GIPA Report Card

Kenya

Country Assessment 2009

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Antiretrovirals
CACC	Constituency AIDS Control Committee
CBO	Community-Based Organisations
CCM	Country Coordinating Mechanism (Global Fund for AIDS, TB & Malaria)
GIPA	Greater Involvement of People Living with HIV and AIDS
HBC	Home Based Care
HIV	Human Immunodeficiency Virus
IDPs	Internally Displaced Persons
IEC	Information, Education and Communication
JAPR	Joint AIDS Review Program
KAIS	Kenya AIDS Indicators Survey
KANCO	Kenya AIDS NGO Consortium
KENEPOTE	Kenya Network of Positive Teachers
KENERELA	Kenya Network of Religious Teachers Living with HIV
KNASP	Kenya National AIDS Strategic Plan
MIPA	Meaningful Involvement of People Living with HIV and AIDS
NACC	National AIDS Control Council
NASCOP	National AIDS, STD Control Programme
NEPHAK	National Empowerment Network for People with HIV/AIDS
NGO	Non-Governmental Organisation
PLHIV	People living with HIV and AIDS
PTAP	Prevention and Treatment Advocacy Project
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCT	Voluntary Counselling and Testing

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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.

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Executive Summary

The Greater Involvement of People Living with HIV and AIDS (GIPA) Report Card is an advocacy tool that measures the application of the GIPA principles in the national response to HIV. In this study a total of 27 organisations from different sectors were purposively sampled and individuals in these organisations interviewed on the application of GIPA principles in Kenya. The sectors represented were the public sector including the National AIDS Control Council, the private sector, civil society, networks of people living with HIV and AIDS (PLHIV), the UNAIDS Secretariat and the country coordinating mechanism (CCM).

GIPA Knowledge

Respondents' knowledge regarding the involvement of people living with HIV in response to HIV was diverse. There was a feeling that the level of representation was still low, and that few PLHIV were involved in policy formation. However, many did report efforts by governments and other organisations to encourage greater participation and involvement of PLHIV in organisational leadership, HIV programming and policy formulation.

National AIDS Plan

Respondents agreed that the GIPA Principles had been incorporated in the National HIV and AIDS Strategic Plan. This has symbolized commitment on the part of the NACC on behalf of the government to allow greater PLHIV participation in key policy and programmatic interventions. This recognition of PLHIV in the National Strategic Plan has resulted in their involvement in HIV programming at the national, provincial, district and constituency levels.

Policy Development

The majority of the respondents said that PLHIV are involved at one point or another in the development of the national HIV and AIDS policy. Respondents said that the NACC involves PLHIV at national policy level through the JAPR and in the review of policies and strategic plans. There was also a feeling that women living with HIV and HIV positive women's networks and organisations have been involved in national level HIV policy development.

Universal Access

Over half of the respondents were aware of targets for universal access to treatment and were also in agreement that the government sets universal targets, including how many people living with HIV will receive ART by 2010.

Representation and Networks of People Living with HIV

Slightly over half of the respondents interviewed were in agreement that PLHIV are still not adequately represented in senior decision-making positions in organisations and in government, and that there was need to increase their level of participation.

Research and Sexual and Reproductive Health

The majority of the respondents agreed that Kenya has a national sexual and reproductive plan. However, the respondents felt that it is important to involve PLHIV more in all stages of the implementation of the national sexual and reproductive health policy.

Poverty Reduction Strategies

Most of the respondents were aware of Kenya's national poverty reduction strategy. However, there was a feeling that there had been little if any input from PLHIV in the development of this strategy.

Employment

Over 60% of the respondents affirmed that the government of Kenya has enacted labour legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work. Few respondents were however in agreement that people living with HIV had been meaningfully involved in the development of these workplace policies, despite some PLHIV involvement through NEPHAK.

Most respondents reported that in their organisations there is no workplace policy regarding the employment of people living with HIV as staff. Respondents intimated that Kenya has introduced in law a clause that an individual is not to be asked to disclose their status before applying or accepting a position. Six respondents who indicated that they were PLHIV cited barriers to employment such as lack of medical care, and the attitudes of colleagues, whether discriminatory or excessively sympathetic. Others however said that they had not experienced obstacles in their place of work.

GIPA Related-Materials

Respondents reported knowledge that many organisations had developed materials focusing on the GIPA principles: GIPA Guidelines, Action AID MIPA Tools, MIPA Checklist, posters and fliers.

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Financial Support

Only half (48%) of the respondents agreed that people living with HIV who participate in government supported HIV initiatives have their travel, accommodation, child care and food related expenses fully reimbursed. In many organisations, PLHIV are expected to contribute as volunteers, who may not even be repaid for the expenses they incur to undertake the work. Few PLHIV who work on HIV and AIDS issues felt that they were paid adequately for their efforts. While budgets often dictate the use of volunteers rather than paid staff, not only can this situation sometimes be considered exploitative, but it also results in representation of PLHIV by only the most privileged among them, those who can afford to work unpaid. Thus better funding for involving PLHIV would result in the interests of the most vulnerable and poorest being better represented and addressed.

Barriers to Involvement

Poverty and fear of stigma were cited as the most significant barriers to the greater involvement of people living with HIV in Kenya's response to HIV and AIDS. Other barriers cited included discrimination in the workplace, actual or feared.

Opportunities for Involvement

Most respondents agreed that there remains scope for greater involvement of PLHIV in HIV and AIDS policy formulation, planning and programme implementation. Many suggestions for constructive engagement were made by respondents, at levels from grassroots to government.

Conclusion

Kenya has made considerable strides in instituting the meaningful involvement of PLHIV in its initiatives to combat HIV and AIDS but challenges still remain. PLHIV contributions are many but often only on a voluntary basis and sometimes as window-dressing more than real participation. Few PLHIV have been involved in high-level decision-making, partly due to a continuing lack of awareness and inadequate skills, but also due to the effects of poverty and of stigmatisation. The recent recognition and appreciation of the role of PLHIV in driving and directing responses to HIV in the national HIV Strategic Plan is a major stride in the right direction. The quality of the country's response is also bound to benefit from increased involvement of PLHIV at all levels.

Introduction

> *"The Greater Involvement of People Living with HIV (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. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response."* (UNAIDS, 2007).

The idea that personal experiences should shape the AIDS response was first voiced by people living with HIV in Denver, United States, in 1983. The 'Denver Principles' stated that people living with HIV should

> *"be involved at every level of decision-making; for example serve on the boards of directors of provider organisations, and participate in all AIDS-related meetings with as much credibility as other participants, to share their own experiences and knowledge"* (UNAIDS, 1999).

Since then, the number of national and global groups promoting the increased involvement of HIV positive people in all HIV and AIDS-related activities has grown dramatically.

An international network of people living with HIV which later became the Global Network of People Living with HIV and AIDS was formed in 1986. In July 1992, the International Community of Women Living with HIV and AIDS was formed by a group of HIV-positive women from 30 different countries attending the 8th International Conference on AIDS in Amsterdam. The Community drew on the growing movement of HIV-positive women in Africa, which led to a new kind of activism extending beyond the immediate concerns of creating self-help and support groups.

The GIPA Principles were 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."*

The commitment to involve PLHIV has globally become known as the GIPA Principles and recognised as the most enduring legacy of the Paris Declaration (1994). Even though Kenya was not a signatory to the Paris Declaration, it became a signatory to later declarations such as the Declaration of Commitment on HIV/AIDS (United Nations 2001). GIPA Principles have

been incorporated into national and international programmes and policy responses; its observance is regarded as a model of best practice in the comprehensive response to HIV and AIDS.

The GIPA Principles are:

- To support the greater involvement of people living with HIV and AIDS (PLHIV) through initiatives to strengthen the capacity and coordination of networks of PLHIV and CBOs stimulating the creation of a supportive political, legal and social environment;

- To involve PLHIV fully in decision-making, formulation and implementation of public policies;

- To protect and promote the rights of individuals, in particular those living with or those most vulnerable to HIV/AIDS, through legal and social environments;

- To make available necessary resources to better combat the pandemic including adequate support for PLHIV, NGOs and CBOs working with vulnerable and marginalized populations;

- To strengthen national and international mechanisms connected to human rights and ethics related to HIV/AIDS.

The Greater Involvement of People Living with HIV and AIDS (GIPA) Report Card is an advocacy tool to assess the application of the GIPA principles in the national response to HIV. This tool is one of four being implemented by and for people living with HIV (PLHIV) under the HIV Leadership and Accountability program. The GIPA Report Card seeks to increase and improve the programmatic, policy and funding actions taken to realize the greater involvement of people living with HIV in a country's HIV response.

In Kenya, the National Empowerment Network for People with HIV/AIDS (NEPHAK) conducted a survey of twenty-seven organisations to assess the level of involvement of PLHIV in HIV and AIDS related activities for an international review of the implementation of the GIPA Principles. This report presents the findings from this survey, as the GIPA Report Card for Kenya.

Policy and Literature Review

HIV and AIDS in Kenya

Kenya has experienced a severe generalized HIV epidemic, but in the recent past, the country has experienced a notable decline in HIV prevalence from over 10 % in the late 1990s. The 2007 Kenya AIDS Indicators Survey (KAIS, 2008) shows an HIV prevalence rate of 9.2% in adult women and 5.8% in adult men, and an overall prevalence of 7.8 % of Kenyan adults (all age 15-49). Women thus may face considerably higher risk of HIV infection than men, and also experience a shorter life expectancy due to HIV: there were 1.6 infections among women for every one infection among men (KAIS 2007): however, the preponderance of women found to be seropositive may partly reflect the roll-out of Prevention of Mother to Child Transmission programmes, which diagnose many asymptomatic women. Peak known prevalence among women is at age 25-29 while prevalence rises gradually with age among men to peak at age 40-44 (Republic of Kenya, 2008). The observable decline in HIV prevalence in Kenya has been attributed to intensive and concerted HIV preventive education programmes by both civil society organisations and the public sector.

GIPA in Kenya

Until recently, the GIPA principle had not been officially integrated into Kenya's response to HIV and AIDS at any level. However, through advocacy initiatives by Kenya AIDS NGO Consortium (KANCO), development partners and civil society organisations (CSOs), the GIPA principle is now fully acknowledged by the National AIDS Control Council (NACC) as key components for combating HIV, and are recommended in every sector and area of intervention (KANCO, 2006). The mainstreaming of the GIPA principle in CSO programming has led to meaningful engagement of PLHIV in HIV programming and management in Constituency AIDS Control Committees, Constituency Development Funds, and other community-based associations.

The Kenya National AIDS Strategic Plan 2005/2010 (KNASP) fully operationalises the principles of greater involvement of people living with HIV/AIDS (GIPA) throughout the components of the strategy. Integration of GIPA principles in KNASP focuses on:

- Involvement of people living with HIV and AIDS (PLHIV) at the highest levels in the development and coordination of the HIV and AIDS response;
- Strengthening the capacity of PLHIV organisations to be involved effectively in prevention, treatment and care and mitigation of socio-economic impact; and

- Supporting the creation of representative and effective PLHIV organisations at all levels (Republic of Kenya, 2005).

In Kenya, the process of implementing the GIPA Principles is spearheaded by the National AIDS Control Council which has developed guidelines for different stakeholders engaged in the national HIV and AIDS response. The guidelines were intended to increase and improve the meaningful participation of PLHIV in different sectors within the broader national response to the AIDS epidemic in Kenya. The GIPA Principles are developed for use by all actors in Kenya's national response to HIV and AIDS including government, civil society, faith communities, PLHIV networks, and the private sector.

In Kenya, the National Empowerment Network of People Living with HIV (NEPHAK) is leading the roll-out of tools designed to gather information on the level of application of the greater involvement of people living with HIV in the national response to HIV. As part of the implementation of the GIPA Report Card, NEPHAK conducted a survey involving a number of organisations in the country to assess the level of involvement of PLHIV in HIV and AIDS related activities. This report highlights the findings of the survey.

Methodology

The methodology for carrying out the survey follows that set out in the GIPA Report Card Guide 2009, published by the Global Network of People Living with HIV (GNP+) in May 2009. NEPHAK selected interviewees for the study by a purposive sampling process which aimed to include a varied range of respondents from those who are:

- Representative of and/or working with key populations
- Engaged in organisations and mechanisms related to the country's HIV response, such as:
  - PLHIV networks
  - Country Coordinating Mechanism (Global Fund for HIV, TB and Malaria)
  - UNAIDS Secretariat and its UN Co-sponsors
  - Development agencies
  - Civil society organisations
  - National AIDS Council
  - Donor organisations

Respondents included in this survey for Kenya were from a wide range of stakeholders including UNAIDS, government departments, international and local NGOs and faith-based organisations, the National AIDS Control, Council (NACC), private companies and organisations of PLHIV: they are enumerated in the results section, with information on their budgets for work on HIV and AIDS, length of service in the field, and their mission statements. Identifying information has been removed from their detailed responses in most cases, in the interests of confidentiality.

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GIPA Report Card Results

Profile of Respondents

A total of 27 respondents from the organisations listed below were selected in the implementation of the GIPA Report Card questionnaire.

Organisations that took part in the Interviews

The following is the distribution of the 27 organisations that responded to the GIPA Report Card questionnaire by sector, with the length of time the sampled organisations had been involved in HIV and AIDS-related work and activities, and their budgets, where this information was available.

Table 1: Organisations Participating in the Survey

National PLHIV Network or Organisation	**Duration of Service in HIV & AIDS sector (years)**	**Annual HIV & AIDS budget (KSh)**
1. Movement of Men Against AIDS	7	KSh 20m
2. Medecins Sans Frontiers France	20	Not disclosed
3. National Empowerment Network of People Living with HIV/AIDS in Kenya	6	KSh 30m
4. Kenya Network of HIV Positive Teachers.	6	KSh 14m
Women PLHIV network, organisation or support group		
5. Women Fighting AIDS in Kenya	16	KSh 70m
6. Malindi Women AIDS fighters	10	Not disclosed
Young people's PLHIV network, organisation or support group		
7. Nyumbani Children's Home	17	US $600,000
Other type of PLHIV network, organisation or support group		
8. International Community for Relief of Starvation & Suffering	7	KSh 1m

9. Kenya Network of Religious Leaders Living With HIV	7	KSh 8m
10. Kisumu Positive Teachers	1.5	KSh 2m
11. Kenya Girl Guides Association	6	KSh 3m
12. Kenya Council of Imams and Ulamats	15	KSh 5m
13. Constituency AIDS Control Committee	8	KSh 0.25m
14. Nairobi Network of Post test Clubs	4	KSh 10m
Non-Governmental Organisations		
15. Compassion International	7	KSh 0.7m
16. Liverpool VCT and Care	5	KSh 12m
17. Kenya Red Cross Society	6	KSh 14m
Country Coordinating Mechanism (GFATM)		
18. CCM (REMADO)	2	KSh 0.45m
19. Kenya OVC Network	4	KSh 0.5m
20. Kenya NGOs Consortium (KANCO)	2.5	KSh 89m
UNAIDS Secretariat and Co-sponsor		
21. United Nations	10	US $300,000
National AIDS Council		
22. National AIDS Control Council	8	Not disclosed
Government Ministries/Bodies		
23. Ministry of Education	5	Not disclosed
24. Ministry of Public Health and Sanitation	10	Not disclosed
25. Kenya Human Rights Commission	6	KSh 1.5m
Private Companies		
26. Keroche Industries	1	0
27. May Flower Farm	6	KSh 0.6m

The participating organisations have been involved in HIV activities for varying periods of time ranging from: Keroche Industries (1 year), Kisumu Positive Teachers (1.5 years) and CCM (2 years), Kenya Council of Imams and Umalats (15 years), Women Fighting AIDS in Kenya (16 years), Nyumbani Children's Home (17 years) and KANCO (20 years).

The overall annual budgets for these organisations vary. Those in the private sector (Keroche and May Flower Farm) do not have a budget allocated to HIV and AIDS activities. The government ministries and the country's National AIDS Control Council did not disclose their budgets on HIV

and AIDS activities. However, for most other organisations, budgets ranged from below KSh. 1 million to significant budgets above USD 300,000 for United Nations agencies (See Appendix).

Employees living with HIV

In terms of the number of people openly living with HIV who are paid employees in the organisations, 32% of the organisations reported no employee openly living with HIV, 47% reported between one and five paid employees while Women Fighting AIDS in Kenya (WOFAK) has 63 paid employees of living with HIV - the highest number recorded. Other substantial numbers were Movement of Men against AIDS with 13 paid employees and May Flower Farm that has 21 paid employees living with HIV.

PLHIV Volunteers

The number of people openly living with HIV who offered voluntary services in these organisations is significant except at the UN and the Kenya Girl Guides Association. The government ministries did not however respond to this question. Five organisations reported having 10 volunteers or less with six others reporting between 30 and 60 volunteers. Those that recorded the highest numbers were Malindi Women AIDS Fighters with 100 volunteers, KANCO 120 volunteers, MSF France with 300 and the highest was Nairobi Network of Post-Test Clubs with 500 volunteers.

Designated paid positions for people living with HIV

Half of the organisations (13 of 27) reported not having any designated positions for people living with HIV, and six did not respond to the question. Organisations that reported having designated positions for people living with HIV are: UNAIDS, Kenya Red Cross Society and KENERELA+, which designate one position each, while Women Fighting AIDS in Kenya and the Movement of Men against AIDS designate two positions each. Nyumbani Children's Home reported a non-discriminatory policy arguing that HIV testing was not a precondition for employment. NEPHAK, on the other hand reported that three-quarters of their employees are HIV positive.

Implementation of internal discussion about the GIPA Principles

The majority of the organisations (19 - 70%) reported implementing formal or informal discussions on the GIPA principles, while four organisations (Liverpool VCT and Care, Ministry of Education, Nyumbani Children's Home and Kenya Girl Guides Association) did not have any discussions on the GIPA principles. NEPHAK reported that it is currently developing an HIV and AIDS workplace policy. The Kenya National AIDS Control Council was

reported to have carried out a situational analysis, developed GIPA Guidelines and to be in the process of printing GIPA Guidelines.

Primary locations where projects are implemented

Different organisations are implementing their projects in multiple locations: Table 2 shows the distribution:

Table 2: Distribution of organisations' primary locations

Name of the Organisation	Country -wide	Urban	Peri-urban	Rural	Border areas	Refugees or IDPs
Movement of Men Against AIDS		✓		✓		
Medecins Sans Frontiers France	✓	✓	✓	✓	✓	✓
Liverpool VCT and Care		✓			✓	
NEPHAK	✓	✓	✓	✓		
Women Fighting AIDS in Kenya		✓		✓		✓
Malindi Women AIDS Fighters			✓			
Nyumbani Children's Home	✓				✓	
International Community for relief of Starvation & suffering		✓		✓		✓
Kenya Network of Religious Leaders Living With HIV	✓					
Kenya Network of HIV Positive Teachers	✓					
Kisumu Positive Teachers	✓					
Kenya Girl Guides Association	✓				✓	
Kenya Council of Imams and Ulamats		✓	✓			✓
Constituency AIDS Control Committee		✓	✓	✓		
Compassion International			✓			
Nairobi Network of Post-Test Clubs	✓	✓	✓	✓		
CCM (REMADO)			✓		✓	
Kenya OVC Network		✓		✓	✓	
Kenya NGOS Consortium (KANCO)	✓					
United Nations	✓	✓	✓	✓		✓
National AIDS Control Council	✓	✓	✓	✓	✓	✓
Kenya Red Cross Society	✓					
Ministry of Education	✓			✓		
Ministry of Public Health and Sanitation	✓			✓		
Kenya Human Rights Commission			✓		✓	
Keroche Industries	✓				✓	
May Flower Farms		✓		✓		

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All the organisations operate in more than one location with at least ten of them operating countrywide, in urban, peri-urban, rural and border areas. At least six organisations operate their projects in the refugee or IDP (internally displaced people) camps.

Table 3: Populations Served by the Organisations

Population Served	Number of Organisations	Percentage
Orphans and vulnerable children	17	63%
Young people (15-24 years of age)	14	52%
Child-headed households	12	44%
Women	18	67%
Men	20	74%
Elderly	15	56%
People living with HIV (target groups as follows)	19	70%
Injecting drug users	1	4%
Men who have sex with men	4	15%
Women who have sex with women	-	-
Transgender people	-	-
Sex workers	6	22%
Migrant laborers and/or other mobile populations (including deportees)	1	4%
Refugees, IDPs or Asylum seekers	1	4%
Prisoners	6	22%
All of the above	3	11%

As illustrated in Table 4, the proportion of organisations in the survey targeting men is highest followed by people living with HIV and then women. While initiatives to work with men who have sex with men is a new phenomenon in HIV and AIDS programming in Kenya, it is noteworthy that four organisations, namely Keroche Industries (a beer manufacturer and distributor), MSF-France, Malindi Women AIDS Fighters and the Kenya OVC Network have programmes specifically targeting this group.

Mission Statements

Below are some mission statements of the organisations as expressed describing how their policies, services and programmes are structured to help them achieve their mission.

- The mission of Kenya Network of Religious Leaders Living with HIV (KENERELA) is to engage, equip and empower religious leaders living with or personally affected by HIV to live openly as agents of change and hope and bring change in their congregations, faith, communities and the entire nation. To implement their policies, services and

programmes to achieve their mission, they work through established religions, faith structures in the country. At the national level through to the grass root levels to reach out to religious leaders through empowerment through education and engage these religious leaders to reach out to their congregations especially on stigma, discrimination, denial, inaction and mis-action. They said that their policies and programmes are clearly structured alongside our mission.

- The Kenya Human Rights Commission's mission is to build a Kenya that protects and promotes human rights and democratic values. To implement their policies, services and programmes to achieve their mission, their programmes and policies are structured to protect, promote and enhance the enjoyment of human rights for all individuals and groups. They have networks countrywide.

- Kenya Network of HIV Positive Teachers (KENEPOTE) has a mission to aspire to create an environment where all HIV positive teachers are free from shame, fear and discrimination. To implement their policies, services and programmes to achieve their mission they empower the members with skills through capacity building, psychological support to ensure that their dignity/confidentiality is not compromised regardless of their HIV status.

- Nairobi Network of Post Test Club's (NNEPOTEC) mission is to have an AIDS-free society. Its programmes are implemented by having Annual General Meetings, through the project director and through its Post-test clubs.

- Kenya Girl Guides Association's mission is improving quality of life for the girl child. To achieve their mission, they run programmes in schools for youth and guide them on best life practices.

Below are the mission statements of some of the organisations as expressed, which did not state how their policies, services and programmes are structured to help them achieve their missions.

- National AIDS Control Council's mission is to be in the forefront of prevention, care and support of PLHIV, to ensure infection and re-infection levels go down and reduce mortality rates of PLHIV through quality access to care and support.

- The May Flower Farm (a privately owned flower farm) aims to support a healthy workforce.

- Movement of Men against AIDS (MMAK) mission is to involve all men from all segments of life to participate greatly in HIV and AIDS prevention.

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- UNAIDS' mission is uniting for solidarity, equality and acceptance for people living with HIV within the workplace/system.

- Kenya NGO Consortium (KANCO)'s mission is to be the premier organisation committed to providing and promoting leadership, collaboration and enhancing capacity among civil society organisations for collective effort towards effective responses to HIV and AIDS and its impact.

- Compassion International's mission is that it exists as an advocate in response to the great commission, to release children from their spiritual, economic, social and physical poverty and enable them to become responsible and fulfilled Christian adults.

- NEPHAK's mission is to promote greater and meaningful involvement of people living with and affected by HIV in the response to the epidemic.

- Kenya Red Cross Society's mission is to work strictly, neutral, impartial and on independent basis to protect and assist people affected by armed conflict, internal disturbances or other disasters.

- Nyumbani Children's Home's mission is to provide quality comprehensive care and support to HIV infected and affected children and families and committed in a sustainable manner.

- CCM (REMADO)'s mission is empowering people living with HIV.

- The mission of the Kenya Council of Imams and Ulamats is to promote the life of its members by building their capacity.

Below are the organisations that did not express their missions but described how their policies, services and programmes are structured to help them implement their programmes.

- The Ministry of Public Health and Sanitation said that their role is to take preventive measures in the fight against HIV and AIDS.

- Liverpool VCT and Care offers PLHIV treatment, care and support.

- Malindi Women AIDS fighters (MWAFO) activities include conducting of health talks in barazas (public meetings), schools, churches and mosques, conduct outreach with their collaborators where they advocate for PLHIV and disclose their status and

encourage people to visit health facilities centres or Comprehensive Care Centres (CCC) for treatment.

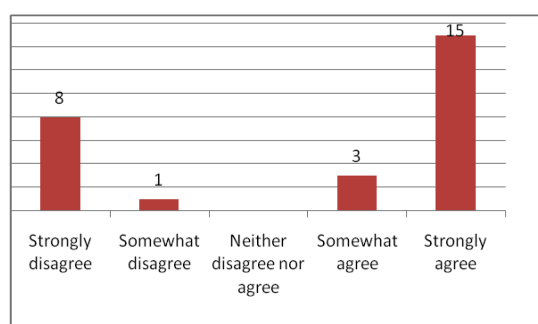
- The Constituency AIDS Control Committee (CACC) serves as an advocacy team in mobilizing the community through organized groups to respond to the HIV and AIDS epidemic at the community level through dissemination of national policies, guidelines and strategies.

The International Community for Relief of Starvation and Suffering and Medecins Sans Frontiers France neither expressed their missions nor how their policies, services and programmes are structured to help them implement their programmes.

Knowledge of GIPA

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

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.



Respondents were split on this point, with a third not familiar with GIPA, and two thirds aware of it.

Meaningful involvement of PLHIV had diverse meanings for the respondents. Some felt that meaningful involvement of PLHIV is for them to participate in formulation of policies and decision-making processes on issues that affect them. Examples given on how PLHIV have been involved in policy-making and implementation included:

- One respondent gave the example of an individual who is said to be positively living with HIV and sits in major committee meetings of HIV stakeholders.
- The Ministry of Health has nurses who are PLHIV.
- A teacher living with HIV is included in the AIDS committee at the district level.
- A KENEPOTE member works at the AIDS Control Unit at the Teachers Service Commission headquarters.

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Respondents reported that PLHIV were being accorded space to articulate and air their issues. For example, in Constituency AIDS Control Committees and Networks of PLHIV, representatives are always invited to their meetings discussing HIV and AIDS, for instance the Joint AIDS Programme Review (JAPR) run by the NACC.

They felt that PLHIV hold meaningful positions in all levels of society, and their involvement should not just be in the HIV and AIDS sector, rather it should be in all sectors of society. Examples include:

- In one of the organisations, PLHIV are paid data collectors.
- Coast Branch was requested to nominate six members to participate in the just concluded Kenya National Population Census 2009.

Other examples of meaningful involvement of PLHIV include:

- Involvement in the development of strategic plans
- Resource mobilization
- Planning and budgeting for HIV and AIDS programmes
- HIV and AIDS programme implementation
- Empowering individuals with correct and accurate information and engaging them to be agents of change in the society.
- HIV and AIDS advocacy and awareness campaigns
- HIV and AIDS research

In addition, one of the respondents said that meaningful involvement of PLHIV implies a formal and structured involvement where the participation and voices of PLHIV are valued and respected. For this to happen, there is need for structures and systems that are responsive to PLHIV, such as specific terms of reference and specific role assignments.

Respondents' descriptions of the current situation in Kenya, and in local communities regarding the involvement of PLHIV in the response to HIV and AIDS were diverse. There are those who felt that it was positive, and those who felt that much more needs to be done.

Respondents who felt that involvement of people living with HIV in the response to HIV is positive had this to say:

> *"PLHIV are now playing a leading role in mobilization and sensitizing the community on HIV and AIDS. They conduct house-to-house campaigns and have formed support groups/post-test clubs where they support one another. They assist in reaching out to other community members with information on ART, adherence to ART, and on prevention measures, and form a very important link between service delivery facilities and the community."*

> *"The PLHIV are involved in the key decision-making of the country, such as the interagency coordinating mechanism. They are represented in all levels of coordination, that is at the constituency and national level; networks of PLHIV are consulted on all issues of PLHIV. There are support groups at the constituency level."*

> *"PLHIV at both district and provincial levels are positively involved in this response. There are numerous representatives of PLHIV networks on the Constituency AIDS Control Committee. One place on the board is designated to a PLHIV. However on a national level PLHIV are not properly represented"*

> *"The impact of religious leaders living with HIV has been enormous. Due to their influence in the society and social standing they are actively engaging not only to reach out to their fellow clergy but also in reaching out to government ministries and parastatals with HIV information. KENERELA+ has adopted the SAVE concept (Safe practices, Access to treatment, Voluntary counselling and testing and empowerment through Education. Both the public and private sectors are accepting this concept, and the religious leaders living with HIV are engaging with these sectors meaningfully in this prevention approach."*

> *"In the community many Community Health Workers are PLHIV and always give hope to newly infected people. In addition, adherence counsellors in many hospitals and VCT counsellors are people living with HIV, though not all".*

> *"PLHIV have been greatly involved in voluntary counselling and testing (VCT) campaigns, door-to-door campaigns and HBC"*

Some respondents felt PLHIV are now accepted in the community and the government has provided support centres for PLHIV, but it has been a long road for them to get to be recognized due to stigma associated with HIV.

Other respondents felt that the PLHIV have not been involved in critical decision-making processes arguing that:

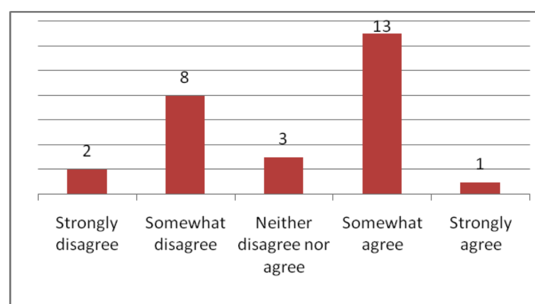
> *"PLHIV have only been involved in matters pertaining to them and have not been elected to key policy and legislative institutions such as parliament. Similarly, respondents averred that PLHIV are not given special consideration in politics arguing that some positions should be reserved for them so that they can advocate for their rights."*
>
> *"Stigma and discrimination are still at centre stage, thereby sidelining PLHIV even in positions that they are qualified to hold."*
>
> *"Stigma prevents many PLHIV from openly stating their status."*
>
> *"PLHIV often face discrimination, fear and ignorance from the community."*
>
> *"The level of involvement of PLHIV is minimal at all levels. Most of them are grouped in voluntary work. GIPA needs to be enhanced."*
>
> *"PLHIV are not fully involved at the national level. Through networks, stakeholders partner with them at the grassroots level to implement programmes."*
>
> *"When it comes to public funds meant for HIV, they are not widely consulted and the funds do not benefit them directly. Many organisations are getting money in the name of fighting HIV but this money does not reach them and is not utilized for the intended purposes. The affected and the infected get only 20% of what has been given by the donors, and financial accountability is poor."*
>
> *"Actual people living with HIV are exploited by being used only in disclosure sessions and are never involved in decision-making and policy formulation."*
>
> *"Most HIV activities in the private and public sector are headed by non-PLHIV."*
>
> *"PLHIV are not involved in accountability of HIV donor funds at the top government level."*

Despite these perceptions, the NACC is striving to ensure that PLHIV are involved at all levels of the HIV and AIDS response but the mechanisms and guidelines for this are not clear. Kenya still does not yet have adequate GIPA guidelines and the National GIPA Task Force is not operational.

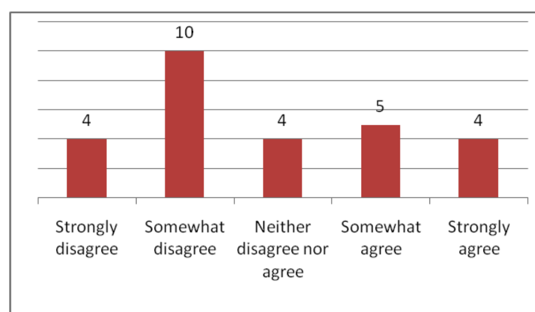
National HIV and AIDS Strategic Plan

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

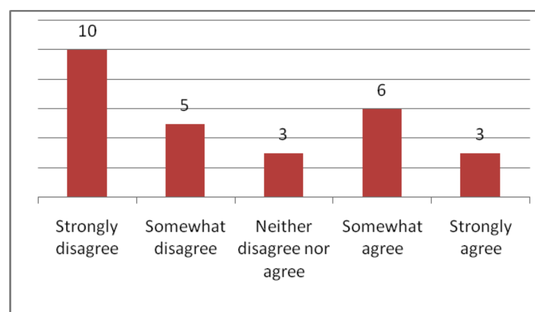
The GIPA principle is fully included in the National AIDS Plan.



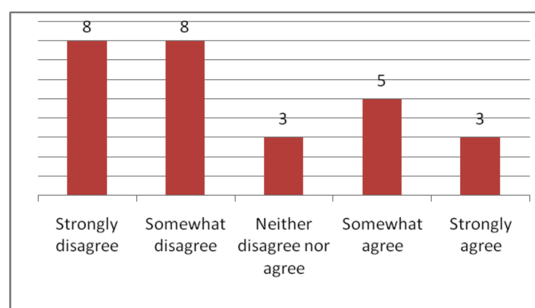
PLHIV were meaningfully involved in developing the National AIDS Plan.



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.



Half of the respondents agreed that the GIPA principle is fully included in the National HIV and AIDS Strategic Plan, but a small majority disagreed that people living with HIV were meaningfully involved in developing this plan, and disputed that there have been studies done looking at the

GIPA principle in Kenya. Most respondents also disagreed that GIPA principles are adequately included in the National HIV and AIDS Strategic Plan monitoring and evaluation framework.

Just over half of the respondents (14, or 52%) concurred that the country has a National GIPA plan.

Below are some of the respondents' comments on the adequacy of the National HIV and AIDS Strategic Plan or GIPA Plan:

> *"The National AIDS Control Council states that the GIPA guidelines have just been developed and are in the process of being printed to be launched and rolled out for implementation"*
>
> *"The NACC strategic plan in Kenya written in June 2005 targets full implementation of GIPA principles but this has not been put into action as it should have been. I don't think they are adequate, because many of those who test positive live in denial and stigma especially in their workplace. Not many men disclose their status or join support groups".*
>
> *"GIPA guidelines are now ready for printing. They will be disseminated widely and feedback sought to identify whether there is need for revision. Many stakeholders including PLHIV and PLHIV networks were involved"*
>
> *"Some respondents said that it was adequate but not comprehensive enough"*

A considerable number of the respondents had never heard of the National GIPA Plan. A few said that the guidelines were inadequate and that they have been shelved.

On budget allocation, some of the respondents said that current HIV and AIDS budgets are not adequate, while others reported no budgets at all. None said budgets are adequate.

Almost none of the respondents responded to the question on whether the National GIPA Guidelines had been put into action. Two said that the guidelines were being rolled out at present, and another said that they are mainly in the bookshelves.

On how the National GIPA Guidelines could be improved, the following suggestions were outlined:

"There is room for improving on the GIPA plan. PLHIV need to be empowered more with knowledge and skills and facilitated to play a crucial role in HIV and AIDS control."

GIPA Report Card

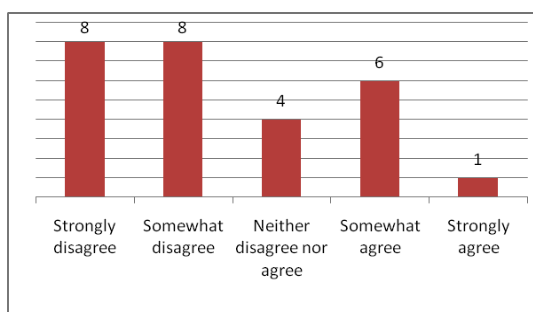
"Involving PLHIV in policy making by allocating slots at all levels for PLHIV, and a corresponding budget"

It was noted that Kenya has a draft of National GIPA Guidelines, but this had not been operationalised because the GIPA National Task Force was not functional. However there was optimism given that a new National HIV and AIDS Strategic Plan had been developed with a budget for GIPA activities.

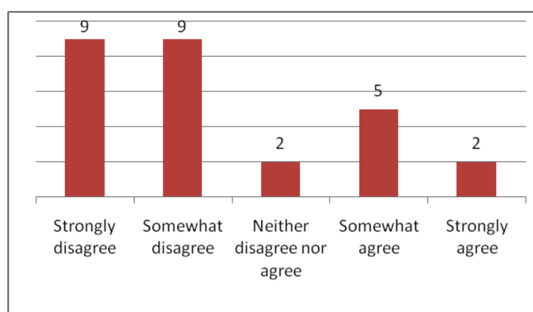
GIPA at State and Provincial Levels

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 or provincial level HIV planning.



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



Around two thirds of the respondents did not agree that the GIPA principle has been adequately implemented in state or provincial level HIV planning, or that PLHIV have been meaningfully involved in developing state AIDS policies. Kenya has no provincial AIDS Policies.

Respondents gave both positive and negative comments on the application of the GIPA principle at the state or provincial level in Kenya. The following are some excerpts from the positive comments:

> *"The GIPA Principle at this level is mostly spearheaded by CSOs, NGOs, CBOs and faith-based organisations and the private sector. We need to see more public organisations and institutions spearheading the GIPA principle through creation of opportunities for this to be practiced".*

"From GIPA situational analysis, it was realized that some groups were implementing some aspects"

"At the provincial level the application of the GIPA principle is encouraging as networks of PLHIV are represented at all provincial meetings of National AIDS Control Council and other such bodies, but still more needs to be done"

"PLHIV have not been fully involved in developing state/provincial level HIV policy. There is need to give them leadership roles in order to meaningfully engage them"

"There is inadequate representation of PLHIV in NACC and CACC committees. The better the representation, the more impact will be felt. The money allocated to AIDS projects should be shared equally between major towns and small towns without favouring anyone. Members who are HIV negative should be removed from the committees starting with politicians and let the PLHIV take their positions because there are those who are more educated and can lead"

People living with HIV were major contributors in the National HIV and AIDS Strategic Plan and other intervention plans with NASCOP"

"There is much improvement in the state since GIPA started. The big issue is to educate or inform the people living with HIV"

The following are excerpts from respondents who had negative perceptions about the application of the GIPA principle at the state or provincial level in Kenya:

"The GIPA principle is still not very effective at all."

"The GIPA Principle is new to almost all people."

"The GIPA principle does not exist at the provincial level and we have never heard about it."

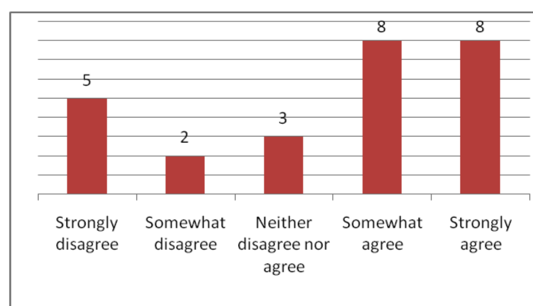
"GIPA Guidelines are only on paper and have not been implemented."

"GIPA guidelines were developed mainly by the national stakeholders in Nairobi. There was some engagement of regional people, but representation of effective and efficient PLHIV in these fora has been minimal."

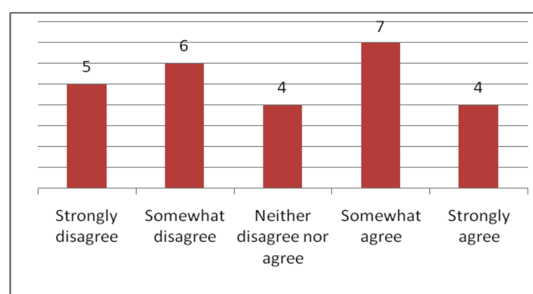
United Nations General Assembly Special Session on HIV/AIDS (UNGASS)

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.



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



The majority of respondents had some familiarity with UNGASS; views on the effectiveness of PLHIV in influencing the report on progress toward these targets were mixed.

Those who commented positively on the country's reports to UNGASS were few, and said, for instance:

> *"The country has always done a UNGASS report that is consultatively developed involving all the stakeholders. The involvement of PLHIV in the development of UNGASS report is always assured"*

Negative comments on United Nations General Assembly Special Session on HIV/AIDS (UNGASS) reports by Kenya were the majority, including:

> *"Many of us are not aware of who developed the report."*

> *"Though the UNGASS report was provided, the government of Kenya did not report correctly on the proceedings."*

Kenya

"CSOs are engaged in developing the UNGASS report, and provided an opportunity to produce a shadow report to UNGASS. PLHIV and other networks are engaged. However representation of effective and efficient personalities to articulate GIPA may be minimal."

"These reports are not widely available to the general public and hence not many people would know about them - including even those involved in HIV and AIDS activities at the grassroots that can help in realizing these targets."

"Feedback is not given by government on any report at the lower levels, but is left at the high levels. Space should even be bought in local dailies to publicize reports and even radio stations, communicating in various languages."

"Kenya as a country is notorious for signing up to international commitments, yet they are never reflected in the community."

"PLHIV are not empowered, neither are they given the opportunity to participate in UNGASS, especially in the rural areas."

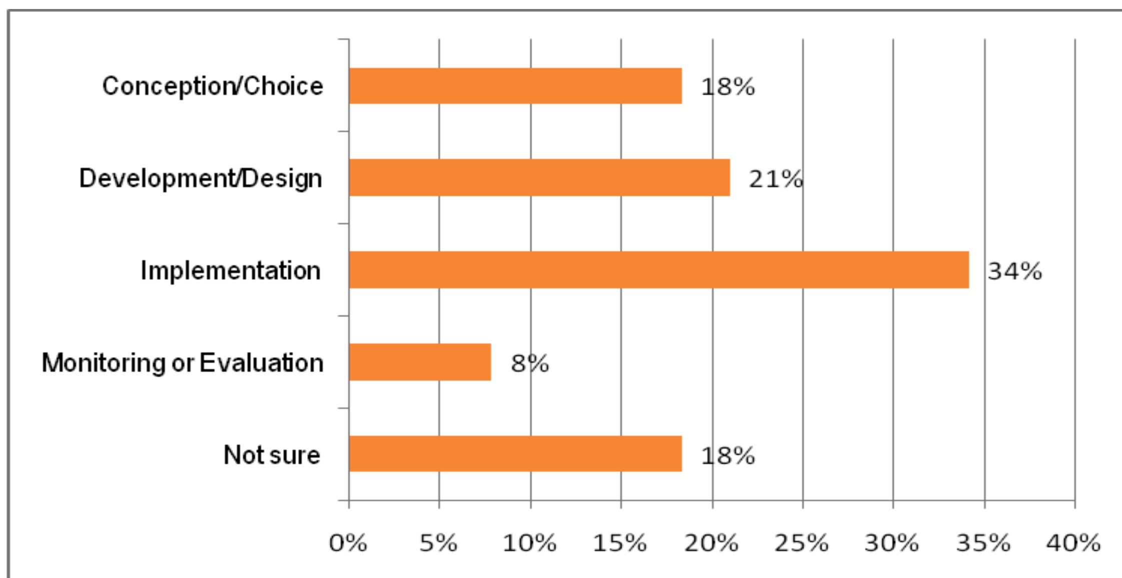
"Information from the government is not passed on to the grassroots level. Communication levels, especially for those who do not understand English or Kiswahili, are very poor. The materials should be translated into many local languages for proper communication."

"There is duplication of the same people attending the sessions instead of diversity."

"These policy reports are normally developed by senior government officials whose views are not necessarily based on the people who are affected by the problems and challenges of HIV."

Policy Development

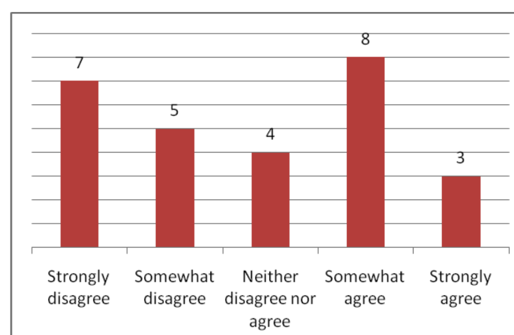
When asked "At which points are people living with HIV most often first involved in national level policy development?", respondents chose the following (multiple selections possible):



The majority of the respondents considered that PLHIV are involved at one point or another in the development of the national HIV and AIDS policy. Involvement was thought to be concentrated in the implementation phase, with less PLHIV input at the inception of policy development, and in the monitoring and evaluation of its execution and impact.

When asked "To what extent do you agree or disagree with the following statement?, respondents indicated the following:

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



The following were the remarks of respondents who reported that PLHIV are involved in national HIV and AIDS policy development:

"The National AIDS Control Council (NACC) involves PLHIV at the national policy level;

PLHIV network representatives participate and inform review of policies and strategic plans. PLHIV are involved in developing GIPA principles."

"PLHIV participate in every annual JAPR meeting and are also involved in the district and constituency committees."

"PLHIV participate in annual JAPR meeting."

Those who did not see PLHIV as having been involved in the national policy development remarked:

"When NACC launched the strategic plan in April 2009, it was NGO figure-heads that attended the launch, not those who are meant to benefit from the NACC strategic plans."

"PLHIV are involved at the outset then sidelined later, but their involvement is quite vital as they are the subject of whatever policy is being discussed."

"There are no PLHIV involved in policy development."

"Policy development is dealt with at the national level where PLHIV are not involved from the beginning. They are only involved at the implementation point."

"The PLHIV engaged by the authorities are mainly the rich and high-class but unknown while the poor lower-class PLHIV are ignored. So the selection of representatives is skewed in favour of the richer and more affluent PLHIV, yet these are not the people with most needs."

"Kenya only uses NEPHAK to involve PLHIV in policy development yet NEPHAK operates mainly in Nairobi."

Other comments on PLHIV involvement in policy development were:

"The percentage of those involved should be proportional to the national prevalence."

"PLHIV should be involved in policy-making, budgeting, decision making, implementation of activities, and monitoring and evaluation."

"It is of utmost importance that PLHIV are involved from conception to national level as the policies are being formulated to impact them positively."

"National GIPA Guidelines are yet to be operationalised, leaving GIPA/MIPA to individual programmes and processes for institutions that desire GIPA."

"PLHIV know where the shoe pinches and therefore it's best for them to be involved from the inception of policies."

"At the national policy level no PLHIV has ever been appointed, elected or nominated to a high position."

"If PLHIV are involved in national policy development, then all issues to do with HIV and AIDS, stigma and discrimination at workplaces can be easily reduced."

Some respondents agreed that women living with HIV and HIV positive women's networks and organisations have been involved in national level HIV policy development, while other respondents denied this.

Comments on women's involvement were as follows:

"Involvement of women in national level HIV policy development of women organisations like NEPHAK, WOFAK and KENWA is quite high."

"Women living with HIV and their organisations have been involved through the monitoring and coordination group in NACC."

"Presently, HIV positive women, networks and organisations have not been overly involved at the national level. However this may also be due to these networks not being well-developed yet."

"Women have been greatly involved and there is a lot of effectiveness and outcomes."

"Women are not fully involved in national level HIV policy development and when women living with HIV and their organisations are involved; their involvement is not effective because there are no formal structures to support their involvement."

Respondents said that despite women having been the first to agitate and champion the rights of PLHIV, the leadership positions in the organisations they created had been usurped by men. These sentiments are captured in the following remarks:

"There are networks of PLHIV and in most cases they have both men and women. Most PLHIV groups comprise more women than men; leadership is however taken by men."

Kenya

"It is women who started fighting stigma and discrimination. It took almost 20 years for men to understand and come out with the message of fighting AIDS. These were SWAK, KENWA and WOFAK".

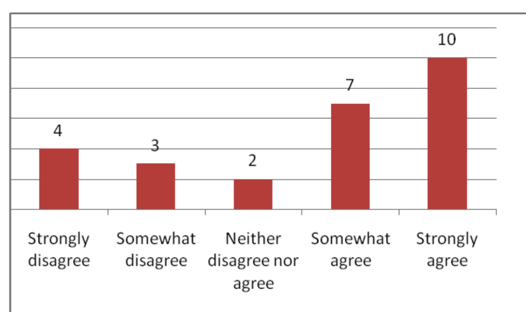
"Women have been involved in national level HIV policy development to some degree through activism but not full involvement."

"Women are even more stigmatized than men and bear the burden of taking care of their sick spouses and children. Often women are told that their rightful place is the kitchen and therefore very few are found in board rooms where policy matters are discussed."

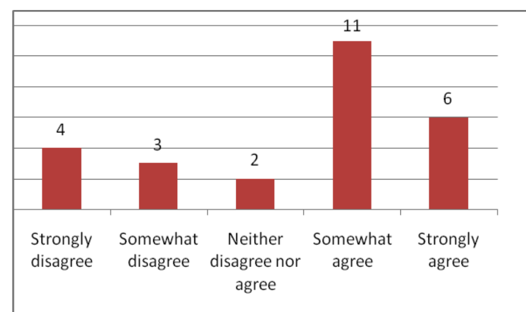
Universal Access

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

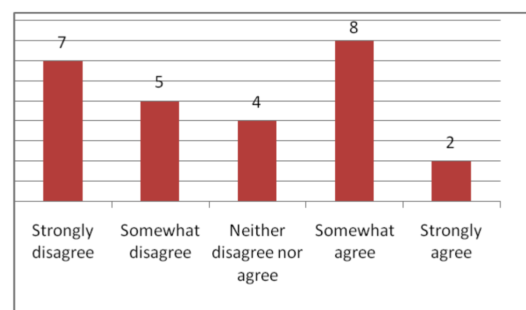
I am familiar with universal access commitments and targets.



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



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



Over half of the respondents were aware of universal access targets and agreed that the government sets universal targets, including the number of PLHIV who will receive ART by 2010. Slightly over a third of the respondents reported that people living with HIV were meaningfully involved in the universal access target-setting process.

The respondents were asked to cite the barriers to achieving the targets, what would help to achieve them, what was working well, and information on drug quality and regularity of supply. Their responses follow:

Of the five respondents who commented on the above question, two respondents reported not to have heard about the targets, two reported that there are national targets on access to antiretroviral drugs, while one said that participation in national policy processes and programmes does not meaningfully engage PLHIV. To some respondents, targets for universal access commitments by government appear to be derived from international commitments rather than national planning.

Barriers to Achieving Targets:

> *"The main barriers to achieving targets on access to ARVs are socio-economic factors which must be considered before initiation and start of ARVs."*

> *"There are challenges whereby PLHIV access ARV from more than one facility hence there is misuse and wrong data are generated."*

> *"There is lack of adequate staff to handle the ART aspect as well as large workload concerns in health facilities."*

> *"Fear of forming resistance to ARV after taking them in large quantities for a long time."*

> *"Inadequate funds and the personnel to supervise; there is frequent stock shortage."*

> *"There is a lack of proper coordinated approach to the whole process, from funding to implementation."*

> *"The bureaucracy in government procurement causes a lot of delays in acquisition of ARVs."*

> *"Initially programmes geared towards PLHIV involved them but these have been overtaken by greed and corruption and PLHIV were sidelined."*

"Political commitment to supply ARV is weak on the part of government."

"The vastness of the country makes supply of ART rather problematic."

"Intense stigma and discrimination in society which means few PLHIV come out openly to disclose their status."

"Limited CD4 testing and viral load testing facilities in health institutions."

"Involvement of PLHIV is minimal and therefore realizing the targets is hard."

"Low uptake of VCT means people who may be infected do not know their HIV status and therefore do not go for treatment."

"Default from ARVs due to religious beliefs and herbalists."

"Lack of clear information on a variety and quality of drugs."

"People handling HIV issues are not PLHIV, and PLHIV are not aware of their rights."

What would help to achieve the targets?

"Through involvement of PLHIV in making decisions and empowering the PLHIV through capacity building."

"If the grassroots interventions are targeted and supported, because a lot of funding ends at the national level and very little reaches down to the grassroots where the shoe really pinches."

"The government should allocate a substantial budget to HIV-related activities, and not necessarily depend on donor support thus putting lives of its people at risk when shortage is realised."

"The government should fund the training of caretakers as "ambassadors of hope" who are ready to commit themselves in helping PLHIV unconditionally."

"Work with communities through opening up of communication and mobilize staff by motivating them to achieve the targets."

"Ensure continuous supply of drugs and laboratory test kits."

"Donors should deal directly with the grassroots level organisations serving PLHIV in the country."

"Advocate for PLHIV rights and empowerment for PLHIV."

What is working well?

"The involvement of PLHIV, in adherence to work plan, proper strategies and planning."

"Community based treatment plans."

Drug Quality and Regularity of Supply

"In terms of drug quality and regulation, it is wanting and the government needs to put checks and balances."

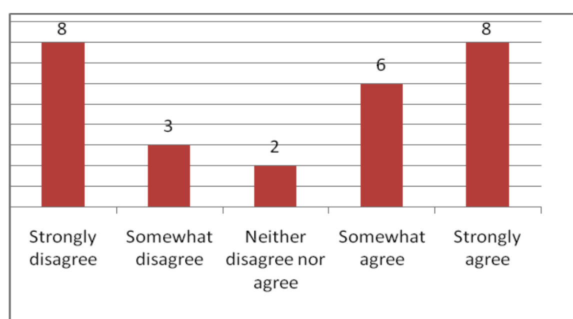
"There is need for coming with a single dosage for a month rather than a continuous intake of drugs in order to ensure adherence and compliance with treatment regimens."

"Supply of the drugs is very good and regular but there is need to improve on the quality because of so many side effects."

Representation and Networks of People Living with HIV

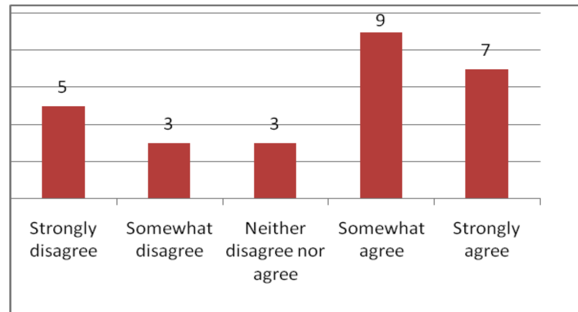
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

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

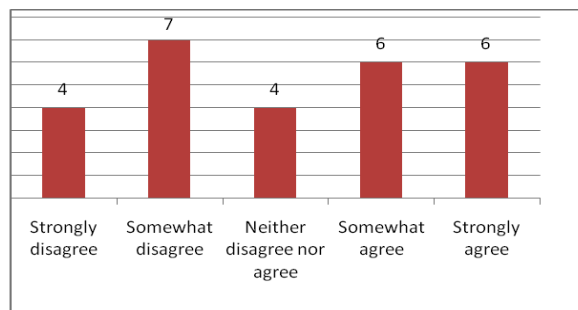


Kenya

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).



National, regional and state level PLHIV networks communicate effectively with their constituents.



Just over half of the respondents interviewed were in agreement that PLHIV representation in decision-making organisations functions to ensure accountability, but almost a third strongly disagreed with this proposition, and almost 60% agreed that the mechanisms for the representation of PLHIV in formal decision making bodies are effective in representing the needs of PLHIV. Views were evenly spread on whether national, regional and state level PLHIV networks communicate effectively with their constituents.

Respondents were asked to comment on whether all PLHIV are well-represented in the networks and on whether these networks are strong. Their responses included:

> *"PLHIV networks are increasingly getting recognition. However, they need to open/set up branches in every location in the country so as to be effective and for their work to be felt in the community. Currently they seem to concentrate their activities in major towns and this needs to change. The faster this is done, the better for the war against HIV and AIDS."*

> *"The capacity of PLHIV support groups is low because of lack of funds."*

> *"The mechanism for the representation of PLHIV is not clear. Most committees mainly comprise prominent persons who are selected in a biased manner. The poor and needy at the grassroots rarely get help, support or representation."*

> *"There has been cohesion especially amongst organisations dealing with HIV and AIDS and networks are very strong."*

"PLHIV networks can effectively reach to the community as long as they build trust and transparency to avoid experiences in the past which they were accused of fleecing the community-intended donor funds."

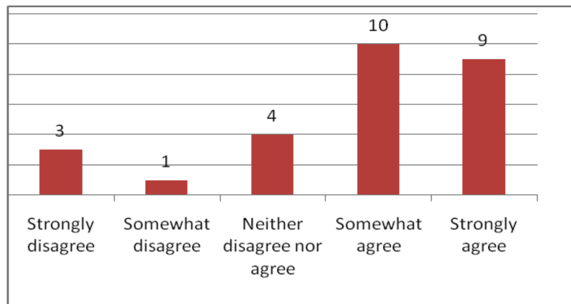
"There should be greater involvement of PLHIV in decision-making at all levels."

"There is provision for formal representation of PLHIV in decision making/policy bodies including CCM. NEPHAK is a member of the county's CCM and also the HIV and TB coordinating committee. The challenge is that NEPHAK and PLHIV are a minority and junior partners in these bodies. In the past, there was also the challenge of effective communication with communities and other members of the constituency. This has to do with the capacity of NEPHAK."

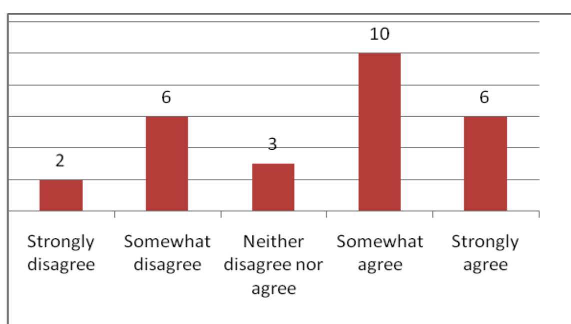
Research and Sexual and Reproductive Health

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.



Two-thirds of the respondents agreed that the Kenya has a national sexual and reproductive plan. There was less satisfaction with the degree to which policies incorporated in such planning addresses the sexual and reproductive health needs of PLHIV, with just over half agreeing.

Respondents' comments on sexual and reproductive health policy:

> *"Policies have been introduced to address reproductive health needs of PLHIV but more needs to be done in implementation."*

> *"Stigma is still high in health institutions and many people living with HIV quite often do not access reproductive health information and services. There is also disjointedness in service delivery. There is need to integrate all these services at one point."*

> *"Most people do not know what is contained in the national Sexual and Reproductive Health policy, so people need to be mobilized and educated on the contents of this policy."*

> *"It is necessary to involve PLHIV in all stages of the plan and implementation of the national sexual and reproductive health policy. "*

> *"Respondents know that the Ministry of Public Health and Sanitation has reproductive health programmes, but the respondents do not know to what extent PLHIV issues have been incorporated."*

> *"If the sexual and reproductive strategy/plan could be followed adequately, issues relating to HIV/AIDS could have been minimal."*

Asked whether people living with HIV are involved in conducting research in the country, for instance in clinical trials and in the research and development of new prevention technologies, 12 respondents (44%) responded in the affirmative. A few said that PLHIV are mainly involved as research subjects, as during drug trials. In essence, PLHIV are almost never the principal investigators, nor the managers of these studies. Two respondents did however report that most PLHIV lack the requisite capacity to conduct such research.

The following are some of the comments made by respondents on PLHIV involvement in research:

> *"Research is a very important aspect of the war against HIV and AIDS. There are many psychosocial factors and new prevention technologies which need to be understood through research."*

> *"If PLHIV groups/networks' capacity is built, they will fully participate and develop new prevention strategies. In addition, communities and PLHIV should be empowered and funded to do their own research. We need research for and by PLHIV."*

"Enough information is not given to PLHIV when a research is taking place; they have just been used as guinea-pigs."

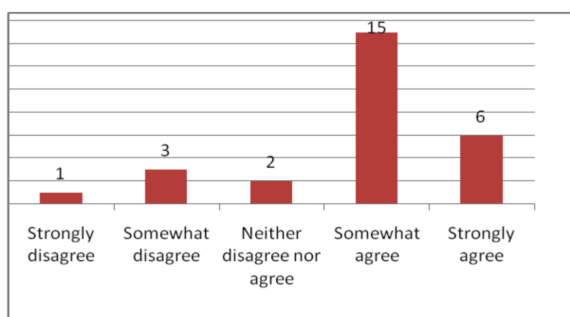
"PLHIV participate in clinical trials by the University of Nairobi that continuously conduct research to find a HIV vaccine and other research work for HIV either as volunteers or community stakeholders."

"PLHIV are used as research subjects without prior information on the research. This brings a lot of mistrust and lack of volunteers for research."

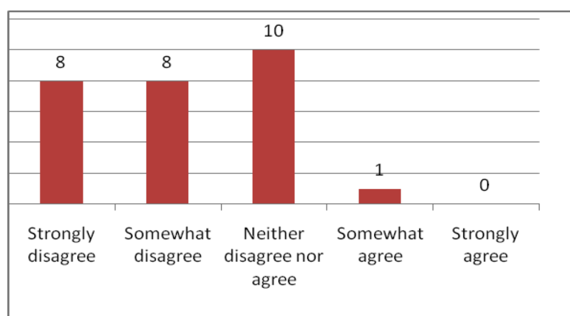
"PLHIV have not been involved even in social research by the government.

Poverty Reduction Strategies

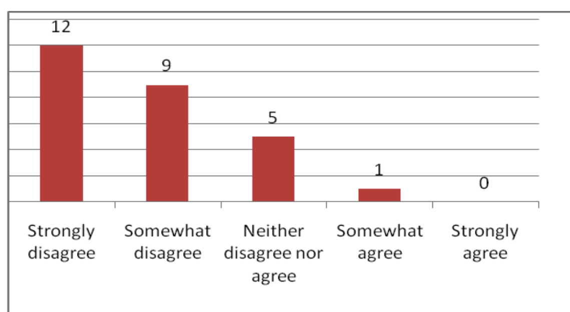
My country has a poverty reduction plan and/or strategy in place.



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



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



Kenya

While most of the respondents agreed that Kenya has a national poverty reduction plan, few were happy with the input of PLHIV into these policies, and satisfaction with the way the policy addresses gender differences in the situations of male and female PLHIV was minimal.

Respondents' comments on the question of poverty reduction strategies were as follows:

> *"HIV and AIDS can bring about worsening of the poverty situation of an individual and on the other hand poverty can lead one to get exposed to HIV. The two are interlinked and no effort should be spared to address them concurrently through deliberate efforts to economically empower PLHIV e.g. through micro-credit schemes and income generating activities."*

> *"The contents of the national Poverty Reduction strategy are not clear to many people, even on how different stakeholders including PLHIV are to be involved."*

> *"Vision 2030 mainly focuses on poverty reduction at the macro level but does not pay attention to the serostatus of the population."*

> *"PLHIV have not been involved in policy making on eradication of poverty such as in developing poverty eradication strategy papers "*

> *"Most development funds in Kenya never trickle down to the grassroots where most PLHIV live."*

> *"The national poverty reduction and eradication plans are developed by technocrats and hardly have any inputs from PLHIV "*

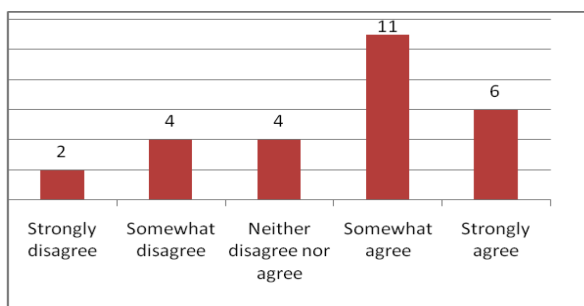
> *"There is no support for PLHIV as far as poverty reduction is concerned."*

> *"The poverty strategy is one of the Millennium Development Goals targets yet PLHIV have not been adequately targeted in national poverty eradication strategies in Kenya."*

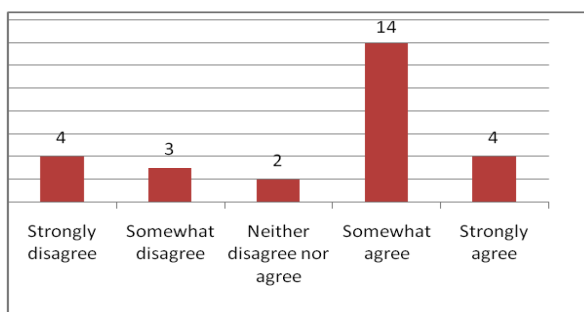
Employment

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

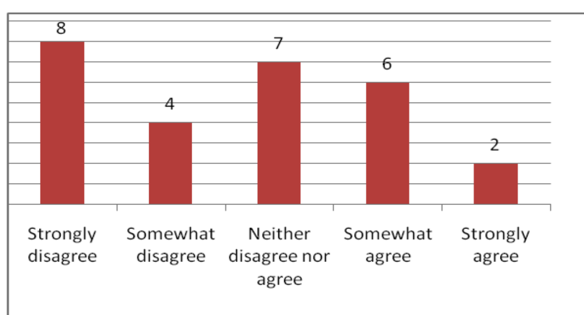
My government has enacted legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work.



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.



Most of the respondents affirmed that the government of Kenya has enacted labour legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work. Few respondents were however in agreement that people living with HIV had been meaningfully involved in the development of these workplace policies. Some noted that PLHIV had been involved through NEPHAK's representation in the development of Employment Code of Conduct. However, NEPHAK was only part of the process and did not drive it.

Most respondents reported that in their organisations there is no workplace policy regarding the employment of people living with HIV as staff. Two respondents did however report that their organisations had a workplace policy but without a budget to implement the policy.

The responses concerning employment and workplace policies follow:

> *"Generally it is envisaged in the law that nobody can be denied employment because of their HIV status."*

> *"Kenya has introduced in law a clause that an individual is not to be asked to disclose their status before applying or accepting a position. You are judged on your ability to deliver and not your status."*

> *"There is no discrimination allowed in the organisation and all employees are treated equally."*

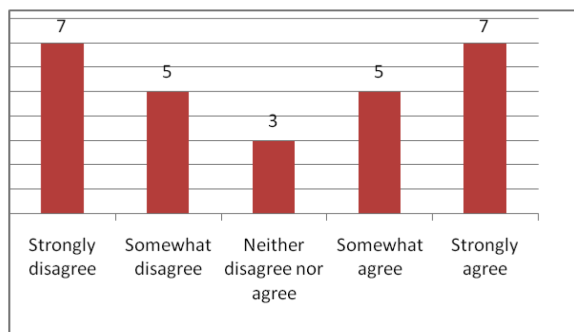
Six of the respondents who answered as PLHIV cited barriers to employment such as lack of medical care, social stigma and the fact that when one openly discloses serostatus, people tend to over-sympathize with them as if they were hopeless.

Others however said that they had not experienced obstacles in their place of work.

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' opinions varied concerning whether their organisation has developed materials focused on the GIPA principle and the meaningful involvement of people living with HIV.

Respondents whose organisations had developed materials focused on the GIPA principle and the meaningful engagement of people living HIV commented as follows:

> *"The materials have impact because they are being used by other organisations especially the church-based organisations and local communities."*

> *"The organisation has a policy on HIV and prepares IEC materials. It also encourages formation of AIDS clubs."*

"Generally there are materials developed by certain organisations but not enough and not widely distributed. This could be because of limited budgets. More and appropriate materials on GIPA needed."

"The network of teachers living with HIV (KENEPOTE) has developed materials for teachers living with HIV."

"Have developed GIPA guidelines, situational analysis of GIPA carried out, PLHIV involved in the Task Force for development of GIPA. Materials will be used once disseminated especially the GIPA guidelines."

"IEC materials on the same have been developed."

"Materials have been developed on Code of Good Practice for NGOs responding to HIV (MIPA checklist)."

"There are materials on HBC, treatment literacy, videos, magazines and posters".

"There are materials about reduction of stigma and discrimination of PLHIV at the work place."

"GIPA guidelines (developed by NACC in consultation with stakeholders)

Action AID MIPA Tools."

Some respondents reported that their organisations had not developed materials on the GIPA principle but they have materials developed by other organisations, though often not enough of them. This was explained as due to limited budgets. More well-designed materials on GIPA are needed.

"Though we have used some materials like posters or fliers, these were basically from network partners."

Some respondents reported that they do not know about the GIPA principle. Others gave the following reasons for lack of their organisation's involvement in developing materials on the GIPA principle and the meaningful involvement of people living with HIV:

"We have no resources or skills to develop materials on the GIPA principles."

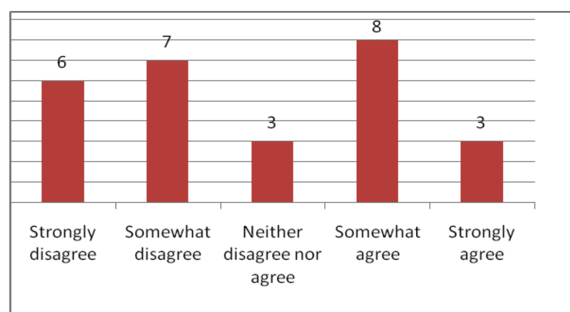
"Ministry of Public Health and Sanitation mainly deal with prevention methods."

Kenya

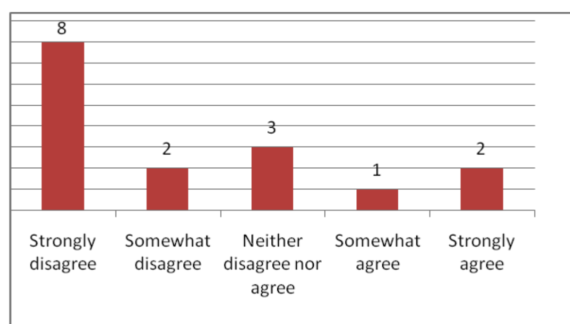
Financial Support

When asked to what extent they agreed or disagreed with the statements below, 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.



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



Many respondents did not think that PLHIV who work with government HIV programming were receiving full reimbursement for the costs involved in their volunteering in this way.

Of the sixteen PLHIV respondents, half strongly disagreed that they were adequately paid for their efforts, with only two fully satisfied with their compensation.

Comments from the respondents concerning reimbursement of expenses are shown below:

"There is usually no discrimination on financial support for anybody participating in such activities so all are compensated equally and fairly as per laid down guidelines where applicable."

"Reimbursement is not pegged on one's status so if there's any to be made then it is done irrespective of a participant's status."

"Child care cost is never reimbursed, and this is not just for PLHIV, but for all people."

"As PLHIV, involvement in the HIV response is not adequately paid for especially travel, health and food."

"No allowances are paid, not even accommodation or transport."

The following are respondent comments from PLHIV on their remuneration for involvement in the HIV response.

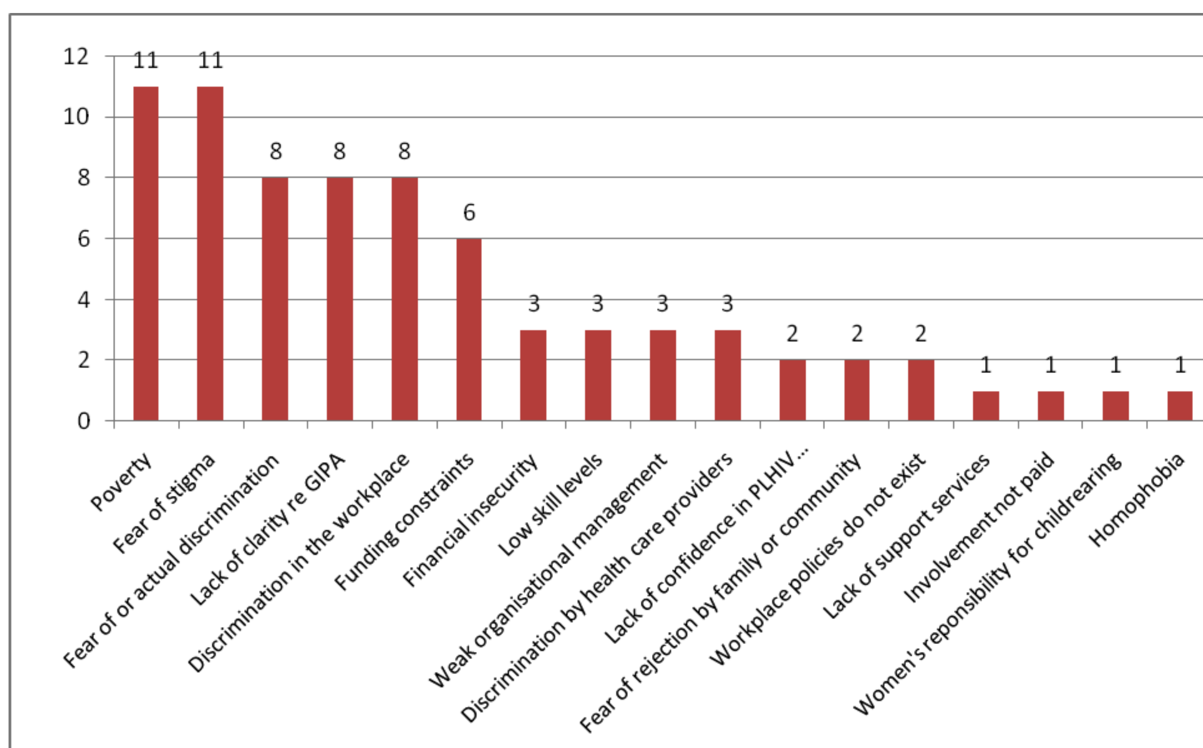
> *"Most of the PLHIV have been used as volunteers for a very long time without being paid any remuneration at all yet they are expected to live a normal life."*

> *"I get my livelihood from HIV and AIDS projects. I get paid for my participation."*

> *"Efforts by PLHIV and their leaders in Kenya are mainly voluntary and there are no resources allocated for GIPA participation or involvement of PLHIV. It is this voluntary arrangement that compromises the role and position of PLHIV in Kenya. The argument is that supporting PLHIV and their leaders is not sustainable."*

Barriers or Obstacles to GIPA

Respondents were asked to identify from a list the three most significant barriers or obstacles to the greater involvement of people living with HIV in the country's national activities. Below are the responses.



Kenya

Poverty and fear of stigma, each cited by 11 people (41%) emerge as the most significant barriers to the greater involvement of PLHIV in the country's national activities. These were followed by fear of actual discrimination, discrimination in the workplace and lack of understanding and clarity on GIPA, each of which was cited by 8 respondents (30%) and funding constraints, cited by 22%. Violence or fear of violence, fear that the individual will experience racism, lack of freedom for women to make independent decisions, lack of access to services, and lack of organisations or networks for people living with HIV were however not cited by any respondent as significant barriers to GIPA in Kenya.

Other barriers identified by the respondents were:

- Rumours and myths regarding the virus;
- Men have not been helped as much as the women have been supported as PLHIV;
- Awareness on GIPA is lacking;
- Some PLHIV cling to the offices without giving others a chance to lead and share ideas.

Respondents' suggestions on possible ways of circumventing these barriers to greater involvement included work on education and information awareness, and capacity building.

Opportunities for Involvement

The following were cited as the best opportunities for the greater involvement of people living with HIV in Kenya:

Policy

> *"PLHIV are not represented on all community and governmental development committees e.g. Constituency AIDS Control Committees, Constituency Development Fund, Health Facility Committees, etc."*

> *"PLHIV should be involved in Joint HIV and AIDS Programme Review meetings and forms (JAPR) and Monitoring Coordinating Groups (MCGs), Inter Agency Coordinating Committees (ICC) and Country Coordinating Mechanism (CCM)."*

> *"Engagement of PLHIV in HIV and AIDS programmes and activities in the community."*

> *"Involvement of PLHIV at the policy development level, implementation and research."*

> *"Kenya's HIV and AIDS strategic plan should adequately address the GIPA principle."*

"Positive discrimination or affirmative action through appointment of PLHIV representatives in key positions in politics, education and governance."

"Nominating PLHIV in parliament to articulate HIV issues."

Advocacy

"PLHIV being involved in rolling out the GIPA principle."

"Encourage PLHIV to fully participate in matters concerning HIV without fear."

"Advocate for the reduction of the cost of ARVs and better health services for PLHIV."

"Funding of programmes that involve PLHIV in development issues."

"Mainstreaming HIV in management and creating awareness on HIV at the workplace."

"Positions in government should have PLHIV according to the prevalence rates."

"The unveiling of the 3rd National Strategic Plan focusing on the need to accelerate efforts towards delivery of universal access targets."

"Completion of GIPA implementation guidelines by the National AIDS Control Council."

"Unveiling of national code of conduct for institutions involved in HIV/AIDS work - this recognizes the importance of GIPA in responding to HIV and AIDS."

Socio-Economic Welfare of PLHIV

"Formation of grassroots support groups/post-test clubs for PLHIV, and strengthening of existing grassroots organisations of PLHIV."

"Strengthening of Networks of PLHIV through capacity-building."

"Train many caretakers, ambassadors of hope, adherence officers, VCT counsellors and community health workers who are PLHIV. Comprehensive Care Centres (CCC) and CACC should be led by PLHIV."

"Formation of school dissemination clubs and community-based activities involving PLHIV."

Discussion

Until recently, the GIPA principle has not been officially integrated into Kenya's response to HIV and AIDS at any level. However, through advocacy initiatives by the Kenya AIDS NGO Consortium to build support with government, development partners and CSOs, the GIPA principle is now fully acknowledged by the National AIDS Control Council (NACC) as key in combating HIV, and is recommended in every sector and area of intervention. CSOs, under the PTAP umbrella, are intensifying advocacy efforts for the full integration and implementation of GIPA principles in the Kenya National AIDS Strategic Plan 2005-2010.

Local leaders, CSOs and communities have increasingly supported the inclusion of PLHIV in Constituency AIDS Control Committees (CACCs), Constituency Development Funds, and other community-based associations. However, despite a spirited attempt by the NACC to promote the GIPA principle in most HIV and AIDS policy formulation, planning, project design and implementation, representation of PLHIV at all levels including NACC Council, CACCs and District Technical Committees remains remarkably low.

The Kenya National AIDS Strategic Plan 2005-2010 supports and provides for GIPA implementation, but from the responses obtained in this study, the GIPA principle still remains unknown to many organisations involved in or implementing HIV and AIDS activities. This calls for concerted public campaigns to enhance public awareness of the GIPA principles.

Respondents also felt that only a few people, who are well-to-do, are involved in policy formulation and decision-making at both national and organisational levels, to the exclusion of the voiceless poor majority. A more inclusive and better funded approach could improve representation of PLHIV from all backgrounds in HIV and AIDS programming. In particular, although the majority of diagnosed Kenyan PLHIV are female, social convention often excludes them from playing a full part in their country's response to HIV and AIDS.

Examination of the progress on universal access to treatment shows that coverage remains inadequate, for various reasons, but that many respondents felt that greater involvement of PLHIV in managing these issues might speed up roll out and enhance continuity of supplies. In this matter, the application of the GIPA principle can be seen as a matter of life and death.

Conclusion

Kenya has made notable progress in applying the GIPA principle, with a strong multi-sectoral response involving the collaboration of government, technical agencies, civil society, and people living with HIV. However, tokenism still exists, and the inclusion of PLHIV mainly as volunteers and in very circumscribed tasks can result in the real issues at the grassroots being neglected. Intensified implementation of the GIPA principle might improve targeting of funds allocated to help PLHIV and increase the proportion reaching them. Funding and skills training to allow more PLHIV to shoulder professional roles in the response might speed progress towards the meaningful involvement of PLHIV in Kenya's national response.

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Notes

GIPA Report Card

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Kenya

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