Measuring Stigma: Where Do We Go From Here?

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Prejudices and negative attitudes directed towards people living with HIV have very real consequences: Stigma discourages people from getting tested for HIV, sharing their HIV positive status with loved ones, and seeking care and sticking to treatment.

Yet in the early years of the HIV epidemic, it was thought that the stigma surrounding HIV was too abstract to be measured. And if it couldn’t be measured, it couldn’t be addressed.

I was first exposed to the impact and opacity of stigma in 2000. I was working on a study exploring community perceptions of programs to prevent mother-to-child transmission (PMTCT) of HIV in Botswana and Zambia. We didn’t ask directly about stigma, but it became a repeated theme in interviews with women, men, community leaders, and health providers. At the time, we couldn’t effectively understand and respond to these findings – a robust body of knowledge on HIV-related stigma just didn’t exist.

Seventeen years later, things have changed. We have more tools than ever to understand, measure, and monitor stigma and its impact on people living with HIV. There are also effective interventions and programs designed to lessen stigma’s negative impact on people living with HIV.

On the heels of Zero Discrimination Day, a day to celebrate diversity and reject discrimination, I presented at a White House meeting on HIV-related stigma. The Office of National AIDS Policy, National Institutes of Mental Health and the NIH Office of AIDS Research convened the meeting to discuss how to translate research into action that will reduce stigma and ultimately ensure more people are successfully tested, cared for, and treated.

Measuring stigma is critical to not only understand its scale and dimensions, but also to design effective programs and evaluate progress. I presented a rapid-scan overview of stigma measurement over the past two decades, highlighting changing trends in the populations among which stigma is measured, where studies were conducted, and the types of stigma measured.

My findings showed that a rapid growth in stigma measurement studies that use validated instruments and span multiple geographies has demonstrated that stigma measurement is both feasible and attainable. Most importantly, the common themes and barriers that emerge in these studies spanning the globe tell us the standardization of measurement tools is possible.
A healthcare worker stigma measurement tool developed under the USAID-funded Health Policy Project is one example. Its five key measurement areas provide a globally-standardized questionnaire to measure stigma and discrimination in health facilities, which can then help facilitate routine monitoring of HIV-related stigma, as well as the expansion and improvement of programming and policies in health facilities.


Now we have the opportunity to take stigma measurement to the next level:

- **We must scale up and standardize** the measurement of stigma and also **integrate stigma** into other measurement tools such as quality of care assessments. **Brevity is key here**; simplicity and clarity will help ensure tools can be used in practical settings across a range of contexts.
- **We must expand what we measure**, investigating the multiple types of stigma that exist – such as stigma that is experienced, perceived, or anticipated – and how these different stigmas can affect prevention, care, and treatment. There is also a gap in understanding how stigma affects adolescents with HIV, given that in 2013 alone **120,000 adolescents** [PDF 7.96 MB] died from AIDS-related causes. We must also increase study on 'layered' stigma – meaning intersecting stigmas faced by individuals who are part of multiple marginalized groups, such as sex workers living with HIV.
- **And finally, stigma measurements must be used to inform the response to HIV, as well as policies and laws.** For example, stigma goals and targets must be integrated into national HIV strategies, with stigma and discrimination indicators included in national monitoring and evaluation frameworks.

Stigma isn’t abstract; it’s very, very real. And it affects not just people living with HIV, but their families, those who care for them, and those who may be at heightened risk for exposure to HIV.

We have come a long way to measure and understand stigma, but we have much further to go to ensure our findings drive real action by governments and donors to
create the programs, policies, and practices that will improve health outcomes and save lives.