SOUTH AFRICA

THE PEOPLE LIVING WITH HIV STIGMA INDEX

SOUTH AFRICA

August 2012
Abbreviations

ARASA  AIDS and Rights Alliance for Southern Africa
ART  Antiretroviral therapy
CCM  Country Coordinating Mechanism (for delivery of Global Fund interventions)
CSO  Civil Society Organization
DFID  UK government Department for International Development
ECAC  Eastern Cape AIDS Council
ECPCC  Eastern Cape Provincial Council of Churches
EPOC  Ekurhuleni Pride Organizing Committee
GIPA  Greater Involvement of People Living with HIV and AIDS
GNP+  Global Network of People Living with HIV
HIV  Human Immunodeficiency Virus
HTL  House of Traditional Leaders
ICW  International Community of Women Living with HIV/AIDS
IPPF  International Planned Parenthood Federation
LGBT  Lesbian, gay, bisexual and transgender
MSM  Men who have sex with men
NAPWA  National Association of People Living with AIDS
NAPWA-SA  National Association of People Living with AIDS, South Africa
NGO  Non-Governmental Organization
OR  Oliver Reginald (as in OR Tambo region)
PLHIV  People living with HIV
PMTCT  Prevention of Mother-To-Child Transmission (also referred to as PVT)
RULIV  Rural Urban Livelihoods
SRH  Sexual Reproductive Health
UNAIDS  Joint United Nations Programme on HIV/AIDS
UNGASS  United Nations General Assembly Special Session on HIV/AIDS
Acknowledgements

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The partnership was coordinated by a steering group comprising NAPWA, the Eastern Cape AIDS Council (ECAC), Oliver Reginald (OR) Tambo District AIDS Council, Rural Urban Livelihoods (RULIV), Eastern Cape Provincial Council of Churches (ECPCC), House of Traditional Leaders (HTL), Transcape, Siyakhanyisa Home Based Care, the AIDS and Rights Alliance for Southern Africa (ARASA), Ekurhuleni Pride Organizing Committee (EPOC) and UNAIDS South Africa. We would also like to acknowledge the clinics and support groups who facilitated access to potential interviewees.

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Executive summary

Stigma is widely recognized as a barrier to accessing HIV prevention, treatment, care and support\(^1\). People living with HIV experience stigma (both received and internalized) that impacts upon their ability to make use of services, where these exist, and make positive choices about their health and lives. This study by the National Association of People Living with HIV/AIDS in South Africa in partnership\(^2\), aimed to explore levels of HIV-related stigma in the OR Tambo District of the Eastern Cape Province in South Africa. Specifically, to collect information on stigma and discrimination as experienced by people living with HIV, in order to

- document the various experiences of HIV-related stigma and discrimination in the OR Tambo District;
- contribute to the evidence base for advocacy, policy change and programmatic interventions to address HIV-related stigma and discrimination; and
- serve as a pilot for scaling up implementation of the People Living with HIV Stigma Index into a national study.

Methodology and Sampling

The study was undertaken between October 2011 and August 2012, and involved a sample of 799 people living with HIV drawn from three local municipalities in the OR Tambo District: King Sabatha Dalindyebo, Nyandeni and Ngquza local municipalities. The study used the People Living with HIV (PLHIV) Stigma Index process and questionnaire developed by GNP+, ICW, IPPF and UNAIDS following the standard methodology\(^3\) as described at [www.stigmaindex.org](http://www.stigmaindex.org). The sample included 621 respondents (77.7%) from rural areas, 121 (15.1%) from small towns or villages, and 20 (2.5%) from large towns\(^4\).

Almost two thirds of the respondents were female (64.7%, n=511) over a third were male (35.1%, n=277) and two were transgender (0.3%). Nearly one third of respondents (32.3%, n=256) were aged 30-39 years, nearly one quarter (23.5%, n=186) were aged 40–49 years, over 20% (21.7%, n = 172) were aged 25-29, and approximately 5% were youth aged 15-19 (6.6%, n

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\(^2\) In collaboration with the Global Network of People living with HIV (GNP+) and in partnership with the Eastern Cape AIDS Council (ECAC), OR Tambo District AIDS Council, Rural Urban Livelihoods (RULIV), Eastern Cape Provincial Council of Churches (ECPCC), House of Traditional Leaders (HTL), Transcape, Siyakhanyisa Home Based Care, ARASA, Ekurhuleni Pride Organizing Committee (EPOC) and UNAIDS.

\(^3\) Though there is a standard methodology there is room within the framework provided to adjust elements to make the tool and process responsive to the country context.

More than half of respondents (58.6%, n=466) had been living with HIV for 1-4 years, over 30% (31.9%, n=254) for 5-9 years and under 10% between 10 and 14 years (9.1%, n=69). Furthermore, 9% of respondents (n=69) report having a physical disability other than HIV-related general ill health.

Nearly half of respondents were in a relationship but not living together (46.8%, n=371) with a further 6.4% (n=51) married or cohabiting but not currently living together; while slightly over 20% were married or cohabiting and currently living together (22.4%, n=178). Nearly a quarter of respondents (24.4%, n=193) were single (unmarried, divorced or widowed). Nearly 80% of respondents (78.6%, n=593) reported that they were sexually active.

More than 80% of the respondents had at least one person living together with them at the time of the survey. Over 75% of respondents (78.4%, n=623) had children; while 12.7% (n=87) of 700 respondents indicated having at least one child living with HIV. In total, 94 respondents (12.1%) reported having children orphaned due to AIDS living in their household.

**Study Limitations in relation to key populations**

In terms of specific sub-populations of people living with HIV (which we have referred to as key populations in this study)\(^5\),\(^6\) It was an aspiration of this study to include these specific key populations as these voices have been neglected in previous studies; the implementing team acknowledge that it was not entirely successful in reaching out to large enough numbers from these populations to provide more than a ‘snapshot’ of their concerns.

In terms of key populations, of the 766 interviewees who responded, 626 (81.7%) did not identify with any key population; while 140 did (18.3%), including 44 migrant workers (5.7%), 39 members of indigenous people (5%), 20 (2.6% gay/lesbians, and 10 (1.3%) sex workers.

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\(^5\) The term ‘key populations’ in terms of this study refers to those from groups within the general population of people living with HIV whose engagement is critical to a successful HIV response i.e. they are key to the epidemic and key to the response. In all countries, key populations include people living with HIV. However In most settings, PLHIV who are men who have sex with men, transgender persons, people who inject drugs, sex workers, prisoners, migrant workers are (dependent upon context) more likely to experience multiple forms of stigma and discrimination hampering their access to equitable care, treatment, and support.

\(^6\) The specific question asks whether the respondents feels that they currently ‘belong’ (or ever have) to any of the following categories; MSM, gay or lesbian, transgender, sex worker, injecting drug user, refugee or asylum seeker, internally displaced person, member of an indigenous group, migrant worker, prisoner.
Major findings

Major findings concerning the experiences of people living with HIV who took part in this study and recommendations arising from these findings are presented in this executive summary, with more extensive details of these findings and recommendations presented in the conclusions and recommendations sections of this report.

Overall, the study showed that HIV-related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention, treatment and care services in OR Tambo District of Eastern Cape Province in South Africa.

Poverty

It is well known that despite high unemployment rates, being HIV-positive confers a disadvantage and reinforces existing inequalities in South Africa. This was found to be true amongst the respondents. Over half of the respondents (52.7%, n=407) indicated food shortages within the household. Over half of respondents (55.6%, n=437) were unemployed, nearly half (48.4%, n=378) reported a monthly income of between R1000-R3000 and a further 12.8% had a monthly income of between R3000-R5000. Those who had gone without food more often had low monthly income (from nothing to R3000 a month) and were mostly unemployed.

Social Exclusion

Social exclusion is known to exacerbate and compound existing inequalities and inequities. Social exclusion and discriminatory practices were found within the participants in this study in the following forms:

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8 If we consider $1 a day as the official poverty line, dividing R5000 by 8 (estimate exchange rate) over 30 days gives R20.80 a day, is more than twice the official poverty line. However, most of interviewees reported either through work earnings (or unemployment) an income of less than R2000, i.e. R8 a day, equivalent to $1 a day.
9 Social exclusion as been defined by Department of International Development (DFID) “a process by which certain groups are systematically disadvantaged because they are discriminated against on the basis of their ethnicity, race, religion, sexual orientation, caste, descent, gender, age, disability, HIV status, migrant status or where they live.
Within the last 12 months HIV-related exclusion from social gatherings\(^\text{10}\) was reported by 10.6\% (n=84) of respondents, 8.9\% (n=71) reported exclusion from family activities\(^\text{11}\) gatherings and by 5.5\% (n=44) from religious activities or places of worship. Nearly a third of respondents (30\%, n=237) reported that they had been gossiped about at least once in the last year with over two thirds (67.4\%, n=145) indicating that it occurred, in whole or in part, because of their HIV-positive status. Over one in five respondents feel that HIV-related stigma and/or discrimination is due to people being afraid of being infected by them.

### Access to work and health and education services

The highest levels of discrimination were reported in work related matters amongst those who responded (10.3\%, n =40), followed by accommodation (9.6 \%, n=77) and access to family planning services (6.5 \%, n=51).

### Internalized stigma and fears

Internalized stigma was prevalent: Over one third of respondents blamed themselves and over a quarter felt ashamed. Nearly 10\% of respondents (9.6\%, n=76) reported feeling suicidal. The most frequent decisions made by respondents during the last 12 months because of HIV status were not to have more children (41.6\%, n=332), not to attend social gathering(s) (18.9\% (n=151), not to marry 16.1\% (n=129); and to isolate themselves from friends and relatives 12.8\% (n=102). Overall, 45.4\% of respondents (n=363) feared being gossiped about and nearly 20\% of respondents (19.5\%, n=156) indicated that they were scared someone would not want to be sexually intimate with them because of their HIV-positive status with higher levels reported by male than female respondents (27.4\%, n= 75 compared to 15.3\%, n= 78).

### Rights, laws and policies

The AIDS Charter on Rights and Responsibilities\(^\text{12}\) was known to nearly one quarter of respondents (23.4\%, n=187); of whom, 48.7\% (n=91) had read or discussed it. During the previous 12 months, over 10\% of respondents (11.2\%, n=89) reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.

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\(^{10}\) E.g. weddings, funerals, parties, clubs.

\(^{11}\) Examples of such family activities that this question covered included cooking, eating together, and sleeping in the same room as other family members.

\(^{12}\) The charter is accessible at http://www.aidsconsortium.org.za/About.htm#charter. The charter of itself has no legal force though it has been adopted as a guiding principle by many organisations responding to HIV in South Africa. See note \(^{28}\) for further information.
Of 99 respondents who experienced a rights violation within the previous 12 months, 18 (18.2%) had tried to get legal redress and 79 (79.8%) had not. Of these respondents 74 respondents had not sought legal redress the most common reason cited was feeling intimidated or scared to take action (20.3%, n=15).

**Effecting change**

During the last 12 months, nearly 20% of respondents (19.8%, n=158) reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against her or him.

Nearly half of respondents (45%, n=358) reported having provided some form of support to other people living with HIV in the previous 12 months with emotional support (37.5%, n=153) being the most common type of assistance rendered.

Over 95% of respondents (98.1%, n=784) felt able to influence policies, laws and programmes at either National or local levels.

In terms of the most important thing organisations should do to address stigma and discrimination, more than one third of respondents (35.7%, n=282) cited providing emotional and physical support to people living with HIV.

**Testing and diagnosis**

Over 30% of respondents (n=240) reported taking an HIV test just to know their status.

Human rights violations associated with involuntary HIV testing and being tested without consent\(^\text{13}\) or any counselling\(^\text{14}\) remain challenges.

**Disclosure and confidentiality**

High levels of disclosure by respondents included to: spouse or partner (86.7%), other adult family members (82.2%), other people living with HIV (85.2%), health care workers (89.4%), children in the family (72.7%), clients (68.2%), social workers and counsellors (66.3%), and friends and neighbours (45.9%).

- Disclosure within relationships remains an issue for some respondents, for example, 6.1% of respondents (n=48) had not disclosed their status to their spouse or partner.
- Over three quarters of respondents described disclosing their HIV status as an empowering experience.

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\(^{13}\) In terms of coerced testing or without a person’s consent, 49 respondents (6.1%) reported that they were forced to take a HIV test or were tested under pressure from others, and 16 respondents (2%) were tested without their knowledge.

\(^{14}\) While nearly 90% of respondents (88.9%, n=694) received both pre and post-test counselling; 4.9% received only pre-test counselling (n=38), another 3.5% received only post-test counselling (n=27); and 2.8% received no counselling at all (n=22).
Stigma Index

Treatment
Over 70% of respondents (70.9%, n=566) were currently taking ART and nearly 90% (89.2%, n =709) said that they could access ART should they need it.
Over 80% (84.2%, n=672) of respondents had discussed HIV treatment options and over 70% (70.2%, n=556) had discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

Having children
Less than 40% of respondents (36.8%, n=291) respondents indicated that they had never received counselling on their reproductive options since their HIV diagnosis.
In relation to PVT, of 484 female respondents, over two thirds (67.1%, n=325) had received ART for PVT, 6.2% (n=30) indicated that they did not know that such treatment existed, 0.8% (n=4) did not have access. Another 1.2 % (n = 6) had been refused such treatment, whereas 24.6 % (n = 119) were not HIV positive when they were pregnant.

Problems and challenges
Respondents’ opinions on what are the main problems and challenges, in relation to the following areas, were:
**Treatment:** over 30% cited ART side effects as the most problematic issue related to ART (31.8%, n=240) followed by access (24.1%, n=182), taking ART for life (23.7%, n=179) and monitoring (20.4%, n=154).
**Having children:** over 60% cited care for children in the event that something happened to them as the most problematic and challenging aspect of having children when HIV-positive (61.7%, n=460), followed by a quarter of respondents citing PVT (27.6%, n=206).

Major Recommendations
The overall recommendation derives from the facts that among the sample high levels of stigma and discrimination were reported in a number of areas (including exclusion of both respondents and household members; access to employment, residency/accommodation, health or life insurance, and health care services (low level); generally low levels of perceived ability to effect change; low socio-economic status, including significant percentages of respondents reporting low levels of education and employment, as well as significant psychosocial needs (for example, high levels of internalized stigma; high rates of fear about the ways they were perceived and treated in the community; and 9.6 % of respondents (n =77) reported feeling suicidal). As such, concerted efforts are required to promote an approach which
supports the positive health, dignity and preventions needs\textsuperscript{15} of people living with HIV. Such an approach must clearly be a priority for the National Association of People Living with HIV and AIDS, civil society responses to HIV, OR Tambo District, the South African National AIDS Council (SANAC) and the National Government. Concerted efforts by all the above stakeholders are required to promote positive living and provide psychosocial and socioeconomic support, including training opportunities to become peer educators counsellors, trainers; to build capacity and networks, and for income generation.

As such concerted efforts are required to promote an approach which supports the positive health, dignity and preventions needs\textsuperscript{16} of people living with HIV.

Other major recommendations directed to the National Association of People Living with HIV and AIDS - South Africa, civil society actors involved in the HIV response, OR Tambo District, the South African National AIDS Council (SANAC) and the National Government are outlined below and in detail in Recommendations.

National Association of People Living with HIV and AIDS - South Africa

- Advocate for the national implementation of the People Living with HIV Stigma Index.
- Encourage and build the capacity of people living with HIV to advocate for their rights to be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes; and to provide support and assistance to people living with HIV individually, and through support groups and other local organisations.
- Advocate for the broadest representation of people living with HIV, including key populations living with HIV, in policy-making fora and in the development and drafting of legislation.
- Undertake further research into the underlying facilitators of disclosure of HIV status, including addressing the needs of key populations living with HIV.

Civil Society actors involved in the HIV response

- Advocate for the National implementation of the People Living with HIV Stigma Index.

\textsuperscript{15} Positive Health, Dignity and Prevention is the new name for a revised concept of HIV prevention for and by people living with HIV, formerly known as 'positive prevention'. It focuses on improving and maintaining the dignity of the individual living with HIV, which has a positive impact on that individual's physical, mental, emotional and sexual health, and which, in turn, creates an enabling environment that will reduce the likelihood of new HIV infections. For more information see http://www.gnpplus.net/en/resources/positive-health-digity-and-prevention/item/86-brochure-on-positive-health-dignity-and-prevention

\textsuperscript{16} ib \textsuperscript{15}
• Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, in particular to younger PLHIV as well as people who inject drugs and those in detention settings.

• Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.

• Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to people living with HIV and the general public.

OR Tambo District

• Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.

• Support broad-based social and community awareness raising and mobilization as part of efforts to reduce stigma and eliminate discrimination against people living with HIV and key populations.

South African National AIDS Council (SANAC)

• Implement the People Living with HIV Stigma Index Nationally.

• Given that there is a low level but consistent pattern of denial of the rights of people living with HIV in health care settings, including SRH rights:

  - revise pre- and in-service training curricula to provide non-judgmental and non-discriminatory services to people living with HIV, including PVT;
  - review and update, if needed, protocols to ensure they are rights-based; and
  - scale up the provision of correct information and appropriate options for ART and the sexual and reproductive health for people living with HIV, including PVT, and specifically for key populations.

Support SRH and HIV linkages, including the integration of SRH services for people living with HIV into HIV programmes.\(^{17}\)

Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

National Government

• Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV, specifically address HIV-related stigma and discrimination,

\(^{17}\) One of the highest levels of discrimination was in relation to access to family planning services (7.3%).
require informed consent for HIV testing, protect confidentiality and provide redress for breaches.

- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in National strategic planning, funding and programmes, including supporting National implementation of the People Living with HIV Stigma Index.
- Include HIV-related stigma and discrimination indicators as part of the National HIV response (including M&E systems) to monitor and evaluate progress over time.
Introduction

Background
Stigma is widely recognized as a barrier to accessing HIV prevention, treatment, care and support. Much of what is known about stigma attached to HIV, and resulting discrimination, is anecdotal or fragmented. People living with HIV experience stigma - both internal and external - that impacts on their ability to optimally make use of intervention services. Strategies to address HIV related stigma are not well understood, and this is impacting on programming and service delivery. In order to provide effective services that take into account the realities that People Living with HIV (PLHIV) face, a better, informed and evidence-based understanding of stigma is required.

The People Living with HIV Stigma Index (Stigma Index – www.stigmaindex.org) is a result of a partnership between:
- GNP+ (the Global Network of People living with HIV)
- ICW (the International Community of Women living with HIV)
- IPPF (The International Planned Parenthood Federation)
- UNAIDS

The Stigma Index is an international collaborative project that aims to develop an evidence base to broaden understanding of the extent and forms of stigma experienced by PLHIV in different countries. It is a survey tool to determine HIV-related stigma among PLHIV, supported by a user guide, process, and an international partnership to ensure that local implementing partners are able to take advantage of well developed guidance in order to conduct the study ethically according to agreed standards, and to address any reliability and validity concerns. It utilizes participatory and operational research methodologies.

The Stigma Index was designed to fill this gap not only within the South African context, but also to contribute to global understanding of stigma and its consequences. This study will contribute to these efforts. It makes use of inferential analysis, aims to increase advocacy and to build the evidence base to inform policy and programme changes, addressing HIV-related stigma.

Country Context and OR Tambo District Municipality
The Eastern Cape Province is the second largest Province in South Africa, covering an area of 168,966 km², with an estimated population of 6.7 million people in 2010\textsuperscript{18}. It is made up of

seven Districts with more than 60% of its region being rural\textsuperscript{19}. More than half (51.6\%) of its population are people of child-bearing age (15 – 49 years old). The Province is made up of seven Districts, with OR Tambo District having a geographically vast area with an average population of 1.6 million people\textsuperscript{20}.

A 2010 National survey conducted by the National Department of Health amongst ANC (antenatal clinic) attendees showed a steady increase of HIV prevalence from 2008 to 2010, from 27.6\% to 29.9 \%\textsuperscript{21}. During the same period, similar results were observed in the OR Tambo District, where the HIV prevalence amongst clinic attendees increased from 29.6\% in 2008 to 31.5\% in 2010, making it one of the two districts with the highest HIV prevalence; Amathole District had an HIV prevalence of 31.6\% in 2010.

**About National Association of People Living with HIV/AIDS in South Africa**

**Mission and Vision**

NAPWA is a non-political, non-discriminatory, non-governmental membership based organization which facilitates and advocates for the social-economic development of people infected and affected by HIV/AIDS and the creation of social structures that address issues of care, support and prevention, working in partnership with relevant organizations and the broader community.

**Objectives:**

- Represent, co-ordinate and communicate the needs of People Living with HIV and AIDS
- Ensure the human rights of all PLHIV are recognized and upheld
- Research of information while protecting PLHIV against any form of exploitation
- Collection and dissemination of accurate and relevant HIV and AIDS information
- Mobilize infected and affected people to unite against the spread & impact of HIV and AIDS
- Develop and sustain PLHIV support groups and structures
- Promote education that is sensitive and specific to the needs of PLHIV
- Provide guidance and support for PLHIV
- Expose and prevent any kind of exploitation of all PLHIV
- Give expression to the needs, demands and human rights of all PLHIV in South Africa


Stigma Index

through advocacy and activism

- Implement and facilitate capacity building for the empowerment of PLHIV

For further information please go to:

Objectives

It has long been recognized that action is needed to address HIV-related stigma and discrimination. By implementing the Stigma Index among HIV-positive members of the National Association of People Living with HIV/AIDS in South Africa (NAPWA-SA), evidence can be obtained to

- Shape the design of programmatic interventions so that they address the issue of HIV-related stigma and discrimination within the OR Tambo District Municipality.
- Involve PLHIV in defining and shaping programmes that meet their specific needs.
- Inform the development and implementation of National policies that protect the rights of PLHIV.

However, the benefits of the Stigma Index, particularly for those involved in it, go further than just collecting this much needed evidence. The process of implementing the Stigma Index is intended to be an empowering one for PLHIV, their networks and local communities – a critical ingredient for ensuring that the Greater Involvement of People Living with HIV/AIDS (GIPA) Principle is respected. It is hoped that the Stigma Index will foster change within communities, as well as being a tool to advocate for the broader needed changes. Ultimately, it is hoped that the Stigma Index will be a powerful tool that acts to support the collective goal of NAPWA-SA and its partners, including Government, community-based organizations, activists and PLHIV to reduce the HIV-related stigma and discrimination.

The National Association of People Living with HIV/AIDS in South Africa, in collaboration with the Global Network of People living with HIV (GNP+)\(^\text{22}\), led a partnership to implement a survey which explores levels of HIV related stigma in OR Tambo District. The partnership was

\(^{22}\) GNP+ is the global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV. As a network of networks, GNP+ is driven by the needs of people living with HIV worldwide. Based on emancipation and self-determination, GNP+ works with independent and autonomous regional and national networks of people living with HIV in all continents. Under the central theme Reclaiming Our Lives!, GNP+ implements an evidence-informed advocacy programme focused on:

- **Empowerment**;
- **Human Rights**;
- **Positive Health, Dignity and Prevention**; and
- **Sexual and Reproductive Health and Rights of people living with HIV**.
developed in 2001 and this study was carried out in 2011, with the fieldwork (interviews) carried out between October 2011 and February 2012. The partnership was coordinated by a steering group comprising the Eastern Cape AIDS Council (ECAC), OR Tambo District AIDS Council, Rural and Urban Livelihoods (RULIV), Eastern Cape Provincial Council of Churches (ECPCC), House of Traditional Leaders (HTL), Transcape, Siyakhanyisa Home Based Care, ARASA, Ekurhuleni Pride Organizing Committee (EPOC) and UNAIDS. These organizations, which had been active in promoting the PLHIV Stigma Index among their contacts and service users when appropriate, were consulted on all aspects of the PLHIV Stigma Index implementation.

**Methodology**

The Stigma Index is intended to embrace a participatory spirit for all those involved. People living with HIV were at the centre of the process as interviewers, interviewees and drivers of how information was collected. It was not possible within the available funds to take a representative sample of the PLHIV population of South Africa and, as a result, the survey was conducted in three local municipalities in the OR Tambo District: King Sabatha Dalindyebo, Nyandeni and Ngquza local municipalities with support groups and clinics in these local municipalities providing an appropriately diverse sample.

**Selection Criteria for Data Collection Sites**

The selection criteria for clinics and support groups from which interviewees were sought was that they were willing to be involved in the study and that (NAPWA-SA or partner organizations had good contacts with them) as well as ease of access.

**Sampling**

Participants aged 15 years old and above were recruited. Snowball sampling was used to identify respondents. Data about who is known to be living with HIV from existing sources such as the National HIV Household Survey was used in refining the sampling frame to ensure that the sample from the three districts was broadly in keeping with what is known about the HIV epidemiology of the region. A total of 799 respondents were recruited.

**Informed consent**

An information sheet and informed consent form were given to each interviewee. For participants below 18 years of age (i.e. 15 – 17 year old), assent was sought from their parent(s) or guardian(s) and consent from the interviewees themselves. Both the assent/consent forms and the questionnaires used were translated into IsiXhosa. Steps were taken to ensure that the minors understood the study and its purpose. Participants were also reminded of their right to refuse to participate or to withdraw at any time.

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23 The most spoken language in the study area.
Confidentiality

Specific efforts were made to ensure that the data collected was kept confidential. Both questionnaires and consent forms identified by unique identifying codes rather than respondent’ names. All interviews were conducted in a confidential space in the clinics. Such spaces were identified on a case by case basis depending on the clinic.

The data collectors, all team leaders and data capturers signed a confidentiality agreement. The people responsible for data entry, cleaning and analysis had no access to the list that contained the personal details of the interviewees, or the informed consent forms. An independent data analyst/statistician from the Walter Sisulu University undertook data analysis, and was also asked to sign a confidentiality agreement.

Data Collection instrument

Guided by a trained PLHIV interviewer, PLHIV respondents completed a questionnaire about their perceptions of stigma in the following 10 areas:

- Experiences of stigma and discrimination and their causes
- Access to work and services
- Internal stigma
- Rights, laws and policies
- Effecting change
- HIV testing
- Disclosure and confidentiality
- Treatment
- Having children
- Problems and challenges

The questions almost exclusively record respondents’ experiences during the previous twelve months. However, some questions asked about lifetime (or since diagnosis) experiences. In this report unless stated otherwise the results relate to respondents’ experiences in the previous twelve months.

The questionnaire delves into the complexity of stigma, and explores how the experience of living with HIV impacts other dimensions of a person’s life (such as work, family, legal knowledge and access to redress, health services, activism and self-esteem). The study methodology and implementation were guided by the international partnership as well as the local partnership established to support and guide the study.

Data analysis
Data was captured and analyzed using the Statistical Package for Social Science software version 18. The results presented are based on the 799 valid questionnaires that were analyzed. However, respondents were free not to answer any question and there were some questions where data was missing. Such anomalies are referred to in the reporting of individual questions and analysis.

Quality control
To assist data reliability a ‘checklist’ for interviewers was attached at the end of the questionnaire. This helped interviewers to check that all questions had been filled in as appropriate, that there was consistency in interviewees responses across questions in different sections, and that it was correctly noted when interviewees had elected not to answer specific questions24. Steps were also taken to ensure that the data from each questionnaire was appropriately captured by cross checking each entry, which was done by a separate person from the one who entered the data. Prior to analysis, the data analyst also cross checked data for consistency.

Ethical considerations
Ethical approval was applied for, and obtained, from the Human Sciences Research Council (HSRC) Research Ethics Committee (REC). A small group of HIV-positive interviewers was used to help ensure confidentiality, as people living with HIV are generally best placed to know and understand the problems that might be caused by any leakage of information about their peers. All interviewers signed a confidentiality agreement. The data capturers and analysts did not have access to the personal details of the interviewees, or the informed consent forms. The data capturers also signed a confidentiality agreement. The data was analysed using SPSS version 19 by an independent statistician from the Walter Sisulu University.

What is in this report?
Following on from the executive summary and introduction this report follows the content of the questionnaire and is divided into sections:

- Section 1: General information about the respondent and her/his household.
- Section 2: Reported experiences of HIV-related stigma and discrimination; internal stigma (felt or internalized stigma); the protection of the rights of PLHIV through law, policy and/or practice; and effecting change at household and community levels in responding to stigma and discrimination.

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24 As noted elsewhere interviewees could elect not to answer specific questions, or indeed decide not to continue with the interview at any point.
Section 3: Experience of testing, disclosure, treatment and having children.

Section 4: Outlines respondents’ opinions on the main problems and challenges in relation to HIV testing and diagnosis, disclosure and confidentiality, ART and having children through a series of open-ended questions.

Finally, conclusions and recommendations are presented.
Section 1: Background characteristics and household composition

1.1 Residency
A sample of 799 respondents was interviewed of whom 621 (77.7%) came from rural areas, 121 (15.1%) from small towns or villages, and 20 (2.5%) from large towns. According to the Social Development analyses of OR Tambo District Municipality (OR Tambo District Municipality Social Development Analysis 2012), about 93.3% of the population resides in rural areas. The distribution pattern of the respondents’ place of residence reflects the broader population distribution. Responses from thirty seven (4.6%) of the respondents as to place of residence were missing.

1.2 Gender and Age
Of the 790 respondents (98.9%) who indicated their gender, 277 (35.1%) were male, 511 (64.7%) female and two (0.3%) were transgender. The gender distribution of the respondents matches that of the population of OR Tambo District Municipality where there are more females than males (OR Tambo District Municipality Social Development analyses, 2012). Nine respondents (1.1%) did not indicate their gender.

Respondents’ ages ranged from 15-50 years and above. Nearly one third of respondents (32.3%, n=256) were aged 30-39 years, nearly one quarter (23.5%, n=186) were aged 40–49 years, over 20% (21.7%) were aged 25-29, and approximately 5% were youth aged 15-19 (6.6%) or those aged 50 or older (5.4%).

When respondents were disaggregated by gender and age, the highest percentages of both males (27.8%, n=77) and females (34.8%, n=176) were in the 30–39 age group. The percentages of males and females in the 50 and above age bracket were similar (approximately 5%). The two transgender respondents were both between 15 and 19 years of age (Table 1).
Table 1 Age distribution of respondents disaggregated by gender.

<table>
<thead>
<tr>
<th>AGE GROUPS</th>
<th>Male</th>
<th>Female</th>
<th>Transgender</th>
</tr>
</thead>
<tbody>
<tr>
<td>Youth aged 15 - 19 years</td>
<td>25 (9.0%)</td>
<td>24 (4.7%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>Adult aged 20 - 24 years</td>
<td>39 (14.1%)</td>
<td>45 (8.9%)</td>
<td>0%</td>
</tr>
<tr>
<td>Adult aged 25 - 29 years</td>
<td>56 (20.2%)</td>
<td>113 (22.3%)</td>
<td>0%</td>
</tr>
<tr>
<td>Adult aged 30 - 39 years</td>
<td>77 (27.8%)</td>
<td>176 (34.8%)</td>
<td>0%</td>
</tr>
<tr>
<td>Adult aged 40 - 49 years</td>
<td>66 (23.8%)</td>
<td>119 (23.5%)</td>
<td>0%</td>
</tr>
<tr>
<td>Adult 50+ years</td>
<td>14 (5.1%)</td>
<td>29 (5.7%)</td>
<td>0%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>277 (100%)</td>
<td>506 (100%)</td>
<td>2 (100%)</td>
</tr>
</tbody>
</table>

1.3 Length of time living with HIV

More than half of respondents (58.6%, n=466) had been living with HIV for 1-4 years, over 30% (31.9%, n=254) for 5-9 years and under 10% between 10 and 14 years (9.1%, n=69). Whereas many of the respondents who lived in rural areas, small towns and villages had been living with HIV for 1–4 years (58.6% and 58.7% respectively), most of those living in urban areas had been living with HIV for 5-9 years (45.0%) (Table 2).

Table 2 Length of time respondents living with HIV by place of residency

<table>
<thead>
<tr>
<th>Location of respondents</th>
<th>0-1 year</th>
<th>1-4 years</th>
<th>5-9 years</th>
<th>10-14 years</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>A rural area</td>
<td>3 (0.5%)</td>
<td>363 (58.6%)</td>
<td>197 (31.8%)</td>
<td>56 (9.0%)</td>
<td>619 (100%)</td>
</tr>
<tr>
<td>A small town or village</td>
<td>0 (0.0%)</td>
<td>71 (58.7%)</td>
<td>39 (32.2%)</td>
<td>11 (9.1%)</td>
<td>121 (100%)</td>
</tr>
<tr>
<td>A large town or city</td>
<td>2 (10.0%)</td>
<td>7 (35.0%)</td>
<td>9 (45.0%)</td>
<td>2 (10.0%)</td>
<td>20 (100%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5 (0.7%)</td>
<td>441 (58.0%)</td>
<td>245 (32.2%)</td>
<td>69 (9.1%)</td>
<td>760 (100%)</td>
</tr>
</tbody>
</table>

1.4 Relationship status

Nearly half of respondents were in a relationship but not living together with their partners (46.8%, n=371) with a further 6.4% (n=51) being married or cohabiting but the spouse or partner is temporarily away from the household; while slightly over 20% were married or cohabiting and currently living with their partners (22.4%, n=178) Nearly a quarter of respondents (24.4%, n=193) were single (unmarried, divorced or widowed) (Table 3).

Table 3 Relationship status of the respondents

<table>
<thead>
<tr>
<th>Relationship status</th>
<th>Frequency (Percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married or cohabiting and husband/wife/partner is currently living in household</td>
<td>178 (22.4%)</td>
</tr>
<tr>
<td>Married or cohabiting but husband/wife/partner is temporarily living / working away from the household</td>
<td>51 (6.4%)</td>
</tr>
<tr>
<td>In a relationship but not living together</td>
<td>371 (46.8%)</td>
</tr>
</tbody>
</table>
A similar percentage of male and female respondents were married and cohabiting and living in household (approximately 22%) but there were higher percentages of males who were in a relationship and not living together with their partners (53.1%, n=146 compared to 43.6%, n=221) or who were divorced or separated (5.1%, n=14 compared to 3.7%, n=19). Higher percentages of female respondents were single and widowed compared to males (11.6%, n=59 compared to 3.6%, n=59 and 12%, n=61 compared to 9.8%, n=27, respectively). Both transgender respondents were married or cohabiting and living in household with their partners (Table 4).

<table>
<thead>
<tr>
<th>Sex</th>
<th>Married or cohabiting and husband/ wife/ partner is currently living in household</th>
<th>Married or cohabiting but husband/ wife/ partner is temporarily living / working away from the household</th>
<th>In a relationship but not living together</th>
<th>Single</th>
<th>Divorced/ separated</th>
<th>Widow/ widower</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>62 (22.5%)</td>
<td>146 (53.1%)</td>
<td>27 (9.8%)</td>
<td>10 (3.6%)</td>
<td>59 (11.6%)</td>
<td>275 (100%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>113 (22.3%)</td>
<td>221 (43.6%)</td>
<td>61 (12.0%)</td>
<td>19 (3.7%)</td>
<td>59 (11.6%)</td>
<td>507 (100%)</td>
<td></td>
</tr>
<tr>
<td>Transgender</td>
<td>2 (100.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>2 (100%)</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>177 (22.6%)</td>
<td>367 (46.8%)</td>
<td>88 (11.2%)</td>
<td>33 (4.2%)</td>
<td>69 (8.8%)</td>
<td>784 (100%)</td>
<td></td>
</tr>
</tbody>
</table>

Of the 702 respondents who responded to the question about the number of years they had been in relationships, 27 (3.8%) had been with their spouse or partner for less than a year, 425 (60.6%) for 1-4 years, 206 (29.0%) for 5–9 years, and 44 (6.2%) for 10-14 years.

1.5 Sexual activity
Of the 754 respondents (94.4%) who answered the question on whether they were sexually active or not, 593 (78.6%) reported being sexually active while 161 (21.4%) were not. A third of those who were sexually active were in the 30–39 age group (33.0%, n=194), with 6.1% (n = 36) in the 15-19 age group, 11.6% (n=68) in the 20 – 24 age group, 22.6% (n=133) in the 25 – 29 age group; 21.9% (n = 129) in the 40-49 age group; while those who were 50 years and
older accounted for 4.8% (n=28). The level of sexual activity was slightly higher among male (83.6%, n=214) than female (75.9%, n=371) respondents. A greater percentage of respondents living in large towns were sexually active (94.4%, n=17) than those who lived in small towns and villages (80.7%, n=96), or rural areas (77.3%, n=435) (Table 6).

Table 5 Respondents sexual activity by area of residence

<table>
<thead>
<tr>
<th>Location of household</th>
<th>Are you sexually active?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural area</td>
<td>Yes (77.3%)</td>
<td>586 (100%)</td>
</tr>
<tr>
<td></td>
<td>No (22.7%)</td>
<td></td>
</tr>
<tr>
<td>Small town or village</td>
<td>Yes (80.7%)</td>
<td>119 (100%)</td>
</tr>
<tr>
<td></td>
<td>No (19.3%)</td>
<td></td>
</tr>
<tr>
<td>Large town or city</td>
<td>Yes (94.4%)</td>
<td>18 (100%)</td>
</tr>
<tr>
<td></td>
<td>No (5.6%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>Yes (78.3%)</td>
<td>723 (100%)</td>
</tr>
<tr>
<td></td>
<td>No (21.7%)</td>
<td></td>
</tr>
</tbody>
</table>

1.6 Key populations

Respondents were asked whether any of them belonged (now or in the past) to any of the ‘key’ populations (other than being HIV+) listed in Table 7 below – or indeed did not identify as being part of any of those populations. Some of the respondents (4.1%; n = 33) did not answer the question whereas 95.9% (n = 766) did. Of the 766 respondents who answered, 626 (81.7%) did not belong to any of these categories; while 140 did (18.3%), including 44 migrant workers (5.7%), 39 members of indigenous people (5%), 20 (2.6%) gay/lesbians, and 10 (1.3%) sex workers (Table 7).

Table 6 Respondents disaggregated by key population

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency (Percentage of respondents)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men who have sex with men</td>
<td>8 (1.0%)</td>
</tr>
<tr>
<td>Prisoner</td>
<td>5 (0.7%)</td>
</tr>
<tr>
<td>I don’t belong to, and have not in the past belonged to, any of these categories</td>
<td>627 (81.9%)</td>
</tr>
<tr>
<td>Gay or lesbian</td>
<td>20 (2.6%)</td>
</tr>
<tr>
<td>Transgender</td>
<td>2 (0.3%)</td>
</tr>
<tr>
<td>Sex worker</td>
<td>10 (1.3%)</td>
</tr>
<tr>
<td>Injecting drug user</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Refugee or asylum seeker</td>
<td>6 (0.8%)</td>
</tr>
<tr>
<td>Internally displaced person</td>
<td>5 (0.7%)</td>
</tr>
<tr>
<td>Member of an indigenous group</td>
<td>38 (5.0%)</td>
</tr>
<tr>
<td>Migrant worker</td>
<td>44 (5.7%)</td>
</tr>
<tr>
<td>Total</td>
<td>766 (100%)</td>
</tr>
</tbody>
</table>
1.7 Physical disability

When asked about having a physical disability, 765 interviewees responded, with 69 respondents (9%) reporting a physical disability of any kind (not including general ill health related to HIV) while 696 respondents (91%) indicated none. Physical disability was more common among the males (11.5%, n=30) than the females (7.3%, n=36). Both transgender respondents reported no physical disability (Table 8).

Table 7 Respondents’ physical disability by sex

<table>
<thead>
<tr>
<th>SEX</th>
<th>Physical disability</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Male</td>
<td>30 (11.5%)</td>
<td>230 (88.5%)</td>
</tr>
<tr>
<td>Female</td>
<td>36 (7.3%)</td>
<td>459 (92.7%)</td>
</tr>
<tr>
<td>Transgender</td>
<td>0 (0.0%)</td>
<td>2 (100%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>66 (8.7%)</td>
<td>691 (91.3%)</td>
</tr>
</tbody>
</table>

1.8 Education

In terms of level of education, 786 (98.4%) of the 799 respondents answered the question with data missing for 13 (1.6%) of the respondents. While over half of the 786 respondents (50.6%, n=398,) had attained secondary school education and 5% (n=39) had attained technical college/university level; over one third of respondents reported only primary level education (34.1%, n=268), and the other 10.3% reporting no formal education (n=81).

When the highest level of education attained was looked at in relation to sex, secondary school education was the highest level of education attained by both males (47.4%, n=127) and females (52.3%, n=265). A slightly higher percentage of male respondents had completed primary and technical/university education compared to female respondents (36.6% (n =98) compared to 33.1% (n=168), and 6.7% (n=18) compared to 3.9% (n=20), while a slightly higher percentage of female respondents reported no formal education than male respondents (10.7%; n = 54 compared to 9.3%; n=25). Of the two transgender respondents one had completed secondary school and the other had completed a technical/university education.

1.9 Employment

Of the 799 survey respondents, 786 (98.4%) answered questions about their employment status. Some 437 respondents (55.6%) reported being unemployed with 349 respondents (44.4%) reporting some form of employment. The high level of unemployment among respondents is a reflection of the situation in the municipality, with an employment level of 65.6%.

Of those who reported being in some form of employment in the last year, 88 (25.2%) were in

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full time employment as employees, 82 (23.5%) in part-time employment, 57 (16.3%) were self-employed and 122 (35%) were doing casual work.

When respondents’ employment status was disaggregated by level of education, a higher number of respondents with no formal education (80%, n=64), primary education (67.3% n=167), and secondary education (49.5%, n=195) were unemployed. More than 45 % (48.7 %, n=19) of those who had reached technical or university level were in full-time employment.

The stratification of respondents according to level of education attained and current employment status is presented in (Figure 1). A greater percentage of males (53.3%, n=145) were engaged in some form of employment, whereas most of the females (60.6%, n=305) were unemployed.

![Figure 1](image.png)

**Figure 1** Relationship between employment status and level of education

### 1.10 Income

Of the 781 respondents (97.7%) who answered the question about income, 378 (48.4%) had a monthly income of between R1000-R3000 and a further 12.8% (n=48) had a monthly income of between R3000-R5000. While over 50% of respondents (55.6%, n= 437) of those answering the question about employment reported being unemployed and not working at all, less than 1% (0.6%, n=5) indicated that they had no monthly income. The two respondents who earned between R10 000 and R15 000 were males who were in full-time employment and who had completed secondary education.

### 1.11 Household size

Respondents were asked to indicate the number of people within specified age groups living in

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26 See footnote 8 for how this relates to official poverty statistics
their household. Some respondents (19.9%, n=155,) indicated that they had no member of their household within the 0 – 14 year age group, more than 25% of the 778 respondents who answered the question on number of household members within the 0 to 14 year old bracket said they had one or two of them in their households (Table 9). The number of people within the specific age groups living in the household of the respondents decreased as the specific ages of the members increased (Table 9). The number of people living in the respondents’ household and their distribution according to the age groups are indicated in Table 9.

**Table 8** Number of people living in the household

<table>
<thead>
<tr>
<th>Number of children</th>
<th>Children aged 0-14 years</th>
<th>Youth aged 15-19 years</th>
<th>Adults aged 20-24 years</th>
<th>Adults aged 25-29 years</th>
<th>Adults aged 30-39 years</th>
<th>Adults aged 40-49 years</th>
<th>Adults aged 50 years and above</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>155 (19.9%)</td>
<td>336 (44.3%)</td>
<td>451 (60.0%)</td>
<td>462 (61.5%)</td>
<td>458 (61.4%)</td>
<td>499 (66.4%)</td>
<td>483 (64.9%)</td>
</tr>
<tr>
<td>1</td>
<td>218 (28.0%)</td>
<td>280 (36.9%)</td>
<td>204 (27.1%)</td>
<td>204 (27.2%)</td>
<td>230 (30.8%)</td>
<td>193 (25.7%)</td>
<td>197 (26.5%)</td>
</tr>
<tr>
<td>2</td>
<td>214 (27.5%)</td>
<td>112 (14.8%)</td>
<td>86 (11.4%)</td>
<td>67 (8.9%)</td>
<td>37 (5.0%)</td>
<td>52 (6.9%)</td>
<td>58 (7.8%)</td>
</tr>
<tr>
<td>3</td>
<td>108 (13.9%)</td>
<td>23 (3.0%)</td>
<td>11 (1.5%)</td>
<td>16 (2.1%)</td>
<td>18 (2.4%)</td>
<td>6 (0.8%)</td>
<td>3 (0.4%)</td>
</tr>
<tr>
<td>4</td>
<td>55 (7.1%)</td>
<td>8 (1.1%)</td>
<td>0 (0.0%)</td>
<td>2 (0.3%)</td>
<td>3 (0.4%)</td>
<td>1 (0.1%)</td>
<td>3 (0.4%)</td>
</tr>
<tr>
<td>5</td>
<td>19 (2.4%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>6</td>
<td>5 (0.6%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>7</td>
<td>3 (0.4%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>10</td>
<td>1 (0.1%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
<td>0 (0.0%)</td>
</tr>
<tr>
<td>Total</td>
<td>778 (100%)</td>
<td>759 (100%)</td>
<td>752 (100%)</td>
<td>751 (100%)</td>
<td>746 (100%)</td>
<td>751 (100%)</td>
<td>744 (100%)</td>
</tr>
</tbody>
</table>

The number of children and youths living in respondents’ households who were orphans as a result of AIDS varied; however, of the 775 respondents who answered the question, 681 (87.9%) indicated that they had no such orphans in their homes (Table 10) while 94 respondents (12.1%) indicated that they had children and youths who are AIDS orphans living in their homes. Most of these respondents were those with many dependents aged 0–14.
Table 9 Number of children and youth in your household who are AIDS orphans

<table>
<thead>
<tr>
<th>Number of children and youths who are AIDS orphans</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>681 (89.9%)</td>
</tr>
<tr>
<td>1</td>
<td>66 (8.5%)</td>
</tr>
<tr>
<td>1–2</td>
<td>7 (0.9%)</td>
</tr>
<tr>
<td>3–4</td>
<td>19 (2.5%)</td>
</tr>
<tr>
<td>5+</td>
<td>2 (3%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>775 (100%)</td>
</tr>
</tbody>
</table>

1.12 Food Security

When asked the number of days in the last month during which any member of the respondents’ households had gone without food, 771 respondents (96.5%) answered. While 364 respondents (47.2%, n=364) indicated there was no day in the last month during which a household member had gone without food; over half of the respondents (52.7%, n=4087) indicated food shortages within the household. Of these, 274 (35.5%) had shortages for 1–4 days, 13.4% (n=103) for 5–10 days, 2.6% (n=20) for 11–19 days and 1.3% (n=10) for 20 and more days. Those who had gone without food more often had low monthly income (from nothing to R3000 a month) and were mostly unemployed.

Section 2: Experience of stigma and discrimination

This section comprises five sub-sections: experiences of HIV-related stigma and discrimination; discrimination related to accommodation, work, education and health services; internalized stigma; protection through the law, policies or practice; and effecting change.

2.1 Experience of HIV-related stigma and discrimination

Exclusion from social gatherings or activities

When asked how often the respondents had been excluded from social gatherings or activities in the last 12 months, 715 respondents (89.5%) indicated that they had never been excluded, whereas, in total, 84 respondents (10.6%) reported being excluded; including excluded once (n=22, 2.8%), a few times (n=45, 5.6%) or often (n=17, 2.1%). Exclusion from social gatherings and activities was highest among those who live in small towns or villages (21.5%, n=26) compared to those living in rural areas (9.1%, n=56) and large towns and cities (10%, n=2). The responses also indicated an increase in exclusion from social gatherings and activities with increase in level of education attained. Of those with technical college and university education (15.4%, n=6) reported exclusion, with lower levels of reported exclusion for other groups: secondary education (11.8%, n=47), primary education (9%, n=24) and no formal education (7.4%, n=6).
Of the 84 respondents, 78 (92.9%) answered a further question on the reason for exclusion while six (7.1%) did not. The reasons given by the 78 respondents for being excluded from social gatherings and activities included HIV status (16.7%, n=13), HIV status and other reasons (35.9%, n=28), other reasons (24.4%, n=19) or unsure why (23.1%, n=18).

Exclusion was slightly higher among males (11.6%, n=36) than females (9.4%, n=48). Among male respondents, HIV status and HIV status and other reasons were the more common reasons cited (61.3%, n=19) compared to other reasons or being unsure why they had been excluded (38.7%, n=12). Among male respondents, the percentage who cited either their HIV status or HIV status and other reasons for exclusion from social gatherings was lower (47.8%, n=22) compared to other reasons or being unsure why they had been excluded (52.2%, n=22).

HIV status was also a common reason for exclusion from social gatherings among those who lived in rural areas (54.7%, n=29). HIV status and other reasons as a cause of exclusion from social gathering was split in small towns and villages (12, 50%) as well as among those who had attained technical college/university education (3, 50%). Among those with primary and secondary education, a higher percentage cited HIV status in part or as a whole with fewer citing other reasons.

**Exclusion from religious activities or places of worship**

The level of exclusion from religious activities or places of worship was lower than from social gatherings or activities with 755 respondents (94.5%) stating that they had never been excluded from religious activities or places of worship during the preceding 12 months. Sixteen respondents (2%) indicated that they had been excluded once, 19 (2.4%) a few times, and nine (1.1%) often.

Exclusion from religious activities was higher among male (6.1%, n=17) than female (4.7%, n=24) respondents. As with exclusion from social gatherings and activities, there was an increase in exclusion from religious activities as the level of education attained increased; highest level of education attained (technical college/university (7.9%), secondary education (5.5%), primary education (4.5%) and no formal education (2.5%). Exclusion from religious activities appears higher among those living in large town and cities (15%, n=3) than in rural areas (4.2%, n=26) and small towns and villages (9.9%, n=12).

When asked for a reason for exclusion, 12 respondents (30%) who had been excluded at least once from religious gatherings or place of worship were not sure why they were excluded, and eight (20%) stated that it was for reasons other than HIV status. In total, 50% cited HIV being the sole (17.5%, n=7) or contributing factor (32.5%, n=13) to their exclusion.
Among female respondents (n=12, 52.1%) excluded from religious activities or places of worship, those living in small towns and villages (n=6, 60%), those with no formal education (n=6, 54.6%), and those with secondary education (n=11, 52.3%), HIV status was more commonly cited to explain exclusion; whereas among male respondents (n=9, 52.9%), those living in rural areas (n=13, 52%), those living in large towns and cities (n=2, 100%) and those who had attained technical college or university education, ‘other’ reasons were cited.

Exclusion from family activities

In total, 71 respondents (8.9%) reported being excluded from family gatherings and activities, including 22 (2.8%) once, 40 (5.0%) a few times, and nine (1.1%) often; 727 (91.1%) indicated that they had never experienced any form of exclusion. There was no difference between male and female respondents with regards to exclusion from family gatherings; however, the reported instances of exclusion increased with level of highest education attained.

In terms of reasons for exclusion, 68 respondents (95.8%) provided a response with 18 (26.5%) indicating that it was because of their HIV status and another 27 (39.7%) citing both their HIV status and other reasons. Ten respondents (14.7%) were not sure why they were excluded, and 13 (19.1%) said they were excluded for other reasons.

High percentages of male (53.8%, n=14) and female (75.6%, n=21) respondents, those living in rural areas (71.3%, n=33) and small town and village (55.6%, n=10), those who had no formal education (66.7%, n=2), primary (75.5%, n=15) or secondary education (63.9%, n=23) cited HIV status and HIV status and other reason to explain why they were excluded from family activities. Other reasons were cited mainly by those who live in large towns and cities (100%, n=2).

Comparison of exclusion from social, religious and family gatherings

These results indicate HIV-related exclusion is more common from social gatherings (10.6%, n=84) or from family gatherings (8.9%, n=71) than from religious activities (5.5%, n=44). Religious institutions have been documented as playing both supportive and detrimental roles towards PLHIV (Campbell et al., 2005; Iwelumnor et al., 2006; Hartwig et al., 2006; and Campbell et al., 2007). However these findings (of relatively low levels of stigma experienced in religious gatherings in the OR Tambo region) bear further exploration; overall the levels of religious exclusion are lower than those reported in PLHIV stigma index reports from other countries in Africa27.

Being gossiped about

South Africa

When asked how often the respondents were aware of being gossiped about, 559 respondents (70.0%) indicated that they had never been gossiped about, however, 237 respondents said they had been gossiped about, including 26 (3.3%) once, 131 (16.4%) a few times, and 80 (10%) often. Of these 237 respondents (29.7%) who indicated that they had been gossiped about, 215 (90.7%) respondents gave reasons for why they thought they were gossiped about, including 65 (30.2%) who said it was mostly because of their HIV status, 80 (37.2%) said it was both because of their HIV status and other reasons, 16 (7.4%) said it was for other reasons, while 54 (25.1%) respondents were unsure.

When an association between the reasons for being gossiped about and the number of times it occurred were analyzed, the highest percentage (40.8%, n=29) was respondents who, because of their HIV status and other reasons, were gossiped about often, and when aggregated with the reason of HIV status, HIV is implicated in 71.8% of instances of frequent gossiping (Figure 2). Many of those who indicated that they had been gossiped about once said they were not sure why this had occurred (31.8%).

![Figure 2 Reason for being gossiped about and frequency of gossip](image)

**Verbally insulted, harassed and/or threatened**

When asked whether they had been verbally insulted, harassed and/or threatened in the last 12 months, 666 respondents (83.4%) said they had never been verbally insulted, harassed and or threatened. However 133 respondents (16.6%) indicated that they had been verbally insulted, harassed or threatened. Of these 133, 46 (34.6%) said this had occurred once, 64 (48.1%) said it had occurred a few times and 23 (17.3%) said this occurred often. There was no significant difference between the experience of male (16.6%) and female (16.2%)
respondents. In relation to place of residency, the level of verbal insults, harassment and threats experienced was highest among those respondents who lived in small towns and villages (28.9%, n=35), followed by those living in large towns and cities (20%, n=4) and then those living in rural areas (14.3%, n=89). There was also a positive association between the highest level of education attained and the level of verbal threats, insults and harassment experienced: technical college/university (33.3%, n=13), secondary education (19.6%, n=78), primary education (12.3%, n=33), and no formal education (9.9%, n=8).

When asked why they thought they were subjected to verbal abuse, 126 (94.7%) of the 133 respondents answered the question, of whom 53 (42.1%) indicated that it was both because of their HIV status and other reasons, 38 (30.2%) cited their HIV status, 24 (19.0%) cited other reasons and 11 (8.7%) were unsure. When the relationship between the reasons for being verbally insulted, harassed or threatened and their frequency were analyzed, 12 respondents who had often been verbally insulted, harassed or threatened (52.2%) cited their HIV status as the reason and when aggregated with the reason of HIV status and other reasons, HIV is implicated in 91.3% of these instances. Further, 50.8% of respondents who had experienced being verbally insulted, harassed or threatened a few times (n=30) believed it was because of their HIV status and other reasons (Figure 4).

![Figure 3 Frequency of verbal insults and reasons for this](image)

Of those who had experience verbal insults (133, 16.6%) a high percentage of male (75%, n=23) and female (70%, n=56) respondents, those living in rural areas (69%, n=58) and small town and village (79.5%, n=27), and among the different levels of education cited HIV status and HIV status and other reason to explain why they had experienced verbal insult, harassment or threat.
Physical harassment and/or threat
Of the 76 respondents (9.6%), who reported being physically harassed and/or threatened in the previous 12 months, 28 (36.8%) experienced this once, 34 (44.7%) a few times and 14 (18.4%) often, though 722 respondents (90.4%) said that they had never been physically harassed and/or threatened.

A higher number of female respondents (54, 10.6%) indicated that they had been physically harassed and/or threatened compared to male respondents (19, 6.9%). Physical harassment and/or threats was highest among those living in small towns and villages (16.5%, n=22) compared to 7.9% (n=49) among those in rural areas and 5% (n=1) among those in large towns and cities. In terms of the relationship between education and respondents being physically harassed and/or threatened: technical college or university (18%, n=7), secondary education (11.2%, n=44), no formal education (7.4%, n=6) and primary education (7.1%, n=19).

When the reasons for physical harassment and/or threat were disaggregated by frequency, half of respondents who had been physically harassed and/or threatened 20% (n=14) said it was because of their HIV status with a further 38.6% (n=27) citing their HIV status and other reasons. Of those who had been physically harassed and/or threatened a few times, 53.3% (n=16) said it was because of their HIV status and other reasons with a further 16.7% (n=5) citing their HIV status (Table 11). Among male and female respondents and when disaggregated by education and residency, HIV status and HIV status and other reasons were cited as the main reasons for physical harassment and/or threats.

Table 10 Reasons for physical abuse of respondents against number of times

<table>
<thead>
<tr>
<th>Number of times physically harassed</th>
<th>Reason for physical harassment and/or threats received</th>
<th>Because of your HIV status N (%)</th>
<th>For an(other) reason N (%)</th>
<th>Both because of your HIV status and other reason(s) N (%)</th>
<th>Not sure why N (%)</th>
<th>TOTAL N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td></td>
<td>2 (7.7)</td>
<td>10 (38.5)</td>
<td>7 (26.9)</td>
<td>7 (26.9)</td>
<td>26 (100)</td>
</tr>
<tr>
<td>A few times</td>
<td></td>
<td>5 (16.7)</td>
<td>4 (13.3)</td>
<td>16 (53.3)</td>
<td>5 (16.7)</td>
<td>30 (100)</td>
</tr>
<tr>
<td>Often</td>
<td></td>
<td>7 (50.0)</td>
<td>3 (21.4)</td>
<td>4 (28.6)</td>
<td>0 (0.0)</td>
<td>14 (100)</td>
</tr>
<tr>
<td>TOTAL</td>
<td></td>
<td>14 (20.0)</td>
<td>17 (24.3)</td>
<td>27 (38.6)</td>
<td>12 (17.1)</td>
<td>70 (100)</td>
</tr>
</tbody>
</table>

Physical assault
Physical assault had been experienced by 56 (7%) of the 799 respondents in the last 12 months while 740 (92.6%) had not experienced physical assault. Of the 56 respondents, 25 (44.6%) had been physically assaulted once, 22 (39.3%) were assaulted a few times and nine (16.1%) had been assaulted often.

When asked why they had been physically assaulted, 52 respondents answered. While 8 (15.4%) were not sure why, five (9.6%) indicated that it was because of their HIV status and 19
(36.5%) said it was because of both their HIV status and other reasons (Table 12); and 20 (38.5%) cited other reasons.

Table 11 Reason for physical assault

<table>
<thead>
<tr>
<th>Reason for physical assault</th>
<th>Frequency (Percentage of respondents)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because of your HIV status</td>
<td>5 (9.6%)</td>
</tr>
<tr>
<td>For (an) other reason(s)</td>
<td>20 (38.5%)</td>
</tr>
<tr>
<td>Both because of your HIV status and other reason(s)</td>
<td>19 (36.5%)</td>
</tr>
<tr>
<td>Not sure why</td>
<td>8 (15.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>52 (100%)</td>
</tr>
</tbody>
</table>

The percentage of female respondents who had experienced physical assault (8.1%, n=41) was nearly double that of male respondents (4.3%, n=12). Among females, the percentage of those who cited their HIV status as a reason for physical assault (50%, n=20) was equally split with those who cited other reasons (50%, n=20); while among male respondents, double the number cited other reasons compared to those who cited their HIV status (n=8, 66.6% compared to n=4, 33.3%).

The percentage of those living in small towns and villages (10%, n=12) and those in large towns and cities (10%, n=2) that had experienced physical assault was equal, while it was lower among those living in rural areas (5.8%, n=36). A higher number of those living in small towns and villages (n=7, 70%) cited their HIV status as the reason for physical assault, while 3 (30%) cited other reasons or were not sure of the reason. Among respondents from the rural areas, nearly two thirds were either not sure or cited other reasons (62.9%, n=22) for their experience of physical assault; while 37.1% (n=13) cited their HIV status as all or part of the reason. Note that none living in large towns and cities cited their HIV status as a reason.

The levels of physical assault experienced among those who had attained primary (7.5%, n=20) and secondary education (7.3%, n=29) were similar and were lower among those who had no formal education (6.2%, n=5) and lowest among those who had attained technical college/university education (5.1%, n=2). Except among those who had attained secondary education of whom a higher percentage (53.6%, 15) indicated that their HIV status was the reason for physical assault; other reasons were cited by all other education level groups to explain physical assault.

When the reasons for physical assault were disaggregated by frequency, 55.6% (n=5) who had been physically assaulted often said it was because of both their HIV status and other reasons with a further 11.1% (n=1) citing their HIV status (Table 13).
Table 12 Respondents who had been physically assaulted for various reasons

<table>
<thead>
<tr>
<th>Number of times assault occurred</th>
<th>Reason for physical assault</th>
<th></th>
<th></th>
<th>Total (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Because of your HIV status</td>
<td>For (an)other reason(s)</td>
<td>Both because of your HIV status and other reason(s)</td>
<td>Not sure why</td>
</tr>
<tr>
<td>Once</td>
<td>3 (12.0%)</td>
<td>13 (52.0%)</td>
<td>6 (24.0%)</td>
<td>3 (12.0%)</td>
</tr>
<tr>
<td>A few times</td>
<td>1 (5.6%)</td>
<td>6 (33.3%)</td>
<td>8 (44.4%)</td>
<td>3 (16.7%)</td>
</tr>
<tr>
<td>Often</td>
<td>1 (11.1%)</td>
<td>1 (11.1%)</td>
<td>5 (55.6%)</td>
<td>2 (22.2%)</td>
</tr>
<tr>
<td>Total</td>
<td>5 (9.6%)</td>
<td>20 (38.5%)</td>
<td>19 (36.5%)</td>
<td>8 (15.4%)</td>
</tr>
</tbody>
</table>

Who physically assaulted

When asked who physically assaulted them, 38 of 56 respondents answered the question. Half (n=19) said that they were assaulted by their spouse or partner, with over one quarter (28.9%, n=11) indicating that it was by other members of the household. Persons outside the household and known to a respondent had assaulted five (13.2%) respondents whereas three (7.9%) had been assaulted by persons unknown to them.

When who physically assaulted was disaggregated by frequency, out of the 19 respondents who were assaulted by their spouse or partner, 10 (55.6%) said it was because of both their HIV status and other reasons and another one solely due to HIV status (5.6%). Of physical assaults by other members of the household, 63.6% (n=7) were for other reasons besides their HIV status (Figure 5).

Figure 142 Reasons for physical assaults and perpetrators

Comparison of the different experiences of respondents
When comparing the frequency of different negative experiences of people living with HIV, Table 14 shows that nearly one third have been gossiped about (29.8%, n=237), over 15% have experienced verbal insults, harassment and/or threats (16.6%, n=133), and less than 10% have experienced physical harassment and/or threats (9.5%, n=76) or physical assault (7.0%, n=56).

Table 13 Comparison of the different experiences by respondents

<table>
<thead>
<tr>
<th>Kind of Stigma experienced</th>
<th>Frequency of experience</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never (%)</td>
<td>At least once (%)</td>
</tr>
<tr>
<td>Gossip</td>
<td>559 (70.2%)</td>
<td>237 (29.8%)</td>
</tr>
<tr>
<td>Verbal insults/harassment/threats</td>
<td>666 (83.4%)</td>
<td>133 (16.6%)</td>
</tr>
<tr>
<td>Physical harassment and/or threats</td>
<td>722 (90.5%)</td>
<td>76 (9.5%)</td>
</tr>
<tr>
<td>Physical assault</td>
<td>740 (93.0%)</td>
<td>56 (7.0%)</td>
</tr>
</tbody>
</table>

Key population-related discrimination

Respondents were requested to elaborate upon the reasons for the discrimination they experienced in instances in which it was not because of their HIV status. Of the 258 respondents who experienced stigma and/or discrimination for reasons other than their HIV status, 33 (12.8%) indicated that the main reasons was their sexual orientation, 26 stated it was because they were a migrant worker (10.1%) and 21 because they were a sex worker (8.1%). Other reasons included being a member of an indigenous group (5.8%, n= 15), an ex-prisoner (3.5%, n=9), refugee or asylum seeker (3.5%, n=9), internally displaced person (1.9% n =5), or person who uses drugs/injecting drug user (1.2%, n=3). More than half of these respondents (53.1%, n=137) cited reasons other than those presented in the questionnaire.

Stigma and discrimination in relationships

To determine whether there was any form of discrimination experienced by the respondents in their relationships, information on how they were treated by their spouse or partner, level of sexual rejection, levels of discrimination by other PLHIV, discrimination from spouse or partner and the reasons for these experiences was requested.

Of the 799 respondents interviewed, 699 (87.8%) indicated that their spouse or partner had never used their HIV-positive status to subject them to any form of psychological pressure or manipulation, though 12.2% had; 709 (89%) had never experienced sexual rejection because of their HIV status, though 11% had; 740 (93%) had never been discriminated against by other PLHIV, though 7% had, While discrimination against spouse or partner or other member of the household because of the respondent’s HIV status had never occurred to 665 (83%) respondents, 17% (n=134) had experienced this. Discrimination experienced by PLHIV from other PLHIV was experienced by 56 (7 %) of the 796 (99.6%) who answered the question.
A total of 293 (36.7%) respondents were asked for reasons why they thought they experienced some form of HIV-related stigma and/or discrimination in the past 12 months with over 30% (32.4%, n=95) stating that they did not know why; while of those who knew, the most common reasons cited were because they felt people were afraid of being infected by them (n=62, 21.2%), 51 respondents (17.4%) believed that people were not aware of how HIV was transmitted and a further 11.6% (n=34) believed it was because they looked sickly with symptoms associated with HIV (Figure 6).

![Figure 6 Reasons respondents felt stigmatized and discriminated against](image)

**Figure 6** Reasons respondents felt stigmatized and discriminated against

### 2.2 Access to accommodation, work, education and health services

**Accommodation**

Most respondents (90.1%, n=720) had never been forced to change their residence or been unable to rent accommodation during the 12 months preceding the study, though 77 (9.6%) had with 53 (6.6%) indicating that this had occurred once, 13 (1.6%) a few times, and 11 (1.4%) often. When asked why this had happened, 74 respondents answered the question with 28 (37.8%) stating that it was because of both their HIV status and other reasons and another 16 (21.6%) because of their HIV status, with 20 respondents (27.0%) citing other reasons and 10 respondents (13.5%) were not sure why this had occurred.

When the number of times the respondents were forced to change place of residence were disaggregated by frequency, 21 (41.2%) and six (54.5%) of those who had been forced to change their residence once or a few times respectively, indicated that it was mainly because of both their HIV status and other reasons. In addition, 45.5% who had frequently changed residence cited other reasons, and not their HIV status (Figure 7).
Over half of respondents were unemployed (55.6%, n=440); while of the 349 respondents who had some form of employment, 40 had lost a job, including 26 (6.7%) once, 11 (2.8%) a few times, and three (0.8%) often. When asked why they thought they lost their jobs, 36 of the 40 respondents answered the question. Of these, 24 (66.72%) were either not sure why they had lost their jobs or cited other reasons; while 12 (33.7%) cited their HIV status in part or as the main reason why they lost their jobs. The respondents who cited their HIV status as the reason said it was either because of discrimination by their employer and co-workers, or because they felt obliged to stop working due to poor health, or both.

Furthermore, 23 (2.9%) of the 799 respondents reported having been refused employment because of their HIV status. Approximately half of the respondents (403, 50.4%) did not answer this question, in part, because over half were unemployed and 22.4% (n=179) were self-employed.

Respondents were asked whether their job description and nature of work had been changed or whether they had been refused promotion in the last 12 months. Among the 317 (39.7%) respondents who answered this question, 302 (95.3%) said there had been no change in their job description and nature of work whereas 15 respondents (4.7%) said this had occurred at least once with eight (53.4%) citing one instance, five (33.3%) a few times, and two (13.3%) often. Among the eight respondents whose job description had been changed or who had been refused promotion once, the main reason was discrimination by their employers and co-workers (75%, n=6); whereas among those who had experienced this a few times, the main
reason was because their poor health prevented them from doing certain things (80%, n=4).

**Education**

Respondents were asked how often they had been dismissed, suspended or prevented from attending an educational institution because of their HIV status in the last 12 months. Of the full sample of 799, 69 respondents reported this was not applicable to them and a further 6 did not respond to the question. Of the remaining 724, 21 respondents (2.9%) reported that they had been dismissed, suspended or prevented from attending an educational institution because of their HIV status in the last 12 months; 16 citing one instance, four a few times, and one stating this had occurred often.  

The respondents were asked whether their children had been discriminated against with regards to access to education in the previous 12 months. Of the full sample of 799, 42 respondents said this was not applicable and a further 8 did not respond to the question. Of the remaining 749, 9 (1.2%) indicated that their child, or children had faced some form of discrimination with this occurring once for 8 of the respondents and more than once for 1 respondent.

**Health Services**

In terms of access to health services (including dental services) in the last 12 months, 759 respondents (95%) indicated that they had never been denied access to health services because of their HIV status; though 22 had, including 19 respondents (2.4%) who had been denied once and three (0.4%) had been denied a few times. None of the respondents indicated that this had occurred often. The remaining 18 respondents either did not answer the question (1.1%, n = 9) or indicated that it was not applicable (1.1%, n = 9).

In terms of access to family planning services in the last 12 months, 51 respondents (6.5%) said they had been denied access because of their HIV status while 643 of them (81.8%) said this had never happened.

In terms of denial of access to sexual and reproductive health services in the last 12 months, 28 (3.5%) of 799 respondents indicated that they had been denied access while 764 (95.6%) said this had never occurred.

**2.3 Internalised stigma**

Feelings experienced by PLHIV

In order to gain insight into respondents’ internalised stigma, interviewees were asked to identify feelings they had experienced because of their HIV status. Responses varied; however, over one third blamed themselves (34.9%, n=279), over one quarter felt ashamed (25.9%,

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28 On analysis the numbers reporting that this was not applicable to them – i.e. that they had not attempted to pursue any educational opportunities in the previous 12 months are small. It is suspected that there was a possible mis-translation or misunderstanding of the question and indeed the numbers may well be higher,
n=207), and less than one in five had low self-esteem (18.3%, n=146) or felt guilty (14.1%, n=113). Furthermore, nearly 10% of respondents (9.6%, n=77) reported feeling suicidal.

According to Wadell and Burton (2006) and Black (2012), individuals who are unemployed tend to be socially isolated and suffer more anxiety and depression. Similarly, a study by Rodgers et al. (2010) found that PLHIV not working had significantly poorer psychological health than those working. The high level of unemployment among respondents (55.6%, n= 437) could be a contributory factor exacerbating levels of internalised stigma, however internalised stigma also existed in similar levels amongst those in the study who were in employment.

Figure 4.45 Feelings experienced because of HIV status

When the data about respondents reporting internalized stigma were disaggregated by gender, 275 male and 508 females were included. Levels of internalized stigma were higher among male than female respondents. For example, 42.9% of male compared to 31.1% of female respondents reported blaming themselves, and 12.7% of male respondents compared to 8.9% of female respondents felt suicidal (Figure 10).
Decisions, resignations, avoidance

Respondents were also asked to indicate the things they had done or not done because of their HIV status. The most frequently cited reaction by 41.6% of respondents (n=332) was the decision not to have (more) children. Furthermore, 18.9% (n=151) chose not to attend social gathering(s), 16.1% (n=129) opted not to marry; and 12.8% (n=102) isolated themselves from friends and relatives (Table 15).

Internalised stigma also affected access to health care: 3.1% (n=25) avoided going to a local clinic when they needed care, and 3% (n=24) avoided going to hospital. In relation to study and employment: 4.6% (n=37) decided not to apply for a job or a promotion, 4.4% (n=35) withdrew from education or training, and 3.4% (n=27) gave up their job (Table 15).

Table 14 Things done and decisions taken by respondents because of their HIV status

<table>
<thead>
<tr>
<th>THINGS DONE BY RESPONDENTS</th>
<th>Number of respondents</th>
<th>Percentage of all respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have chosen not to attend social gathering(s)</td>
<td>151</td>
<td>18.9</td>
</tr>
<tr>
<td>I have isolated myself from my family and/or friends</td>
<td>102</td>
<td>12.8</td>
</tr>
<tr>
<td>I took the decision to stop working</td>
<td>27</td>
<td>3.4</td>
</tr>
<tr>
<td>I decided not to apply for a job/work or for a promotion</td>
<td>37</td>
<td>4.6</td>
</tr>
<tr>
<td>I withdrew from education/training or did not take up an opportunity</td>
<td>35</td>
<td>4.4</td>
</tr>
<tr>
<td>I decided not to get married</td>
<td>129</td>
<td>16.1</td>
</tr>
<tr>
<td>I decided not to have sex</td>
<td>111</td>
<td>13.9</td>
</tr>
<tr>
<td>I decided not to have (more) children</td>
<td>332</td>
<td>41.6</td>
</tr>
<tr>
<td>I avoided going to a local clinic when I needed to</td>
<td>25</td>
<td>3.1</td>
</tr>
<tr>
<td>I avoided going to a hospital when I needed to</td>
<td>24</td>
<td>3.0</td>
</tr>
</tbody>
</table>
When disaggregated by gender, greater percentages of male than female respondents chose not to attend social gatherings (25.3% (n =70) compared to 15.7% (n =80)), isolated themselves from their family and/or friends (17.3%; n=48 compared to 10.4%; n=53), stopped working (4.3%; n=12 compared to 2.9%; n=15), not to apply for a job/work or promotion (4.7%; n=13 compared to 4.5%; n=23), withdrew from education/training or did not take up opportunity for education/training (4.7% compared to 3.9%), decided not to get married (20.2%; n=56 compared to 14.1%; n=72), and avoided going to local clinic (4.7%; n=13 compared to 2.2%; n=11) or hospital when needed to (4%; n=11 compared to 2.4%; n=12). Conversely, greater percentages of female than male respondents decided not to have sex (14.3%; n =73 compared to 12.6% (n =35) and more children (42.4%; n=216 compared to 40.1%; n=111),

Though these gender-based differences were statistically significant only between male and female respondents who chose not to attend social gatherings, isolated themselves from family and friends, and chose not to get married; the findings indicate that overall men living with HIV in the study reported more internalised stigma than women living with HIV.

Fears experienced by respondents

Respondents were asked whether they were fearful of gossip, verbal insults, physical harassment and physical assault. Some respondents (45.4%, n=363) indicated that they were fearful of being gossiped about, with nearly 20% (17.5%, n=140) afraid of being verbally insulted, harassed and/or threatened, while approximately 10% were afraid of being physically harassed and/or threatened (10.5%, n=84) or being physically assaulted (9.3%, n=74). These findings highlight the fact that gossip is what the respondents fear the most followed by verbal insults/harassment/threats, with fear of physical insult being the least. There was little difference between the levels of fear when the data was disaggregated by gender (Figure 12).

In addition, nearly 20% of respondents (19.5%, n=156) indicated that they were scared someone would not want to be sexually intimate with them because of their HIV-positive status with higher levels of fear among male than female respondents (27.4%, n=75 compared to 15.3%, n=78).
2.4 Rights, laws and policies

Knowledge of the Declaration of Commitment and AIDS Charter

The level of awareness of rights of and policies related to PLHIV was addressed. The results indicate that 210 (26.3%) had heard of the Declaration of Commitment on HIV/AIDS, with higher levels of awareness among male than female respondents (29.6%, n=81 compared to 24.3%, n=124).

When asked whether they had read or discussed the Declaration of Commitment, 71 of 210 (33.8%) had; there was gender-based difference among respondents: male, 29.6% (n=24) and female, 33.9% (n=42). There was a positive association between respondents’ level of education and awareness of the Declaration of Commitment on HIV/AIDS i.e. levels of awareness increased with higher levels of education (Figure 13).

With regards to the AIDS Charter on Rights and Responsibilities\(^\text{29}\), nearly one quarter of (23.4%, n=187) had heard of it; of whom, 48.7% (n=91) had read or discussed it. There was no

\(^{29}\) The ‘charter’ (accessible at –http://www.aidsconsortium.org.za/About.htm#charter) was first drafted in 1992 by Edwin Cameron, Edward Swanson and Mahendra Chetty. It follows the Freedom Charter of South Africa, the Universal Declaration of Human Rights and is a forerunner to the Bill of Rights in the Constitution of South Africa 1996. Translated into Afrikaans, Zulu, Tsonga, Venda, Xhosa and Sotho, it has been adopted as a guiding principle by many organisations responding to HIV in South Africa. In July 2009, it was re-launched, taking into consideration the current context of the HIV epidemic in South Africa. The charter of itself has no legal force; but as The AIDS Consortium (the originators of the document) put it ‘calls upon every South African to continue their passion of activism by interacting with this document and taking ownership for its implementation’.
significant gender-based difference of awareness of the AIDS Charter: male, 47.1%; n=33 and female, 50%; n=56). However, level of education seems to have had an effect on the level of awareness, with those who had attained technical/university education being the most aware of the AIDS Charter (38.5%; n=15), followed by those who had completed secondary education (26.8%; n=213). In summary, more respondents knew about the Declaration of Commitment on HIV/AIDS (n=210, 26.3%) than about the AIDS Charter on Rights and Responsibilities (n=187, 23.4%).

Any violation of rights
During the previous 12 months, over 10% of 796 respondents (11.2%, n=89) reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions; while 62.1% (n=494) had not and 26.8% (n=213) were not sure, with little gender-based difference between respondents: male, 13.1%; n=36 and female, 10.2%; n=52.

Discriminatory treatment by governmental, legal, and/or medical institutions
The most frequent violation reported by 5.9% of 758 who answered the question was being denied health or life insurance (n=45); followed by being forced to submit to a medical procedure (including HIV testing) at 4.7%, n=36. Smaller percentages indicated that they had been detained, quarantined, isolated, or segregated (0.4% n=3); with 0.1% (n=1) reporting arrest or being taken to court on an HIV-related charge, or having to disclose their HIV status in order to enter another country.

![Figure 778 Percentage of respondents who had their rights violated](image)

Legal Redress
When asked whether they had tried to get legal redress 99 replied, with 18 (18.2%) indicating that they had tried to get legal redress, 79 (79.8%) had not tried to get legal redress, and two were not sure (2%). When asked when the process began, 16 (88.9%) said that the process of legal redress had begun during the preceding 12 months. When asked whether the matter had been dealt with, nine (52.9%) of the 17 who responded indicated that the matter had been dealt with, five (29.4%) said the matter was still in process, while the remaining three (17.6%) said nothing happened or the matter was not dealt with.

When the reasons why respondents had not tried to get legal redress were investigated, 74 responded with 15 (20.3%) indicating they felt intimidated or scared to take action, nine (12.2%) felt that the process of addressing the problem was too bureaucratic, and over 10% cited lack of financial resources (10.8%, n=8). In addition, 34 respondents (45.9%) replied that none of the reasons suggested had led them not to seek legal redress.

![Reasons for not trying legal redress in the abuse of rights of PLHIV](image)

**Figure 889** Reasons for not trying legal redress in the abuse of rights of PLHIV

When all respondents were asked whether they had tried to get a government employee to take action against abuse of their rights in the preceding 12 months, 140 (17.5%) answered with 17 (12.1%) reporting trying to get government employee(s) to take action, of whom nine (52.9%) indicated that the matter had been dealt with, five (29.4%) said the matter was still in the process of being dealt with and the remaining three (17.6%) said either nothing had been done or the matter was not dealt with.

When all the respondents were asked whether they tried to get a local or National politician to take action against an abuse of their rights as a person living with HIV, 135 (16.9%) answered
with 18 (13.3%) reporting trying to get a local or National politician to take action. When asked when this happened, 16 (94.1%) of the 17 who responded to this question said the process had started during the preceding 12 months of the study. Outcomes varied with five (31.3%) of the 16 respondents who answered indicating that the matter had been dealt with, four (25.0%) saying the matter is still in process and seven (43.8%) saying nothing had been done or the matter had not be dealt with.

Legal services (56.3%) and government employees (52.9%) were the most proactive with regards to providing or assisting in providing redress; while in 40% of instances brought to local or National politicians, no action was taken.

Figure 9.10 Outcome of action taken to redress abuses of rights

2.5 Effecting change
This sub-section explores respondents’ reactions to incidents of stigma and discrimination; awareness of potential sources of assistance when confronted with stigma and discrimination; and participation in policy reform on HIV-related stigma and discrimination.

Reactions to incidents of stigma and discrimination
When asked whether they had confronted, challenged or educated someone who was stigmatizing and/or discriminating against them, 796 respondents replied with over 80% (80.2%, n=638) stating they had not while nearly 20% (19.8%, n=158) said they had.

Awareness of potential sources of assistance
When asked whether they knew of any organization or groups that they could go to for help if
they experienced stigma, 786 respondents replied with over 70% (70.9%, n=556) knowing of organizations or groups while nearly 30% did not (29.1%, n=228).

Over 50% of respondents (50.6%, n=282) cited both support groups and other organizations, while a further 45% of respondents (44.3%, n=247) cited support groups only. People living with HIV support groups were the most widely known. Further, over one quarter of respondents (27.8%, n=155) said they knew of both the people living with HIV support group and a legal practice. Just over 5% of respondents (5.1%, n=28) cited any other place of help and support that they could go to.

Support to other PLHIV

Nearly half of respondents (45%, n=358) reported having supported other people living with HIV, including through emotional support (37.5%, n=153), physical support (19.6%, n=80), referral to other services (14%, n=57), and combinations of these (28.9%, n=118) (Table 15).

Table 15 Type of support provided by respondents to other PLHIV

<table>
<thead>
<tr>
<th>Type of support provided</th>
<th>Number of respondents (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional support (e.g. counselling, sharing personal stories and experiences)</td>
<td>153 (37.5%)</td>
</tr>
<tr>
<td>Physical support (e.g. providing money or food, doing an errand for them)</td>
<td>80 (19.6%)</td>
</tr>
<tr>
<td>Referral to other services</td>
<td>57 (14.0%)</td>
</tr>
<tr>
<td>Emotional support, physical support and referral to other services</td>
<td>46 (11.3%)</td>
</tr>
<tr>
<td>Emotional support, and referral to other services</td>
<td>72 (17.6%)</td>
</tr>
<tr>
<td>Total</td>
<td>408 (100%)</td>
</tr>
</tbody>
</table>

Involvement in programmes, legislation, policies or guidelines

Some 367 respondents (46.2%) indicated that they were members of a PLHIV support group and/or network. Respondents were also asked whether they had been involved as a volunteer or employee in any programme or project providing assistance to PLHIV in the 12 months with 107 (13.7%) of the 783 respondents who answered stating to have done this.

In addition, 115 (14.6%) of 787 respondents indicated that they had been involved in efforts to develop HIV-related legislation, policies or guidelines.

Those who had attained secondary education formed the majority of those who had volunteered in any programme to provide assistance to PLHIV (68.2%; n= 73) or involved in effort to develop HIV-related legislation, policies or guidelines (59.8%; n= 67) (Figure 11).
Figure 10.1.1 Level of education and involvement of respondents in effecting change

**Ability to influence policies, laws and programmes**

Table 16 focuses on feelings of being able to influence policies, laws and programmes. Over 95% of respondents (98.1%, n=784) felt able to influence any of the areas. Among these respondents, 190 (24.2%) felt they could influence legal/rights matters affecting people living with HIV while 111 (14.2%) felt they had the power to influence local government policies affecting PLHIV (Table 16).

**Table 16 Areas which respondents felt they could influence decisions**

<table>
<thead>
<tr>
<th>Areas which respondents felt they could influence decisions</th>
<th>Number of respondents (Valid percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal/rights matters affecting people living with HIV</td>
<td>190 (24.2%)</td>
</tr>
<tr>
<td>Legal/rights matters affecting people living with HIV and Local government policies affecting PLHIV</td>
<td>111 (14.2%)</td>
</tr>
<tr>
<td>Legal/rights matters affecting PLHIV and National programmes/projects intended to benefit PLHIV</td>
<td>1 (0.1%)</td>
</tr>
<tr>
<td>Local government policies affecting PLHIV</td>
<td>130 (16.6%)</td>
</tr>
<tr>
<td>Local projects intended to benefit PLHIV</td>
<td>84 (10.7%)</td>
</tr>
<tr>
<td>National government policies affecting PLHIV</td>
<td>16 (2.0%)</td>
</tr>
<tr>
<td>National program/projects intended to benefit PLHIV</td>
<td>41 (5.2%)</td>
</tr>
<tr>
<td>International agreements/treaties</td>
<td>2 (0.3%)</td>
</tr>
<tr>
<td>None of these things</td>
<td>205 (26.1%)</td>
</tr>
<tr>
<td>Legal/rights matters affecting PLHIV, Local government policies affecting PLHIV, National government policies affecting PLHIV</td>
<td>4 (0.5%)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>784 (100%)</td>
</tr>
</tbody>
</table>

**Most important thing that organizations of PLHIV should be doing**

More than one third of respondents (35.7%, n=282) cited providing emotional and physical support to people living with HIV with over 20% (20.2%, n=160) felt these organizations should be educating PLHIV about living with the HIV and slightly over 15% of respondents (15.7%,
n=124) cited advocating for the rights of all people living with HIV. Less than 5% (4%, n= 32) mentioned work in support of particularly marginalized groups.
Section 3: Experience of testing, disclosure, treatment and having children

This section comprises four sub-sections: testing and diagnosis; disclosure and confidentiality; treatment; and experience of having children.

3.1 Testing and diagnosis

Reason for undergoing HIV testing

Respondents were asked to indicate why they underwent HIV testing (Table 18) with over 30% (n=240) indicating they simply wanted to know their HIV status (30.1%, n=240); while nearly a quarter had been referred due to suspected HIV-related symptoms (23.0%, n=183) and 10% due to illness or the death of spouse, partner or family member (n=80).

<table>
<thead>
<tr>
<th>Reasons</th>
<th>Number of respondents (Valid percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>10 (1.3%)</td>
</tr>
<tr>
<td>Pregnant</td>
<td>118 (14.8%)</td>
</tr>
<tr>
<td>To prepare for a marriage/sexual relationship</td>
<td>16 (2.0%)</td>
</tr>
<tr>
<td>Referred by a clinic for sexually transmitted infections</td>
<td>80 (10.0%)</td>
</tr>
<tr>
<td>Referred due to suspected HIV-related symptoms (e.g. tuberculosis)</td>
<td>183 (23.0%)</td>
</tr>
<tr>
<td>Husband/wife/partner/family member tested positive</td>
<td>43 (5.4%)</td>
</tr>
<tr>
<td>Illness or the death of husband/wife/partner/family member</td>
<td>103 (12.9%)</td>
</tr>
<tr>
<td>Just wanted to know</td>
<td>240 (30.1%)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (0.5%)</td>
</tr>
<tr>
<td>Total</td>
<td>797 (100%)</td>
</tr>
</tbody>
</table>

Whether HIV testing was voluntary

Respondents were asked about their decision to be tested for HIV and whether their HIV test was undertaken voluntarily, under pressure or coercion, or without their knowledge. Of the 788 respondents who answered, over 80% reported being tested voluntarily (85.8%, n=676), 48 respondents (6.1%) reported that they were forced to take an HIV test or were tested under pressure from others. The remaining 16 respondents (2%) reported that they were tested without their knowledge.

Counselling

Counselling before and after the HIV test was widely instituted as nearly 90% of the 781 respondents who provided information indicated that they received both pre- and post- test counselling (88.9%, n=694). Furthermore, 4.9% of respondents reported receiving pre-test counselling (n=38), another 3.5% received post-test counselling (n=27); while only 2.8% received no counselling (n=22).

Figure 111113 Receipt of counselling when testing for HIV
3.2 Disclosure and confidentiality

In an attempt to assess issues related to disclosure and confidentiality, respondents were asked about how different groups of people were first told about their HIV status, if they had been told. A summary of the findings are presented in Figures 20, 21 and 22.

Disclosure

More than 75% of respondents had personally informed their spouse or partner (86.7%; n=688), other adult family members (82.2%; n=657), other people living with HIV (85.2%; n=679) and health care workers (89.4%; n=711). There were also high levels of disclosure to children in the family (72.7%; n = 580), clients (68.2%; n = 542), social workers and counsellors (66.3%; n=527), and friends and neighbours (45.9%; n=365). However, 6.1% (n=48) had not disclosed their status to their permanent partner.

Disclosure of a respondent’s HIV status without their consent was uncommon with the exceptions of friends and neighbours (17.1%; n=136) and community leaders (6.1%; n=48). Significant percentages of respondents indicated that their HIV status had not been disclosed to different groups of people, including community leaders (58.9%; n=466), religious leaders (54.3%; n=430), teachers (35%; n=277), and government officials (30.7%; n=244).

As over half of respondents were unemployed and most were not undertaking education, these may, in part, explain why disclosing HIV status to groups of people, including co-workers (52.6%; n=417), employers (52.1%; n=414), teachers (52.3%; n=415), government officials (59.3%; n=472) and the media (70.3%; n=558) was not applicable to many respondents.

Pressure to disclose HIV status

Most respondents reported that they had not felt pressured to disclose their HIV status by others30, though:

- 6.1% (n=48) of respondents reported having felt pressure from other PLHIV to disclose their HIV status and
- 11% (n=86) of respondents report having ever felt pressure from people (other than PLHIV) to disclose their HIV status.

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30 Unlike the majority of the questions asked, these questions asked about interviewees experiences since diagnosis, rather than only in the previous 12 months.
Health Care Workers

When asked whether a health care professional had ever told anyone about the respondents’ HIV status without their consent, over half of the 720 respondents answering said this had never happened (56.8%, n=409), nearly 40% were not sure (39.7%, n=286), and 25 stated that this had happened (3.5%).

There was equal percentages of respondents (46.8%, n=311) who were sure that their medical records were kept completely confidential and those who did not know; while 43 respondents (6.5%) said it was clear to them that their medical reports were not being kept confidential.

The reaction of different groups of people when first told of the respondent’s HIV status varied, though most were supportive, very supportive or indifferent. Less than 7% of respondents said the reaction of any of the groups was discriminatory or very discriminatory (Table 19). When respondents were asked whether they found disclosure of their HIV status an empowering experience, 600 (75.7%) of the respondents said yes.
Table 18 Reactions people when first told of the HIV status of respondents

<table>
<thead>
<tr>
<th>PEOPLE TOLD</th>
<th>REACTIONS OF PEOPLE WHEN FIRST TOLD OF RESPONDENTS’ HIV STATUS (number of respondents (valid percent ))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very discriminator</td>
</tr>
<tr>
<td>Your husband/wife/partner</td>
<td>50 (6.3%)</td>
</tr>
<tr>
<td>Other adult family members</td>
<td>32 (4.0%)</td>
</tr>
<tr>
<td>Children in your family</td>
<td>31 (3.9%)</td>
</tr>
<tr>
<td>Your friends/ neighbours</td>
<td>33 (4.4%)</td>
</tr>
<tr>
<td>Other people living with HIV</td>
<td>12 (1.5%)</td>
</tr>
<tr>
<td>People who you work with</td>
<td>13 (1.6%)</td>
</tr>
<tr>
<td>Your employer(s)</td>
<td>18 (2.3%)</td>
</tr>
<tr>
<td>Your clients</td>
<td>15 (1.9%)</td>
</tr>
<tr>
<td>Injecting drug partners</td>
<td>13 (1.6%)</td>
</tr>
<tr>
<td>Religious leaders</td>
<td>13 (1.6%)</td>
</tr>
<tr>
<td>Community leaders</td>
<td>16 (2.0%)</td>
</tr>
<tr>
<td>Health care workers</td>
<td>12 (1.5%)</td>
</tr>
<tr>
<td>Social workers/counselors</td>
<td>10 (1.3%)</td>
</tr>
<tr>
<td>Teachers</td>
<td>7 (0.9%)</td>
</tr>
<tr>
<td>Government officials</td>
<td>15 (1.9%)</td>
</tr>
<tr>
<td>The media</td>
<td>33 (4.2%)</td>
</tr>
</tbody>
</table>

3.4 Treatment

Self-description of health

Table 20 shows that over 40% (44%, n=351) described their health as ‘excellent’ or ‘very good’, while nearly one third (33.3%, n=262) described their health as ‘good’; though nearly a quarter (23.2%, n=185) indicated that their current health was ‘fair’ or ‘poor’. Though there were no significant gender-based differences between health descriptions, higher percentages of female respondents described their health as excellent or very good compared to male respondents (Figure 24).

Table 19 Health description of the respondents

<table>
<thead>
<tr>
<th>Health description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>85 (10.7%)</td>
</tr>
<tr>
<td>Very good</td>
<td>266 (33.3%)</td>
</tr>
<tr>
<td>Good</td>
<td>262 (32.8%)</td>
</tr>
<tr>
<td>Fair</td>
<td>174 (21.8%)</td>
</tr>
<tr>
<td>Poor</td>
<td>11 (1.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>798 (100%)</td>
</tr>
</tbody>
</table>
Antiretroviral treatment

In terms of access to antiretroviral therapy (ART), over 70% of respondents (70.9%, n=566) were currently taking ART and nearly 90% said that they could access ART should they need it (89.2%, n=709). A small percent of respondents (2.3%, n=18) indicated that they did not know whether they had access or not. There was no gender-based difference with regards to access to ART (Figure 25).

Opportunistic infections

Over 60% of respondents (62.7%, n=500) indicated that they were taking some medication to prevent or to treat opportunistic infections, and 81.9% (n=652) reported having access to these medications even if they were not currently taking it. Furthermore, 2.1% of respondents
(n=17) did not know whether they had access or not while 16.0% (n=127) did not have access, if needed. There was also no significant gender-based difference with regards to access to medication for opportunistic diseases: 81.1% of female respondents (n=413) compared to 84.1% of male respondents (n=212).

**Discussions with health care workers**

During last 12 months, over 80% of respondents (84.2%, n=672) indicated that they discussed HIV treatment options with a health care professional; while over 70% of respondents (70.2%, n=556) reported that they have discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional.

**3.5 Having children**

This sub-section focuses on respondents’ experiences regarding reproductive options and sexual and reproductive health services. Female respondents were asked additional questions relating to pregnancy and infant feeding practices.

**Number of children**

Overall, over 75% of respondents (78.4%, n=623) had children; while 12.7% (n=87) of the 700 respondents who answered the question on their children’s HIV status indicated that the children were HIV positive.

**Reproductive Health Counselling**

Since learning their HIV status, over 50% of respondents (55.8%, n=441) have ever been counselled on reproductive health and childbearing, though over one third had not (36.8%, n=291) (Table 21).

| Table 20 Counselling related to reproductive health options since HIV diagnosis |
|----------------------------------|------------------|
|                                  | Number of respondents |
| Yes                              | 441 (65.8%)       |
| No                               | 291 (36.8%)       |
| Not applicable                   | 58 (7.3%)         |
| Total                            | 790 (100%)        |

Nearly 80% of respondents (79.8%, n=632) indicated that they had never been advised to have more children, though 11.9 % (n=94) had. Furthermore, nearly 80% of respondents (78.4%, n=619) indicated that they had never been coerced to consider sterilisation, though 6.6 % (n = 52) had. When asked about their ability to obtain ART on condition that they use certain forms of contraception, over 10% of respondents indicated that this is the case (11.5%, n=92) while over half (55.8%, n=446) said this is not the case (Figure 26).
Provision of ART conditional on kind of contraceptive used by respondent

While most female respondents, who have been pregnant in last 12 months, had experienced no coercion; 4.5% (n=36) indicated being coerced by health care professionals into terminating a pregnancy.

PMTCT/PVT

Women who had been pregnant since diagnosis were asked about their access to prevention of vertical transmission (PVT) services; of 484 female respondents, over two thirds (67.1%, n=325) had received ART for PVT, 6% (n=30) indicated that they did not know that such treatment existed, 1% (n=4) did not have access to this treatment, and 25% (n=119) were not HIV-positive when pregnant (Figure 27).
When female respondents were asked whether they had been given information about healthy pregnancy and motherhood as part of PVT, 408 responded, of whom, 77.9 % (n=318) reported receiving information about healthy pregnancy and motherhood though 90 women (22.1 %) reported that they were not given this information.
Section 4: Qualitative questions

In addition to the quantitative questions opinions were sought on what interviewees believed to be the main problems and challenges in relation to antiretroviral treatment, having children when HIV-positive, testing and diagnosis, and disclosure and confidentiality about being HIV-positive. Responses to these four open ended questions were coded for themes and frequencies where possible as well as being cross tabulated against other qualitative responses given. The analysis of the open ended responses regarding antiretroviral treatment and having children when you are HIV-positive is reported below.

4.1 Treatment

Over 755 (94.5%) of the 799 respondents answered the question on challenges related to ART. Nearly a third of respondents indicated that ART side effects was the most problematic issue related to ART (31.8%, n=240) followed by access (24.1%, n=182), taking ART for life (23.7%, n=179) and monitoring (20.4%, n=154) (Figure 31). There were no gender (or aged) based differences between respondents with regards to ART-related problems and challenges.

![Figure 31 Problems and challenges related to ART](image)

In terms of the relationship between education level and challenges and problems related to ART, respondents who had attained technical and university education, the greatest challenge was the fact that they had to take ART for life, followed by access. For those with no formal education and secondary education side effects was the greatest challenge, while among those with primary education both side effects and access were both significant challenges (Figure 32).

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31 The qualitative responses regarding testing and diagnosis and disclosure and confidentiality did not easily lend themselves to this type of analysis within the time scale allowed for this report or the resources available, however they do contain a rich vein of data and it is the intention of NPAWA to revisit this data at a later date.
Figure 32 Relationship between level of education and challenges and problems related to ART

4.4. Having children

Over 60% of the 746 respondents, who provided answers, said that care for children in the event that something happened to them was the most problematic and challenging aspect of having children when HIV-positive (61.7%, n=460). PVT (PMTCT) was identified by over a quarter of respondents as a significant challenge (27.6%, n=206) (Figure 33).

Having children when HIV-positive posed the same problems and challenges for both male and females, among different age groups, and across all education levels.
Conclusions

The study shows that HIV-related stigma and discrimination is ongoing and acts as a barrier for people living with HIV to access HIV prevention treatment and care services in OR Tambo District of Eastern Cape Province in South Africa. The findings of the experiences of people living with HIV by study area are outlined below.

Exclusion

- HIV-related exclusion is more common from social gatherings (10.6%, n=84) than from family gatherings (8.9%, n=71) or religious activities (5.5%, n=44).
- Nearly a third of respondents (30%, n=237) reported that they had been gossiped about at least once in the last year with over two thirds of these respondents (67.4%, n=145) indicating that it occurred, in whole or in part, because of their HIV-positive status.
- Significant percentages of respondents reporting having been verbally insulted/harassed/threatened (16.6%, n=133), physically assaulted or threatened (9.5%, n=76), and/or physically assaulted (7%, n=56) at least once in the last year. Of these, 72.3% (n=91) indicated being insulted/harassed/threatened, 58.6% (n=41) physically harassed or threatened, and 25% (n=24) physically assaulted, in whole or in part, due to their HIV-positive status.
- Half of the respondents who reported being assaulted said that they were assaulted by their spouse or partner (n=19), with over one quarter (28.9%, n=11) indicating that it was by other members of the household.
- Levels of discrimination against a spouse or partner of PLHIV or other member of the household because of the respondent’s HIV status (17%) are higher than against respondents themselves (e.g. in relation to HIV status-related psychological pressure or manipulation by a spouse or partner (12.2%), discriminated against by other PLHIV (7%) or experienced HIV status-related sexual rejection (11%).
- Over one in five respondents (21.2%, n=62) feel that HIV-related stigma and/or discrimination is due to people being afraid of being infected by them, while 17.4% believed that people were not aware of how HIV was transmitted (n=51).

Access to work and health and education services

- The highest levels of discrimination were reported in work-related matters (10.3%), followed by accommodation (9.7%) and access to family planning services (6.5%).
- Nearly 10% of respondents (9.6%, n=77) had been forced to change residency/refused accommodation in the last year of whom over half (58.4%, n=44) thought the reason was HIV status-related.
- Over 10% of the 349 respondents who had some form of employment reported having lost a job or another source of income in the last 12 months (n=40). Twelve, of these (33.7%) cited their HIV status in part or as the main reason.
In terms of denial of access to health related services because of HIV status in the last 12 months, while access in all categories is over 80%, there is a low level of denial occurring, including access to:

- health services; 22 respondents (2.8%) said they had been denied access.
- family planning services; 51 respondents (6.5%) said they had been denied access.
- sexual and reproductive health services; 28 respondents (3.5%) indicated that they been denied access.
- Of 724 respondents, 21 respondents (2.9%) reported that they had been dismissed, suspended or prevented from attending an educational institution because of their HIV status in the last 12 months; 16 citing one instance, four a few times, and one stating this had occurred often.

**Internalised stigma and fears**

- Over one third blamed themselves (34.9%, n=279), over one quarter felt ashamed (25.9%, n=207), and less than one in five had low self-esteem (18.3%, n=146) or felt guilty (14.1%, n=113).
- Nearly 10% of respondents (9.6%, n=77) reported feeling suicidal.
- Levels of internalized stigma were higher among male than female respondents. For example, 42.9% of male compared to 31.1% of female respondents reported blaming themselves, and 12.7% of male respondents compared to 8.9% of female respondents felt suicidal.
- The most frequent decisions made by respondents during the last 12 months because of HIV status were not to have more children (41.6%, n=332), not to attend social gathering(s) (18.9% (n=151), not to marry 16.1% (n=129); and to isolate themselves from friends and relatives 12.8% (n=102).

**The impact of internalised stigma:**

- Access to health care: 3.1% (n=25) avoided going to a local clinic when they needed care, and 3% (n=24) avoided going to hospital.
- Study and employment: 4.6% (n=37) decided not to apply for a job or a promotion, 4.4% (n=35) withdrew from education or training, and 3.4% (n=27) gave up their job.
- Overall, 45.4% of respondents (n=363) feared being gossiped about (17.5%, n=140) were afraid of being verbally insulted, harassed and/or threatened and approximately 10% were afraid of being physically harassed and/or threatened (10.5%, n=84) or being physically assaulted (9.3%, n=74).
- Nearly 20% of respondents (19.5%, n=156) indicated that they were scared someone would not want to be sexually intimate with them because of their HIV-positive status with higher levels reported by male than female respondents (27.4%, n= 75 compared to 15.3%, n= 78).
Rights, laws and policies

- The AIDS Charter on Rights and Responsibilities\(^{32}\) was known to nearly one quarter of respondents (23.4%, n=187); of whom, 48.7% (n=91) had read or discussed it.
- During the previous 12 months, over 10% of respondents (11.2%, n=89) reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- The most frequent violation reported by 5.9% of respondents (n=45) was being denied health or life insurance, followed by being forced to submit to a medical procedure (including HIV testing) (4.7%, n=36).
- Of 99 respondents who experienced a rights violation within the previous 12 months, 18 (18.2%) had tried to get legal redress and 79 (79.8%) had not. Further, of 74 respondents who had not sought legal redress the most common reason cited was feeling intimidated or scared to take action (20.3%, n=15), followed by feeling that the process was too bureaucratic (12.2%, n=9).

Effecting change

- During the last 12 months, nearly 20% of respondents (19.8%, n=158) reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against her or him.
- Overall, 70.9% of respondents (n=556) knew of an organization or groups providing support to those experiencing stigma or discrimination while nearly 30% did not (29.1%, n=228).
- 80 respondents (21.6%) indicated that they had sought help from an organization for problems related to stigmatization or discrimination.
- Nearly half of the respondents (45%, n=358) reported having provided some form of support to other people living with HIV in the previous 12 months with emotional support (37.5%, n=153) being the most common type of assistance rendered.
- Nearly half of the respondents (46.2%, n=367) reported being a member of a support group and/or network of people living with HIV.
- Over one in ten respondents (13.7%, n=107) had been involved, either as a volunteer or as an employee, in a programme or project providing assistance to people living with HIV in the previous 12 months.
- Some 115 respondents (14.6%) had been involved in efforts to develop HIV-related legislation, policies or guidelines.
- Over 95% of respondents (98.1%, n=784) felt able to influence policies, laws and programmes at either National or local levels.
- People living with HIV support groups were the most widely known organisations

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\(^{32}\) See\(^{19}\).
In terms of the most important thing organisations should do to address stigma and discrimination, more than one third of respondents (35.7%, n=282) cited providing emotional and physical support to people living with HIV.

Testing and diagnosis

- Over 30% of respondents (n=240) reported taking an HIV test just to know their status.
- Nearly a quarter of respondents (23.0%, n=183) were referred for HIV testing when already symptomatic.
- In terms of coerced testing or testing without a person’s consent, 48 respondents (6.1%) reported that they were forced to take an HIV test or were tested under pressure from others, and 16 respondents (2%) were tested without their knowledge.
- While nearly 90% of respondents (88.9%, n=694) received both pre- and post-test counselling; 4.9% received only pre-test counselling (n=38), another 3.5% received only post-test counselling (n=27); and 2.8% received no counselling at all (n=22).

Disclosure and confidentiality

- High levels of disclosure by respondents included to: spouse or partner (86.7%), other adult family members (82.2%), other people living with HIV (85.2%), health care workers (89.4%), children in the family (72.7%), clients (68.2%), social workers and counsellors (66.3%), and friends and neighbours (45.9%).
- 6.1% of respondents had not disclosed their status to their spouse or partner and a further 14.4% had not disclosed to injecting drug partners.
- Significant percentages of respondents indicated that their HIV status had not been disclosed to community leaders (58.9%), religious leaders (54.3%), teachers (35%), and government officials (30.7%).
- Approximately 90% of respondents reported that they had not felt pressured to disclose their HIV status by others, though:
  - 6.1% of respondents report having ever felt pressure from other PLHIV to disclose their HIV status and
  - 11% of respondents report having ever felt pressure from people other than PLHIV to disclose the HIV status.
- In general confidentiality of respondents’ HIV status as far as health care professional are concerned is respected, with 25 of 720 respondents stating that a health care professional had told other people about their HIV status without their consent.
- Nearly half of respondents (46.8%, n=311) indicated that they do not know if their records are kept confidential; while it was clear to 43 respondents (6.5%) that they were not being kept confidential.
- The reaction of different groups of people when first told about the respondent’s HIV status varied, though most were supportive, very supportive or indifferent. Less than
7% of respondents said the reaction of different groups of people was discriminatory or very discriminatory.

- Over three quarters of respondents described disclosing their HIV status as an empowering experience.

Treatment

- Over 40% described their health as 'excellent' or 'very good', while nearly one third described their health as 'good'; though nearly a quarter indicated that their current health was 'fair' or 'poor'. Approximately 65.9 % (n = 122) of the 185 who described their health status as being poor or fair were on ARV treatment and 34.1 % (n = 63) were not.
- Over 70% of respondents were currently taking ART and nearly 90% said that they could access ART should they need it.
- Over 60% of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections, and 81.9% reported having access to these medications even if they were not currently taking it.
- Over 80% of respondents had discussed HIV treatment options and over 70% had discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

Having children

- Less than 40% of respondents (36.8%) indicated that they had never received counselling on their reproductive options since their HIV diagnosis.
- Nearly 80% of respondents (79.8%, n=632) indicated that they had never been advised to have more children, though 11.9 % (n= 94) had.
- Nearly 80% of respondents (78.4%, n=619) indicated that they had never been coerced to become sterilized, though 6.6 % (n= 52) had.
- Over 10% of respondents (11.5%, n=92) reported that their ability to obtain ART was conditional on using certain forms of contraception.
- While most female respondents, who have been pregnant in last 12 months, have experienced no coercion; 4.5% (n=36) indicated being coerced by health care professionals into terminating a pregnancy.
- In relation to PVT, of 484 female respondents, over two thirds (67.1%, n=325) had received ART for PVT, 6.2 % (n= 30) indicated that they did not know that such treatment existed, 0.8 % (n=4) did not have access, and 24.6% (n=119) were not HIV-positive when pregnant.
Furthermore, of 408 female respondents, 77.9% (n=318) reported receiving information about healthy pregnancy and motherhood, though 90 women (22.1%) reported that they had not received this information.

Problems and challenges

- Opinions on what the main problems and challenges were, in relation to the following areas:
  - **Treatment**: over 30% cited ART side effects as the most problematic issue related to ART (31.8%, n=240) followed by access (24.1%, n=182), taking ART for life (23.7%, n=179) and having access to and understanding monitoring (20.4%, n=154).
  - **Having children**: over 60% cited care for children in the event that something happened to them as the most problematic and challenging aspect of having children when HIV-positive (61.7%, n=460), followed by a quarter of respondents citing PVT (27.6%, n=206).
  - **Respondents** were also asked what the main problems and challenges were, in relation to the HIV testing and diagnosis, and disclosure and confidentiality. Unfortunately the qualitative responses given did not lend themselves to easy statistical analysis within the resources and time-scale available for this report\(^\text{33}\).

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\(^{33}\) This has been identified as an area for future research and analysis by NAPWA.
Recommendations

The following recommendations are made in light of:
high levels of stigma and discrimination in a number of areas, including exclusion of both respondents and household members; access to employment, residency/accommodation, health or life insurance, and health care services;
generally low levels of perceived ability to effect change were reported by the people living with HIV in OR Tambo district, South Africa, involved in this study.

Furthermore, among the sample there was low socio-economic status, including significant percentages of respondents reporting low levels of education and employment, as well as significant psychosocial needs, for example, high levels of internalized stigma; high rates of fear about the ways they were perceived and treated in the community; and suicidal feeling. As such, socioeconomic and psychosocial support must clearly be a priority for the National Association of People Living with HIV and AIDS, civil society, OR Tambo District, the South African National AIDS Council (SANAC) and the National Government. Concerted efforts by all the above stakeholders are required to promote positive living and provide psychosocial and socioeconomic support, including training opportunities to become peer educators counsellors, trainers; to build capacity and networks, and for income generation.

Other specific recommendations directed to the National Association of People Living with HIV and AIDS, civil society, OR Tambo District, the South African National AIDS Council (SANAC) and the National Government are outlined below.

National Association of People Living with HIV and AIDS - South Africa

- Advocate for the National implementation of the People Living with HIV Stigma Index.
- Disseminate the findings of this study to the Government, South African National AIDS Council (SANAC), civil society, UN agencies and donors.
- Advocate for the rights of all people living with HIV, including key populations, and advocate against and challenge rights violations.
- Intensify education efforts with people living with HIV on positive health, dignity and prevention.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to the general public.
- Encourage and build the capacity of people living with HIV to advocate for their rights; be actively involved (either as a volunteer or as an employee) in developing and implementing stigma and discrimination reduction projects and programmes; and to
provide support and assistance to people living with HIV individually, and through support groups and other local organisations.

- Empower HIV-positive people to know and assert their rights.
- Advocate for the inclusion of more people living with HIV in policy-making for and in the development and drafting of relevant legislation.
- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, including key populations, and in particular people who inject drugs and those in detention settings.
- Undertake further research into the underlying facilitators of disclosure of HIV status, including disclosure-related feelings of empowerment and stigma, and to address the needs of key population living with HIV.

Civil Society actors involved in the AIDS response

- Advocate for the National implementation of the People Living with HIV Stigma Index.
- Build the capacity of support groups and other local organisations to challenge stigma and discrimination, and to provide adequate counselling and other support to people living with HIV, in particular to younger PLHIV as well as people who inject drugs and those in detention settings.
- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission to people living with HIV and the general public.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.

OR Tambo District

- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.
South African National AIDS Council (SANAC)

- Implement the People Living with HIV Stigma Index Nationally.
- Promote voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.
- Given that there is a low level but consistent pattern of denial of the rights of people living with HIV in health care settings, including SRH rights:
  - revise pre- and in-service training curricula to provide non-judgmental and non-discriminatory services to people living with HIV, including PVT;
  - review and update, if needed, protocols to ensure they are rights-based; and
  - scale up the provision of correct information and appropriate options for ART and the sexual and reproductive health for people living with HIV, including PVT, and specifically for key populations.
- Support SRH and HIV linkages, including the integration of SRH services for people living with HIV into HIV programmes34.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Build the capacity of support groups and other local organisations to provide adequate counselling and other support to people living with HIV and key populations.

National Government

- Take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV, specifically address HIV-related stigma and discrimination, require informed consent for HIV testing, protect confidentiality and provide redress for breaches.
- Support the National implementation of the People Living with HIV Stigma Index.
- Support the active participation of people living with HIV in the development of laws, polices and guidelines; and in providing community-based services and support.
- Support broad-based social and community awareness raising and mobilization as part of efforts to eradicate stigma and discrimination against people living with HIV and key populations, including through a human rights-based approach, addressing HIV-related myths.
- Prioritize HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in National strategic planning, funding and programmes, including supporting National implementation of the People Living with HIV Stigma Index.
- Include HIV-related stigma and discrimination indicators as part of the National AIDS response M&E systems to monitor and evaluate progress over time.

34 One of the highest levels of discrimination was in relation to access to family planning services (7.3 %).
References


The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower People living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming and policy responses in the National response to HIV.

The data is not available as a source of allegations of individual instances of wrong-doing.