STRIVE
Tackling the structural drivers of HIV

Measuring HIV stigma and discrimination

TECHNICAL BRIEF
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This brief is designed to guide researchers in the study of HIV-related stigma and discrimination, either as the main focus of research or as a complement to related topics. It outlines the key domains of HIV-related stigma and discrimination that need to be measured if we are to understand how stigma operates and how it can be reduced in a particular setting. The brief proposes specific questions for measuring the key conceptual domains of stigma and discrimination across three populations: people living with HIV, the general population and healthcare providers. It lists areas requiring further question development, testing and validation.

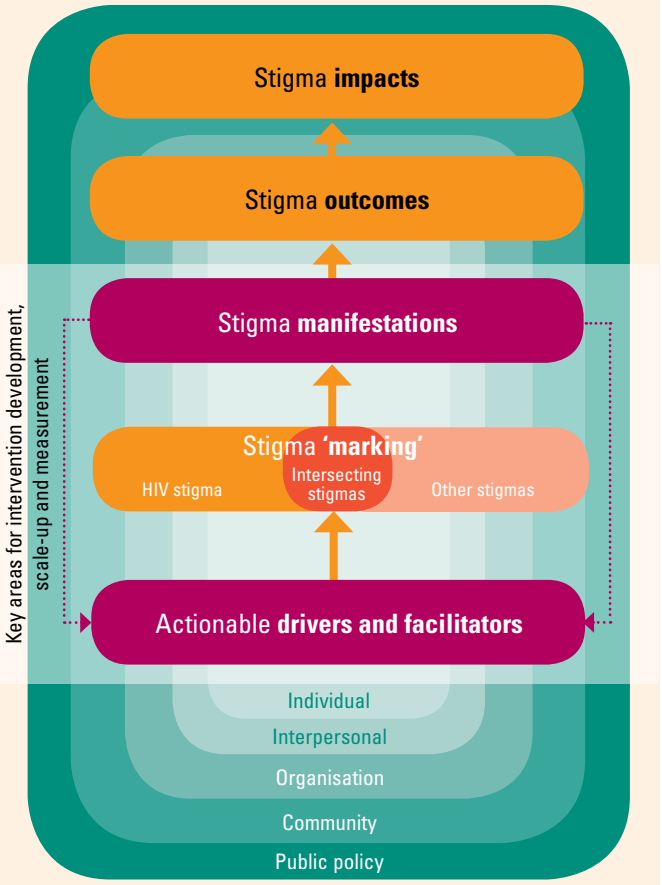
HIV-related stigma and discrimination continue to be experienced across the globe, impeding access to and scale-up of HIV prevention, treatment, care and support programmes.[i] In 1987, HIV stigma was described as the 'third epidemic'[1], coming after those of HIV and AIDS and no less crucial. While many individuals, organisations and governments have worked diligently to reduce HIV-related stigma and discrimination, such efforts are not implemented at a scale necessary to have a significant impact on HIV outcomes, thus stigma continues to fuel HIV transmission.[2]

A large body of research has been conducted to conceptualise HIV stigma, explore its forms, contexts and consequences and understand individual and community responses.[ii] This research has yielded a large number of survey questions and scales to measure stigma in a variety of cultural contexts and with various populations, including people living with HIV, the general population and healthcare workers.[iii-vi] The sheer number and diversity of questions and scales used in stigma research over the years, however, have made it difficult to compare findings across contexts. To be able to characterise stigma as a global driver of HIV infection, it is necessary to measure it more uniformly and accurately. This brief presents recommendations for doing so. The measures presented here were developed by a consortium of stigma researchers[3] and are based on a systematic review and synthesis of the research literature.

Key conceptual domains

The new framework[4] in Figure 1 illustrates how stigma manifest across the socio-ecological spectrum to produce key opportunities and areas for intervention as well as its impacts and outcomes. The framework illustrates and expands upon three key areas for intervention development:
1) actionable drivers and facilitators, 2) stigma 'marking', and 3) stigma manifestations.

Figure 1. Reducing HIV stigma and discrimination: A framework for programme implementation and measurement[viii]



The first refers to factors that drive or facilitate HIV stigma. They are described as 'actionable' because they have been shown to shift as a result of interventions. Drivers, such as fear of infection through casual contact and social judgment, are conceptualised as inherently negative, while facilitators could have either positive or negative influences – for example, laws that criminalise HIV can fuel stigma and discrimination, whereas those that protect the rights of people living with HIV may reduce discrimination. Drivers and facilitators are expressed through different stigma 'marking', i.e. intersecting stigmas such as sexuality, drug use, race, etc. This leads to a number of manifestations of HIV stigma such as discrimination, shame and internalised stigma, which influence the outcomes and impacts of stigma in a given context. The framework is based on the assumption that any individual can anticipate, experience and/or perpetuate HIV-related stigma and

discrimination, regardless of his or her own HIV status. While the framework is specific to HIV stigma, it recognizes that HIV stigma often co-occurs with other, intersecting stigmas, such as those related to sexual orientation, gender, drug use and poverty.

Among the *actionable drivers and facilitators*, key conceptual domains for measurement include:

- fear of infection through casual contact with people living with HIV
- social judgment, including shame, blame, prejudice and stereotypes
- the legal and policy environment.

Fear and social judgment are well-documented drivers of stigmatising behaviours among the general population and healthcare workers and should be measured with those groups.[ix-xiii] To measure the domain described as 'legal and policy environment', researchers need to identify the laws, institutional policies and social norms that may either increase or reduce stigma and discrimination towards people living with HIV and towards key populations, (such as sex workers, men who have sex with men, people who use drugs, migrants, prisoners and women). It is important to know whether these regulations are enforced and the level of awareness of these regulations among employees of relevant institutions, HIV-affected populations and the general population.

Specific measures for research and evaluation

Among the *manifestations of stigma*, key conceptual domains for measurement include:

- anticipated stigma (the fear of negative ramifications should one's HIV status become known, should one associate with a person living with HIV or should one test positive for HIV)
- perceived stigma (community members' perception of stigma that is directed toward people living with HIV by community members)
- internalised stigma (the acceptance among people living with HIV of negative beliefs and feelings associated with HIV about themselves)
- experienced stigma (the experience of discrimination, based on HIV status or association with a person living with HIV or other stigmatised group, that falls *outside* the purview of the law[5])
- discrimination (the experience of discrimination that falls *within* the purview of the law[6])
- resilience (overcoming and resisting stigma and discrimination experienced).[viii]

Table 1 presents illustrative questions that can be asked to assess each domain of stigma by population of interest (general population, healthcare workers and people living with HIV). It is recommended that researchers assess all conceptual domains of HIV stigma that are relevant to their population of interest to reach a comprehensive understanding of HIV stigma and discrimination and of the impact of specific stigma-reduction activities on the stigmatisation process.

Additional questions are available[v] for each domain and may be needed, depending on the type of stigma-reduction intervention being evaluated. It is also recommended that researchers include several questions per domain, where possible, in order to allow for the development of scales, which may be more robust than individual questions in statistical analyses. Also, researchers should ask parallel questions across these three populations to allow for comparison; 'parallel' because it is not always appropriate or possible to ask exactly the same question across all three populations. For example, under the parallel domains of perceived and experienced stigma, community members would be asked about their perceptions of stigmatising behaviours towards people living with HIV in the community, whereas people living with HIV would be asked about their actual experiences of stigma.

Methodology

Questions to assess stigma and discrimination in the general population can be included in large, population-based surveys using multi-stage cluster samples, such as the Demographic and Health Surveys, to enable generalisability. It should be noted that people living with HIV are a part of the general population, and can be expected to make up a greater or smaller portion of the sample depending on location. For health facilities, sampling procedures are typically based on the size of the facilities being assessed. For example, in a large hospital, a random sample of healthcare workers could be selected. Alternatively, a census of all healthcare workers may be needed for small, rural clinics.

Until recently, studies of people living with HIV and key populations have been conducted using community-based sampling approaches such as snowball, time-location and respondent-driven sampling (RDS). Results from these sampling techniques are inherently biased, however, as it is not possible to survey people living with HIV who have not disclosed their sero-status to anyone. Likewise, individuals who do not identify with a key population or those who are not networked will not be captured with RDS. In response to these challenges, some researchers have begun asking respondents to share their HIV status in large, population-based surveys and then including a module on HIV-related stigma for those who indicate they are living with HIV.[xiv] While response bias is still possible with this sampling approach, the data are likely to be more representative of people living with HIV in a given context. Regardless of sampling approach, researchers are advised to complement quantitative data collection with qualitative methods (such as in-depth interviews, focus group discussion and participatory action research methods) to allow for a more comprehensive understanding of HIV stigma and discrimination in a given setting.

Table 1. Illustrative questions by domain of HIV stigma and discrimination

GENERAL POPULATION	HEALTHCARE WORKERS*	PEOPLE LIVING WITH HIV**
DOMAIN Fear of infection		
Do you fear that you could contract HIV if you come into contact with the saliva of a person living with HIV?	How worried would you be about getting HIV if you did the following? • Touched the clothing of a patient living with HIV • Dressed the wounds of a patient living with HIV • Drew blood from a patient living with HIV • Took the temperature of a patient living with HIV Do you typically use any of the following measures when providing care or services for a patient living with HIV? • Avoid physical contact • Wear double gloves • Wear gloves during all aspects of the patient's care • Use any special infection-control measures with patients living with HIV that you do not use with other patients	Not applicable
DOMAIN Social judgment		
Do you agree or disagree with the following statement: • I would be ashamed if someone in my family had HIV	Do you strongly agree, agree, disagree, or strongly disagree with the following statements? • Most people living with HIV do not care if they infect other people. • People living with HIV should feel ashamed of themselves. • Most people living with HIV have had many sexual partners. • People get infected with HIV because they engage in irresponsible behaviours. • HIV is punishment for bad behaviour. • Women living with HIV should be allowed to have babies if they wish.	Not applicable
DOMAIN Legal and policy environment		
National-level indicators Is there a course on HIV-related stigma and discrimination and human rights institutionalised in degree programmes for duty bearers (i.e. medicine, nursing, social work, law, law enforcement). (Yes/No for each programme) Is there a law criminalising HIV exposure? (Yes/No) Is there a law criminalising LGBT relationships? (Yes/No) In the past 12 months, number of harmful laws impeding access to HIV services removed or replaced (specify laws changed)	Do you strongly agree, agree, disagree, or strongly disagree with the following statements? • In my facility it is not acceptable to test a patient for HIV without their knowledge. • I will get in trouble at work if I discriminate against patients living with HIV. • There are adequate supplies in my health facility that reduce my risk of becoming infected with HIV. • There are standardised procedures/ protocols in my health facility that reduce my risk of becoming infected with HIV. • My health facility has written guidelines to protect patients living with HIV from discrimination.	Do you know if there are any laws in your country to protect people living with HIV from discrimination? In the past 12 months, I was forced to get tested for HIV or disclose my status in order to: • obtain a visa or to apply for residency/ citizenship in a country • apply for a job or get a pension plan • attend an educational institution or get a scholarship • get healthcare • get medical insurance

* These questions have been validated: Jain, A., D. Carr, and L. Nyblade. 2015. 'Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire User Guide'. Washington, DC: Futures Group, Health Policy Project.

** These questions are currently collected in The People Living with HIV Stigma Index tool (www.stigmaindex.org).

GENERAL POPULATION	HEALTHCARE WORKERS*	PEOPLE LIVING WITH HIV**
DOMAIN Legal and policy environment (cont.)		
		In the past 12 months: • I was arrested or taken to court on a charge related to my HIV status • I was detained or quarantined because of my HIV status • I was denied a visa or permission to enter another country because of my HIV status • I was denied residency or permission to stay in another country because of my HIV status
DOMAIN Anticipated stigma		
In your opinion, are people hesitant to take an HIV test due to fear of people's reaction if the test result is positive for HIV?	How hesitant are healthcare workers in this facility to work alongside a co-worker living with HIV, regardless of their duties?	In the last 12 months, have you been fearful of any of the following things happening to you – whether or not they actually have happened to you? • Being gossiped about • Being verbally insulted, harassed and/or threatened • Being physically harassed and/or threatened • Being physically assaulted In the past 12 months, did fears about someone learning your HIV status lead you to miss a dose of your HIV (antiretroviral) treatment? (Y/N)
DOMAIN Internalised stigma‡		
Not applicable	Not applicable	Do you agree or disagree with the following statements? • It is difficult to tell people about my HIV infection • Being HIV-positive makes me feel dirty • I feel guilty that I am HIV positive • I am ashamed that I am HIV positive • I sometimes feel worthless because I am HIV positive • I hide my HIV status from others • I have lost respect or standing in the community because of my HIV status • I think less of myself because of my HIV status
DOMAIN Perceived stigma		
Do people talk badly about people living with or thought to be living with HIV to others? Do people living with or thought to be living with HIV lose respect or standing?	In the past 12 months, how often have you observed the following in your health facility? • Healthcare workers unwilling to care for a patient living with or thought to be living with HIV • Healthcare workers providing poorer quality of care to a patient living with or thought to be living with HIV, relative to other patients • Healthcare workers talking badly about people living with or thought to be living with HIV	In the past 12 months: • Have you felt excluded from social gatherings or activities (e.g. weddings, funerals, parties, clubs) because of your HIV status? • Have you felt excluded from religious activities or places of worship because of your HIV status? • Have you felt excluded from family activities because of your HIV status? • Have you felt that family members have made discriminatory remarks or gossiped about you because of your HIV status?

‡ Parallel questions for the general population and healthcare providers can be found under the 'social judgment' domain.

‡‡ This is one example of experienced stigma that people living with HIV may experience. The People Living with HIV Stigma Index asks about a number of additional types of experienced stigma.

GENERAL POPULATION	HEALTHCARE WORKERS*	PEOPLE LIVING WITH HIV**
DOMAIN Experienced stigma (outside legal purview)		
Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?	In the past 12 months, how often have you: • Experienced people talking badly about you because you care for patients living with HIV • Been avoided by friends and family because you care for patients living with HIV • Been avoided by colleagues because of your work caring for patients living with HIV	In the past 12 months: • Has someone talked badly about you because of your HIV status? • Has someone verbally insulted, harassed and/or threatened you because of your HIV status? • Have you been excluded from family activities because of your HIV status? • Have you been excluded from religious activities or places of worship because of your HIV status?
DOMAIN Discrimination (inside legal purview)		
Do you think children living with HIV should be able to attend school with children who are HIV negative?	In the past 12 months, how often have you observed other healthcare providers? • Performing an HIV test on a pregnant woman without her informed consent • Neglecting a woman living with HIV during labor and delivery because of her HIV status • Using additional infection-control procedures (e.g., double gloves) with a pregnant woman living with HIV during labor and delivery because of her HIV status? • Disclosing the status of a pregnant woman living with HIV to others without her consent? • Making HIV treatment for a woman living with HIV conditional on her use of family planning methods	In the past 12 months: • Has someone physically harassed you (e.g. pushed, hit or was otherwise physically abusive) because of your HIV status? • Have you been refused employment or a work opportunity because of your HIV status? • Have you lost a source of income or job because of your HIV status? • Has your job description or the nature of your job changed or have you been refused a promotion because of your HIV status? • Has your wife/husband or partner experienced discrimination because of your HIV status? • Has someone disclosed your HIV status without your permission? In the past 12 months, when seeking HIV-specific healthcare, have you experienced any of the following from health facility staff? • Denial of health services, because of your HIV status • Physical abuse (pushing, hitting or being otherwise physically abusive) because of your HIV status • Telling other people about your HIV status without your consent • Being forced to have an HIV test without your consent • Being pressured or forced by staff to start antiretroviral treatment for HIV In the past 12 months, when seeking care outside of where you receive your regular HIV care, have you experienced any of the following treatment by health facility staff? • Denial of health services because of your HIV status • Denial of dental services because of your HIV status

GENERAL POPULATION	HEALTHCARE WORKERS*	PEOPLE LIVING WITH HIV**
DOMAIN **Resilience**		
Not applicable	In the past 12 months, how often have you observed the following in your health facility? • Healthcare workers confronting or educating someone who was mistreating or speaking badly about people living with HIV	In the past 12 months, have you done any of the following because you are HIV-positive? • Confronted, challenged or educated someone who was stigmatising and/or discriminating against a person living with HIV • Supported others living with HIV in relation to stigma and/or discrimination (such as, helping someone take action, referring someone to a source of help, providing emotional or practical support for someone, etc.) • Participated in an organisation or group that works to address stigma and discrimination against people living with HIV • Tried to get a community leader to take action about issues of stigma and discrimination against people living with HIV • Tried to get a government leader or a local/national politician to take action about issues of stigma and discrimination against people living with HIV • Spoke to the media about issues of stigma and discrimination against people living with HIV

Additional research needed

Now that validated measures are available to assess most of the domains of HIV-related stigma and discrimination among the general population, healthcare workers and people living with HIV, it is critical that researchers utilise these measures to rigorously examine the relationship between stigma and discrimination reduction efforts and HIV outcomes. All too often researchers assess only one domain of stigma, which leads to inconsistent and incomplete evidence about the success or failure of stigma-reduction efforts. In this new era of shrinking development funds and a global push for more strategic AIDS investments,[xiv] strong evidence linking stigma reduction with positive HIV and health outcomes is needed to ensure that countries include stigma reduction as a key component in their national HIV responses.

With regard to stigma measurement, few measures are available to assess the law and policy environment that either reinforces and perpetuates stigma or challenges it. At present, the measures available in this domain only assess the presence and awareness of laws and polices related to people living with HIV and key populations. These measures need to be expanded to capture other aspects of this domain, such as the level of representation of people living with HIV and affected populations in governance structures and the inclusion of sensitivity and stigma and discrimination reduction training in curricula for medical students, teachers, media and police. Current tools in use to understand the legal and policy environment in the context of HIV include:

- **the National Composite Policy Index (NCPI)**, developed by UNAIDS to measure progress in the development and implementation of national level HIV and AIDS policies, strategies and laws, which is reported routinely by all UN member countries; and
- **Legal Environment Assessments (LEAs)**, supported by UNDP and the Global Fund, which are designed to assist governments in identifying human rights barriers and understanding how they affect HIV, TB and/or malaria, including key populations, to inform action for strengthened legal and policy environments.

Among the manifestations of stigma at the individual level, new measures are now available to assess resilience among people living with HIV (see Table 1). These measures will enable critical research to understand the impact of resilience on health and well-being outcomes for people living with HIV and test the effectiveness of interventions to increase resilience among people living with HIV. An area of measurement requiring further development is the intersection of HIV stigma with other stigmas affecting key populations at risk of HIV infection. Intervention research suggests that HIV stigma reduction programmes may be more effective if they also address intersecting stigmas, particularly in targeted epidemic contexts. For example, in Vietnam, the stigma associated with injecting drug use is fairly high and drug use is inextricably linked with HIV. Thus, interventions addressing HIV stigma alone have not effected significant reductions in stigmatising attitudes at the community level.[ix, xiii] It is critical to develop and test measures

and methodologies to assess the intersection of HIV and other stigmas faced by key populations to enable evaluation of multi-faceted stigma reduction interventions.

Lastly, as standardised questions begin to be asked across the general population, healthcare workers, people living with HIV and key populations, it will be important to develop appropriate analytical methods to compare and interpret these data. It is thought that comparisons of responses will provide a more accurate reflection of the level of stigma and discrimination in a given setting. Analyses using parallel HIV-related stigma data are beginning to emerge,[xv] however, more research is needed to develop a standardised methodology to compare and interpret data across these three populations.

Endnotes

1. By Jonathan Mann, then director of the WHO Global Programme on AIDS, in a statement at an informal briefing on AIDS to the 42nd Session of the United Nations General Assembly, 20 October, New York.
2. It has been estimated that 26-53% of vertical HIV transmissions may be attributed to stigma (Watts C, Zimmerman C, Eckhaus T, Nyblade L. Stigma and discrimination as an important barrier to universal access to PMTCT: model projections. Poster session presented at: International AIDS Conference (IAS); 2010 July, Vienna Austria).
3. The Global Stigma and Discrimination Indicator Working Group (GSDIWG) involves experts from 17 organisations led by a partnership between the Global Network of People Living with HIV (GNP+), the International Center for Research on Women (ICRW), International Planned Parenthood Federation (IPPF), John Hopkins Bloomberg School of Public Health (JHU) and The Joint United Nations Programme on HIV/AIDS (UNAIDS).
4. Developed by GSDIWG, informed by current knowledge and best practice [iii, vi, ix-xiii] and presented in full elsewhere (forthcoming).
5. Examples of discrimination that fall outside the purview of the law include: blaming, discrediting, gossip, verbal harassment, avoiding everyday contact, ostracism and abandonment.
6. Examples of discrimination that fall within the purview of the law include: being fired from a job due to HIV-positive status, denial of access to school for children living with HIV, denial of access to healthcare services and physical violence.

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