

THE PEOPLE LIVING WITH HIV STIGMA INDEX



**Evidence Brief** 

# Stigma and Discrimination at Work

Findings from the People Living with HIV Stigma Index

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This report was written on the basis of information provided by nine country teams who have implemented the People Living with HIV Stigma Index. The countries and the lead organisations involved are:

Argentina (Red de Personas con vih/sida - Mar del Plata Fundación Huésped), Estonia (ENPLWH, Estonian Network of People Living With HIV), Kenya (NEPHAK, National Network for Empowerment of People Living with HIV in Kenya), Malaysia (MTAAG+, Positive Malaysian Treatment Access and Advocacy Group), Mexico (Red Mexicana de Personas que Viven Con VIH/SIDA, A.C. & Fundación Mexicana para la Planificación Familiar, A.C., MEXFAM), Nigeria (NEPWHAN, Network of People Living with HIV and AIDS in Nigeria), Philippines (Pinoy Plus Philippines, Babae Plus, Pinoy Young Positives), Poland (SIEĆ PLUS, Polish Network of People Living with HIV/AIDS Association) and Zambia (NZP+, Network of Zambian People Living with HIV (NZP+).

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Most importantly we would like to acknowledge the invaluable role of people living with HIV who participated in the studies and research carried out at country level, whether as interviewers or interviewees. We thank them for their time and for sharing their stories. We trust that these findings will contribute to a better understanding of HIV-related stigma and discrimination in the workplace and promote discussion and action on how it is best countered.

We would also like to thank the other founding partners of the PLHIV Stigma Index:









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HIV is a major obstacle to employment security. People living with HIV may be unable to find or maintain employment as a result of ill health. However, evidence from the People Living with HIV Stigma Index (PLHIV Stigma Index) reveals that HIV-related stigma and discrimination are as frequently or more frequently a cause of unemployment/denial of work opportunity as ill health in many national settings.

This evidence brief has been prepared by the Global Network of People Living with HIV (GNP+), and was funded by the ILO Programme on HIV/AIDS and the World of Work (ILO/AIDS). It includes PLHIV Stigma Index findings from nine countries in four regions: Kenya, Nigeria and Zambia (sub-Saharan Africa), Estonia and Poland (Eastern Europe), Malaysia and the Philippines (Asia-Pacific,) and Argentina and Mexico (South America). PLHIV Stigma Index data clearly shows that HIV-related stigma and discrimination directly impede access to work by people living with HIV by:

- obstructing entry to the labour market
- changing the type of work individuals are allowed to perform
- preventing promotion to more senior positions
- triggering people being fired from their jobs
- impeding access to adult education and training

Findings show a wide range for all key questions. Key highlights include:

- 13% of respondents in Poland to 40% in Kenya and Zambia reported loss of job or source of income during the preceding 12 months.
- 8% of respondents in Estonia to 45% in Nigeria had lost their job or source of income during the previous 12 months as a result of their HIV status alone.
- 15% of respondents in Malaysia to 45% in Mexico had lost their employment/source of income as a result of their poor health. This suggests the crucial link between access to effective HIV treatment and employment security.
- 5% of respondents in Mexico to 27% in Nigeria were refused the opportunity to work.
- 4% of respondents in Estonia to 28% in Kenya had had their nature of work changed or had been refused promotion due to their HIV status.
- wide ranging discriminatory attitudes from employers and co-workers were reported. 8% of respondents in Estonia to 54% in Malaysia reported discriminatory reactions from employers once aware of employees HIV status. Similarly, 5% in Estonia to 54% in Malaysia reported discriminatory reactions from co-workers who became aware of their colleagues HIV status.

Accompanying each unit of the PLHIV Stigma Index data is an individual's story of personal frustration, and frequently individual and familial disaster. At a macro level, local and national economies are weakened or underperform. The consequences of HIV-related stigma and discrimination in the workplace remain economically and socially profound. Action by government, international agencies and civil society is urgently required to protect rights at work by implementing the ILO Recommendation on HIV and AIDS and the World of Work (No.200), which is also included in the political declaration on HIV/AIDS adopted at the high level meeting in June 2011.

This briefing has been prepared by the Global Network of People Living with HIV (GNP+), funded by the ILO Programme on HIV/AIDS and the World of Work (ILO/AIDS). It aims to provide a global snapshot of HIV-related stigma and discrimination impacting work. It is based on 2009 - 2011 PLHIV Stigma Index data from nine countries in four regions: Kenya, Nigeria and Zambia (sub-Saharan Africa), Estonia and Poland (Eastern Europe), Malaysia and the Philippines (Asia-Pacific), and Argentina and Mexico (South America).

All people have a right to earn a living and to social participation through work. That right is enshrined at Article 23 of the *Universal Declaration of Human Rights*<sup>1</sup> and also in the *International Covenant on Economic, Social and Cultural Rights*<sup>2</sup>. 'Full and productive employment and decent work for all' are specifically named as a target of Millennium Development Goal 1<sup>3</sup>.

HIV remains a major obstacle to individuals attaining decent work and to the sustainable development of states. HIV intersects with employment at individual, community and national levels. Individuals may be unable to find or continue working as a result of ill health or discrimination. Families and communities manage the burden of decreased income and capital. National economies suffer from depleted national workforces and the cost of healthcare and other support for those unable to work. Consequences extend far beyond economics as people living with HIV are socially excluded and their social standing and capacity to contribute to their communities is undermined at significant psychological and social cost.

UN member states have pledged to develop national legal and policy frameworks that protect the workplace rights and dignity of people living with and affected by HIV and AIDS. The recent *Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS* (2011)<sup>4</sup> reaffirms governments' commitments to mitigate the impact of the HIV epidemic on workers, their families, their dependants, workplaces and economies, including consideration of International Labour Organization (ILO) conventions, and particularly the ILO's Recommendation concerning HIV and AIDS and the World of Work, 2010 (No. 200) which outlines the inter-relationship of HIV and work and general principles to inform states' responses. Those principles include that:

there should be no discrimination against or stigmatization of workers, in particular jobseekers and job applicants, on the grounds of real or perceived HIV status or the fact that they belong to regions of the world or segments of the population perceived to be at greater risk of or more vulnerable to HIV infection<sup>5</sup>.

<sup>&</sup>lt;sup>1</sup>UN General Assembly, Universal Declaration of Human Rights, 10 December 1948, 217 A (III), available at: http://www.unhcr.org/refworld/ docid/3ae6b3712c.html [accessed 27 December 2011].

<sup>&</sup>lt;sup>2</sup> UN General Assembly, International Covenant on Economic, Social and Cultural Rights, 16 December 1966, United Nations, Treaty Series, vol. 993, p. 3, available at: http://www.unhcr.org/refworld/docid/3ae6b36c0.html [accessed 27 December 2011]

<sup>&</sup>lt;sup>3</sup> Millennium Development Goal 1 aims to eradicate extreme poverty and hunger. Goal 1 includes three targets including target 1.B: 'Achieve full and productive employment and decent work for all, including women and young people'. United Nations, Millennium Development Goals Report 2011, June 2011, ISBN 978-92-1-101244-6, available at: http://www.unhcr.org/refworld/docid/4e42118b2.html [accessed 27 December 2011].

<sup>&</sup>lt;sup>4</sup> UN General Assembly, Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS. 10 June 2011. available at: http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610\_UN\_A-RES-65-277\_en.pdf [accessed 27 December 2011].

<sup>&</sup>lt;sup>5</sup> Recommendation concerning HIV and AIDS and the World of Work, 2010 (No. 200), paragraph 3. (c). available at: http://www.ilo.org/aids/WCMS\_142706/lang--en/index.htm.

That goal remains unrealised. For many people living with HIV, stigma is pervasive, informing their experience of private and public life. Stigma and discrimination deny individuals dignity, respect and full participation in their communities. Stigmatising attitudes are frequently expressed as discrimination against individual persons but even discriminatory comments framed as negative generalisations about people living with HIV impact individuals. Such statements increase anticipation of discrimination. They also work to increase internalised shame, which in turn leads to reduced self-confidence, motivation and forward planning as well as withdrawal from social contact: all of which decrease individuals' employment performance and employment prospects.

#### The People Living with HIV Stigma Index

The People Living with HIV Stigma Index (PLHIV Stigma Index) was developed as a joint initiative of several organizations, including the Global Network of People living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). The PLHIV Stigma Index aims:

- 1. to increase the evidence base for policies and programmes to reduce HIV-related stigma and discrimination by documenting HIV-related stigma and discrimination and providing a mechanism to compare experiences in different settings and across time.
- 2. to ensure the Greater Involvement of People Living with HIV and AIDS principle (GIPA principle) is enshrined in local, regional and national responses to HIV. All interviews of people living with HIV are undertaken by people living with HIV who have been trained in the PLHIV Stigma Index interview process. The process is led in each state by PLHIV representative organisations.

The PLHIV Stigma Index has now been rolled out in more than 40 countries, providing an enormous quantity of data to improve national, regional and international responses to HIV.

This briefing is based on PLHIV Stigma Index findings from the following countries:

Country	Respondents	Local Lead Partner Organisation (s)
Argentina	1198	Red de Personas con vih/sida- Mar del Plata Fundación Huésped
Estonia	300	Estonian Network of People Living With HIV (ENPLWH)
Kenya	1086	National Network for Empowerment of People Living with HIV in Kenya (NEPHAK)
Malaysia	421	MTAAG + (Positive Malaysian Treatment Access and Advocacy Group)
Mexico	931	Red Mexicana de Personas que Viven Con VIH/SIDA, A.C. & Fundación Mexicana para la Planificación Familiar, A.C. (MEXFAM)
Nigeria	706	Network of People Living with HIV and AIDS in Nigeria (NEPWHAN)
Philippines	80	Pinoy Plus Philippines, Babae Plus, Pinoy Young Positives
Poland	502	SIEĆ PLUS Polish Network of People Living with HIV/AIDS Association
Zambia	854	Network of Zambian People Living with HIV (NZP+)

The PLHIV Stigma Index questionnaire includes more than 100 questions about experiences and understanding of stigma and discrimination. This briefing is based on answers to 11 of those questions.

Data from all nine countries were reviewed and disaggregated across different factors, particularly gender and regional residential location. In most instances, only minimal differences were identified or sample sizes related to specific questions were too small for generalisations to be made. That is not to say that gender and regional location do not impact experience of HIV and work opportunity, but instead that further scrutiny is required at country level in conjunction with local knowledge, particularly that of PLHIV representative organisations and organisations that are experts in local labour market structures. Limited references to the impact of gender and regional location are included in this briefing for illustrative purposes. In most instances, the cut off for reporting statistical significance was

a difference of less than 10% of the survey population or responses from less than 20 respondents. Further disaggregated data may be obtained from GNP+ or national partner organisations.

The survey instrument (the PLHIV Stigma index) has been used as the tool to accurately record, analyse and reflect the experiences of the thousands of people living with HIV whose lives are reflected in this briefing. Still, care should be exercised when using the PLHIV Stigma Index data below to understand HIV-related stigma and discrimination in countries and making comparisons between countries. The data record instances of employment discrimination experienced by those interviewed. It is not definitive of discrimination in each country. It is also reported without local context. For example, low levels of HIV-related job loss may result from numerous intersecting factors including: low levels of stigma or discrimination; strong legal protections preventing discrimination (in conjunction with or despite on-going stigma); low levels of disclosure in work settings (perhaps due to highly stigmatised and discriminatory environments); the impractically of dismissing large numbers of HIV-positive individuals in high prevalence settings (which again may occur in contexts of high or low levels of stigma/discrimination); as well as limited access to antiretroviral treatment in different locales (i.e. more people may lose their jobs because of HIV associated poor health rather than HIV discrimination).

This briefing highlights a number of findings which are evident across all countries represented here (and in fact many more of the 40 countries in which the PLHIV Stigma Index has been undertaken). HIV-related stigma and discrimination deny many the right to work; undermine individuals' ability to secure and retain employment, and damage employment and career progression. Furthermore, it prevents access to education and training, which is generally a conduit to increased employment prospects and a means to move from informal to formal sectors.



#### **Job Security**

*Too many hospital visits that I could not provide an explanation for – so they just let me go.* Poland

Many people living with HIV manage their HIV infection in a context of insecure employment. The PLHIV Stigma Index reveals that many respondents had lost a job or source of income during the preceding 12 months: ranging from 13% (Poland) to 40% (Kenya & Zambia).



## **Employment loss resulting from HIV**

Those who had lost a job or other source of income were asked whether HIV had played a role. The PLHIV Stigma Index found HIV is a significant factor undermining security of employment. Many respondents had lost their job or source of income during the previous 12 months as a result of their HIV status alone: ranging from 8% (Estonia) to 45% (Nigeria). Respondents were also asked more generally whether HIV had played a role in job/income source loss, i.e. they had lost employment as a result of HIV alone or HIV in combination with other factors. Responses ranged from 11% (Estonia and Poland) to 69% (Kenya). In four of nine countries, HIV or 'HIV and other factors' triggered employment loss for more than half of all those who lost their jobs/source of income. The data did not reflect whether respondents had (also) experienced instances of job loss more than 12 months ago.



In fact, HIV may contribute even more greatly to employment loss. The above charts:

- include cases where employers were not aware of respondents' HIV-positive status, suggesting HIV-related discrimination would likely be higher if all employees' HIV positive status were known.
- exclude data from those who were able to identify their loss of employment/income resulted from a reason other than their HIV positive status. It is likely that HIV contributed to employment loss for at least some of those who were not aware of the reason for their job/income loss.

The data reflected minimal differences in most locales when disaggregated by gender, and those differences did not follow a clear pattern. For example, HIV was more likely to have triggered women's loss of employment in some countries but more likely to have triggered men's loss of employment in others. Mexico and Nigeria were two countries reflecting larger differences by gendered response than most other countries.



The data also reflected limited differences in the impact of residence location on employment. In most countries, people living in rural areas were more likely to have lost employment as a result of HIV or HIV combined with another reason, however, that was not true of all countries so no global generalisation is possible. For example, data from three countries is included below.



#### **Reason lost employment during last 12 months**

These findings on gender and regional location reiterate the importance of building a local evidence base, including formal disaggregated data and input from local PLHIV representative organisations to ensure regional variation is well understood and informs responses to HIV and employment security.

## **Employment loss resulting from HIV stigma and discrimination**

HIV effected individual's job security both through its impact on respondents' health and as a result of discrimination against people living with HIV.



Many respondents had lost their employment/source of income as a result of their poor health, suggesting the crucial inter-relationship of access to effective HIV treatment and employment security. HIV-related poor health (alone) was cited as the reason for job/income source loss in all countries but Poland: ranging from 15% (Malaysia) to 45% (Mexico).

Conversely, the above data means poor health (alone) did not trigger employment loss for 55% (Mexico) to 100% (Poland) of individuals who lost their jobs because of their HIV positive status. Many respondents were unable to separate discrimination and poor health as reasons for employment/income source loss, stating employment loss resulted from a combination of the two: ranging from 14% (Poland) to 60% (Mexico). It is not possible to ascertain whether those who lost employment as a result of 'poor health and discrimination' would have lost employment had they been in good health, however, some may have. Discrimination related employment loss confirms the limitations of HIV antiretroviral treatment as a remedy against HIV-positive persons' employment/income source insecurity.



HIV-related discrimination was a major trigger for loss of employment/income source. In four of eight countries HIV-related discrimination (alone) was a more frequent trigger for employment/income source loss than poor health (alone). In all countries but Mexico, HIV-related discrimination and HIV-related discrimination combined with poor health was a more frequent trigger than poor health alone.



Men reported job loss resulting from discrimination with similar frequency to women (with gendered variance inconsistent across national settings) or sample sizes where too small for generalisations to be made. In most instances, PLHIV Stigma Index data reflected limited differences in the impact of residence location on employment, and these varied from country to country. For example, in Zambia, respondents living in rural areas were more likely to have experienced employment/income source loss triggered by HIV discrimination, whereas in Nigeria, people living in large towns or cities were more likely to have experienced by HIV discrimination, particularly 'discrimination only'.



### **Access to Employment**

Many people living with HIV are unable to secure employment once their HIV status is known. During the previous 12 months, many respondents had been refused the opportunity to work. The chart below reflects the responses of all those who responded to this question, whether or not their prospective employers were aware of respondents' HIV positive status: ranging from 5% (Mexico) to 27% (Nigeria).



Men and women reported relatively similar frequency of refusal of employment or work opportunity because of HIV status during the previous 12 months in most settings. Notably, the two countries with the greatest variance reflect very different gendered experiences of respondents. In Estonia (6% of

men: 11% of women) women were almost twice as likely as men to have been refused employment/ work opportunity, while in Malaysia (15% of men: 8% of women) men were almost twice as likely as women to have been refused employment/work opportunity.



In many instances, the data reflected only small differences in the impact of HIV-related discrimination on employment security when disaggregated by location of residence, and these differences were not uniform across countries. It is not clear whether the data below accurately reflects the impact of HIV stigma by geographic area or whether bias has occurred as a result of small samples in some locations, particularly Estonia and the Philippines.



*I am afraid of discrimination because I plan to work abroad.* Philippines

The intersection of HIV stigma/discrimination and migration for work is not directly explored by the PLHIV Stigma Index, however migrants are included among respondents, as are respondents who state they had hoped to migrate, and those who continue to hope to migrate across national borders for work. HIV testing is often a requirement when applying for overseas employment (even when prohibited for domestic employment), with an HIV-positive result precluding recruitment for overseas work. Diagnoses overseas may result in loss of employment and forced deportation. The intersection of HIV stigma and migration for work requires further study.

#### **Retaining employment status and career advancement**

I was demoted from work, when I was found to be HIV-positive. Zambia

The PLHIV Stigma Index found that during the previous 12 months, many respondents had had their job description or nature of work changed, or had been refused promotion as a result of having HIV. This ranged from 4% (Estonia) to 28% (Kenya).



While many experienced a change in their job description or nature of their work, or had been refused promotion, only a minority of those changes/refusals had resulted from poor health: ranging from 13% (Philippines) to 40% (Mexico). In many cases, changes to job description/nature of work or refusal of promotion had resulted from discrimination (alone): between 13% (Philippines) and 42% (Nigeria). In six of nine settings, discrimination (alone) was a trigger at least as frequently as poor health (alone). Discrimination had either been the reason or was a factor in between 21% (Philippines) to 62% (Nigeria) of cases.



#### **Disclosure of HIV status**

Employers should not have the right to test me. Malaysia

Confidentiality of HIV status remains a central workplace issue. Many respondents reported having their HIV-positive status disclosed to employers or coworkers without their consent. Such disclosures by a third party to an employer without the respondent's consent ranged from 3% (Mexico) to 15% (Nigeria). Disclosures by a third party to a coworker without the respondent's consent ranged from 4% (Estonia and Mexico) to 19% (Zambia). Of course this data relates only to instances of disclosure by third parties of which respondents are aware<sup>6</sup>.



<sup>6</sup>The relatively low number of respondents in most settings precluded effective disaggregation of data by gender and residential location. That data is available, however, from GNP+ and partner organisations.

People living with HIV should be able to choose the circumstances in which they disclose their HIVpositive status. In this context, confidentiality of HIV status remains an important issue because not only can it significantly impact work outcomes (as outlined above) but workplaces are not isolated from the broader community. Once disclosed, even in particular contexts, information about individuals' HIV-positive status can and does travel back into their communities. In these same PLHIV Stigma Index surveys, individuals reported loss of respect and isolation from families and friends, excommunication from church, physical assault, and social segregation.

> I felt internal or self-stigma and discrimination already. Thus I do not have enough strength to tell others of my HIV status. Philippines

The PLHIV Stigma Index survey asked respondents how their HIV disclosure had been received in employment contexts. In many instances, employers and co-workers were supportive or did not treat the respondent differently after learning of their HIV-positive status. Other respondents noted discriminatory or very discriminatory reactions from employers or colleagues both within formal and informal sectors. Discriminatory reactions from employers who became aware of respondents' HIV status ranged from 8% (Estonia) to 54% (Malaysia). Discriminatory reactions from co-workers who became aware of respondents' HIV status ranged from 5% (Estonia) to 57% (Malaysia).

My friends at the market wanted to chase me because I was HIV-positive. Other people living with HIV and the market leadership helped resolve the issue. Zambia



The figures above illustrate that workplaces remain key sites for HIV education, including education to reduce stigma and discrimination.

### Access to adult education and training<sup>7</sup>

The PLHIV Stigma Index found people living with HIV were precluded from attending an educational institution because of HIV in all countries during the previous 12 months: ranging from 1% (Mexico) to 14% (Nigeria). Such practices impact employability as access to adult education and training is generally a conduit to increased employment prospects and a means to move from informal to formal sectors. This data must be interpreted in the context that in many instances, individuals' HIV-positive status would not be known by educational institution staff.



<sup>7</sup> The relatively low number of respondents in most settings precluded effective disaggregation of data by gender and residential location. That data is available, however, from GNP+ and partner organisations.

There are over 30 million people living with HIV of working age. Most are able and willing to work. Denying their right to work delivers no advantage. Instead it undermines states' social capital, while causing individuals untold harm and destabilising families, communities, business and national economies.

In the countries surveyed the PLHIV Stigma Index provides clear evidence that HIV-related stigma and discrimination is causing individuals to be:

- refused entry to the labour market
- forced to change the kind of work they perform
- denied promotion
- fired from their jobs
- refused access to adult education and training.

Accompanying each unit of PLHIV Stigma Index data is an individual's story of personal frustration, and frequently individual and familial disaster. At macro level, local and national economies are weakened or underperform. The consequences of HIV-related stigma and discrimination in the workplace remain economically and socially profound.

The workplace is an effective entry point to facilitate access to HIV prevention, treatment, care and support services. It is also a key site to enforce human rights obligations by ensuring HIV stigma is minimised and discrimination does not occur. The ILO Recommendation concerning HIV and AIDS and the World of Work, 2010 (No. 200) provides that there should be no discrimination or stigmatisation of workers, particularly job applicants and jobseekers in either access to employment or occupation, terms and conditions of work or the right to remain in employment. It builds upon the *ILO code of practice on HIV/AIDS and the world of work* (2001)<sup>8</sup> and enumerates a number of key principles that should be integrated in workplace policies and programmes, including that such world of work action contributes to the realization of human rights, fundamental freedoms and gender equality.

The recent Political Declaration on HIV/AIDS<sup>9</sup> reaffirms this commitment to mitigate the impact of the HIV epidemic on workers, their families and their dependents. Retention in work and recruitment of persons living with HIV needs to be promoted, and programmes of care and support should include measures of reasonable accommodation in the workplace. Real or perceived HIV status should not be a ground of discrimination for employment purposes, including in access to employment and occupation. Persons living with HIV should enjoy the possibility of continuing to carry out their work and their recruitment should be promoted.

The PLHIV Stigma Index findings drawn from these nine national settings clearly demonstrated that HIV-related stigma and discrimination remains a barrier to people living with HIV accessing full and productive employment and decent work. In light of those findings, GNP+ recommends that:

- governments increase efforts to deliver human rights based on the ILO Recommendation No.200 enabling access to full and productive employment and decent work for people living with HIV. Areas of focus should include the introduction or review of work based antidiscrimination laws or other mechanisms for resolving work based disputes, including effective restitution processes;
- governments, international and local HIV agencies review and modify HIV programming to more effectively promote human rights obligations, including the right to full and productive employment and decent work for people living with HIV;
- governments and international agencies increase funding for community based legal support services, as well as centred and driven education campaigns addressing the myths and beliefs that drive stigma and discrimination;

<sup>&</sup>lt;sup>8</sup>Available at: http://www.ilo.org/public/english/protection/trav/aids/code/languages/hiv\_a4\_e.pdf.

<sup>&</sup>lt;sup>9</sup> Political Declaration on HIV/AIDS: Intensifying our Efforts to Eliminate HIV/AIDS (2011)

- people living with HIV, working through representative HIV organisations, need to be supported to actively participate alongside employers and trade unions in the development and review of policies around HIV, including issues of employment related stigma and discrimination;
- business and labour leaders be encouraged to champion HIV anti-discrimination measures and stigma-free workplaces, the delivery of HIV education in work settings, and other measures needed to support the employment of people living with HIV;
- that further qualitative studies be undertaken where required to improve the evidence base on work related stigma and discrimination so that targeted and effective intervention strategies may be devised.

#### **Disclaimer:**

The People Living with HIV Stigma Index is designed as an evidence-gathering and advocacy tool led by and for people living with HIV to raise awareness of stigma and discrimination as experienced by people living with HIV (PLHIV). To that end, the methodology is designed to capture respondents' perceptions and experiences of stigma and discrimination, external as well as internalised. As research respondents, the PLHIV participating in the research have a right to anonymity and to confidentiality regarding their responses. Survey questions are limited to this focus and the methodology does not include follow-up questions to re-confirm respondents' perceptions or to take action to respond to the stigma and discrimination documented. As a result, while the data present information and evidence on perceived and experienced stigma, the survey is not intended to be used as a fact-finding tool or as a source of allegations of individual instances of wrong-doing.