

# Lessons learned in adapting the Stigma Index 2.0 to South African context

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## Introduction

### Background

- Stigma and discrimination against people living with HIV remain some of the key barriers to effective prevention and management of HIV in Africa.
- The outbreak of COVID-19 put key and vulnerable groups – including people living with HIV – at heightened risk given that containment measures to slow the pandemic including lockdowns and disruption of basic services which exacerbated existing economic and social inequalities.
  - With the onset of the COVID-19 pandemic, fear of infection also increased social exclusion and stigmatisation
- The Stigma Index was developed by various international organisations (GNP+; ICW, IPPF and UNAIDS) to assess different forms of stigma and discrimination experienced by people living with HIV
- For the first time in South Africa, this study made use of the **Stigma Index 2.0**: an updated version of the Stigma Index that reflects shifts in the HIV epidemic and the global response to HIV.

## Overall aim

We measured the levels of stigma and discrimination experienced by people living with HIV, as well as stigma and discrimination attached to TB, COVID-19, disability, sex work, and sexual orientation and gender identity (SOGI), and through cyberbullying

- Importantly:
  - More than just collecting this much-needed evidence
  - Intended to be an empowering for people living with HIV, their networks and local communities

## Ensuring the greater involvement of people living with HIV in the Stigma Index 2.0 project

- **Participatory** –
  - The People Living with HIV Stigma Index 2.0 is not intended to be an abstract academic exercise that is done “to” our community.
  - Ideally, the interviewer and interviewee will sit side by side, and the interviewee will be able to fill in the questionnaire with help from the interviewer, or both the interviewee and the interviewer can work together in filling in the questionnaire.
    - “face-to-face interviewing” (normal in survey work) where the interviewer faces the interviewee and the interviewee cannot see the questionnaire; the interviewee just provides information without being in control of how it is written down – a very disempowering experience.

## Measures

- Key indicators of stigma are outlined in detail in the questionnaire domains of the Stigma Index 2.0.
- These include:
  - Disclosure
  - The experience of stigma and discrimination
  - Internalised stigma, resilience
  - Interaction with healthcare facilities, and;
  - Human rights and effecting change

# Measures

- The Stigma Index 2.0 included the following modules:
  - New questions focused on specific populations to better understand how different groups of people living with HIV and key populations are affected by stigma and discrimination.
  - An expanded healthcare section to look at the impact of stigma on health and access to healthcare across the whole continuum of care, not just HIV services.
  - A new questionnaire that is streamlined and easier to use, using digital data collection (see [www.stigmaindex.org/about-stigma-index](http://www.stigmaindex.org/about-stigma-index)).

# Measures

	Stigma Index	Stigma Index 2.0	Indicator
<b>Section C: YOUR EXPERIENCE OF STIGMA AND DISCRIMINATION</b>	<p>In the last 12 months, how often have you been excluded from social gatherings or activities (e.g. weddings, funerals, parties, clubs)? (Tick one box only.)</p> <p>Never, once, a few times, often</p> <p>If never skip...</p> <p>5 pages</p>	<ul style="list-style-type: none"> <li>• Not just questions posed, where respondents must answer yes or no</li> <li>• The interviewer-interviewee relationship can be disempowering and the use of statements counters this</li> <li>• More streamlined</li> </ul>	Percentage of people living with HIV aged 15 years or older who report experienced stigma and discrimination in the general community EVER and in the last 12 months
<b>Section D. INTERNALISED STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) AND RESILIENCE</b>	<p>In the last 12 months, have you experienced any of the following feelings because of your HIV status?</p> <p>(Tick one box for each category.)</p> <p>I feel ashamed</p> <p>I feel guilty</p>	More streamlined – statements help with the flow of the interview, compared to questions posed	Percentage of people living with HIV aged 15 years or older who report internalized stigma and resilience in the last 12 months
<b>Section E. INTERACTIONS WITH HEALTHCARE SERVICES</b>	<ul style="list-style-type: none"> <li>• Divided into 3 separate sections</li> <li>• SECTION 3 YOUR ACCESS TO WORK AND HEALTH AND EDUCATION SERVICES</li> <li>• SECTION 7 TESTING/DIAGNOSIS</li> <li>• SECTION 9 TREATMENT</li> </ul>	<p>Most revised/changed section</p> <ul style="list-style-type: none"> <li>• An <u>expanded healthcare section</u> to look at the impact of stigma on health and <u>access to health across the whole continuum of care</u>, not just HIV services</li> <li>• Questions about the interviewee’s experiences of healthcare services and of related stigma and discrimination due to their HIV status.</li> <li>• The questions focus on: HIV testing, care and treatment; general health status; service delivery experiences; and sexual and reproductive health.</li> </ul>	Percentage of people living with HIV aged 15 years and older who have experienced stigma and discrimination EVER and in the last 12 months

## Process of adapting questions to South African context

- The PLHIV Sector engaged with the researchers (i.e., the Human Sciences Research Council) and the South African National AIDS Council (SANAC) in a process of learning which indicators are relevant in promoting human rights to end stigma and discrimination.
- Within the sector we approached the index based on experiences of people living with HIV on the ground.
- Looking into the South African context the focus was on which questions reflect the experiences of people living with HIV and what kind of change or lack of change we would document.
- In addition to the aforementioned items, the PLHIV Sector together with the research team, recommended to include measures on:
  - TB-related stigma
  - COVID-19 stigma and access to healthcare during lockdown
  - Cyberbullying.



# Lessons learned

- Taking into consideration the high burden of HIV/TB co-infection in South Africa, the next Stigma Index 2.0 should consider expanding to issues beyond feelings of dirtiness or uncleanness with regard to TB measures.
  - For example, did clients experience internalised feelings of shame, isolation from society, and fear of discriminatory practices because of their TB status?
  - More importantly, was there greater stigma experienced by persons with DR-TB, and finally, did TB-related stigma impact a client's willingness to interface with the healthcare system?
- Specifically, more research is needed to further refine the national understanding of stigma and discrimination among key and vulnerable populations.
  - We need more understanding of stigma and discrimination amongst key and vulnerable populations in terms of the language used.
  - We needed more advice as to what would be the specific questions that would inform the indicator