



GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV



HIV-related

Stigma

Measures
& Measurement Tools:

Consultation with PLHIV to contribute to
the development of common indicators

July to September 2010

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Executive Summary

As part of a process to develop better indicators to measure HIV-related stigma, GNP+ conducted a consultation with people living with HIV (PLHIV) to determine priorities for addressing stigma, to identify key indicators, and to enable measurement of progress in efforts to reduce stigma.

An online questionnaire was developed and made available in four languages (English, French, Spanish, and Russian) to which 517 replies were received, and semi-structured interviews were conducted with a purposive sample of 19 PLHIV.

Respondents to the on-line survey reported experiencing stigma during the last 12 months due to their HIV-positive status in each area explored by the survey.

Between 5-30% (depending on the geographical region of origin)¹ had perceived or experienced exclusion from taking part in family and social interactions, love and sexual relationships, work and education. A similar and sometimes larger percentage had avoided participation in activities in that domain. Exclusion from religious practice affected 8% of respondents in Africa and the Caribbean. During the last year, 5% of respondents overall had been forced out from their homes because of living with HIV.

The survey also explored the impact of stigma on accessing health services; 12-20% of respondents, dependent on region, reporting being denied access to or disadvantaged in accessing health services in the last year. Some of the respondents state that they were excluded from health services specifically set up to serve PLHIV such as HAART and PMTCT, and others from accessing services provided to reduce HIV transmission, such as condom distribution.² Several reported clinicians failing to protect their health, while undertaking unnecessary precautions to protect themselves.

Insulting behaviour directly attributable to HIV-positive status was reported by 12% of respondents from developed countries, 31% in Africa, and 37% in the rest of the world. Being physically assaulted in the last year due to HIV-positive status was reported by 2% of respondents in developed countries, 4% in Africa, and 6.5% in the rest of the world. Perpetrators included family members, medical authorities and police.

Overall, 13% of respondents from Western Europe, North America, Australia and Singapore, reported that they felt or had experienced some kind of abuse of their rights over the past year, as compared to 23% to 24% from outside these regions. Respondents identified shame, blame and fear as underlying the treatment they had experiences, with religious beliefs and moral judge-

¹For some of the analysis, respondents' analysis is split into three geographic groups which share important aspects in common epidemiologically. These are:

- Africa and the Caribbean. These are mainly countries with generalised epidemics;
- Western Europe, the USA, Canada, Australia and Singapore, which have concentrated epidemics and generally good health care and social services;
- The rest of the world: countries with concentrated epidemics and generally weak health care and social services.

²HAART (highly active anti-retroviral therapy) and PMTCT (Prevention of mother-to-child transmission)

ments playing a major role in some parts of the world. Many PLHIV reported self-blame, guilt and other negative emotions, with nearly a quarter of those in developed countries reporting suicidal feelings; the proportion for the rest of the world was one in eight.

Compilation of the priorities for action on stigma by survey respondents produced the following top choices, for each of the following six geographical regions:

| | |
|-----------------------|---|
| Asia Pacific: | social and community interactions/love and relationships (equal)) |
| Caribbean: | family relationships/social and community interactions (equal) |
| Europe: | access to health care (Eastern Europe) |
| North America: | love and relationships |
| South America: | household income |

African countries returned several answers of equally high priority:

- Physical and verbal abuse
- Family relationships
- Legal protection
- Access to health care
- Emotional well-being
- Social and community interactions

The fact that there is so much variety in the choice of highest priorities may indicate that all these aspects of stigma must be assessed for any measurement to be meaningful.

While it is clear that indicators covering all domains are required, this consultation has attempted to locate the minimum number of indicators which can address the magnitude of this complexity, based on the priorities set by PLHIV. The suggestions below for informing key indicators that have a resonance with PLHIV were generated from this process, as follows:

- Have you disclosed your HIV status to a family member?
- Have you been excluded from health services you need because you are HIV-positive in the past year?
- Have your medical providers treated you with respect during the last year?

For informing indicators at the national, local or facility-based level the following health-outcome indicators were suggested as providing a useful baseline to measure progress toward universal access to treatment, and care and support:

- What is the average CD4 count of people at HIV diagnosis during the past year?
- What is the average clinical stage of those diagnosed with HIV during the past year?

Talking points:

The following talking points arose from the semi-structured interviews which addressed directly the drafting of HIV-related stigma indicators:

- Interviewees were in favour of measuring impact of stigma programming, rather than only inputs and activities. They suggested measuring perception of PLHIV about stigma levels in their environment, measures of access to medical care in particular, and measures of

limitations imposed by stigma on the lives of PLHIV (such as barriers to health care, employment, education, accommodation, etc).

- Doubts were expressed about the level of honesty with which population indicator questions will be answered, because of shame of admitting to unkind or intolerant behaviour or attitudes.
- All were persuaded that HIV-related stigma needed to be addressed urgently and comprehensively, and highlighted the obstacles in the response.

Conclusions and recommendations:

Though indicators that measure PLHIV-related stigma generated through consultations with the general population (about how they treat or would treat PLHIV) were welcomed by respondents (PLHIV) as a mark of the issue being taken seriously by the general population, it was indicated as a weak proxy for asking PLHIV themselves how they are treated by those aware of their HIV-positive status.

The development of common indicators that support a scaled-up response to reducing HIV-related stigma should:

- Concentrate as much as possible on the perception of the stigma experienced by PLHIV as measurement of the stigma toward PLHIV in a 'notional' general population.
- Acknowledge that PLHIV are well placed to determine the priorities for stigma 'reduction programmes' within specific country contexts and, if properly supported and resourced, to analyse the relative importance and impact that such programmes are having in their communities.

Introduction

It is now well documented that stigma causes abuses of the human rights of those living with HIV. As found by the Network of Zambian People Living with HIV (NZP+),³ it is also impeding HIV programme impact in the following ways:

- Lower uptake of HIV Preventive Services, and Testing and Counselling;
- Reduced and delayed disclosure;
- Postponement or rejection of treatment, care and support;
- Stigma and discrimination disproportionately affect women and girls;
- Magnified effects among socially vulnerable groups.

These findings from Zambia have also been reported in other countries and regions.⁴

UNAIDS, IPPF, GNP+, ICRW⁵ and John Hopkins Bloomberg School of Public Health initiated a process in 2009 to review current HIV-related stigma measures and measurement tools in order to develop a set of standardised stigma and discrimination indicators. So far this process has accomplished: a literature review of current stigma measures; a technical meeting that resulted in the identification of the areas of stigma that need to be measured to fully understand it; establishment of a stigma indicator working group which has come up with a list of indicators ready for field testing; consultations by IPPF with civil society organisations involved in stigma reduction work; and consultations by GNP+ with PLHIV. Consensus has emerged that the experience of people living with HIV is fundamental in assessing levels of HIV-related stigma and in evaluating efforts to reduce stigma and the discrimination which flows from it.

The Global Network of People Living with HIV (GNP+) has, therefore undertaken the consultation presented in this document to gather the views of PLHIV on which aspects of HIV-related stigma need to be addressed most urgently. In addition to this prioritisation exercise, input was directly solicited on which indicators are most appropriate to use for the assessment of stigma. The output from this consultation will be used to inform the development of programme, national and global level stigma indicators.

The consultation was conducted through a short on-line questionnaire circulated to PLHIV through national networks and existing list serves. In addition, semi-structured interviews with nineteen PLHIV to gather data on existing stigma indicators being used, and to solicit suggestions for what aspects of stigma are most important to measure and how key indicators for HIV-related stigma should be worded and used.

This report analyses these various sources of information to arrive at a set of recommendations for input into the international stigma indicator consultation process. The data gathered will also be useful in helping shape the agenda of future work by the international and national networks of PLHIV on reducing HIV-related stigma, and in identifying common themes and priorities for future action.

³For PLHIV Stigma Index country report in publication

⁴See: http://data.unaids.org/pub/BaseDocument/2010/20100526_non_discrimination_in_hiv_en.pdf and http://data.unaids.org/pub/Report/2009/20091130_stigmasummary_en.pdf

⁵The acronyms of The Joint United Nations Programme on HIV and AIDS (UNAIDS), The International Planned Parenthood Federation (IPPF), The Global Network of People Living with HIV (GNP+), and the International Centre for Research on Women (ICRW) are used throughout this document.

Methods

Quantitative/qualitative survey

The survey was based on pretested questions, selected to cover key demographic data and experiences across various different domains of life in which PLHIV are known to suffer stigma, as follows:

- Family relationships
- Love and sexual relationships
- Social and community interactions
- Household income
- Education
- Access to health care
- Access to social services
- Religious practice
- Accommodation
- Emotional well-being
- Physical and verbal abuse
- Legal Protection

The questionnaire included a demographic section with eight multiple choice questions, and a section on experience of and views on the different facets of stigma consisting of fifteen multiple choice questions, of which seven contained text boxes to allow respondents to add comments. It concluded with two subdivided multiple choice questions allowing respondents to rank their priorities for action (for themselves and PLHIV generally) and a final text box providing an opportunity to suggest how stigma should be addressed. Respondents were given the option to provide contact details for follow up if they wished (196 out of 517 did so), but there was no requirement for inclusion of any contact details as a condition of participation. A large number of the quantitative questions was aligned closely to those used in the PLHIV Stigma Index⁶ – which in turn have been based on other survey tools.^{7,8}

Respondents were asked for a ranking of the importance of these areas as regards to programming to address HIV-related stigma, and also for a suggestion for high-priority action against stigma.

Participants were all PLHIV. Relative to the global population of PLHIV from which they were drawn, they may represent those having access to the internet and the ability to read one of the four languages (English, French, Spanish, and Russian) in which the survey was distributed. Many are leaders and activists in the response to HIV in their countries.

There was a particularly enthusiastic response from PLHIV in the United States and the United Kingdom; these countries together provided just under half the sample. All contributions are

⁶ The PLHIV Stigma Index is a tool devised for and by PLHIV. It is the product of a founding partnership of GNP+, ICW, IPPF and UNAIDS. It has been implemented in over 20 countries worldwide. It is a process which gathers evidence about PLHIV Stigma through a process of participative research to inform action at the personal, organisation

⁷ The work in 2001-2002 'AIDS discrimination in Asia' by APN+ (the Asia Pacific Network of People Living with HIV/AIDS) provides many of the key questions used in this survey and can be accessed at www.apnplus.org/main/Index.

⁸ Though there is an alignment of the questions used in this survey it is important to note that the online survey can in no way be seen as a replacement for the full process of a national implementation of the PLHIV Stigma Index. A full implementation of the Index where it occurs is a participative process owned by a PLHIV led partnership at the national level; an iterative process involving partnership and capacity development, the establishing of sufficiently robust and fit for purpose sample to inform ongoing action and advocacy, setting of priorities and testing out of perceived concerns through the research and data gathering process, as well providing a base-line for future research activities and measurement of change.

valued equally and have been included, but for reporting purposes the imbalance has been compensated by splitting the responses from all geographical areas into three regions: grouping the United Kingdom and United States responses with those from other developed world economies, and separating them from responses from the generalised epidemics of sub-Saharan Africa, and the concentrated epidemics elsewhere in the world.

Qualitative interviews on stigma indicators

Contacts were made for interviews with key informants through national PLHIV networks. Respondents were selected based on the global epidemiology of HIV. Informants comprised six PLHIV who work in different parts of the African continent, five nationals from the WHO Euro region spanning the terrain from France to Uzbekistan, two from contrasting countries of the Asia and Pacific region, including one regional activist and a representative from the only generalised epidemic in Asia, and six people from the Americas. Several informants had experience of working on HIV outside their own home country. The sample included thirteen men and six women.

Eleven of the interviews were carried out face-to-face during the Vienna 2010 International AIDS Conference, and seven telephone interviews were undertaken during the three weeks following the conference. One interview was conducted by e-mail due to language constraints. A brief introductory explanation of the background and purpose of this PLHIV consultation was offered in the context of:

- the current international technical consultation on stigma indicators;
- the assessment of stigma as the most serious barrier to HIV services, and;
- the continuing frequent occurrence of the abuse of the human rights of people living with HIV.

Following the introduction, semi-structured interviews were centred on the following interview guide:

1. How could we measure the impact of attempts to address HIV-related stigma?
2. What are the gaps in efforts to address stigma? What are the gaps in indicators to measure the success of efforts to address stigma?
3. What are some examples of good practice in measuring stigma:
 - a. at programme level?
 - b. at policy level?
4. Why is it important to improve how we measure and monitor stigma?

This interview guide was developed in consultation with IPPF which carried out an aligned exercise with 'civil society' via a list serve consultation over a 4-week period, a series of telephone interviews with 'key informants', and a reflection session as part of a satellite meeting at the 2010 International AIDS Conference in Vienna.

Limitations of the samples

It is acknowledged that both the on-line and the key informant interviews sample are not representative of the global PLHIV community. Apart from an imbalance in terms of gender, there was an over representation of respondents from the United States and the United Kingdom. However, the findings do represent a 'snapshot' of concerns and priorities by respondents from more than 70 countries.

Discussion of findings

Survey coverage

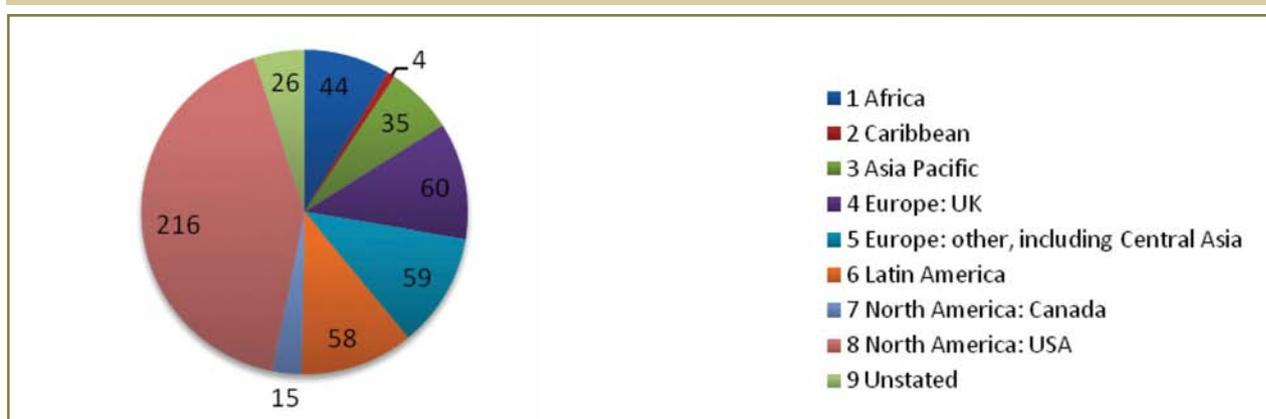
In total, after cleaning of the data, there were 517 responses from PLHIV received. The survey was available on-line for three weeks. It is estimated that there were 1,600 invitations to reply sent out which were dispatched either directly (700) or forwarded to list serves and network mailing lists. There were particularly high numbers of responses from the United States (216) and United Kingdom (60). Of the responses 403 were received in English, 17 in French, 26 in Russian, and 71 in Spanish.

As expected there was a high degree of difficulty in completing the survey in one uninterrupted session where internet access is not stable – especially Francophone Africa; over half of the partially completed duplicate submissions received came from this region.⁹

The respondents came from the following countries:

Argentina (3), Australia (11), Azerbaijan (1), The Bahamas (1), Belarus (1), Belgium (1), Bolivia (2), Botswana (1), Brazil (7), Burma (2), Cameroon (1), Canada (15), China (Hong Kong, 1), Colombia (3), Czech Republic (1), Democratic Republic of Congo (2), Ecuador (4), El Salvador (2), Fiji (1), France (1), Germany (2), Ghana (1), Guyana (1), India (1), Indonesia (1), Italy (1), Ivory Coast (4), Jamaica (1), Kazakhstan (2), Kenya (8), Latvia (1), Lesotho (1), Malawi (1), Malaysia (3), Mali (2), Mauritius (4), Mexico (23), Moldova (4), Morocco (1), the Netherlands (2), Niger (3), Nigeria (3), Norway (1), Peru (6), the Philippines (1), Poland (1), Russia (11), Singapore (14), South Africa (5), Spain (23), Switzerland (3), Tajikistan (1), Tanzania (1), Thailand (3), Togo (1), Trinidad and Tobago (1), Turkey (1), Uganda (1), Ukraine (5), United Kingdom (60), United States (216), Uruguay (1), Zambia (2), Zimbabwe (2). 26 respondents did not specify their country.

Figure 1: Region of respondents.



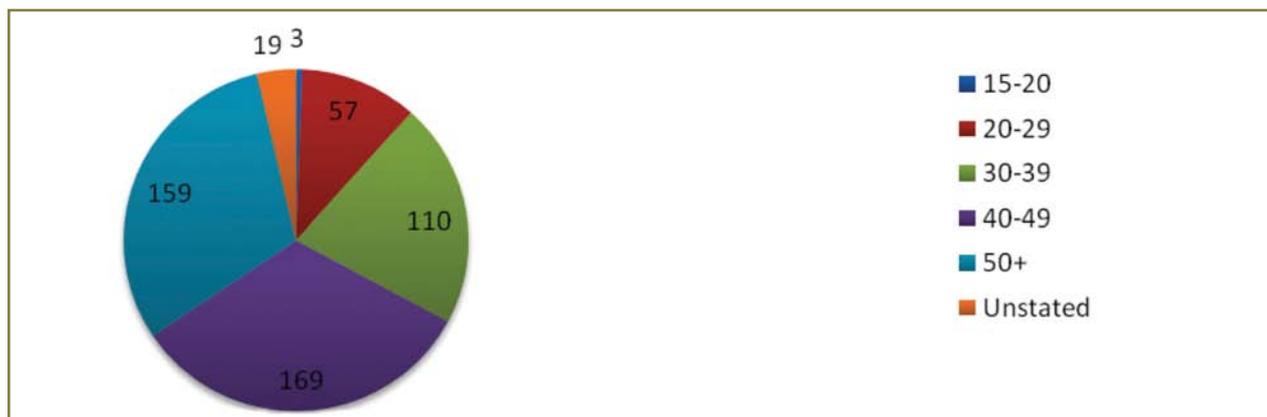
⁹The data was cleaned to weed out potential duplicate answers (35), those who revealed during the course of their answers that they may not be PLHIV (27) or those who opened the questionnaire but did not fill in the informed consent that was required (22). Respondents were offered the opportunity of leaving the questionnaire at any point and could elect to not respond to any individual questions or series of questions. Overall 'full' completion of the survey, respondents electing to go through the survey to the end, was high (at over 80%) for an online survey.

For several of the following analyses, the results have been presented split into three areas which share common epidemiologically (concentrated, low or generalised epidemics). These are:

- Africa (all 19 countries included here are sub-Saharan) and the Caribbean (4 countries). These are in the main countries which have generalised epidemics: 49 respondents;
- Western Europe (9 countries), the United States, Canada, Australia and Singapore, which have concentrated epidemics and generally good health care and social services: 407 respondents;
- Responses from other countries and regions (11 countries of Eastern Europe and the former Soviet Union, 8 Asian countries, and 9 Latin American nations). These are countries with concentrated epidemics and generally weak health care and social services: 117 respondents.

This geographical splitting analysis has the benefit of avoiding skewing the overall findings due to the high number from the United States and United Kingdom responses. They are grouped together with other similar countries which also produced a fairly high response rate of 11 to 23 responses each: Australia, Singapore, Canada and Spain. The 26 respondents who did not complete country information were included in global information sets and in the “rest of the world” category.

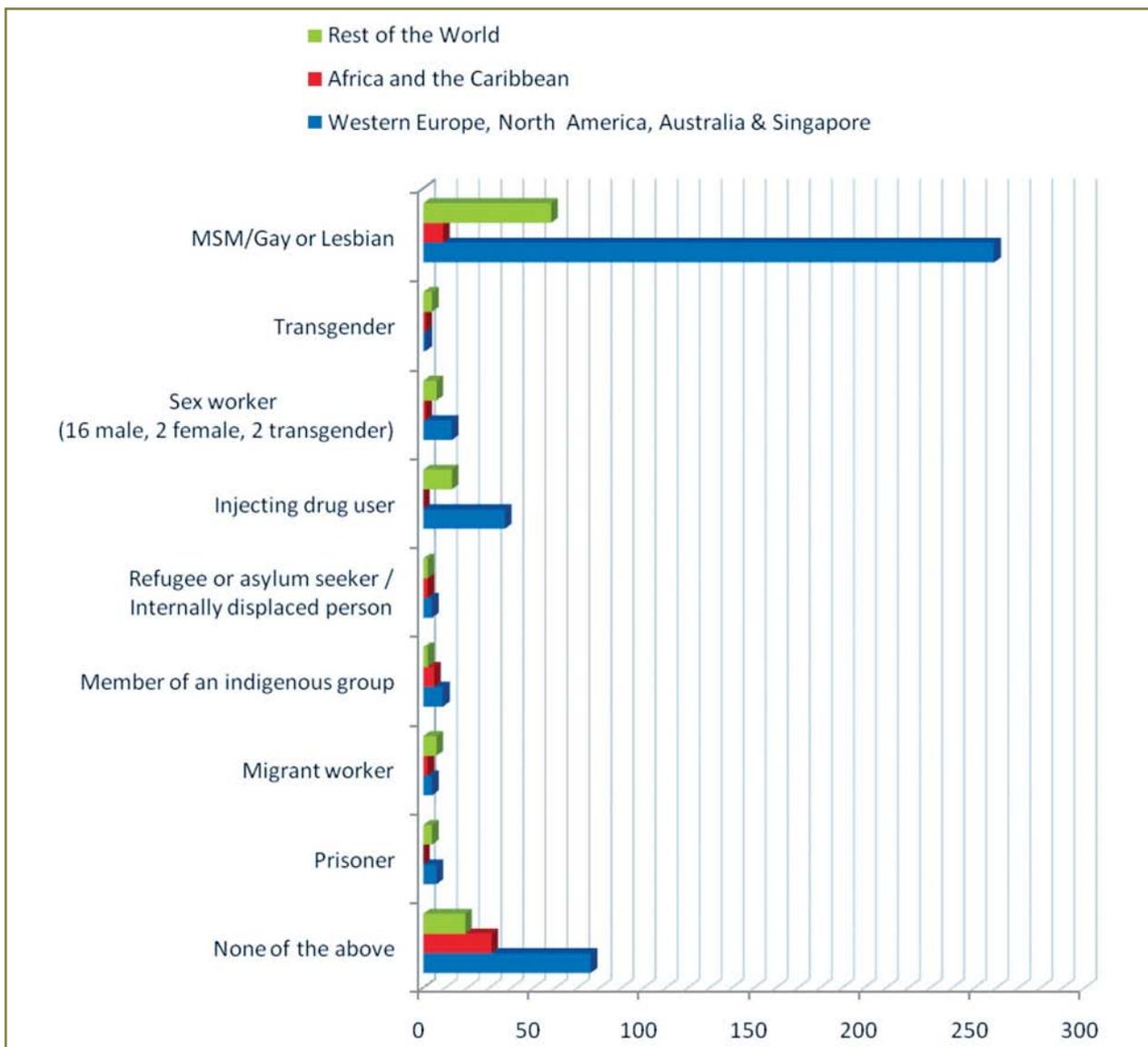
Figure 2: Age of respondents.



Of the 517 respondents, 122 were female, 361 male, 6 transgender, and 28 did not state their gender. More than two-thirds of the sample is male. Of the male participants, two thirds identified themselves as gay. Many women living with HIV also responded; they came from countries around the world, reflecting the global feminisation of the epidemic. 1% of the sample identified as transgender, and they were nationals of North America, a Mediterranean country, an African country, and two Latin American countries.

Half of the respondents were in a full-time paid work, with a further fifth earning a living through part-time employment. Several were combining two occupations, commonly studying with work or homemaking.

Figure 3: Past or present membership of at risk populations.



Experiences of stigma relating to family, relationships and social occasions

Table 1: Exclusion from normal association with other people due to living with HIV in the last year

| | Excluded often | Excluded once or a few times | Preferred to avoid this activity because of living with HIV |
|--|----------------|------------------------------|---|
| Family activities (e.g., cooking, eating together, or sleeping in the same room) | 3% | 5% | 33% |
| Romantic or sexual contacts | 12% | 30% | 35% |
| Social gatherings or activities (e.g., weddings, funerals, parties, clubs, community meetings) | 3% | 15% | 37% |

These figures appear to suggest that many PLHIV pre-empt the painful experience of being excluded by opting not to try to participate. In the absence of this behaviour it is likely that rejection by families, communities and sexual partners might be even more severe than displayed in the above analysis.

For 26% of those to whom this question applied, a family member had suffered discrimination during the past year, because of the HIV-positive status of the respondent. Examples cited included:

“My husband has been asked why he stays with me and what he is going to do when I die. No one else gets such personal questions.” (United States)

“My mother runs a food shop at the Community, when, people discovered that I am positive, they decided not to buy food from her, and that really made me sick.” (Nigeria)

“When my brother’s wife was in labour, my brother went to provide blood for her transfusion, so his blood was tested, and it turned out that he was HIV-infected. Our mother was later refused service in a shop, and when she asked why they said it is because your son is HIV-positive, you have lost all your rights.” (Moldova)

Upsetting gossip is common where PLHIV choose to disclose or where other people break confidentiality. 28% of respondents reported they were aware of repeated gossip about them, and 22% cited examples. Sometimes the gossip is fairly neutral, and some respondents said they were able to ignore it. Some respondents reported that they did not suffer from gossip because they made sure that hardly anyone could find out about their HIV-positive status.

Sometimes the spreading of information regarding someone’s HIV-positive status is for the purposes of demonising the HIV-positive individual: one respondent from Latin America had his medical file taken from his hospital and confidential details were broadcasted on television, together with unfounded allegations of corrupting minors and rape.

Experiences of stigma concerning livelihoods, education and accommodation

Respondents were asked whether they had been excluded from education, or lost income or work opportunities in the past 12 months, because of their HIV-positive status. Responses were as follows:

Table 2: Exclusion from work or education due to living with HIV in the last year

| | Lost income from work | Been denied work opportunities | Been excluded from education |
|---|-----------------------|--------------------------------|------------------------------|
| Africa & Caribbean | 16% | 18% | 6% |
| W Europe, N America, Australia & Singapore | 14% | 6% | 2% |
| Rest of World | 10% | 9% | 1% |

“I spent 10 years facing a legal process against my employer, a multinational company - in 2002 I was fired because I am positive. I was able to prove that I was fired because of HIV...” (Brazil)

“I was given an opportunity to work overseas but my application was being rejected due to my HIV status. I was force to declare my HIV status which end up being denied to enter, to work and to stay in that country.” (Singapore)

Respondents were also asked whether in the last year they had done any of the following things because of their being HIV-positive

Question: In the past year, have you done any of the following things because of your HIV status?

Table 3: Self-exclusion from work or education due to living with HIV in the last year

| | Decided to stop working | Decided not to apply for a job/ work/promotion | Withdrew from or declined an opportunity for education/training |
|---|-------------------------|--|---|
| Africa & Caribbean | 6% | 16% | 18% |
| W Europe, N America, Australia & Singapore | 13% | 18% | 12% |
| Rest of World | 9% | 14% | 9% |

Exclusion was reported as a serious impact of HIV-related stigma in all regions with regard to work and education, with Africa and the Caribbean worst affected. Across all respondents from these regions, more than a third reported being disadvantaged by their HIV-positive status during the last year, with almost a fifth overall reporting work opportunities being denied to them. These are the regions where there may be the least effective enforcement of laws against HIV-related discrimination, to the extent that such legislation exists. Across the other regions, more than a quarter of the respondents had been deterred from accessing a work opportunity during the last year, directly or indirectly.

Experiences of exclusion from or mistreatment in health services

Respondents from across the globe reported being commonly excluded from or discriminated against by health services, and/or avoiding using health services to avoid unpleasant or humiliating experiences.

On average, more than one in eight of respondents in Africa, the Caribbean, Western Europe, Australia and Singapore reported that they had been denied healthcare during the past year. This figure rose to almost one in four elsewhere in the world. A quarter of respondents in Africa and the Caribbean, and more than a sixth elsewhere had avoided seeking care during the past year because they are living with HIV.

Some respondents reported being denied essential care:

“I was refused emergency assistance by an ambulance crew.” (Russia)

Others reported that some clinicians appear to be very misinformed about the risk of infection from treating someone with HIV, and what they should be doing to implement “universal precautions”:

“In a dentist’s office, the dental assistant put on gloves and with the gloves on she touched many surfaces, then she put the cross-contaminated gloves in my mouth. Who was she protecting? She was protecting only herself.” (United States)

The most severe and ironic example of apparent medical malpractice received through the survey was this report:

“I contracted HIV in 2006 through treatment in one of the hospitals of our town. My relations with the doctors there are now poor, as they think it is dangerous to serve me and my 14-year old son.” (Kazakhstan)

Denial of key sexual and reproductive health services

Respondents were asked questions about whether they had been denied, or felt excluded, from a range of sexual and reproductive health services. The numbers of respondents who felt that they had been treated inequitably because of being HIV-positive are displayed in table 4 below.

Table 4: impeded access to sexual and reproductive health interventions

| Access to: | ART | PMTCT | Condoms | Other HIV prevention methods | Treatment for sexually transmitted infections | Contraception | Antenatal or postnatal care |
|---|-----|-------|---------|------------------------------|---|---------------|-----------------------------|
| Africa & Caribbean | 3 | 2 | 3 | 0 | 2 | 1 | 1 |
| W Europe, N America, Australia & Singapore | 0 | 2 | 3 | 3 | 2 | 2 | 2 |
| Rest of the world | 3 | 0 | 6 | 2 | 1 | 1 | 0 |

While these figures are not high overall, they are indications of possibly serious inadequacies in services being provided.

Perception of undue pressure in medical treatment

Amongst respondents, 16% reported that since their diagnosis (as opposed to within the last year as in responses above) they have felt unduly influenced into accepting medical interventions against their wishes.

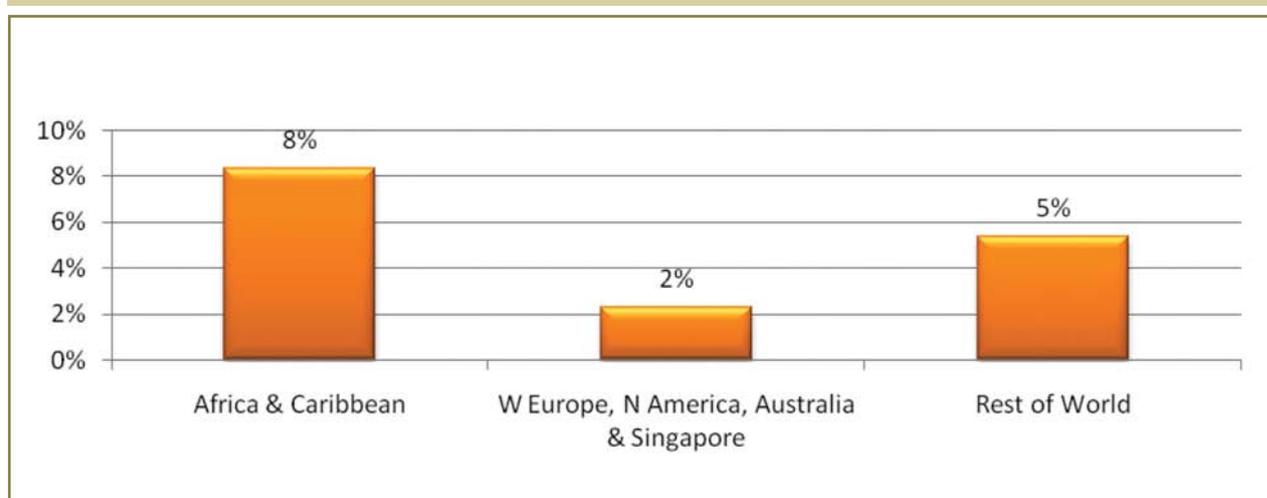
Reported responses included feeling pressure to accept antiretroviral treatment. One respondent had felt 'railroaded' into an abortion, and another respondent reported that upon diagnosis sterilisation was suggested.

Duress to reveal information about sexual partners, statements that patients must cease sexual activity permanently were cited, threats of quarantine and arrest, as well as threats to withdraw care for non-compliance with the advice given.

Experiences of stigmatisation by religious leaders and congregations

A number of respondents had been excluded from religious worship or places of worship during the last twelve months:

Figure 4: Exclusion from religious activities or places of worship in the past year



Although the numbers affected were not high, this might not indicate absence of discriminatory practice, but instead could indicate low levels of religious faith among the sample, exclusion in previous years, or lack of disclosure of HIV-positive status within these settings.

Eviction from home or exclusion from normal access to accommodation

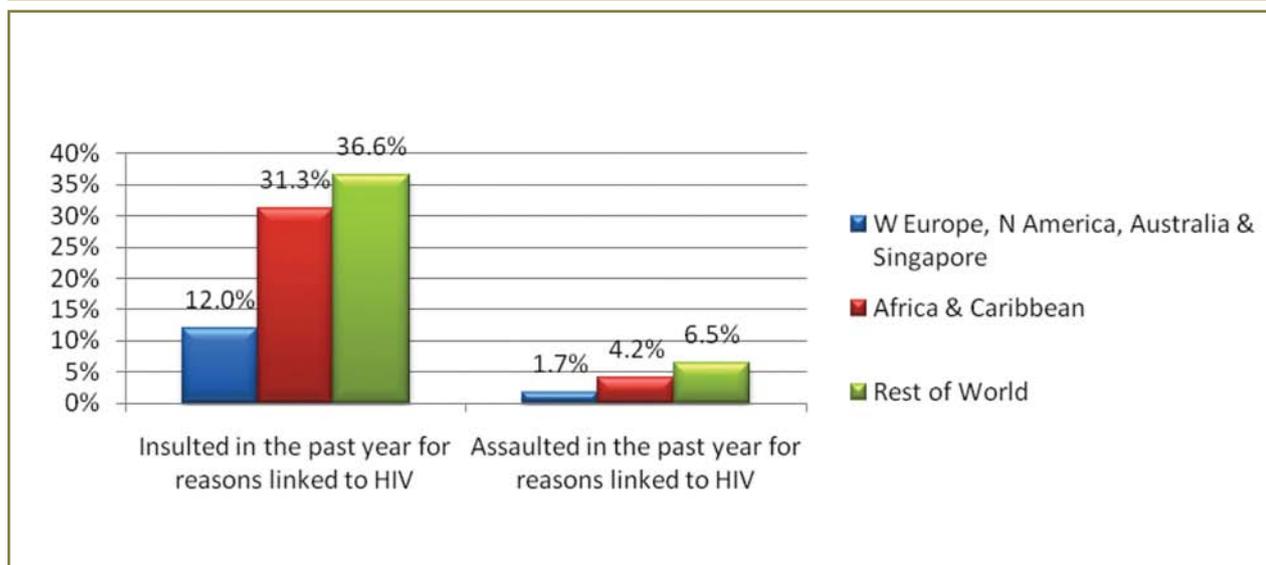
Twenty-eight (5%) of the respondents had been forced out of their accommodation in the last year because of their being HIV-positive. The most vulnerable are also those most likely to be made homeless:

“Persons with physical disabilities due to HIV are at risk to be discriminated against much more than people who look “normal” but are HIV-positive.” (United States)

Physical and verbal abuse

Reports of physical and verbal abuse, perpetrated for any reason, were solicited by the questionnaire. These showed that an overall total of 31% had been verbally abused in the last year, and 7% had been physically attacked. Figure 5 shows only those respondents who considered that the physical and verbal abuse they had encountered was attributable to their HIV status:

Figure 5: % of respondents insulted or assaulted at least once during the past year for reasons relating to HIV



Some people had suffered insult or assault repeatedly during the last year. Often the reason for the attacks was believed to be the combination of HIV-positive status and some other factor, such as the intersecting stigmas of homophobia and those concerning drug use, sex work or transgender.

In many cases, the perpetrators were spouses or life partners of the respondents, and sometimes family members.

"[It was] my mother. I have been cut off by the rest of my family and now have two friends only." (United Kingdom)

"My eldest brother." (Ivory Coast)

Some people reported abuse of power by authorities:

"It was the police who stopped us, and the abuse was as much physical as verbal dealt out to me and to my four companions who are also HIV-POSITIVE. They think that the people with HIV and drug- users are bad people and we are going to infect them with contaminated syringes." (Mexico)

Some respondents attributed the abuse they had suffered to structural factors affecting society as a whole:

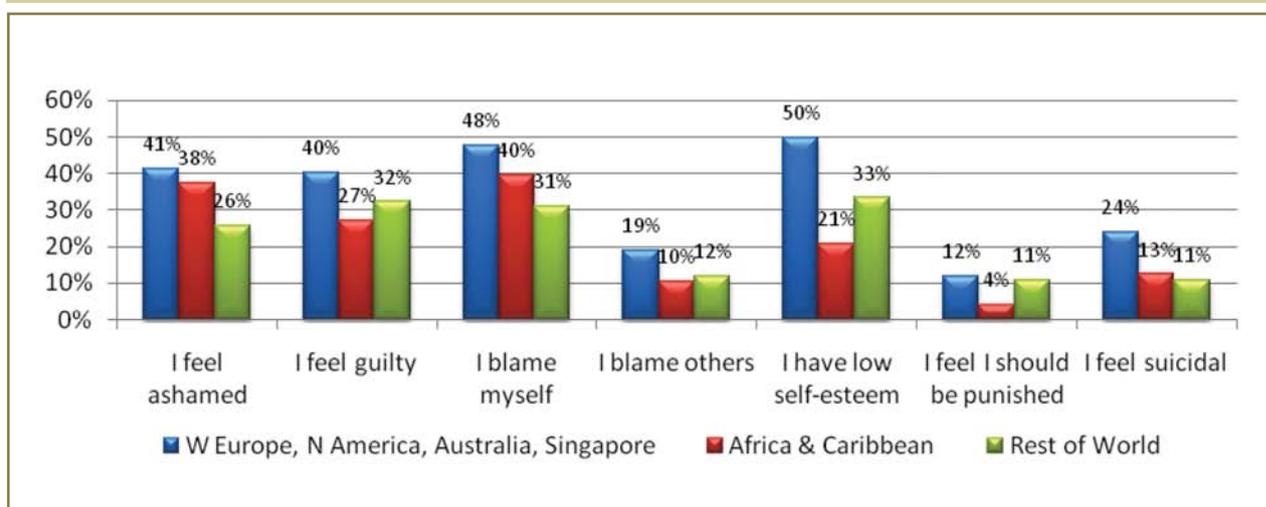
"It seems to me that some people do not have education and social awareness, they do not know how to respect and they are very rigid in applying religious and family values." (Mexico)

"Because of the machismo which exists in this country." (Ecuador)

Prevalence of internalised stigma

Many respondents reported forms of internalised stigma. In the past year, many respondents had experienced negative feelings linked with their HIV-positive status.

Figure 6: Experience of self-stigma amongst respondents



24% of PLHIV from Western Europe, North America, Australia, and Singapore felt suicidal. This was also reported by one in eight African and Caribbean respondents and one in nine in the rest of the world.

One interviewee repudiated the idea of internalised stigma as diverting attention from a more fundamental problem explaining this as follows:

"I have a problem with the concept of internalised stigma. It blames people for reacting to their experiences of stigma. This excuses the ill-treatment that caused the [self-stigma]. It is a measure of psychological impact: how severe the external stigma has been that this abuse has been internalised." (Country not given)

Abuse of rights and discrimination by the authorities

Respondents were asked whether their rights were protected under the laws of their country.

Africa and the Caribbean:

Of the respondents from Africa, 52% were aware of some legal provisions supposed to protect them. However, there was dissatisfaction with some of these laws:

"I've heard of it, I don't think it works because I was still denied employment in the army, it's just there on paper but not in action." (Kenya)

"I was among those advocating for the adoption of the law which was supposed to protect PLHIV, but this law criminalises the transmission of HIV, and obliges PLHIV to inform partners of their HIV status as soon as possible, which violates confidentiality." (Democratic Republic Congo).

Western Europe, North America, Australia and Singapore:

The countries in this group generally have anti-discrimination legislation, but not all respondents were aware of these provisions: 53% said that they knew of such laws. Many made comments on the protection their state affords them, and the gap between theory and practice:

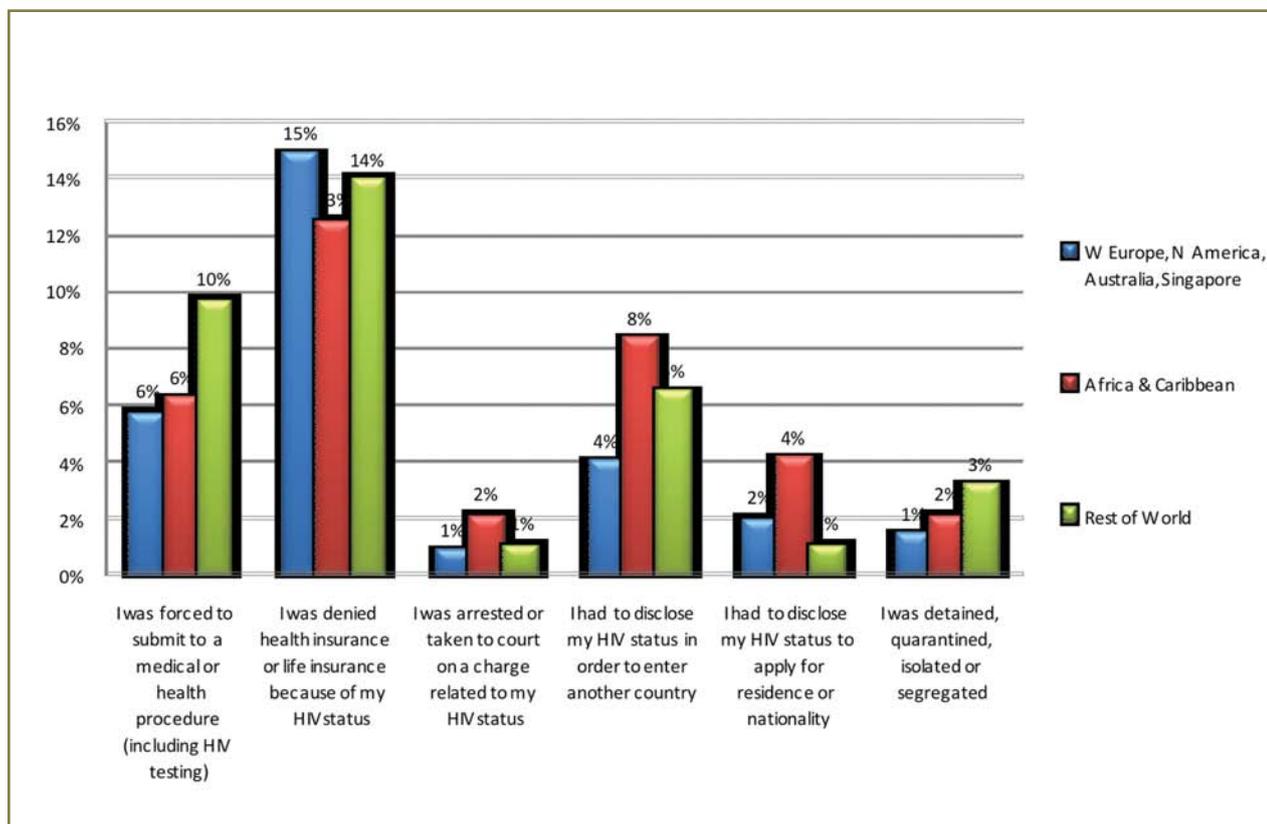
“In Michigan, merely being HIV positive places you in a suspect felony class if you have sex. You must disclose before “any penetration, however slight” which has been read by the courts to include mutual masturbation and sex toy use. However, it is not a crime to share a needle and not disclose your status. A county prosecutor earlier this year attempted to charge a HIV positive with bio-terrorism for biting another person during a fight.” (United States)

Rest of the World:

In these countries, 57% of respondents overall were aware of laws which protect their rights. While respondents felt that formal laws are a step in the right direction, they will provide little or no protection without buy-in from the community, and without mechanisms being in place to achieve redress that do not cause further stigmatisation from taking place.

Respondents were also requested to answer questions regarding problems they have encountered due to their HIV-positive status, other than the ones reported above

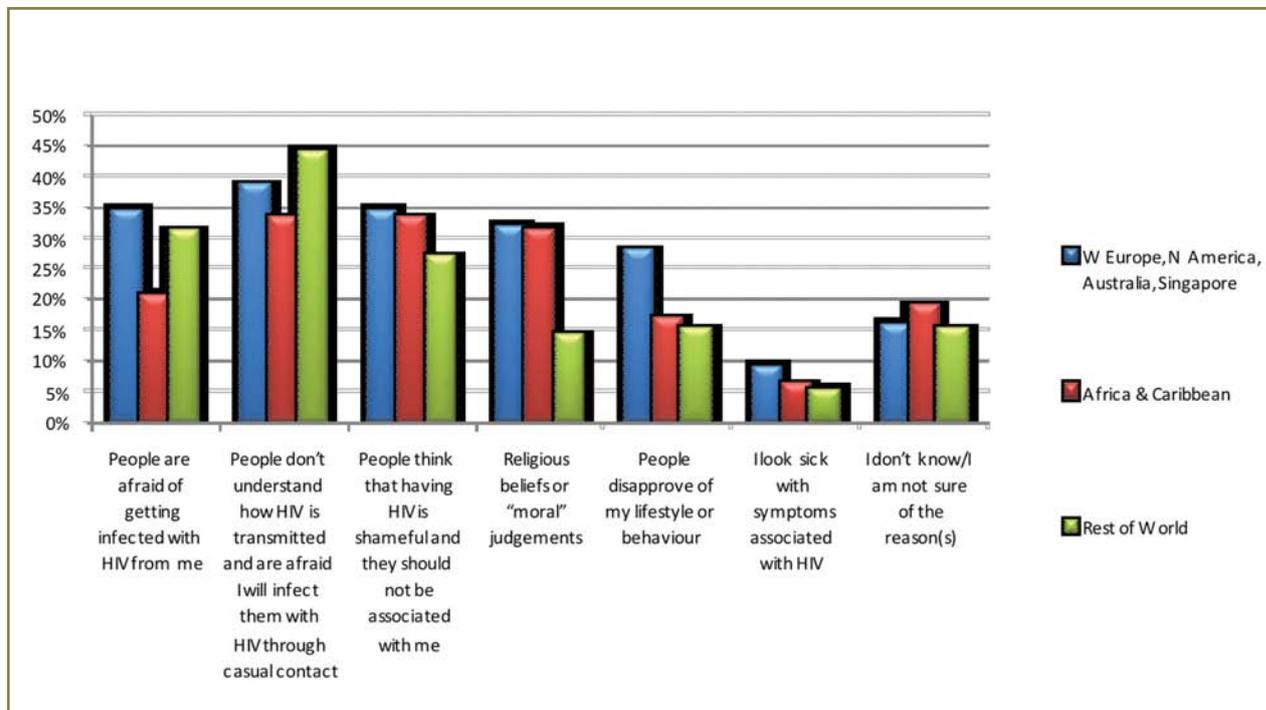
Figure 7: Discriminatory treatment in the past year because of HIV+ status



Views on reasons for stigma suffered

Respondents were asked to identify why they thought that people around them behaved in a discriminatory or stigmatising fashion; the questionnaire permitted selection of more than one option.

Figure 8: Reasons for stigma attributed by respondents



The involvement of the cross-cutting stigmas attaching to “high-risk groups” was identified as an important contributor to HIV-related stigma.

These intersecting stigmas compound each other, with stigma attached to behaviour intensifying the disapproval of PLHIV (unless a “blameless” route of infection is explicitly claimed), and the association with HIV infection increasing disapproval of sex workers, injecting drug users and men who have sex with men.

Respondents' priorities for tackling stigma

The survey asked PLHIV to rank aspects of life valued by their importance (as they relate to having had impact from HIV-related stigma). The overall ranking below was determined by adding all individual rankings together.

1. Love and sexual relationships
2. Emotional well-being
3. Legal Protection
4. Family relationships
5. Access to health care

When respondents were asked to consider which areas should be tackled through programming as the highest priorities, variance in responses was recorded.

| | |
|-----------------------|--|
| Asia Pacific: | social and community interactions/love and relationships (equal) |
| Caribbean: | family relationships/social and community interactions (equal) |
| Europe: | access to health care (especially Eastern Europe) |
| North America: | love and relationships |
| South America: | household income |

Respondents from African countries returned a large spread of equally high priority answers, with the following ranking the highest:

- Physical and verbal abuse
- Family relationships
- Legal protection
- Access to health care
- Emotional well-being
- Social and community interactions

Except for the strong dominance of selection of “love and sexual relationships” by North American respondents, which is responsible for the primary ranking of this choice in the overall ranking above, no strong preferences emerged in any region. Access to health care seemed to rank higher in countries where it is less accessible (for instance this was the top preference in Eastern Europe, whereas in Western Europe, love and relationships dominated the choices), but otherwise rankings were fairly evenly spread between the options. It would seem that all of the areas of stigma require action in all regions.

Interviews

In addition to the questionnaire-based survey, Interviewees answered questions according to the semi-structured interview guide as follows:

1. How could we measure the impact of attempts to address HIV-related stigma?

The interviewees made various references to ways this is currently being done, such as pre and post-testing of knowledge and attitudes of recipients of training workshops for health care providers and others providing services to PLHIV. Interviewees also put forth suggestions on how to undertake HIV-related anti-stigma programmes which are underway or planned, which do not at present include means to measure baseline situational analysis or impact of HIV-related stigma. A large proportion of the participants were involved in the PLHIV Stigma Index and several cited this as an important tool which contributes in measuring stigma.

2. What are the gaps in efforts to address stigma? What are the gaps in indicators to measure the success of efforts to address stigma?

Interviewees expressed a dearth of stigma programming. Interviewees suggested areas for priority action relevant to their country context. While some suggestions were made for means to measure stigma, several interviewees indicated a gap in skills and/or a lack of funding to undertake any form of contextual analysis (lack of funding was identified as a problem especially in the United States and Caribbean).

One interviewee noted that the Jamaican national response includes a great deal of stigma-related work, which has contributed to a reduction in stigma somewhat but neglects to address some key underlying problems which generate stigma.

3. What are some examples of good practice in measuring stigma:

- at programme level?
- at policy level?

The PLHIV Stigma Index was mentioned by interviewees; both those involved in the PLHIV Stigma Index and others who were aware of it. Other than this there were two contributions made of examples of good practice. One was the comment that locally led community level projects were sometimes able to measure impact and effect change due to the micro-level of the intervention. The other example cited was that of the work done in Australia through the Australian Research Centre in Sex, Health and Society (**ARCSHS**) which conducts a national program of social research focusing on the lived experience of HIV. Part of this research is the HIV Futures Surveys, which are self completed, mail-back, anonymous, national, non-clinical, omnibus, surveys conducted every 2 years.¹⁰

4. Why is it important to improve how we measure and monitor stigma?

Respondents said, inter alia:

“Stigma is a cross-cutting issue, affecting everything, and should be looked at holistically. We need an evidence base on how to measure whether stigma has reduced.” (Kenya)

“Stigma remains the biggest obstacle to programmes and interventions across the board: prevention, care and support, and reluctance to test.”

(Zambia)

“The present challenge in South Africa is the narrowing of the perceived interests of PLHIV down to treatment access only: it is seen as unacceptable to ask for anything else. Issues of stigma, harm reduction, and nutrition are not being addressed, and we have not succeeded in making a case for a balanced approach. Stigma threatens access too.” (South Africa)

“Disclosure happens only on death among South African elites. We must create new social norms. The problem is how to make the ‘undiscussable’ ‘discussable, as has happened over the last few decades with the normalisation of cancer.” (South Africa)

“Stigma remains the biggest obstacle to programmes and interventions across the board: prevention, care and support, and reluctance to test.” (Zambia)

“Because data is a campaigning tool, from government ministers to clinicians.” (United Kingdom)

“It will be pretty expensive to tackle, so we need to measure where the investment is most needed. A full-fledged campaign would be costly. Therefore start with research for prioritisation, to see who is worst-affected. Also to measure how effective interventions have been. In the future regular monitoring of impact on stigma will be needed also.” (Uzbekistan)

“Because [it] is a barrier to testing, to treatment, to everything.” (United States)

¹⁰ More information at <http://www.latrobe.edu.au/hiv-futures/>

“It is important to measure HIV-related stigma:

- *To create a baseline*
- *To find out how best to tackle it*
- *To see how stigma impacts services.” (United States)*

“Because many of the barriers to accessing information, prevention, care and treatment are related to stigma. Until people feel more comfortable, these barriers will remain.” (Dutch Antilles)

“Because we are all born equal with dignity and rights and it is the obligation of government to guarantee us the opportunity to enjoy those rights. In addition, people are driven away from programmes by stigma.” (Jamaica)

“Because stigma leads to discrimination which leads to violation of people’s rights, which will lead to people going underground, and then they won’t get tested, in a self-perpetuating cycle. Those who are hard to reach will become even harder to reach, especially MSM, IDUs, and SWs.” (Australia)

Some interviewees were able to make specific suggestions for indicators that should be used, others identified the priority areas for action on HIV-related stigma in their home/work contexts. Interviewees noted the drawbacks of using population indicators to assess stigma, specifically:

- a long time-frame to measure change;
- remoteness from any proven impact on treatment access experienced by PLHIV;
- embedded assumptions and difficulty in interpreting results;
- difficulty in attributing causality or even correctly identifying association with possible causes; and
- the likelihood of dishonesty in replies in order to present a more appealing impression to researchers.

“Because we are all born equal with dignity and rights and it is the obligation of government to guarantee us the opportunity to enjoy those rights. In addition, people are driven away from programmes by stigma.”

(Jamaica)

Despite this being a very experienced group of programmers specialised in working on PLHIV issues in many different parts of the world, only two respondents were able to suggest any models of good practice in stigma indicators other than their own organisations’ work. Several stated that this is an important gap. This suggests that few good models exist as yet.

Suggestions arising from interviews

Development of indicators based on the findings of the consultation

Interviewees were asked to make suggestions on what could be a single indicator for HIV-related stigma which would apply to all contexts and to the widest possible numbers affected. One interviewee noted that a good indicator should ideally assess the combination of internalised stigma and external stigma: such a construction is possible for PLHIV-centred indicators but not for general population indicators. Asking the general population about how they treat (or would treat) PLHIV seems a weak proxy for asking PLHIV themselves how they are treated by those aware of their status.

Most suggestions were focussed in two broad areas:

Internalised stigma, level of emotional coping and ability to disclose

- ▶ Are you able to disclose information related to HIV in social, professional and familial situations?

Health related issues

Appropriate indicators are needed to capture stigmatizing attitudes or behaviours by health care workers. Access to medical treatments could serve as the main area for an indicator.

- ▶ Do you have access to the health services you need?
- ▶ Are health care services available, affordable and acceptable to you?

For an overview of the integrated effect of stigma in the community, biological or clinical indicators which correlate well with stigma were suggested. A key measure here:

- ▶ A measure of degree of late presentation for care.

This could be assessed through the average CD4 count or clinical stage¹¹ when diagnosed. It could also be assessed by average WHO clinical stage at diagnosis. Data for clinical staging is likely to be most universally available, while the CD4 count is more objective and probably a more reliable measure of delay in testing.

A suggestion for an integrating indicator for stigma at a whole-society level without asking individuals was to consider the language used in the media concerning HIV. This would appear to be feasible with a suitable sampling strategy.

¹¹For WHO staging, Stage 1 is the stage of primary infection and the asymptomatic stage which follows it. Stage 2 is characterised by mild weight loss and the appearance of sporadic opportunistic infections such as TB which are also found commonly in non immune-suppressed people. Stage 3 covers the phase when illness is persistent and weight loss is more severe. Stage 4 involves the appearance of severe wasting and multiple opportunistic infections which rarely appear in non immune-suppressed people. CDC staging could alternatively also be used, but this is particular to the US spectrum of opportunistic infection, and it would make a less sensitive measure as it has only three stages, not four.

Conclusions and Recommendations

While it is clear that indicators covering all domains are required, this consultation has attempted to locate the minimum number of indicators which can address the magnitude of this complexity, based on the priorities set by PLHIV. The suggestions below for informing key indicators that have a resonance with PLHIV were generated from this process, as follows:

- ▶ Have you disclosed your HIV status to a family member?
- ▶ Have you been excluded from health services you need because you are HIV-positive in the past year?
- ▶ Have your medical providers treated you with respect during the last year?

For informing indicators at the national, local or facility-based level the following health-outcome indicators were suggested as providing a useful baseline to measure progress toward universal access to treatment, and care and support:

- ▶ What is the average CD4 count of people at HIV diagnosis during the past year?
- ▶ What is the average clinical stage of those diagnosed with HIV during the past year?

Talking points:

The following talking points arose from the semi-structured interviews which addressed directly the drafting of HIV-related stigma indicators:

- ▶ Interviewees were in favour of measuring impact of stigma programming, rather than only inputs and activities. They suggested measuring perception of PLHIV about stigma levels in their environment, measures of access to medical care in particular, and measures of limitations imposed by stigma on the lives of PLHIV (such as barriers to health care, employment, education, accommodation, etc).
- ▶ Doubts were expressed about the level of honesty with which population indicator questions will be answered, because of shame of admitting to unkind or intolerant behaviour or attitudes.
- ▶ All interviewees were of the opinion that HIV-related stigma needed to be addressed urgently and comprehensively, and highlighted the obstacles in the response.

Recommendations:

Though indicators that measure PLHIV-related stigma generated through consultations with the general population (about how they treat or would treat PLHIV) were welcomed by respondents

(PLHIV) as a mark of the issue being taken seriously by the general population, it was indicated as a weak proxy for asking PLHIV themselves how they are treated by those aware of their HIV-positive status.

The development of common indicators that support a scaled-up response to reducing HIV-related stigma should:

- Concentrate as much as possible on the perception of the stigma experienced by PLHIV as measurement of the stigma toward PLHIV in a 'notional' general population;
- Acknowledge that PLHIV are well placed to determine the priorities for stigma 'reduction programmes' within specific country contexts and, if properly supported and resourced, to analyse the relative importance and impact that such programmes are having in their communities.

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