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## Updating the people living with HIV stigma index

Project SOAR

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# Updating the People Living with HIV Stigma Index

Stigma experienced by people living with HIV has resulted in poor quality health care, coercion and violence, job loss, and exclusion from social gatherings. HIV-related stigma and discrimination is not only a human rights violation, but it also impedes people's ability to access HIV testing, care, and treatment. Given its impact on the HIV epidemic, addressing stigma and discrimination is a high priority.

The People Living with HIV Stigma Index was developed by the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV (ICW), the International Planned Parenthood Federation (IPPF), and UNAIDS to provide evidence on stigma and discrimination that can be used to advocate for the rights of people living with HIV. In keeping with the GIPA principle (greater involvement of people living with HIV/AIDS), the Stigma Index is both a data collection tool and an empowering intervention for both the interviewers collecting data and the interviewees who are sharing their experiences of stigma.

The Stigma Index was launched in 2008 and as of October 2017 it had been translated into 54 languages, 100,000 people living with HIV from 90 countries had been interviewed and 2,000 people living with HIV had been trained as interviewers.

## WHY UPDATE THE STIGMA INDEX?

Since the Stigma Index was launched, there have been shifts in the HIV epidemic, growth in the evidence base on how different populations are affected by stigma, and changes in the global response to HIV—particu-

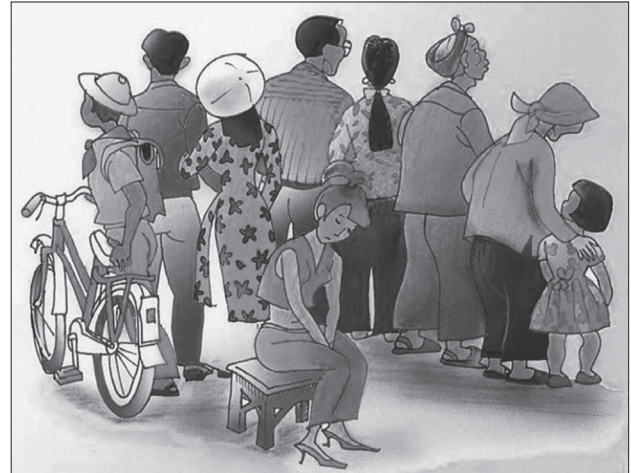
**Research Partners:** Project SOAR, GNP+, ICW, UNAIDS, USAID

**Location:** Global

**Study Duration:** 2016–2017

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larly given the recommendation of early initiation of treatment. These developments highlighted the need to update and strengthen the Stigma Index to be even more useful as a measurement and advocacy tool.

In October 2015, supported by USAID/PEPFAR, Project SOAR established a small working group (SWG) with representatives from GNP+, ICW, UNAIDS, USAID, and several experts within and external to SOAR. The SWG outlined a process for evaluating and updating the Stigma Index that would be transparent and incorporate as many perspectives as possible in the process.

## KEY UPDATE STEPS

### Stakeholder consultation, April 2016

A two-day consultation was held in Washington, DC to develop specific recommendations for updating the Stigma Index and its implementation. The meeting brought together 42 people with direct experience implementing the tool, as well as donors, bilateral organizations, and researchers with expertise in stigma research or scale development. Based on a desk review of country and regional Stigma Index reports, interviews with key informants from different countries with experience using the tool, and discussions at the consultation, the SWG revised the tool.

## Questionnaire pre-test workshops, July 2016

The first draft of the updated Stigma Index was pre-tested at the AIDS 2016 Conference in Durban, South Africa. More than 60 people living with HIV attended three workshops where they administered the survey to each other and provided feedback. The SWG developed a second draft based on input from the workshops and comments from external reviewers.

## Pilot testing, March–September 2017

The post-Durban version of the revised Stigma Index was formally pilot tested among 1,200 people living with HIV in Cameroon, Senegal, and Uganda. Participants in Uganda completed the survey on mobile phones and those in Cameroon and Senegal responded on tablet computers. Interviewers were recruited from local networks of people living with HIV. In-country NGOs, Project SOAR (i.e., Population Council and Johns Hopkins University researchers), and local consultants provided technical support. The SWG reviewed the pilot results and made final recommendations, resulting in a re-structured and streamlined tool, the People Living with HIV Stigma Index 2.0.

## WHAT'S NEXT?

The People Living with HIV Stigma Index International Partnership of GNP+, ICW, and UNAIDS will continue to lead this initiative with the improved and revised survey tool. We encourage implementing and supporting agencies to work with GNP+ and people living with HIV networks in country to use the tool for data collection and advocacy purposes. As part of this:

- Countries are encouraged to incorporate implementation of the Stigma Index 2.0 into Country Operating Plans (COPs) to be supported by PEPFAR.
- Other initiatives such as the Global Fund and regional networks are encouraged to contact GNP+ for information and partnerships.

GNP+, on behalf of the International Partnership, will update the Stigma Index website, [www.stigmaindex.org](http://www.stigmaindex.org), reflecting the revised tool and the guidance necessary for implementation, and will maintain the data from country implementations. The data portal will allow open access to anonymized research data for cross comparisons and analyses.

## NEW FEATURES

Below are some examples of how the Stigma Index 2.0 differs from the original tool.

**Expanded healthcare section**—the Stigma Index 2.0 now captures experiences around:

- Delays in seeking HIV testing, care and treatment, and reasons for these delays.
- Antiretroviral treatment use, adherence, and viral load suppression.
- Experiences of stigma and discrimination within HIV care and other health care settings.

**Added additional measures of stigma and discrimination among sex workers, gay men and other men who have sex with men, lesbians, transgender individuals, and people who inject drugs:** the scale now allows more explorations than previously of the intersectionality between stigma due to HIV or membership of a specific population.

**Incorporated existing, validated scales that assess internal stigma and mental health.**

**Developed a new scale to measure resilience:** In response to feedback around the need to capture positive modes of coping with an HIV diagnosis, in addition to negative, stigmatizing experiences, a new 'resilience' scale was created.

**Timeframe concentrated on the last 12 months to better measure changes over time.**

## CONTACT US

It is the role of GNP+ (with the International Partnership) to field and coordinate all questions about the questionnaire and implementation. GNP+ can be contacted at [plhivstigmaindex@gnpplus.net](mailto:plhivstigmaindex@gnpplus.net).

For questions related to US Government support of the Stigma Index, contact Alison Cheng, USAID: [acheng@usaid.gov](mailto:acheng@usaid.gov).

For more information about the Stigma Index update process or the pilot studies, contact: Barbara Friedland, Population Council: [bfriedland@popcouncil.org](mailto:bfriedland@popcouncil.org).