



# THE PEOPLE LIVING WITH HIV STIGMA INDEX

*Abdulkadir Ibrahim  
(National Coordinator)*

*Network of People Living with HIV/AIDS  
in Nigeria (NEPWHAN)*



1. Background information on NEPWHAN
  2. Methodology of the PLHIV Stigma Index
    - Geographical scope of the study
    - Total sample size
    - Sample size and composition (by state, gender and KP typology)
    - Formula for calculating sample size
    - Recruitment of participants - %VBS and %LCR approach
  3. Findings and Recommendations
  4. Implementation Challenges
  5. Lessons Learnt
-



## BACKGROUND INFORMATION ON NEPWHAN



- NEPWHAN is the national umbrella body that coordinates and administers all Support Groups, constituencies, associations and organizations of persons living with HIV/AIDS in Nigeria.
  - Membership of over 1,030 Support Groups across 36 States of Nigeria and the Federal Capital Territory, Abuja.
  - State Chapters in all the 36 States in Nigeria.
  - NEPWHAN has 3 sub-networks - Association of Positive Youth in Nigeria (APYIN); Association of Women Living with HIV/AIDS in Nigeria (ASWHAN); and Association of Religious Leaders Living with HIV/AIDS.
-



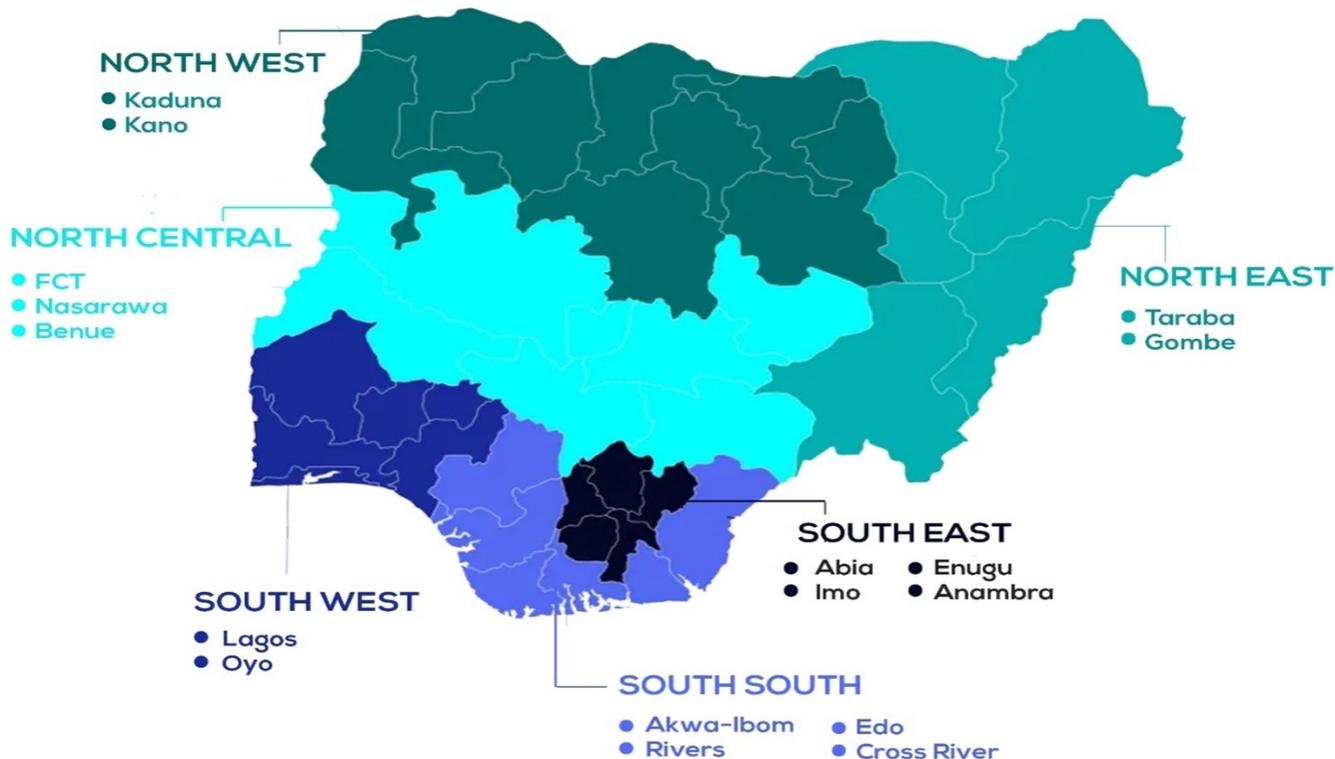
## BACKGROUND INFORMATION ON NEPWHAN (Cont.)



- Our mission is to empower, strengthen and coordinate all support groups, State networks, constituencies, associations and organizations of PLHIV in Nigeria to contribute meaningfully to the national response on HIV/AIDS.
  - Our core activities include coordination and advocacy, community-led interventions (treatment adherence/retention on treatment - Second 95), monitoring and evidence gathering, resource mobilization, and sustainability.
  - Our guiding framework is the Corporate Affairs Commission (CAC) registration, NEPWHAN Constitution, operational manuals, 5-year strategic plan, and internal policies/procedure documents.
-

# METHODOLOGY: GEOGRAPHICAL SCOPE FOR STIGMA INDEX

## Geo-Political Zone 16 States + FCT





## METHODOLOGY: SAMPLE SIZE AND COMPOSITION



- Target for total sample size for Stigma Index 2.0 was 1,235 (spread across 16 + 1 study States). However, 1240 was achieved.
  - Sample size was calculated following the standardized methodology developed by the International Partnership of the PLHIV Stigma Index ([https://hall.shinyapps.io/PLHIV Stigma Sample Size Calculator/](https://hall.shinyapps.io/PLHIV_Stigma_Sample_Size_Calculator/)).
  - The formula  $n_0 = z^2 * p * (1-p) / d^2$  was applied.
-

## METHODOLOGY: FORMULA FOR SAMPLE SIZE CALCULATION - INTERPRETATION

- $$n_0 = z^2 * p * (1-p) / d^2$$

Where:

z =	1.96 (z statistic for a confidence level at 95%)
p =	Anticipated % reporting avoidance of going to a healthcare facility (local clinic/hospital), based on data from Stigma Index Study in 2012 (NEPWHAN, 2012)
d =	Degree of precision

---

## METHODOLOGY: SAMPLE SIZE COMPOSITION / STATE

	State	Sample Size	Proportion (%)	No. of data collectors for 3-4 respondents /day for 10 days)
1	Abia	52	4.2	2
2	Anambra	78	6.3	3
3	Edo	39	3.2	1
4	Enugu	51	4.1	2
5	Gombe	17	1.4	1
6	Imo	49	4	2
7	Kaduna	50	4	2
8	Kano	47	3.8	2
9	Oyo	46	3.7	2

---

## METHODOLOGY: SAMPLE SIZE COMPOSITION / STATE (Cont.)

S/NO	State	Sample Size	Proportion (%)	No. of data collectors for 3-4 respondents /day for 10 days)
10	Taraba	47	3.8	2
11	Akwa Ibom	175	14.2	6
12	Rivers	172	13.9	6
13	Cross River	40	3.2	1
14	Lagos	116	9.4	4
15	FCT	41	3.3	1
16	Nasarawa	56	4.5	2
17	Benue	159	12.9	5
	Total	1235	100	44

- Out of 1,240 that participated in the study, 802 (64.7%) were women, while 438 (35.3%) were men.
  - Sample size disaggregation by PLHIV and KP was 75% PLHIV, and 25% for KP.
  - KP group was further disaggregated by typology as follows:
    - 161 (13.0%) were female sex workers (FSW)
    - 81 (6.5%) were men who have sex with men (MSM)
    - 57 (4.59%) were people who use drugs (PWUD)
-



## METHODOLOGY: SAMPLING STRATEGY

### *Venue-based Sampling & Limited Chain Referral*



To capture the diverse and intersectional experiences of stigma, 2 strategies were used to recruit participants: Venue-Based sampling, and Limited Chain Referral.

- 79.3% of respondents were recruited using the ***Venue-based sampling (VBS)***
- 20.7% were recruited using the ***Limited chain referral (LCR)***.

**NOTE:** Prior to participants' recruitment, formative key informant interviews were conducted to determine and validate the sites for recruiting study participants.

---

### Findings

- PWID and MSM (26% and 31%) experienced HIV-related stigma and discrimination in the last 12 months in greater proportion, compared to other groups.
- North-East and North Central geo-political zones reported experiencing greater proportion of stigma and discrimination within the last 12 months.
- HCWs revealing respondents' HIV status without their consent was the most reported stigma issue, and PLHIV were not able to seek redress.

### Recommendations

- PLHIV and KP must be educated on their rights and actions they can take to seek redress on issues of rights abuse.
- Engage, sensitize and train HCWs, community leaders, women's groups, FBOs, youth groups, NGOs and CSOs on HIV and stigma, including the risk of involuntary disclosure for PLHIV and KP.
- Systemic approach to sensitize educational institutions, and inclusion of HIV/AIDS in the school curriculum.

## CHALLENGES WITH IMPLEMENTATION OF THE STANDARDIZED METHODOLOGY

- Sample Size: More people were willing to participate, but the target was limited/tied to available funds, while the protocol did not factor in volunteers with no incentives.
  - Insecurity/Civil unrest in the Southeast Zone: Curfews and lockdowns (in 4 States) made it difficult to recruit participants from some communities in those States despite use of community members.
  - NEPWHAN staff that coordinated different aspects of the study did not have previous training in handling similar study – Network relied on experiences of other partners, which was not healthy at some points.
-

## CHALLENGES WITH IMPLEMENTATION OF THE STANDARDIZED METHODOLOGY

- No clarity on available funds for the study at the point of developing study protocol and budget. So, it was difficult to factor in all that was required/needed.
  - At the time of protocol development, data for TG was not forthcoming in-country for referencing – partly due to effect of COVID-19 on meetings at that period. However, in the course of data collection, 9 TG participants representing 0.73% were recruited. Which shows that TG exist in the country.
  - Generally, experience with using the standardized methodology of the PLHIV Stigma Index 2.0 was complex especially at the point of protocol development. This is because, previous stigma index studies (2011 and 2014) had higher sample sizes compared to the current standardized method where 1235 sample size was used – this looked like retrogression instead of progression.
-

## LESSONS LEARNT

- Trends in stigma and discrimination over the last 3 waves (2011, 2012 and 2021) of implementing Stigma Index in Nigeria showed improvements across key indicators.
  - Involvement of community actors at all stages of the study implementation was helpful. The community people were involved from stage of planning to implementation and post implementation – so, there is community ownership of the result.
  - Inter-organizational support from the Technical and Steering Committees created a huge resource-base that helped to minimize technical errors which would have affected the result of the study negatively.
-

---

## CONTACT US:



[www.stigmaindex.org](http://www.stigmaindex.org)



[plhivstigmaindex@gnpplus.net](mailto:plhivstigmaindex@gnpplus.net)



+31 20 423 4114



[@gnpplus](https://www.facebook.com/gnpplus)



[@gnpplus](https://twitter.com/gnpplus)



[@gnpplus](https://www.linkedin.com/company/gnpplus)

