STRIVE
Tackling the structural drivers of HIV

Measuring HIV stigma and discrimination

TECHNICAL BRIEF
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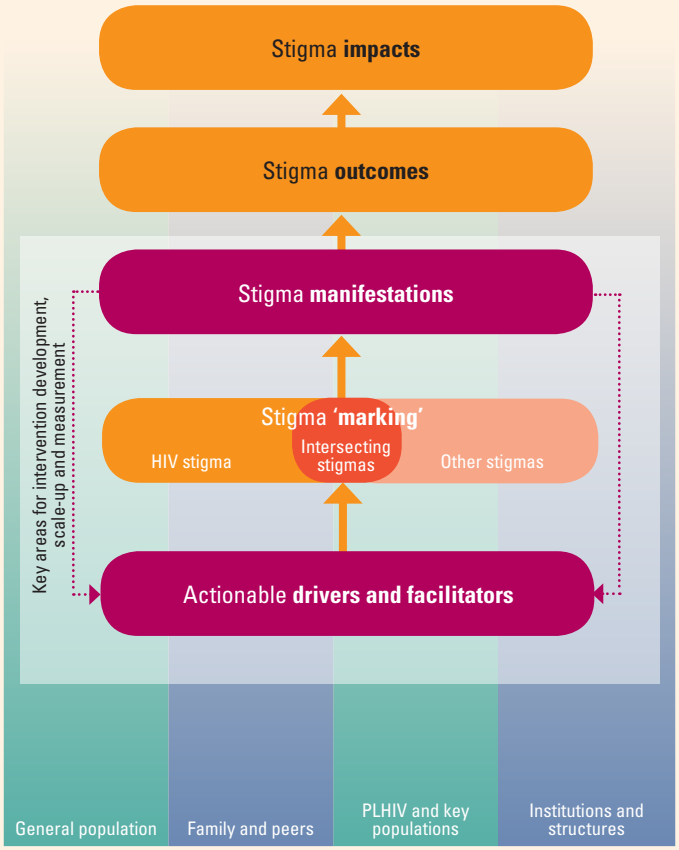
This brief is designed to guide researchers in the study of HIV-related stigma and discrimination, either as the main focus of research or as a complement to related topics. It outlines the key domains of HIV-related stigma and discrimination that need to be measured if we are to understand how stigma 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[ii], 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 conceptualize HIV stigma, explore its forms, contexts and consequences and understand individual and community responses.[iii] 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.[iv-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 characterize 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.

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



Adapted from: A. Stangl, V. Go, C. Zelaya, et al, poster presentation, IAS 2010, Vienna.

Key conceptual domains

The new framework[4] shown in Figure 1 illustrates how stigma functions, how it can be measured and where to intervene. It breaks stigma into several constituent parts. At the bottom are 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 social judgment and fear of infection through casual contact, are seen as inherently negative, while facilitators could have either positive or negative influences – for example, laws that criminalize HIV can fuel stigma and discrimination whereas those that protect the rights of people living with HIV may reduce discrimination. *Drivers* and *facilitators* lead to a number of manifestations of HIV stigma that in turn influence the outcomes and impacts of stigma in a given context. This 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.[viii-ix] 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.

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

DOMAIN	GENERAL POPULATION	HEALTHCARE WORKERS*	PEOPLE LIVING WITH HIV**
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 of getting HIV if you did the following? • 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? • Avoiding physical contact †† How worried are you about assisting in labour and delivery if: • The woman is living with HIV? • The woman's HIV status is unknown?	Not applicable.
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?** • People living with HIV could have avoided HIV if they wanted to • People living with HIV should feel ashamed of themselves • **I would be ashamed if someone in my family were infected with HIV**	Do you agree or disagree with the following statement: • People think that having HIV is shameful and they should not be associated with me
Legal and policy environment	Further development needed. Currently national governments have to report whether they have an anti-discrimination policy and whether they have incorporated stigma into their national plans for addressing HIV.	My health facility has policies to protect HIV-positive patients from discrimination I will get in trouble at work if I do not follow the policies to protect patients living with HIV Since I have been working at my institution, I have been trained in protecting the confidentiality of patients' HIV status	Have you heard of *[insert the best-known national law/policy or set of guidelines from your country]*, which protect(s) the rights of people living with HIV in this country? If yes, have you ever read or discussed the content of this law/policy/set of guidelines? In the last 12 months, have you been involved in any efforts to develop legislation, policies or guidelines related to HIV? Do you feel that you have the power to influence decisions in any of the following aspects…? • Legal/rights matters affecting people living with HIV • Local government policies affecting people living with HIV • National government policies affecting people living with HIV
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?**	**In your opinion, how hesitant are healthcare workers in this facility to take an HIV test due to fear of other people's reaction if the test result is positive result?** How hesitant are healthcare workers in this facility to work alongside a co-worker living with HIV regardless of their duties?	Did fears about how other people (for example, your friends, family, employer, or community) would respond if you tested HIV-positive make you hesitate to get tested? Yes/No 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

* These questions are currently being piloted by the Health Policy Project and partners and are thus illustrative at present.
** These questions are currently collected in The People Living with HIV Stigma Index tool (www.stigmaindex.org)
† Just one example is provided here; a complete questionnaire would list several different patient care scenarios.
†† Just one example is provided here; a complete questionnaire would list several different situations.

DOMAIN	GENERAL POPULATION	HEALTHCARE WORKERS*	PEOPLE LIVING WITH HIV**
Internalized stigma ‡‡	Not applicable.	Not applicable.	**In the last 12 months, have you experienced any of the following feelings because of your HIV status?** • **I feel ashamed** • **I feel guilty** • **I blame myself** • **I blame others** • **I have low self-esteem** • **I feel I should be punished** • **I feel suicidal**
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 talking badly about people living with or thought to be living with HIV**	See parallel questions under 'experienced stigma'
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 assumed to be HIV positive because you care for with patients living with HIV	In the last 12 months, how often have you been aware of being gossiped about because of your HIV status? In the last 12 months, how often have you been excluded from social gatherings or activities?‡
Discrimination (inside legal purview)	Do you think children living with HIV should be able to attend school with children who are HIV negative? In your opinion, if a female teacher has HIV but is not sick, should she be allowed to continue teaching in the school?	I would never test a patient for HIV without informed consent. No matter my views or feelings, it is my professional responsibility to maintain the confidentiality of patients living with HIV. *To assess key population stigma:* I would prefer not to provide services to: • People who inject illegal drugs • Men who have sex with men • Sex workers • Transgender people • Women who have sex with women • Migrants For each of the key populations listed, there is a follow-up question: I strongly agree/agree because of the following reasons: (Please check all reasons that apply) • They put me at higher risk for disease • This group engages in immoral behaviour • I have not received training to work with this group • I am worried that people will think I am part of this group	**In the last 12 months, how often have you been denied health services, including dental care, because of your HIV status?** Was the decision to be tested for HIV up to you? • Yes, I took the decision myself to be tested (i.e. it was voluntary) • I took the decision to be tested, but it was under pressure from others • I was made to take an HIV test (coercion) • I was tested without my knowledge • I only found out after the test had been done *To assess key population stigma:* If you experienced stigma and/or discrimination for reasons other than your HIV status, please choose one category that best explains why you felt you were stigmatised and/or discriminated against. • Sexual orientation (men who have sex with men, gay or lesbian, transgender) • Sex worker • Injecting drug user • Refugee or asylum seeker • Internally displaced person • Member of an indigenous group • Migrant worker • Prisoner • None of the above – an(other) reason(s)
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 last 12 months, have you confronted, challenged or educated someone who was stigmatising and/or discriminating against you?** In the last 12 months, have you supported people living with HIV? If yes, what types of support did you provide? • Emotional support • Physical support • Referral to other services

‡ 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.

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

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)
- internalized 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).[vii]

Specific measures for research and evaluation

Table 1 presents illustrative questions that can be asked to assess each domain of stigma by target population (general population, healthcare workers and people living with HIV). If possible, researchers should assess all conceptual domains of HIV stigma that are relevant to their target population in order to understand HIV stigma and discrimination and to measure the impact of specific stigma-reduction activities on the stigmatization process. Additional questions are available for each domain.[vi] Where possible, researchers should include several questions per domain, in order to develop 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. For example, ask community members about their perceptions of stigmatising behaviours towards people living with HIV in the community, but ask people living with HIV about their actual experiences of stigma.

Now that validated measures are available to assess most domains of HIV-related stigma, it is critical that researchers utilize them to examine rigorously the relationship between stigma-reduction efforts and HIV outcomes. Assessing only one domain of stigma leads to inconsistent and incomplete evidence about the success or failure of stigma-reduction efforts. As development funding shrinks and "more strategic AIDS investments" are demanded[x], strong evidence is needed of the link between stigma reduction and positive HIV and health outcomes, to ensure that countries include stigma reduction as a key component of national HIV strategies.

For studies in which stigma-reduction is not the main aim, but where researchers want to measure the influence of stigma on HIV-related outcomes, it is possible to add two or three survey questions on HIV stigma. For surveys among the general population, key domains to include are: fear of infection, social judgment and perceived stigma. Among healthcare workers, social judgment, perceived and experienced stigma should be assessed. In high prevalence settings, the questions assessing anticipated stigma among the general population and health care workers will provide an estimate of the influence of stigma on uptake of HIV testing. For surveys among people living with HIV, key domains for inclusion are: internalized stigma, discrimination and resilience. Suggested questions for each domain are highlighted in colour in Table 1.

Additional research needed

Research is needed to develop and test measures to:

- assess whether the policy environment reinforces or challenges stigma (existing measures assess only the presence and awareness of laws and polices related to people living with HIV and key populations)
- capture other aspects of the regulatory environment, such as the level of representation of people living with HIV and affected populations in governance structures and the inclusion of sensitivity and stigma-reduction training in curricula for medical students, teachers, media and police
- assess resilience among people who experience HIV-related stigma and discrimination
- assess the comparative impact of multi-faceted interventions that address the intersection of HIV stigma with other stigmas affecting key populations (more effective, according to initial studies, for example of drug-use and HIV in Vietnam[viii])

Appropriate analytical methods are needed to compare and interpret data from across 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 [ii, iv, viii-ix] 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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