STRIVE
Tackling the structural drivers of HIV

HIV-related stigma and discrimination

TECHNICAL BRIEF
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What have we learned?

Research confirms that reducing HIV-related stigma is critical to the success of prevention, care and treatment efforts.

A disparity of measures of stigma had previously hindered progress in the field, but a practical framework and validated measures of HIV-related stigma and discrimination are now available for national monitoring and research efforts. The Global HIV Stigma and Discrimination-reduction Framework conceptualises how stigma functions, how it can be measured and where to intervene. The Demographic Health Survey (DHS) and the US Center for Disease Control's Behavioral Surveillance Survey have now included key questions from this framework, with significant implications for research, programming and regulations.

STRIVE and ICRW's systematic review of stigma reduction programmes identifies and compares successful interventions – including those aimed at achieving population-level impact – that are available and ready to be up scaled. One key approach is to secure and enforce the human rights of people living with or particularly vulnerable to HIV (including men who have sex with men, sex workers, health care workers and injecting drug users). Removing human rights-related barriers to HIV prevention, care and treatment services is critical and can have a positive impact on HIV-related health outcomes.

What is the issue?

Stigma is a human rights infringement[1] and is linked to poor physical and mental health outcomes[2,3]. Stigma continues to be experienced across the globe and disproportionately affects the most vulnerable populations[4]. In the context of HIV, it is important to mitigate the effects of stigma and discrimination because they hamper efforts to prevent new HIV infections and engage people living with HIV in care and treatment[5]. Stigma is a documented barrier to HIV testing and retention in care, as well as uptake of and adherence to antiretroviral therapy. A broad mandate to reduce stigma and discrimination exists, as HIV-related stigma reduction is a key priority in the US government's PEPFAR Blueprint for Achieving an AIDS-Free Generation, in the Joint United Nations Programme on HIV and AIDS (UNAIDS) HIV investment framework[6,7] and in the UN's Sustainable Development Goals (SDGs).

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. Additionally, a large body of research has been conducted to conceptualise HIV stigma and explore its forms, contexts and consequences, but the sheer number and diversity of questions and scales used in stigma research over the years has made it difficult to compare findings across contexts.

Methodologies

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[8]. 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.

Recommendations

Now that validated measures are available to assess most of the domains of HIV-related stigma and discrimination among the general population, health care workers and people living with HIV, it is critical that researchers utilise these measures to rigorously examine the relationship between efforts to reduce stigma and discrimination and HIV outcomes.

Interventions

STRIVE recommends:

- integrating the Global HIV Stigma and Discrimination-reduction Framework into national HIV responses and using it to guide programming and evaluation
- developing a research framework of human rights barriers to HIV prevention, care and treatment and standardised indicators
- funding for rigorous evaluations of human rights interventions should match the demand for rights-based and structural approaches

Research

STRIVE recommends:

- consistently using globally relevant, validated scales of HIV-related stigma and discrimination
- comparing the effectiveness of different HIV-related stigma-reduction strategies, including peer-led approaches
- assessing the influence of HIV-related stigma reduction on behavioural and biomedical outcomes
- examining the intersection of HIV stigma with other stigmas (those based on gender, profession, race, sexuality and so on)
- examining the gendered dynamics of stigma
- including measures of HIV-related stigma in biomedical prevention trials (such as parallel measures developed for the HPTN 071 (PopART) trial – a large-scale cluster-randomised trial of the impact of combination prevention, including universal HIV testing and intensified ART care, on population-level HIV incidence in 21 communities in South Africa and Zambia[9]
- analysing new HIV-related stigma indicators in the Demographic Health Survey (DHS) as country data becomes available and specifically examining gender differences
- conducting studies to compare the effectiveness of human rights programmes that target multiple socio-ecological levels

1 **Key finding:** A practical framework and validated measures of HIV-related stigma and discrimination are essential for national monitoring and research efforts.

Existing evidence

Extensive research has been conducted to conceptualise HIV-related stigma; explore its forms, contexts and consequences; and understand individual and community responses[10]. 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[11-13]. 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[14].

STRIVE findings

We developed a framework to inform monitoring and evaluation efforts and proposed a set of indicators to capture each stigma domain articulated in the framework[15]:

- actionable drivers and facilitators
- stigma 'marking'
- stigma manifestations

Factors that drive or facilitate HIV stigma 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. These factors are expressed through different stigma 'marking' – intersecting stigmas such as sexuality, drug use and race. This leads to a number of manifestations of HIV stigma such as discrimination and shame, which influence the outcomes and impacts of stigma in a given context.

We tested the framework in India in terms of its ability to inform stigma-reduction interventions with a range of populations throughout the country[16]. To be able to characterise HIV-related stigma as a global driver of HIV infection, it is necessary to measure it more uniformly and accurately[17]. Accurate measurement and identification will in turn inform more effective stigma-reduction programming.

2 **Key finding:** Reducing HIV-related stigma is critical to the success of prevention, care and treatment efforts, and successful interventions are available and ready to be scaled.

Existing evidence

HIV-related stigma and discrimination hamper efforts to prevent new HIV infections and engage people living with HIV in care and treatment[18-20]. Effective interventions to reduce HIV-related stigma and discrimination are crucial to the success of biomedical prevention[21,22]. HIV-related stigma reduction is a key priority in PEPFAR's Blueprint for Achieving an AIDS-Free Generation and UNAIDS' HIV investment framework[23,24] and in the SDGs.

STRIVE findings

Our systematic review of interventions showed that considerable progress has been made in the stigma-reduction field over the last decade. The number, geography and complexity of interventions have notably expanded. A very high percentage of studies that showed reductions in stigma were of high quality, which is a marked improvement from previous systematic reviews. However, critical challenges and gaps do remain that are impeding the identification of effective stigma-reduction strategies[25].

Current evidence is strongest for interventions with students, health workers and community members; and for interventions using counselling and structural approaches. Structural approaches encompass activities aimed at removing, reducing or altering for the better those structural factors that influence the stigmatisation process. Along with laws that criminalise HIV[26], examples include hospital or workplace polices that institutionalise the discrimination of people living with HIV, for instance by:

- labelling beds
- imposing mandatory HIV testing prior to employment
- failing to provide supplies to allow health workers to practice universal precautions[27]

Structural interventions to reduce HIV-related stigma and discrimination address the underlying power structures that enable the stigmatisation process[28].

Nine articles reporting positive results from stigma-reduction interventions across a range of countries and contexts were included in a UNAIDS, National Institute of Mental Health (NIMH) and STRIVE-supported supplement of JIAS[29].

3 Key finding: Removing human rights barriers to HIV prevention, care and treatment services is critical and can have a positive impact on HIV-related health outcomes.

Existing evidence

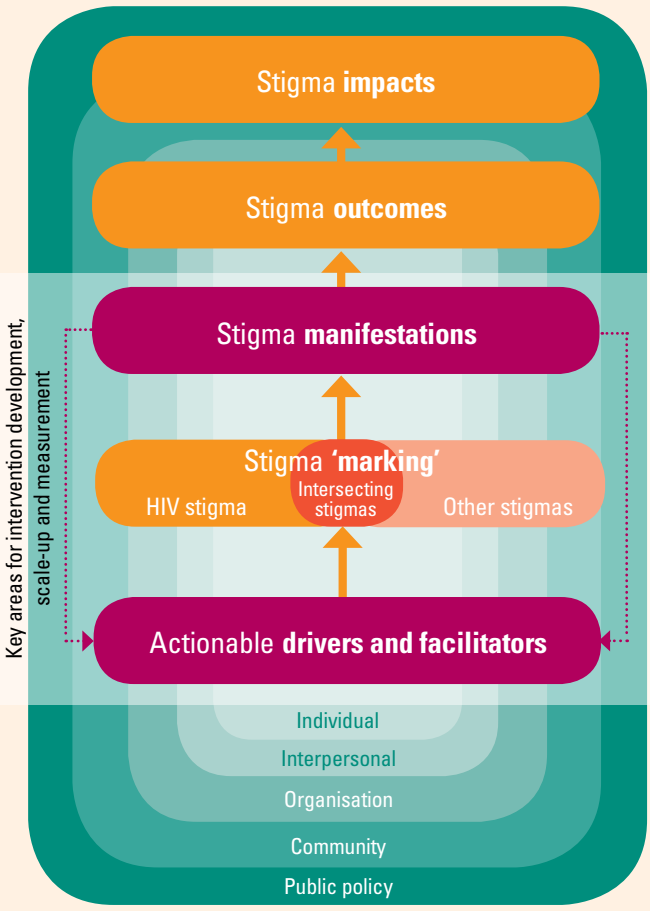
International consensus has now been established on the importance of respecting, protecting and promoting human rights and incorporating the principles of a rights-based approach in the HIV response.[30] Adoption of the Greater Involvement of People Living with HIV (GIPA) principle has meant further progress towards eliminating HIV-related stigma (UN member states, 2001). UNAIDS recommends seven key programme areas to reduce stigma and discrimination and increase access to justice for people living with and affected by HIV, including:

1. stigma and discrimination reduction programmes
2. HIV-related legal services
3. monitoring and reforming laws, policies and regulations
4. legal literacy programmes
5. sensitisation of lawmakers and law enforcement agents, including police, judges and elected representatives
6. training for health care providers on human rights and medical ethics related to HIV
7. reducing discrimination against women in the context of HIV

STRIVE findings

Since the UN's adoption of a human rights-based approach in 2003, human rights programmes to improve HIV-related health outcomes have evolved. Our systematic review identified 24 studies, targeting 15 populations in 15 countries. Diverse approaches are being employed, and the majority of studies found a positive influence on HIV-related outcomes. There is evidence in support of the inclusion of human rights interventions in a comprehensive response to HIV, yet critical gaps remain[31]. Efforts to evaluate the individual or public health benefits have not kept pace, leaving critical questions for implementation and scale-up at local, sub-national, national and regional levels.

Figure 1. Global HIV Stigma and Discrimination-reduction Framework



The measurement brief* concisely lays out:

- The key domains of HIV-related stigma and discrimination that need to be measured
- Specific questions for measuring stigma and discrimination across three populations: people living with HIV, the general population and health workers
- A framework for programme implementation and measurement
- Areas requiring further question development, testing and validation

STRIVE PUBLICATIONS

STRIVE and ICRW-ARO (2013). **Stigma reduction case studies – Local government, industry, female sex worker collectives, education, health care providers;** International Center for Research on Women, Delhi, India; London School of Hygiene & Tropical Medicine, London, UK; UNDP, New York, USA.

*Stangl, A., Brady, L., Fritz, K. **STRIVE Technical Brief: Measuring HIV stigma and discrimination;** International Center for Research on Women, Washington D.C., USA; 2012 (updated in 2018).

Stangl, A., Barre, I. (2017). **STRIVE Impact Case Study: Stigma framework and measurement;** International Center for Research on Women, Washington D.C., USA.

Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). **A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come?** *Journal of the International AIDS Society*. https://doi.org/10.7448/ias.16.3.18734

Hargreaves, J. R., Stangl, A., Bond, V., Hoddinott, G., Krishnaratne, S., Mathema, H., Hayes, R. (2016). **HIV-related stigma and universal testing and treatment for HIV prevention and care: Design of an implementation science evaluation nested in the HPTN 071 (PopART) cluster-randomized trial in Zambia and South Africa.** *Health Policy and Planning*, 31(10), 1342–1354. https://doi.org/10.1093/heapol/czw071

What impact have we had?

Our work has contributed to evidence-based influence on decision-making about programming, research and policies to reduce HIV-related stigma and discrimination.

- Between 2010 and 2011, with support from UNAIDS, ICRW led a global process with multiple collaborators to develop a measurement framework and test new indicators of HIV-related stigma.
- In 2012, with STRIVE support, ICRW adapted the measurement framework into a Global HIV Stigma and Discrimination-reduction Framework conceptualising how stigma functions, how it can be measured and where to intervene (Figure 1).
- The 2013 Journal of the International AIDS Society (JIAS) published a supplement of 13 papers on "Global Action to Reduce HIV-related Stigma and Discrimination", guest co-edited by Anne Stangl and Cynthia Grossman.
- Our 2013 systematic review of interventions, included in the JIAS supplement, has been cited more than 250 times to date. It incorporated two new intervention categories, biomedical and structural, that had been absent in previous reviews. It has been influential in pushing for better measurement practices and has called attention to the need to scale-up tested interventions.
- In 2015, seven standardised measures of stigma were included in the standard questionnaire of the Demographic Health Survey (DHS) that is currently implemented in 180 countries.
- Since 2015, the UN has required all member countries to report annually on discriminatory attitudes towards people living with HIV as part of Global AIDS Monitoring (GAM) for the United Nations Political Declaration on HIV and AIDS. The indicator is calculated using two of the new DHS measures on stigma.
- Since 2015, the US State Department has included an indicator on HIV-related stigma and discrimination in the Annual Human Rights Report. The indicator is calculated using two of the new DHS measures on stigma.
- In 2016, ICRW and STRIVE received an invitation from the US President's Advisory Council on HIV/AIDS (PACHA) to participate in a two-day meeting organised by the disparities committee. The stigma reduction framework was discussed as a foundation for PACHA recommendations to the US Secretary of Health and Human Services to influence national policy.

In collaboration with academic colleagues and bridging partners, particularly through the Stigma Action Network, STRIVE supported ICRW to achieve impact through:

- sustained engagement with key end-users of the framework and measures
- responding to strategic opportunities as they arose
- publicising the work on appropriate platforms, including blogs and STRIVE Learning Labs

Additionally, from the stigma ancillary study of the HPTN 071 (PopART) trial, a number of publications are in progress to explore if and how HIV-related stigma affected or was affected by the PopART intervention.[32]

REFERENCES

1. The Universal Declaration of Human Rights. (2011). The Universal Declaration of Human Rights. Retrieved from http://www.un.org/en/universal-declaration-human-rights/
2. Ahern, J., Stuber, J., Galea, S. (2007). Stigma, discrimination and the health of illicit drug users. *Drug and Alcohol Dependence*, 88(2–3), 188–196. https://doi.org/10.1016/j.drugalcdep.2006.10.014
3. Puhl, R. M., Heuer, C. A. (2010). Obesity stigma: Important considerations for public health. *American Journal of Public Health*, 100(6), 1019–1028. https://doi.org/10.2105/AJPH.2009.15949
4. King, E. J., Maman, S., Bowling, J. M., Moracco, K. E., Dudina, V. (2013). The influence of stigma and discrimination on female sex workers' access to HIV services in St. Petersburg, Russia. AIDS and Behavior, 17(8), 2597–2603. https://doi.org/10.1007/s10461-013-0447-7
5. Katz, I. T., Ryu, A. E., Onuegbu, A. G., Psaros, C., Weiser, S. D., Bangsberg, D. R., Tsai, A. C. (2013). Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *Journal of the International AIDS Society*. https://doi.org/10.7448/ias.16.3.18640
6. Department of State. (2012). PEPFAR Blueprint :Creating an AIDS-free Generation. Department of State.
7. UNAIDS. (2014). A new investment framework for the global AIDS response, 2019–2020.
8. Hargreaves, J. R., Stangl, A., Bond, V., Hoddinott, G., Krishnaratne, S., Mathema, H., Hayes, R. (2016). HIV-related stigma and universal testing and treatment for HIV prevention and care: Design of an implementation science evaluation nested in the HPTN 071 (PopART) cluster-randomized trial in Zambia and South Africa. *Health Policy and Planning*, 31(10), 1342–1354. https://doi.org/10.1093/heapol/czw071
9. Hargreaves, J. R., Krishnaratne, S., Mathema, H., Lilleston, P. S., Sievwright, K., Mandla, N., Stangl, A. (2018). Individual and community-level risk factors for HIV stigma in 21 Zambian and South African communities: Analysis of data from the HPTN071 (PopART) study. AIDS, 32(6), 783–793. https://doi.org/10.1097/QAD.0000000000001757
10. Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS* (London, England), 22(Suppl 2), S67-79. https://doi.org/10.1097/01.aids.0000327438.13291.62
11. Earnshaw, V. A., Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS and Behavior*. https://doi.org/10.1007/s10461-009-9593-3
12. Nyblade, L. C. (2006). Measuring HIV stigma: existing knowledge and gaps. Psychology, Health & Medicine, 11(3), 335–345. https://doi.org/10.1080/13548500600595178
13. Zelaya, C. E., Sivaram, S., Johnson, S. C., Srikrishnan, A. K., Solomon, S., Celentano, D. D. (2008). HIV/AIDS stigma: Reliability and validity of a new measurement instrument in Chennai, India. *AIDS and Behavior*, 12(5), 781–788. https://doi.org/10.1007/s10461-007-9331-7
14. Nyblade, L., Jain, A., Benkirane, M., Li, L., Lohiniva, A. L., McLean, R., Thomas, W. (2013). A brief, standardized tool for measuring HIV-related stigma among health facility staff: results of field testing in China, Dominica, Egypt, Kenya, Puerto Rico and St. Christopher & Nevis. *Journal of the International AIDS Society*, 16(3 Suppl 2). https://doi.org/10.7448/IAS.16.3.18718 [doi]
15. Stangl, A., Brady, L., Fritz, K. (2012) (updated 2018). STRIVE Technical Brief: Measuring HIV stigma and discrimination. http://strive.lshtm.ac.uk/resources/technical-brief-measuring-hiv-stigma-and-discrimination
16. STRIVE and ICRW-ARO: Stigma reduction case studies – Local government, Industry, Female sex worker collectives, Education, Health care providers; International Center for Research on Women, Delhi, India; London School of Hygiene & Tropical Medicine, London, UK; UNDP, New York, USA; 2013. http://strive.lshtm.ac.uk/resources/stigma-reduction-case-studies
17. Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: how far have we come? *Journal of the International AIDS Society*. https://doi.org/10.7448/ias.16.3.18734
18. Deribe, K., Woldemichael, K., Wondafrash, M., Haile, A., Amberbir, A. (2008). Disclosure experience and associated factors among HIV positive men and women clinical service users in southwest Ethiopia. *BMC Public Health*, 8. https://doi.org/10.1186/1471-2458-8-81
19. Katz, op cit
20. Turan, J. M., Bukusi, E. A., Onono, M., Holzemer, W. L., Miller, S., Cohen, C. R. (2011). HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: Results from the MAMAS study. *AIDS and Behavior*, 15(6), 1111–1120. https://doi.org/10.1007/s10461-010-9798-5
21. Earnshaw, V. A., Bogart, L. M., Dovidio, J. F., Williams, D. R. (2013). Stigma and racial/ethnic HIV disparities: Moving toward resilience. *American Psychologist*, 68(4), 225–236. https://doi.org/10.1037/a0032705
22. Hargreaves, op cit.
23. Department of State, op cit.
24. UNAIDS, op cit.
25. Stangl et al, 2013, op cit.
26. UNAIDS (2005). HIV-Related Stigma, Discrimination and Human Rights Violations: Case studies of successful programmes. UNAIDS Best Practice Collection.
27. Nyblade, L., Stangl, A., Weiss, E., Ashburn, K. (2009). Combating HIV stigma in health care settings: What works? *Journal of the International AIDS Society*. https://doi.org/10.1186/1758-2652-12-15
28. Stangl et al, 2013, op cit.
29. Grossman, C. I., Stangl, A. L. (2013). Global action to reduce HIV stigma and discrimination. *Journal of the International AIDS Society*, 16(3 Suppl 2):18881. https://doi.org/10.7448/IAS.16.3.18881
30. El Feki, S., Avafia, T., Fidalgo, T. M., Divan, V., Chauvel, C., Dhaliwal, M., Cortez, C. (2014). The Global Commission on HIV and the Law: Recommendations for legal reform to promote sexual and reproductive health and rights. *Reproductive Health Matters*, 22(44), 125–136. https://doi.org/10.1016/S0968-8080(14)44807-9
31. Stangl, A, Singh, D, Windle, M, Sievwright, K, Footer, K, Iovita, A, Mukasa, S, Baral, S. A systematic review of human rights programs to improve HIV-related outcomes from 2003 to 2015: what do we know? *BMC Infectious Diseases* (in press).
32. Hargreaves et al, op cit.

More information: http://strive.lshtm.ac.uk/resources/technical-brief-measuring-hiv-stigma-and-discrimination

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STRIVE research consortium

A DFID-funded research programme consortium, STRIVE is led by the London School of Hygiene & Tropical Medicine, with six key research partners in Tanzania, South Africa, India and the USA. STRIVE provides new insights and evidence into how different structural factors – including gender inequality and violence, poor livelihood options, stigma, and problematic alcohol use – influence HIV vulnerability and undermine the effectiveness of the HIV response.

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