

siyam'kela

measuring
related
hiv/aids
stigma

HIV/AIDS STIGMA INDICATORS:
A tool for measuring the progress of
HIV/AIDS stigma mitigation



...siyam'kela:
measuring HIV/AIDS
related stigma...



Siyam'kela

Siyam'kela [SI-YUH-MU-GE-LAR] is an African word from the Nguni language. Translated it means “We Are Accepting” expressing a collective embracing, understanding and acceptance of a challenge at a particular time. The word has thus been interpreted as “Together We Stand” for this project.

The Project has been designed to explore HIV-related stigma, an aspect of the HIV/AIDS epidemic, which is having a profoundly negative effect on the response to people living with, and or affected by HIV/AIDS. Within the context of the Project, Siyam'kela denotes a collective approach in working towards reducing HIV/AIDS related stigma and discrimination.



...siyam'kela:
measuring HIV/AIDS
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HIV/AIDS stigma indicators

*A tool for measuring the progress of
HIV/AIDS stigma mitigation*

A joint project of the:

- POLICY Project, South Africa;
- Centre for the Study of AIDS, University of Pretoria;
- United States Agency for International Development (USAID); and
- Chief Directorate: HIV/AIDS & TB, Department of Health

Researched by:

- Insideout Research

Supported by:

- Representatives from the Siyam'kela Reference Groups



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1. Introduction

1.1 Project overview

The Siyam'kela Project is a joint endeavour of the POLICY Project, the Centre for the Study of AIDS at the University of Pretoria, the United States Agency for International Development (USAID), and the Chief Directorate: HIV/AIDS and TB, National Department of Health. Siyam'kela is an African word meaning "we are accepting", expressing a collective embracing. The word has been interpreted as "together we stand" for this project to symbolise a unity in challenging HIV/AIDS stigma.

Because stigma has an impact on prevention and care it is important to address it directly. However stigma mitigation practice has not been well informed by theory and research. An urgent need was identified for indicators of stigma which can be used to develop interventions and measure their success.

The Siyam'kela Project thus aims to pave the way for a stigma mitigation process by developing **well-researched indicators** of HIV/AIDS stigma and discrimination. The Project has focused on three key areas essential to South Africa's response to HIV/AIDS:

- Faith-based organisations and communities as important sources of support to people living with HIV/AIDS (PLHAs)
- National government departments as workplaces committed to dealing with HIV/AIDS related stigma through good policy and practice
- The relationship between people living with HIV/AIDS (PLHAs) and the media as an example of how empowered individuals can impact positively on perceptions and attitudes towards HIV/AIDS

A comprehensive literature review, two consultative workshops and the establishment of reference groups in the focus areas of the project ensured that a diverse range of opinions and experiences were reflected. The use of an independent research organisation, Insideout, for the fieldwork, also brought in a fresh perspective.

The project consists of **five aspects**:

- A qualitative exploration of stigma experiences and perspectives through focus group discussions and key informant interviews across South Africa
- The development of indicators of internal and external stigma through this field work and in consultation with experts in the field
- A media scan to contextualise and locate the field work in a particular time and place
- The documentation of promising practices which mitigate HIV/AIDS stigma
- The development of guidelines to assist those who wish to develop interventions to impact positively on HIV/AIDS stigma

1.2 Overview of this document

This document outlines proposed indicators of HIV/AIDS stigma, specifically focussing on internal and external stigma. Before the indicators are presented some key terms are defined. This is followed by an overview of the research approach which highlights the research process undertaken to develop these indicators.



1.3 Definitions

1.3.1 Indicators

An indicator is the measure that is used to assess if an objective has been achieved, or what progress has been made.

Indicators are measures which alert project managers and their colleagues to the changes and progress of their project.

1.3.2 Stigma

Even though the words **stigma** and **discrimination** are often used interchangeably, their meanings do differ. **Discrimination** focuses on behaviour: the “unjustifiably different treatment given to different people or groups.”¹ **Stigma** is defined as an attribute or quality which “significantly discredits” an individual in the eyes of others. Importantly, stigma is a process. Within a particular culture or setting, certain attributes are seized upon and defined by others as discreditable or unworthy.²

Stigma and stigmatisation are most easily understood as social processes, which play a key role in producing and reproducing relations of power and control in social systems. Stigma is therefore linked to social inequality. Stigma operates in relation to difference. By making social inequalities seem reasonable, it creates and reinforces social exclusion³.

Fear and **moral judgement** are considered to be the root sources of HIV/AIDS stigma. HIV/AIDS is associated with many different fears. People may fear the casual transmission of the virus, fear the loss of productivity of PLHAs, fear that resources may be wasted on PLHAs, fear living with the disease or fear imminent death. Similarly, **moral judgement** may cause stigma. PLHAs are often seen as culpable and deserving because the transmission of the virus is linked to stigmatised behaviour, which allows people to understand HIV/AIDS in terms of the concept of blame. It is important to note that HIV/AIDS stigma can be experienced not only by people living with HIV/AIDS but also by people who are suspected to be living with HIV/AIDS because of their association with HIV/AIDS.

Stigma may manifest itself externally or internally and may have different effects.

External stigma (enacted) refers to **actual experiences of discrimination** (UNAIDS,2000). This may include the experience of domination, oppression, the exercise of power or control, harassment, categorising, accusation, punishment, blame, exclusion, ridicule, or resentment. It may sometimes lead to violence against a person living with HIV/AIDS⁴.

External stigma refers to actual experiences of discrimination.

Internal stigma (felt or imagined stigma) is the **shame** associated with HIV/AIDS and PLHAs' fear of being discriminated against. Internal stigma is a powerful survival mechanism to protect oneself from enacted or external stigma and often results in the refusal or reluctance to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help⁵.

Internal stigma is the shame associated with HIV/AIDS and a PLHAs' fear of being discriminated against.

¹ Manser & Thompson, (ed.) (1999) *Combined Dictionary Thesaurus*. Edinburgh; Chambers

² UNAIDS (2002) *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination*. Geneva

³ The POLICY Project, (2003) *Examining HIV/AIDS stigma in selected South African media: January - March 2003, A summary*. Siyam'kela Research Study, South Africa

⁴ The POLICY Project, (2003) *Literature review*. Siyam'kela Research Study, South Africa

⁵ *ibid*



1.4 Approach

The process of developing these indicators began with a consultative meeting in November 2002, where 20 participants, which included participants specializing in HIV/AIDS and research, came together. The group developed a set of draft indicators to measure HIV/AIDS stigma within the three project areas.

The field work commenced in January 2003. The purpose of the field work was to capture, record and review stigma experiences from the three project sectors namely: PLHAs, faith groups and national government.

This involved a total of **205 participants** who participated in 23 focus groups conducted across the country. In addition, 32 in-depth interviews were held with key informants. Of the focus group participants, 55% were women and 43% were people living with HIV/AIDS. The intention of the study was not to focus only on PLHAs, but to hear the experiences and perceptions of a range of South Africans – those who were living with HIV and those who were not.

Within the **faith sector**, a total of nine focus groups were held – one in each of the 9 provinces. Three focus groups were conducted with each category of participants, namely faith leaders, congregation members and PLHAs who belong or used to belong to a faith group. Participants were drawn from the Christian (including Catholic, Anglican, Methodist, United Presbyterian, Dutch Reformed) and Islamic faiths. Faith leaders selected the participants for the congregation focus groups, while the PLHAs were invited through the National Association of People living with HIV/AIDS (NAPWA). It should be noted that the Islamic faith was not consistently well represented in all focus groups, and that in some cases faith leaders were not ordained leaders but rather opinion leaders working with HIV/AIDS within the church setting.

*An **opinion leader** is a lay person belonging to a faith based organisation, who has a deep level of understanding of issues related to HIV/AIDS. They have a strongly influential voice about HIV/AIDS issues within the structure of their faith based organisation.*

National government was selected as an example of a workplace setting. A total of 50 employees from 12 government departments participated in five workplace focus groups. Three focus groups were held with employees from different levels within the public sector, namely junior staff, middle managers and senior managers. The two remaining groups were held with union representatives and with HIV/AIDS co-ordinators from selected National Government Departments. An effort was made to include representatives from each of the participating departments in each focus group, including; Agriculture, National Treasury, The Presidency, The Public Service Commission, The South African Police Service, Land Affairs, Correctional Services, Housing, Justice, Arts and Culture, Science and Technology, and Social Development. In addition to the focus groups, eight in-depth interviews were held with Director-Generals – or their nominated representatives – from the participating departments. Four key informant interviews were conducted with PLHAs working in different government departments.

The third focus area of this study was **PLHAs** who have interacted with the **media** in one form or another. In total, nine focus groups were held – one in each province – reaching a total of 59 participants. An effort was made where possible to have gender and race specific groups, but this was not always possible. The participants were invited through the provincial offices of NAPWA on the basis that they had interacted with the media before.

Participants were selected through the help of people within their organisation (for example, by faith leaders, HIV/AIDS co-ordinators or by NAPWA staff) and as a result people who are actively involved in the HIV/AIDS field were more likely to participate. The findings can therefore not be generalised to average South Africans not working with HIV/AIDS.

Based on the collected experiences and perspectives of stigma, the research team analysed the data according to themes and out of these developed draft indicators. These indicators were then refined at a second consultative meeting with 20 participants who were selected based on their HIV/AIDS expertise. The indicators were then refined once again and set within this framework. Ten HIV/AIDS experts were then asked to share their comments with the research team to finalise the indicators.



2. Presentation of indicators

The indicators are presented according to **themes**. The **12 themes** are divided across two categories, namely internal and external stigma, and include:

- *External stigma:*
 1. Avoidance
 2. Rejection
 3. Moral judgement
 4. Stigma by association
 5. Unwillingness to invest in PLHAs
 6. Discrimination
 7. Abuse
- *Internal stigma:*
 8. Self-exclusion from services and opportunities
 9. Perception of self
 10. Social withdrawal
 11. Overcompensation
 12. Fear of disclosure

The indicators for each theme are presented in a table (see example below). The table relates the indicators to the relevant field work finding, names the indicators, provides important definitions, notes how the indicators may relate to pre-existing stigma, suggests how the indicators may be verified in different settings and lists conditions for use of the indicators. It is important to read through the example below to understand how the indicators were arrived at and how they can be used effectively. The reader will also note that some indicators can be used in settings where there is a significant number of PLHAs who have disclosed their HIV status and some can be used when no PLHAs have disclosed.

theme:	
<i>Finding</i>	The overall finding of the study is presented together with some illustrative quotes taken from the fieldwork.
<i>Indicators</i>	<p>This block presents the relevant indicator/s. An effort has been made to make the indicators general and applicable to various settings, including workplace, faith-based organisations, and other social settings, such as recreational groups.</p> <p>Two sets of indicators are presented. The first set requires a significant number of openly disclosed PLHAs within an organisation, while the second set does not require this condition. The second set appear in the lighter shaded block.</p>



	<p>All the indicators listed below measure how high the levels of stigma are within a setting. Only indicators 12.1 and 12.2 measure low levels of stigma within an environment, namely:</p> <p>12.1 Number of PLHAs who have disclosed their HIV positive status</p> <p>12.2 Number of PLHAs who are willing to publicly disclose their status to the media</p>
<i>Definitions</i>	<p>It is up to the user to specifically define the indicators so as to ensure that they apply within their own context. Terms used in the indicators have been defined to guide the user when applying the indicators to a specific project. The list of examples, however, is not comprehensive since it is limited to reflect the findings of the Siyam'kela study.</p>
<i>Relationship to pre-existing stigma</i>	<p>Stigma operates in relation to difference and can, in principle, function in relation to any “key axes of structural inequality”, such as gender, class, race, and sexuality. HIV/AIDS stigma has been found to function in relation to pre-existing and/or independent forms of stigma and exclusion, which heightens its impact. HIV/AIDS stigma can have especially negative responses when it is based on pre-existing stigma and discrimination.⁶</p> <p>For all themes it is important to remember that some groups may experience HIV/AIDS stigma differently based on, for example, their gender, age, sexual orientation and geographic location. Even though the study did not always find differences in experience, the main purpose of this block is to remind the reader of the possibility of pre-existing stigma and of its possible effects on stigma mitigation.</p> <p>It is therefore important to measure these possible differences when assessing the progress of a stigma mitigation process. All of the indicators presented below can be made more specific so that they measure these different experiences. For example, the indicator “Number of PLHAs who report cases of others not sharing objects with them” can be re-written as: “Number of female PLHAs who report cases of others not wanting to share objects with them.” Other categories can similarly be included.</p>
<i>Means of verification</i>	<p>The possible means of confirming the indicator are presented, listing the tools and the denominators. Denominator refers to the total sample size.</p>
<i>Conditions</i>	<p>The necessary conditions for using the indicator are listed in this block.</p>

⁶ Parker, R and Aggleton, P (2002) *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action*. New York: Horizons Program.



3. Indicators

3.1 External Stigma

theme 1: avoidance	
<i>Finding</i>	<p>PLHAs report being avoided by others, often because of a fear of casual transmission of HIV or because of a perception of PLHAs as immoral and dirty. Avoidance may take the form of not wanting to share items or spend time with PLHAs.</p> <p><i>“They are nice to you but they keep their distance. You don’t really have many friends.”</i> Female person living with HIV/AIDS</p> <p><i>“You sit down [in church] and they all get up and go sit somewhere else.”</i> Male person living with HIV/AIDS</p> <p><i>“Many a times I have had people shout at me saying “Don’t come near me, I am scared of you.”</i> Male person living with HIV/AIDS</p>
<i>Indicators</i>	<p>I.1 Number of PLHAs who report cases of others not sharing objects with them</p> <p>I.2 Number of PLHAs who report cases of others who distance themselves from them socially</p> <p>I.3 Number of PLHAs who report an experience where they feel like others reduce them to the HI virus, and no longer see them as a whole person</p> <p>I.4 Number of PLHAs who report cases of others who distance themselves from them physically</p> <p>I.5 Number of PLHAs who report cases of others gossiping behind their backs</p>
	<p>I.6 Number of people who would not share objects with PLHAs</p> <p>I.7 Number of people who would distance themselves socially from PLHAs</p> <p>I.8 Number of people who would distance themselves physically from PLHAs</p> <p>I.9 Number of reports of people distancing themselves from PLHAs, and/or their affected friends and family</p>



theme I: avoidance

<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Objects may include utensils, facilities, equipment and furniture ■ Social distancing may include spending less time with PLHAs than before they learnt of their HIV positive status and/or excluding PLHAs from social events or conversations ■ Reducing to the HI virus may include individuals no longer recognising other aspects of a PLHA's life ■ Physical distancing may include no longer wanting to be touched by a PLHA, keeping greater distance between themselves and PLHAs than before they learnt of their HIV positive status ■ Organisation/social setting refers to any social structure, for example, workplace, faith groups, recreational groups, interest groups and family
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Race: "We still have the division in South Africa that AIDS is a black thing so it won't come to me. You know, in the white community we find ourselves in a difficult situation of not accepting, and of thinking that this is a black thing." HIV/AIDS co-ordinator ■ Gender ■ Age ■ Sexuality ■ Geographic region
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Survey with PLHAs: Sample size as the denominator
	<ul style="list-style-type: none"> ■ Survey with people within the organisation or social setting using a social distance scale⁷
<p><i>Conditions</i></p>	<ul style="list-style-type: none"> ■ PLHAs need to have openly disclosed within the organization or social setting
	<ul style="list-style-type: none"> ■ Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma

⁷ www.cps.nova.edu



theme 2: rejection

<p><i>Finding</i></p>	<p>Many PLHAs have suffered rejection from their spouses, families, friends and colleagues due to the perception that PLHAs deserve the illness or that HIV can be transmitted through casual contact.</p> <p><i>“You experience it [rejection], especially at home. When you tell your family that you are [HIV] positive they start to chase you away. Like they did to me. They said that I must leave, and must stay away.”</i> Male person living with HIV/AIDS</p> <p><i>“He told me he loved me and I asked him if he’s sure and he said yes. Then I tell him I’m HIV positive and he just went quiet for fifteen minutes. He doesn’t want to be associated with me.”</i> Female person living with HIV/AIDS</p>
<p><i>Indicators</i></p>	<p>2.1 Number of PLHAs who have been abandoned by significant people in their lives</p> <p>2.2 Number of PLHAs who were pressurised to leave their organisation/social setting after publicly disclosing their status</p> <p>2.3 Number of PLHAs who were pressurised to leave their place of residence</p>
	<p>2.4 Number of people who would abandon significant people in their lives if they would find out that they are HIV positive</p> <p>2.5 Number of people who feel that PLHAs should not be welcomed within their organisation/social setting</p> <p>2.6 Number of people who feel that PLHAs would not be welcomed in their homes</p>
<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Significant people may include a spouse/ partner, family members, friends and colleagues ■ Organisation/social setting refers to any social structure and setting, including for example workplace, faith groups, and recreational groups
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender: <i>“She disclosed to her partner when she was three months pregnant and he didn’t say anything. He then left and never came back again. When he went away he never came to visit and even now the child is sick he doesn’t come to check on the baby in the hospital.”</i> Female person living with HIV/AIDS ■ Race ■ Age ■ Sexuality ■ Geographic region



theme 2: rejection	
<i>Means of verification</i>	<ul style="list-style-type: none"> Survey with PLHAs: Sample size as the denominator
	<ul style="list-style-type: none"> Survey with people within an organisation/social setting using a social distance scale
<i>Conditions</i>	<ul style="list-style-type: none"> Existence of sufficient number of openly disclosed PLHAs
	<ul style="list-style-type: none"> Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma

theme 3: moral judgement	
<i>Finding</i>	<p>Moral judgement involves viewing PLHAs as either “guilty” or “innocent” in terms of how they contracted HIV. Such thinking allocates blame and allows people to distance themselves from PLHAs. This “othering perception” dismisses PLHAs as “promiscuous”, “sinful” or “irresponsible” and allows discrimination to appear justified.</p> <p>Some organisations struggle to find appropriate non-judgemental prevention message in relation to HIV/AIDS.</p> <p><i>“If you contracted HIV/AIDS it must have been through sex. It must have been unlawful sex. Therefore you are a sinner and it’s a punishment from God.”</i> Faith leader</p> <p><i>“People look at you and they start thinking, she’s been sleeping around.”</i> Female person living with HIV/AIDS</p>
<i>Indicators</i>	<p>3.1 Number of PLHAs who report cases of the others using the concept of blame to inform their response to them</p> <p>3.2 Number of PLHAs who report cases of others who present HIV/AIDS in terms of a moral judgement</p>
	<p>3.3 Number of people who use the concept of blame to inform their response to PLHAs</p> <p>3.4 Number of people who present HIV/AIDS in terms of a moral judgement</p>



theme 3: moral judgement

<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Concept of blame may include the perception of PLHAs as innocent, guilty or deserving based on their behaviour and perceived responsibility ■ Moral judgement is similar to the concept of blame, as it labels (according to perceived set of norms) PLHAs as immoral based on a religious belief or on values ■ Organisation refers to any social structure and setting, including for example workplace, faith groups, and recreational groups
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender: <i>"I still have to find a woman who will openly say 'I messed around'. They all became infected through their partners innocently. I find it difficult to believe sometimes."</i> Male person living with HIV/AIDS <i>"They say people who have HIV are prostitutes only."</i> Female person living with HIV/AIDS <i>"I think that especially a female, once that person has found out that she is HIV positive and then she does not have any offspring but she decides to have a child, knowing that she is HIV positive, [she is then] also labeled as guilty because of the possibility that the offspring might get the virus."</i> Female person living with HIV/AIDS ■ Race ■ Age ■ Sexuality
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Survey of PLHAs: Sample size as denominator
	<ul style="list-style-type: none"> ■ Survey of members of organisation/social setting: Sample size as denominator ■ Content analysis of organisations' newsletters: Number of newsletters as denominator
<p><i>Conditions</i></p>	<ul style="list-style-type: none"> ■ Existence of sufficient number of openly disclosed PLHAs
	<ul style="list-style-type: none"> ■ Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma



theme 4: stigma by association

<p><i>Finding</i></p>	<p>As a result of the silence surrounding HIV/AIDS and fear of casual transmission, a culture of suspicion has developed whereby some people try to identify possible PLHAs through associations.</p> <p><i>“If we see that you are losing weight, whether you are exercising or whatever, we just assume that you have AIDS.”</i> Junior staff member</p> <p><i>“Sometimes I wonder if people don’t think we are all [HIV] positive because we work in this field.”</i> HIV/AIDS co-ordinator</p>
<p><i>Indicators</i></p>	<p>4.1 Number of PLHAs who report cases of others who stigmatise those who are associated with them</p>
	<p>4.2 Number of people within an organisation/social setting who stigmatise individuals based on associations related to HIV/AIDS</p> <p>4.3 Number of people who report having been stigmatised by others as a result of their association with HIV/AIDS</p>
<p><i>Definitions</i></p>	<p>Associations may include:</p> <ul style="list-style-type: none"> ■ Medical conditions (such as TB, pneumonia, weight loss, skin diseases, no cause of death specified) ■ Work in the field of HIV/AIDS, campaign for HIV/AIDS issues ■ Befriended by or related to a PLHA ■ Part of a group vulnerable to HIV infection, for example a commercial sex worker, migrant worker or drug user
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region



theme 4: stigma by association

<i>Means of verification</i>	<ul style="list-style-type: none"> ■ Survey with PLHAs ■ Reports from care workers, affected family and friends
	<ul style="list-style-type: none"> ■ Survey of members of organisation/social setting: Sample size as denominator ■ Focus group with members of the organization or social setting
<i>Conditions</i>	<ul style="list-style-type: none"> ■ Existence of sufficient number of openly disclosed PLHAs
	<ul style="list-style-type: none"> ■ Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma

theme 5: unwillingness to invest in PLHAs

<i>Finding</i>	<p>In some cases people claimed that they would not disclose their HIV status if they learnt that they were [HIV] positive for fear that there would be career limiting consequences within their organisations. This is based on a commonly held belief that investing in PLHAs is a waste since they assume that PLHAs are not productive and will die very soon.</p> <p><i>“Because obviously the minute you disclose you will lose everything. They won’t bother training you anymore.”</i> HIV/AIDS co-ordinator</p> <p><i>“There is also the perception that if you disclose you are not going to be considered for senior positions and that your supervisor is not going to invest in you. Why should the department invest in you, spend R30 000 on you if they are only going to get 5 years out of you?”</i> Senior manager</p>
<i>Indicators</i>	<p>5.1 Number of PLHAs who are marginalised within their organisations after having disclosed their HIV status, despite adequately performing their assigned roles</p>
	<p>5.2 Number of leaders within an organisation who would not consider investing in openly disclosed PLHAs</p>



theme 5: unwillingness to invest in PLHAs

<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Marginalised is understood as not receiving training and development, promotion or given less responsibility than before disclosing ones HIV status ■ Investing may include training or ongoing formation, promotion or giving a person more responsibility ■ Organisation in this particular theme of indicators, refers to formal social structures such as workplace settings and faith groups
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Survey with PLHAs: Sample size as denominator ■ Focus group with PLHAs
	<ul style="list-style-type: none"> ■ HR records (training records, job descriptions): Number of trainees/members of organisation as denominator ■ Survey with people within the organisation: Sample size as denominator
<p><i>Conditions</i></p>	<ul style="list-style-type: none"> ■ Existence of sufficient numbers of openly disclosed PLHAs ■ Existence of HR and training records within organisations
	<ul style="list-style-type: none"> ■ Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma



theme 6: discrimination

<p><i>Finding</i></p>	<p>Some service providers perceive providing services and opportunities to PLHAs as a waste of resources because HIV/AIDS is not understood as a chronic disease. Similarly, PLHAs have experienced discrimination within their organisations.</p> <p><i>“When I go to the police to ask for help they tell me they are tired of HIV/AIDS. And the magistrate also said he doesn’t accept cases of HIV/AIDS.”</i> Female person living with HIV/AIDS</p> <p><i>“The policy is just there in name only. It’s there but nobody bothers to read it and it is not enforced. So its like the policy is not really there.”</i> Male senior manager</p>
<p><i>Indicators</i></p>	<p>6.1 Number of PLHAs who have been denied services because of their HIV positive status</p>
	<p>6.2 Number of people who would deny services to an HIV positive person</p> <p>6.3 Number of reported cases of HIV/AIDS stigma and discrimination in the organisation/social setting</p>
<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Denied services includes, among other services, emergency services, financial institutions, medical practitioners and insurance companies ■ Reported cases implies the use of formally constituted channels of complaint ■ Organisation/social setting refers to any social structure and setting, including for example workplace, faith groups, and recreational groups
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Survey with PLHAs: Sample size as denominator ■ Focus group with PLHAs ■ Records from organisations dealing with workplace discrimination and unfair labour practices



theme 6: discrimination

<i>Means of verification</i>	<ul style="list-style-type: none"> ■ Survey with people providing the services ■ HR records within organisations: Number of all HR reported cases as denominator ■ Records of organizations that specialize in HIV/AIDS law. For example in South Africa, the AIDS Law Project and AIDS Legal Network
<i>Conditions</i>	<ul style="list-style-type: none"> ■ Existence of a sufficient numbers of openly disclosed PLHAs ■ Existence of HIV/AIDS policies and formally constituted channels of complaints within organisations
	<ul style="list-style-type: none"> ■ Implementation of a monitoring system ■ Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma

theme 7: abuse

<i>Finding</i>	<p>Some PLHAs have experienced abuse by others because they were perceived as immoral or as a threat to the community.</p> <p><i>“Twice I was threatened with my life where people openly told me: If you don’t leave now we will kill you.”</i> Male person living with HIV/AIDS</p> <p><i>“When you go back to your man and disclose, tell him you are HIV positive, he runs away or he beats you.”</i> Female person living with HIV/AIDS</p> <p><i>“In your social life people call you names ...you’re a flipping bad guy, or you’re an addict or say I never knew he was in the closet, things like that.”</i> Male person living with HIV/AIDS</p>
<i>Indicators</i>	<p>7.1 Number of PLHAs who have been verbally abused as a result of their HIV status</p> <p>7.2 Number of PLHAs who have been physically abused as a result of their HIV status</p>
	<p>7.3 Number of people who think that verbally abuse of PLHAs is justified</p> <p>7.4 Number of people who think that physical abuse of PLHAs is justified</p>



theme 7: abuse	
<i>Definitions</i>	<ul style="list-style-type: none"> ■ Verbally abused includes name-calling, insults and threats ■ Physically attacked includes cases of violence by others and even murder
<i>Relationship to pre-existing stigma</i>	<ul style="list-style-type: none"> ■ Gender: <i>"I mean for a woman it is difficult to negotiate the use of a condom. Maybe she's my partner and we start negotiating the use of a condom. The response is that I am going to beat the hell out of her and she may admit that she doesn't trust me."</i> Male person living with HIV/AIDS ■ Gender, Race, Geographic location: <i>"When you go to rural areas I think women are more vulnerable in terms that in some cultures like Venda, Zulu, Xhosa and the like, you find that women don't have the power to have a say when it comes to sexual intercourse {...}, especially when they are married. Whether the man is HIV positive or not, women just have to submit and give the man what he wants."</i> Female person living with HIV/AIDS ■ Age ■ Sexuality
<i>Means of verification</i>	<ul style="list-style-type: none"> ■ Survey of PLHAs: Sample size as denominator using the "conflict tactic" scale⁸ ■ Focus group with PLHAs ■ Records from organisations dealing with workplace discrimination and unfair labour practices
	<ul style="list-style-type: none"> ■ Survey of people within organisation/social setting
<i>Conditions</i>	<ul style="list-style-type: none"> ■ Existence of sufficient number of openly disclosed PLHAs
	<ul style="list-style-type: none"> ■ Respondents are honest in sharing their perceptions and feelings on the sensitive topic of stigma

⁸ www.cps.nova.edu



3.2 Internal stigma

theme 8: self-exclusion from services & opportunities

<i>Finding</i>	<p>Some PLHAs have chosen not to seek out services or opportunities associated with HIV/AIDS because of their fear of stigmatisation.</p> <p><i>“Even if there is an offer of a job, I would not apply. It is hard because you think that they will draw blood or look at your urine and see that something is wrong.”</i></p> <p>Male person living with HIV/AIDS</p>
<i>Indicators</i>	<p>8.1 Number of PLHAs who choose not to access existing support services</p> <p>8.2 Number of PLHAs who choose not to apply for a job because of their fear of being exposed as HIV positive</p>
<i>Definitions</i>	<ul style="list-style-type: none"> ■ Existing services may include support groups, material assistance programmes, clinics
<i>Relationship to pre-existing stigma</i>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region
<i>Means of verification</i>	<ul style="list-style-type: none"> ■ Survey of PLHAs: Sample size as denominator ■ Service records: Number of clients as denominator
<i>Conditions</i>	<ul style="list-style-type: none"> ■ Existence of a sufficient number of openly disclosed PLHAs



theme 9: perception of self

<p><i>Finding</i></p>	<p>PLHAs seem to be more vulnerable to internalising stigma after being diagnosed with HIV when they have poor coping mechanisms, are within a non-supportive environment, and/or have past experience of external stigma and discrimination.</p> <p><i>“I wouldn’t feel comfortable... because I was feeling that I disappointed those people.”</i> Female person living with HIV/AIDS</p> <p><i>“First I apologised to the church and asked them to take me as I am. And I asked them to give me a second chance to prove myself.”</i> Female person living with HIV/AIDS</p>
<p><i>Indicator</i></p>	<p>9.1 Number of PLHAs who have low self-esteem as a result of their HIV positive status</p>
<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Low self-esteem may include perceiving yourself as less valuable than those who are not living with HIV/AIDS, as a disappointment to others, as guilty and immoral, or as a threat to others’ health
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Survey with PLHAs: Sample size as the denominator ■ Focus group with PLHAs ■ Application of self concept and depression scales with PLHAs⁹
<p><i>Conditions</i></p>	<ul style="list-style-type: none"> ■ Existence of a sufficient number of openly disclosed PLHAs

⁹ www.cps.nova.edu



theme 10: social withdrawal

<p><i>Finding</i></p>	<p>PLHAs may perceive the need to withdraw socially in order to protect themselves (and/or their family and friends) from stigmatisation and discrimination.</p> <p><i>“HIV has changed something in me. It has changed the way I conduct myself in front of people. I cannot be comfortable with my family because they... look at me differently. So then I also changed and became a loner. I decided to hide myself.”</i></p> <p>Male person living with HIV/AIDS</p> <p><i>“Although I’ve accepted the virus myself, the thing is I don’t want anyone next to me.”</i></p> <p>Male person living with HIV/AIDS</p>
<p><i>Indicators</i></p>	<p>10.1 Number of PLHAs who have fewer interactions with people than before they learnt of their HIV status</p> <p>10.2 Number of PLHAs who choose not to have intimate relationships</p> <p>10.3 Number of PLHAs who have fewer interactions with HIV negative people</p>
<p><i>Definitions</i></p>	<ul style="list-style-type: none"> ■ Fewer interactions could be defined in terms of number of people (close friends and associates) spoken to for a specified time period ■ Intimate relationships may refer to a close relationship between two people that may include a sexual relationship
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Survey with PLHAs: Sample size as the denominator ■ Focus group with PLHAs
<p><i>Conditions</i></p>	<ul style="list-style-type: none"> ■ Existence of a sufficient number of openly disclosed PLHAs



theme 11: overcompensation

<i>Finding</i>	<p>PLHAs may perceive the need to overcompensate in terms of their behaviour in order to prove and to protect themselves from stigmatisation and discrimination.</p> <p><i>“For me, I would say that earlier I thought I was doing what I thought was godly. I was doing my best to serve God. But when I found out that I was [HIV] positive I said no, I think it was not enough.”</i></p> <p>Female person living with HIV/AIDS</p>
<i>Indicator</i>	<p>11.1 Number of self reports from PLHAs who believe they contribute more than people who are not living with HIV/AIDS as a means of proving themselves</p>
<i>Definitions</i>	<ul style="list-style-type: none"> ■ Contributing more may include working harder or making more of an effort than people who are not living with HIV/AIDS
<i>Examples of pre-existing stigma</i>	<ul style="list-style-type: none"> ■ Gender ■ Race ■ Age ■ Sexuality ■ Geographic region
<i>Means of verification</i>	<ul style="list-style-type: none"> ■ Survey with PLHAs: Sample size as the denominator ■ Focus group with PLHAs ■ Survey of leaders or family members of openly disclosed PLHAs ■ Reports from managers who employ PLHAs
<i>Conditions</i>	<ul style="list-style-type: none"> ■ Existence of sufficient number of openly disclosed PLHAs



theme 12: fear of disclosure

<p><i>Finding</i></p>	<p>Disclosure of an HIV positive status is a very difficult challenge as PLHAs are concerned of the consequences for themselves and those close to them. As a result many PLHAs do not disclose to others the news of their HIV status.</p> <p><i>“Some PLHAs just cannot find it in themselves to disclose because of the stigma. They just have so much to lose – the respect of their community and family. Their friends will reject them. So they live in silence. It is an enormous burden to be scared of stigma.”</i> Female person living with HIV/AIDS</p> <p><i>“Now the very same issues that you as the [HIV] infected person has to deal with, your partner and child go through the very same thing.”</i> Male person living with HIV/AIDS</p>
<p><i>Indicators</i></p>	<p>12.1 Number of PLHAs who have disclosed their status</p> <p>12.2 Number of PLHAs who are willing to publicly disclose their status to the media</p>
	<p>12.3 Number of people who would not disclose their HIV positive status due to fear of stigmatisation</p>
<p><i>Definitions</i></p>	<p>Disclosure includes different levels of disclosure associated with varying degrees of risk and include, among others, disclosure to sexual partner, family, children, friends and the public</p>
<p><i>Relationship to pre-existing stigma</i></p>	<ul style="list-style-type: none"> ■ Gender <i>“You fear that I’m going to lose friends, people thinking that maybe I’m just a prostitute. That kind of thing. So that’s why it’s difficult sometimes to tell someone your [HIV positive] status.”</i> Female person living with HIV/AIDS ■ Race ■ Age ■ Sexuality ■ Geographic region
<p><i>Means of verification</i></p>	<ul style="list-style-type: none"> ■ Focus groups with PLHAs ■ Survey with PLHAs: Sample size as denominator

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