



STANDARDS FOR COUNTRY ROLLOUT

The People Living with HIV Stigma Index:

This document outlines practical ways to ensure that in practice, the implementation of the *People Living with HIV Stigma Index* (the 'Index') remains true to the ethos that it is an initiative by and for people living with HIV. It provides good practice standards to guide country teams rollout the index in their country. These Standards, the User Guide and related Index documents are intended to ensure that the Index is implemented in accordance with the principles of a human rights-based approach.

1) NATIONAL PARTNERSHIP RESPONSIBLE FOR IMPLEMENTING THE INDEX

- The national partnership should be driven by people living with HIV networks, ensuring full participation of people living with HIV throughout the process of implementation, including building the partnership, strategically planning for the implementation, budgeting and resource allocation, research and data analysis, monitoring, evaluation, communicating the research results and other advocacy.
- Representatives from UNAIDS, IPPF, the national partners of ICW and GNP+, government representatives and civil society organizations should be involved in the planning stages for the index and be active in the partnership and implementation as agreed and appropriate. Other partners should be identified as appropriate to support the specific needs of each country implementation plan.
- Each national partnership should include a research partner (e.g. an academic institution)
- Multisector government participation is recommended in the national partnership, and involved as appropriate in the planning, implementation and reporting on the Index. National AIDS Council and ministries responsible for health, human rights, education and other related areas could be included in information meetings, reviewing project proposals and research dissemination activities. Interested multilateral and bilateral donor agencies should also be included.

2) METHODOLOGY

- The questionnaire should not be changed or adapted.
- Additional sections can be added as required by national partnership to focus on specific issues such as specific themes (e.g. gender violence), key populations (e.g. MSM), accessing services (e.g. experiences in different health care settings), and/or cultural needs (e.g. religion).
- The national partnership should ensure that support (logistical, emotional, technical) is provided to the interviewers involved in the research
- The national partnership should ensure that appropriate referrals, follow-up and support are provided to participants in the research, particularly interviewees and interviewers.
- Each national partnership should seek to develop qualitative work to compliment the work conducted through the Index, in consultation with the International Index Coordinator and the International Steering Group for the Index. Guidelines and a collection of complimentary qualitative methodologies are currently being developed.
- Each national partnership should ensure that the research done with the *People Living with HIV Stigma Index* is implemented and linked with other studies on stigma and discrimination relating to HIV in the country context.
- The national partnership should seek to maintain a gender balance in terms of women and men living with HIV involved in the project at the level of leadership, capacity building, and data collection. Referrals, follow up or support should be gender sensitive. Any problems with meeting either of these standards should be communicated to the International Coordinator of the Index

3) ETHICAL REVIEW

The People Living with HIV Stigma Index, like other studies that collect data from people, must observe certain standards with regard to ethical issues and data protection.

- In each country where this survey is carried out, those responsible for conducting the study should make sure that it conforms to that country's ethical and data protection requirements (see part 3 of the User Guide regarding ethical issues). Two issues are of particular importance:
 - 1) **Informed consent:** The principle of informed consent means that each interviewee must be asked to consent to the collection and processing of their personal data after being fully informed about the

nature of the study, who is involved in it, how the data will be processed and stored, and what the data will be used for.

- 2) Confidentiality: Confidentiality is crucial with regard to with the issue of who has the right to access data provided by the participants of a research study. When conducting research, one should always ensure that appropriate measures are put in place so as to make absolutely certain that the information participants have disclosed and their identity are kept in confidence.
- In each country, the national partnerships should ensure that participation is open to all people living with HIV from a variety of different organisations and networks. Mechanisms should be put in place to protect the confidentiality of all individuals involved in the implementation of the Index, not only of interviewees.
 - Transparency regarding the coordination of the national rollout and accountability to all stakeholders (national and international) is essential.

4) COMMUNICATION

- The questionnaire should be translated into local languages as appropriate.
 - For country-to-country comparison the questionnaire should be the same regardless of the language it is in. The translation therefore needs to ensure that the meaning of each question remains the same as the original English
 - Each translation should be checked for accuracy and sensitivity to ensure that the questions retain the same meaning as the English original
 - Each translation should be reviewed by at least one person living with HIV
- Where possible, country teams should share reflections and best practice with each other.
- Any publications resulting from *The People Living with HIV Stigma Index* should include the logo; be communicated to appropriate national and international partners (before and after finalization); and should be listed on the website www.stigmaindex.org.

5) BUDGETING AND RESOURCE ALLOCATION

- At least 50% of each budget should be spent on the capacity building of networks of people living with HIV and of the people living with HIV who will be involved in the research team.
- Each budget should include a budget line for advocacy and communication.

6) RELATIONSHIP WITH THE INTERNATIONAL INITIATIVE

- Consistent communication and reporting should be maintained with the International Coordinator of the Index to ensure consistency with other country initiatives.
- Technical assistance can be provided by the International Coordinator of the Index on behalf of the International Steering Group. Technical assistance can also be sought from the regional partners—the UNAIDS Regional Support Teams, the regional networks of people living with HIV, and regional offices of IPPF.
- All ideas and suggested additions for the questionnaire should be discussed with the International Coordinator; and approved by the International Coordinator in consultation with the International Steering Group.
- All ideas and suggested qualitative methodologies to compliment the work of the Index should be discussed with the International Coordinator; and approved by the International Coordinator in consultation with the International Steering Group.

7) INTENDED USE

The People Living with HIV Stigma Index is intended for use as an empowering research tool for developing evidence based advocacy by and for people living with HIV. The Index has been developed through extensive field testing in pilot studies and when implemented in its entirety (as outlined in the User Guide) has shown to be a valid and reliable tool. It is not intended for any other use.

