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addressing hiv/aids related stigma in South Africa

FROM INDICATORS TO ACTION
Monitoring and Evaluation Tools

The Siyam'kela Project, Centre for the Study of AIDS (CSA), University of Pretoria

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.

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FROM INDICATORS TO ACTION

Monitoring and Evaluation Tools

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Acronyms

FBO	Faith Based Organizations
HIV	Human Immunodeficiency Virus
M&E	Monitoring and Evaluation
MSC	Most Significant Change
PLHA	Person / People Living with HIV/AIDS
STI	Sexually Transmitted Infection

Terms

Qualitative	Data or information that deals with how people feel and their opinions, experiences. Qualitative information paints the picture in more detail.
Quantitative	Measurable (in numbers) information or data that provides basis descriptions of the situation or community by looking at averages of the group rather than on individuals.
Logframe	Logical framework that provides a clear logical pathway of results, on which levels on one level is expected to lead to results on another level and to achieving to overall goal. The major levels include: inputs, outputs, outcomes, impacts.
Indicator	Measurable sign that change took place
Input	The resource (people, training, equipment, etc) required for an event to take place or an activity to be completed (outputs to be achieved).
Output	Activities or services that were delivered as a result of the intervention. This includes changes in behaviour or skills and is often reported in reports.
Outcome	Major changes that occurred due to the activities, for example a decrease in stigma.
Impact	These include major impacts that are usually only visible, measurable after two or more years. The measurement is complex and involves larger groups.
Variable	A changing element of the situation that could influence the situation
Frequency	The number of times an event occurs.
Average	The typical amount or number. The average is obtained by adding the numbers in the set and dividing it by the total number of items.
Ratio	The ratio gives the relative value as compared to the larger group. The ratio is calculated by dividing the number of people who answered all questions correct compared to the number of people who attempted all the questions. The ratio is converted to a percentage by multiplying by 100. This allow for ease of comparison.
Biannually	Twice a year
Kernel	The central part around which MSC stories are build. It specifies four domains. The kernel guides the direction and content of stories to be collected.
Domain	The MSC method uses four domains that are specialized fields to be included in the stories. The domains are specified in the kernel and include: a timeframe, a location, a project and a target group.

1. Background

This monitoring and evaluation tool was developed to be used in different settings and is based on the stigma indicators as developed by Siyam'kela. The indicators can be used as markers to inform whether stigma is increasing or decreasing in any context.

The two main forms of stigma are the ***externalised or symbolic stigma*** that which is overt ostracism and discrimination towards PLHA there is ***internalised stigma, self stigmatisation*** — which is said to be protective strategies by those, living with HIV and AIDS.

Indicators of external or enacted stigma

- Avoidance
- Rejection
- Moral judgment
- Stigma by association
- Unwillingness to invest in PLHA
- Discrimination
- Abuse

Indicators of internalised stigma

- Self-exclusion from services and opportunities
- Negative perceptions of self
- Social withdrawal
- Overcompensation
- Fear of disclosure

Although some broad aspects are included on evaluation, the tools were designed to enable continuous monitoring of stigma mitigation projects and interventions.

2. Methodology

A culture of monitoring and evaluation should be built in the programmes doing stigma mitigation activities. From these activities good practices and lessons learned can be shared that will enable programmes to develop their activities. Monitoring should never be seen as a punitive measure, but rather as a positive information tool.

A logical framework (logframe) method provides the structure on which to build and plan activities at different levels that will all contribute to achievement of results. The logframe includes basic information needed to monitor the stigma programmes. The logframe should be revised and adjusted especially regarding targets. Additional indicators could be included, but care should be taken not to include too many monitoring indicators. Each indicator must have specific relevance and must contribute to the program development.

The monitoring tools as ordered in the logframe include indicators from all levels and targets the following aspects:

- ***Input:***

  People, training, equipment and resources put into a project in order to achieve outcomes.

- ***Output:***

  Activities or services delivered in order to achieve outcomes. Processes associated with service delivery including quality, unit costs, access and coverage.

- ***Outcome:***

  Changes in behaviour or skills, increased ability to cope.

- ***Impact:***

  Outcomes are intended to lead to major measurable health impacts, reduced STI/HIV transmission and reduced AIDS impact.

Participation in monitoring is an important aspect and different levels of participation were included in the logframe, for example:

- Siyam'kela level: Annual reports submitted to Siyam'kela and prepared by Siyam'kela), field visits
- Programme / project level:
- Participants level: Training evaluation, Most Significant Change Method (with decision making power and immediate direct feedback)
- Broader community: Impact surveys
- National and provincial level can also be included where statistics are available on indicators such as disclosure.

Each level of the logframe contains specific areas that need to be monitored. The indicator column provides the specific change that needs to take place. The tool column specifies the specific method to measure the indicator. Some of these measures are existing quantitative tools such as statistics and evaluation forms. Additional tools include stigma indicator tools (external and internal stigma) and the MSC method. The targets are set standards to be achieved and a time frame is also set for each level and activity to aid in determining targets.

Quantitative and qualitative tools were included to allow for a complete reflection of outcomes and program impact. The following tools will assist in measuring the achievement of the different goals and is described and included in following sections:

- External stigma indicator tool to measure external stigma in the general population, or specific target groups such as workplaces or FBO
- Internal stigma indicator tool to measure internalised stigma in specific populations (PLHA)
- The Most Significant Change method is especially useful as a qualitative method and as a participatory approach.

3. Logical framework with tools

Siyam'kela Stigma Evaluation Logical Framework					
		Indicator	**Tool**	**Targets**	**Frequency**
Impact	Internal and external stigma	Improved quality of life for PLHA	Impact survey (community or setting specific)	Improvement of QoL of PLHA	1-2 years
		Number of additional organisations trained by primary partners	Annual reports	Each organisation to train 1 additional organisation or support group	Annually
		Community level of stigma	Community based household impact surveys	Decrease from baseline	1-2 years
Outcome	Internal stigma	Percentage of respondents who correctly reject 5 stigma indicators.	Internal stigma indicator tool *	Increase of 10 percent per quarter	Quarterly
		Number of people who have disclosed their status	Monthly statistics	Increase realistic to specific setting (to be set by each programme)	Monthly
	External stigma	Percentage of respondents who correctly reject 7 stigma indicators.	External stigma indicator tool *	Increase of 10 percent per quarter	Quarterly
		Qualitative measure of involvement of members of specific setting	Most Significant Change focus groups *	Increase in number of positive stories and in stories related to public support of PLHA	Quarterly
Output		Technical support	Field visits by Siyam'kela		Quarterly or Biannually
		Capacity development	Outcomes groups	Number of people trained (target set by programme)	Quarterly
Input		Training sessions, resources	Number of training sessions	Number of training sessions held (target set by programme)	Quarterly
			Siyam'kela training evaluation forms adapted for each setting and type of training	Improvement of quality	After each training session

* see tools section below

3.1 Quantitative tools

Stigma indicator tools

Both the external and internal stigma indicator tools are quantitative measures and are applied in a similar method. The only difference lies within the target group. For the internal stigma indicator tool it is important to apply to those affected by internalised stigma (including PLHA).

Methodology

Preparation and sample:

A time frame is set for measuring and monitoring stigma indicators. In the current logframe this is set at quarterly. A realistic sample size is selected and the necessary number of questionnaires prepared and printed (description of tools not included). The participants are recruited and the questionnaires distributed for completion. Confidentiality and anonymity (no personal identification information is required) should be explained.

Questionnaires:

The questionnaire for external stigma consists of 7 questions (to measure the 7 externalised stigma indicators), while the internalised stigma tool consists of 5 questions or items.

Administration:

Each participant is requested to complete the questionnaire (should take between 5 and 10 minutes). They are required to provide the following information:

Date of completion of questionnaire

Location of completion (should not be taken home)

Sex of participant

They are requested to complete the questions by indicating whether they agree (true) or disagree (false) with each of the statements.

Data analysis:

Each individual questionnaire is then marked. The total number of questions answered correctly is indicated in the block named A and the total number of questions attempted in block B. Male and female questionnaires are separated.

When all questionnaires have been marked, frequencies are calculated in the following manner. All those questionnaires in which all the questions (7 out of 7 for external stigma and 5 of 5 for internal stigma) have been answered are counted (Block B). Of all these questionnaires those who answered all the questions correctly (Block A) are counted and the numbers transferred to the stigma indicator tool.

The number of respondents who answered all the questions correctly (A) is divided by the total number of respondents who answered all the questions (B). The obtained ratio is then multiplied by 100 to ease comparison. This value gives an indication of the stigma levels.

For additional information individual stigma questions can be calculated. The number of respondents correctly answering each individual question is also indicated in the stigma indicator tool according to male and female groups.

The following sections include the following documents:

- External stigma indicator tool description
- External stigma indicator tool (for data analysis and to calculate ratios)
- External stigma questionnaire (for collecting data and to be completed by participants
- Internal stigma indicator tool description
- Internal stigma indicator tool (for data analysis and to calculate ratios)
- Internal stigma questionnaire (for collecting data and to be completed by participants

External Stigma Indicator Tool Description

Percentage of people in specific setting able to correctly reject misconceptions about external stigma related to HIV/AIDS.

Purpose:

To assess progress in achieving universal knowledge, attitude and behavioural change about HIV internal stigma.

Applicability:

To be administered to PLHA who have openly disclosed in different settings including support groups, FBO, workplace, within communities.

Targets:

Increase of 10% per quarter

Frequency:

Quarterly

Measurement tool:

Survey administered in specific setting (e.g. FBO, workplace, support group)

Method of measurement:

The indicator is constructed from responses to the following set of questions:

1. People do not want to be associated with PLHA.

2. PLHA are rejected by there family and friends.

3. PLHA are guilty and have only themselves to blame.

4. Family and friends of people living with HIV or AIDS should be avoided.

5. PLHA are not productive.

6. PLHA should not be given loans or other support.

7. It is not wrong to verbally or physically abuse a PLHA.

Numerator: Number of respondents who gave the correct answer to all seven questions

Denominator: Number of respondents who gave answers to all seven questions

Weighted average: Result as ratio of population investigated and expressed as a percentage

Notes:

Individual indicators are important to direct activities towards specific external stigma indicator.

Composite indicator is important to measure outcome.

External Stigma Indicator Tool			
Site:			
Date:			
Officer name:			
Data collected:	**Male**	**Female**	**Total**
1. People do not want to be associated with PLHA.			
2. PLHA are rejected by their family and friends.			
3. PLHA are guilty and have only themselves to blame.			
4. Family and friends of people living with HIV/AIDS should be avoided.			
5. PLHA are not productive.			
6. PLHA should not be given loans or other support.			
7. It is not wrong to verbally or physically abuse a PLHA.			
A. Number of respondents giving correct answers to all 7 questions			
B. Number of respondents who answered all 7 questions (incuding don't know)			
Calculation: A/B *100 Divide number of respondents with correct answers to all 7 questions (A) by those who answered all 7 questions and multiply by 100.			
Weighted average: Divide calculated number by average number who attended meetings / population size			

External Stigma Questionnaire

For each question please indicate whether the answer is true or false by marking the correct column with an X.

This questionnaire is anonymous and your name will not appear anywhere. All information will be treated confidential.

Date:				
Site:				
Sex:	Male		Female	

Questions:	**True**	**False**	**Don't Know**
1. People do not want to be associated with PLHA.			
2. PLHA are rejected by their family and friends.			
3. PLHA are guilty and have only themselves to blame.			
4. Family and friends of people living with HIV/AIDS should be avoided.			
5. PLHA are not productive.			
6. PLHA should not be given loans or other support.			
7. It is not wrong to verbally or physically abuse a PLHA.			

Office use only:	
A. Total questions answered correctly:	**B. Total questions answered:**

Internal Stigma Indicator Tool Description

Percentage of people in specific setting able to correctly reject misconceptions about internal stigma related to HIV/AIDS.

Purpose:

To assess progress in achieving universal knowledge, attitude and behavioural change about HIV internal stigma.

Applicability:

To be administered to PLHA who have openly disclosed in different settings including support groups, FBO, workplace, within communities.

Targets:

Increase of 10% per quarter

Frequency:

Quarterly

Measurement tool:

Survey administered in specific setting (e.g. FBO, workplace, support group)

Method of measurement:

The indicator is constructed from responses to the following set of questions:

1. I chose not to seek services associated with PLHA because of fear of stigma.
2. I perceive myself as less valuable than those not living with HIV/AIDS.
3. I have fewer interactions with close friends after being diagnosed.
4. I have to contribute more towards proving myself than people who are not living with HIV/AIDS
5. I find it difficult to disclose my status due to fear of stigmatization.

Numerator: Number of respondents who gave the correct answer to all five questions

Denominator: Number of respondents who gave answers to all five questions

Weighted average: Result as ratio of population investigated

Notes:

Individual indicators are important to direct activities towards specific external stigma indicator.

Composite indicator is important to measure outcome.

Internal Stigma Indicator Tool				
Site:				
Date:				
Officer name:		**Male**	**Female**	**Total**
Data collected:				
1. I chose not to seek services associated with PLHA because of fear of stigma.				
2. I perceive myself as less valuable than those not living with HIV/AIDS.				
3. I have fewer interactions with close friends after being diagnosed.				
4. I have to contribute more towards proving myself than people who are not living with HIV/AIDS.				
5. I find it difficult to disclose my status due to fear of stigmatization.				
A. Number of respondents giving correct answers to all 7 questions				
B. Number of respondents who answered all 7 questions (including don't know)				
Calculation: A/B *100 Divide number of respondents with correct answers to all 7 questions (A) by those who answered all 7 questions and multiply by 100.				
Weighted average: Divide calculated number by average number who attended meetings / population size				

Internal Stigma Questionnaire

For each question please indicate whether the answer is true or false by marking the correct column with an X.

This questionnaire is anonymous and your name will not appear anywhere. All information will be treated confidential.

Date:				
Site:				
Sex:	Male		Female	

Questions:	**True**	**False**	**Don't know**
1. I chose not to seek services associated with PLHA because of fear of stigma.			
2. I perceive myself as less valuable than those not living with HIV/AIDS.			
3. I have fewer interactions with close friends after being diagnosed.			
4. I have to contribute more towards proving myself than people who are not living with HIV/AIDS.			
5. I find it difficult to disclose my status due to fear of stigmatization.			

Office use only:	
A. Total questions answered correctly:	**B. Total questions answered:**

3.2 Qualitative tool

MSC focus groups description

MSC is a participatory form of monitoring and evaluation. It is participatory because stakeholders are involved both in deciding the sorts of change to be recorded and in analyzing the data. It provides data on impact and outcomes that can be used to help assess the performance of a program or intervention (Davies & Dart, 2005; Mosse, Farrington & Rew, 1998).

The process involves the collection of significant change stories emanating from the field level, and the systematic selection of the most significant of these stories by panels of designated stakeholders. The designated stakeholders are initially involved by "searching" for project impact. Once changes have been captured, various people sit down together, read the stories aloud and have in-depth discussions about the value of the reported changes (Davies & Dart, 2005; Mosse, Farrington & Rew, 1998).

This monitoring and evaluation method has the benefit that:

- It can identify unexpected change
- It is a good way to clearly identify the value prevailing in an organization,
- It is a participatory form of monitoring that requires no special training and it could be used by the organizations independent of this study for continuous monitoring purposes,
- It is easy to communicate across cultures,
- It can be used to evaluate initiatives that do not have predefined outcomes against which to evaluate,
- It focuses on learning rather than just accountability.

Sampling: Focus groups

Inclusion criteria need to be set for participation in the MSC focus group discussions for example people from the same church, age groups, male or female groups (as is needed by the specific topic to be investigated).

Focus groups steps

- Selection of focus group participants, and providing invitation information and consent documents. This is done on an individual level and information needs to be provided to the participants to ensure full participation.
- Collecting significant change stories. Stakeholders are invited to participate in a focus group. They are requested to search for and document a most significant change story (not necessarily personal, but verifiable) that captures most significant change related to stigma. A date and time are set and appointments made with all participants.
- The stories are shared and evaluated by the focus group. The facilitator is not required to do more than facilitate story telling and assist in the voting process.
- The most significant change story from each focus group is fully documented.

The following need to be set:

- The domains identified as change in stigma related to HIV/AIDS for men and women.
- The reporting period set for: the past 3 months.
- The specific project or programme to be evaluated.
- The specific target group (e.g. broad community or PLHA).

The kernels could possibly include the following:

*"Looking back over the past six months, what do you think was the most significant change in stigma related to HIV/AIDS for men and women at **[insert programme name]**?"*

Training for the conduction of the MSC focus groups need to be done initially to enable full participation. No additional resources will be needed in addition to this training.

Facilitation Guide for Story Collection

The facilitator writes all the titles of the stories on the whiteboard, grouped by domain. They leave a space next to each story for comments e.g.

Domain	Title	Comments
4	My life is getting better	Strong, written by a beneficiary, but incomplete, story not finished.
4	Feeling empowered	Moving story, beginning middle and end. Attribution to project is questionable. Great story, not sure if it is about the project.
4	Better decisions for the family	Good solid story. Heard many times before. Small change yet crucial. Not sure about the dates mentioned.
4	Now I understand	OK, not enough information to really understand what is going on.

1. The facilitator invites volunteers to read out all the stories belonging to the first domain of change. After each story ask:

- What is this story really about?
- What is your opinion of the story?

2. The facilitator writes any comments next to the title on the white board as above.

3. When all the stories have been read out for the first domain, ask people to vote for the story that they find most significant. Voting can be done by a show of hands.

4. When the votes have been cast, if there is a range of scores, encourage participants to discuss why they chose the story they chose. Ask questions such as:

- Why did you choose this story above all other stories?
- But some of you chose a different story – can you explain why you didn't choose this story?
- What do you think of the stories in general?

5. Next to each story makes notes of the reasons why they were and were not selected.

6. Once everyone has heard why certain stories were voted for above others, the facilitator might call a second vote; this time there may be more consensus.

If there is still no consensus about which story to choose, facilitate a discussion on the options with the group and come to an agreement, for example:

- Choose two stories to reflect the range of views
- Decide that none of the stories adequately represents what is valued
- Choose one story but add a caveat explaining that not all people voted for this story because…

7. Move onto the next domain (if applicable).

MSC Focus groups: Instructions to participants

You are requested to participate in this study in the following manner:

- Identify a "story" (this must be a real event that can be verified) that illustrates the ***most significant change*** that occurred during the past 6 months in this community that can be directly linked to the stigma intervention **[insert programme name]**. This need not be a personal story, but you must be able to trace all the relevant details.
- Use the attached Story Report Format to document the story. Please also describe why you selected this story to be the most significant.
- Please bring this document to the focus group discussion. During the focus group we will ask you, as part of the expert panel, to describe the story to the group and to clarify your reasons for selecting it. The other participants will be requested to do the same.
- As a panel you will select the most significant story from the group. You will also be able to learn from each others stories.

The following should be able to help you identify and document your most significant story:

"Looking back over the past six months, what do you think was the most significant change in stigma related to HIV/AIDS for women at [insert community name] by [insert programme name]?"

We thank you for your valuable time and expertise that you will share with us.

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