

# Frameworks and Measures for HIV-Related Internalized Stigma, Stigma and Discrimination in Healthcare and in Laws and Policies: A Systematic Review

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## BACKGROUND

HIV-related stigma and discrimination constitute significant barriers to HIV responses around the world, and can occur at many levels.

There is strong commitment to eliminating HIV-related stigma at global, national, and local levels.

Interventions exist that are designed to mitigate against the experience and harmful impacts of stigma.

Yet, learning across interventions can be hindered, in part, by the multitude of frameworks and measures in use to assess stigma's different dimensions.

## KEY QUESTION

Which conceptual frameworks and measures have been proposed to assess each of the three stigma & discrimination domains?

## METHODS

### ANALYTIC FRAMEWORK

Established working definitions of the concepts of HIV-related stigma and discrimination grounded in existing literature.

### SEARCH STRATEGY

Databases mined for primary research studies; Websites targeted for grey literature; Systematic reviews for reference-mining

### DATA ABSTRACTION

Addresses HIV-related internalized stigma, stigma and discrimination in healthcare, or in laws and policies.

### ELIGIBILITY CRITERIA

### CRITICAL APPRAISAL

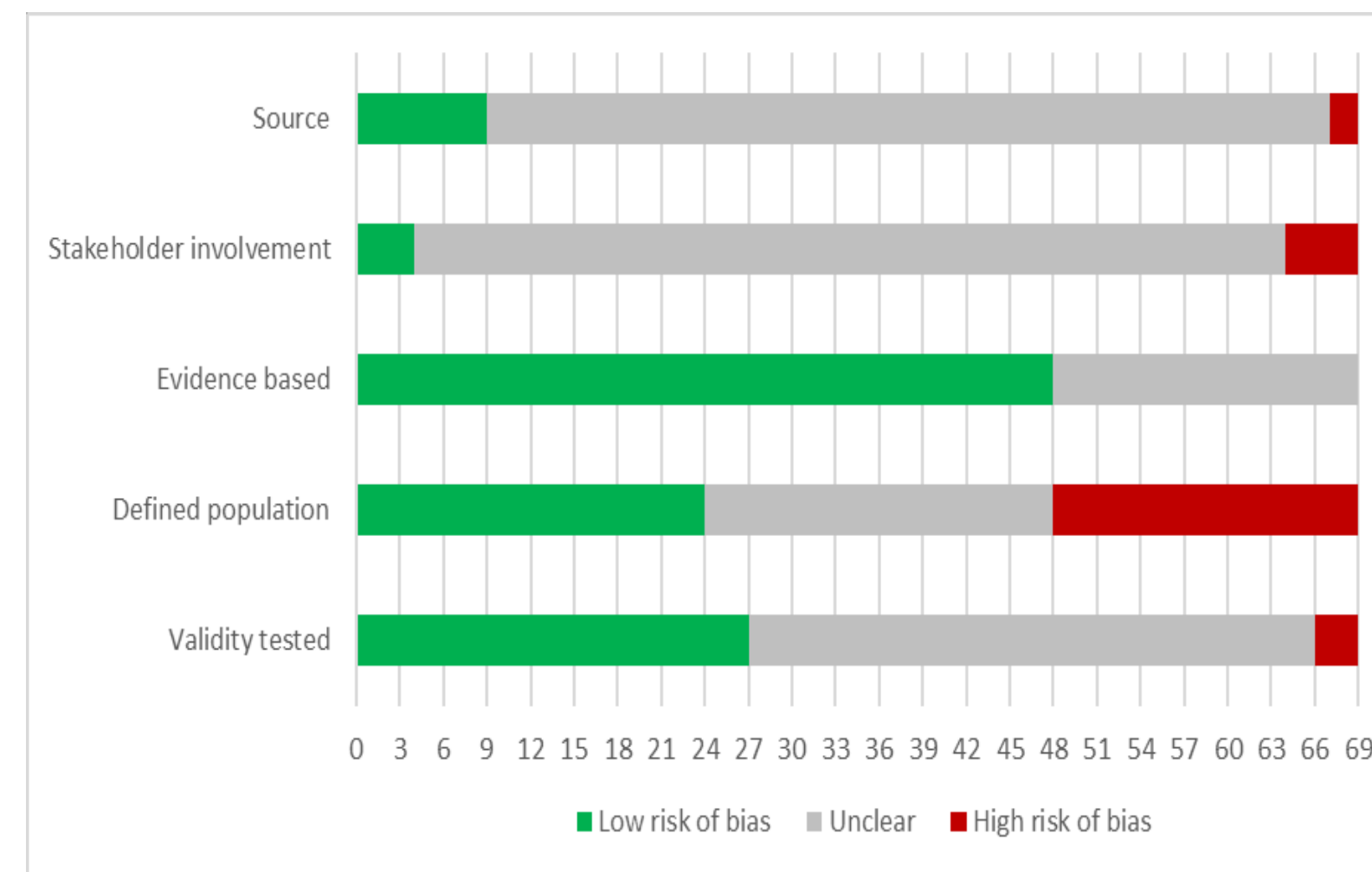
### NARRATIVE SYNTHESIS

Focuses on frameworks and measures that address more than one of our three focus domains.

## RESULTS

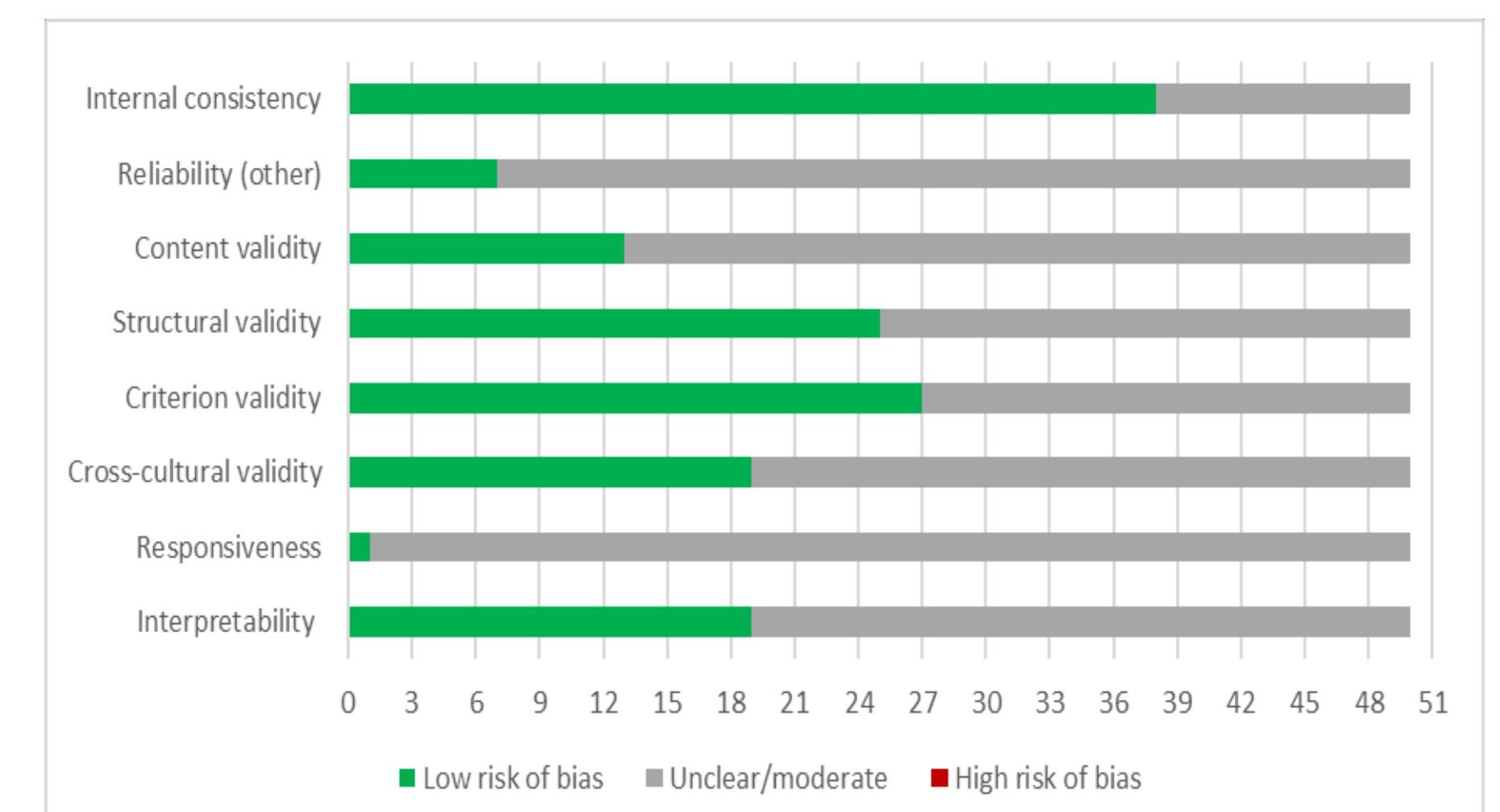
Sixty-nine frameworks and 50 measures met the inclusion criteria.

Figure 1 summarizes the critical appraisal of the identified frameworks.



Notes: Source: Assesses whether the framework was published or endorsed by a relevant organization; Stakeholder involvement: Assesses whether the framework was established with relevant stakeholder input; Evidence based: Assesses whether the components of the frameworks were based on a systematic literature review or empirical data; Defined population: Assesses whether the population the framework is designed to address is clearly reported; Validity tested: Assesses whether the validity of the framework was assessed (e.g., goodness of fit to empirical data assessed, framework applied in different contexts)

Figure 2 summarizes the critical appraisal of all 50 identified measures.



Internal consistency: Assesses whether the internal consistency of the scale was reported and it was acceptable (e.g., Cronbach's alpha >0.70); Reliability (other): Assesses whether other measures of reliability were reported and results were acceptable (e.g., test-retest reliability, rater agreement); Content validity: Assesses whether the content of the measure was assessed for validity and the results were acceptable (e.g., face validity rated, expert review); Structural validity: Assesses whether the structural validity of the measure was assessed and the results were acceptable (e.g., through factor analysis); Criterion validity: Assesses whether convergent or discriminant validity to external criteria or other measures was determined and the results were acceptable; Cross-cultural validity: Assesses whether measures were taken to ensure cross-cultural validity (e.g., translation and back-translation of items; measure exists in multiple languages or was used in multiple geographic settings); Responsiveness: Assesses whether the measure demonstrated sensitivity to change (e.g., scores changed after an intervention as predicted); Interpretability: Assesses whether guidance is reported on the interpretation of scores (e.g., minimal clinical difference)

Seventeen frameworks and ten measures addressed at least two of our focus domains, with least attention to stigma and discrimination in law and policy.

### Frameworks addressing multiple stigma domains

Author, year	Scope and Aim/Purpose
<b>Framework name</b>	
<b>Domain</b>	
<b>Terminology</b>	
<b>Empirical/Categorical</b>	
<b>Frameworks addressing internalized stigma, stigma and discrimination in healthcare and in law</b>	
Stangl, 2019	<b>Scope:</b> Health-related stigmas <b>Framework name:</b> The Health Stigma and Discrimination Framework <b>Domain:</b> Internalized stigma, Stigma or discrimination in healthcare settings, Stigma or discrimination in law <b>Terminology:</b> Stigma, Discrimination <b>Conceptual model</b>
UNAIDS, 2017	<b>Scope:</b> Stigma and discrimination as health care service barriers <b>Framework name:</b> Effects of Stigma and Discrimination on Health Care Access for Prevention, Testing and Treatment <b>Domain:</b> Internalized stigma, Stigma or discrimination in healthcare settings, Stigma or discrimination in law <b>Terminology:</b> Stigma, Discrimination <b>Conceptual model</b>
Woodgate, 2017	<b>Scope:</b> Stigma and discrimination on the lives of Indigenous people who contracted HIV in their youth (i.e. 15-29 years of age) who are HIV positive within their various settings in Manitoba, Canada <b>Framework name:</b> Social Ecological Framework <b>Domain:</b> Internalized stigma, Stigma or discrimination in healthcare settings, Stigma or discrimination in law <b>Terminology:</b> Stigma, Discrimination <b>Conceptual model</b>
	<b>Aim/Purpose:</b> Developing a better structural understanding of the impacts of stigma and discrimination on the lives of Indigenous people who are HIV positive

### Measures addressing multiple stigma domains

ID	Stigma / discrimination subtype	Target population	Scale structure	Reported psychometric characteristics
Framework title and type	Framework	Surveyed participants	Number of items	Answer mode
Domain	Framework			
<b>Measures addressing internalized stigma, stigma and discrimination in healthcare and in law</b>				
Biemba, 2019	<b>Stigma subtype addressed:</b> Internalized, perceived, enacted <b>Underlying framework:</b> NA	<b>Target population:</b> People living with HIV <b>Surveyed participants:</b> People living with HIV and health workers	<b>Scale structure:</b> Both quantitative and qualitative questions, narrower and modified form of legal environment assessment; questions separate for people living with HIV and health workers <b>Number of items:</b> NR <b>Answer mode:</b> Rating scale, Dichotomous scale, Free text, Answer mode varies by item	<b>Reliability:</b> NA <b>Validity:</b> NA
Friedland, 2020	<b>Stigma subtype addressed:</b> Internalized <b>Underlying framework:</b> Adapted from the original People Living with HIV (PLHIV) Stigma Index	<b>Target population:</b> People living with HIV <b>Surveyed participants:</b> People living with HIV at least 18 years old who had known their status for at least 1 year	<b>Scale structure:</b> Sections consist of: disclosure, your experience of stigma and discrimination, internalized stigma and resilience, interactions with healthcare services, human rights and effecting change, stigma and discrimination experienced for reasons other than your HIV status, personal experience related to stigma/discrimination <b>Number of items:</b> 6 items <b>Answer mode:</b> Rating scale, Free text, Answer mode varies by item	<b>Reliability:</b> Good internal consistency (Cronbach's alphas for Cameroon, Senegal, and Uganda were 0.70, 0.65, 0.75) <b>Validity:</b> Cognitive interview respondents indicated that most questions were well understood and focus group participants said that the Stigma Index 2.0 addressed issues that were relevant to their lives, good construct validity

## DISCUSSION

Having comparable data is essential for tracking change over time within and between interventions. **The lack of common definitions and variability** in scope and structure of HIV-related frameworks and measures creates challenges in understanding what is being addressed and measured.

**Frameworks are more encompassing than measures**, bringing to attention the wide range of factors that influence experiences and outcomes.

**Many of the frameworks use variations of the socio-ecological framework** to capture relevant factors from the individual to environmental levels. However, very few operate across all levels.

### Internalized Stigma

Within **frameworks** that address internalized stigma, the most common associations are between internalized stigma and mental health or HIV-related clinical outcomes.

**Measures** varied in how internalized stigma was defined and evaluated.

### Stigma & Discrimination in Healthcare

Some **frameworks** focus exclusively on stigma and discrimination in healthcare while others include this as component of a broader HIV-related stigma framework.

Some **measures** of stigma and discrimination in healthcare are general, some capture something more specific, e.g. how stigma impacts decisions around childbearing among people living with HIV, and some also capture additional stigma.

### Stigma & Discrimination in Law & Policy

**Frameworks** are usually generic with laws and policies mentioned as part of the macro-system or structural factors within a socio-ecological model.

There is a dearth of **measures** relating to HIV stigma and discrimination in law and policy. This may be due to the complexity and sensitivity of measuring these topics and the extensive investment that would be required to do this effectively at scale.

## CONCLUSIONS

**With people living with HIV at the centre, more accurate frameworks and measures are needed that are broadly acceptable and will be widely used to help understand, measure and help mitigate the impact of different types of HIV-related stigma on people's health and quality of life.**