HIV Leadership through Accountability NIGERIA

GIPA Report Card Nigeria

Country Assessment 2009

March 2010

NEPWHAN

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

UKaid from the Department for International Development

Nigeria

Published by:
Network of People Living with HIV and AIDS in Nigeria (NEPWHAN)
1B Udo Udoma Street, Off Yakubu Gowon Crescent
Asokoro, Abuja
Nigeria

Website: www.nepwhan.org
Email: coord@nepwhan.org, nepwhan.coord@yahoo.com

ISBN: 978-978-908-649-8

Acronyms

ARV	Antiretroviral
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CEDPA	Center for Development and Population Activities
CiSHAN	Civil Society on HIV/AIDS in Nigeria
CSO	Civil Society Organisation
DfID	UK government Department of International Development
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
IEC	Information, education and communication
ICW	International Community of Women Living with HIV/AIDS
LACA	Local Action Committee on AIDS
LGBT	Lesbian, gay, bisexual and transgender
MIPA	Meaningful Involvement of People Living with HIV and AIDS
MSM	Men who have sex with men
NACA	National Agency for the Control of AIDS
NAPEP	National Poverty Eradication Programme
NARN	Nigeria AIDS Research Network
NDE	National Directorate of Employment
NEEDS I & II	National Economic Empowerment and Development Strategies
NEPWHAN	Network of People Living with HIV/AIDS in Nigeria
NIBUCAA	Nigeria Business Coalition Against AIDS
NGO	Non-Governmental Organisation
NSF	National HIV/AIDS Strategic Framework
NYNETHA	Youth Network on HIV/AIDS in Nigeria
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
SACA	State Agency for the Control of AIDS
SEEDS	State Economic Empowerment and Development Strategies
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

Acknowledgements

The Network of People Living with HIV and AIDS in Nigeria (NEPWHAN) is immensely grateful to the UKaid from the Department for International Development (DFID) for the financial support, from the Governance and Transparency Fund, which made this study possible.

We are especially grateful to Chidozie Ezechukwu, the consultant who led the research process and developed the final report.

We would like to acknowledge the invaluable role of people living with HIV, the organisations who participated in this study for their time and participation and the role of the data collectors: Victor Omoseyin, Taiwo Oyelakin and Monisola Ajiboye. We trust that these findings will contribute to improving the health and quality of the lives of all people living with HIV.

NEPWHAN acknowledges the support from the Global Network of People living with HIV (GNP+) and the World AIDS Campaign (WAC) for their work on the HIV Leadership through Accountability programme. We would like to thank Edward Ogenyi , National Coordinator at NEPWHAN; Peter Nweke, Programme Manager at NEPWHAN and Georgina Caswell, Programme Officer at GNP+ for the technical guidance provided throughout the study. We also acknowledge the support from the National Agency for control of AIDS (NACA) and the National Bureau of Statistics as well as our Civil Society partners and Lucy Reynolds, a consultant who reviewed and edited the report. Finally we would like to thank UNDP and UNAIDS for their support in disseminating the report findings and recommendations.

The GIPA Report Card is one of five evidence-gathering tools being implemented through the HIV Leadership through Accountability programme. The programme combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy to achieve Universal Access to prevention, treatment, care and support. For more information about the HIV Leadership through Accountability programme please visit www.hivleadership.org.

Contents

Introduction

The Greater Involvement of People living with HIV and AIDS (GIPA) is a principle that "aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives... [to] enhance the quality and effectiveness of the AIDS response" (UNAIDS 2007). In addition to this, the meaningful involvement of people living with HIV can greatly enhance the quality of policies and interventions by incorporating their contributions which are informed by their experiences. Ill-designed programmes may not just fail, they may be counterproductive, and in some instances can result in significant harm.

The GIPA principle was formalized at the 1994 Paris AIDS Summit when 42 countries agreed to "support a greater involvement of people living with HIV at all…levels…and to…stimulate the creation of supportive political, legal and social environments" (UNAIDS 1999). Through the Paris Declaration of 1994, participating nations committed:

- to mobilize all of society - the public and private sectors, community based organisations and people living with HIV - in a spirit of true partnership;
- to make available necessary resources to better combat the pandemic, including adequate support for people living with HIV, non-governmental organisations and community-based organisations working with vulnerable populations;
- to support a greater involvement of people living with HIV through an initiative to strengthen the capacity and coordination of networks of people living with HIV and community-based organisations. By ensuring their full involvement in our common response to the pandemic at all - national, regional and global - levels, this initiative will, in particular, stimulate the creation of supportive political, legal and social environments.

In 2006, 192 United Nations member countries endorsed the GIPA principle.

Civil society networks and networks of people living with HIV are now scaling-up advocacy activities to actualise the GIPA principle at global, regional and country levels. It is within this context that the Global Network of People Living with HIV (GNP+), the Network of African People Living with HIV (NAP+), the Network of people living with HIV/AIDS in Nigeria (NEPWHAN) and other groups and networks are taking on a key role by providing leadership in promoting the GIPA principle in the HIV response at global, regional and country levels and developing structures and tools to facilitate this.

Nigeria

Sixteen years after the Paris declaration several questions remain outstanding:

I. To what extent has GIPA been truly and effectively operationalised beyond mere rhetoric and tokenism at global, regional and country levels?
II. What laws, policies and programmes are in place to support effective GIPA implementation at all levels?
III. Are adequate resources channelled towards effective implementation of GIPA?

Attempts have been made by individuals and organisations[1] to answer these. One such attempt is a study conducted in five countries (Benin, Brazil, Cambodia, South Africa and Ukraine) by the Policy Project run by Futures Group International. The study report elucidates the disparity between GIPA awareness and practice which was attributed to:

- stigma;
- poor knowledge of HIV among people living with HIV;
- weak understanding of its impact at individual and policy levels;
- lack of supportive policy and legal frameworks; and
- poor comprehension of the rationale behind GIPA at policy level (Stephens 2004).

Funded by the UK's Department for International Development, the HIV Leadership through Accountability Programme is a global research and advocacy initiative between GNP+, the World AIDS Campaign and national networks of people living with HIV. Its GIPA Report Card component sets out to contribute to the body of knowledge and inform action on the implementation of the GIPA principle at country level. GNP+ identified NEPWHAN as its implementing partner in Nigeria, to assess the progress of GIPA implementation by compiling the GIPA Report Card for the country. The GIPA Report Card is designed to assess the application of the GIPA principle in Nigeria's response to HIV, and to provide a tool for on-going evidence-based advocacy for improvement in areas of weakness. In assessing the application of the GIPA principle in Nigeria's response to HIV, NEPWHAN sought the opinions of 25 respondents representing actors in the national response including civil society, development partners and government establishments. Analyses of the views expressed by these respondents are presented herein as Nigeria's GIPA Report Card (2010).

Policy and Literature Review

HIV and AIDS in Nigeria

Twenty-three years after the first case of HIV in Nigeria, HIV poses major health and development challenges for Nigeria. The 2008 HIV sero-prevalence sentinel survey among

[1] GNP+ conducted a study among 13 countries in 2004 to assess level of involvement of PLHIV in their CCMs. Full report of this study can be accessed at: www.gnpplus.net/files/multi_country_study.pdf

antenatal clinic (ANC) attendees put the national average HIV prevalence at 4.6% (FMOH, 2008). Even though Nigeria's epidemic is generalised, there exists significant disparity of HIV prevalence by geographical location, sex, age and sub-population groups. By geopolitical zone, HIV prevalence is lowest in the South West (mean = 2.0%) and highest in the South South region (mean = 7.0%); Ekiti state in the South West emerges as having the lowest prevalence at 1.0%, whilst Benue State in the North Central is highest with 10.6% (FMOH, 2008).

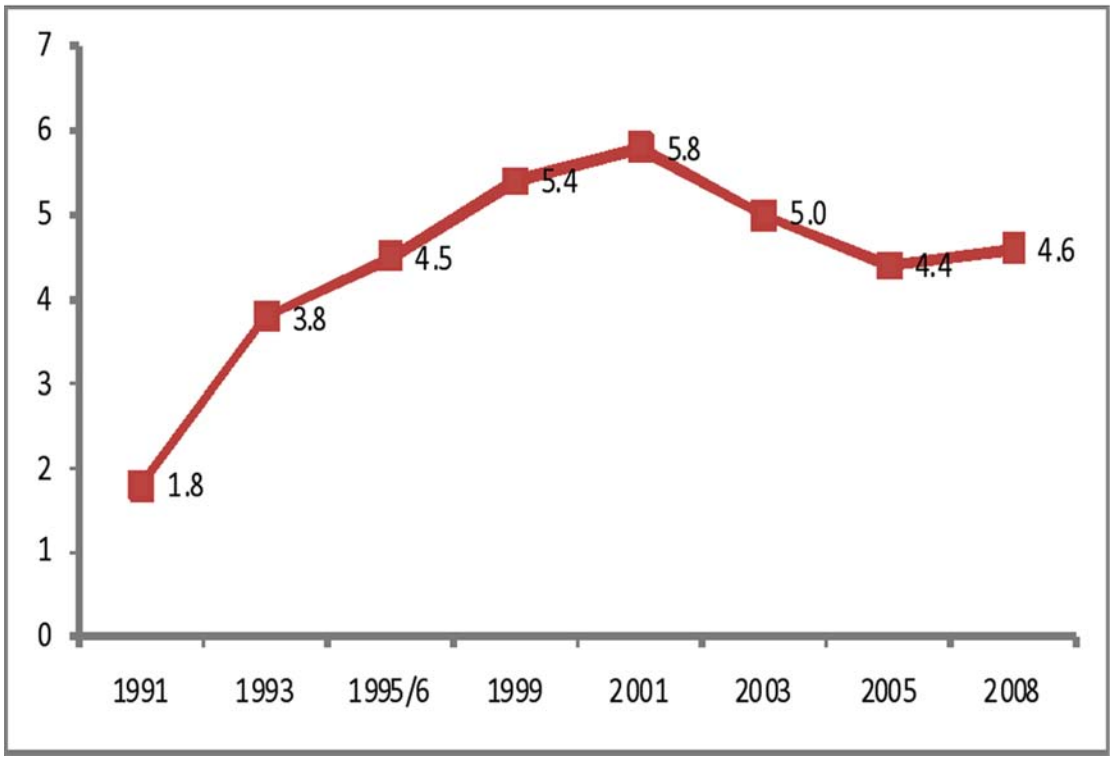


Figure 1. Trends in National HIV Sero-Prevalence Rate, Nigeria, 1991-2008 (Source: NACA, 2009)

HIV prevalence is highest within the 25 - 29 years age group (5.6%), with more women than men living with HIV (FMOH, 2008). Sex workers, men who have sex with men (MSM) and injecting drug users have HIV prevalence higher than the national average of 4.6% based of the results of the integrated bio-behavioural surveillance survey (FMOH, 2007).

Nigeria's multisectoral response to HIV led by the National Agency for the Control of AIDS (NACA) has recorded remarkable achievements by lowering national HIV prevalence from 5.8% in 2001, to 5% in 2003 and down to 4.4% in 2005 (NACA, 2007). This decline was followed by a recent rise to 4.6% in 2008, probably due to the recent dramatic increase in availability of antiretroviral treatment, which increases HIV prevalence because it largely prevents the deaths that would otherwise occur among people living with HIV who do not have treatment.

According to NACA (2007) the drivers of the HIV epidemic in Nigeria include low risk perception, multiple concurrent partners, informal transactional and inter-generational sex,

lack of effective services for sexually transmitted infections (STIs), gender inequalities, and inadequate health services. Based on the 2008 HIV prevalence rate, NACA (2009) estimates that about 2.95 million people are living with HIV in Nigeria (Male-1.23 million; Female-1.72 million). Of this figure 833,000 adults and children have CD4 counts below 200 and therefore are in urgent need of antiretroviral (ARV) drugs. As at March 2009, 267,710 Nigerian adults and 14,857 children living with HIV are on ARVs (FMOH, 2009).

HIV treatment in Nigeria

Antiretroviral drugs (ARVs) were introduced in Nigeria in the early 1990s, but were only available to those who paid for them. At this time and the overwhelming majority of Nigerians were living on less than $2 a day, and the medication was at full market price, most PLHIV were excluded from treatment by the cost, with only a small minority wealthy enough to afford treatment.

The Nigerian government commenced a subsidised antiretroviral treatment programme in 2002, intended to supply 10,000 adults and 5,000 children with antiretroviral drugs within its first year. It was announced as “Africa’s largest antiretroviral treatment programme”. The monthly cost was to be $7 per person, and an initial $3.5 million worth of ARVs were to be imported from India.

Unfortunately the recruitment of patients had outstripped the drug supply by 2004. People living with HIV already on treatment had to wait up to three months to replenish their supply: such supply interruptions greatly increase the risk of HIV becoming resistant to these subsidised ARVs. After some time, another $3.8 million worth of drugs was ordered to continue the programme.

ARVs were at that point being supplied through only 25 treatment centres across the country, insufficient for the estimated 550,000 people requiring antiretroviral therapy, especially for those in areas with poor roads. In 2006 Nigeria opened up 41 new HIV treatment centres and started providing free ARVs. Treatment scale-up during the following year (2006-7) was impressive, increasing from 81,000 people (around 15% of those in need in 2006) to 198,000 by the end of 2007 (26% of the need at that time). There are currently about 552,000 people in the country who do not have access to the ARV treatment that they need, and reaching universal access remains a challenge.

The National HIV/AIDS Strategic Framework (2005 to 2009) incorporates targets for the ARV scale-up. By 2010 Nigeria aims to provide ARVs to 80% of adults and children with advanced HIV infection and 80% of HIV-positive pregnant women.

GIPA in Nigeria's Response to HIV and AIDS

The GIPA principle was not mentioned as such in the National HIV/AIDS Policy (introduced in 2003), but the policy provides for the inclusion of PLHIV representatives on the governing board of the new statutory agency proposed to coordinate the national response to AIDS. The National HIV/AIDS strategic Framework (NSF 2005 – 2009) stipulates that the GIPA principle will guide implementationof the national AIDS plan. The NSF notes that owing to expressed opinions of PLHIV and other stakeholders about a tokenistic approach to 'GIPA' there is a tendency to prefer using the term 'meaningful involvement of PLHIV' (MIPA) (NACA, 2005). The policy and the NSF have just been reviewed and the revised editions commit to ensuring greater involvement of people living with HIV in the HIV response at all levels (NACA, 2009).

The revised National Policy on HIV/AIDS states that "Commitment to protecting rights of PLHIV, reduction of stigma and discrimination and ensuring greater involvement of PLHIV in national HIV/AIDS programme at all levels" will be one of its guiding principles (NACA, 2009). The revised NSF (2010 – 2015), in its Thematic Area Five (Policy, Advocacy, Legal Issues, and Human Rights), sets out to ensure GIPA implementation with regards to PLHIV representation on decision-making bodies. This is clearly stated as objective two of this thematic area with a clear indicator in the results framework to track its implementation. The NSF provided a framework for the development of states' and sectoral HIV and AIDS strategic plans from 2010 to 2015, with the expectation that each of them would have clear interventions aimed at actualizing GIPA in their plans. These indicate synergy of purpose with regards to GIPA by the two overarching national guidelines guiding Nigeria's response to HIV and AIDS.

The terms of reference for the various HIV technical working groups at the national level usually make provisions for representation of the PLHIV constituency by NEPWHAN in such groups. This is also applicable to such national bodies as the Country Coordinating Mechanism (CCM), the Expanded Theme Group and the Ministerial Task Force on HIV/AIDS recently constituted by the Honourable Minister of Health.

The Nigeria Business Coalition against AIDS (NIBUCAA)[2] together with NACA, NEPWHAN, Society for Family Health (SFH) and UNAIDS, initiated and rolled out a successful GIPA programme which identifies people living with HIV, trains and places them as paid employees in private firms. They are referred to as 'GIPA Officers' and, in addition to their primary duties within the firms, implement workplace HIV and AIDS interventions. The success of this programme generated demand for its scale-up and was consequently

[2] NIBUCAA is the national organisation that coordinates the private sector strategic response to HIV and AIDS in Nigeria. www.nibucaa.org

included in Nigeria's proposals to the Global Fund to Fight AIDS, Tuberculosis and Malaria for Rounds 5 and 9 grants, which were successful and are being implemented.

Over 50% of Nigerians remain officially poor despite efforts to improve quality of life and poverty has been correlated with preventable diseases. Considered against the backdrop that about 70% of health financing in Nigeria is from out-of-pocket expenditure at the point of delivery, this situation places the PLHIV in a position of double jeopardy: the majority of the 74% PLHIV who are untreated but in need will either be paying for OI treatment which is not free at the moment or becoming too ill to earn a living. The national HIV and AIDS workplace policy recommends that a PLHIV who is becoming weak be reassigned to other less demanding tasks. No assessment has been conducted to ascertain how this is being implemented.

Whilst recognizing that poverty reduction is the most difficult challenge facing Nigeria and its people and the greatest obstacle to pursuit of sustainable socioeconomic growth, the government of Nigeria, in 2004, launched an ambitious national economic and empowerment development strategy (NEEDS) which seeks to make poverty a thing of the past for all citizens. It recognizes that though people want higher incomes, it is never the totality of human life. For most people, health, security, freedom, love, *recognition*, and fulfillment through *active participation* and accomplishment are some of the important things in life. This captures the principles of GIPA. Huge amount of money has been spent on poverty eradication through the National poverty eradication programme (NAPEP), but presently there is no evidence to show that HIV has been mainstreamed into the programmes of NAPEP to specifically target PLHIV for socio-economic empowerment towards improving their quality of life.

Methods

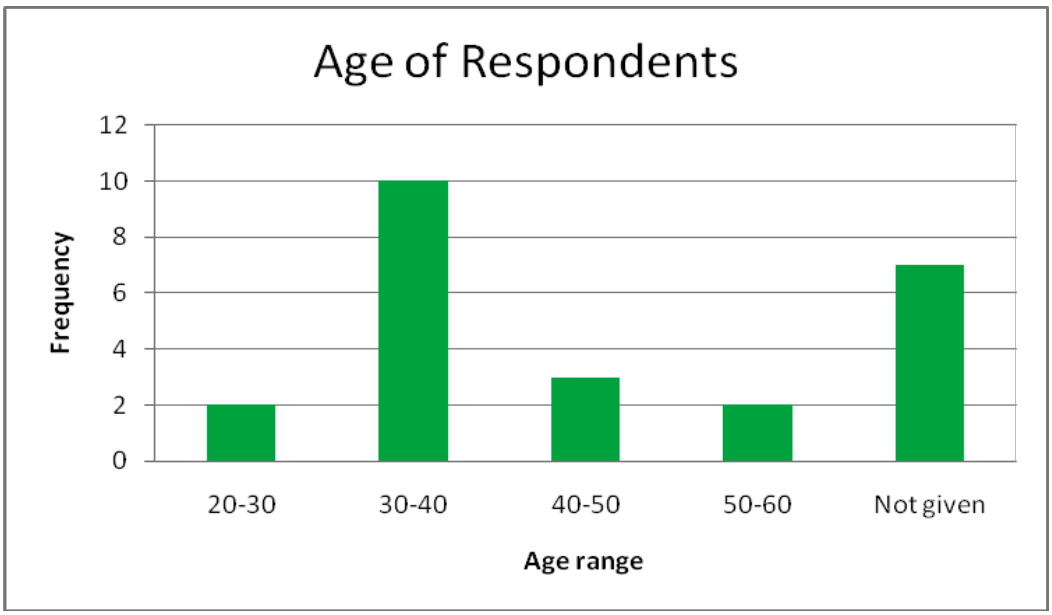
Sampling

A multi-stage sampling procedure was employed in this study, with initial purposive cluster sampling to capture six key sectors involved in response to HIV in Nigeria: civil society; government agencies; development partners; organised private sector; and international non-governmental organisations. Organisations were purposively chosen from lists of organisations from each of the six clusters.

A total of 25 respondents from 22 organisations were sampled using the standard questionnaire developed by GNP+. Three people living with HIV were recruited and given a three-hour orientation on the use of the questionnaires following which they commenced data collection for the following two weeks. Twenty-five questionnaires were administered by the interviewers and three were self-administered. Three of the 25 interviewer-administered questionnaires were excluded from data analysis because of incompleteness and replaced with 3 other respondents to maintain the sample size.

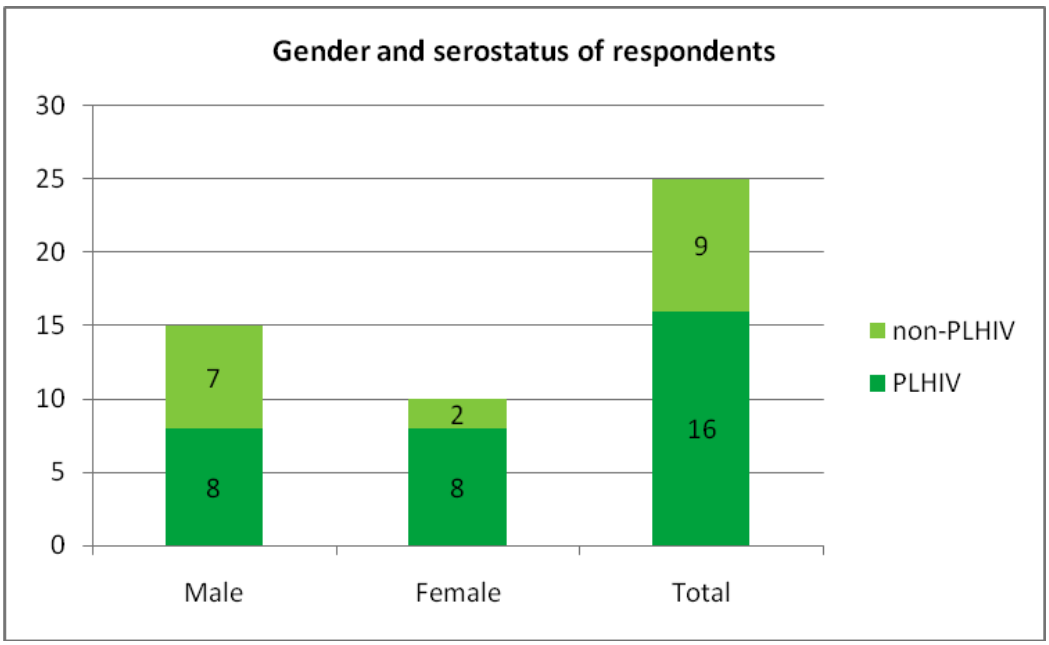
Profile of respondents and organisations

The age range of respondents was between 29 and 53 years with seven respondents not stating their age. The chart below gives a summary of the age of respondents.

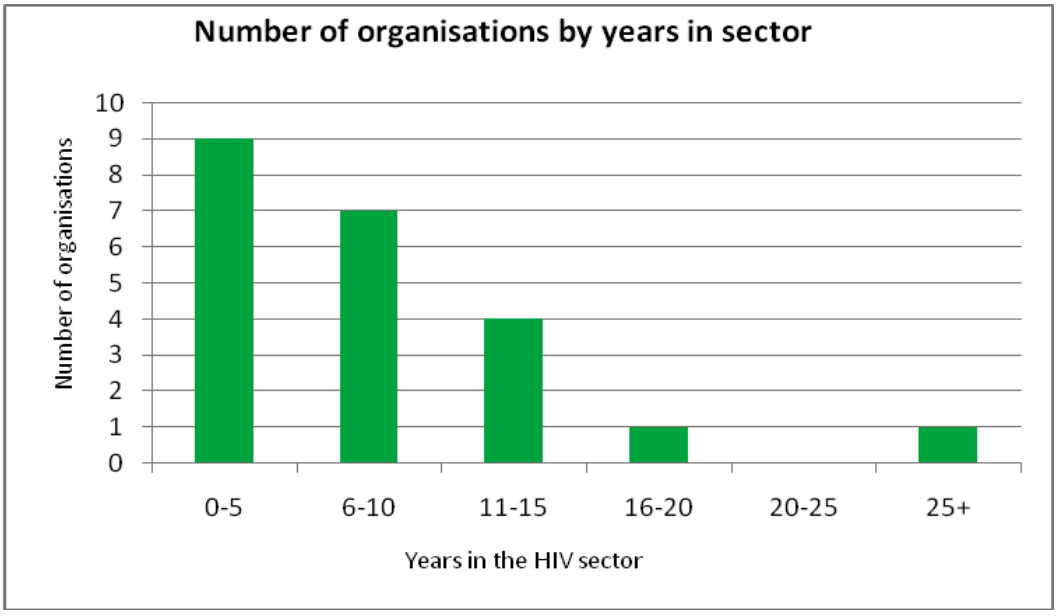


Nigeria

Fifteen of the 25 respondents were men and ten were women. Sixteen of the respondents were themselves living with HIV, and nine considered themselves not to be PLHIV. The chart below is a graphical representation of the respondents disaggregated by gender and serostatus:



A minority (36%) of the organisations which participated in the study have worked in the HIV sector for not more than five years. Only one has worked in the sector for over 25 years. The following chart summarises duration of work in the HIV sector for all contributing organisations.



GIPA Report Card

List of organisations that participated in the study and their annual budgets						
	Organisation	**Type of organisation**	**Annual Budget (₦)**	**Organisational mission and target groups**	**No of known PLHIV working in the organisation**	**GIPA discussions held**
1	Association of Positive Care	PLHIV support group	4 million	To provide care to PLHIV in the Community, especially nutritional support	5	Yes
2	Association of Positive Youths In Nigeria	PLHIV support organisation	10 million	To lead the efforts of mitigating the physical, psychosocial and economic impact of HIV & AIDS among young people living with HIV and affected by HIV & AIDS through information sharing, education, advocacy, capacity building & economic empowerment.	3	Yes
3	Association of Religious Leaders Living with or directly affected by HIV And AIDS in Nigeria (NINERELLA+)	PLHIV support organisation	13 million	To engage and empower religious leaders living with HIV and AIDS to be models of positive change within their faith communities.	2	Yes
4	Association of Women living with HIV/AIDS in Nigeria	PLHIV support organisation	30 million	Support organisation for women PLHIV	4	No
5	BBC World Service Trust	International NGO	Undisclosed	The media play an important role in the mitigation of HIV/AIDS, hence we see ourselves as an important actor in sustainable development efforts	Not stated	Yes
6	British Department for International Development (DFID)	Foreign donor	30,000 million	Our global mission is to eradicate poverty and our programmes are structured to intervene in issues associated with poverty. In Nigeria the strategy anchors on the national poverty reduction strategy (NEEDS).	0	No
7	Center for Development and Population Activities (CEDPA)	Development Agency	225 million	To mobilise and equip women and their families to achieve equality at all levels of society.	0	Yes

Nigeria

8	Civil Society on HIV/AIDS in Nigeria (CiSHAN)	Civil Society Organisation	150 million	Not stated	0	Yes
9	Diversity Support Group (DSG)	PLHIV support organisation	Undisclosed	To serve positive lesbian, gay, bisexual an transgender(LGBT) communities in Nigeria: • to create a favourable environment for HIV positive men who have sex with men(MSM); • provide information on HIV/AIDS to LGBT communities • provide information on sexual and reproductive health & rights • increase key stakeholders' support for positive MSM communities; and • strengthen referral system between health facilities and MSM support group.	4	Yes
10	FAHUZ Youth Group	PLHIV support organisation	1 million	Impact mitigation & involvement of people living with HIV/AIDS, especially for children, young people and women	4	Yes
11	Joint United Nations Programme on HIV and AIDS (UNAIDS)	UN	225 million	UNAIDS focuses on mobilizing leadership and advocacy for effective action on the HIV epidemic in partnership with all stakeholders and advocates the involvement of most at risk populations in the national response. It also provides strategic information and policies to guide the AIDS response at all levels, while mobilizing financial, human and technical resources to support effective response. In addition, it engages civil society and develops partnerships as well as monitoring the Epidemic.	1	Yes
12	Journalist Against AIDS (JAAIDS) Nigeria	Civil Society Organisation	Undisclosed	To mitigate AIDS through capacity building & training; GIPA officer is focal person in some projects.	0	Yes

GIPA Report Card

13	Katsina State Action Committee on AIDS	State government	Undisclosed	Prevention and coordination awareness, voluntary testing and counselling, medical and psychosocial care, advocacy and support for PLHIV in Katsina State	Not stated	Yes
14	Linkpoint Resources International Limited	Private Sector	Undisclosed	To be the best brand activation company by 2012. Very open and supportive to issues of HIV.	0	Yes
15	Nigeria AIDS Research Network (NARN)	Civil Society Organisation	16 million	NARN is contributing to the prevention, control and management of HIV/AIDS and STI infection in Nigeria by promoting evidence-based policies and interventions	In process	Yes
16	Network of People living With HIV/AIDS in Nigeria (NEPWHAN)	National PLHIV network	200 million	National PLHIV network; particular focus on children, youth and women.	Yes	No
17	Nigeria Business Coalition Against AIDS (NIBUCAA)	Civil Society Organisation	Undisclosed	To prevent the spread and mitigate the impact of HIV & AIDS in the private sector as well as positioning members to contribute to the national response in their host communities	1	Yes
18	Oyo State Action Committee on AIDS	State AIDS Council	Undisclosed	State AIDS Council Serves general population (not high-risk groups)	0	Yes but not actioned
19	Society for Family Health (SFH)	NGO Principal Recipient for Global Fund for AIDS, TB & Malaria	1,000 million	To empower Nigerians, particularly the poor and vulnerable, to lead healthier lives. Working with the private and public sectors, SFH adopts social marketing and behaviour change communication to improve access to essential health information, services, and products to motivate the adoption of healthy behaviours.	5	Yes

20	The Nation Newspaper	Private Sector	Undisclosed	To be Nigeria's newspaper of first choice among readers. Provision of information to the general public on the need to be free and self governing in a democratic society; service as an independent monitor of power and holding those entrusted with its exercise accountable	0	Yes
21	United Nations Population Fund (UNFPA)	UN	Undisclosed	To make every person count irrespective of the gender or sex. To promote sexual health and rights.	Not known by respondent	Not known by respondent
22	Yaresh Cleaning Services	Private Sector	Undisclosed	To be the best-preferred cleaning agency	0	Yes

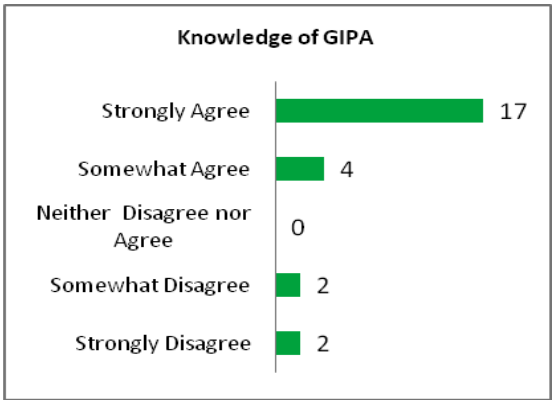
GIPA Report Card Results

Q1. GIPA Knowledge

Respondents were asked to what extent they agreed or disagreed with the statement:

> **"I know that the GIPA principle means meaningfully involving PLHIV in the programmatic, policy and funding decisions and actions that impact on our lives by ensuring that we participate in important decisions"**

The majority of respondents strongly agree they know this whilst only 16% either somewhat or strongly disagree.



"Meaningful involvement of PLHIV" was interpreted in various ways by respondents. However, a dominant view among respondents is that they understand the statement to mean opportunity for PLHIV to play an active role in decision-making related to policy and programme development and implementation at all levels of the national response to HIV and AIDS. Two respondents defined such decision-making processes to include resource allocation to HIV and AIDS programmes. One respondent included evaluation of policies and programmes as integral components of the meaningful involvement of PLHIV. Their comments follow:

> *"Meaningful involvement of PLHIV means involving PLHIV at all levels of HIV programming policies and activities".*

> *"Giving the PLHIV themselves the opportunity of having the driving force to take part in the fight against HIV and how it affects them, by empowering them to make an informed decision in policy formulation process in regard to the National response strategy"*

> *"The principle allows for the inclusion of PLHIV in the planning and implementation of policies and programmes, as well as participation in key decision making processes on issues concerning them and the overall response to "HIV"*

"It means that PLHIV are in charge of their situation. They are involved in decision-making procedures that affect their lives".

From the above, respondents seem to be saying that meaningful involvement of PLHIV entails deliberate effort by government and stakeholders to stimulate, promote and support influence of PLHIV upon policies and programmes in public and private sectors, and at national and sub-national levels.

Some respondents went further to include the element of leadership roles for PLHIV in their description of what they understand by meaningful involvement of PLHIV. For example:

"PLHIV being in the driving seat in policy and programme issues that concern them. NEPWHAN is in the driving seat of the anti-discrimination bill process where they canvassed against criminalisation of HIV transmission in the proposed bill".

"…allowing persons living with HIV/AIDS to take the driving seat in the strategic decision-making process as it relates to the HIV/AIDS response"

These respondents seem to be saying that beyond inclusion and participation of PLHIV, meaningful involvement will be better actualised when PLHIV take the lead in promoting their cause and giving strategic direction to the national response to HIV and AIDS.

When asked to describe the current situation at national, state and/or community regarding the involvement of people living with HIV in the response to HIV, the majority of the respondents acknowledged that appreciable achievements have been recorded in this regard especially at the national level. These achievements are in the areas of:

- representation of PLHIV in NACA, SACA and LACA boards;
- implementation of the GIPA in the workplace programme;
- participation of PLHIV in HIV and AIDS policy and National Strategic Framework review processes; and
- resource allocation to impact mitigation interventions in national HIV and AIDS projects.

However almost all who hold this view add that more still need to be done at all levels to meet their expectations in relation to GIPA:

"PLHIV actively participated in focus group discussions conducted during the review of the National HIV/AIDS Policy. They also participated in the development of the National Strategic Framework (II) at national and state levels. They also participate in NACA, SACA, LACA, CCM and Civil Society governance boards".

"Though UNAIDS in collaboration with the Business Coalition (NIBUCAA) and Society For Family Health (SFH) trained and engaged 20 HIV persons in small and medium scale enterprises. This level of implementation can be improved. UNAIDS and other partners are engaging multinational companies and other private sector entities through NIBUCAA to ensure implementation of the GIPA principle by private sector players. There is also a certain level of implementation of GIPA by government at the national level".

"So far, so good, but we need companies to provide an enabling environment for PLHIV to come out and be open about their status. More opportunities need to be provided for meaningful employment for professionals infected with HIV".

On the other hand, a good number of the respondents hold contrary views on the current situation of PLHIV involvement in the response to HIV. Generally they are of the opinion that PLHIV involvement is still practised as mere tokenism, especially at state level. Some of the views expressed by such respondents are captured below.

"In [my] state, the GIPA principle is just on paper that never sees the light of the day. PLHIV are only called and used during planning but are not carried along/dumped when it comes to implementation especially on issues of funding decisions and project implementations. The state coordinating mechanism (SACA) seems not to believe in the GIPA principle".

"Most organisations do not have people living with HIV on their pay roll. They do not want to employ PLHIV. PLHIV are not fully involved in policy formulation that affects their health"

"It is not very prominent in the state where I operate from because non PLHIV still dominate establishments running HIV and AIDS issues".

"There is not enough participation of people living with HIV in a proactively involving way in policy formulation and implementation. Most organisations do not lay claim to the employment of people living with HIV".

"Not really meaningfully involved but the act of tokenism is very much".

Some of these responses reaffirm the presence of a structural framework to promote GIPA in Nigeria through legislations and policies establishing NACA, SACA, LACA and CCM which provide for representation of PLHIV on their boards. Some also reflect the fact that the reviewed national HIV and AIDS policy and the national strategic framework (2010 – 2015) identify roles for PLHIV organisations in the national response.

Nigeria

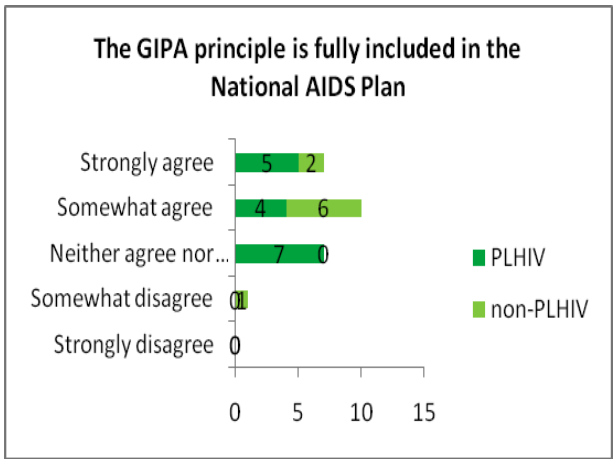
Whilst these are clearly commendable, some responses suggest that their impacts are yet to be felt by PLHIV across the country. There are varying levels of implementation particularly at the state level, and poor communication of the provisions of the legislations, policies and plans amongst PLHIV to facilitate advocacy leading to their translation into meaningful action.

NEPWHAN has a key role to play in this regard through communication and capacity building in GIPA and advocacy for its member organisations across the country. A broad-based GIPA plan with adequate funding and measurable targets holds some potential to actualise this. It is also clear from the responses that more also needs to be done by government and other stakeholders to improve on the current situation.

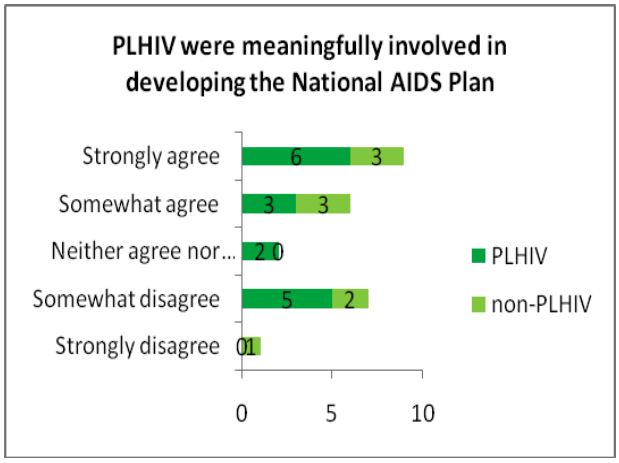
Q2. National HIV/AIDS Strategic Plan

When asked to what extent they agreed or disagreed with the statements below, respondents gave the following corresponding responses:

The GIPA principle is fully included in the National AIDS Plan

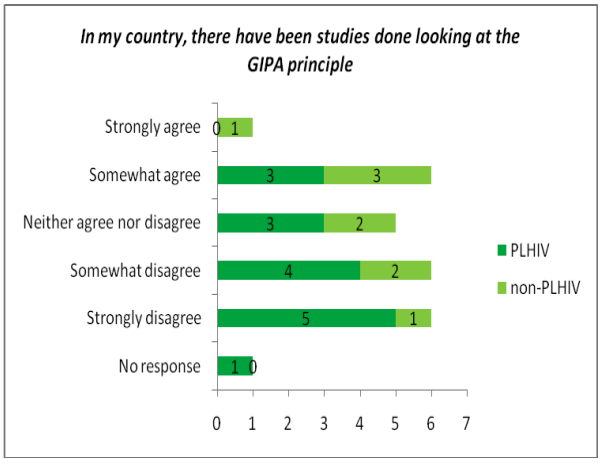


PLHIV were meaningfully involved in developing the National AIDS Plan

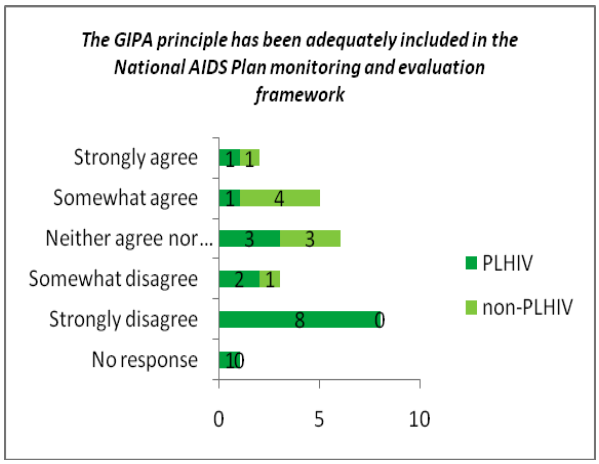


GIPA Report Card

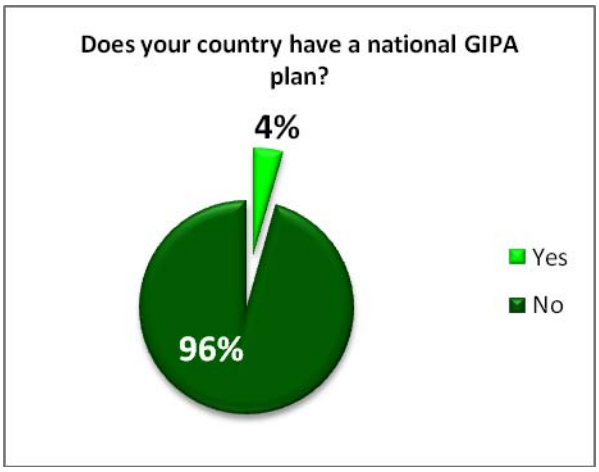
In my country, there have been studies done looking at the GIPA principle



The GIPA principle has been adequately included in the National AIDS Plan monitoring and evaluation framework.



Does your country have a National GIPA Plan, National GIPA Guidelines or equivalent?



The level inclusion of GIPA in the National AIDS Plan met with general agreement. Some respondents considered that perhaps people living with HIV should have had more input, particularly into the monitoring and evaluation framework.

Nigeria

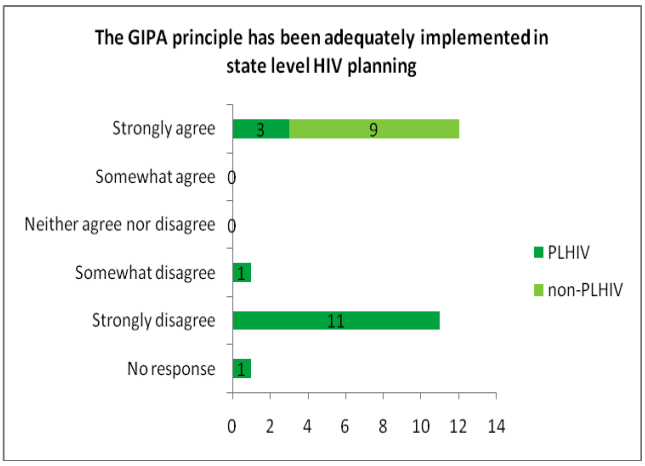
When asked *"Are the National AIDS Plan and/or National GIPA Plan adequate? Do they have allocated budgets? How have they been put into action? How could they be improved?"*, respondents indicated the following:

> *"No implementation for GIPA plan"*
>
> *"The National HIV/AIDS plan in place has the budget centred around the workplace. I will advise that GIPA also look into the plan of empowering individuals both PLHIV and people affected by HIV and AIDS"*
>
> *"We do not have any National Plan on GIPA in the country".*
>
> *"For the ones that I know that practice it they have limited budget line. Most of the practices are limited to the issues of employment. It could also be scaled up to issues of education in terms of promoting self employed people".*
>
> *"Nigeria has no GIPA plan"*
>
> *"The National GIPA plan, if at all is available are not widely circulated and I don't think is adequate. A good example is National NEPWHAN or State branch of NEPWHAN that do not have any budgetary allocation from the National/State coordinating mechanism or ministries of health".*

Q3. GIPA at State and Provincial Levels

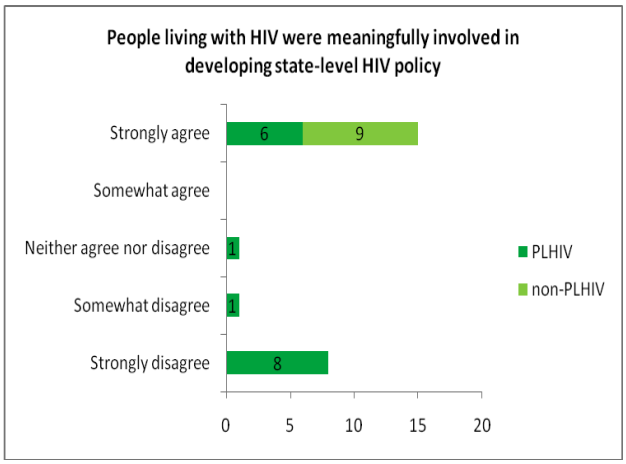
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

The GIPA principle has been adequately implemented in state level HIV planning.



GIPA Report Card

People living with HIV were meaningfully involved in developing state -level HIV policy.



In contrast to views on the National AIDS Plan, covered in Question 2 above, opinions were strongly split concerning the implementation of GIPA at state level. Here, people living with HIV felt that meaningful involvement by people living with HIV into state AIDS policy was very much lacking, and that the states had not implemented the GIPA principle in general. It is interesting that all of the non-PLHIV respondents were much more positive on this point.

Respondents made the following comments on the application of the GIPA principle at the state or provincial level. Here there was no great split between people living with HIV and other practitioners: almost all said that much more needed to be done:

"It is nonexistent at this level".

"No GIPA principle in Nigeria except through the few initiatives implemented by NIBUCAA and Society for Family Health (SFH)".

"GIPA principle is not deepened at the state and local government level".

"It has not been really implemented except for states that have strong state action committees on AIDS (SACA)".

"GIPA is a visible principle if accepted and implemented".

"It should be extended to the state level with a lot of follow-up for a better implementation".

"There is no potential commitment to the GIPA principle at the state Level".

"PLHIVs are participants".

Nigeria

"The state SACAs have gotten some support from donor agencies & state governments have also supported"

"Needs to be improved and given the adequate publicity it deserves".

"Tokenism"

"Gradually coming up but much could still be done"

"It is nothing to write home about"

"None"

"Not existing"

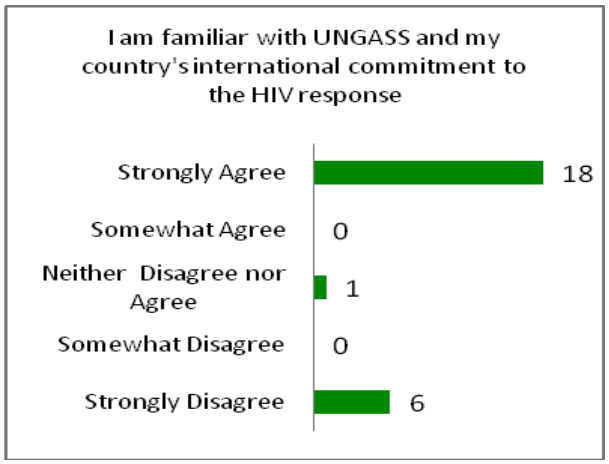
"The state SACAs need to be mandated from the national response coordinating mechanism to implement GIPA principle as most states are insincere with its implementation".

"The whole essence of GIPA has been reduced to mere rhetoric and not practical implementation at the state level. PLHIV are yet to be meaningfully involved in policies, programmes and issues that concern them. GIPA cannot be effectively implemented without a national GIPA plan. There is also need for a study to inform the plan development".

Q4. United Nations General Assembly Special Session on HIV/AIDS (UNGASS)

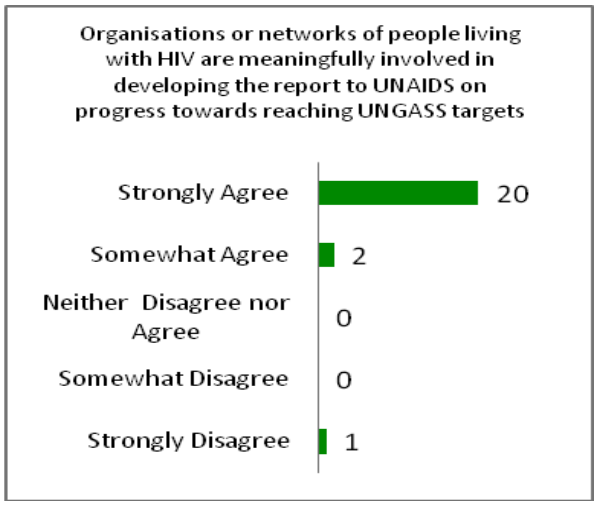
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

I am familiar with UNGASS and my country's international commitments to the HIV response.



GIPA Report Card

Organisations or networks of people living with HIV are meaningfully involved in developing the report to UNAIDS on progress towards reaching UNGASS targets.



Respondents commented as follows:

"HIV responses are not so impressive".

"My country's international commitments to the HIV response are not impressive".

"The fact is these are not properly done because there are lapses".

"They should involve PLHIV more on the policy formulation and implementation to reduce infection".

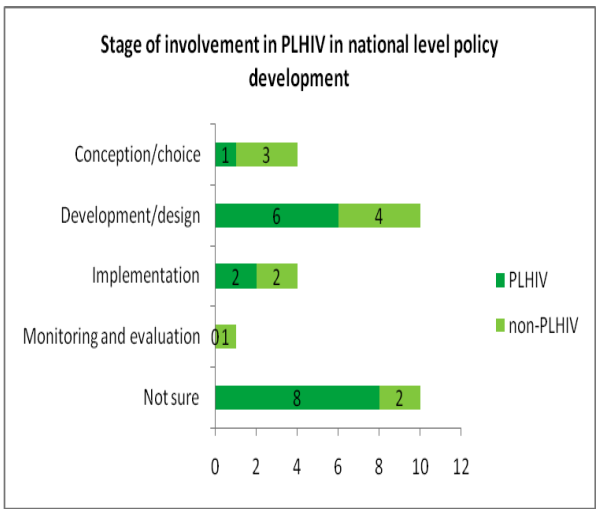
"There are little involvement of persons living with HIV in terms of policy implementation and formulation".

Q5. Policy Development

When asked about policy development, respondents indicated the following:

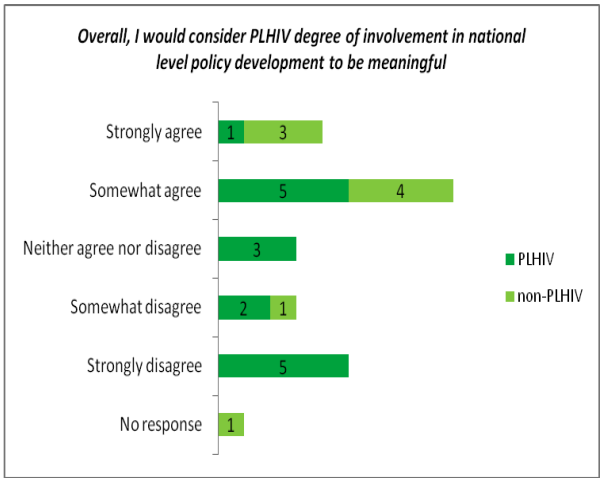
At what point are people living with HIV most often first involved in national level policy development?

These figures total to more than the number of respondents because one person chose development and design and implementation, and one chose all four options.



Nigeria

Overall, I would consider PLHIV degree of involvement in national level policy development to be meaningful.



Feelings were mixed about the meaningfulness of this policy involvement. The view that PLHIV are not as involved in monitoring and evaluation of the policy as they should be emerged again here, and there seems also to be less involvement than perhaps is desirable at the conception stage, and in policy implementation. However, many felt that there is involvement at the stage of policy design and development.

Respondents provided the following examples and comments on the above questions:

"Young people living with HIV are not recognized by the National AIDS control Agency in Nigeria".

"The umbrella associations of PLHIV are involved in programming and policy development by NACA".

"They have been involved in all the process only that the level of involvement varies at all times. The involvement of PLHIV is evolving but it is increasing compared to previous years".

"We have those that are HIV positive who are experts and makes difference in National policy".

"PLHIV are usually involved at the implementation stage. They are the ones affected and also know how to implement like the formulation of support groups which was constituted by the PLHIV themselves to encourage those who are infected that all hope is not lost living positively".

"NEPWHAN was involved with other civil society".

"It is still limited to the implementation by SFH and NIBUCAA in Kaduna and Lagos respectively".

"A representative of PLHIV is always involved in programme conception development and implementation".

"Most policies are developed from the top and passed down to the bottom".

"Donor programmes respond to HIV and AIDS issues using programmes designed without any form of input from PLHIV who are the target beneficiaries of such programmes and projects".

"As I said earlier, most of PLHIV involvement are mostly at developmental/design level but when it comes to implementation and decision-making about funding PLHIV are mostly not well represented or taken into consideration".

When asked "Have women living with HIV, and HIV positive women's networks and organisations, been in involved in national level HIV policy development? Has this involvement been effective?", respondents described the following:

"Not at all levels".

"Not really and not involved in policy issues".

"I know women's HIV networks exist but cannot really explain their level of involvement".

"All I can say is that the level of involvement is still evolving".

"Women living with HIV have to some extent trying to get fully included in the HIV policy development. This will be very effective if they are allowed to take the lead in the HIV policy development. They have done well in this regard too".

"Yes they have been involving them but their involvement is not meaningful".

"Yes. Women networks have been involved in national level HIV policy development".

"Yes but I am not in a position to address the effectiveness or otherwise".

"Yes but needs improvement".

Nigeria

"They have been involved to a limited extent".

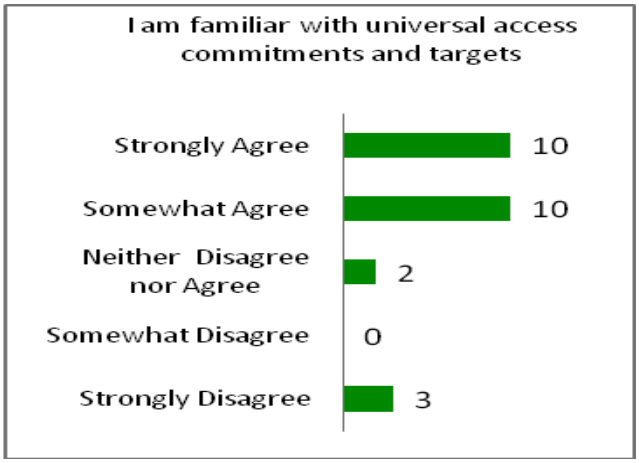
"No they have not been involved".

"There has been improvement in involvement of women living with HIV recently".

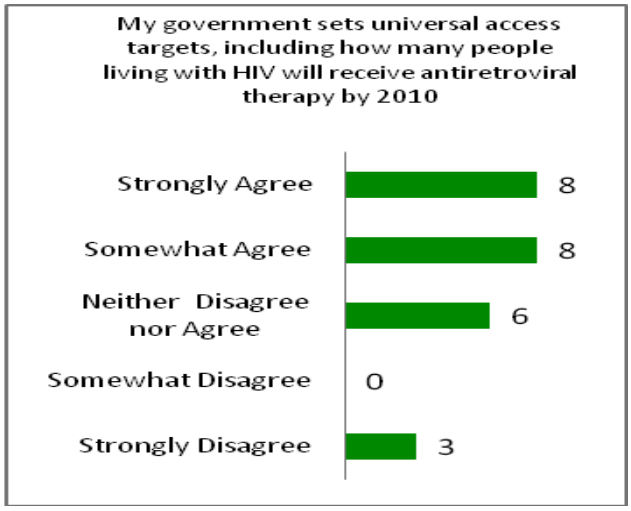
Q6. Universal Access

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

I am familiar with universal access commitments and targets.

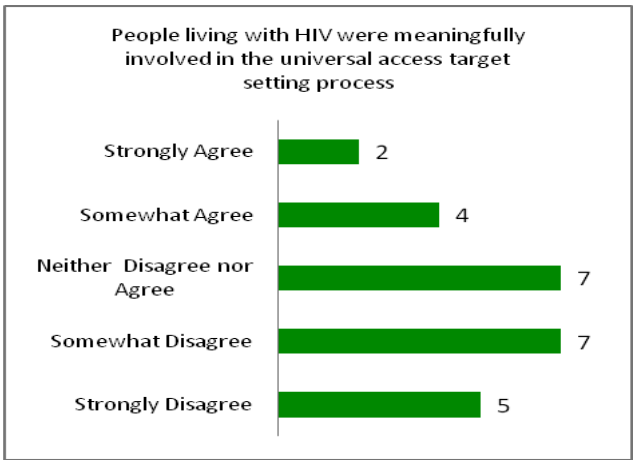


My government sets universal access targets, including how many people living with HIV will receive antiretroviral therapy by 2010.



GIPA Report Card

People living with HIV were meaningfully involved in the universal access target setting process.



When asked "Please comment on the above questions and the following questions: *What are barriers to achieving targets? What would help to achieve those targets? What is working well? Also please include information on drug quality and regularity of supply",* respondents described the following:

"The barrier to achieving targets is that the government do not have the political will"

"Government lack of serious commitment to achieving set targets."

"Government has not shown enough commitment to universal access. International donor agencies are largely responsible for expanding service outlets for ART, care and support services while government support is minimal."

"The fact is I am familiar with the universal access, but these things are not properly done, there are some community-based organisations that they can work with, but they are not identifying with PLHIV and that is causing barriers. Integrity positions and organisations will help to achieve the said targets."

"Get PLHIV more involved. "

"Poverty, stigma & discrimination"

"Our government is not committed."

"Government is not serious to set targets."

"The barrier to achieving targets is that government itself does not have the will or commitment."

Nigeria

"Barriers	*- Hard to reach communities* *- lack of ARV centres"*
"Major barriers:	*i. The complexity of Nigeria as a whole is really a barrier. But setting the target has been helpful* *ii. The targets have mainly been donor driven. So they were set based on PEPFAR funding. The government has not been on the driving seat* *iii. No national policy statements to really drive the process* *iv. Inadequate number of testing sites*
What will help:	*scaling up testing sites,* *Government being at the driving seat*
What is working well:	*I think having the national policy in place has helped in setting direction for intervention. The contribution of the global fund is also helpful. Because the drug supply has been PEPFAR and Global Fund driven it has helped to guarantee the quality of drug supply. The snag is the compliance of the users to quality/standard of usage. This is also affected by the level of poverty and nutrition of the recipients."*
"The Barriers	*i. Drugs not readily available* *ii. Lack of trained health workers* *iii. Health centres are not accessible* *iv. Poverty (not being able to afford drugs)* *v. stigma and discrimination* *vi. lack of good roads to access health services*
Achieving targets	*- Drugs should be made available at all the facilities, at the national, state and local level and in good time* *- All facility health workers should be properly trained* *- Health centres should be located where people can easily access them* *-The issue of poverty has to be addressed, employ PLHIV so that they can cater for themselves* *- Stigma and discrimination policy should be put in place and in use.* *- Put in place good roads leading to the facilities*

GIPA Report Card

What is working well	*People are beginning to know more about HIV (awareness very high)"*
"The Barriers	*- the bottleneck of government is not making the target work* *- lack of strong political will* *- inadequate distribution of the ARV services*
What would help	*- If the treatment services can be delivered by the primary health care institutions in the country the target would have been reached."*
"Barriers	*1. stigma and discrimination* *2. Accessibility to health facilities* *3. Availability of drugs* *4. Lack of manpower*
To Achieve those targets	*1. Implement programs to reduce stigma and discrimination* *2. transfer of treatment services to secondary and primary health care facilities.* *3. recruit more hands* *4. Involvement of PLHIV and alternate hands in treatment*
What is working well	*Services at the tertiary health facility is working well* *Involvement of CSO on HIV awareness is also working well"*
"Barriers:	*Poverty*
What would help	*If the country's economy improves then poverty will reduce"*
"Barriers to achieving targets	*i) The present poor state of the National Health system and inadequate human resource and equipment* *ii) HIV services are not fully integrated in other health services* *iii) Primary Health care not fully involved with the delivery of HIV prevention, treatment and care services*
What is working well?	*-Treatment services are being successfully scaled up in a programme manner* *- NACA coordination role has improved progressively"*
"Barriers:	*inadequate funding; low capacity for effective response*

Nigeria

Facilitating Factors: *Increase budgetary allocation to HIV and AIDS;*
Build capacity for effective programme implementation at national and state levels.

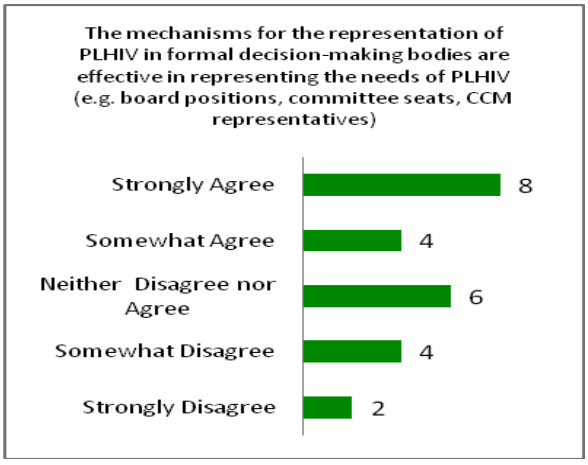
What Works: Access to ARV; Access to OI drugs"
One of the barriers to universal access to treatment is government insincerity to budget commitment of providing these services to PLHIV. Stigma and discrimination still pose barrier to access to universal treatment. Disparity in treatment centres across the country is another factor limiting access to universal treatment. These are the things that would help to achieve targets: Government commitment in terms of funding; treatment standardisation in all treatment centres; meaningful involvement of PLHIV."

Q7. Representation and Networks of People Living with HIV

When asked to what extent they agreed or disagreed with the below statements, respondents indicated the following:

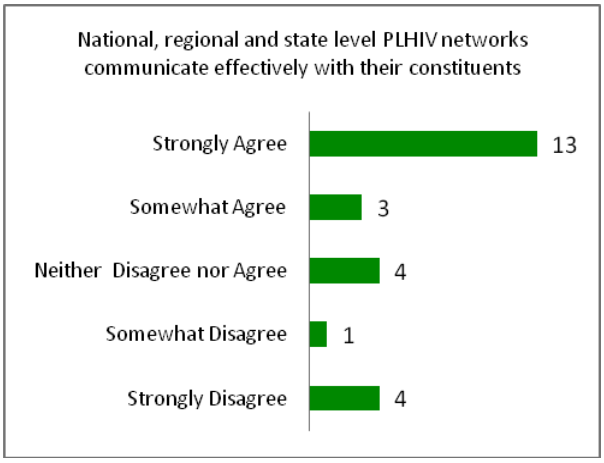
Formal PLHIV representation positions on decision-making bodies work to ensure accountability to PLHIV in my country.

These responses were fairly evenly distributed across respondents, irrespective of their HIV-status



GIPA Report Card

The mechanisms for the representation of PLHIV in formal decision-making bodies are effective in representing the needs of PLHIV (e.g. board positions, committee seats, CCM representatives).



Some respondents felt that the existing mechanisms were a success:

"The PLHIV network is trying and a best model of practice in the world".

"Network of people living with HIV/AIDS in Nigeria (NEPWHAN) has fully been involved in the decision making body representing all PLHIV in Nigeria and this is well coordinated because they are one body now".

"The national network of people living with HIV/AIDS in Nigeria (NEPWHAN) is a good example where information are being disseminated to states and even local support groups".

"The national networks are the closest constituents get to government, they are the ones that help plead our cases before government and donors".

Others disagreed:

"Young people living with HIV have no representative anywhere in policy and decision making board; not in the NACA board, not in country coordinating mechanism (CCM) – youth representative is by a negative youth and that is not GIPA. Nigeria has no GIPA principle in practice"

"In-fighting, rancour and selfish motives among the networks of PLHIV limit accountability and benefits accruable in the communities".

"PLHIV are not adequately represented at decision-making body level. With the institution of the Network of People Living with HIV in Nigeria, there is better coordination of their needs and demands from community to the state and national level".

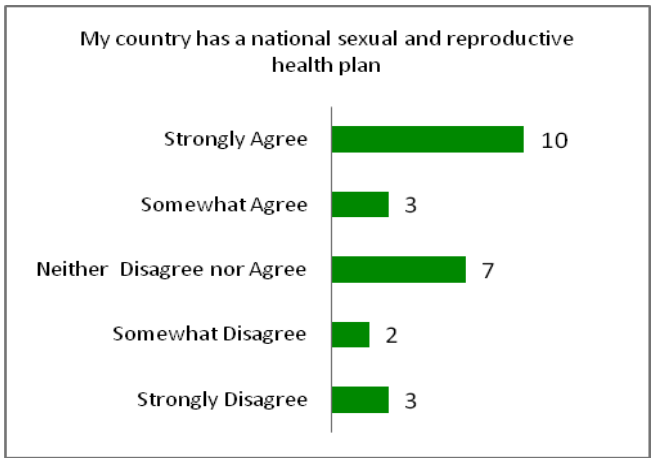
Nigeria

"While it is effective at national level, same cannot be said for state level representation"

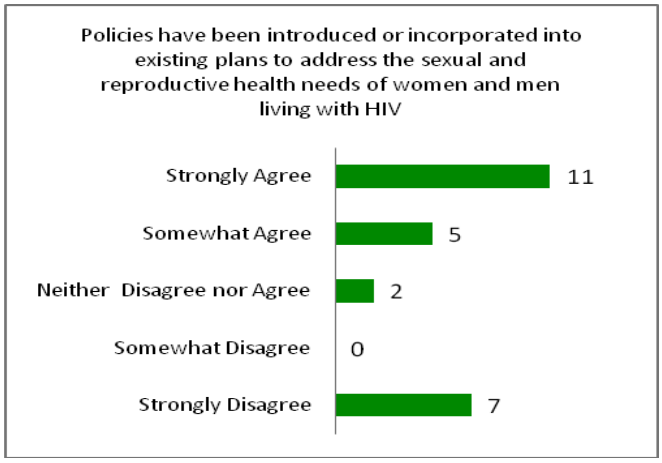
Q8. Research and Sexual and Reproductive Health

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

My country has a national sexual and reproductive health plan



Policies have been introduced or incorporated into existing plans to address the sexual and reproductive health needs of women and men living with HIV



These responses were fairly evenly split across both gender and serostatus.

When asked "Are people living with HIV involved in conducting research in your country e.g. in clinical trials and in the research and development new prevention technologies?", respondents stated:

"Not to my knowledge".

"I do not believe that"

"Clinical trials into the development of new prevention technologies have been suspended at the moment."

"Somehow, because they need their specimens"

"Some people came to our organisation sometime ago to collect blood samples from our members for research purposes".

"In most of the cases where research is done PLHIV were only being used and not involved"

"Yes but they are not being given proper hands and chances to carry out better research activities and prevention technologies method".

"Yes, because of the increasing involvement of civil society organisations like CISHAN, NEPWHAN, NYNETHA".

"The national sexual and reproductive health plans need to be reviewed"

Several spoke of the work on developing microbicides and other new prevention technologies:

"Researches are done on sexual and reproductive health as related to the HIV/AIDS issue in Nigeria. And with the clinical trials done which involves youths and especially women in the development of new prevention technologies like microbicides and lubricants".

"There are careful thoughts on research & programs on sexual & reproductive health issues targeting the infected population especially youths. There are also clinical trials especially on microbicides which have greatly involved women during the trial period in Nigeria. Currently there is a strong media campaign on family planning services sponsored by Society for Family Health".

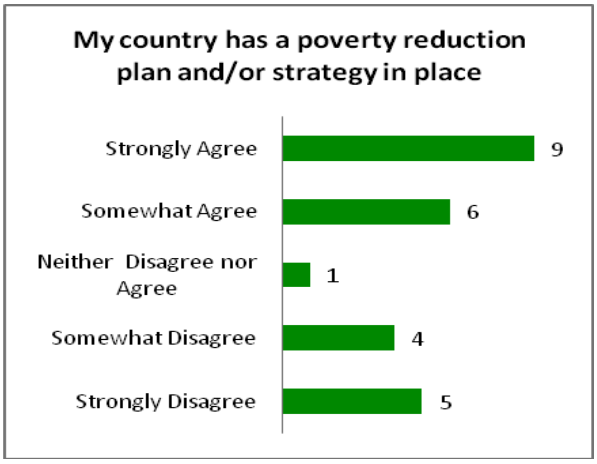
"During the microbicide training some PLHIV were involved in Lagos, Nigeria".

Nigeria

Q9. Poverty Reduction Strategies

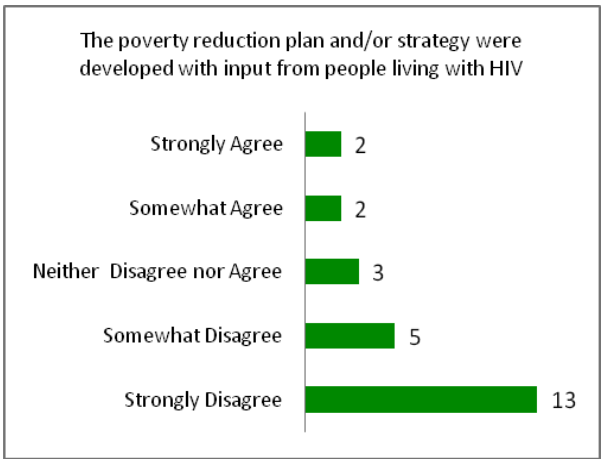
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

My country has a poverty reduction plan and/or strategy in place.

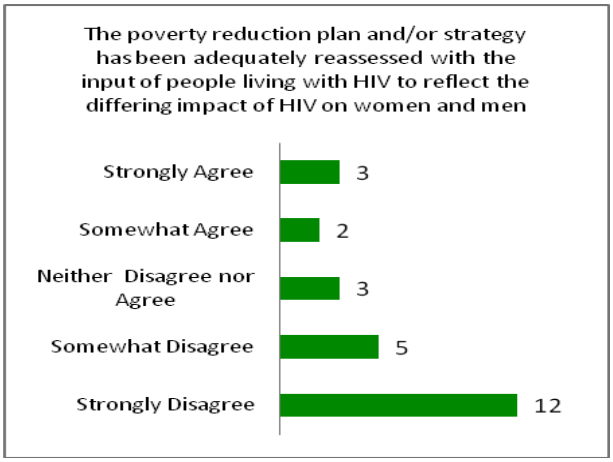


The poverty reduction plan and/or strategy were developed with input from people living with HIV.

14 of the 16 people living with HIV in the sample either somewhat or strongly disagreed.



The poverty reduction plan and/or strategy been adequately reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men.



Respondents provided the following additional comments:

"The government's agency for poverty eradication (NAPEP) has no specific programme targeting PLHIV. NAPEP has poverty eradication programs that target the generality of populace. Some development agencies however fund income generating activities (IGA) as part of the strategies for poverty reduction".

"The NEEDS II [poverty reduction plan] had a broad consultation compared to NEEDS I, but it is yet to be published and operationalised as other government plans like the 7-point Agenda, and Vision 2020 have overtaken its release".

"The poverty reduction plan or strategy should address PLHIV, both men and women, so it could go a long way to reduce poverty at all levels, the implementation process should be carried out well".

"Nigeria has the

"Proper implementation of the poverty reduction strategy utilizing the due process strategy would address the different needs or impact of PLHIV irrespective of gender".

National Poverty Alleviation Plan but PLHIVs were not involved or directly targeted".

"Poverty reduction strategies in place are not specifically targeted at PLHIV; they are targeted at the general population, e.g. NEEDS, SEEDS, NDE and NAPEP".

"This is what we have been clamouring for: that issues of HIV and AIDS especially women and gender matters to be integrated into all government poverty reduction plan/strategy. Involvement of PLHIV in developing poverty reduction plan/strategy is very important to achieve a good result. Take for example, a PLHIV with four children that is given N10, 000 as a business loan will not only get back to square one but will also not be able to pay back such money because he/she must have used the money to buy food/drugs".

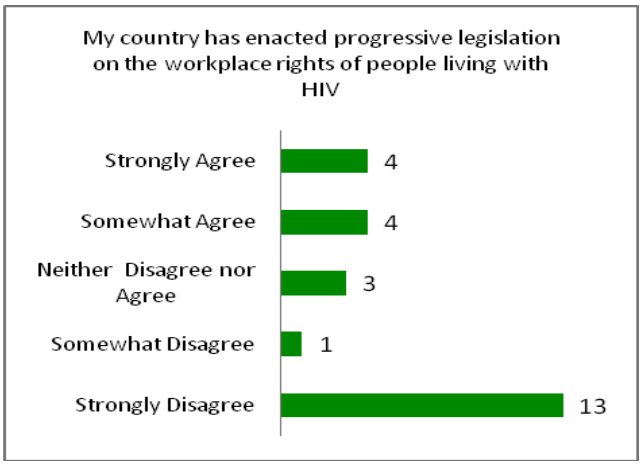
Nigeria

Q10. Employment

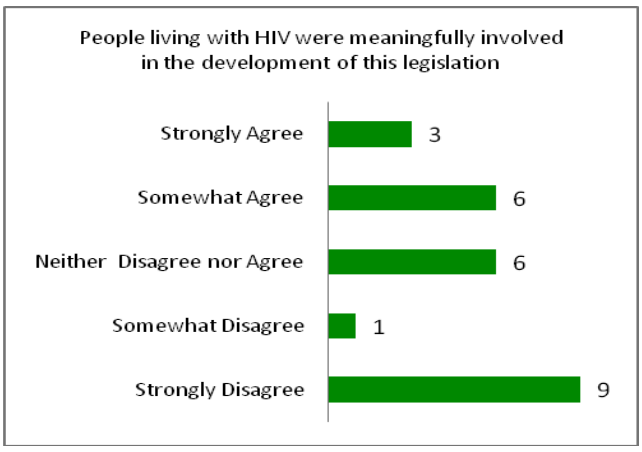
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

My government enacted legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work.

My country has enacted progressive legislation on the workplace rights of people living with HIV.



People living with HIV were meaningfully involved in the development of this legislation.



GIPA Report Card

When asked *"If you were in agreement with the last question, how were people living with HIV involved in the development of this legislation?",* respondents provided the following comments and specific examples:

Some said that both policy and budget were already in place or being set up:

> *"Yes. There is a budgetary allocation. For instance any staff who test positive will have access to ARV for a lifetime even when he/she no longer works with DFID".*
>
> *"Yes, the budget is already being put in place".*
>
> *"Yes. There is a budget line supporting their employment"*
>
> *"All budgets caters for people living with HIV/AIDS"*
>
> *"UNAIDS employs a PLHIV. This is in keeping with the UNAIDS policy".*
>
> *"Yes. People are not discriminated against on the basis of their HIV status. In addition nobody is maltreated if status is disclosed".*
>
> *"My organisation is purely an HIV organisation and everyone is PLHIV"*

Others reported policies unsupported by allocation of resources to implement them:

> *"My organisation has but there is no budget. The Ministry I do not know".*
>
> *"Yes. There is UN personnel policy on HIV and AIDS; there is however no budget".*
>
> *"The policy speaks to the issue but there is no financial backing through budgetary allocation"*
>
> *"Except at the federal level where this policy exists on paper, its practice at the state level is nothing to write home about"*

Interviewees were asked *"Are you a person living with HIV who is employed in a NGO, the government or United Nations organisation? If YES, what are some barriers you have encountered, and if applicable, what has contributed to overcoming these barriers?*

Some respondents reported no problems with barriers:

"My barriers have been minor and I have been able to deal with it because I have an understanding and encouraging boss".

"There is not any barrier encountered because it is with NGO".

"Yes, barriers encountered is not much because I am above work place stigma".

"Not applicable; employment is not based on serostatus".

"I was employed into my organisation not on the basis of my status".

Others were experiencing various obstacles:

"Yes I work with a private media organisation, and time and lack of funds are barriers I encounter in doing HIV/AIDS programming".

"Yes. Workplace and community stigma & discrimination; finance towards implementing GIPA; it is difficult to ensure input from religious leaders due to ignorance".

"The barriers are that staffs do not actively participate in HIV and AIDS activities because it is not included in their performance appraisals, trainings and orientation session become difficult to organise".

"Yes, stigma and discrimination"

"There are no barriers except for the stigma issue externally".

"My barriers are just the regular excuse of taking a day off from office for ARV uptake. To me [it would be better] if provisions are made for Saturday, for drug pickup to reduce stigma".

"My barriers are enormous no tools to work with where I am placed. Nothing has been contributed to overcoming it".

GIPA Report Card

Q11. GIPA-related Materials

When asked to what extent they agreed or disagreed with the statement below, respondents indicated the following:

My organisation has developed materials focused on the GIPA principle and the meaningful involvement of people living with HIV.

Respondents were asked: *"If in agreement with the above, are these materials being used by the government or other organisations? Please elaborate and provide specific examples of success below. If not in agreement with the above, why has your organisation not been involved in developing materials on the GIPA principle and the meaningful involvement of people living with HIV?"*

The following responses were given by those whose organisations had developed materials:

> *"The material is the GIPA compendium which comprises the details of trained GIPA officers and their biographies".*
>
> *"Yes, we distribute the materials to our programme implementers".*
>
> *"Our drama series and our intervention programs are geared towards these services".*
>
> *"My organisation has developed materials on the GIPA and MIPA and these materials are used by government and other organisations".*
>
> *"Posters are pasted to government offices and schools".*
>
> *"UNAIDS provides technical support for the development of these materials to relevant organisations as part of the UN learning strategy which is facilitated by*

Nigeria

UNAIDS in Nigeria, materials are regularly developed to aid workplace HIV and AIDS programs for staff and their families".

"Materials are produced from GIPA companies (IEC [information, education and communication materials], posters and other promotional materials)".

These were the responses given by those whose organisations had not (or not yet) developed materials:

"Because it has not actively imbibed the GIPA principle and, because of funding constraints"

"CEDPA positive living project targets PLHIV to improve quality of lives at the community level. Though GIPA principles are applied, there has not been a conscious effort to develop materials focusing on GIPA".

"Lack of financial resources and materials"

"Lack of funding and awareness"

"Funds meant for programme are channelled towards sustainable activities that cut across issues for people living with or without HIV/AIDS".

"We are yet to have capacity to develop these documents".

"The GIPA principle is not imbibed".

"Because of funding constraints the GIPA principle is not properly and actively incorporated".

"Lack of funding to develop such materials".

"Most of the state response/coordinating mechanism are insensitive to the issue of GIPA and only say it when they only want to use PLHIV to achieve their aims or get their data".

When respondents were asked to provide examples of materials on the GIPA principle that their organisations had produced, the following resources and materials were described:

"Banner"

"1. HIV and you: A guide for employees of the BHC. DFID and the British Council working in Nigeria.
2. Global HIV/AIDS strategy
3. A work place policy"

"Posters, films, drama & shows"

"UN Plus calendars and posters"

"We developed a compendium of PLHIV trained as GIPA Officers."

"Posters, leaflets, handbills"

"Posters, Flex banners"

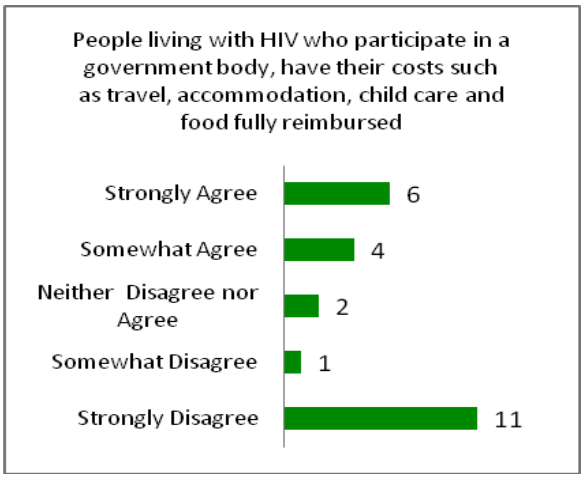
"IEC, Poster, Promotional"

"Posters, stickers, hand bands"

Q12. Financial Support

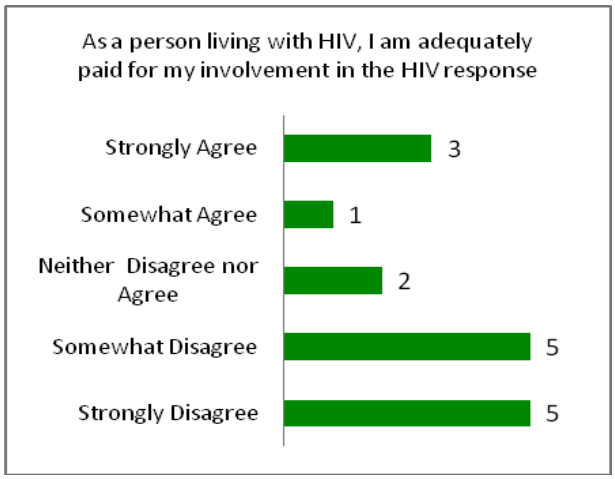
When asked to what extent they agreed or disagreed with the below statements, respondents indicated the following:

People living with HIV who participate in a government body, have their costs such as travel, accommodation, child care and food fully reimbursed.



Nigeria

As a person living with HIV, I am adequately paid for my involvement in the HIV response.



Respondents provided the following comments on the above questions. Those on a GIPA Officer stipend said:

"I am paid by Global Fund (a stipend of ₦40, 000) and this is really not meeting my demand, as I plan to further my education".

"Being paid by the Global fund as GIPA officer the stipend (40,000) is not sufficient to fully take care of my needs because of the inflation rate in the market and economy".

"As a GIPA officer I am not adequately paid for my involvement in the HIV response, as the stipend of 40,000 I am paid is not enough to take care of my needs and responsibilities".

"Global Fund pays my stipend which is not enough for ends meet".

Others commented on expense reimbursement:

"Government agencies and development organisations pay in full, costs such as travel, accommodation and per diem to PLHIV when invited to programs".

"Government does not reimburse".

"Not all government level reimburses".

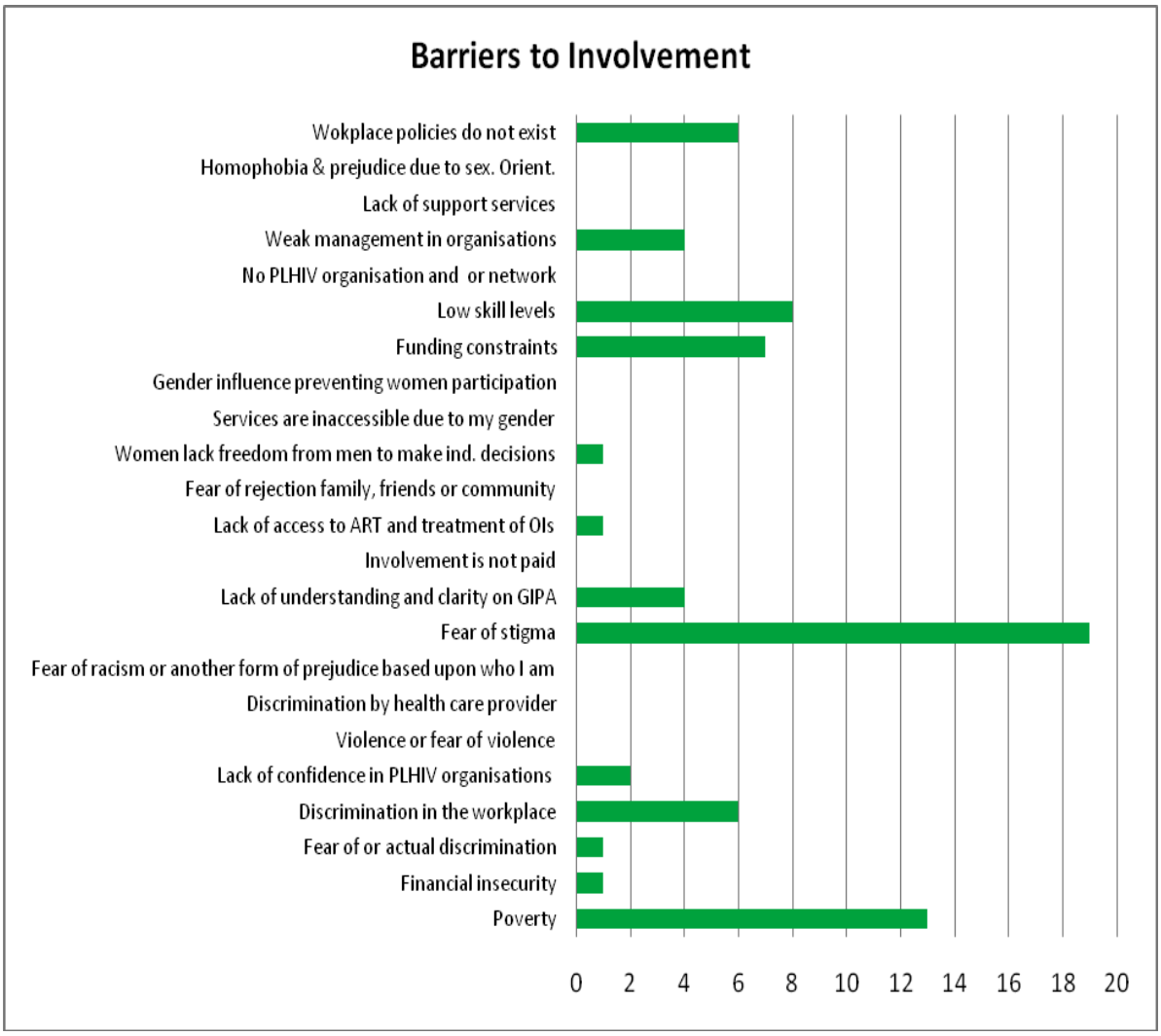
"Provision of funds for personnel during projects is very low".

One respondent commented on the fairness of current treatment of work by PLHIV at the state government level

"At state level, PLHIV are mostly used as volunteers and when sometimes demand for payment of their services they tag them as being too 'demanding".

Q13. Barriers to involvement

When asked to select what are the three greatest barriers to the greater involvement of people living with HIV, respondents indicated the following:



76% of respondents named fear of stigma as one of their three choices, and 52% selected poverty.

Respondents provided the following comments on the above questions:

"There should be HIV policies at all levels; the anti-stigma bill should be passed at all levels; there should be not just employment but meaning".

Nigeria

"Workplace policies do not exist; funding constraints; fear of actual discrimination; discrimination in workplace".

"When a person is discovered to be HIV positive is sent out of the office where he works which can lead to emotional trauma, fear of stigma can easily kill the person and not the HIV. The person might not be able to afford ARV or the payment for his/her opportunistic infection. Policies should be put in place to address all these by GIPA".

"We have not really sold the ideas of GIPA principles to the communities, government and private organisations in Nigeria".

"Due to lack of existing policies that guide on the rights of PLHIV there is fear of open comment to processes that could better the life of PLHIV; lack of understanding and clarity of what GIPA is; weak political commitment".

"Stigma is the worst issue that prevents people living the virus to come out openly to access services or jobs".

"Workplace policies do not exist (only in paper); the anti stigma bill is yet to be passed; fear of being discriminated; rejection from family".

"Low skills levels; lack of understanding and clarity on what GIPA is; fear of actual discrimination".

"There should be HIV policies at all levels; the anti-stigma bill should be passed at all levels; PLHIV should be fully involved in all aspects of HIV programming".

"Other barriers to GIPA in Nigeria are greed and insincerity. There is also lack of understanding and clarity on what GIPA is. The workplace policy only exists at the national level and is not monitored to be effective. Most of the states are yet to adopt the workplace policy. Private sector involvement in the GIPA principle is also low and poor".

Q14. Opportunities for involvement

When asked "What are the three current best opportunities for the greater involvement of people living with HIV in your country?" respondents focussed on fighting stigma and poverty, on enabling PLHIV organisations, and paid employment of PLHIV:

"Must be legislation on anti-HIV stigma and discrimination; rebates and tax incentives for companies and organisations that deliberately employ qualified people

living with HIV; providing adequate funding for HIV and AIDS targeted programmes that practically encourage and employ people living with HIV".

"The presence of a vast National Network of PLHIV; the recognition of this network by critical stakeholders like the government, donor agencies, etc; the availability of funding like the US Government, World bank, DFID etc".

"People living with HIV/AIDS fully participating in Government body; presence of Non- Governmental organisations advocating for rights of PLHIV"

"Awareness and to some extent knowledge; policy decision making and participation; to some extent getting employed especially by NGOs and donor agencies"

"Poverty reduction among PLHIV; creation of employment"

"Existence of a vibrant network of people living with HIV and AIDS; support from donors to support implementation of the GIPA principle; inclusion of the GIPA/MIPA principle in the National Strategic Framework".

"The GIPA principles have been established for stakeholders to key-in into; the Private Sector Response driven by NIBUCAA is up and running and is a good platform for actualising GIPA; SMEs are beginning to show interest in HIV/AIDS Workplace programmes".

"The national HIV policy is being reviewed. Therefore GIPA issues could be negotiated into the new policy; the second National strategic framework will be developed by the end of December 2009. There exists the opportunity to ensure that GIPA issues are addressed; state HIV programmes will be developed immediately after the national strategic framework has been reviewed. there is a opportunity to have specific activities in the state programme for GIPA".

"The success strategy of the current Global Fund implemented program; availability of skilled manpower to implement programmes; availability of systems to measure result".

"It enhances programme planning; it tends to achieve more result especially in HIV counselling and testing services; it promotes volunteerism and reduces stigma & discrimination".

Nigeria

"There should be an anti-stigma bill in all states; provide adequate funding on HIV/AIDS programming; encourage the existing GIPA officers with enhanced living wages: the stipend is not encouraging as we have children etc".

"Providing adequate funding for HIV/AIDS programme that employ people living with HIV; ensuring that all the states in the country to imbibe the workplace policy and discrimination bill"

"There should be an anti-stigma bill in all states; provide adequate funding on HIV/AIDS programming encourage the existing GIPA officers with improved living wages".

"Existing national policies and programmes, e.g. Revised National HIV/AIDS Policy and the NSF II; Existing network of PLHIV and Civil Society network on HIV/AIDS to promote GIPA; Existing human resource capacity to engage in surveys in support of effective GI[PA implementation".

"1) Mainstreaming issues of HIV/AIDS into poverty reduction plan/strategies both at national and state level;
2) Speedy passage of anti-stigma bill and enforcement of the law when in place;
3) Mandating all the state and local governments to adopt and implement the national workplace policy. Both public and private sector organisations should also be mandated to develop or adopt the national workplace policy;
4) Meaningful representation and involvement of PLHIV in planning/development design, implementation (programmatic/funding decision) and actions that will impact on their lives".

Discussion

It is clear from the results of this study that considerable strides have been made in Nigeria towards the meaningful involvement of people living with HIV in decisions affecting them as a group. NEPWHAN and other civil society organisations received praise, and the efforts of central government were also appreciated. It was noted that HIV awareness in Nigeria has increased substantially in recent years.

However, a number of substantial problems were reported. Some organisations working on HIV interventions are not interested in the participation of people living with HIV: this was identified as being a particular problem for state governments, though there were some honourable exceptions to this. Some organisations have passed policies, but there is need for worthy policies to be backed by adequate budgets for implementation.

It seems that many national organisations remain unaware that involving people living with HIV in their HIV planning is not just politically correct, but can have a major impact on the effectiveness and value for money of the programmes that result.

Many organisations which work on issues around HIV do value the involvement of PLHIV. However, while some PLHIV who work on this issue are appropriately paid for their contribution of their understanding of the local dynamics of the epidemic and of the stigma which derails so much well-intentioned programming, most are not. There may be several contributors to this problem, which is widespread outside as well as within Nigeria.

- It may occur partly because PLHIV workers are perceived as part of the beneficiary group of programming, who therefore under normal development practice should work as volunteers rather than being paid to be assisted. Organisations who employ PLHIV may in taking this perspective overlook the fact that PLHIV may not always be in good health or full strength due to either the effects of untreated HIV on their bodies, or the side-effects of antiretroviral treatment. PLHIV will also tend to have extra family responsibilities due to HIV itself: for instance many HIV are single parents due to the death of a spouse from HIV or abandonment on diagnosis. Expecting PLHIV to work as long-term volunteers is therefore less reasonable than asking the same of an HIV-negative worker.
- Another possibility is that PLHIV often come from marginalised groups and are thereby disadvantaged in negotiations with those in positions of power. However, if organisations work on HIV, they should certainly ensure that they do not act in an exploitative manner towards those that they are ostensibly trying to help.

- A further problem is tokenism: some organisations who receive external funding are expected to involve PLHIV as a matter of international best practice, but the staff executing the programmes may not consider that this is useful or appropriate, or may not want to reduce the funds available to their organisation by paying outsiders. Where the donor requires that PLHIV be involved, the result is often that PLHIV are asked to contribute to satisfy contract conditions and fulfil grant proposals, but their views are undervalued and persistently sidelined, and they are not paid properly for their essential contributions. Engagement of PLHIV as unpaid workers for key roles in policy-making and programming (when it may be a condition of funding) may reasonably be seen as exploitative when this arrangement is set up by salaried HIV-negative professionals who themselves make a good living and an enviable career from their working in the HIV response.

Respondents listed stigma as the most significant barrier to the full participation of PLHIV in the Nigerian response to PLHIV. It is to be hoped that the work on the Stigma Index which is now being undertaken by NEPWHAN may offer some guidance on how stigma may be reduced and GIPA thus increased. A research paper by Okemgbo and Odimegwu (2004) carried out in Imo and Osun States demonstrates the magnitude of this problem in Nigeria: 45% of the sample interviewed said that they would reject an HIV+ family member, 10% think that PLHIV should not obtain any medical treatment, 58% consider that a PLHIV should not be allowed to hold a factory job, and 68% would discontinue schooling in a school attended by a PLHIV.

Interviewees listed poverty as the second worst barrier for GIPA. The poverty issue could be addressed to some degree by increasing access to ARVs without charge, by paying fair salaries for the specialist knowledge about the experience of living with HIV that PLHIV can bring to their work, and by strategic grants to allow PLHIV from poorer backgrounds, or whose livelihoods have been destroyed by stigma or ill-health resulting from their HIV infection, to develop skills to help them contribute. Donors and subcontracting NGOs who understand the immense value of a beneficiary perspective in achieving effective programming might undertake stronger efforts to persuade staff of organisations which do not see the value of this: merely imposing this condition, without explaining the benefits, or monitoring the outcomes, will merely heap the further insult of tokenism on those PLHIV who attempt to help others in their situation, and result in their time being taken up in trying to assist such organisations without being listened to or recompensed appropriately.
Nigeria has an active programme of poverty alleviation, but this neglects to take into account the multiple interactions between HIV and poverty, for instance:

- For young people especially, poverty can increase the risks of contracting HIV: this applies particularly to girls and young women who may enter into marriages or sexual relationships with much older men who can provide them with enough

money for school fees or basic living expenses;

- Where people are forced into selling sexual services because of poverty, they may swiftly contract HIV, and then pass it on to many others;
- The cost of ARVs and other medical care associated with HIV infection, where these are not available without charge, may drive PLHIV and their families into poverty;
- The death of a spouse may result in a large drop in family income;
- The costs of maintaining a household can be increased greatly by the need to support children and teenagers orphaned by the death of close relatives
- Stigma against PLHIV deprives many of their livelihoods and often results in destitution;
- Abandonment by their husbands can force women living with HIV and their children into poverty, especially when their difficulties are compounded by the effects of stigma in the wider community.
- Physical weakness and ill-health resulting from untreated HIV or the side-effects of ARVs can cut earnings dramatically.

Clearly poverty strategy in Nigeria should consider these interactions with HIV: inclusion of the views of PLHIV in policy and programme design would be a good way to commence this. It may be that UNAIDS, via UNDP, could assist in making these links explicit to decision makers, and thus enhance GIPA in policies and programmes which strongly affect PLHIV but are not explicitly directed at them.

There is a role for better information sharing among both PLHIV and HIV professionals in Nigeria: quite a few interviewees were not aware of key work that is being done on HIV programming or poverty reduction in the country. If the desire is to involve PLHIV more in these issues, then making both constituencies better aware of what is already done is a key step in moving towards improving it. Involvement of PLHIV in setting UNGASS targets appears to be an exception: almost all respondents were aware of UNGASS and considered that PLHIV had been able to contribute appropriately to this process.

Nigeria

Conclusion and Recommendations

While Nigeria has made great progress in recent years in addressing HIV, better impact could be achieved at less cost if the country's PLHIV were more effectively involved in contributing to policy and programme design. This study suggests that the main barriers are lack of awareness of the value of involving PLHIV in navigating the immense complexities of the social problems that HIV sets up as a generalised epidemic takes hold, lack of understanding of how best to incorporate the contribution that they can make, and the stigma and poverty which prevent many PLHIV from assisting decision makers and implementers in correctly targeting their resources. The result of the current situation is an avoidable waste of efforts and funds.

Recommendations which flow from the contributions of the HIV professionals who contributed to this report, the majority of whom are themselves living with HIV, are as follows:

- Firstly and most importantly, these findings should be presented to key players in the Nigerian epidemic. It would appear from the responses to question 5 that there is a gap in perception between those in charge of HIV programming and their PLHIV colleagues: the former feel that GIPA is doing well in Nigeria, but many of those most directly affected do not agree. It would be helpful to educate donors and implementers about the existence of this divide, and its consequences. Those organisational representatives who truly subscribe to the belief that PLHIV need to be involved if programming and policies are to be effective can use the information to ensure that their own organisations facilitate meaningful involvement, and act as advocates with other institutions that remain to be persuaded.
- Donors could use monitoring and evaluation to ensure that PLHIV involvement in the programmes they fund is both effective. Ideally they should require PLHIV involvement in both project design and monitoring an evaluation, as a condition for grants
- Donors should also act to ensure that the GIPA representatives in programmes where they encourage or require such participation are appropriately remunerated. It appears that it may be appropriate to reconsider the level of the 40,000 Naira stipend paid to GIPA staff from the Global Fund, since many commented that it was not providing a living wage.
- Training bursaries could be provided by interested donors to increase the number of PLHIV who have useful skills to contribute in HIV programming, in addition to their valuable perspective as "insiders" to the HIV epidemic.

- The value of incorporating PLHIV perspectives into poverty planning should be brought to the attention of NAPEP. This step could reduce both poverty and the spread of HIV in Nigeria.
- As well as involving PLHIV in research as its subjects, their views should be sought on how to carry out research interventions in the community. This could both improve the quality of the research carried out and reduce the possibility of it doing harm in the communities where it is carried out.
- Advocacy on stigma would not only reduce the amount of human rights abuse against Nigerian PLHIV, it would also facilitate the greater involvement of PLHIV in Nigeria's endeavours to prevent further spread of HIV and to treat those in need. PLHIV should review HIV prevention materials whenever possible to ensure that these will not provoke more stigmatisation: this is a key role for GIPA, but not one that is often highlighted.

References

1. Federal Ministry of Health (2007) 'HIV/STI Integrated Bio-Behavioural Surveillance Survey (IBBSS)'. Abuja, Nigeria
2. Federal Ministry of Health (2008), 'Technical Report: 2008 National HIV Sentinel Sero-Prevalence Survey among the Antenatal Clinics Attendees in Nigeria'. Abuja, Nigeria
3. Federal Ministry of Health (2009), 'NDHIS Quarter One Data' Abuja, Nigeria
4. National Action Committee on AIDS (2003), 'National HIV/AIDS Policy'. Abuja, Nigeria
5. National Action Committee on AIDS (2005). 'HIV/AIDS National Strategic Framework for Action (2005 – 2009)'. Abuja, Nigeria
6. National Agency for the Control of AIDS (2007), 'National HIV/AIDS Prevention Plan' Abuja, Nigeria
7. National Agency for the Control of AIDS (2009), 'National HIV/AIDS Strategic Framework (2010- 2015)'. Abuja, Nigeria
8. National Agency for the Control of AIDS (2009), 'National Policy on HIV/AIDS' Abuja, Nigeria
9. Okemgbo C.N. and Odimegwu C.O. (2004), 'International Conference on AIDS (15th: 2004: Bangkok, Thailand). *Int Conf AIDS.* 2004 Jul 11-16; 15: abstract no. ThPeD7787. Main author Obafemi Awolowo University, Ile-Ife, Nigeria
10. Stephens D. (2004), 'OUT OF THE SHADOWS: Greater Involvement of People Living with HIV/AIDS (GIPA) in Policy'. POLICY Working Paper Series No. 14 [online] Available at: http://www.policyproject.com/pubs/workingpapers/WPS14.pdf (Accessed: 5 January 2010)
11. UNAIDS (1994), 'The Paris Declaration Paris AIDS Summit' [online]. Available at: http://data.unaids.org/pub/ExternalDocument/2007/theparisdeclaration_en.pdf (Accessed: 18 December 2009)
12. UNAIDS (1999), 'From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA). Best Practice Key Material' *cited in* UNAIDS (2007). Policy Brief: Greater Involvement of People Living with HIV (GIPA). Policy Brief [online] Available at: http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf (Accessed: 18 December 2009)
13. UNAIDS (2007), 'Policy Brief: Greater Involvement of People Living with HIV (GIPA)' Policy Brief [online] Available at: http://data.unaids.org/pub/Report/2007/JC1299-PolicyBrief-GIPA_en.pdf (Accessed: 18 December 2009)

GIPA Report Card
Nigeria

Published by:
Network of People Living with HIV and AIDS in Nigeria (NEPWHAN)
1B Udo Udoma Street
Off Yakubu Gowon Crescent
Asokoro, Abuja
Nigeria