The People Living with HIV Stigma Index 2.0: generating critical evidence for change worldwide

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Objective(s): To describe the process of updating the People Living with HIV (PLHIV) Stigma Index (Stigma Index) to reflect current global treatment guidelines and to better measure intersecting stigmas and resilience.

Design: Through an iterative process driven by PLHIV, the Stigma Index was revised, pretested, and formally evaluated in three cross-sectional studies.

Methods: Between March and October 2017, 1153 surveys ($n = 377$, Cameroon; $n = 390$, Senegal; $n = 391$, Uganda) were conducted with PLHIV at least 18 years old who had known their status for at least 1 year. PLHIV interviewers administered the survey on tablet computers or mobile phones to a diverse group of purposively sampled respondents recruited through PLHIV networks, community-based organizations, HIV clinics, and snowball sampling. Sixty respondents participated in cognitive interviews (20 per country) to assess if questions were understood as intended, and eight focus groups (Uganda only) assessed relevance of the survey, overall.

Results: The Stigma Index 2.0 performed well and was relevant to PLHIV in all three countries. HIV-related stigma was experienced by more than one-third of respondents, including in HIV care settings. High rates of stigma experienced by key populations (such as MSM and sex workers) impeded access to HIV services. Many PLHIV also demonstrated resilience per the new PLHIV Resilience Scale.

Conclusion: The Stigma Index 2.0 is now more relevant to the current context of the HIV/AIDS epidemic and response. Results will be critical for addressing gaps in program design and policies that must be overcome to support PLHIV engaging in services, adhering to antiretroviral therapy, being virally suppressed, and leading healthy, stigma-free lives.

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Introduction

Stigma has shaped the context within which people living with HIV (PLHIV) have had to navigate their lives since the earliest days of the AIDS pandemic [1]. Despite significant biomedical advances that have transformed HIV from a terminal illness to a manageable condition, stigma continues to impact the quality of life and health outcomes of PLHIV and is an impediment to ending the epidemic [2–15]. Gay men and other MSM, sex workers, people whose gender identity differs from what was assigned at birth, people who use drugs, and other marginalized populations–often collectively referred to as 'key populations'–face additional stigmas that increase risk of HIV acquisition and transmission, limit access to treatment and care, and worsen health outcomes [16–20].

Tackling stigma requires empirical evidence on the types, extent, and impact of stigma on the lives of PLHIV. To facilitate measuring and developing interventions to address HIV-related stigma, the PLHIV Stigma Index (Stigma Index) was developed in 2008 by the Global Network of PLHIV (GNP+), the International Community of Women Living with HIV (ICW), International Planned Parenthood Foundation, and UNAIDS. The Stigma Index is the most widely used survey measuring stigma and discrimination experienced by PLHIV from their perspective [21]. Although the term 'index' is often used to describe a compound measure that aggregates multiple indicators, in this case, it describes a survey with nearly 100 questions assessing different types of stigma and related phenomena. The Stigma Index operationalizes the GIPA principle (greater involvement of people living with HIV and AIDS) [22]; PLHIV lead the research, including data collection and dissemination. Since its launch, more than 2000 PLHIV have been trained as interviewers and over 100 000 PLHIV from more than 100 countries have been interviewed in 55 languages [21]. Data generated from the Stigma Index have informed advocacy efforts, public campaigns against discrimination, policies guiding healthcare provision for PLHIV, including sexual and reproductive health options, and challenged discriminatory provisions within laws [23].

In 2015, UNAIDS, ICW, and GNP+ – the International Stigma Index Partnership (ISIP) – spearheaded a process to update the Stigma Index to better understand the continued barriers to HIV testing and treatment, particularly in response to global 'treat all' guidelines [24] and UNAIDS targets [25], and to systematically measure the impact of intersecting stigmas on key populations living with HIV, which had been limited previously [26]. Project SOAR, a research consortium led by the Population Council, guided the Stigma Index update in collaboration with the ISIP and funded by the United States Agency for International Development (USAID). The current article describes the process of updating the Stigma Index, presents key features of the resulting 'Stigma Index 2.0,' and summarizes the results of testing the updated survey in three countries.

Methods

Overview of Stigma Index update process

Project SOAR established a Working Group with representatives from the ISIP, USAID, and stigma research experts that outlined an iterative, transparent process to incorporate as many perspectives as possible (Fig. 1). Guided by the ISIP, Project SOAR reviewed 13 Stigma Index country reports [27–29], four regional reports [30–33], and five related documents [34–38]; mapped other tools measuring HIV [39–49] and key population [50–59] stigma; and interviewed 15 key informants involved in implementing the Stigma Index. A consultation was convened (April 2016) with a diverse group PLHIV, including key populations, donors, bilateral organizations, and researchers who recommended capturing both HIV-related and key population-related stigma, measuring key population-related stigma by identity (i.e., gay or MSM) and by behavior (i.e., has sex with other men) and separating gender identity from sexual orientation in questions and responses. Stakeholders also suggested incorporating previously validated scales, where possible, and adding a resilience measure to capture positive experiences alongside stigma and discrimination. Table 1 outlines the sections and content areas of the Stigma Index 2.0, highlighting notable changes to the original survey including: a widely-used two-part gender identity question [56]; a new section containing previously-validated key population-related stigma items [57,58]; an expanded healthcare section [59]; a refined set of reproductive health questions; validated scales to assess anxiety and depression [60] and internalized stigma [41]; and a new PLHIV Resilience Scale [61]. A draft of the updated questionnaire was pretested by 60 PLHIV at the 2016 AIDS Conference (Durban, South Africa) and reviewed by select stakeholders who had attended the consultation. Feedback from the workshops and stakeholder review informed the version of the Stigma Index 2.0 questionnaire that was formally tested in three studies (described below). After evaluating the study data and retaining most of the piloted

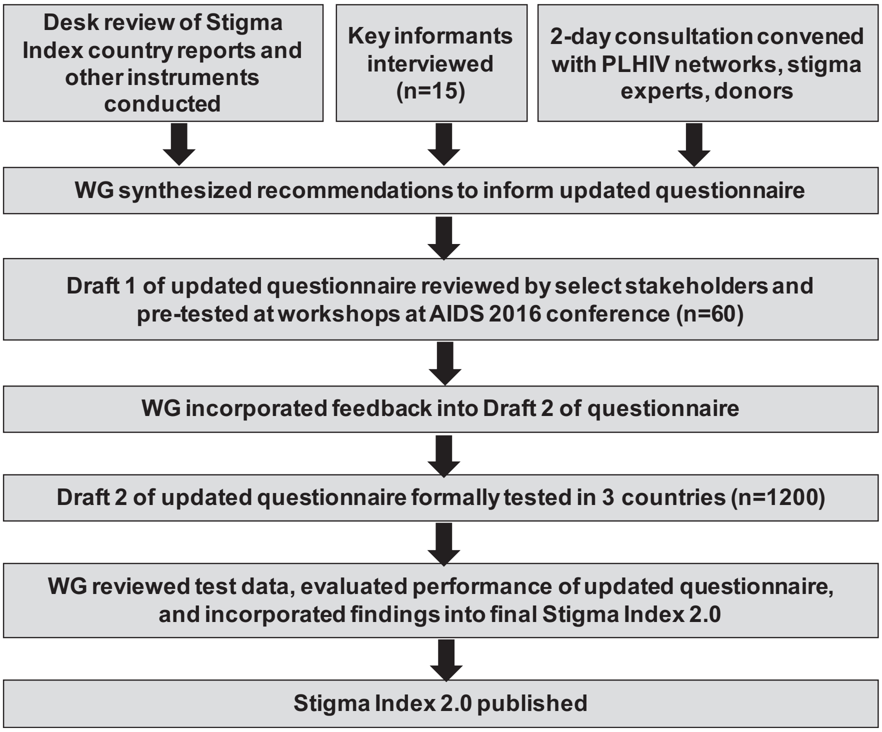

Fig. 1. Stigma Index update process outlined by working group.

questions, the Working Group finalized the Stigma Index 2.0, which has been available since 2018.

Testing the Stigma Index 2.0 in Cameroon, Senegal, and Uganda

Study design and population

Three cross-sectional studies were implemented by: Metabiota and Réseau Cameronais des Associations de Persones Vivant avec le VIH (RéCAP+) in Douala and Yaoundé, Cameroon; Enda Santé and Réseau National des Associations de PVVIH du Sénégal (RNP+) in Dakar and Ziguinchor, Senegal; and the National Forum of People Living with HIV Networks in Uganda (NAFOPHANU) in greater Kampala, Uganda. These three countries were selected for their varying HIV epidemiology (incidence, prevalence, populations affected) and previous Stigma Index experience [28,29,62]. The Population Council, RTI International, and Johns Hopkins University provided technical support to the country teams.

Eligible individuals were aged 18 years or older, had lived in the study area for at least 3 months, had known their HIV positive status for at least 1 year, and spoke one of the local languages: French or English (Cameroon); Wolof, Joola, Mandinka, or French (Senegal); and Luganda or English (Uganda). A diverse group of PLHIV were recruited using two nonprobabilistic, purposive sampling methods – venue-based and snowball. Purposive sampling was beneficial for reaching specific key populations and minimizing inadvertent disclosure of HIV status or key population membership (by recruiting at venues or via peers to whom respondents had already disclosed their status). Probability-based sampling was not feasible due to the challenges and costs of defining a complete sampling frame of all PLHIV in the study areas. A sample size of 400 was chosen to detect sufficient variability in responses to survey questions, including between sub-groups of interest (such as gender identity and key population status).

For venue-based sampling, PLHIV networks, community-based organizations (CBOs) serving key populations, and antiretroviral therapy (ART) clinics linked potentially interested PLHIV with data collectors. For snowball sampling, respondents who completed the survey were given coupons to invite up to five peers as a way to recruit PLHIV who may not have been connected to networks or treatment centers.

Data collection

Before data collection began, community meetings were held to engage PLHIV networks, CBOs, and HIV service providers in recruitment plans and selection of interview venues. Interviewers were from PLHIV networks or CBOs and represented a mix of genders and populations. All interviewers, many with prior Stigma Index experience, were trained on research ethics; data collection techniques; gender, sexuality; and other sensitive topics; and working with PLHIV and key populations.

Table 1. Stigma Index 2.0 sections, content areas, and key changes made during the update process.

Section name	Content area	Key changes from the original Stigma Index based on stakeholder recommendations
A. About you (demographics)	Gender identity Age, education, employment, relationship status Length of time living with HIV Key population membership (can be tailored by country) Group identity (e.g., migrant, ethnic minority); can be tailored by country	Incorporated Reisner 2-part gender identity question [56] Created separate questions about membership in 'key populations' (such as MSM, sex workers, transgender individuals, PWUDs) and about belonging to other marginalized groups (such as migrant workers, ethnic minorities, people living with disabilities). User Guide indicates that response options can be tailored by country Added a question about partner's HIV status (if applicable)
B. Disclosure	Individuals/groups who know status Feelings about disclosure process over time	Streamlined questions Changed matrix to ask about whether different individuals/groups know the respondent's HIV status (versus whether respondent had actively disclosed to that individual/group), and whether disclosure was ever without consent
C. Your experience of stigma and discrimination	11 items specific to stigma experienced due to HIV status, in last 12 months and ever	Replaced questions that previously combined stigma experienced due to HIV status and 'due to other reasons' and created two separate sections: one for HIV-related stigma (section C) and a separate section for stigma experienced due to key population membership (section G)
D. Internalized stigma and resilience	6-item internalized stigma scale 10-item resilience scale Self-censoring of activities due to HIV status	Added validated IA-RSS scale [41] Developed and validated a new scale during the update process to assess resilience among PLHIV [61]
E. Interactions with healthcare services	HIV testing experiences ART/viral load status HIV stigma experienced in healthcare settings Physical and mental health status Sexual and reproductive health service experiences, including specific questions for women only	Consolidated health-related questions from the original Stigma Index into one expanded healthcare section with focus on current HIV response Added questions about ART and viral load testing/suppression to reflect changes in treatment guidelines since the Stigma Index was introduced in 2008 Added sets of questions previously used by the Health Policy Project and Health Policy Plus about stigma experienced in healthcare settings, separately for HIV care and other (nonspecific HIV) care settings [59] Added validated PHQ-4 Depression scale [60] Refined questions related to reproductive healthcare experiences
F. Human rights and effecting change	Rights abuses Redress Awareness of legal protections Efforts to effect change	Strengthened questions about awareness of legal protections against stigma and discrimination for PLHIV Explicitly named human rights abuses (such as being arrested due to HIV status, forced to disclose status, etc.) as such to educate respondents about what constitutes a human rights abuse Broadened focus from legal redress for rights violations to include any type of help/support respondents sought
G. Stigma and discrimination experienced for reasons other than your HIV status	7 items specific to stigma experienced in last 12 months, and ever, related to each key population group relevant to each respondent; questions are skipped if not relevant (i.e., questions for men about sex with other men are not asked to women and vice versa)	Added separate section to assess key population-related stigma with sub-sections for MSM, transgender individuals, women who have sex with women, sex workers, and people who use drugs Structured key population stigma questions and HIV stigma questions the same way, to the extent possible, to facilitate assessment of intersectional stigma Incorporated existing questions assessing stigma experienced due to key population membership [57,58]
H. Personal experience related to stigma/discrimination	Single open-ended question for respondent to describe a specific experience related to stigma/discrimination	Replaced the several open-ended questions in the original Stigma Index with a single open-ended question enabling each respondent to describe a specific, personal experience related to stigma or discrimination

In addition to the changes described above related to specific sections of the questionnaire, the following overarching changes were incorporated into the Stigma Index 2.0 based on stakeholder recommendations: Used a 12-month reporting time frame consistently; streamlined skip patterns and restructured questions to facilitate analysis; replaced ambiguous question wording with more precise wording; replaced technical terms with more understandable ones; framed all questions neutrally. ART, antiretroviral treatment; IA-RSS, Internalized AIDS-Related Stigma Scale; PHQ-4, patient health questionnaire short version (4 questions); PLHIV, people living with HIV; PWUDs, person who uses drugs.

Quantitative. The Stigma Index 2.0 questionnaire was implemented on tablet computers (Cameroon, Senegal) or smart phones (Uganda) using Open Data Kit (Creative Commons, Mountain View, CA, USA). A 'side-by-side' process, in which the interviewer and respondent sit next to versus across from each other, was used to create a supportive environment for interviewees. Data were entered in real-time by interviewers, transmitted daily to a server in each country, and uploaded weekly to analysts. The questionnaire was translated into the local languages and pretested before use.

Qualitative. In Uganda, cognitive interviews were implemented among 20 PLHIV who had not taken the survey to ensure questions and response options were understood by respondents as intended [63,64]. Cognitive interview respondents were asked to restate each question in their own words, if any questions were difficult to understand and, if so, to suggest alternative wording for questions or response options. One-on-one interviews were conducted in Senegal and Cameroon ($n = 20$ per country) to gather feedback on several specific questions that the Working Group revised based on preliminary analysis.

In Uganda only, focus group discussions (FGDs) were conducted to explore how well the questionnaire reflected the experiences of PLHIV, and particularly, key populations living with HIV. Six FGDs with respondents who had completed the survey, stratified by population group (e.g., cisgender men, MSM, sex workers, heterosexual cisgender women) and two FGDs with PLHIV interviewers were conducted and audio recorded.

Data analysis

Quantitative data were analyzed separately by country using Stata 15.0 (StataCorp, College Station, Texas, USA). Descriptive statistics (frequencies/means; measures of dispersion; extent of missing data) were used to summarize all data, by country, and, for relevant questions, by key population subgroup. Questions were considered to perform adequately and not require revision if, in each country, they had minimal missing data due to nonresponse (<5%) and demonstrated adequate variability (categorical variables with <95% of responses in any one category; continuous variables not highly skewed). To gauge performance of the three multi-item psychometric scales [41,60,61], internal consistency reliability was assessed via Cronbach's alpha. Construct validity of scales was assessed using confirmatory factor analysis (and exploratory factor analysis for the new PLHIV Resilience Scale [61]). Cognitive interview and FGD transcripts were transcribed and translated into English and analyzed using content analysis [65].

Ethics

All respondents provided informed consent before taking the survey or being interviewed, and were reimbursed for transportation, but not otherwise compensated. The protocols, questionnaire and interview guides were approved by the Institutional Review Boards of the Johns Hopkins Bloomberg School of Public Health (Baltimore, Maryland, USA), the Population Council (New York, New York, USA), and by the Comité National D'Ethique de la Recherche pour la Santé Humaine (Cameroon), the Comité National Ethique pour la Recherche en Santé (Senegal), and the Mildmay Uganda Research Ethics Committee (Uganda).

Results

Between March and October 2017, 1207 PLHIV completed the survey, of whom 1158 ($n = 377$, Cameroon; $n = 390$, Senegal; $n = 391$, Uganda) were eligible and included in analyses (knew HIV status $\geq$1 year). Selected descriptive results from each survey section are presented below, followed by a summary of the survey's performance, to provide a sense of the content and quality of data generated by the Stigma Index 2.0.

Descriptive results

About you (demographics, section A)

On average, participants were 36–42 years old and had known their HIV status for about 7 years (Table 2). Over half of respondents were cisgender women, and more than one-third were key populations by identity (e.g., gay) or practice (e.g., has sex with other men). Approximately 5% identified as transgender/a different gender from their sex assigned at birth. Relationship status, employment, and education varied within and between countries.

Disclosure (section B)

Most respondents said at least one person knew their HIV-positive status (other than a healthcare provider), and about half felt disclosure had become easier over time. A quarter of respondents in Cameroon, and less than 10% in Senegal, and Uganda reported that their status was ever disclosed without their consent (Table 2).

Your experience of stigma and discrimination (due to HIV, section C and key population membership, section G)

HIV-related stigma was experienced by 54, 13, and 37% of all respondents from Cameroon, Senegal, and Uganda, respectively (Table 3). In Cameroon and Senegal, key populations experienced higher rates of HIV-related stigma than non-key populations (62 versus 49% and 20 versus 10%, respectively). The most common experiences across countries and population groups were verbal harassment and family members making discriminatory remarks or gossiping. Blackmail

Table 2. Participant characteristics by country (*N* = 1158).

	Cameroon, *n* = 377 (%)	Senegal, *n* = 390 (%)	Uganda, *n* = 391 (%)
Section A. About you (demographics)			
Age, mean (range)	38.2 (1869)	42.4 (1870)	36.2 (1881)
Years knowing HIV status, mean (range)	7.6 (127)	6.8 (124)	6.6 (132)
Sex assigned at birth			
Female	71	78	61
Male	29	22	39
Currently in a relationship	44	38	47
Number of children 18 years old, mean (range)	2.4 (011)	3.0 (021)	3.1 (015)
Highest level of education completed			
No formal education	2	23	18
Some primary/secondary (includes some/completed primary, some secondary)	58	57	66
Secondary	17	12	6
University/tertiary or higher	16	2	7
Current employment status			
Full time employment	38	19	56
Part time employment	18	15	16
Other (student [full or part time], homemaker, retiree, volunteer)	18	23	15
Unemployed and not working at all	15	29	7
Always able to meet basic needs (food, shelter, clothing) in past 12 months	20	17	31
Current/past group member[a]			
Racial, ethnic, religious minority group	11	19	1
Living with disability (such as visual impairment, physical disability, etc.)	8	7	4
Internally displaced person	5	12	1
Currently/previously identified with key population group[b]			
MSM/Gay	13	11	9
Lesbian/Gay	3	3	4
Transgender/gender identity differs from sex assigned at birth	5	4	6
Sex worker/person who sells sex or exchanges sex for goods	31	27	33
Person who uses drugs	3	4	8
Section B. Disclosure			
Status known by at least 1 person/group (other than healthcare provider)	96	72	94
Disclosure has become easier over time	57	47	64
Status was ever disclosed without consent	27	5	7
Section D. Internalized stigma and resilience			
Internalized stigma, mean scale score from 0-6 (SD, range)	3.3 (1.7, 06)	2.7 (1.5, 06)	2.1 (1.8, 06)
Resilience, past 12 months; mean scale score from 1010 (SD, range)	2.7 (4.0, 1010)	0.42 (4.0, 1010)	0.69 (4.4, 1010)
Self-censored activity due to HIV status, past 12 months			
Chose not to attend social gatherings	47	24	22
Chose not to seek (health) care	15	2	4
Chose not to apply for jobs	32	7	16
Chose not to seek social support	38	18	11
Isolated self from family and/or friends	54	15	17
Decided not to have sex	61	26	32

[a] Less than 5% reported being a member of an Indigenous/Aboriginal group, a refugee/asylum seeker, a migrant worker, or incarcerated/in prison.
[b] Includes respondents who identified as gay/MSM or reported ever having sex with another man; identified as lesbian or reported ever having sex with another woman; reported being transgender or sex at birth was different from gender identity; identified as a sex worker or reported transactional sex (men, women or transgender); identified as a person who uses drugs or reported regularly injecting/using addictive drugs (heroin, cocaine, methamphetamines).
Missing data were 4% for all variables included in this table.

and physical harassment were also common in Cameroon and Uganda.

The new section on key population-related stigma indicated that 90, 43, and 40% of MSM from Cameroon, Senegal, and Uganda, respectively, experienced stigma because they had had sex with other men (Table 3). Similarly, 94% of transgender women in Cameroon, 25% in Senegal, and 52% in Uganda were stigmatized due to their gender identity. Verbal harassment was the most common key population-related stigma experienced, although blackmail and physical harassment were also prevalent. Stigma also affected key population's healthcare-seeking behaviors: up to 45% had been afraid to seek services and up to 41% had avoided services because of fears someone would discover their key population identity.

Internalized stigma and resilience (section D)

Average internalized stigma scores (scale range 0–6; higher = more internalized stigma) [41] were 3.3, 2.7, and 2.1 in Cameroon, Senegal, and Uganda, respectively (Table 2). The new PLHIV Resilience Scale [61] indicated substantial resilience, as well as variation

Table 3. Stigma and discrimination experienced by respondents by country and key population status, past 12 months.

	Cameroon			Senegal			Uganda		
	KP, $n=142$ %	Non-KP, $n=235$ %	TOTAL, $n=377$ %	KP, $n=120$ %	Non-KP, $n=270$ %	TOTAL, $n=390$ %	KP, $n=162$ %	Non-KP, $n=229$ %	TOTAL, $n=391$ %
Percentage of respondents who experienced stigma/discrimination due to HIV status, (section C), past 12 months									
Excluded from social gatherings or activities (such as weddings, funerals, parties, clubs)	20	10	14	6	1	3	3	2	2
Excluded from religious activities/places of worship	6	2	3	3	<1	1	2	1	2
Excluded from family activities	20	13	16	6	1	2	4	2	3
Family members made discriminatory remarks/gossiped[a]	33	26	29	10	3	5	19	19	19
Verbally harassed (yelled at, scolded, or otherwise verbally abused)	35	23	27	6	3	4	22	17	19
Blackmailed	30	18	23	1	1	1	12	13	13
Physically harassed (pushed, hit, or otherwise physically abused)	11	3	6	3	<1	1	10	9	10
Refused employment or work opportunity	8	9	9	2	0	1	10	5	7
Lost source of income/job, job description/ nature of job changed, denied a promotion[b]	18	15	16	5	6	6	7	14	11
% who experienced ≥1 of above types of stigma or discrimination, past 12 months	**62**	**49**	**54**	**20**	**10**	**13**	**39**	**36**	**37**
Of those, mean number of types of stigma or discrimination experienced (range)	2.9 (1–8)	2.4 (1–7)	2.7 (1–8)	2.0 (1–6)	1.4 (1–4)	1.7 (1–6)	2.3 (1–7)	2.3 (1–9)	2.3 (1–9)

Percentage of respondents who experienced stigma/discrimination due to being a key population member (section G), past 12 months[c]

	Cameroon, $n=142$[d]				Senegal, $n=120$[d]				Uganda, $n=162$[d]			
	MSM, $n=49$	FSW, $n=87$	TGF, $n=17$	PWUDs, $n=7$	MSM, $n=40$	FSW, $n=68$	TGF, $n=12$	PWUDs, $n=14$	MSM, $n=35$	FSW, $n=109$	TGF, $n=21$	PWUDs, $n=29$
Excluded from family activities[e]	59	8	71	0	10	6	8	14	6	6	14	17
Family members have made discriminatory remarks/gossiped[f]	76	18	82	14	23	13	17	29	17	18	19	31
Afraid to seek health services	45	8	47	29	13	3	17	0	6	8	24	3
Avoided seeking health services	37	11	41	29	13	3	17	0	9	4	24	7
Verbally harassed	84	30	88	0	38	19	25	43	23	24	33	28
Blackmailed	69	26	71	0	25	29	25	14	20	26	33	17
Physically harassed or hurt	55	24	59	0	25	18	17	21	11	19	14	14
% who experienced ≥1 of above types of stigma or discrimination, past 12 months	**90**	**54**	**94**	**43**	**43**	**44**	**25**	**43**	**40**	**41**	**52**	**41**
Of those, mean number of types of stigma or discrimination experienced (range)	4.7 (1–7)	2.6 (1–6)	4.9 (3–7)	1.7 (1–3)	3.4 (1–6)	2.1 (1–5)	5 (4–6)	2.8 (1–4)	2.3 (1–7)	2.5 (1–7)	3.5 (1–7)	2.8 (1–5)

Table 3 (*continued*)

Percentage of respondents who experienced stigma/discrimination in HIV healthcare settings due to HIV status (section E), past 12 months

	KP, $n = 141$	Non-KP, $n = 233$	TOTAL, $n = 374$	KP, $n = 119$	Non-KP, $n = 267$	TOTAL, $n = 386$	KP, $n = 158$	Non-KP, $n = 229$	TOTAL, $n = 387$
Denied health or dental services	12	4	7	0	2	2	12	7	9
Advised not to have sex	14	12	13	3	4	4	26	26	26
Talked badly or gossiped about	31	13	20	3	2	2	15	19	17
Verbally abused (yelled at, scolded, called names or otherwise verbally abused)	33	13	21	3	3	3	13	14	13
Physically abused (pushed, hit, or otherwise physically abused)	5	2	3	1	1	1	10	8	9
Healthcare workers avoided physical contact/took extra precautions (e.g., double gloving)	17	10	13	13	3	6	10	9	9
Healthcare workers disclosed HIV status to other people without his/her consent[g]	28	14	19	1	1	1	9	10	10
% who experienced ≥ 1 of above types of stigma or discrimination, past 12 months	**54**	**36**	**43**	**18**	**10**	**13**	**34**	**41**	**38**
Of those, mean number of types of stigma or discrimination experienced (range)	2.6 (1–7)	1.9 (1–7)	2.2 (1–7)	1.3 (1–4)	1.6 (1–7)	1.5 (1–7)	2.3 (1–7)	2.8 (1–7)	2.5 (1–7)

FSW, female sex worker; KP, key population; PWUDs, person who uses drugs; TGF, transgender female.

[a] Missing 5.6% of responses from KP in Cameroon, 5% from KP in Senegal, and 7% from non-KP in Uganda.

[b] Missing 18.3% of responses for nature of job changed (one question comprising this variable) for KP in Senegal, 14.4% for non-KP in Uganda, and 5.6% for KP in Uganda.

[c] Specific questions were addressed to each KP group about stigma or discrimination experienced due to identifying as gay/MSM or ever having sex with another man; identifying as lesbian or ever having sex with another woman; being transgender or having a gender identity that differs from sex at birth; identify as a sex worker or ever had transactional sex (men, women or transgender); identify as a person who uses drugs or has regularly injected/used addictive drugs (heroin, cocaine, methamphetamines).

[d] Total *n* does not equal sum of individual key population groups because respondents can be in more than one group; lesbians and transgender men are not included in the table due to low *n*s. Missing data 5% except as noted:

[e] Missing 14.3% of responses for PWUDs in Cameroon.

[f] Missing 5.8% of responses for FSW in Cameroon, 14.3% for PWUDs in Cameroon, and 14.3% for PWUDs in Senegal.

[g] Missing 15.7% of responses for non-KP in Cameroon, 16.2% for KP in Cameroon, 14.2% for KP in Senegal, 13.3% for non-KP in Senegal, and 15.7% for non-KP in Uganda.

between individuals, in terms of the negative, neutral, or positive effect of HIV status on attainment of needs, such as the ability to cope with stress, find love, or achieve goals. Overall resilience (scale range −10−+10; higher = more resilience) was −2.7 in Cameroon, 0.42 in Senegal, and 0.69 in Uganda.

Interactions with healthcare services (section E)

One-quarter to one-third of respondents hesitated to get tested due to fears of how others would respond if they tested HIV-positive (Table 4). Most respondents had tested for HIV voluntarily, although approximately 10% felt pressured by others to test. Lack of consent was reported by less than 3% of respondents. A majority received their regular HIV care from government or community-based nongovernmental organization-run clinics. Almost all were currently on ART, nearly two-thirds of whom reported starting treatment within 6 months of diagnosis. Viral load suppression was reported by 64, 43, and 62% of respondents from Cameroon, Senegal, and Uganda, respectively; 3–14% had been tested and were not virally suppressed, almost 20% had not been tested, and up to 35% did not know if they had been tested or what a viral load test was. Finally, up to one-third had missed an ART dose at least once in the last 12 months due to fear of inadvertent disclosure.

Most respondents rated their overall health as good or fair (versus poor), although up to half had been diagnosed with another condition (other than HIV) in the last 12 months. Average depression scores per the depression scale [60] (scale range 1–4; higher = more depression)

Table 4. HIV care and treatment by country ($n = 1158$).

	Cameroon $n = 377$ %	Senegal $n = 390$ %	Uganda $n = 391$ %
HIV testing			
Voluntariness of HIV testing			
Tested for HIV voluntarily, without pressure from others	63	81	84
Chose to be tested, but pressured by others	12	10	8
Forced to take an HIV test without consent	3	1	2
Tested without knowledge and found out after test had been done	21	8	4
Born with/acquired HIV as an infant and unaware of being tested	1	1	2
Reasons tested for HIV[a] (more than one response possible)[b]			
Just wanted to know	32	35	54
Provider recommended testing	18	39	6
Felt ill/had symptoms that might be HIV-related	18	18	26
Hesitated to be tested due to fears of how other people would respond	24	33	41
HIV care and treatment			
Primary source of HIV care is government/NGO/community-run clinic	84	82	62
Currently on ART	99	98	97
Length of time between diagnosis and starting ART (of those on ART)	$n = 360$	$n = 377$	$n = 335$
Within 30 days of being diagnosed	33	50	47
More than 1 month to 6 months after being diagnosed	26	15	17
More than 6 months to 2 years after being diagnosed	19	16	20
More than 2 years after being diagnosed	23	19	16
Reasons for delaying care or treatment[c]	$n = 96$	$n = 47$	$n = 90$
Was not ready to deal with HIV infection	34	32	14
Worried partner, family, friends would find out status	15	11	6
Afraid health workers would treat badly/disclose status without consent	4	4	2
Bad experience with health worker previously	1	6	0
Results of viral load testing, past 12 months			
Virally suppressed/undetectable	64	43	62
Has not had a viral load test in the past 12 months	18	19	17
Does not know what viral load/viral suppression is/whether tested	5	35	13
Not virally suppressed/detectable viral load	14	3	8
Missed ART at least once due to fear of disclosure at least, past 12 months	31	19	24
Health status, overall			
Current self-rated health, overall			
Good	44	50	68
Fair	44	48	28
Poor	11	3	5
Diagnosed with ≥1 other condition (TB, Hepatitis B, hepatitis C, STI, mental health condition, or other), past 12 months	49	35	43
Depression score (range 1.0–4.0), mean (SD)	2.3 (0.87)	1.8 (0.83)	1.5 (0.65)

ART, antiretroviral therapy; NGO, nongovernmental organization; STI, sexually transmitted infection; TB, tuberculosis.

[a] Includes only respondents who were tested for HIV voluntarily.

[b] Responses selected by at least 25% of participants.

[c] Includes respondents who did not seek care within 6 months of diagnosis.

Missing data were <3% for all variables included in this table.

were 2.3, 1.8, and 1.5 in Cameroon, Senegal, and Uganda, respectively.

Stigma in HIV-healthcare settings in the last 12 months was experienced by 43, 13, and 38% of respondents in Cameroon, Senegal, and Uganda, respectively (Table 3). Up to one-quarter of respondents had been advised not to have sex, talked badly or gossiped about, or experienced verbal abuse. Key populations were more likely to have experienced stigma within healthcare settings than non-key populations in Cameroon and Senegal, whereas in Uganda, the reverse was true. Less than 2% of respondents had been advised to terminate a pregnancy due to their HIV status. More women than men (and more respondents, overall) had been advised not to have children: 7 versus 6%; Cameroon, 4 versus 1%; Senegal, and 12 versus 3%, Uganda.

Human rights and effecting change (section F)

Approximately one-third of respondents in Cameroon, half in Senegal, and one-third in Uganda were aware of laws in their countries to protect PLHIV against discrimination. A minority (13%, Cameroon; 3% Senegal; 15%, Uganda) reported being arrested or denied a visa, citizenship or residency due to their HIV status; or forced to disclose their HIV status; however, less than half of those contacted a lawyer, community organization, or PLHIV network (data not shown).

Personal experience of stigma/discrimination (section H: open-ended question)

Less than half of respondents shared specific experiences of stigma or discrimination. Experiences ranged widely from the people involved and severity of the situations. Two common themes were family disassociation and disclosure without consent.

Performance of the questionnaire

Overall, the Stigma Index 2.0 performed well. Most questions captured substantial variability in responses within each country (e.g., categorical variables had <95% in any one category; continuous variables were normally distributed/not highly skewed; and missing data were minimal). Cognitive interview respondents indicated that most questions were well understood and FGD participants said that the Stigma Index 2.0 addressed issues that were relevant to their lives. A few questions were reworded for greater clarity and some response options with very low frequency of responses (e.g., <1%) across countries were eliminated or combined with others.

The 6-item internalized stigma scale (IA-RSS), 4-item depression/anxiety scale (PHQ-4), and 10-item PLHIV Resilience Scale demonstrated generally good internal consistency reliability and construct validity. Cronbach's alphas for Cameroon, Senegal, and Uganda, respectively were: IA-RSS: 0.70, 0.65, 0.75; PHQ-4: 0.80, 0.88, 0.80; Resilience Scale: 0.81, 0.92, 0.89. Confirmatory factor analyses for the previously validated IA-RSS and PHQ-4 scales demonstrated good model fit per conventional cutoff criteria (for the IA-RSS with binary items, all three R^2 were >0.74; for the PHQ-4, all root mean square error of approximation were <0.06, comparative fit index and Tucker-Lewis Index >0.98, and standardized root mean square residual < 0.02). For the new Resilience Scale, exploratory factor analyses suggested a unidimensional scale (i.e., single factor) and confirmatory factor analyses demonstrated good model fit [61].

Only the Disclosure section was revised significantly to simplify the complex matrix of questions that had been designed to capture detailed disclosure experiences with 12 distinct groups. The revised section asks if 10 individuals or groups know the respondents' status (Yes/No) and if any of these people found out without their consent. These revisions were made after extensive discussion within the Working Group about how disclosure often occurs passively over time versus as a one-time event.

Discussion

Since its launch in 2008, the Stigma Index has been an important tool for documenting stigma and discrimination and informing interventions [21]. The Stigma Index was updated in an iterative, consultative process driven by and incorporating the views of PLHIV, in keeping with the GIPA principle. The Stigma Index 2.0 performed well in the three countries where it was tested, capturing a range of experiences among a diverse group of PLHIV. Although the Stigma Index 2.0 cannot measure causal relationships due to the cross-sectional nature of the survey, results can inform the focus of policy and interventions. And, repeating implementation of the Stigma Index 2.0 every few years (as was done in many countries for the original Stigma Index), can enable tracking of changes in stigma and related phenomena over time, including in response to stigma reduction interventions or policy changes.

A key benefit of the Stigma Index 2.0 is its ability to shed new light on the growing body of research on intersecting stigmas [66–69]. The updated questionnaire enables more precise measurement of the separate and combined burden of HIV-related and key population-related stigmas, and how these intersecting stigmas impede HIV testing and care. The high rates of stigma and discrimination against key populations in all three countries in this study reinforces the critical need to address harmful legal and policy environments that pose significant barriers to engagement in care. In another recent Stigma Index 2.0 implementation in the

Dominican Republic, Yam *et al.* [70] found that MSM who experienced more stigma in HIV-specific services had significantly lower odds of knowing they had undetectable viral load, and that higher internalized stigma among female sex workers was significantly associated with missing a dose of ART.

A second benefit of the Stigma Index 2.0 is the expanded healthcare section, which facilitates documentation of how stigma and discrimination impact PLHIV at each point in the HIV care cascade. For example, although almost all respondents were currently taking ART, nearly one-third had missed a dose in the past year due to fear of disclosure, and less than two-thirds knew they were virally suppressed. The Stigma Index 2.0 can distinguish the differences between people who reported receiving viral load testing and having measurable viral load, not having had a viral load test in the past 12 months, or not knowing what viral load testing/viral suppression means. Each of these responses indicates different issues – problems with ART adherence/retention, viral load testing practices, or lack of patient education about their care – which require different interventions.

A third benefit is the addition of the new PLHIV Resilience Scale, which was developed and validated in the context of the Stigma Index update process [61]. Alongside assessing multiple facets of stigma, the new 10-item resilience scale can gauge this more positively framed response to living with HIV. Including this scale in the context of the diverse questions in the Stigma Index 2.0 can facilitate the development of multilevel interventions by analyzing how resilience is shaped by factors at multiple levels, as has been done by Gottert *et al.* [71] in this issue.

There were several limitations of the Stigma Index update process and related study designs. First, as the updated questionnaire was tested in three sub-Saharan countries, implementation in other regions and countries will be required to determine how well the Stigma Index 2.0 performs in those settings. Second, the questionnaire was not retested after the technical Working Group made changes based on results from the pilot studies in Cameroon, Senegal, and Uganda. However, feedback from respondents in Cameroon and Senegal indicated that the changes worked well, and future administrations of the Stigma Index 2.0 will provide additional insights. Finally, the sampling methods determined to be most appropriate in this setting did not include random sampling, and thus the results may not be statistically representative of the total PLHIV population in each setting.

In conclusion, the Stigma Index 2.0 is an instrument that is now more relevant to the current context of the HIV/AIDS epidemic and response. Findings from testing the Stigma Index 2.0 in three countries reinforce the continuing need for interventions, advocacy and policy change efforts to tackle stigma and discrimination, as well as careful monitoring of progress. Over time, results from implementing the Stigma Index 2.0 will provide critical information for global stakeholders to address gaps in program design and policies that support PLHIV to engage in services, adhere to ART, be virally suppressed, and have a higher quality of life. Without significant reductions in stigma and discrimination, ending the epidemic will be challenging, if not impossible.

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Conflicts of interest

There are no conflicts of interest.

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