

People Living with HIV Stigma Index

Implementation Brief

What is the PLHIV Stigma Index?

The PLHIV Stigma Index is a research and action initiative that leverages a standardized questionnaire and sampling strategy to gather evidence on intersecting stigmas and discrimination affecting people living with HIV. The PLHIV Stigma Index monitors HIV-related stigma and discrimination across different domains of life, with particular attention to related stigmas that affect the diverse populations of people living with HIV, and provides evidence for advocacy to address the key barriers to HIV treatment, prevention, care and support.

The PLHIV Stigma Index was first launched in 2008. Ten years later, with support from PEPFAR, it was updated as the PLHIV Stigma Index 2.0. The revised questionnaire was launched in 2018 and, after the need for a more rigorous sampling methodology was identified in 2019, an updated standardized methodology was launched in 2020. Since the project began, more than 100 countries have completed the PLHIV Stigma Index, and over 100.000 people living with HIV have been interviewed. The PLHIV Stigma Index is governed by the International PLHIV Stigma Index Partnership of GNP+, ICW, and UNAIDS.

Objectives of the PLHIV Stigma Index 2.0

- To document the experiences of people living with HIV regarding HIV-related stigma and discrimination with a key focus on intersectional stigma based on gender and gender identity, age, sexuality, occupation in sex work and drug use.
- To strengthen the capacity of PLHIV networks/groups to generate and disseminate evidence-based data to inform policy and programming, as well as to monitor progress, and support accountability toward the elimination of HIV-related stigma and discrimination;
- To establish, strengthen, and revitalize partnerships among stakeholders to implement and scale up programs towards ending all forms of HIV-related stigma and discrimination;

The use of the PLHIV Stigma Index 2.0 over time will be instrumental in increasing the understanding of the burden of stigma, downstream consequences of individual and intersecting stigmas, and trends regarding HIV-related stigma and discrimination in individual countries as well as regionally and across the world.

The Process

In this initiative, the process is equally important as the product. The *Greater Involvement of People living with HIV and AIDS* (GIPA) principle forms the foundation of the research methodology used by the PLHIV Stigma Index. People living with HIV are at the centre of the process, starting from research design, through implementation, to using the findings for advocacy. The methodology requires that the project and the funds to implement the PLHIV Stigma Index are managed by the national PLHIV network(s), to ensure that the whole process is fully owned by the PLHIV community. In addition to collecting critical data, the PLHIV Stigma Index is a catalyst for network strengthening and building solidarity across a diversity of people living with HIV and for creating and fostering change in the communities in which it is used.

The Research

The PLHIV Stigma Index 2.0 follows a rigorous research process, based on a validated questionnaire and standard implementation methodology. In each country, the PLHIV network(s) establish broad partnerships with other key population groups, government, research partners (if needed), UN agencies, as well as other national stakeholders to steer the project. Data are gathered through a peer-to-peer interview process, with people living with HIV from diverse backgrounds serving as trained interviewers.

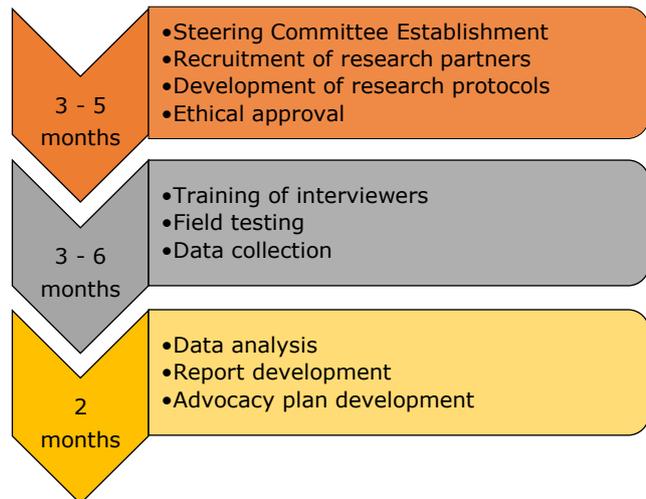
The PLHIV network(s), with the steering committee and support from the International Stigma Index Partnership and Johns Hopkins University, develops a sampling plan to ensure geographic

and population diversity of people living with HIV. The sample reflects the country epidemic and focuses on inclusion of PLHIV who are gay men and other men who have sex with men, people who use drugs, sex workers, and transgender people, with additional focus in all groups of people living with HIV on inclusion of those not currently engaged in HIV treatment services.

Participants are recruited in places where people living with HIV receive health and care services, including community-based services, as well as through a limited-chain referral process designed to reach key populations living with HIV and those not currently in HIV care. On average, the sample sizes range from 750 – 1500 respondents and are calculated based on historical data on avoidance of health care among PLHIV.

The entire process of research implementation takes, on average, 8 to 12 months. The PLHIV Stigma Index should be implemented every two to three years.

The cost for the PLHIV Stigma Index varies based on geographical scope and sampling size as well as local context. However, a country can estimate a budget of USD 50.000 - 150.000 for community-led implementation. Since the launch of PLHIV Stigma Index 2.0, it is eligible for PEPFAR and Global Fund funding.



The Results: Evidence-informed Advocacy

Stigma remains one of the biggest barriers to health care, social inclusion, and quality of life for people living with HIV. The PLHIV Stigma Index increases our understanding of how stigma and discrimination are experienced by people living with HIV, across intersections of age, gender, gender identity, sexual orientation, and experience of drug use and sex work. Once these data are collected, the goal of the PLHIV Stigma Index is to put this evidence into action through advocacy to inform policy development and programmatic interventions to mitigate intersecting stigmas affecting quality of life, health, including mental health, and engagement in HIV treatment services. Therefore, it is necessary to ensure adequate resources in the budget to conduct at least one year of dissemination and outreach for advocacy approaches using the results from the PLHIV Stigma Index.

Technical Assistance

The PLHIV Stigma Index International Partnership is hosted by GNP+ with support from UNAIDS and technical partners in providing technical assistance to implementing countries, including:

- Initial planning and partnership building
- Protocol development
- Ethical approval
- Training of interviewers
- Data collection and data storage
- Data analysis
- Report development
- Advocacy plans