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THE PEOPLE LIVING WITH HIV STIGMA INDEX SURVEY IN UGANDA- 2019

Uganda Country Assessment

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About the PLHIV Stigma Index Survey

- HIV related Stigma is a process of devaluation' of people either living or associated with HIV and is often accompanied by discrimination. Which is unjust and unfair treatment
- The PLHIV Stigma Index is a survey for, by and with People living with HIV.
- Is an evidence-based process of empowering PLHIV to share lived experiences
- The 2019 PLHIV Stigma Index explored the components of:
 - ✓ HIV Status disclosure
 - ✓ Experiences of External Stigma
 - ✓ Internal Stigma & resilience
 - ✓ Interactions with healthcare systems (ART,VL monitoring, HTS, Mental Health)
 - ✓ Human Rights & effecting change
 - ✓ Stigma & discrimination experienced for reasons other than HIV status.



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Why the PLHIV Stigma Index Survey

Measures/quantifies HIV Stigma and discrimination related experiences

Describes the stigma and discrimination as perceived by PLHIV

Measure and document stigma to develop evidence-based, responsive strategies

Provides for evidence-informed advocacy, policy reform and service delivery

Broadens understanding of the extent and forms of stigma and discrimination



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Methodology

- The 2019 Uganda Country assessment adopted the 2017 Stigma Index Questionnaire 2.0 / www.stigmaindex.org
- Sample size of 1,398 respondents selected from PLHIV networks, ART Clinics and KP organizations.
- The PLHIV Stigma Index survey adopted a one-group post only cross-sectional design .
- Used largely quantitative research methods for data collection and analysis and qualitative based on case stories.
- Data collection from 9 representative regions of Uganda covering 21 districts.
- Time Scope: on PLHIV stigma experiences of the last year .
- Content Scope based on experiences be it internal or external in the era of social behavioral and biomedical interventions in Uganda.



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Background Characteristics

- 1,398 respondents (874 female , 524 male) to represent 1.3 million Ugandans living with HIV.
- **General Population 842, PWD 30, UPDF 30, PWUID 83, Sex Workers 205, Gay/lesbian 33, gay/ homosexual 18, Transgender 51, Men who have sex with Men 33, Religious leaders 23 and Prison Community 50.**
- 51% in intimate relationships, 63.48% with HIV+ partner, 22.66% in discordant relationship & 13.86% unsure about the HIV status of partner.
- 54.18% member of a network of PLHIV.
- 29.24% no formal education, 39.53% primary/ elementary education or equivalent, 24.23% secondary/ high school/ local equivalent, 2.57% trade/ vocational school, 4.43% university/ tertiary education.



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Key Findings: Disclosure & Access to Services.

- Disclosure / knowledge of status by others was largely to family members at 80.77% and to a less extent employer (s) and co-workers at 24.5%.
- 36.38% reported that it was difficult to disclose HIV status and 32.02% hid their status from others.
- 7.93% chose not to attend social gatherings, 4.36% not to seek social support, 6% not apply for job(s), and 6.79% decided to isolate self from family & majority 20.30% decided not have sex.
- HIV testing was voluntary at 86.1%, with main reason as sickness at 33.5% while 27.3% felt were at risk at. 62.2% took less than 6 months to enroll on ART.
- 99.71% taking ART, rated health as good but fears about someone learning of the person's status led to more than 21.41% males compared to 19.68% females, missing a dose of their treatment.
- 70.17% reported viral load suppression, 9.08% had not done VL test, 9.01% awaiting results, 7.5% unsuppressed and 4.22% unaware of VL.
- STIs were most common co-infection at 13.87%, followed by TB at 8.08%.



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Key Findings: External Stigma

- Exclusion experiences of discrimination due to HIV status were minimal at social gatherings by 60 (4.29%).
- Awareness of family members who made discriminatory remarks or gossip was reported by 246(17.58%), while that of non-family members was by 367(26.23%).
- There was minimal exclusion at family level with 50 (3.57%) and at places of worship with 17 (1.22%).
- Verbal harassment including yelling, scolding was reported by 316 (22.59%) blackmail was reported by 175 (12.51%), physical harassment by 123 (8.79) while husbands/wives/partners of PLHIV experienced discrimination with 127 (9.08%).
- 111(7.93%) reported refusal of employment or loss of income, while 52(3.72%) reported changes in job descriptions or nature and denial of promotion.



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Key Findings: Internal Stigma & Resilience

- 509(36.38%) found it difficult to tell people, 172(12.29%), HIV positive status makes them feel dirty, 297(21.23%), feel ashamed, 340(24.30%) felt worthless and 448 (32.02%) hid status from others.
- 208(23.80%) females chose not to have sex and 76(14.50%), 1.5% decided not to seek health care, 7.93% chose not to attend social gatherings, 6% chose not to apply for a job.
- Despite the status, resilience which is the ability to cope with a crisis was positive.
- Resilience was a score used to determine the level of coping given a range of factors from self confidence to ability to practice a religion.
- It can be zero (0), which implies no change or effect) or could be up to positive (+10) which means that despite HIV, ability to cope.
- The highest level of resilience was in Karamoja region at 7.3, followed by Bugisu at 6.2 and Buganda at 5.2. with the worst scores observed in Teso at 7.05 and South West at 2.2.



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Key Findings: Human Rights & Effecting Change

- Out of the 186 respondents who reported experiencing abuse or human rights violations, 35 (18.82%) mentioned that they had tried to do something about the situation.
- 42.86%) reported that matters had been dealt with, 3 (8.57%) said the matter was in the process of being dealt with, and 17(48.57%) said nothing happened or the matter was not dealt with.
- 82(5.86%) did not know where to go or how to act.
- 678 (48.50%) of the respondents, were aware of laws in Uganda that are geared towards protecting the rights of PLHIV, 150 (10.73%) while 570 (40.77%) did not know if such laws exist.



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Key Findings: Key Populations

- Besides HIV related stigma, Key Populations experienced double or triple stigma due to their sexual orientation or nature of work.
- Three quarters of the respondents reached belong to a network
- Discriminatory remarks or gossip about the PLHIV were the commonest non-HIV stigma discriminatory experiences within among all the groups e.g. transgender at 33.65%, MSM at 24.24%, gay homosexual at 16.67%, gay lesbian at 39.39%, sex workers at 28.78 and PWUID at 28.92%.
- This data confirms the concept of double stigma- that KP face both sex/work-oriented stigma in addition to HIV related stigma
- Note also situation similar for PWD



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Conclusion

- Internal stigma levels remain high compared to the study that was conducted in 2013, external levels have reduced.
- Disclosure eases with time
- The longer the person lived with HIV, the lesser stigma related experiences.
- Workplace environment remains unpallatable for PLHIV.
- KPs face double or even triple stigma due to their sexual orientation or nature of work.



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Recommendations

Health Systems Strengthening/social support

- Utilization of the research findings by various stakeholders as part of planning and programming.
- Deliberate funding for stigma reduction interventions especially those that have worked e.g. MDD, co-save initiatives, use of PLHIV champions, media, messages on overcoming and challenging stigma.
- Workplace environment should be more supportive for PLHIV.
- Empower PLHIV in various areas like psychosocial support/ buddy systems, economic empowerment, life skilling and advocacy.

Prevention

- Inclusion of KPs in healthcare programming.



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Thank you