



THE PEOPLE LIVING WITH HIV STIGMA INDEX

DOING IT FOR OURSELVES: PLHIV led research into stigma in 3 African countries: Kenya, Nigeria, Zambia

Authors: K. Sikwese¹, P. Nweke², R. Mwanik³, J. Hows⁴, G. Reid⁵

The Leadership through Accountability Programme

The "HIV Leadership through Accountability" Programme is funded by UKaid from the Department for International Development (DFID) Governance and Transparency Fund (GTF). It combines specific evidence-gathering tools, national AIDS campaigns and targeted advocacy for good governance and Universal Access to HIV prevention, treatment, care and support.

It contributes to the setting of national, regional and global evidence-based campaign agendas based on the GIPA principle through a community driven process. It will be implemented in fifteen countries around the world, and though time-limited, effects are anticipated to be long-lasting, delivering significant capacity building beyond the direct research and advocacy impact.

Experiences from Kenya, Nigeria and Zambia

In 2009-2010, networks of people living with HIV (PLHIV) in **Kenya, Nigeria and Zambia**, led the planning and implementation of five research tools by and for PLHIV aimed at strengthening evidence in:

- 1) Stigma and discrimination experienced by people living with HIV;
- 2) The level and quality of involvement of people living with HIV in HIV responses;
- 3) Criminalisation of HIV transmission and exposure;
- 4) Human rights violations against PLHIV;
- 5) Sexual and reproductive health and rights of people living with HIV.

The PLHIV Stigma Index

While research shows that HIV related stigma is a barrier to prevention, treatment, care and support, the perspective of people living with HIV is rarely included in this analysis. The People Living with HIV Stigma Index (www.stigmaindex.org) provides a tool that will measure and detect changing trends in relation to stigma and discrimination experienced by people living with HIV.

The PLHIV Stigma Index is a Global Partnership Initiative being coordinated 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 The UN Joint Programme on HIV/AIDS (UNAIDS)



The People Living with HIV Stigma Index is a participative research tool (questionnaire) intended to be administered by trained PLHIV researchers to members of their community. It has several sections dealing with different aspects of stigma:

Experience of stigma & discrimination from others Access to work and services Internal stigma and fears Rights, laws and policies Effecting change Testing & diagnosis; disclosure & confidentiality Treatment; Having children Self-assessment of stigma & discrimination

Emphasis is placed on how people living with HIV perceive and self-assess stigma. Though the same questionnaire was applied across all three countries - additional questions were developed by national networks of people living with HIV to cover local concerns and priorities.

Experiences from Kenya, Nigeria and Zambia

Methodology:

In line with the Index ethos and the GIPA principle:

- » 80 people living with HIV were trained and supported across Kenya, Nigeria and Zambia to carry out 'side-by-side' interviews
- » Over 3,000 people living with HIV were interviewed.
- » Interviews were conducted in several languages, in rural and urban settings, and diverse communities of people living with HIV – different faiths, ages, 'identities', and life experiences;
- » Partnerships with a diverse group of civil society organisations, National AIDS Councils, Research Institutes and UN agencies



Lessons learned:

- Preliminary results across all three countries show:
- » High levels of stigma and discrimination is being experienced by people living with HIV in specific domains and settings across all three countries;
 - » Women were almost universally more likely to report encountering stigma and discrimination than men in almost all areas that the study covered.
- This work is already being used to inform the national networks' advocacy and programmatic responses.

AIDS Fonds (Netherlands) made a significant financial contribution to the implementation of the PLHIV Stigma index in these three countries- allowing the sample size to be increased as well as tools for project management at the local level to be developed, and monitoring and evaluation of the process.

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