

STIGMA FRAMEWORK AND MEASUREMENT

SUMMARY

Tackling HIV-related stigma and discrimination is critical if we are to reduce and even end the AIDS epidemic. Effective stigma reduction requires an accurate understanding of the different ways in which it operates and standardised measures to identify it and design and monitor efforts to address it. The International Center for Research on Women (ICRW), a partner in the STRIVE consortium, led collaborative efforts to develop a global stigma-reduction framework and test standardised measures of HIV stigma and discrimination. Since the publication of the framework in 2012, ICRW has led efforts to ensure adoption of the framework by key agencies. Questions capturing key stigma domains articulated in the framework are now included in the standard survey of the Demographic and Health Survey (DHS)¹. As a result, stigma data are now reported annually by all UN member countries through the Global AIDS Monitoring process and also in the U.S. State Department's Annual Human Rights report since 2015².

STRIVE and ICRW published a technical brief with recommendations on how to apply the global stigma reduction framework and to measure HIV stigma and discrimination among the general population, healthcare workers and people living with HIV. The brief is designed to support calls for a standardised framework in order to improve understanding of and action on HIV-related stigma. The brief outlines:

- the key domains of HIV related stigma and discrimination that need to be measured
- specific questions for measuring stigma and discrimination
- a framework for programme implementation and measurement
- areas requiring further question development, testing and validation


With ongoing analysis, publication and engagement, ICRW has contributed to and sometimes led efforts to ensure global guidance on standardised measurement.

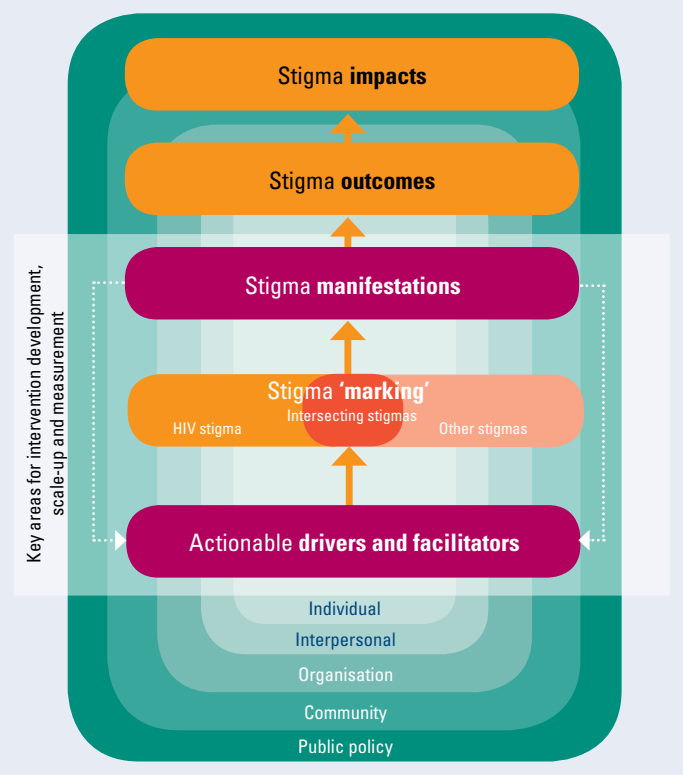
WHAT IS THE ISSUE?

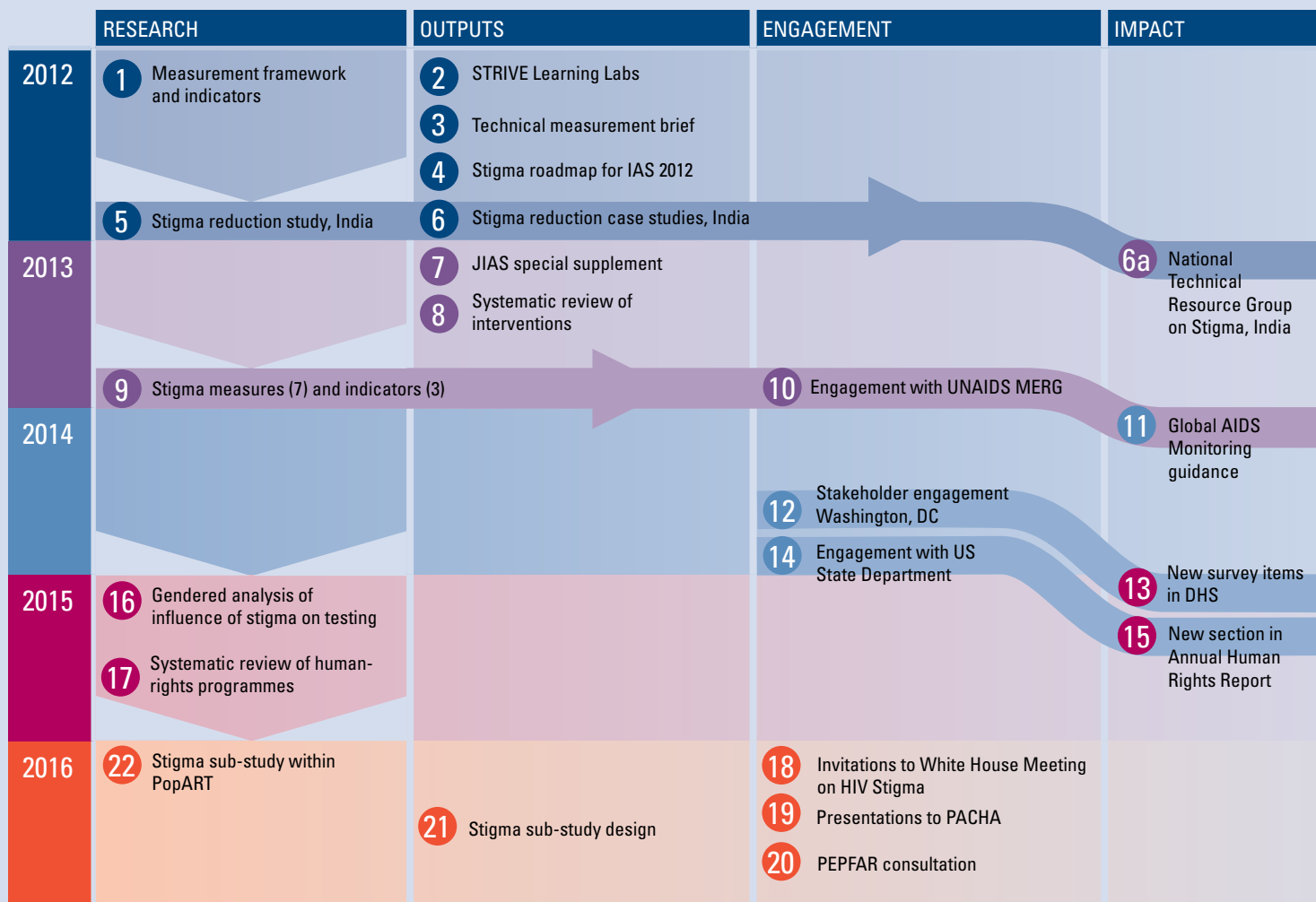
More than three decades into the HIV epidemic, stigma and discrimination continue to impede global efforts to 'end AIDS in a generation'³⁻⁵. HIV-related stigma is a commonly cited barrier to HIV testing^{6,7}, disclosure to partners^{7,9}, engagement in biomedical prevention approaches^{6,7,9,10} and medication adherence¹¹, particularly for vulnerable and key populations^{12,13}. In response to this evidence, stigma-reduction is now a key priority in PEPFAR's Blueprint for Achieving an AIDS-free Generation³ and the UNAIDS' HIV investment framework¹⁴. UNAIDS has highlighted that our ability to challenge inequality, stigma and marginalisation in the context of HIV is also critical to the success of the Sustainable Development Goals and the principle of 'leaving no one behind'.¹⁵

ADDRESSING THE ISSUE

To be able to characterise and tackle stigma as a global driver of HIV infection, it is necessary to measure it more uniformly and accurately. 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 Stigma Reduction Framework conceptualising how stigma functions, how it can be measured and where to intervene (Figure 1).

 **Figure 1:** Reducing HIV stigma and discrimination: A framework for programme implementation and measurement





1 Measurement framework and indicators

ICRW/Stigma Action Network/UNAIDS/STRIVE

How stigma functions, how to measure it and where to intervene

2 STRIVE Learning Labs

ICRW/STRIVE

Two one-hour webinars, recorded and available online: Stigma and HIV Overview; Reducing HIV Stigma

3 Technical measurement brief

ICRW/STRIVE

Concise accessible outline of domains of HIV stigma and discrimination; a framework for stigma reduction and measurement; survey questions to measure stigma and discrimination – to guide researchers in the study of HIV-related stigma and

discrimination (either as the main focus of research or as an element within related studies)

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

4 Stigma roadmap for IAS 2012

ICRW/ Stigma Action Network/STRIVE

Guide (print and online) to stigma-related presentations and events at the 2012 International AIDS Conference, Washington, DC

5 Stigma reduction study, India

ICRW-ARO/UNDP

Evaluating the impact of the stigma framework in action, adapted for specific populations (healthcare, education, sex-worker collectives, local government, industry)

6 Stigma reduction case studies, India

ICRW-ARO/STRIVE

Set of accessible case studies (print and online) outlining the process and impact of stigma-reduction activities with five populations, plus an overview report

<http://strive.lshtm.ac.uk/resources/stigma-reduction-case-studies>

6a National Technical Resource Group on Stigma, India

ICRW-ARO

Appointment of Regional Director, Dr Ravi Verma, to lead newly formed stigma TRG to advise the National AIDS Control Organisation (NACO), as detailed in a separate impact case study



required to report on one of the three indicators (discriminatory attitudes)

12 Stakeholder engagement in Washington, DC

ICRW/STRIVE

Meetings with the US Global AIDS Coordinator and Special Representative for Global Health Diplomacy (OGAC), USAID, Macro International and UNAIDS to build support for including 7 new measures on stigma the revised Demographic and Health Survey (DHS) standard questionnaire

13 New survey items in DHS

ICRW/STRIVE

Adoption of new survey items for inclusion in standard DHS module, implemented in 180 countries

14 Engagement with US State Department

ICRW/STRIVE

Meeting to present evidence in support of the inclusion of an indicator on HIV-related stigma and discrimination in the Annual Human Rights Report

15 New section in Annual Human Rights Report

US State Department

One indicator on discriminatory attitudes, using two of the new DHS measures approved for inclusion; 50 countries included the indicator in a new section specific to HIV-related stigma and discrimination in the 2015 HR report

16 Gendered analysis of influence of stigma on testing

ICRW/STRIVE

Further analysis of data from ICRW's general population survey in Rwanda that piloted the new stigma measures

17 Systematic review of human-rights programmes

ICRW/STRIVE/UNAIDS/Open Societies Foundation

Impact of human rights programming on improving HIV-related outcomes

18 White House Meeting on HIV Stigma

ICRW/LSHTM/STRIVE

Panel facilitation and participation by Drs Anne Stangl (ICRW) and James Hargreaves (LSHTM) in two-day meeting on 'Research for a Robust Response' organised by the US Office of National AIDS Policy and the National Institutes of Mental Health



19 Presentations to PACHA

ICRW/STRIVE

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 discussed as a foundation for PACHA recommendations to the US Secretary of Health and Human Services to address HIV-related stigma and discrimination could PACHA make; additional presentation of the framework by Dr Stangl to the full PACHA meeting

20 PEPFAR consultation

ICRW/STRIVE

Participation in two-day Stigma and Discrimination Expert Consultation of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) to discuss a strategy to address stigma and discrimination within PEPFAR's contribution to the global HIV response

21 Stigma sub-study design

ICRW/LSHTM/STRIVE

Mixed-method evaluation nested within PopART (HPTN 071)

<http://strive.lshtm.ac.uk/resources/hiv-related-stigma-and-universal-testing-and-treatment-hiv-prevention-and-care-design>

22 Stigma sub-study within PopART

ICRW/LSHTM/STRIVE

Evaluating the extent to which HIV-related stigma affects and is affected by the implementation of PopART, a comprehensive combination HIV prevention intervention including a universal test and treatment approach

7 JIAS special supplement

ICRW/UNAIDS/NIMH/STRIVE

Co-introduced by ICRW's Dr Anne Stangl, the Journal of the International AIDS Society (JIAS) supplement of 13 papers on "Global Action to Reduce HIV-related Stigma and Discrimination"

<http://strive.lshtm.ac.uk/resources/global-action-reduce-hiv-stigma-and-discrimination-jias-special-edition>

8 Systematic review of interventions

ICRW/STRIVE

Included in the JIAS supplement, a paper co-authored by Stangl covering interventions between 2002 and 2013 in order to assess "How far have we come?"

<http://strive.lshtm.ac.uk/resources/systematic-review-interventions-reduce-hiv-related-stigma-and-discrimination-2002-2013-how>

9 Stigma measures (7) and indicators (3)

ICRW/UNAIDS/Global Stigma and Discrimination Indicator Working Group
Developed and tested 2011–2014

10 Engagement with UNAIDS MERG

ICRW and colleagues/STRIVE

Presenting 7 stigma measures and 3 stigma indicators to UNAIDS' Monitoring and Evaluation Reference Group, for potential inclusion in global monitoring

11 Global AIDS Monitoring guidance

GAM

New indicators approved and included in GAM guidance; all UN member countries

IMPACT

Key stakeholders at global level have adopted standardised measures of stigma and discrimination. As detailed on the timeline, STRIVE partner ICRW contributed significantly to achieving this impact.

- 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. Fifty country reports included this indicator in 2015.

How did STRIVE achieve impact?

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
- presentations to key change agents including US government, UN and the DHS
- responding to strategic opportunities as they arose
- publicising the work on appropriate platforms, including blogs and STRIVE Learning Labs

CONCLUSION

As a result of national and global dissemination efforts by ICRW, the global stigma-reduction framework and measures are now influencing decision-making about programming, research and policies to reduce HIV-related stigma and discrimination. The framework sets out how stigmatisation operates, in practice, and this resonates with a variety of audiences, from advocates to policy makers to development partners. As a result, it has fostered excitement about practical action to reduce HIV-related stigma and discrimination globally. The systematic collection of data on stigma contributes, in turn, to improved programme design to address the structural drivers of HIV-related stigma and to measure the impact of interventions.

References

1. DHS. *Demographic and Health Surveys Model Woman's Questionnaire*. 2016; Available from: <http://dhsprogram.com/What-We-Do/Survey-Types/DHS-Questionnaires.cfm>.
2. USSD. *U.S. State Department. Human Rights reports*. 2016; Available from: <https://www.state.gov/j/drl/rls/hrrpt/index.htm>.
3. PEPFAR. *PEPFAR Blueprint: Creating an AIDS-free Generation*. 2012; Available from: <https://www.pepfar.gov/documents/organization/201386.pdf>.
4. UNAIDS. *Getting to zero: 2011–2015 strategy*. 2010; Available from: http://www.unaids.org/sites/default/files/sub_landing/files/JC2034_UNAIDS_Strategy_en.pdf.
5. UNAIDS. *Fast-track: ending the AIDS epidemic by 2030*. 2014; Available from: http://www.unaids.org/sites/default/files/media_asset/UNAIDS_FastTrack_highlights_en.pdf.
6. Turan, J.M., et al., HIV/AIDS stigma and refusal of HIV testing among pregnant women in rural Kenya: results from the MAMAS Study. *AIDS Behav*, 2011. 15(6): p. 1111-20.
7. Karim, Q.A., Meyer-Weitz, A., Mboyi, L., Carrara, H., Mahlase, G., Frohlich, J. A., & Abdool Karim, S. S.. The influence of AIDS stigma and discrimination and social cohesion on HIV testing and willingness to disclose HIV in rural KwaZulu-Natal. South Africa. *Global Public Health*, 2008. 3(4): p. 351-365.
8. Tsai, A.C., et al., Internalized Stigma, Social Distance, and Disclosure of HIV Seropositivity in Rural Uganda. *Annals of Behavioral Medicine*, 2013. 46(3): p. 285-294.
9. Deribe, K., et al., Disclosure experience and associated factors among HIV positive men and women clinical service users in Southwest Ethiopia. *BMC Public Health*, 2008. 8: p. 81.
10. Brou, H., et al., When do HIV-Infected women disclose their HIV status to their male partner and why? A study in a PMTCT programme, Abidjan. *Plos Medicine*, 2007. 4(12): p. 1912-1920.
11. Katz, I.T., et al., Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis. *J Int AIDS Soc*, 2013. 16(3 Suppl 2): p. 18640.
12. Mahajan, A.P., et al., Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*, 2008. 22 Suppl 2: p. S67-79.
13. Stahlman, S., et al., The Prevalence of Sexual Behavior Stigma Affecting Gay Men and Other Men Who Have Sex with Men Across Sub-Saharan Africa and in the United States. *JMIR Public Health Surveill*, 2016. 2(2): p. e35.
14. Schwartlander, B., et al., Towards an improved investment approach for an effective response to HIV/AIDS. *Lancet*, 2011. 377(9782): p. 2031-41.
15. UNAIDS. *Leaving no one behind in the implementation of the new SDGs*. 2015; Available from: http://www.unaids.org/en/resources/presscentre/featurestories/2015/september/20150925_Interactive_dialogue.

Acknowledgements

Anne Stangl wrote this impact case study, with input from Iman Barre, Annie Holmes and Mitzy Gafos.

Suggested citation

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

STRIVE is supported by UKaid from the Department for International Development. However, the views expressed do not necessarily reflect the department's official policies.

