

THE PEOPLE LIVING WITH HIV STIGMA INDEX

A RESEARCH INITIATIVE BY AND FOR PEOPLE LIVING WITH HIV

“Being interviewed by another person living with HIV does make a difference - as you feel they really would understand more about how you feel about things related to being HIV positive,”

RESEARCHER, PILOT PHASE, SOUTH AFRICA, JUNE 2006



“The index provides the best opportunity for people living with HIV to tell their secrets—so we need to develop the skills to ask them”

PRINCEY MANGALIKA, LANKA+, MARCH 2008

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What is the aim of the Index?

Stigma and discrimination continue to pose a critical barrier to achieving universal access to HIV related prevention, treatment, care and support. Much of what we know about the stigma attached to HIV, and resulting discrimination, is anecdotal or fragmented, and does not include the perspectives of people living with HIV. The People Living with HIV Stigma Index will fill this gap in our global understanding, and build an evidence base to inform policy and practice. The index can be used as a tool to advocate for evidence based policy and practice that is grounded in the real experiences and perspectives of people living with HIV.

How was the Index developed?

The People Living with HIV Stigma Index is a new research initiative to measure stigma, by and for people living with HIV. The index is the product of an ongoing partnership between two networks of people living with HIV (GNP+ and ICW), UNAIDS and IPPF. The index was piloted in five countries (Kenya, Lesotho, Trinidad and Tobago, India and South Africa) and developed in collaboration with activists, research experts and human rights champions around the world. The first full-scale national implementation of the index is underway in the Dominican Republic and findings and initial reflections will be finalized in September 2008.

What did the pilot study discover?

The questionnaire was piloted to test the questions themselves rather than find answers, yet some interesting results emerged. A mixture of 64 men and women aged between 20 and 52 year were interviewed in five countries during the pilot. Included in this number were people from vulnerable groups such as men who have sex with men and sex workers. Some findings include:

- Physical abuse: Harassment or assault had been experienced by 64% of participants in the last 12 months, of whom 79% indicated that this was related to their HIV status
- Displacement: One quarter of participants had been forced to move or change their living situation in the last 12 months—87% said this was related to their HIV status
- Unemployment: More than a third of participants reported losing a job (or other source of income) in the last 12 months—83% said this was related to their HIV status
- Disclosure: Disclosing their HIV status was an empowering experience for 75% of participants even in light of other stigma or discrimination they may have experienced
- Lacking information: More information and advocacy is needed about rights, laws and policies that may exist nationally and internationally to support people living with HIV. 64% of participants had no knowledge of the relevant national law or HIV policy referred to in the questionnaire.

These findings are illustrative only, and indicate that the index can be significant for:

- documenting the experiences of people living with HIV
- sharing information about human rights and relevant legislation to support people living with HIV in the specific countries.

How has role-out of the Index been implemented?

In 2008, regional capacity development has been undertaken with representatives of different networks of people living with HIV to work with the tool to strengthen efforts to confront stigma and discrimination in their country. Five regional workshops have been conducted (in Kathmandu, Bangkok, Nairobi, Dakar and Santo Domingo) with additional ones planned for Europe, the Middle East and North Africa. To date 80 people living with HIV from 44 countries have been trained to strategically integrate the tool with their work and build partnerships to strengthen the research process and catalyse implementation in their countries.

What materials are available?

Materials to support the rollout of the index include a Questionnaire and User Guide. Both are currently available in English, Spanish and French, with translation underway (to be completed by October 2008) into Arabic, Russian, Chinese and Portuguese. More information about the Index and further resources are also available from www.stigmaindex.org.

What are some of the key lessons?

- Putting people living with HIV at the centre of the research process can be empowering for the interviewers and the interviewees
- Partnership and peer-learning are very important for the successful implementation of the index
- New partnerships have been forged, especially between people living with HIV and the research community
- The interviewers have valued meeting new people in the field research and sharing information about rights, laws and policies that support people living with HIV
- The process of referral and follow-up is very important for each interview, but this can be difficult where the interviews are anonymous and confidentiality has been assured
- The index is a valuable tool in documenting the experiences of many people in a robust manner. In addition the individual stories are also illuminating of the realities of people living with HIV. Qualitative case studies and life stories compliment the findings of the index and strengthen the research process

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