SOUTH AFRICA HIV Leadership through Accountability

GIPA Report Card
South Africa

Country Assessment 2011

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NAPWA SOUTH AFRICA

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community Based Organisation
DOTS	Directly Observed Treatment Support
EAP	Employee Assistance Program
EPOC	Ekurhuleni Pride Organising Committee
FBO	Faith Based Organisation
GDARD	Gauteng Department of Agriculture and Rural Development
GIPA	Greater Involvement of People Living with HIV
GNP+	Global Network of People Living with HIV
HCT	HIV Counselling and Testing
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
HSRC	Human Sciences Research Council
ICAP	International Centre for American Professionals
IDP	Internally Displaced Persons
IEC	Information, Education and Communication
LGBTI	Lesbians, Gays, Bisexuals, Transgender and Intersex people
NACOSA	The Networking HIV/AIDS Community of South Africa
NAPWA	National Association of People Living with HIV and AIDS
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NIMART	Nurse Initiated and Managed Antiretroviral Treatment
NPO	Non-Profit Organisation
NSP	National Strategic Plan
OVC	Orphaned and Vulnerable Children
PLHIV	People Living with HIV
SANAC	South African National AIDS Council
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

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Executive Summary

Profile of Respondents

A total of 24 respondents participated in the implementation of the GIPA Report Card. According to the participants, their organisations have been providing services to people living with HIV (PLHIV) for between 3 and 70 years. However, it seems unlikely that an organisation would have provided HIV and AIDS related services for 70 years.

The annual budgets of the participating organisations varied greatly. Some budgets were as low as R150 000 while one government department reported an annual budget of R1 billion. Organisations had between zero and 70 employees living with HIV, and between zero and 50 volunteers living with HIV. Few of the organisations had designated paid positions for PLHIV; those that did mainly employed PLHIV as counsellors and mentors. Projects were implemented in a host of different locations. The population groups served by these projects varied widely too, ranging from women, men and children to sex workers and people who use drugs.

Mission Statements

The mission statements and goals of the participating organisations covered a wide range of activities aimed at addressing the HIV epidemic. These included, improving the lifestyles of people, monitoring and evaluating programmes, providing technical support to health service providers, supporting government, conducting testing campaigns, encouraging home based care and support, developing Integrated Development Programmes (IDPs) and LGBTI services, enhancing delivery and empowering sex workers. Some participants did not provide information about their mission statements.

Knowledge of GIPA

Respondents were split on how the GIPA principle was understood and interpreted in the South African context. Some participants considered that PLHIV involvement at policy development level was minimal. According to them, this was due to enduring stigma, lack of funding, fear of discrimination and human rights violations. Others were of the opinion that PLHIV involvement was a reality at almost all levels including, policy programming, implementation, advocacy, and resource mobilisation. Suggestions were made to promote greater involvement. These included participation in stakeholder forums, partnerships and collaborations with relevant stakeholders, provision of home based care, food parcels, and support.

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National HIV and AIDS Strategic Plan

Respondents differed as to whether the GIPA principle was included in the National AIDS Plan and whether studies had been carried out on the GIPA principle in South Africa. Most respondents, however, agreed that PLHIV played a meaningful role in the development of the National AIDS Plan. Nine respondents did not agree or disagree that GIPA had been included in the National AIDS Plan’s monitoring and evaluation framework; while seven respondents stated that they somewhat agreed with this statement. Thirteen (59.1%) respondents stated that South Africa did have a National GIPA Guideline or Plan or an equivalent, while nine (40.9%) thought that South Africa did not.

GIPA at State and Provincial Levels

None of the respondents strongly agreed with the statement that GIPA had been adequately implemented into state or provincial level HIV planning, while 10 respondents did not agree or disagree with this statement, seven respondents somewhat agreed and five somewhat disagreed. Seventeen respondents agreed that PLHIV had been meaningfully involved in developing state or provincial level HIV policy and none of the respondents disagreed with this statement. Some participants stated that PLHIV involvement is non-existent whereas others were unsure as to whether there is any involvement at state and provincial levels. Most participants mentioned that there is involvement but noted a lack of coordination when it comes to planning and policy development. One participant also observed that the spheres of government were not complementing each other.

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

Although some respondents did notice that PLHIV had been meaningfully involved in the development of the progress report on UNGASS, respondents were concerned about the lack of feedback. Some of them had never heard about UNGASS. Lack of resources made it difficult for them to access the relevant information. Conference attendance by communities was suggested as a way to access information. Several participants stated that the provinces had not been involved in developing the UNGASS report. According to some respondents, inadequate consultation had made it difficult for PLHIV to be meaningfully involved.

Policy Development

Many of the respondents stated that at this level, PLHIV were mainly being involved through organisations such as TAC and NAPWA. SANAC was also seen as playing an important role in setting a national agenda. Respondents made it clear that the continued involvement of PLHIV was imperative in order to decrease stigma and discrimination, especially since they have a better understanding of the actions that need to be taken. A few of the respondents were concerned about the lack of governmental engagement from national to provincial level.

Universal Access

Policy implementation, stakeholder involvement, as well as counselling and prevention strategies were working well. The strengths and weaknesses of medication supply systems were both mentioned. For instance, participants considered the medication provided as being of first quality. But although, a significant number of people had access to medication, there were however, no follow up systems in place for side effects. As a consequence, patients defaulted and became resistant to the medication. Furthermore, fundraising and service delivery issues were mentioned as barriers on the supply side.

Representation and Networks of People Living with HIV

The general feeling was that PLHIV are represented on the decision-making bodies. Several platforms were mentioned where participants believed that PLHIV participate and give input. PLHIV were also well known for providing frameworks that lead to better policies. Obstacles to participation, involvement and representation included amongst others, stigma, lack of HIV sero-status disclosure, politics and power struggles, and competition over scarce resources. Suggestions included amongst others: promoting accountability, implementing monitoring and evaluation exercises once the infrastructure is in place, strengthening advocacy and lobbying organisations like NAPWA in order to promote coverage/outreach, and improving communication between the networks and their respective constituencies.

Research and Sexual and Reproductive Health

Microbicides research (e.g. Voice 004) and clinical trials (e.g. the CAPRISA ARV trial) were among the research projects in which, PLHIV were involved. They were also engaged in, focus group facilitation, community-based research and field visits, either as subjects or respondents. Some participants were of the opinion that PLHIV should be more involved in research. For example, they should be part of the developmental agenda on research studies.

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Poverty Reduction Strategies

According to the respondents, government departments such as Agriculture, Social Development and Health, all had a poverty reduction plan in place. These programmes were reported to be targeting key communities such as Orphaned and Vulnerable Children (OVC) and positive mothers. Some participants were not certain if this strategy existed and indicated that they would to do some research after the interview. Some suggested that if there is such a document, it should be made accessible. Participants considered that a poverty reduction strategy was crucial, since proper treatment involves adequate nutrition. Some participants mentioned projects aimed at reducing poverty and reported that their organisations had allocated a budget for poverty reduction. Recommendations on poverty reduction strategies and PLHIV involvement included, holding a summit on poverty reduction, providing nutritional supplements, and organising workshops to promote consultation, information dissemination and education.

Employment

Participants were asked if they are living with HIV, and if they are employed by an NGO, government or the UN. If they responded ‘yes’, participants were asked about barriers they may have encountered and the contributory factors that may have assisted them in overcoming those barriers. Sixty seven per cent (67%) of the participants reported that they were not living with HIV whereas 19% answered affirmatively. Fourteen per cent (14%) did not respond to the question. This again highlighted the lack of disclosure in South Africa, which results from different factors including stigma and discrimination. Some respondents further explained that they were not in a position to disclose, whereas others reported not having been tested at that time. This was interesting considering that most AIDS awareness organisations and campaigns support HCT and disclosure. In South Africa, disclosing ones HIV sero-status is voluntary.. Stigma, low disclosure rates, lack of capacity building and inadequate funding for workshops on empowerment were listed as barriers. At the municipal level, the fragmentation/lack of integration of wellness programmes supporting PLHIV was mentioned.

GIPA-Related Materials

While some organisations stated that they had worked extensively with and for PLHIV, and had provided training to partners on stigma and the GIPA principle, a number of organisations stated that this was the first time that they had heard about the GIPA principle. One organisation also declared that in the case of service delivery their involvement with PLHIV had been minimal.

Financial Support

Some of the participants said that it was unethical to discriminate against PLHIV within organisations. Some thought it went against the organisations’ own guiding documents and policies, while others stated that it contravened the Employment Equity Act. A handful of participants stated that it did not apply to them since they were volunteers and their organisation depended on volunteer work only. However, a number of participants considered that PLHIV should be reimbursed for their involvement and work in the HIV response. The reason being, according to one respondent, that they were ‘positive ambassadors’. But other participants stated that PLHIV should be encouraged to lead normal lives and be economically active, and should not be funded because of their status but only because of the work they perform.

Barriers and Obstacles to GIPA

None of the organisations cited the following issues as barriers or obstacles to GIPA: Violence or fear of violence, unpaid involvement, lack of access to ART and to treatment for opportunistic infections, services being inaccessible due to a person’s gender, and absence of PLHIV organisations or networks. Funding constraints were mentioned by nine of the organisations, while seven organisations saw poverty as a barrier or obstacle. One respondent noted that poverty and funding constraints acted as a dual burden. Eight organisations stated that the fear of stigma and the lack of understanding and clarity surrounding GIPA acted as obstacles or barriers.

Opportunities for Involvement

Community-based initiatives, research and advocacy, collaboration and partnerships were cited as the best opportunities for the greater involvement of PLHIV.

Key Recommendations

- Allocate resources to support organisations of people living with HIV to implement community-based initiatives and to undertake research and advocacy;
- Promote stigma reduction initiatives to remove barriers to visible leadership positions and encourage greater involvement of people living with HIV;
- Increase awareness of the GIPA principle within NAPWA and partner organisations;
- Increase awareness of the GIPA principle within government departments;
- Enhance collaboration amongst PLHIV organisations and promote a cohesive PLHIV voice to articulate the involvement of people living with HIV in all matters affecting their lives;
- Support PLHIV in developing their skills in gathering and using evidence for effective advocacy, implementation, monitoring and evaluation.

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Introduction

The greater involvement of people living with HIV (GIPA) is a guiding principle that calls for the active and meaningful participation of people living with HIV in the inception, development, implementation, monitoring and evaluation of policies and programmes. The GIPA principle is a rights-based approach, which is recognised as good practice in programming and policy. It acknowledges the universal rights of people living with HIV to self-determination and participation in decisions that affect their lives.

Violating people's rights to self-determination and participation has serious consequences for them, their communities, organisations seeking to serve them and the countries they are citizens of. Rights violations can impact people in many ways and result in social isolation, alienation and depression. Thus, to be successful, the involvement of people living with HIV should be mainstreamed across all aspects of the HIV response, including, prevention, treatment, care and support.

Participation of those who will be affected by decisions is widely regarded as good practice by international development practitioners, community development workers and health promotion specialists. These stakeholders recognise that participation leads to ownership, which is essential for sustainable social change. The GIPA principle specifically recognises the value of participation in the context of the HIV response.

Increased resources, support and commitment are needed to enable the meaningful participation of people living with HIV. Successful implementation of the GIPA principle requires leadership and strategic planning within organisations. This includes a commitment to ensuring that the involvement of people living with HIV is sustainable by addressing barriers to participation, including discriminatory policies and procedures; ensuring the availability of financial, technical and human resources to facilitate participation; and building capacity for meaningful participation among people and organisations of people living with HIV.

There are many practical reasons to involve people living with HIV in your programmes and organisations, including:

1. **Programmes and policies are tailored and responsive**
   Practicing the GIPA principle enhances the effectiveness of policies, programmes and services. Involving people living with HIV ensures that your policies, programmes and services are grounded in their daily lives and realities. Policies,

programmes and services that are based on the experiences of people living with HIV are more likely to:

- Respond to the needs and priorities of other people living with HIV
- Become more open and non-judgemental
- Be seen as acceptable and credible
- Increase access to programmes and services
- Make sure that your organisation's human and financial resources are directed towards the most relevant and realistic interventions
- Sustain funding and resources

2. **Stronger community systems and better local responses to HIV**

   Practising the GIPA principle by working with people living with HIV and organisations of people living with HIV strengthens community systems and results in better local responses to HIV by:

   - Ensuring that policies, programmes and services are tailored to the local context and key populations
   - Creating peer support networks in communities
   - Challenging negative attitudes about people living with HIV by signalling that they have something to contribute and are valued members of the community
   - Increasing demand for services
   - Building capacity within the community to provide an increased range and quality of services, including improved access to physical infrastructure (such as office space, bank accounts and communications technology) and opportunities to learn skills and tools that support organisational systems (such as financial management, strategic planning, monitoring and evaluation, and information management capacities)
   - Mainstreaming HIV in other sectors and building partnerships at the local level to improve coordination, enhance impact and avoid duplication of service delivery

3. **Increased self-determination and personal development for people living with HIV**

   Practising the GIPA principle recognises the rights of people living with HIV to self-determination and participation in decisions that affect their lives. It respects their knowledge and abilities to address their own needs.

   The GIPA principle supports the personal development of people living with HIV by:

   - Reducing social isolation, depression, and self-stigma
   - Building self-esteem

- Promoting confidence and overall health and well-being
- Creating support networks through peer connections
- Increasing employability

Since the early years of the HIV epidemic, HIV responses have been sparked and propelled by social movements of people living with HIV and populations most affected by HIV, such as gay men, women, sex workers, young people, people who use drugs, migrants and people living in poverty. The call for active and meaningful involvement of people living with HIV was formally recognised in 1994 when 42 countries signed the Paris Declaration. This declaration formalised and declared: "The Greater Involvement of People Living with, or affected by HIV/AIDS is critical to ethical and effective national responses to the epidemic".

The GIPA principle aims to achieve the following:

- To support the greater involvement of people living with HIV (PLHIV) through initiatives aimed at strengthening the capacity and coordination of networks of PLHIV and CBOs, and stimulating the creation of a supportive political, legal and social environment;
- To fully involve PLHIV 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 and AIDS, through legal and social environments;
- To make available necessary resources to better address 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 and AIDS.

The GIPA Report Card is an assessment of the application of the GIPA principles in the national response to HIV. The GIPA Report Card is also an advocacy tool, which aims to increase and improve the programmatic, policy and funding actions taken to realise the GIPA objectives within South Africa.

NAPWA conducted a survey, based on interviews, among 24 organisations in South Africa. The South African GIPA Report Card assesses 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.

Policy and Literature Review

HIV and AIDS in South Africa

South Africa has been severely impacted by a generalised HIV epidemic and has the highest number of people living with HIV in the world – millions of South Africans are living with the virus. However, there are major disparities amongst and between males and females, and different age groups. In general, there has been a notable decline in the HIV prevalence rate amongst all South Africans. The estimated HIV prevalence for individuals aged two years and above is 10.8%. The prevalence rate is higher amongst females (13.3%) than males (8.2%) – women in South Africa are more likely to contract HIV than men (Shisana et al. 2005). The HIV prevalence rate, however, is considerably lower amongst children aged two to 14 years (3.3%) than amongst individuals aged 15 to 49 years (16.2%). Furthermore, there are great geographic disparities in the HIV prevalence rate – KwaZulu-Natal, Free State and Mpumalanga have the highest HIV prevalence rate, while Western Cape and Northern Cape have the lowest. Also, individuals living in informal settlements and in rural areas in South Africa show a higher HIV prevalence rate than those living in formal and urban areas (Shisana et al. 2005; NSP 2012-2016).

GIPA in South Africa

The GIPA principle as such has not been officially integrated into the South African response to HIV and AIDS, although involvement of people living with HIV has been acknowledged as one of the key tenets of the national response to the disease. The latest South African National Strategic Plan (2012-2016) does not look at HIV in isolation, but brings together HIV and TB in its guiding principles and the programmes it wishes to introduce. One of the NSPs guiding principles is to promote meaningful involvement of people living with HIV and affected by TB. In other words, governance structures will recognise the important role to be played by people living with HIV and TB and will involve them in governance structures. The NSP 2012-2016 also introduces a clear programme of action that covers both innovative and established methods of stigma elimination, one of which is the greater involvement of people living with HIV and TB. The NSP acknowledges that this is critical in programmes that aim to empower and educate communities and individuals. Furthermore, together with the greater involvement of people living with HIV and TB, a Stigma Mitigation Framework will be implemented and efforts to reduce stigma will be monitored by a Stigma Index.

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Methodology

The methodology used in collecting results for the GIPA Report Card was identical to the one set out in the GIPA Report Card Guide, published by the Global Network of People Living with HIV (GNP+) in May 2009. NAPWA used purposive sampling to create a list of potential interviewees for the study. Participants were selected from a wide range of organisations and key populations, including:

- Representatives of key populations or those working with them;
- Representatives of organisations and mechanisms involved in the country's HIV response, such as:
    - PLHIV Networks
    - Country coordinating mechanisms
    - UNAIDS co-sponsors
    - Development agencies
    - Donor organisations

Respondents included in the South African survey came from a wide range of stakeholders including women's, youth, and other types of PLHIV networks, organisations or support groups; development agencies; civil society organisations; municipal, provincial and national governments; and a private construction company.

Data Collection

The NAPWA Research Coordinator played a supportive role in recruiting participants on behalf of the interviewers. The interviewers were selected from NAPWA and its provincial offices. Each of the interviewers was allocated three provinces. Due to a number of delays, the originally selected participants were not interviewed and interviewers recruited participants using purposive sampling and collected data.

The standardised GIPA Report Card Guide was used in the survey. Prior to data collection interviewers received training on the guide, the consenting process, interviewing techniques and the use of digital recorders. Training was conducted over two days between 16th and 17th August 2010.

Languages Used

Although interviews were mainly conducted in English, interviewers sometimes asked questions in vernacular languages when participants preferred this.

Reimbursements

None of the participants were reimbursed or rewarded, except for those from KwaZulu-Natal who received NAPWA t-shirts as a token of appreciation for their participation in the survey.

Duration of Interviews

On average, interviews took between one and two hours each.

Audio-recording

Initially, it was hoped that most interviews would be recorded. However, due to technical problems with audio-recorders and inadequate venues or noisy surroundings, most interviews could not be recorded. A majority of respondents preferred not to be recorded.

Response Rates

Interviewers reported that the response rates were low. Reasons provided by participants for their inability to participate included amongst others, work commitments and time constraints. Interviewers reported that most participants did not see the benefits of participating in the GIPA research even after receiving standardised generic information on GIPA. Some of the prospective participants stated that they were only involved in the HIV sector for professional reasons..

Study Limitations

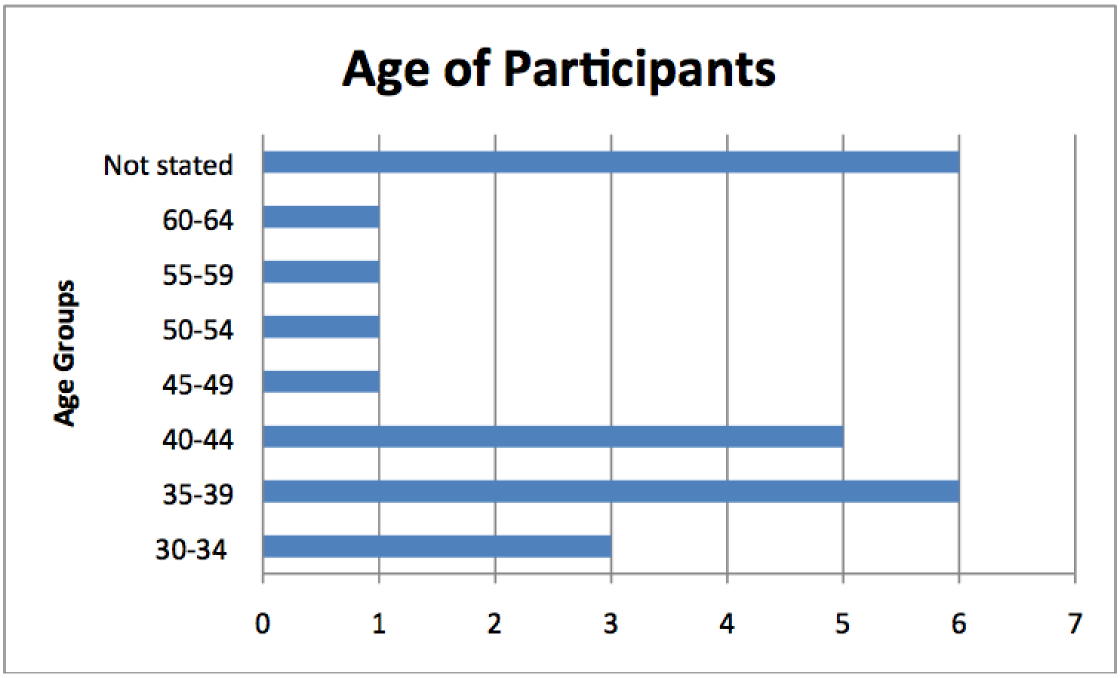
- The study relied on individual responses. However, no records were available to verify the responses.
- The sample size is small. The study seeks to provide a snapshot of perceptions about the implementation of the GIPA principle.
- Although, NAPWA data collectors conducted most of the interviews, there were cases where participants preferred to self-administer the questionnaire. This led to some of the questions being answered incorrectly, such as giving more than three answers to a question when only three answers were requested.

GIPA Report Card Results

Profile of Respondents

A total of 24 respondents participated in the survey on the GIPA Report Card implementation.

Although six participants did not provide their age, those that did were all above the age of 30. Three participants were between the ages of 30 and 34, while the majority (11) were between the ages of 35 and 44. Four participants were older than 45 years and the eldest was 61 years old.



Organisations that took part in the interviews

The 24 organisations that responded to the GIPA Report Card questionnaire are listed by sector.. The number of years that the sampled organisations have been involved in HIV and AIDS related work and activities, as well as their annual HIV and AIDS budgets are also shown in Table 1 below.

Table 1: Organisations who participated in the survey

		Duration of Service in HIV and AIDS Activities (in Years)	Annual HIV and AIDS Budget (in Rands)
Women PLHIV network / organisation / support group			
1.	Positive Women's Network	No Information	600 000
2.	Sisonke African Sex Workers' Alliance	3	Not Disclosed
Youth PLHIV network / organisation / support group			
3.	Sibusisiwe Support Group	5	Not Disclosed
Other PLHIV network / organisation / support group			
4.	Ekurhuleni Pride Organising Committee (EPOC)		No funding, relying on donors and membership.
5.	Olive Leaf Foundation	22	Not known
Development Agency			
6.	Engenderhealth	70	11.1 million
Civil Society Organisations			
7.	Children's Rights Centre	20	Not Disclosed
8.	International Centre for American Professionals (ICAP)	5	18 million
9.	Jhpiego	20	Not Disclosed
10.	Legbonsy Home Base Care	No Information	Not Disclosed
11.	Newstart Kimberley	No Information	Not Disclosed
12.	Regolele Support Services	4	150 000
13.	South African Council of Churches	20	3 million
14.	The Aurum Institute	No Information	208 million
Government Bodies and Departments			
15.	Gasegonyana Municipality	5	
16.	John Taolo Gaetsewe	No Information	Not Disclosed
17.	Department of Roads Transport	5	1 million
18.	Multi-sectoral AIDS Unit	No Information	47 million
19.	Health and Social Development	7	1.5 million
20.	Gauteng Department of Health and Social Development.	No Information	1 billion
21.	City of Johannesburg Health Department	No Information	30 million
22.	City of Tshwane AIDS Unit.	No Information	6 million
23.	Gauteng Dept. of Agriculture and Rural Development	No Information	500 000
Private Companies			
24.	Robenco Construction	6	20 million

Only thirteen respondents provided an answer when asked how many years their organisation had been involved in HIV and AIDS services. Eight out of the thirteen stated they had been providing these services for between 3 and 7 years. Three organisations stated they had been involved in these activities for 20 years, one for 22 years, and one for 70 years. However, it might well be the case that some organisations confused duration of years providing HIV services and duration of active services of the organisation in general. Thus, it is particularly unlikely that an organisation would have been involved in the provision of HIV and AIDS services for 70 years.

Eight out of the 24 respondents did not know, or did not wish to disclose the annual HIV and AIDS budget of their organisation. For those that did respond, their annual budgets varied greatly. Some budgets were as low as R150 000, followed by R500 000 and R600 000; other budgets ranged from 1 million to 6 million Rands. Five of the organisations had budgets of between 10 million and 208 million Rands, and one government department had an annual budget of 1 billion Rands according to the respondent.

Employees living with HIV

Fourteen respondents accepted to provide the number of employees living with HIV working within their organisation. One organisation stated that they had no employees living with HIV among their staff. The remaining organisations stated that they had the following numbers of employees known to be living with HIV working in their organisations:

- 1 employee living with HIV: 2 organisations
- 2 employees living with HIV: 3 organisations
- 6 employees living with HIV: 2 organisations
- 9 employees living with HIV: 1 organisation
- 10 employees living with HIV: 1 organisation
- 12 employees living with HIV: 1 organisation
- 30 employees living with HIV: 2 organisations
- 70 employees living with HIV: 1 organisation

Volunteers living with HIV

Sixteen respondents provided the number of volunteers living with HIV within their organisation. Five organisations stated that they had no volunteers living with HIV among their staff. These may have included organisations that did not have any volunteer workers in their organisation. The remaining organisations stated that they had the following numbers of volunteers known to be living with HIV working in their organisations:

- 2 volunteers living with HIV: 3 organisations

- 6 volunteers living with HIV: 1 organisation
- 7 volunteers living with HIV: 1 organisation
- 10 volunteers living with HIV: 1 organisation
- 19 volunteers living with HIV: 1 organisation
- 30 volunteers living with HIV: 2 organisations
- 40 volunteers living with HIV: 1 organisation
- 50 volunteers living with HIV: 1 organisation

Designated paid positions for people living with HIV

Five of the respondents stated that this was not applicable to their organisation. Eight of the organisations stated that they did not have designated posts for people living with HIV, as they believed that this would increase stigmatisation of PLHIV and/or contravene their non-disclosure policy. Those organisations that did have designated positions for PLHIV, had the following positions available:

- National Trainer for “Openly Living with HIV”
- Counsellors
- Mentor counsellors
- Peer educators
- Outreach coordinators
- National, provincial and district coordinators

Implementation of formal or informal internal discussions on the GIPA principle

Although eight organisations stated that they had implemented either formal or informal discussions on the GIPA principle, most of the organisations had not done so – and for some it was the first time they heard of the GIPA principle.

Primary locations where projects are implemented

Although five organisations did not respond to the question, of the remaining 19 organisations 12 operate in multiple locations. Seven organisations operate in only one location, Gasegonyana Municipality only implements its project in a rural area and Health and Social Development stated that they only operate in border areas (Table 2).

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Table 2: Primary locations where projects are implemented

Organisation	National	Urban	Peri-urban	Rural	Border Areas	Refugees / IDPs	Other
Olive Leaf Foundation	X	X		X			
Children's Rights Centre		X	X	X		X	
South African Council of Churches		X	X	X			
Jhpiego		X					
International Centre for American Professionals (ICAP)	No information available						
Newstart Kimberley							X
Legbonsy Home Base Care							X
Regolele Support Services	No information available						
Gasegonyana Municipality				X			
John Taolo Gaetsewe							X
Department of Roads and Transport		X	X	X			
Ekurhuleni Pride Organising Committee (EPOC)		X					
Positive Women's Network							X
Multi-sectoral AIDS Unit		X	X	X			
The Aurum Institute		X	X	X			
Sibusisiwe Support Group		X					
Health and Social Development					X		
Gauteng Department of Health and Social Development.	No information available						
City of Johannesburg Health Department							X
Sisonke African Sex Workers Alliance	X	X	X		X		
City of Tshwane AIDS Unit	No information available						
Robenco Construction	No information available						
Engenderhealth	No information available						
GDARD	No information available						

Five organisations stated that they had projects implemented in primary locations in areas other than those listed in table 2 above. They did not stipulate which areas.

Populations served by the organisations

Table 3 shows that most organisations do not only target one population group, but serve a number of different populations. However, only one organisation stated that they serve injecting drug users and only one organisation targets all PLHIV. Ten organisations serve youth and men, and 12 organisations serve women.

Table 3: Populations served by the Organisations

Populations Served	Number of Organisations
Orphans and Vulnerable Children	7
Youth (15 – 24 years)	10
Child Headed Households	5
Women	12
Men	10
Elderly	7
PLHIV:	12
Injecting Drug Users	1
Men who have Sex with Men	5
Women who have Sex with Women	4
Transgender People	4
Sex Workers	6
Migrant Labourers and / or mobile populations (incl. deportees)	6
Refugees, internally displaced people or asylum seekers	4
Prisoners	3
All of the Above	1
Other:	1
District Population	1

South Africa

Mission statements

The organisations that participated in this research highlighted various missions when addressing the HIV epidemic; others had additional goals as their statements below indicate. The mission statements ranged from improving the lifestyles of people, monitoring and evaluating programmes, providing technical support to health service providers, supporting government, conducting testing campaigns, encouraging home-based care and support, developing Integrated Development Programmes (IDPs) and LGBTI services, enhancing delivery and empowering sex workers.

The mission statements according to the participants were as follows:

*The **South African Council of Churches** aims to improve the lifestyle of the people. This is achieved through a committee that monitors and evaluates staff policy and programmes, and includes Constitutional and Human Rights, Poverty Alleviation and Peace Building. The Policy Unit, and the Health Programme play an important role in this regard.*

***Jhpiego** develops innovative trends in order to save lives and gives technical support to health service providers. Their operations were reported to include developing standards and Scopes of Practice as well as policy procedures. Their services and programmes include HIV Counselling and Testing (HCT) as well as Cancer and Prevention of Mother to Child Transmission (PMTCT) campaigns.*

***ICAP** reported striving to assist the government in fighting against the HIV pandemic by building ARV facility sites.*

***Newstart's mission** is to serve the health needs of the members of the community by conducting testing campaigns.*

***Legbonsy Home Based Care** strives to give a quality home based care to communities by training carers to use Directly Observed Treatment Support (DOTS) for clinic patients and by helping with general household work when necessary.*

*The mission of the **Regolele Support Services** is to provide care and support for people and orphans living with HIV and AIDS.*

*The **Gasegonyana Municipality** reported that its mission was to provide* *service delivery (e.g. water, roads and housing) to local communities. It also disseminated information based on the IDP strategic document in order to assist Home Based Carers (HBC) with the health kit implementation; and provided assistance and resources to fieldworkers.*

The *mission* ***of the John Taolo Gaetsewe municipality*** *is to support local municipalities through integrated planning and development.*

The mission of the ***Department of Roads and Transport*** *is to address the socio-economic situation and wellness of the employees through treatment, care and support as well as on-going counselling for their families.*

The mission of the ***Ekurhuleni Pride/EPOC*** *is to provide gay and lesbian oriented services by conducting workshops and training, and highlighting hate crime against LGBTIs.*

The ***Multi-sectoral AIDS Unit seeks*** *to develop a strategic agenda and advocates for the funding and management of civil society programmes, such as the secretariat of the provincial council.*

Aurum Health Institute *aims to improve knowledge and enhance service delivery.*

Sibusisiwe Support Group ensures that *policies are aligned with Non-Profit Organisation (NPO) requirements. Management runs the operatives and the team leaders coordinate the services and the programmes.*

The mission of the ***City of Johannesburg Health Department*** *is to provide education on HIV and AIDS as well as clinical health services.*

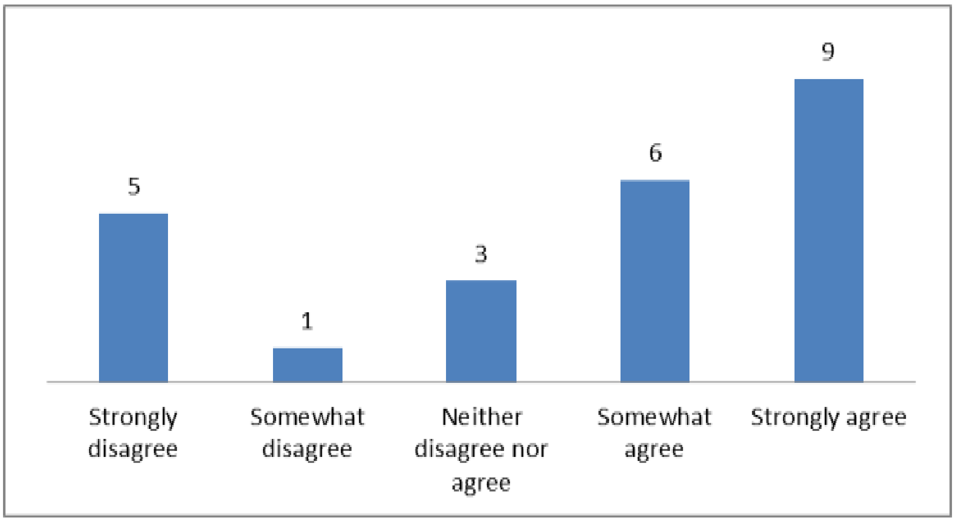
The mission of the ***Sisonke African Sex Workers Alliance*** *is to empower sex workers with safe models of security through education and training sessions. The aim is to create opportunities for sex workers to find work outside the sex industry.*

Several participants did not provide information about their organisations’ mission statements.

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 whether they agreed or not that this statement correctly reflected what the GIPA principle stood for. Six organisations either strongly or somewhat disagreed with this statement, and fifteen organisations somewhat agreed or strongly agreed with the statement.

For those respondents who were familiar with the GIPA principle, it meant that:

- Voices should be heard, especially when organisations speak of the budget for PLHIV
- PLHIV were given leadership and decision-making roles thus empowering PLHIV
- The presence of PLHIV within the organisation was recognised, and that they were given equal opportunities
- PLHIV were taking part in consultative decision-making processes and the programming and implementation of all HIV activities.
- PLHIV are involved in programmes relating to HIV in their institutions

One respondent likened the GIPA principles to the work done by organisations such as NAPWA and TAC, while another one stated that GIPA was helping to influence policy; for instance, in the case of the roll out of the treatment campaign.

Respondents who thought that involving people living with HIV in the response to HIV is positive said this:

> *"For me, this means giving PLHIV an opportunity to be visible in organisations, workplaces let them take over HIV and AIDS programs and involve them in policy making/decision-making structures because they are human beings with potential."*
>
> *"If this was implemented in our organisation, it would assist in terms of running programs. Discrimination and stigma will be reduced."*
>
> *"Provision of Care and Support for the PLHIV employees as well as training PLHIV on the information about the HIV and AIDS and empowering the immediate partners and family."*
>
> *"I have seen people managing HIV and AIDS program, driving it successfully and people disclosing their HIV status and fully participating in a program."*

However, one respondent noted that GIPA could not be applied in their organisation because the sector they were working in was prone to violence, stigma and discrimination.

Other respondents who felt that PLHIV have not been involved in critical decision-making processes provided various reasons.

When asked to describe the current situation regarding the involvement of PLHIV in response to HIV in South Africa, some participants indicated that they were not certain as to whether PLHIV were involved, whereas others were of the opinion that PLHIV were involved.

The activities of the South African National AIDS Council (SANAC) and the National Association of People Living with HIV (NAPWA), together with participation in various conferences and in local and provincial platforms, were regarded as positive engagement by PLHIV. The activities mentioned included participation in community dialogues, disclosure and awareness campaigns, information dissemination campaigns/workshops, education and advocacy on adherence to treatment.

Even though, some participants considered the level of involvement in policy development as being minimal, others mentioned that there were instances of involvement at almost all levels including, policy programming, implementation, advocacy, and resource mobilisation.

Those that mentioned limited involvement regarded stigma, lack of funding, fear of discrimination and violation of human rights as contributory factors. The scaling up of services targeted at migrants and refugees was considered a priority.

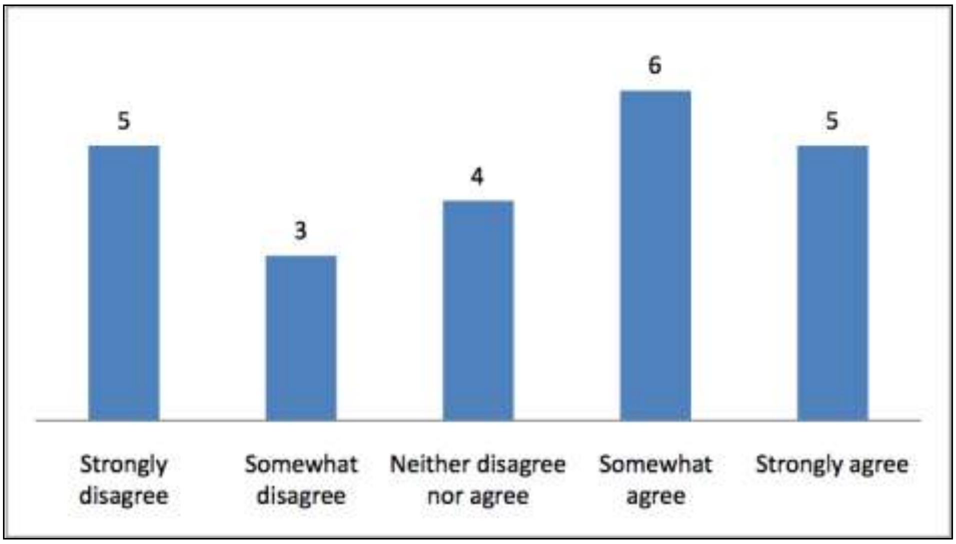
In addition, participants perceived the PLHIV movement as being fragmented and disunited due to personality clashes and power dynamics. Poor coordination and support of the sector from government and coordinating bodies such as SANAC were also mentioned. However, Telkom and the Department of Health were regarded as examples of good implementation. Findings indicate that participants had different opinions regarding PLHIV involvement in South Africa; this indicates that there is still room for improvement.

Suggestions for greater involvement included, participation in stakeholder forums, collaboration with relevant stakeholders, provision of home-based care, and access to food parcels and support. Once knowledge of GIPA had been imparted, participants solicited further information on whether the National AIDS and GIPA Plans were adequate.

National HIV and AIDS Strategic Plan

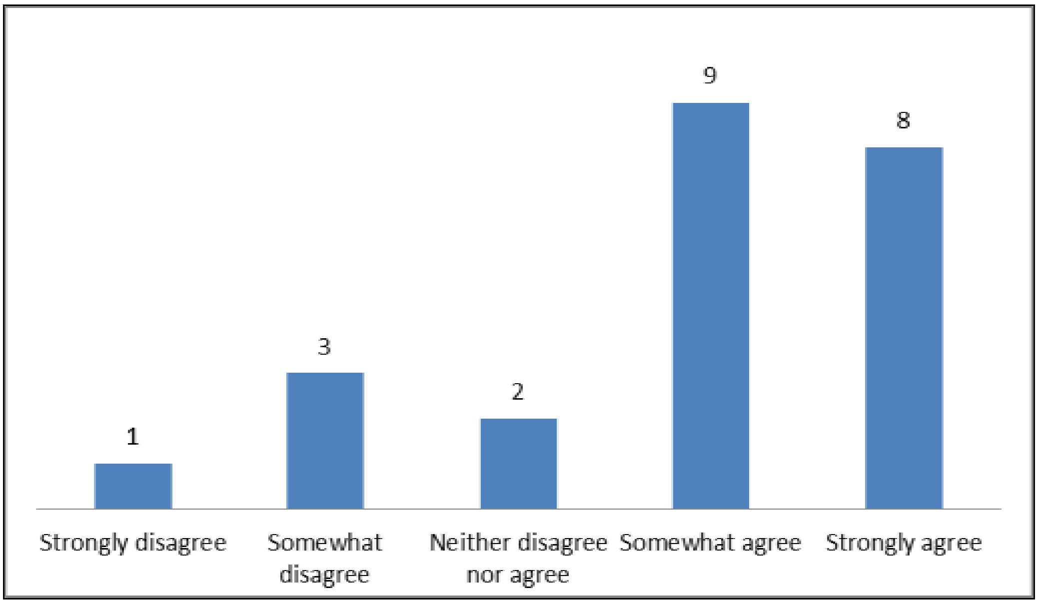
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

"The GIPA Principle is fully included in the National AIDS Plan."



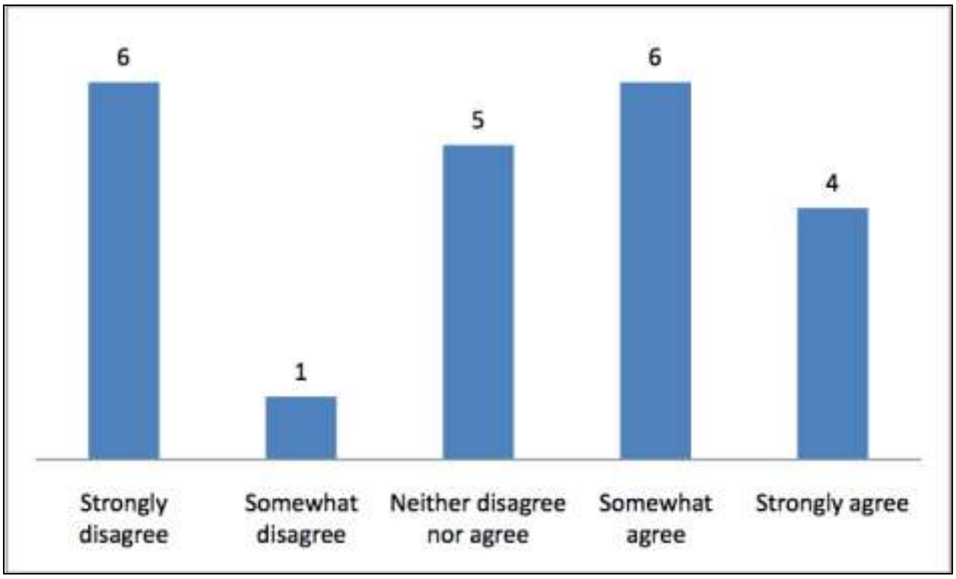
Respondents were somewhat split on whether they agreed that the GIPA principle was included in the National AIDS Plan. Although 11 respondents agreed with this statement, eight disagreed and four could not decide whether they agreed with this statement or not.

"PLHIV were meaningfully involved in developing the National AIDS Plan."



Most respondents, however, agreed that PLHIV played a meaningful role in the development of the National AIDS Plan (17 respondents).

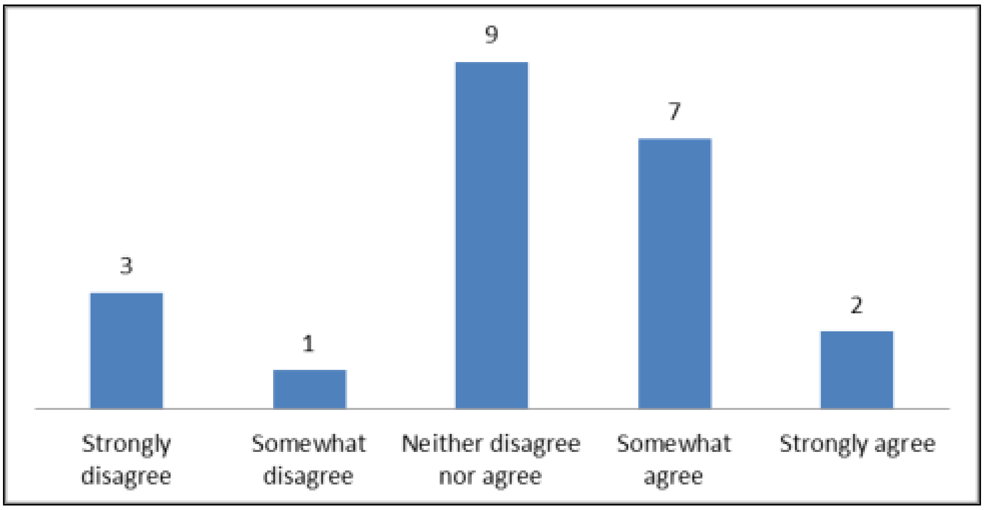
"In my country, there have been studies done looking at the GIPA principle."



Seven respondents disagreed that studies had been done on the GIPA principle in South Africa, while 10 agreed. Five respondents, did neither agree nor disagree with this statement.

South Africa

> *"The GIPA principle has been adequately included in the National AIDS Plan's monitoring and evaluation framework."*



Nine respondents did not agree or disagree that GIPA had been included in the National AIDS Plan's monitoring and evaluation framework; while seven respondents stated that they somewhat agreed with this statement.

Thirteen (59.1%) respondents stated that South Africa did have a National GIPA Guideline or Plan or an equivalent, while nine (40.9%) said that South Africa did not have these. Two respondents did not answer this question.

When participants were asked if the budget allocations of the National AIDS and GIPA Plans were adequate, their responses varied greatly:

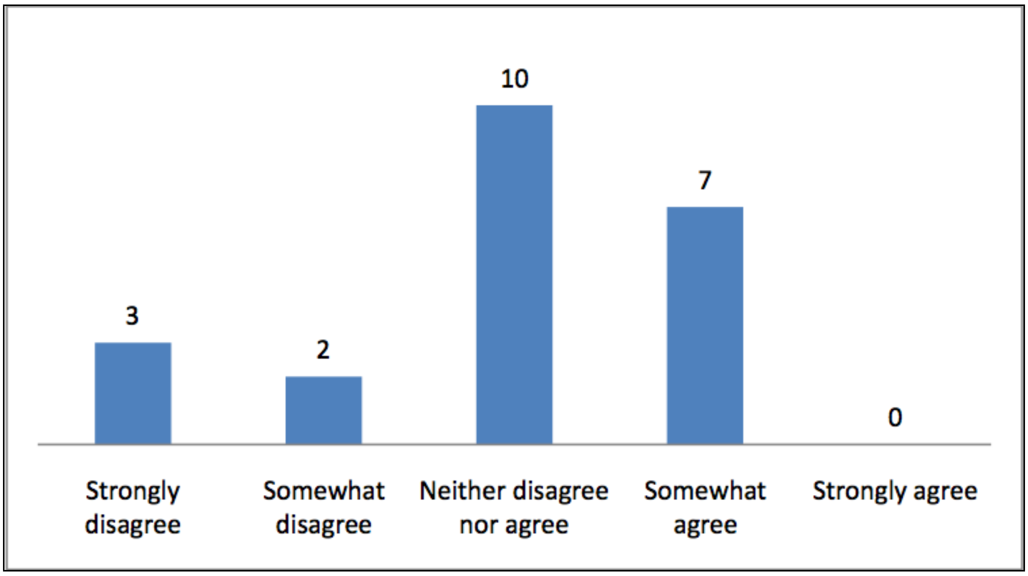
Some were unaware of the Plans or unsure that they actually existed. Those that knew about the Plans were split as to whether the funding was adequate or inadequate. Those participants who thought them adequate were either not certain of the level at which they were being implemented or unsure if the budget was actually being used. Some were aware that the Plans are put in action by using the national HIV conditional grant for health care service delivery and a provincial budget.

Those participants who considered the Plans to be adequate made suggestions for improvement. These included, participation in community dialogues, making the Plans available in print form, inclusion of PLHIV in local level consultations, allocation of financial and human resources, and the establishment of a consultative coordination structure for both Plans.

GIPA at State and Provincial Levels

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

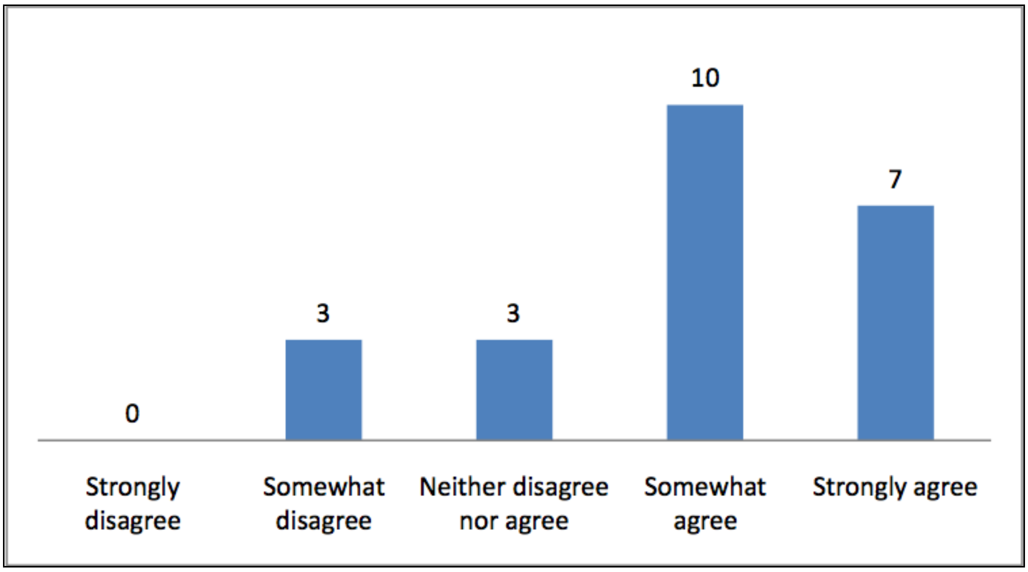
> *"The GIPA principle has been adequately implemented into state or provincial level HIV planning."*



None of the respondents strongly agreed with the statement that GIPA had been adequately implemented into state or provincial level HIV planning, while 10 respondents did not agree or disagree with this statement. Seven respondents, however, somewhat agreed and five disagreed.

> *"People living with HIV were meaningfully involved in developing state or provincial level HIV policy."*

South Africa



Seventeen respondents agreed that PLHIV had been meaningfully involved in developing state or provincial level HIV policy and none of the respondents disagreed with this statement.

When participants were asked to comment on the application of the GIPA principle at state and provincial levels, they responded as follows:

Some participants stated that the involvement is non-existent, whereas others were not certain as to whether there is any involvement at state and provincial levels. This is illustrated by the following quote, “Don’t know if any does exist”.

Some participants were of the view that involvement exists but that there is still room for improvement as the following quotes illustrate:

> *“Not fully involved especially in the children sector.”*
>
> *“We saw their involvement on SANAC and PAC.”*
>
> *“There is still more that needs to be done to improve the current situation.”*
>
> *“I will not say that it is meaningful but sometimes people living with HIV are involved, we see them in televisions.”*
>
> *“They are involved but not necessarily given priority, you are either qualified for the job, not necessarily that you are a PLHIV.”*

> *"The application has been done as a token but is not fully implemented."*
>
> *"It's not fully applicable at all levels since the rights of PLHIV are violated almost every day."*

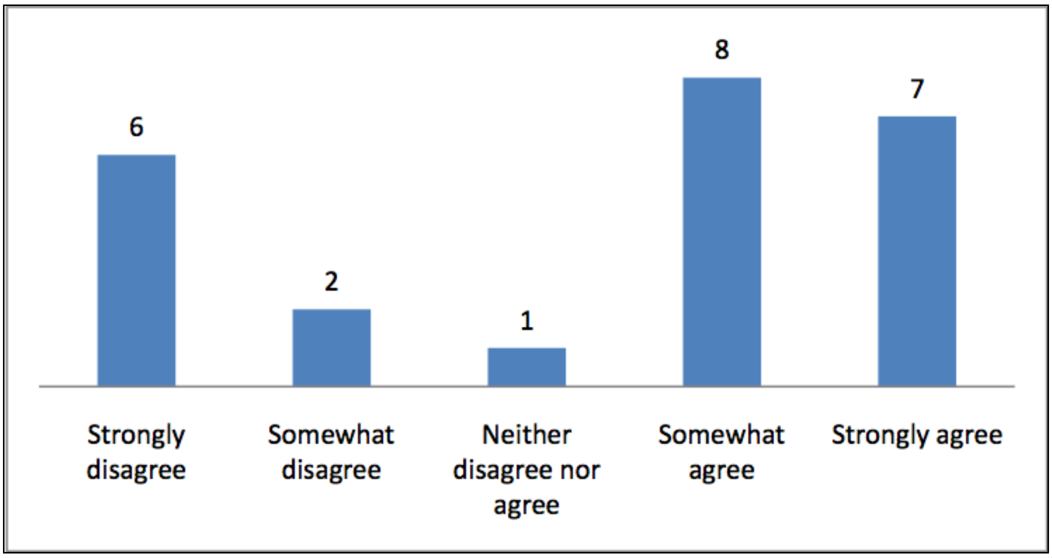
The participants who agreed that there is involvement mentioned NAPWA, SANAC and TAC as the bodies through which PLHIV were involved in developing policy at the provincial level. However, some were not aware of the criteria used for inclusion. Some participants were of the opinion that the application of GIPA to the LGBTI sector does not apply at a provincial level but mentioned the wellness programme for employees as one of the avenues for involvement:

Although most participants agreed that there is involvement, they mentioned a lack of coordination in planning and policy development. One participant observed that the spheres of government were not complementing each other.

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

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

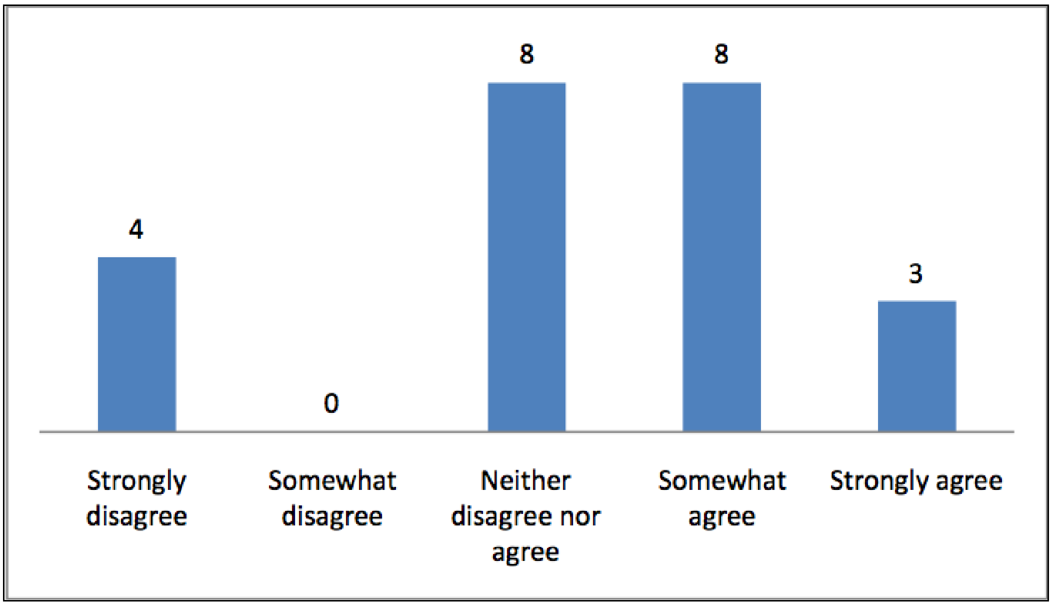
> *"I am familiar with UNGASS and my country's international commitments to the HIV response."*



South Africa

Fifteen respondents stated that they were familiar with UNGASS and South Africa's commitment to the international HIV response, while six respondents strongly disagreed with this statement.

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



Only four respondents strongly disagreed that organisations and networks of PLHIV were meaningfully involved in developing the report to UNAIDS on the progress of the UNGASS targets. Eleven respondents agreed with this statement. Eight respondents neither agreed nor disagreed and none of the respondents somewhat disagreed.

The negative comments regarding the involvement of PLHIV included:

> *"There is no involvement of PLHIV in the country report and no reporting to people on the ground."*
>
> *"There is no involvement of the province in developing the UNGASS report."*

Although some respondents did notice that PLHIV had been meaningfully involved in the development of the progress report on UNGASS, respondents were concerned about the lack of feedback they received:

> *"We seldom get reports from outside the country."*

> *"National organisations are involved but are not giving back the information to CBOs and the FBOs."*
>
> *"There should be information made available on the activities of UNGASS."*
>
> *"There should be coordinated structures to manage feedback and representation from theses high-level meetings."*
>
> *"No media coverage. No information through reports."*

When asked to comment on UNGASS and the International Commitments to the HIV response, participants made the following comments:

They were not aware of UNGASS and it was the first time that they had heard about it. As a result they were not able to effectively engage in the interview. A need was identified for people living with HIV and AIDS to be sensitised. Lack of resources made it difficult for them to access information. Community attendance at conferences was one option to access information.

Some participants stated that provinces were not involved in developing the UNGASS report. For some, inadequate consultation made it difficult for the PLHIV to be meaningfully involved. There were instances, some participants observed, where national organisations do get involved but do not provide feedback to CBOs and the FBOs.

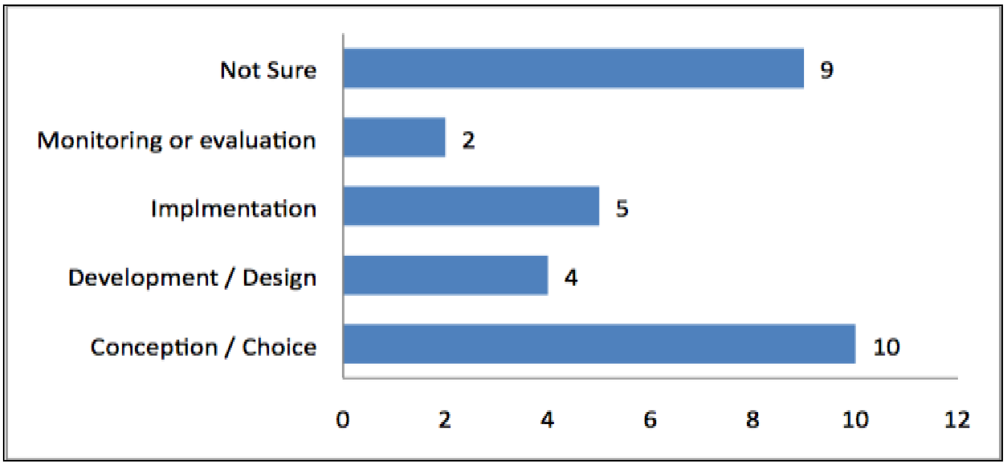
To promote involvement in and raise awareness about HIV activities the following suggestions were made:

- UNGASS activities need to be widely publicised
- A coordinated structure needs to be established with a view to manage feedback and representation from high-level meetings.
- Media coverage and information spreading through reports must be encouraged.

South Africa

Policy Development

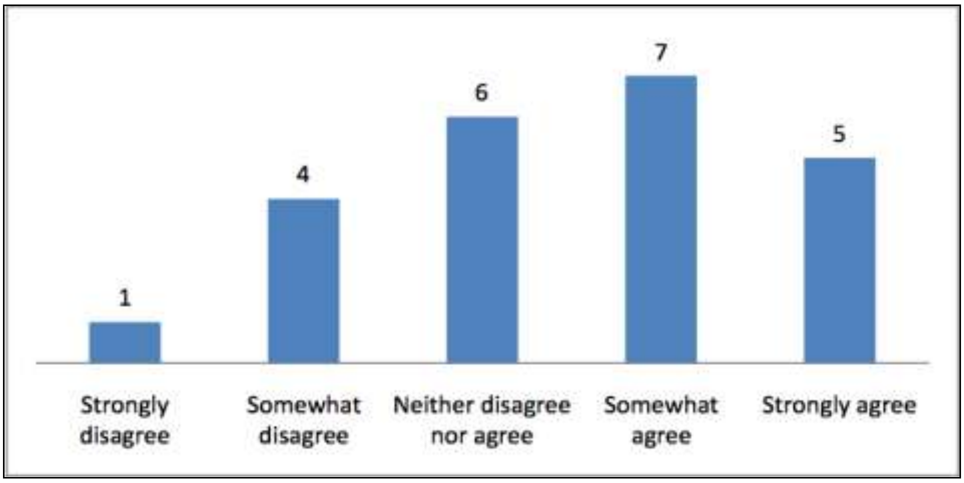
When asked at which point people living with HIV most often became involved in national policy development, respondents chose the following (multiple selections were possible):



Ten of the respondents noted that PLHIV were most involved in the conception or choice stage of the national level policy development, while nine respondents were not sure. Five and four respondents respectively stated that PLHIV were most involved in the development/design and implementation stages.

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

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



When asked whether they considered the level of PLHIV involvement in national policy development as meaningful, 12 participants agreed, while six were undecided. Five participants disagreed with this statement.

Many of the respondents stated that at this level PLHIV were mainly involved through organisations such as TAC and NAPWA. They also thought that SANAC played an important role in setting a national agenda. However, one respondent stated that although SANAC had been involved at this level, there was a lack of consultation with and feedback to the organisations, networks and PLHIV.

Although one of the respondents specifically stated that there was no involvement of PLHIV at the implementation stage, a number of respondents were concerned that while PLHIV were involved in the implementation stage, they were not sufficiently involved in the planning or design stages.

> *"No general consultation at design and development at this stage. The involvement is not fully representative of the general PLHIV population."*
>
> *"Organisations are invited to participate in the developmental agenda through conferences and summits locally and internationally."*
>
> *"There is a lack of consultation at grassroots and local levels."*
>
> *"At conceptual level, most organisations exclude PLHIV but are only included when it's time to implement."*

Respondents stated that sustained PLHIV involvement was imperative in order to decrease stigma and discrimination, since they are in a better position to understand what needs to be done:

> *"If they are planning a role, stigma and discrimination will be reduced and awareness will be raised."*
>
> *"HIV affects their lives, so they need to be involved."*
>
> *"The PLHIV are better placed in the position to lead the developmental agenda on the issues affecting them and addressing them meaningfully."*
>
> *"A PLHIV is able to speak with empathy, experience and a good knowledge of the*

> *disease/stigma attached."*

A few of the respondents were concerned about the lack of engagement at national and provincial levels of government:

> *"The decision-making procedures don't involve provincial AIDS councils."*
>
> *"There is greater involvement at national level but with the two spheres, there is lack of degree of engagement as well as the monitoring and evaluation is lacking or simply not done."*

To the question: "Have women living with HIV and the organisations and networks representing them been involved in national HIV policy development, and has this involvement been effective?" respondents expressed various opinions.

Some thought that women were indeed being involved, although with varying degrees of engagement and effectiveness, while others thought that women were not being involved.

Those participants who responded affirmatively supported their stance by indicating that South Africa is a democratic society in which, gender discrimination in decision-making structures does not exist. Others qualified their statements by alluding to the fact that NGOs working on HIV were gender balanced.

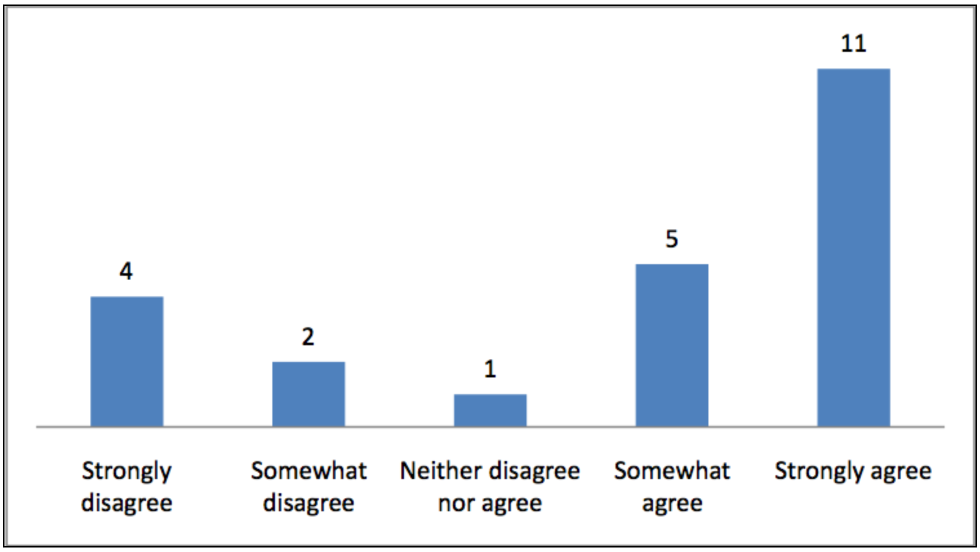
SANAC's Women Sector and other women's networks were mentioned as platforms for women involvement. Respondents were, however, unsure about the effectiveness of women's involvement in the PLHIV sector. The patriarchal nature of South Africa's society and certain cultural beliefs were seen as preventing women from taking up leadership positions at community level. Lack of skills and the absence of adequate platforms also limited women's participation in decision-making structures, even more so if they are HIV positive.

For some, the effectiveness and progress (or lack thereof) of women involvement was difficult to establish in South Africa due to inadequate monitoring and evaluation tools. Some participants indicated that the effectiveness of women involvement should be evidence-based and the outcomes made available to all sectors. Others highlighted the lack of transparency in communication.

Universal Access

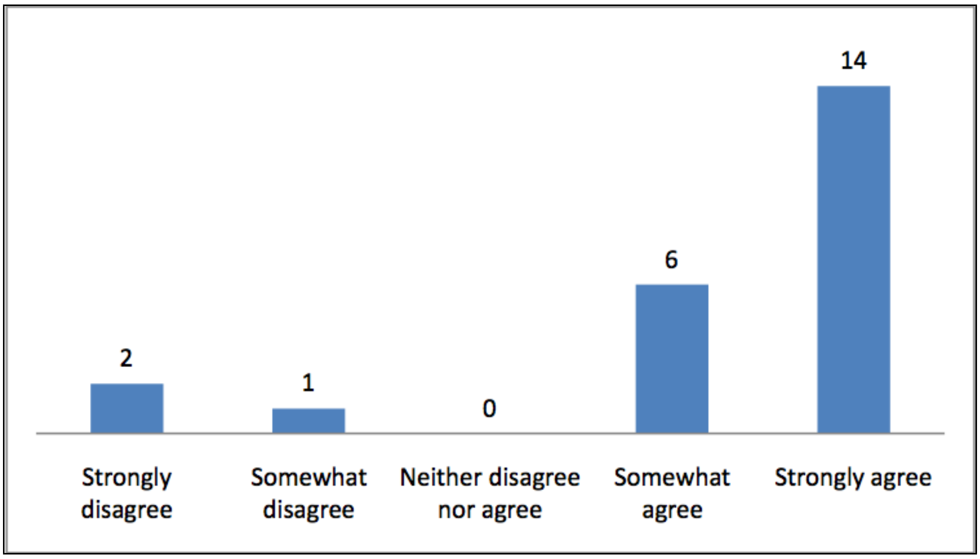
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

> *"I am familiar with universal access commitments and targets."*



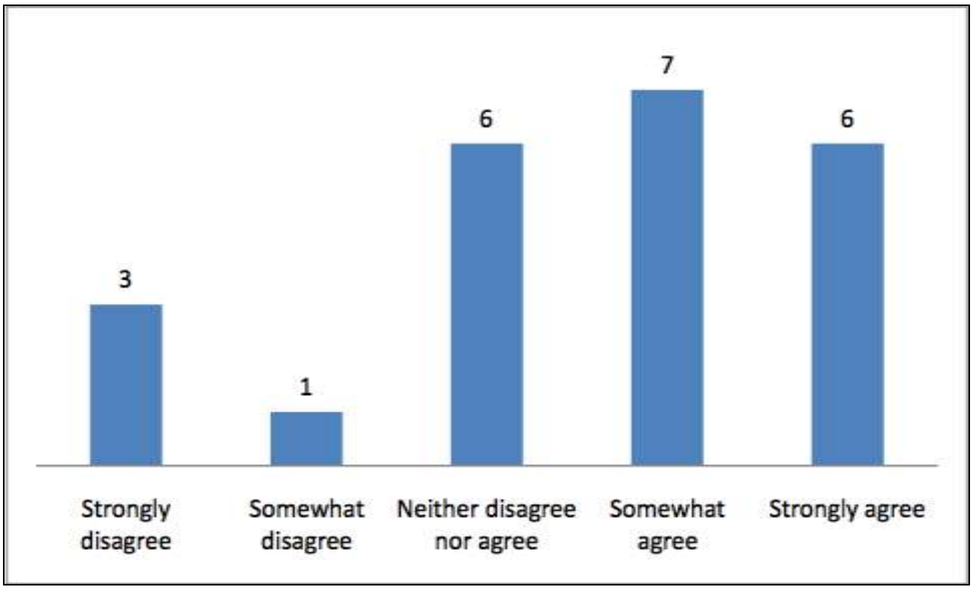
Sixteen respondents agreed that they were familiar with universal access commitments and targets, while six respondents disagreed with this statement.

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



Only three respondents disagreed that the South African government set universal access targets, while 20 respondents agreed with this statement.

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



Although 13 respondents agreed that PLHIV were meaningfully involved in the universal access target setting process, six respondents neither agreed nor disagreed with this statement.

Barriers to achieving targets included:

- Inadequate planning, budget constraints and poor financial support.
- Lack of capacity and/or of skilled and trained personnel. Few Health Care Workers (HCW) on the HCT have the required skills.
- Long waiting periods, as well as duplication and fragmentation of programmes were also mentioned.
- Stigma and poverty contribute to programme failure.
- Low literacy levels, ignorance and cultural beliefs still have a negative impact.
- Insufficient funding and high treatment costs.
- Participation of PLHIV and key population groups, as stipulated in the NSP, is not detailed.
- Access to ART sites is often difficult due to distance and poor location.
- A very high number of people are living with HIV.
- The staff is sometimes uncaring and prone to disclose private information.

- Health facilities are often instructed to provide ARTs without the necessary budgets. Under these circumstances most clinics are unable to do so..

To achieve targets, participants suggested the following actions:

- Sensitising and involving women at ground level.
- Developing clearer policies and targets. Those released by the National Department of Health are often too scientific.
- Involve PLHIV in support groups in order to train HCWs and change their attitudes on HIV issues.
- Increase human and financial resources, and empower PLHIV.
- Promote proper planning, research and monitoring to ensure successful programme implementation.
- Improve planning and control to accommodate and include refugees and non- South African citizens.
- Raise awareness regarding HIV medication and access to treatment. This is particularly crucial in South Africa where the rollout of HIV treatment was delayed and surrounded by controversy.
- Empower the workplace to provide HIV-related services so as to relieve over-stretched and under-resourced clinics.
- Promote greater PLHIV involvement so that monitoring and evaluation can be effectively implemented.
- Support the local production of ARTs in order to avoid shortages.

When asked what they currently considered to work well, participants mentioned that:

Policy implementation, stakeholder involvement and counselling and prevention strategies were on track.

They also added the following:

- Coherent collaboration between government and civil society
- Increased number of accredited facilities and health care professionals
- NIMART
- Successful HCT days
- Down referrals to primary health care practitioners

On the quality of medication, participants reported that:

HIV medication was of first quality but that no follow-up systems existed to monitor side effects. As a result, patients often defaulted and became resistant to the medication.

On the supply/delivery side:

Funding was still considered to be a barrier. In addition, some provinces, especially the rural ones, run out of drugs due the cumbersome tendering processes. This in turn delays service delivery and makes the supply of medication non-consistent.

Service providers also continue to be affected; namely by:

- Lack of human and financial resources
- Inadequate infrastructure
- Negative attitude of HCWs
- Inaccessibility of the ARV sites
- Absence of or less rigorous monitoring
- Stigma related to HIV

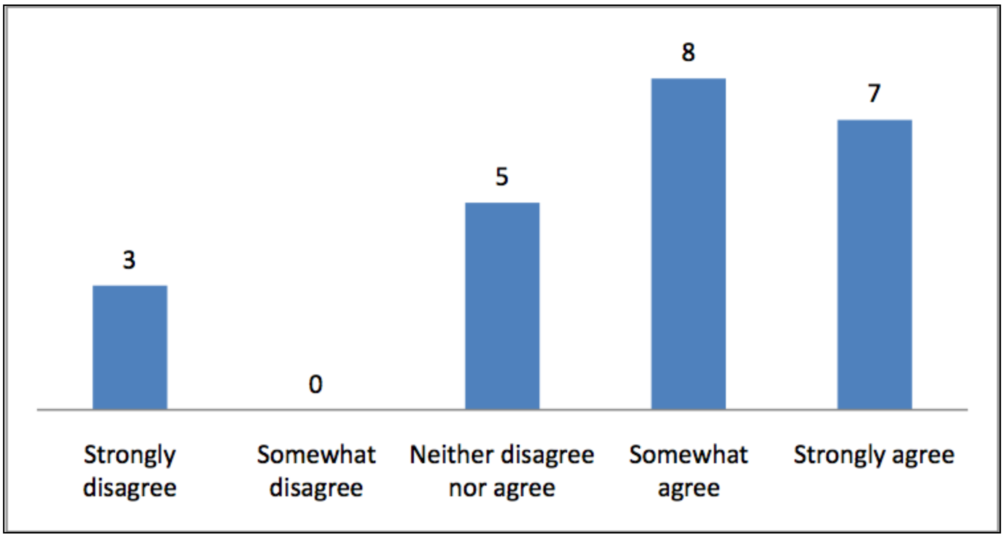
Service-related delivery issues have a negative impact on medication uptake. The following suggestions were made to improve the supply of medication:

- Proper planning
- Manufacturing drugs locally if capacity exists
- Provision of medication by all facilities
- Education to target stigma
- Training of HIV professionals
- Funds from the Gates Foundation should be used to ensure consistent medication supply
- Increasing the number of accredited centres
- Promoting behaviour change

Representation and Networks of People Living with HIV

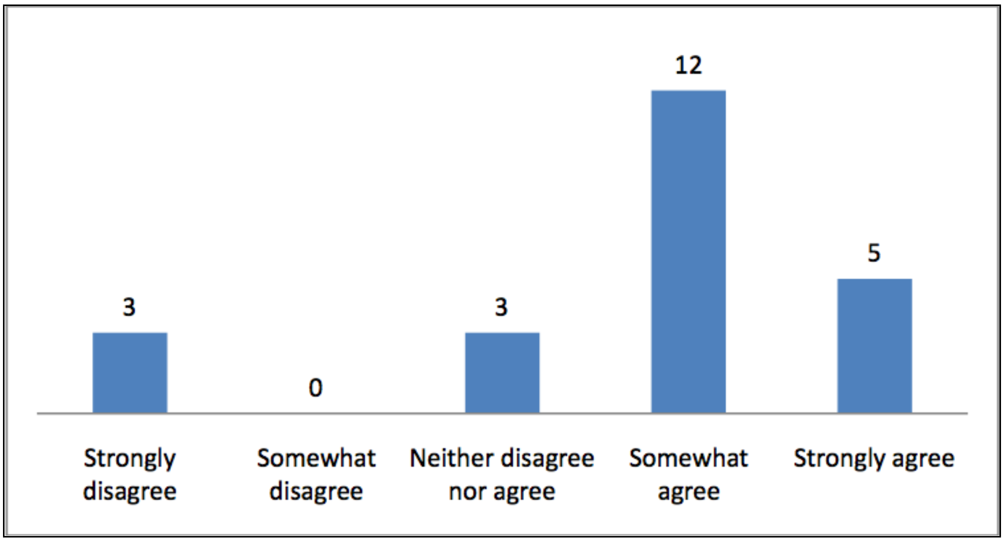
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

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



Only three respondents strongly disagreed that formal PLHIV representation positions on decision-making bodies ensured accountability to PLHIV in South Africa. The vast majority (15) of respondents either somewhat or strongly agreed with this statement.

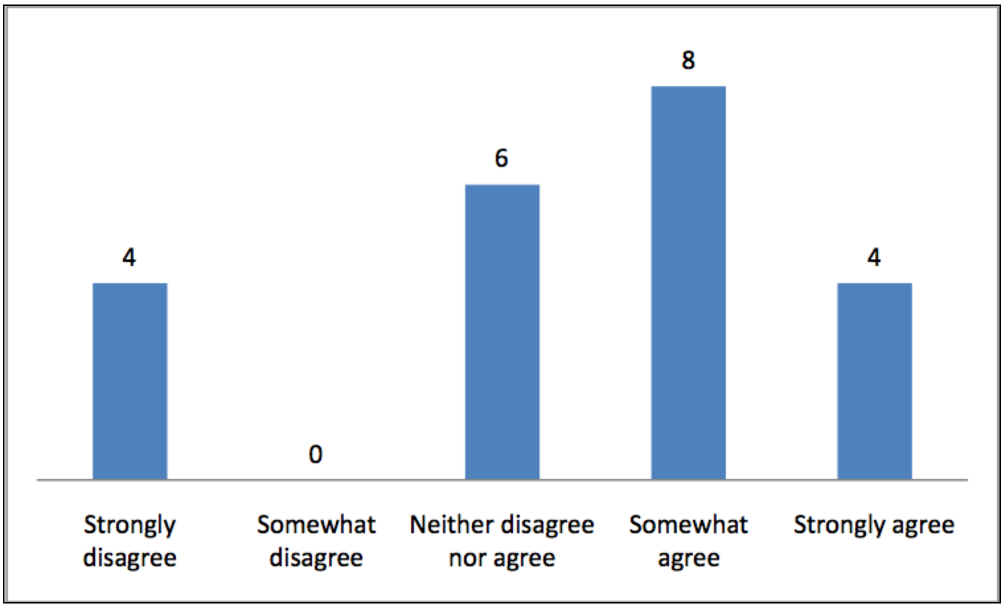
> *"The mechanisms for the representation of PLHIV in formal decision-making bodies are effective in representing the needs of PLHIV."*



Similarly, three respondents strongly disagreed that the mechanisms for the representation of PLHIV in formal decision-making bodies are effective in representing the needs of PLHIV, while 17 respondents agreed with this statement.

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

South Africa



Twelve respondents somewhat or strongly agreed that national, regional and state level PLHIV networks communicate effectively with their constituents. While six respondents neither agreed nor disagreed with this statement. Four respondents strongly disagreed.

Participants included the following comments on the above questions:

Generally, it was felt that PLHIV are represented on decision-making bodies. Several platforms were mentioned (e.g. NSP and the process leading to the design of the IEC material) where respondents believed that PLHIV were able to take part and provide input PLHIV also participated in various conferences, as well as council and board meetings, where they were recognised for providing frameworks that lead to better policies.

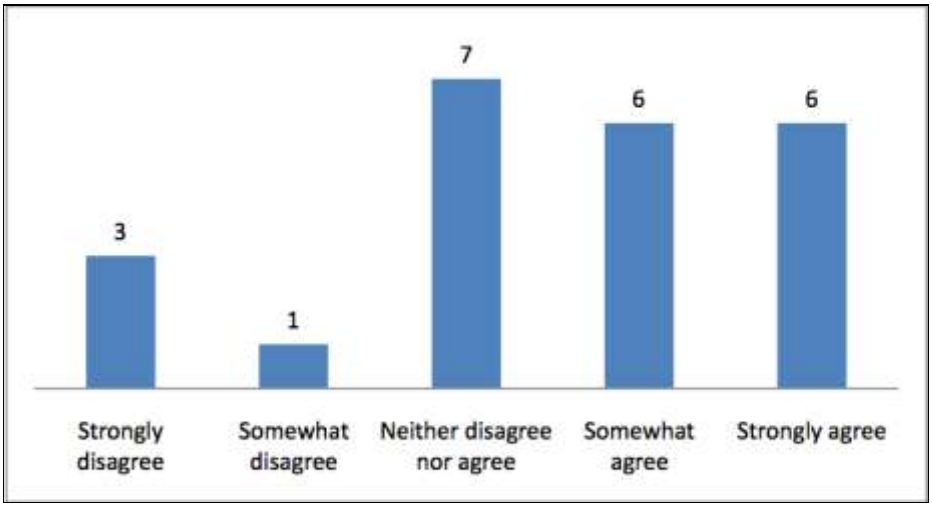
Barriers to participation and involvement/representation included amongst others, stigma, lack of HIV sero-status disclosure, politics and power struggles, and competition over scarce resources.

Suggestions were made to bring down these barriers. These included: greater accountability, conducting monitoring and evaluation exercises once the infrastructure is in place, strengthening advocacy and lobbying organisations like NAPWA in order to increase coverage and outreach, improving communication and response time between networks and their constituencies.

Research and Sexual and Reproductive Health

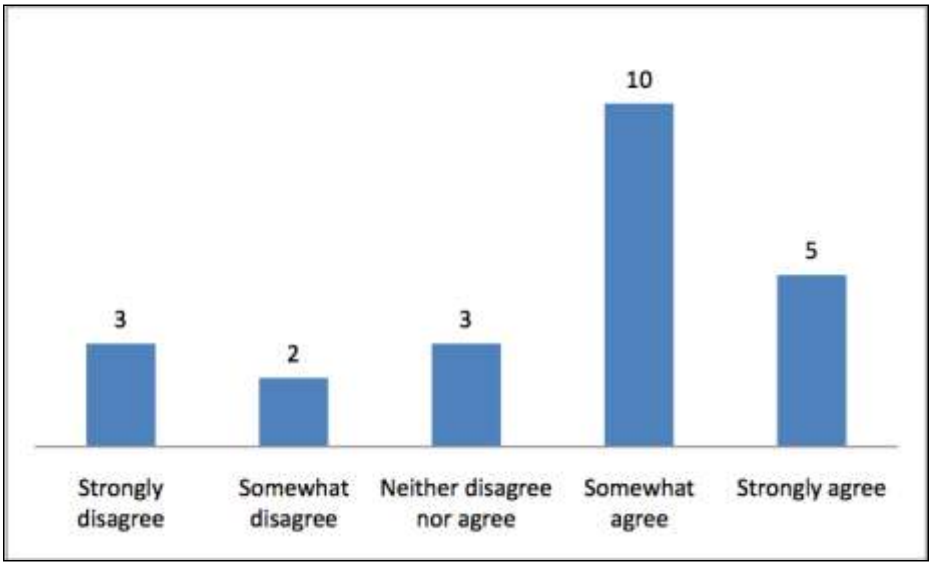
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

"My country has a national sexual and reproductive health plan."



Seven respondents neither agreed nor disagreed that South Africa has a national sexual and reproductive health plan; while 12 respondents either somewhat or strongly agreed with this statement.

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



South Africa

Ten respondents somewhat agreed that policies have been introduced or incorporated into existing plans to address the sexual and reproductive health needs of women and men living with HIV, and five respondents strongly agreed with this statement. Three of the respondents did not agree or disagree, while a further three strongly disagreed.

When participants were asked if PLHIV are involved in clinical research and the development of new prevention strategies, the following comments were made:

PLHIV participate in Microbicides research (e.g. Voice 004) and clinical trials such as CAPRISA.

PLHIV involvement included the facilitation of focus groups, conducting research in the community and doing field visits. Some participants were of the opinion that PLHIV should be more involved in research. For instance, they should be part of the developmental agenda on research studies.

Those participants who thought that PLHIV are not involved in research, mentioned the following reasons:

- They are not included in protocols due to inclusion and exclusion criteria.
- It is not mandatory for PLHIV to participate in clinical trials.
- The Department of Women, Children and People with Disabilities is addressing sexual and reproductive needs, but progress is slow and not yet effective.
- The HIV challenge in South Africa is still new, and thus priority has been given to education and treatment.

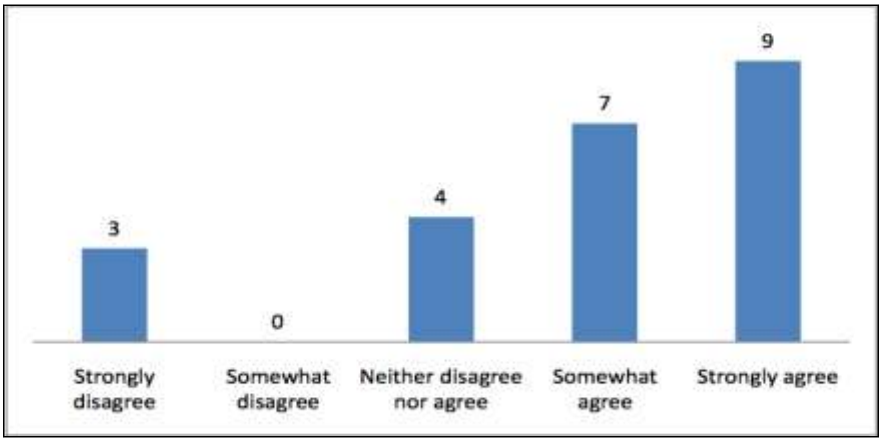
The following suggestions were made to accelerate PLHIV involvement in research:

- Promote involvement in the LGBTI research.
- Incorporate new challenges and topics such as reproductive health for PLHIV.
- PLHIV should be part of the developmental agenda on research studies.
- Rural areas should be included in research and clinical trials

Poverty Reduction Strategies

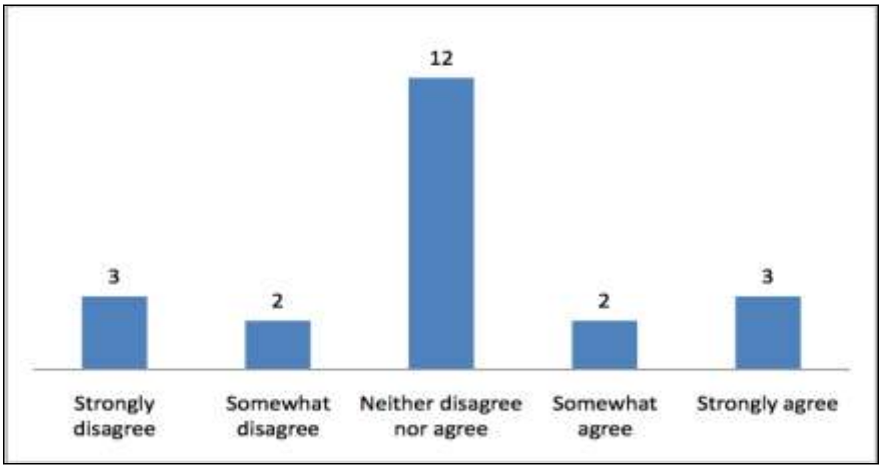
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

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



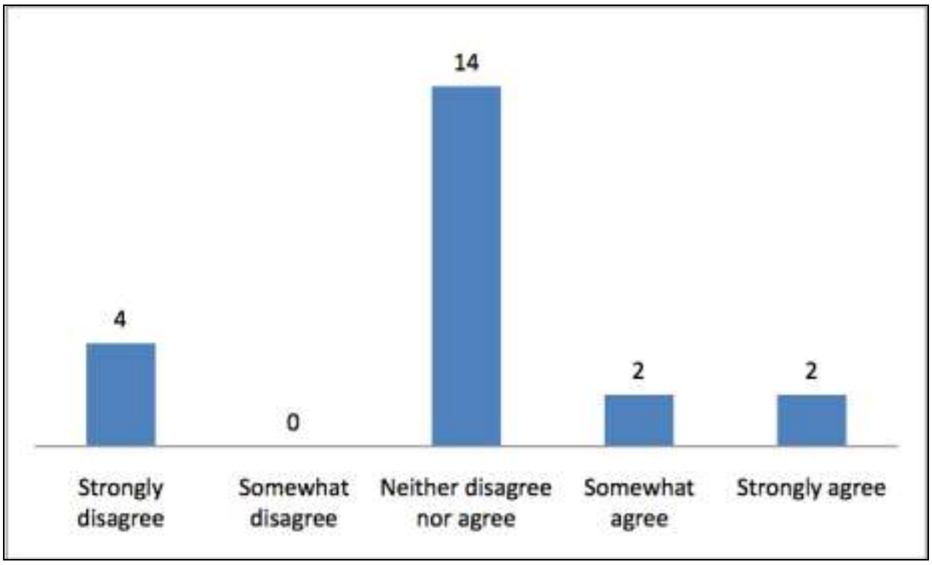
Only three respondents strongly disagreed, while four respondents did neither disagree nor agree with the statement that South Africa has a poverty reduction plan and/or strategy in place. Sixteen respondents either somewhat or strongly agreed with this statement.

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



Twelve of the respondents neither agreed nor disagreed that the poverty reduction plan and/or strategy were developed with input from people living with HIV. Five respondents agreed while another five disagreed with this statement.

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



Fourteen of the respondents neither agreed nor disagreed that the poverty reduction plan and/or strategy have been adequately reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men. Four respondents agreed while another four strongly disagreed with this statement.

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

Some participants thought that there is a lack of PLHIV involvement on this issue. Some added that although, a poverty reduction strategy exists, it is not specific to PLHIV, but aimed at all the citizens of South Africa. The Departments of Agriculture, Social Development and Health, all have poverty reduction plans in place. These focus on key communities, such as Orphaned and Vulnerable Children (OVCs) and positive mothers.

Several participants were unsure if a strategy existed and indicated that they would do some research after the interview. Others suggested that if a document on poverty reduction existed it should be made widely accessible. Participants were of the opinion that since HIV treatment is inseparable from nutrition, a poverty reduction strategy was indeed crucial. Several projects were mentioned as means of addressing the issue.

Some organisations reported that they had allocated a budget for poverty reduction. The Integrated Development Plan was also seen as instrumental in poverty alleviation projects.

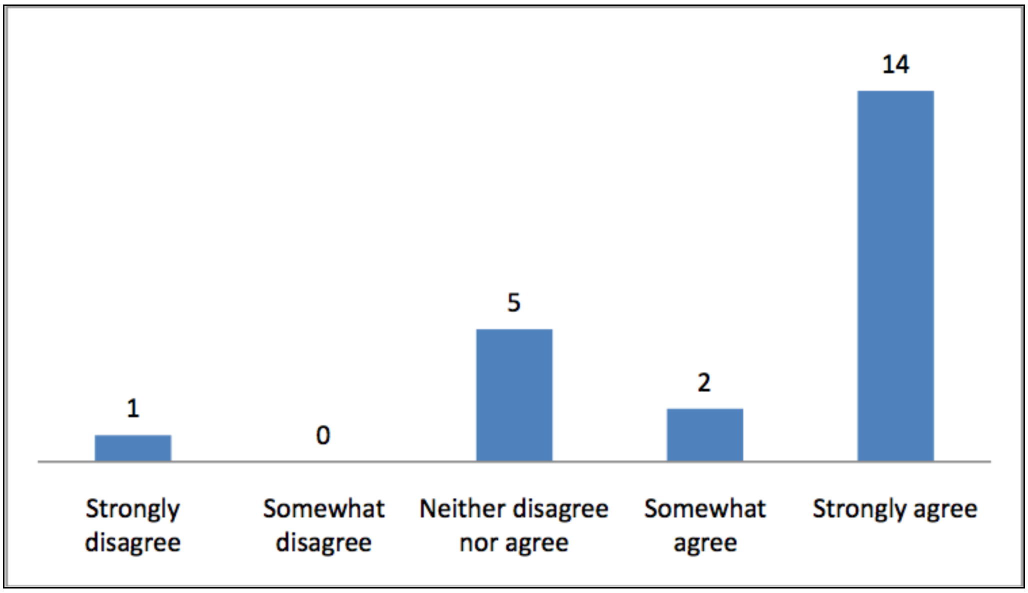
Child-Headed and Female-Headed Households were mentioned as prospective beneficiaries from those projects.

Recommendations on poverty reduction strategies and PLHIV involvement included, convening a summit on poverty reduction, providing nutritional supplements, and organising consultations/workshops to promote information dissemination and education.

Employment

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

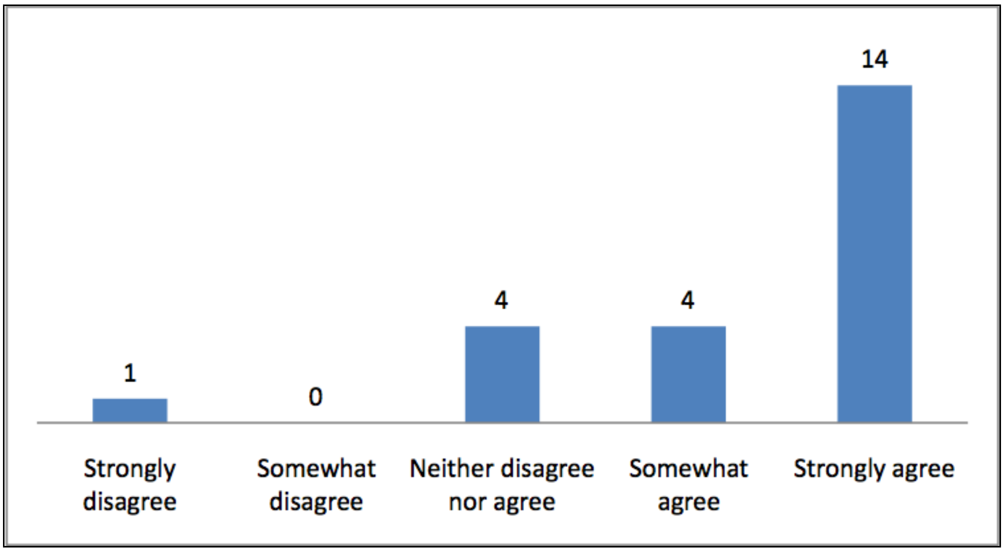
> *"My government has enacted legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work."*



Sixteen respondents agreed that the South African government has enacted legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work. Only one respondent strongly disagreed.

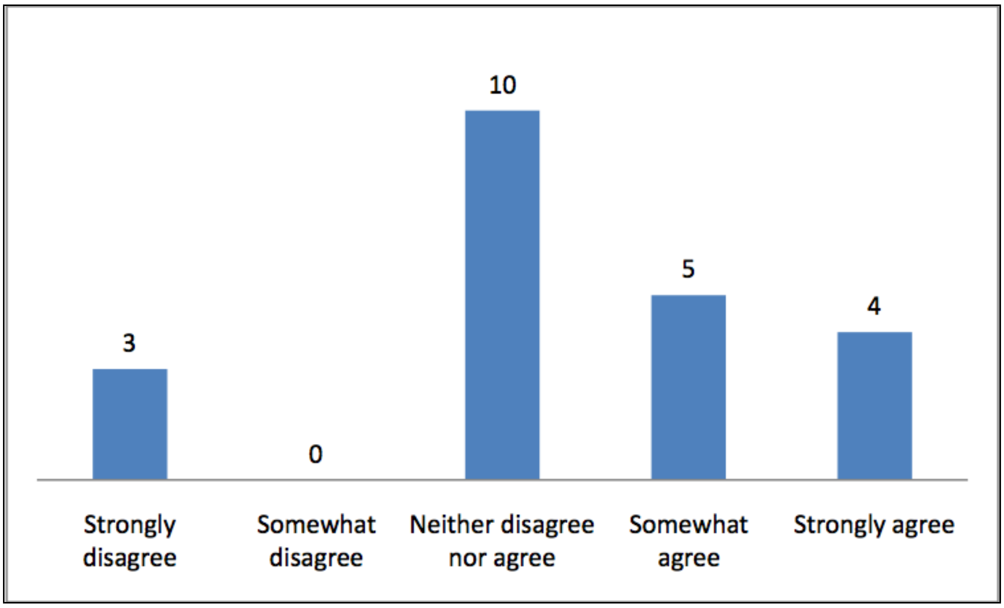
> *"My country has enacted progressive legislation on the workplace rights of people living with HIV."*

South Africa



Similarly, eighteen respondents agreed that South Africa has enacted progressive legislation on the workplace rights of people living with HIV. Only one respondent strongly disagreed.

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



Ten respondents neither agreed nor disagreed that PLHIV were meaningfully involved in the development of this legislation, while five somewhat agreed and four strongly agreed with this statement.

When asked if their organisations or government departments had policies in place for employees living with HIV, and if there was a specific budget allocated, participants responded as follows:

- Yes, there is a policy but there is no budget.
- It is a general policy for everyone so that it doesn't discriminate.
- We don't discriminate therefore we don't have a separate budget for PLHIV, all the staff share the budget.
- Yes, there is a policy but the budget is only for the community.
- Yes, through a workplace employee wellness programme, called the Employee Assistance Program (EAP). The allocated budget is around two million rand.
- No policy.
- Yes, the Employment Equity Act doesn't discriminate against PLHIV.
- Not that I know of, but I know that PLHIV are protected from discrimination based on their status.
- Yes, but dependent on Board decision and profits.

Participants were asked if they are living with HIV, and if they are employed by an NGO, government or the UN. If the response was 'yes', participants were further asked about barriers they may have encountered and the contributory factors that may have assisted them overcoming those barriers. They responded as follows:

Living with HIV

- Sixty seven per cent (67%) of participants reported not living with HIV whereas 19% answered affirmatively. Fourteen per cent (14%) did not answer the question. This was seen as a further indication of the lack of disclosure in South Africa, which results from different factors including stigma and discrimination. Several participants explained that they were not in a position to disclose their status, whereas others reported not having been tested at that time. This was interesting considering that most HIV awareness organisations and campaigns support HCT and disclosure. HIV status disclosure is voluntary in South Africa.

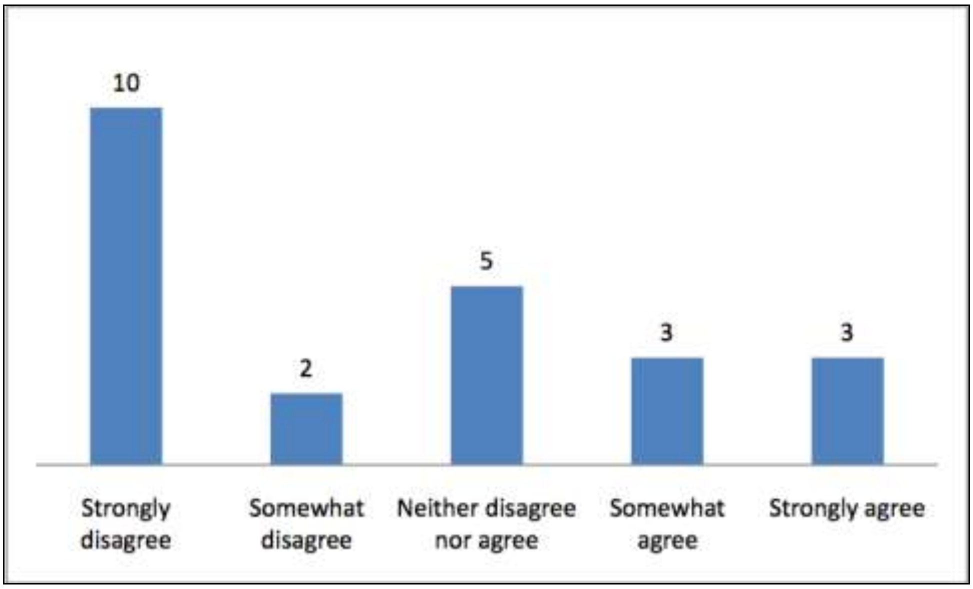
Contributory factors

- Enduring stigmatisation, low disclosure rates, lack of capacity building and insufficient funding for workshops on empowerment were listed as barriers. At the municipal level, fragmentation/lack of integration of wellness programmes that support the needs of PLHIV were also considered as contributory factors.

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."*



Only six respondents somewhat or strongly agreed that their organisation has developed materials focused on the GIPA principle and the meaningful involvement of people living with HIV. Twelve respondents disagreed and a further five neither agreed nor disagreed with this statement.

While some organisations have worked extensively with and for PLHIV, and have provided training to partners on stigma and the GIPA principle, a number of organisations stated that this was the first time that they had heard about the GIPA principle. One organisation also stated that with regard to service delivery their involvement with PLHIV had been minimal.

When asked if they have developed materials related to the GIPA principle and the meaningful involvement of people living with HIV, participants answered as follows:

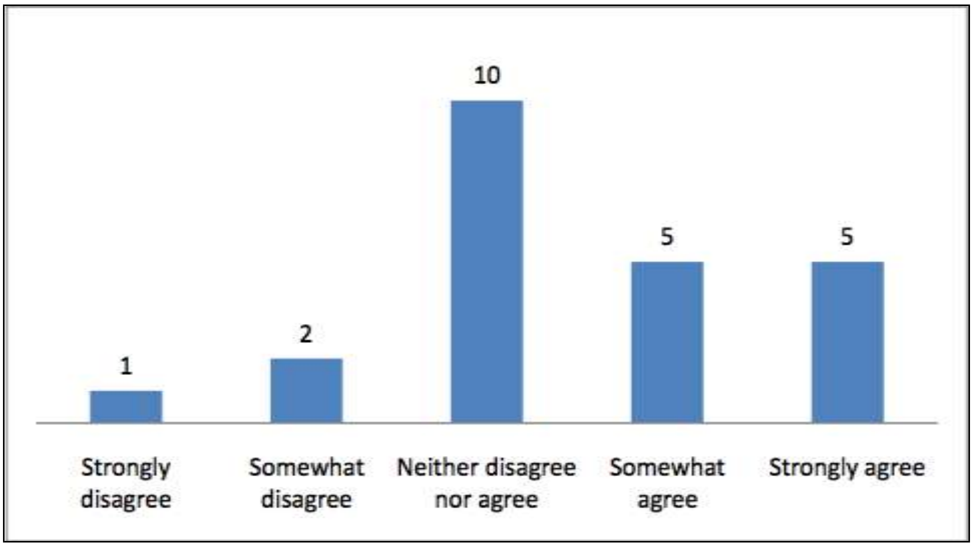
A few organisations did not develop GIPA-related materials (among these those that were unaware of GIPA), while those that did develop GIPA-related materials, used and discussed these on various occasions:

- Three-day training session on the GIPA principle;
- Stigma training, media relations, workplace interventions and internalised stigma for PLHIV;
- Policy development, CD recordings compiling their life stories, hand-outs and clippings;
- Support group on cancer and gender based violence;
- Training pack for PLHIV.

Financial Support

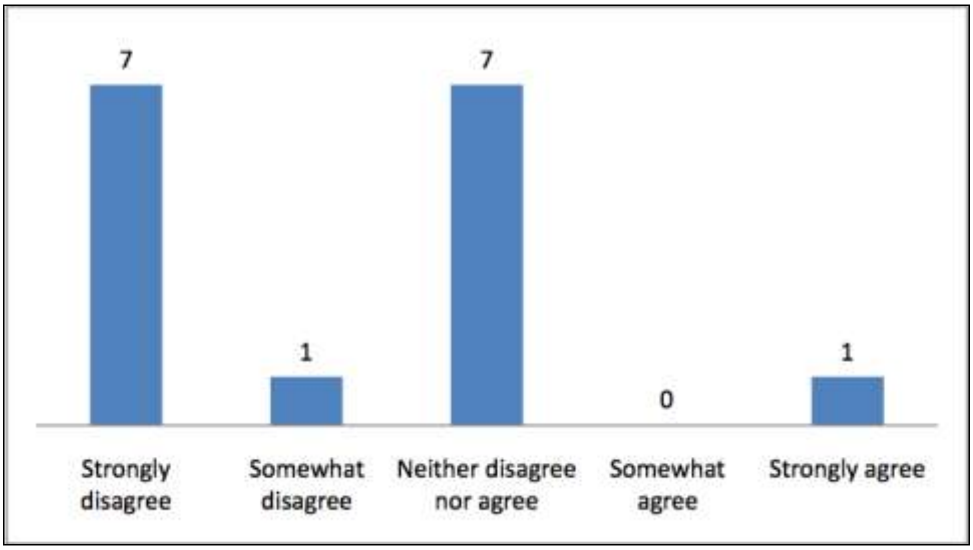
When asked to what extent they agreed or disagreed with the statement below, respondents indicated the following:

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



Ten respondents had no opinion, while another 10 agreed with this statement..

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



Only sixteen respondents provided an answer. Seven had no opinion while seven strongly disagreed. Only one participant strongly agreed with this statement.

Some of participants stated that it was unethical to treat people within the organisation differently, whether they were PLHIV or not. For some, it went against the organisations' own guiding documents and policies. Others stated that it contravened the Employment Equity Act. A handful of participants stated that it did not apply to them since they were either volunteers or their organisation depended on volunteer work only.

A number of participants stated that while it was not yet the case, PLHIV should be reimbursed for their work and involvement in the HIV response. One of the reasons being that PLHIV are 'positive ambassadors'.

Other participants stated that PLHIV should be encouraged to lead normal lives and be economically active; they should not be funded because of their status but for the work they do. Another concurred with this, stating that:

> *"I believe in developing programmes that will help those who are in need to get out and to lead normal lives. If there is a PLHIV who requires government assistance, let it go through the relevant government departments and the criteria should be economic and not status based. Being HIV positive isn't a disability."*

Barriers and Obstacles to GIPA

Table 4 below shows the number of organisations that experience obstacles or barriers to GIPA. Although respondents were requested to select only three obstacles or barriers, a number of respondents selected more than three.

Violence or fear of violence, non-remunerated involvement, lack of access to ART and treatment of opportunistic infections, services being inaccessible due to the person's gender, and the absence of PLHIV organisations or networks, were not selected as barriers or obstacles to GIPA by any of the organisations.

Table 4: Barriers or obstacles to GIPA experienced by the organisations

Barriers / Obstacle to GIPA	**Number of Organisations that experience Obstacles or barriers to GIPA**								
	1	2	3	4	5	6	7	8	9
Poverty							X		
Financial insecurity			X						
Fear of or actual discrimination				X					
Discrimination in the workplace					X				
Lack of confidence in PLHIV organisations and/or networks				X					
Discrimination by health care providers		X							
Fear of racism or another prejudice	X								
Fear of stigma								X	
Lack of understanding and clarity on what GIPA is								X	
I fear that I will be rejected by family, friends or my community		X							
Women lack freedom from men to make independent decisions		X							
Women have primary responsibility for raising children, preventing their participation		X							
Funding constraints									X
Low skill levels	X								
Weak management in organisations			X						
Lack of support services					X				
Homophobia and other forms of prejudice due to sexual orientation	X								
Workplace policies do not exist	X								

Funding constraints were an obstacle or barrier cited by nine organisations, while seven organisations considered poverty as a barrier or obstacle. One respondent noted that together poverty and funding constraints acted as a dual burden, stating that:

> *"Poverty has contributed to the lack of adherence to treatment. Treatment is costly and creates budget fatigue."*

Eight organisations stated that the fear of stigma and the lack of understanding and clarity about GIPA were obstacles or barriers. Specifically, some respondents stated the following:

> *"Cultural beliefs impact-women lack freedom. Stigma is still a challenge and the fear that they will be rejected by the family. "*
>
> *"Because of lack of confidence PLHIV cannot get involved; they fear rejection and discrimination. They don't know their rights including leaders in the field. If you talk about HIV in the workplace, people start to discriminate."*
>
> *"Some employers would feel that you are a burden to the organisation. This is discrimination."*
>
> *"It is not easy to disclose and work with HIV positive people, most of the time you are stigmatised and discriminated."*

Opportunities for Involvement

The following were cited as the best opportunities for the greater involvement of PLHIV:

Community Based Initiatives

- Support groups and development of PLHIV-run organisations and projects
- Poverty reduction, health and human right projects
- Community awareness campaigns and peer education training
- HIV Counselling and Testing Campaigns
- Universal access to and availability of ARVs

Research and Advocacy

- More research and evidence-based advocacy
- Presentations at conferences and meetings
- National Strategic Plan and active participation of PLHIV in lobbying and advocacy.
- Monitoring and Evaluation

Collaboration and Participation

- Participation in all activities, specifically through organisations such as NAPWA that include the GIPA principle
- Leadership roles within the AIDS councils
- Greater collaboration of NAPWA with other organisations to improve the skills of NAPWA
- Government's willingness to include new ideas and involve PLHIV

Discussion, conclusion and recommendations

South Africa is a democratic country with progressive legislation. According to the South African constitution, discrimination against citizens as a result of their HIV positive status is prohibited. Several bodies have been put in place in South Africa to monitor and coordinate HIV efforts. The South African National AIDS Council (SANAC) has a PLHIV Sector with representatives from both NAPWA and TAC. In addition, other organisations, such as NACOSA, also represent PLHIV.

The GIPA Report Card assessed the level of involvement of PLHIV and related activities. Several respondents have highlighted the lack of awareness of the GIPA principle, the National AIDS Plan and UNGASS. It is crucial that efforts are made to enhance awareness of the afore-mentioned. Some of the participants stated that it was unethical to treat people within the organisation differently, whether they were PLHIV or not. Some thought that this would be against the organisations' own guiding documents and policies, while others stated that it would contravene the Employment Equity Act.

None of the respondents strongly agreed with the statement that the GIPA principle had been adequately implemented into state or provincial level HIV planning. Most participants mentioned that although there is involvement, they had observed a lack of coordination regarding planning and policy development. One respondent observed that the spheres of government were not complementing each other.

The general feeling was that PLHIV are represented on the decision-making bodies. In addition, several platforms were mentioned where participants believed that PLWH participate and give input. PLHIV were also regarded as providing frameworks that lead to better policies. Obstacles to greater participation, involvement and representation included amongst others, stigma, lack of HIV disclosure, politics and power struggles, and competition over scarce resources. Community-based initiatives, research and advocacy, collaboration and partnerships were cited as the best opportunities for the greater involvement of PLHIV.

A number of participants noted that until now, PLHIV involvement in policy development had been minimal. Lack of capacity was mentioned as a reason for this and building capacity was seen as instrumental in enabling PLHIV to engage at this level. Several participants voiced their willingness to collaborate with NAPWA on research projects and saw it as an opportunity to increase their capacity. Factors that prevented involvement included, lack of adequate funding, stigma, fear of disclosure, shortage of skills in dispensing ARVs and negative attitude displayed by HCWs.. Further efforts will need to be made in order to address these issues.

Overall, the study found that in South Africa only a few of the participants knew about the GIPA principle. The rest of them heard about the GIPA principle for the first time by taking part in this survey. They were of the opinion that GIPA awareness would have a positive impact by promoting acceptance of PLHIV and other target populations.

Given the barriers and opportunities identified by the GIPA Report Card, the study suggests the following recommendations:

- Increasing resources for organisations of people living with HIV that implement community-based initiatives and undertake research and advocacy;
- Promote stigma reduction initiatives to remove barriers to the visible leadership and involvement of people living with HIV;
- Increase awareness of the GIPA principle within NAPWA and partner organisations;
- Increase awareness of the GIPA principle within government departments;
- Promote greater collaboration amongst organisations of PLHIV and support a cohesive PLHIV voice to articulate the involvement of people living with HIV in all matters that affect their lives;
- Support PLHIV in developing their skills in gathering and using evidence for effective advocacy, implementation, monitoring and evaluation.

References

International HIV/AIDS Alliance and GNP+. (2010). *Greater Involvement of People Living with HIV (GIPA): Good Practice Guide.*

Republic of South Africa. (2011). *National Strategic Plan, 2012-2016*. Pretoria: Government of South Africa.

Shisana, O.; Rehle, T.; Simbayi, L.; Parker, W.; Zuma, K.; Bhana, A.; Connolly, C.; Jooste, S.; Pillay, V. et al (2005). *South African National HIV Prevalence, HIV Incidence, Behaviour, and Communication Survey 2005.* Cape Town: HSRC Press.

UNAIDS (1999). *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. Geneva: UNAIDS

UNAIDS (2007). *The Greater Involvement of People Living with HIV (GIPA).* Geneva: UNAIDS

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