclosure of HIV-positive status**

The majority of the respondents indicated that their spouses/partners (89%), other adult family members (92%), friends/neighbours (78%), other PLHIV (94%), health care workers (93%) and social workers/counsellors (91%) were mainly very supportive after the disclosure of an HIV-positive status by respondents. The majority of respondents (82%) affirmed that they had felt empowered when disclosing their positive status.

### Who is more likely to disclose their HIV status

When looking at the links between disclosure of HIV status and various socio-demographic variables, the following were more likely to disclose:

- respondents in the age group 25-49 years
- respondents who had lived five years and more with a HIV-positive diagnosis
- respondents who were married or cohabiting and whose husband/wife/partner were currently living in the household and those who were a widow/widower
- respondents living in rural areas
- respondents who often or never went without enough food to eat
- respondents from North West, Mpumalanga, Northern Cape and Free State

## SECTION 8: HIV TESTING AND TREATMENT

When asked why they had tested for HIV, 37% of the respondents indicated that it was because they just wanted to know followed by 17% of respondents who reported that they had tested for HIV due to illness or the death of a husband/wife/partner/family member and 16% reported that they had tested for HIV because of pregnancy.

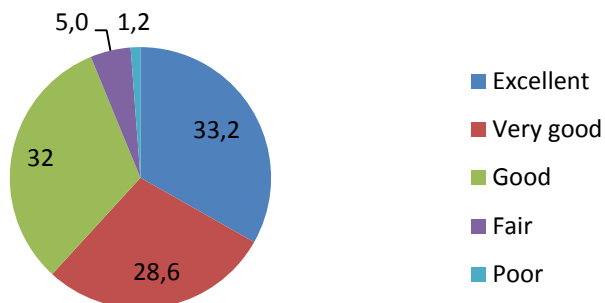
When asked about making the decision to be tested for HIV, 82% of the respondents indicated that they took the decision to test by themselves.

In terms of the place where the testing was done, 67% of the respondents reported that they had done so at a public clinic or doctor and 24% had done so at a public hospital.

With regards to having received counselling when testing for HIV, 92% reported that they received both pre- and post-HIV test counselling. It is important to note that 4% of respondents received only pre-test HIV counselling while 2% received only post-test HIV counselling. It is also worth noting that 2% did not receive any counselling whatsoever when they tested for HIV.

The figure below shows the self-reported health status of respondents. The overwhelming majority of respondents reported good to excellent

health (94%). A very small proportion (1%) indicated that their health status was poor.



#### Current self-reported health status of respondents

When asked questions regarding ARV treatment, the following was found:

- 88% reported that they were currently taking ARV treatment
- 89% reported that they had access to ARV treatment, even if they are not currently taking it
- 58% of the respondents said they were not currently taking any medication to prevent or to treat opportunistic infections
- 79% reported that they had access to medication for opportunistic infections, even if they are not currently taking it
- 74% reported having had a constructive discussion with health care professional(s) or a trained peer educator (63%) on the subject of their HIV-related treatment options in the last 12 months
- 63% of respondents also reported having had a constructive discussion with a health care professional(s) or a trained peer educator (55%) on other subjects such as their SRH, sexual relationship(s), emotional well-being, and drug use in the last 12 months.
- 34% of the respondents did not have a useful discussion about SRH which is a highly important finding.

## RECOMMENDATIONS

This is the first PLHIV Stigma Index study that has been conducted in South Africa on a national level among PLHIV who attend support groups and/or attending care and treatment support services. The following recommendations based on the main findings in this report are made to SANAC.

### 1. Share the results of the study

The findings of this study should urgently be disseminated by SANAC to all relevant stakeholder groups at national, provincial, district, municipal and ward levels.

### 2. Start a national campaign against stigma

There is an urgent need to develop and implement a national stigma mitigation campaign led by SANAC to address internal and external stigma. Taking into consideration that stigma levels were high in the 15-24 age group, as well as in the provinces of KwaZulu-Natal, Mpumalanga, and the Free State, we recommend prioritization of the implementation of the campaign especially within this age group and provinces respectively.

### 3. Address internalized stigma

Particular emphasis should be placed on addressing internalized stigma on an individual level, where existing support group structures should be utilised and invigorated to implement psychosocial support for PLHIV. A process of greater involvement of PLHIV in support groups (and taking ownership) in order to manage their own health and social wellbeing should be implemented by the South African Government and monitored by SANAC.

### 4. Address TB-related stigma

TB-related stigma should also be addressed as part of the new national Stop TB campaign. SANAC should put systems in place in order to monitor this.

### 5. Strengthen confidentiality of health records

It is of concern that some respondents believed that health care professionals had breached confidentiality or believed that their records would not be kept completely confidential. We recommend that current systems should be strengthened by the

Department of Health together with Social Development, Basic Education and the Department of Justice in order to maintain confidentiality of health records. The strengthening of these systems should be monitored by SANAC.

#### **6. Address poverty and food security of PLHIV**

Current government poverty reduction programmes such as the Expanded Public Works Programme or Community Work Programme and the nutritional supplement schemes for PLHIV should be strengthened to address issues of poverty and food security for PLHIV respectively. The process of evaluating the performance of these programmes should be done in consultation with SANAC and the SANAC PLHIV Sector.

#### **7. Monitor and evaluate stigma related to TB and HIV**

There is a need for on-going monitoring and evaluation (M&E) of stigma and discrimination issues related to both HIV and TB at all levels by SANAC. This could, among others, include adding TB-related stigma items to national HIV household surveys.

### **CONCLUSIONS**

In conclusion, moderate levels of HIV-related external and internalized stigma and discrimination were found. Moderately high TB-related stigma was also found. The present study provides baselines on which to assess levels of HIV- and TB-related stigma and discrimination. In addition, this study found evidence of great strides made with regards to combating stigma and discrimination as experienced by PLHIV especially in the health care sector as only a very small proportion in the present study reported having experienced discrimination because of their HIV-positive status. Nevertheless, there is still some evidence of stigma and discrimination of PLHIV experienced in the health care sector. Of concern is the level of internalized stigma found in this study, which is probably a consequence of the lack of adequate psychosocial support that is currently available for PLHIV to address the psychological consequences of receiving an HIV-positive diagnosis including associated mental health issues. As getting to zero stigma is the ultimate goal of SANAC the implementation of stigma mitigation campaigns are greatly needed in the South African context.