



The Power of the PLHIV Stigma Index 2.0

An introduction to community-led research and data collection

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What is the PLHIV Stigma Index 2.0?

- ▷ Standardized peer-driven research tool for collecting data on stigma and discrimination
- ▷ Designed to be used by and for people with HIV to reflect the GIPA principle
- ▷ Supported by an International Partnership since 2008
 - Ensure that the Stigma Index non-negotiables, methodology and quality standards are met.
 - Meaningful leadership and ownership of networks of people living with HIV, networks of women living with HIV and networks of key populations living with HIV.
 - Achieve gender equity within the implementations

What is the PLHIV Stigma Index 2.0?

Where does the data come from?

Implemented **2020–2025**

- **50+** countries globally
- Led by networks of people living with HIV

+70,000 people living with HIV interviewed using the standardized methodology

12,000+ women included in reproductive coercion analysis

10,700+ women included in ART adherence analysis

The **Evolution** of the Stigma Index

200

8

The PLHIV Stigma Index is launched by GNP+, ICW, IPPF and UNAIDS.

Created **by and for people living with HIV** to systematically document stigma and discrimination, putting the GIPA principle into practice and generating evidence for advocacy.

2018

PLHIV Stigma Index 2.0 released

Updated to reflect changes in the HIV response, with greater attention to key populations, intersectional stigma, healthcare experiences across the continuum of care, and a streamlined questionnaire

2020

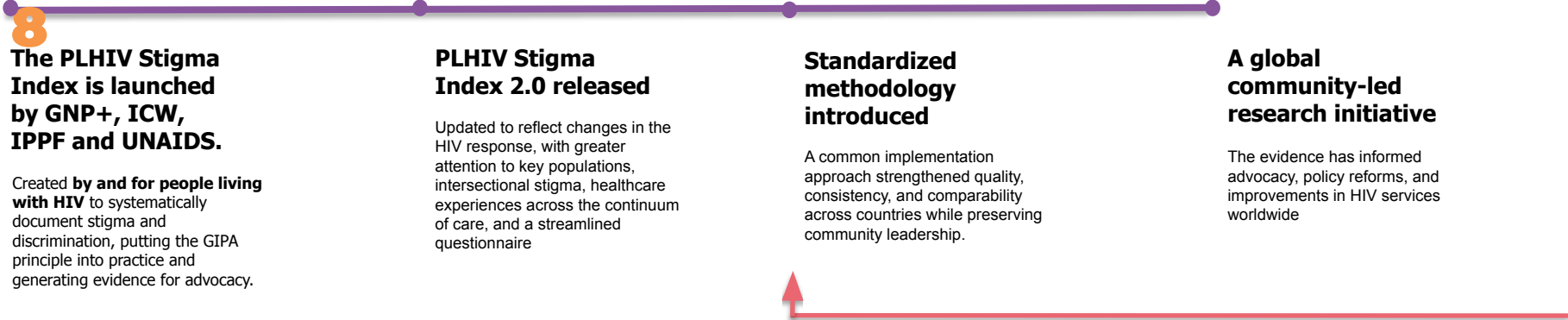
Standardized methodology introduced

A common implementation approach strengthened quality, consistency, and comparability across countries while preserving community leadership.

Today

A global community-led research initiative

The evidence has informed advocacy, policy reforms, and improvements in HIV services worldwide



More than 56 countries have completed the 2.0 using the standardized methodology, with over 70,000 people living with HIV interviewed, generating comparable evidence to strengthen advocacy, policies, and programmes

The **non-**negotiables

- 1 Leadership of PLHIV networks**

The PLHIV Stigma Index 2.0 implementation must be led by networks of People Living with HIV. This leadership role must include decision-making in all phases of implementation as well as program and financial management.
- 2 Standard methodology**

The PLHIV Stigma Index 2.0 implementation must follow the 2020 standardized methodology provided by the International Partnership. For information: PLHIV Stigma Index website.
- 3 Sampling frame**

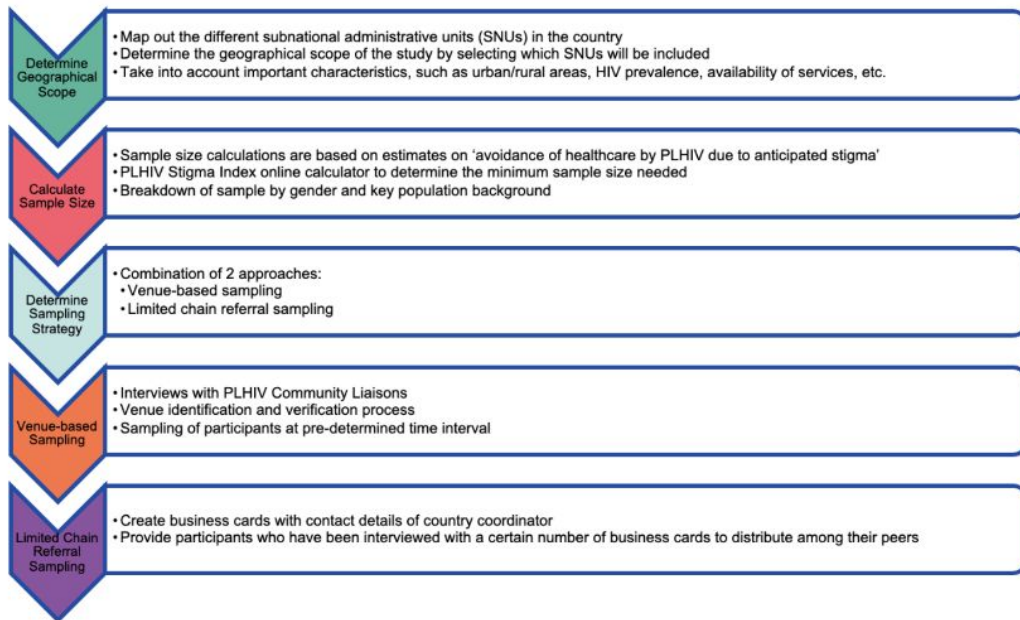
The PLHIV Stigma Index 2.0 requires a sample that is inclusive of all sub-populations (above the national age of consent) of people living with HIV. Specific attention is needed to ensure the inclusion of populations that often encounter barriers to their access to health, including women, young people, people who use drugs, sex workers, gay men and other men who have sex with men, and transgender people.

The **non-**negotiables

- 4** **Quality assurance**
For quality assurance and reliability, every country implementing the PLHIV Stigma Index 2.0 must comply with the review process from the IP on its research protocol and can only continue the implementation process upon approval.
- 5** **Data security and sharing**
All data must be securely maintained in accordance with ethical standards throughout the implementation. Post-implementation, the data will be securely stored by the IP in designated cloud/ electronic data storage.
- 6** **Dissemination**
All presentations and reports produced from these analyses will include authors from the implementing national network(s) of PLHIV. For analyses, presentations, and reports developed separately from the initial implementation, authors will be included from the International Partnership in accordance with international standards of authorship.

How Does the Stigma Index Methodology Work?

A standardized, community-led approach to generating evidence



What **Data** Does the Stigma Index Generate?

Violence and discrimination undermine treatment outcomes

Among 10,757 women across 11 SSA countries:

- **Sexual violence** → 72% lower odds of consistent ART (AOR = 0.28)
- **Partner control** → 82% lower odds (AOR = 0.18)
- **Physical violence** → significantly reduced adherence (AOR = 0.65)
- **Employment discrimination** → reduced adherence (AOR = 0.57)

Stigma Index Data has been incredibly useful for secondary analysis which has allowed networks working with researchers to examine more closely the impacts of stigma and discrimination at regional and local levels.

REF: Violence, discrimination, and protective policies and their associations with consistent antiretroviral therapy use among women living with HIV in 11 countries across sub-Saharan Africa (N=10,757)

Understanding Intersectional Stigma

Stigma and discrimination are not experienced in isolation.

People living with HIV may experience discrimination related to multiple aspects of identity, including race, gender, sexual orientation, disability, economic circumstances and HIV status.

The Intersectional Discrimination Index (InDI)

Developed by Scheim and Bauer (2019), the InDI measures experiences of discrimination without requiring participants to identify a single cause.

Anticipated

Expectations of unfair treatment

Day-to-day

Everyday exclusion and mistreatment

Major

Significant discriminatory events

- Documents discrimination without requiring attribution to a specific cause
- Considers experiences associated with the person as a whole
- Adds complementary dimensions of discrimination

"because of who I am."



Interested in **Implementing** the **PLHIV Stigma Index 2.0?**

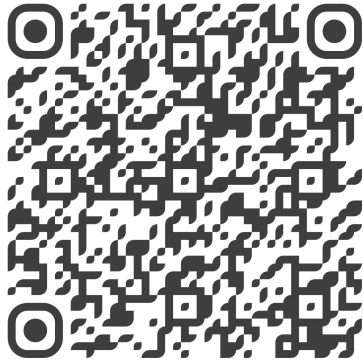
You don't have to start from scratch!

The International PLHIV Stigma Index Partnership provides standardized tools, resources, and technical guidance to support implementation.

Resources available:

- Implementation guidelines: Step-by-step guidance for planning and conducting the study.
- Standardized research tools and templates: Questionnaires, protocols, training materials, and reporting templates.
- Sample Size Calculator: An online tool to determine the minimum sample size required for implementation.
- REDCap: A ready-to-use electronic data collection platform, provided free of charge for Stigma Index implementation.
- Fundraising concept note template: A resource to support proposal development and resource mobilization.
- Technical support: Guidance throughout the planning, implementation, analysis, and dissemination processes.

Additional resources





Thank You!

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