GNP+’s mission is to improve the quality of life of people living with HIV. We seek to achieve our mission by facilitating equitable access to treatment, care and support services for people living with HIV around the world. Our activities in support of this goal fall into three principal, mutually supporting programme areas: advocacy; knowledge management; and community development. The promotion of human rights, leadership and the meaningful involvement of people living with HIV cuts across and underpins all of our work.

STOP AIDS NOW!'s mission is the end of AIDS in a world where all people affected by HIV and STIs can access prevention, treatment, care and support. STOP AIDS NOW! is the collaborative initiative between Aids Fonds, Cordaid, Hivos, ICCO and Oxfam Novib concentrating on poverty and AIDS. STOP AIDS NOW! works in Sub-Saharan Africa, in countries with large generalised epidemics. It focuses on funding and implementing programmes in collaboration with local and international partners. Main program areas are youth and prevention, women and children, and HIV and STIs in combination with sexual and reproductive health and rights.
With this tool, you can measure the involvement of people living with HIV at community level. It includes:

**Background information**

1. Background information ......................... 4
   1.1. What is GIPA? .............................................4
   1.2. Measuring GIPA at national level ...............5
   1.3. Understanding how GIPA works at community level ...........................................5
   1.4 About From the Ground Up ..................5

**Guidance on how to use the tool**

2. Steps to implementing this tool ................. 6
   2.1. Who leads his work? ...............................6
   2.2. What do you need? .................................6
   2.3. Who are you partnering with to do this work? 6
   2.4. Who are you interviewing? ......................6
   2.5. Preparation for implementation team ........7
   2.6. The data collection process ..................8
   2.7. Analysing the data ..................................9
   2.8. Writing the report and validating your findings ....10
   2.9. Using the evidence for advocacy ...........11

**A questionnaire to capture information about the involvement of people living with HIV at community level**

Annex 1: Questionaire ................................... 12

1. Background of the respondent and his/her community ...........................................12
2. Background of organisation where respondent is involved ..................................13
3. How are people living with HIV engaging in your community? ...............................17
4. What are the challenges you are experiencing? ..................................................18
5. The involvement of people living with HIV who are also part of other marginalised groups ........21
6. Hearing your suggestions: what more could be done to support the leadership and involvement of people living with HIV in your community? ........22

Sample Informed Consent Sheet

Annex 2: Example of informed consent sheet ........ 24

GIPA Information Sheet

GIPA Information Sheet ..................................... 26
1. Background information

1.1 What is GIPA?

GIPA stands for the Greater Involvement of People Living with HIV. It is a principle that requires the active and meaningful participation of people living with HIV in the design, development, implementation, monitoring and evaluation of all policies and programmes that affect their lives. Meaningfully involving people living with HIV in different levels of HIV responses:

- Improves the quality of policies at all levels by taking into account the perspectives of the people who have direct and personal experience, and in-depth understanding of “on the ground” realities;
- Increases the effectiveness of service delivery by involving people who can reach others health services have difficulty reaching;
- Improves, verifies, and clarifies the quality of information and data and puts knowledge into a context that reflects real situations;
- Increases accountability and transparency in the governance of AIDS responses that can lead to a more participatory and democratic decision making processes;
- Improves attitudes towards people living with HIV, including health care providers, and can subsequently reduce stigma and discrimination against people living with HIV.

The GIPA principle is not new. It is recognised as a good practice by all stakeholders working in HIV and has been used as primary principle on the part of networks and communities of people living with HIV in many countries. The participation and leadership of people living with HIV shapes the way we think about HIV and guides the work we do. As such it contributes to improving the quality of our work and the goals we are trying to achieve.

1.2 Measuring GIPA at national level

There is an information-gathering tool called the GIPA Report Card, which measures the extent to which people living with HIV are involved in processes and decision-making at national level. This tool has been used by national networks of people living with HIV in several countries to understand how different national stakeholders perceive the involvement of people living with HIV in various levels of decision-making and policy development. The findings from the tool have been used to advocate for change where countries are failing to involve people living with HIV meaningfully or in enough areas of reflection, decision-making and action.

To see the GIPA Report Card, go to www.gnpplus.net/assets/grc_user_guide.pdf

1.3 Understanding how GIPA works at community level

The GIPA Report Card gives us a picture of how people living with HIV are involved (or not involved) in processes and decision-making at national level, but it does not capture the actual engagement of people living with HIV in their communities. Yet, we know people living with HIV play critical roles in delivering health services, support other people living with HIV and participate in some of the decision-making at community level.

Understanding how people living with HIV are engaged in their communities is essential for a bottom-up response to HIV. If people living with HIV are visible at community level and have a voice that can influence changes, they are able to challenge discrimination and promote the acceptance, inclusion and leadership of people living with HIV within different settings: in the home; at the workplace; in healthcare settings; or in local government. Additionally, if people living with HIV have decision-making power at the community level, they can influence policy at local level, which in turn can shape national policy. People living with HIV at community level are best placed to identify the specific actions required to support people living with HIV in reaching higher and more meaningful levels of involvement, and in doing so, to drive change at community level.

The ideal advocacy scenario would be that the networks and groups of people living with HIV have a complete picture of the involvement of people living with HIV both at the national level and at the community level. Then, the community can propose and advocate for more structural, broader change. This means that, in addition to using the GIPA Report Card to document the level of involvement at the national level, advocates should use also use From the Ground Up, to document engagement at the community level.

1.4 About From the Ground Up

With this tool, you do simple research to gather information about how people living with HIV are engaged in activities at community level. The tool is for groups of people living with HIV – including women living with HIV, men living with HIV, transgender people living with HIV, men who have sex with men living with HIV, young people living with HIV, sex workers living with HIV, people who use drugs living with HIV, and all other groups of people living with HIV – to use within their communities to assess the extent to which they are meaningfully involved in activities at community level (see Annex 1 for the Questionnaire). Who is the community? A community is a group of people who have something in common. They may share similar interests, share geographical or virtual space or interact socially. In the context of our tool, some examples include:

- People who are affected by shared health and social issues, such as
  - people living with HIV
  - young people
  - women
  - sex workers
  - men who have sex with men
  - people who use drugs
  - transgender people
- Members of civil society organisations championing specific issues, such as HIV prevention advocates or treatment activists
- People who live in a geographic area, such as a village or town
- People accessing services and support at a certain place, such as a support group or health facility
- People who have a similar trade or profession, such as tailors, lawyers or sex workers
2. Steps to implementing this tool

2.1 Who leads this work?

The work is led by groups of people living with HIV who would like to assess the extent to which they are meaningfully involved in community level work or groups. The latter could be networks, organisations, support groups or other groups of young people living with HIV, women living with HIV, men living with HIV, men who have sex with other men and are living with HIV, people who use drugs living with HIV, sex workers living with HIV – and all other groups of people living with HIV at community level.

The people leading the work needs the following:
- A coordinator for the project;
- 2-3 people with skills to do the interviewing;
- A team member/partner organisation/consultant to analyse the data and write up the findings; and
- If need be a trainer on how to use the tool, and a translator for local languages.

2.2 What do you need?

Before you begin, it is important to understand what GIPA is and how others have promoted GIPA in their communities and countries. You could read and discuss the GIPA Good Practice Guide, which has case studies from countries around the world. You need three things to be able to do this study:
- Information on the steps to implementing GIPA at community level (i.e., this chapter);
- The questionnaire (Annex 1); and,
- The informed consent sheet, which must be signed by ALL interviewees if they agree to participate in the research (Annex 2).

Once your team is formed and you have become familiar with all the documents, the process can begin.

Important:
It is good to note that the implementation of GIPA can be very influenced by local culture, social conditions and other specific circumstances that can vary from country to country. Therefore, it is good to use the tool as a guide; however, if you feel that there is a need to add, revise or remove some of the questions, it is possible to do so. We would suggest that you discuss this in the workshops and with people who have more experience with study methods and research.

2.3 Who are you partnering with to do this work?

You may decide to partner with a local community-based organisation or non-governmental organisation to do this study. They could provide you with advice on the steps to take in your specific community. Or they may be able to connect you with those you want to interview in your community (such as decision-makers and other people with power who are not easy to organise appointments with). There will be other practical aspects they can help you with, such as offering to help you with the analysis and report-writing (or paying a consultant to help you with this important step in the project). Partners are also useful in helping to share with others the work you have done and the findings from your work to help you in your advocacy.

If your organisation is partnering with other organisations on specific parts of the process (for example, data analysis), it would be good for your organisation to participate actively in that process as well. GIPA is important in implementing this tool too!

2.4 Who are you interviewing?

It is important to diversify your sources of information so you can present different perspectives. Documenting perspectives from different communities will also help you in your advocacy efforts; you will be able to get early buy-in from those communities. Therefore, in each community, you can aim to interview a range of important actors – people within other groups and organisations who would have something to say about the extent to which people living with HIV are involved or not involved at community level. Some of these people would represent:
- Other groups of people living with HIV
- Other groups of people particularly affected by HIV
- Local businesses
- Schools and other institutions of learning (teachers)
- Faith based organisations
- Social and health managers and workers (expert clients, nurses, doctors, social workers, community workers, traditional healers)
- Local media
- Local civil government or traditional leadership groups (Elders)
- Labour unions (or similar committees)
- Other appropriate local stakeholders
Try to interview about 30-50 people in total. Ideally, the interviews should be held with people in different positions who could speak about their group or organisation’s position on certain issues. This would give you a solid snapshot of what people think in your community.

2.5 Preparation for implementation team

Once you have a team to do this work, the tools you need (methodology and questionnaire, informed consent form, information sheet about the project) and a clear idea of who you will be interviewing, you will need to prepare your team for the research process:

A. Objectives
The GIPA at Community Level project is a research project. The team leading this study needs some basic research skills to ensure the work is done properly. Therefore, the implementation team should be supported to understand and review how to conduct interviews, research ethics (including the importance of keeping information confidential and keeping the completed questionnaires private), the analysis of data and using the data to call for change.

B. Draft programme
The draft programme of the preparation session would therefore include the following:
- What is GIPA?
- What are good and bad examples of the meaningful involvement of people living with HIV?
- Why is GIPA important?
- Measuring GIPA
- The questionnaire (Annex 1) to gather
  - quantitative data (data that can be measured numerically; this is the kind of data you will be gathering with the agreement or disagreement questions in the questionnaire); and
  - qualitative data (the interview respondent’s thoughts, ideas and feelings; this is the kind of data you will be collecting through the comments sections and open-ended questions of the questionnaire)
- The research process: who to interview, the interview process, after the interviews
- Practicing the interview process
- Tips on how to do interviews well
- Tips on how to keep and manage data to minimise loss of data
- Tips on how to pull together and analyse the data

C. Useful resources
The GIPA Good Practice Guide provides useful background information about GIPA, what it is, challenges other organisations have faced, and how they have overcome challenges and measured their success.
www.gnpplus.net/resources_greater-involvement-people-living-hiv-gipa-good-practice-guide/

ICW’s “Tree of Participation”, developed by the political cartoonist Kate Charlesworth, is meant to convey to others what people living with HIV mean by “meaningful participation” to others. The Tree is an adaptation of Roger Hart’s ladder of participation of children, published by UNICEF in 1997. The Tree is meant to stimulate awareness, reflection and dialogue.
www.icw.org/icw/files/icw_poster.jpg

While not recent, this UNAIDS Policy Brief on GIPA provides a breakdown of the actions different stakeholders can do that remains just as relevant today. This may help you in determining the types of people you want to interview.
data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

This report from a Horizons and International HIV/AIDS Alliance multi-country study on the involvement of people living with HIV may be useful for showing to others that GIPA works and brings practical improvements.
2.6 The data collection process

There are a number of steps in the data collection process:

A. Organise an appointment with each interviewee to visit them;
B. Before each interview starts, make sure they understand what the project is about;
C. Then it is important to ask the interviewee to complete the informed consent sheet (Annex 2) to state they are happy to participate in the study (at this stage, they may agree to provide their contact information, in case the team would like to do follow-up interviews to get further information or evaluate the way the project was done);
D. Conduct and record the interview: interviews should be conducted one-on-one and face-to-face (not in groups or via email). The interviewer needs to let the interviewee know the questionnaire may take up to one (1) hour and they can ask to stop at any time. If the interviewer has an audio recorder, the interviewer should ask for permission to record the interview;
E. Review the tips for the interview process below.

Tips for the interview process

What if they know very little about GIPA?
In many cases, the interviewee may not have heard the term ‘GIPA’ before. However, the questionnaire is designed to ask people about the involvement of people living with HIV in general. So even if the interviewee is not familiar with the term ‘GIPA’, please proceed. You can share the GIPA information sheet (Annex 3). If the interviewee does not know anything about GIPA, you can use the opportunity to educate them about the basics, including what GIPA stands for and how it came to exist. You can adapt the information sheet in the annex and give it to the interviewee at any point during the interview. Be careful not to give specific examples, otherwise, you will not get an accurate sense of their understanding. The fact that they may not know anything about GIPA is something you would also want to capture.

What if they are in a hurry?
If the interviewee is in a hurry, then reschedule the appointment so you have some dedicated time to do it properly.

What if they do not want to be recorded?
If you have a recorder and would like to record the interview, but they are not comfortable, then put the recorder away and write as much as you can during the interview. It is important your interviewee feels very comfortable. Otherwise you will not get the depth of information you would like.

What if they do not want to be open about their status as a representative of a group of people living with HIV?
The interviewee may not want to answer the question about their HIV status. This is their personal choice. It is important they feel comfortable saying so, and you respect their wishes. Often interviewees can be more comfortable if they understand the interviewer is also coming from the same background. However as mentioned above, this is also a personal decision of the interviewers.

What if it is difficult to find key population representatives to interview?
Work with partners who work with key population groups to organise an appointment. Key population groups are marginalised in society. It is important to make extra effort to reach out and ensure their voices are heard in this process. It is important to document your methodology (no names, just in general terms) so you capture this in the methodology section of the final report.

How can we ask people about sensitive topics, such as belonging to key populations?
It is very important to capture information from marginalised groups such as sex workers, men who have sex with men,
2.7 Analysing the data

Once you have all the data written up by hand in questionnaires and recorded, in some cases using digital recorders, then you will need to collate and analyse the data. This is an opportunity to work with the interviewers to clarify any of the data that was gathered. At this stage, you need to think about whether you have the skills internally or whether you need support from a partner organisation. If you do decide to work with an external partner to help with data analysis, ensure it is a participatory process where you are also involved closely. This will help build your own capacity to take this work further.

As you analyse your own data, you might want to compare your findings to data that is already available from other sources. For example, you could compare your findings to information available from annual national AIDS reports, UNGASS reports or national strategic plans. You could include a discussion of how your findings are similar or different when you write your report.

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Steps to implementing this tool

transgender people, and people who use drugs. However, in many contexts, it can be difficult to raise such topics. Sex work, drug use and sex between men might be stigmatised and criminalised. During the preparation for the interviews, take some time to discuss within the team how this information can be captured in a way safe for both the interviewer and the interviewee. This can include a discussion on which wording to use given your local context, and role-playing to practice asking questions in a respectful, safe manner.

What if all the interviewees seem to be men, or all of them seem to be women?

It is very important to ensure gender balance. In the initial selection of interviewees, be aware and look out for the gender balance. Once the interview process starts and you feel you have a gender imbalance, then try to redress it by inviting new interviewees or asking organisations whether they could suggest a woman or man (whichever gender is underrepresented).

What if they ask for resources to support them to apply GIPA in their context?

Before starting the study, make sure you have some information to give to your interviewees. You can photocopy the GIPA Good Practice Guide or use it to develop your own briefing document. That way, the study also becomes an opportunity to educate others about GIPA.
2.8 Writing the report and validating your findings

Once you’ve analysed your data, you need to develop a report with your key findings. You need to first think about your audience – who are you doing the report for? For example, you may want to target your local government because you would like them to put in place a policy to promote the involvement of people living with HIV. You may also target groups and organisations doing work in your community because you would like them to see the extent to which they are involving (or not involving) people living with HIV.

When you are clear about your audience, then you can start writing (or you can get support to write the report). You can structure your report along the following lines:

- Background to the study (about your group, why you conducted the study, what you will use it for)
- Methodology (how you did the study, consent of the participants, the limitations of the study)
- Findings (you can use tables to illustrate the quantitative data, and you can share quotes to illustrate the qualitative data)
- Discussion
- Conclusion
- Recommendations
- References
- Annex: the questionnaire and a list of relevant materials you picked up on GIPA during the interviews

Share your findings with the study participants so they can validate the findings. This is an important part of making sure the information and data gathered actually reflect the circumstances and views of participants and that nothing in the description of the findings could put any of the participants in jeopardy. Sharing findings is also a key way of ensuring the findings are being articulated in a way that is accessible and can be utilised by the participants in favour of implementing GIPA. Finally, it helps ensure the continuity of the participants’ involvement in the study, and their ownership over it and the results.
You can also share your drafts with partners so they can help you review them, and to get an early buy-in from other stakeholders. This will help you in your advocacy process. This final report will be an important tool in your advocacy for people living with HIV at community level!

2.9 Using the evidence for advocacy

Once you have your report, use it for advocacy. Share it with study participants, all partners, the local government, traditional leaders, etc. so they are aware of your findings and can apply the recommendations you are suggesting in their work. Perhaps you can organise a meeting with the stakeholders you are trying to influence, or you can share the data via local radio. The important thing is to revisit the reason you wanted to do this work and make sure you achieve your goal of getting your findings out there and advocating for the necessary change!
Annex 1: Questionnaire

Before the interview starts

Give a short introduction to the respondent about the study and the interview. The interviewer should ideally explain:

- The purpose of the research project
- The process of the research project (interviews, analysing the data, writing the report, sharing the findings with the respondent)
- This research measures how people experience the involvement of people living with HIV. This means that all answers are valuable, there are no wrong answers.
- The signing of the consent form

Ask the respondent to sign the consent form and ask if you are allowed to tape record the interview.

1. Background of the respondent and his/her community

<table>
<thead>
<tr>
<th>Interview date</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview number</td>
<td></td>
</tr>
<tr>
<td>1.1 Name of organisation</td>
<td></td>
</tr>
<tr>
<td>1.2 Position/Job Title</td>
<td></td>
</tr>
<tr>
<td>1.3 Gender (for example: female, male, transgender)</td>
<td></td>
</tr>
<tr>
<td>1.4 Openly living with HIV</td>
<td>Yes</td>
</tr>
<tr>
<td>1.5 Have you ever heard of GIPA? It is sometimes called the GIPA Principle. GIPA stands for the “Greater Involvement of People Living with HIV”</td>
<td>Yes*</td>
</tr>
</tbody>
</table>

*If the person answers yes, ask the following question: How would you explain GIPA in your own words?
2. Background of organisation where respondent is involved

If respondents are involved with an organisation/group/network, ask them questions from section 2. Otherwise, skip to section 3.

If they are staff members or on the Board of Directors of the organisation, proceed to section A. If they are volunteers, clients or members, proceed to section B.

| 2.1 Are you involved with a community group/organisation/network? | □ Yes (proceed to the next question)  
<table>
<thead>
<tr>
<th></th>
<th>□ No (skip to section 3)</th>
</tr>
</thead>
</table>
| 2.2 How are you involved? | □ I am a staff member (proceed to section A)  
| | □ I am on the Board of Directors (proceed to section A)  
| | □ I am a volunteer (proceed to section B)  
| | □ I am a member or client (proceed to section B)  
| | □ Other: __________________________________ |
| | (determine whether section A or B is more appropriate) |

**Section A: Staff members or Board of Directors**

| 2.3 Type of organisation | □ Carers/caregivers living with HIV  
| | □ Children living with and/or affected by HIV  
| | □ Journalists living with HIV  
| | □ Teachers living with HIV  
| | □ People living with HIV  
| | □ Women living with HIV  
| | □ Young people living with HIV  
| | □ Men who have sex with men living with and/or affected by HIV  
| | □ People who use drugs living with and/or affected by HIV  
| | □ Sex workers living with and/or affected by HIV  
| | □ Religious group(s) living with HIV (please specify)  
| | □ Other: __________________________________ |
| | (please specify)  
|---|---|
| Other group/organisation | □ Civil society organisation (please specify)  
| | □ Community committee/authority (please specify)  
| | □ Health care centre  
| | □ Healthy/sanitary authority  
| | □ Labour Union  
| | □ Local administrative authority  
| | □ Political party  
| | □ Private company  
| | □ Sports group  
| | □ Women’s rights organisation  
| | □ Other: __________________________________ |
| | (please specify) |
2.4 **Groups your organisation works with**

Please tick as many as apply

- Carers
- Children (ages 0 – 14 years)
- Men who have sex with men
- People who use drugs
- Sex workers
- Teachers
- Young people (ages 15 - 24 years)
- Women
- Other: ____________________________________________
  (please specify)

2.5 **When was your organisation created?**

Please specify year

2.6 **Membership of your group**

- 0 to 50 people
- 51 – 100 people
- 101 – 200 people
- 201 – 500 people
- 501 and more people
- Not applicable

2.7 **Annual operating budget of your organisation**

Please specify

2.8 **Number of paid staff members**

Please specify

2.9 **Number of volunteers working at your organisation**

Please specify

2.10 **Number of paid staff members openly living with HIV at your organisation**

Please specify

2.11 **Number of volunteers openly living with HIV working at your organisation**

Please specify

2.12 **Has your organisation ever talked about or organised anything on ‘GIPA’? If so, please specify**


2.13 **Any additional information about your organisation**
## Section B: Volunteers, Clients or Members

### 2.3 Type of organisation

Group/ organisation/ network of people living with HIV at community level

- Carers/caregivers living with HIV
- Children living with and/or affected by HIV
- Journalists living with HIV
- Teachers living with HIV
- People living with HIV
- Women living with HIV
- Young people living with HIV
- Men who have sex with men living with and/or affected by HIV
- People who use drugs living with and/or affected by HIV
- Sex workers living with and/or affected by HIV
- Religious group(s) living with HIV (please specify)
- Other: ________________________________ (please specify)

Other group/ organisation

- Civil society organisation (please specify)
- Community committee/ authority (please specify)
- Health care centre
- Health/ sanitary authority
- Labour Union
- Local administrative authority
- Political party
- Private company
- Sports group
- Women’s rights organisation
- Other: ________________________________ (please specify)

### 2.4 Groups your organisation works with

Please tick as many as apply

- Carers
- Children (ages 0 – 15 years)
- Men who have sex with men
- People who use drugs
- Sex workers
- Teachers
- Young people (ages 16 - 30 years)
- Women
- Other: ________________________________ (please specify)

### 2.5 From what you have observed in your interactions with the organisation:

- Do people living with HIV work there as staff members? □ Yes □ No
- If so, do you know how many?
- Which proportion of the staff is positive?
- In which positions people living with HIV are working there?
<table>
<thead>
<tr>
<th>2.6 From what you have observed in your interactions with the organisation:</th>
</tr>
</thead>
</table>
| Are people living with HIV on the Board of Directors? | □ Yes  
| Do you know how many people? |
| Which proportion of the Board? |

<table>
<thead>
<tr>
<th>2.7 From what you have observed in your interactions with the organisation:</th>
</tr>
</thead>
</table>
| Do people living with HIV volunteer there? | □ Yes  
| Do you know how many people? |
| What kind of tasks are they doing? |

<table>
<thead>
<tr>
<th>2.8 From what you have observed in your interactions with the organisation:</th>
</tr>
</thead>
</table>
| Are people living with HIV consulted, for example when it comes to making decisions about the programmes and services the organisation offers? | □ Yes  
| How are they consulted? |
| How often? |
3. How are people living with HIV engaging in your community?

### 3.1 What are the different ways in which people living with HIV are engaged in your community?
Open-ended question with some probing ideas:

<table>
<thead>
<tr>
<th>In homes: carers/caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>In the community (including in organisations/networks of people living with HIV): activist, volunteer, community-based researchers, health motivators, peer educators</td>
</tr>
<tr>
<td>In clinics: expert clients, mentor mothers, peer educators</td>
</tr>
<tr>
<td>In schools and workplaces: representatives in committees, representative of people living with HIV within the organisation (in the field(s) or in the office)</td>
</tr>
</tbody>
</table>

### 3.2 Can you describe some examples of where you have seen the greatest participation of people living with HIV?
Open-ended question with some probing ideas:

| Community structures, such as committees, councils, chiefdoms |
| Settings, such as homes, schools, workplaces, clinics |
### 3.3 How could this participation in the community be improved?

### 3.4 To what extent do you feel people living with HIV are involved in activities that affect their lives?

- Very much
- Sometimes
- Not at all

### 3.5 To what extent do you feel people living with HIV are involved in decision-making about the health and social services available to them?

- Very much
- Sometimes
- Not at all

### 3.6 Any additional comments

---

### 4. What are the challenges you are experiencing?

#### 4.1 What challenges have you observed in involving people living with HIV in activities in your community?

Open-ended question with some probing ideas:

<table>
<thead>
<tr>
<th>Discrimination experienced by people living with HIV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrimination experienced by certain groups of people living with HIV (such as sex workers)</td>
</tr>
<tr>
<td>Lack of access to treatment and other services for people living with HIV</td>
</tr>
<tr>
<td>Question</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Level of knowledge and/or skills of people living with HIV</td>
</tr>
<tr>
<td>Level of knowledge and/or skills of other community members</td>
</tr>
<tr>
<td>Openness about one's HIV status</td>
</tr>
<tr>
<td>4.2 <strong>What challenges have you observed in involving people living with HIV in decision-making in your community?</strong></td>
</tr>
<tr>
<td>Difficulty in finding people living with HIV open about their status</td>
</tr>
<tr>
<td>The social and economic insecurity of people living with HIV</td>
</tr>
<tr>
<td>People feel uncomfortable in meetings because of their HIV status, gender or sexuality</td>
</tr>
<tr>
<td>People feel incompetent in participating in technical meetings</td>
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<tr>
<td>-------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Lack of support for people living with HIV to build their skills</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4.3 To what extent do you feel organisations/networks/groups working in your community value the involvement of people living with HIV in activities that affect their lives? Please explain.</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Very much</td>
</tr>
<tr>
<td>□ Sometimes</td>
</tr>
<tr>
<td>□ Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4.4 To what extent do you feel the local government supports the involvement of people living with HIV in decisions that affect their lives? Please explain.</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Very much</td>
</tr>
<tr>
<td>□ Sometimes</td>
</tr>
<tr>
<td>□ Not at all</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4.5 Any additional comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
5. The involvement of people living with HIV who are also part of other marginalised groups

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 How are people living with HIV who are also part of other often marginalised groups (such as women, young people, sex workers, men who have sex with men, people who use drugs) involved in activities and decision-making in your community? Please specify</td>
<td></td>
</tr>
<tr>
<td>5.2 What are some of the challenges you have observed in involving groups that are particularly marginalised? Please specify</td>
<td></td>
</tr>
<tr>
<td>5.3 To what extent do you feel organisations working in your community involve marginalised groups of people living with HIV in activities that affect their lives? Please explain.</td>
<td>□ Very much □ Sometimes □ Not at all</td>
</tr>
<tr>
<td>5.4 To what extent do you feel the local government supports the involvement of marginalised groups of people living with HIV in decision-making that affects their lives? Please explain.</td>
<td>□ Very much □ Sometimes □ Not at all</td>
</tr>
<tr>
<td>5.5 Any additional comments</td>
<td></td>
</tr>
</tbody>
</table>
6. Hearing your suggestions: what more could be done to support the leadership and involvement of people living with HIV in your community?

<table>
<thead>
<tr>
<th>6.1 What kind of support do you think people living with HIV need to enable them to lead or participate in community activities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open-ended question with some probing ideas:</td>
</tr>
<tr>
<td>- Information about how they can participate, mentoring, employment, knowing their rights</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.2 People living with HIV from marginalised groups often face ‘double stigma’. This means they face stigma because of their HIV status and also because they are part of a marginalized group (like sex workers, for example). Given this experience of ‘double stigma’, is there additional support that people living with HIV from marginalised groups need to engage?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please specify</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.3 Who do you think could be doing more to improve the involvement of people living with HIV in your community? Please explain.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open-ended question with some probing ideas:</td>
</tr>
<tr>
<td>- People living with HIV, Networks of people living with HIV, NGOs, Faith-based organisations, Central government, Local government, Health facilities, Workplaces</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6.4 How could groups/organisations/networks of people living with HIV better support the involvement of other people living with HIV in their communities?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please specify</td>
</tr>
<tr>
<td><strong>6.5</strong> How could health facilities better support the involvement of people living with HIV in their communities?</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Please specify</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>6.6</strong> How could workplaces better support the involvement of people living with HIV in their communities?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Please specify</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>6.7</strong> What do you see as the role of local government? What could they do better?</th>
<th></th>
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<tbody>
<tr>
<td>Please specify</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>6.8</strong> Is there anything else that you would like to tell us?</th>
<th></th>
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<tbody>
<tr>
<td>Please specify</td>
<td></td>
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</tbody>
</table>

Thank you very much for sharing your thoughts and experiences with us!
Annex 2: Example of informed consent sheet

**Title of Project:** GiPA at community level

**Purpose of Project:** To support people living with HIV in gathering information about how other people living with HIV are engaged in decision-making and activities at community level.

**Project team:** This project is being coordinated by:

Name of group:

I understand that if I have any questions about the project, I can contact:

Name, title:

**The interview:** I understand that I am being asked to participate in a project to increase understanding of how people living with HIV are meaningfully involved in decision-making and activities at community level.

I understand that I will be taking part in an interview that will last approximately 1 hour. I will be asked questions about the involvement of people living with HIV in my community, including the challenges and opportunities.

I understand that the interview may be recorded (audio) and written up and that all the information I share will be coded in a manner that I cannot be identified. The information I give will only be used for the study and for the development of a report.

I understand that my participation in the interview is absolutely voluntary. If I feel uncomfortable with a question, I can choose to skip that question or to end the interview altogether.

**My privacy:** I understand that my name will not be recorded. I understand that only the project team will have access to the information I have provided in the interview. All recordings and data will be destroyed at the conclusion of the study.

**Copy of informed consent for participant:** I am being given a copy of this informed consent to keep for my own records.

Participant signature Date

Interviewer signature Date

Interviewer name:
I can get involved!

Have you ever heard of the GIPA Principle? The Greater Involvement of People Living with HIV/AIDS (GIPA) Principle was created to make sure people living with HIV are involved in the decisions that affect our lives. Most countries around the world support the GIPA Principle.

Maybe you have heard the expression “nothing about us without us”. For people living with HIV, it means that when anyone does something about HIV in our community, we must be involved. We must have a voice in what healthcare providers, governments, and community groups are doing in our community. A community is a group of people who have something in common. For example, we are a community when we live close to each other in the same place, or when a group of us who are HIV-positive get together.

We are experts in our own lives. We can contribute to efforts to fight HIV. There are many different ways in which people living with HIV can get involved. This means YOU can get involved too!

I can connect with other people living with HIV in my community!

The GIPA Principle talks about the importance of creating networks for people living with HIV. And about making community groups stronger. Are there already support groups in your community? You can join a group. Or you can create a group if none exists already. Connecting with other people living with HIV can be powerful. We can connect with each other. We can support each other. We can make a difference in each other’s lives.

I can influence decisions in my community!

People who work in governments, in community groups, and in healthcare make decisions about the services they offer to the community. Sometimes they make these decisions without talking to people living with HIV. Other times, they want to include people living with HIV in making decisions. We need to be at the table when decisions are made that affect our lives. Ask around in your community: are there groups or committees that you could join? You could help make sure that services in your community meet the needs of people living with HIV. How? By talking about our own lives, our own experiences, our own needs.

I can help protect the rights of people living with HIV in my community!

People living with HIV have the same human rights as anyone else. That includes things like the right to healthcare, the right to have children, and the right to work. But sometimes the rights of people living with HIV are not respected. You can work with others in your community to make sure this does not happen anymore. You can find out more about the human rights of people living with HIV. Then you can educate others about those rights. And you can help people living with HIV stand up and defend their rights.

Hola! My name is Francisco. I am a man from Bolivia. I am 42 years old and I meet once a month with other people living with HIV in my community. I have learned so much from them about how I can live a healthy life with HIV. And now I am helping new members in the group.

Jambo! My name is Rahid. I am a married 34-year man and I am a volunteer with the Kenyan National Network of People Living with HIV. I sit on the National AIDS Control Council with government ministers and very experienced staff from community groups.

Hello! My name is Oksana and I am an HIV-positive woman from Ukraine. I am 27 years old and a former drug user. Now I fight for the rights of people living with HIV who use drugs in my community. I want to make sure they have access to services, just like everyone else.
I can support the response to HIV in my community!
The GIPA Principle says that people living with HIV and community groups that address HIV should be supported. You can connect with other people living with HIV and groups in your community. You can work together to address HIV. You can make sure more people do not become infected. You can also make sure people living with HIV receive the support and services they need to live a healthy life. And you can ask your government for help to do this. You can also fight the policies and laws that drive people living with HIV away from services, make services potentially unsafe, and increase stigma and discrimination, such as policies and laws on HIV exposure, non-disclosure and transmission.

Hello! My name is Ming, and I am young woman from China. I have been living with HIV for five years. I teach other women in the clinic in my region about the benefits of taking antiretroviral treatment for HIV.

I want to learn more about GIPA!
If you’d like to learn more about GIPA and how it might affect you, there are a few ways you can get more information. You can ask people who do HIV work in your community if they have documents about GIPA. If you can get access to a computer, then you could look for information on the Internet. You can go to Google and search for “GIPA” or you can search for these resources:
- The GIPA Good Practice Guide. This was created by the International HIV/AIDS Alliance and the Global Network of People Living with HIV (GNP+).
- One Foot Forward: A GIPA Training Toolkit. This series of 9 modules was developed by the Canadian AIDS Society.
- The UNAIDS GIPA Policy Brief.
- GIPA Report Card.
- From the Ground Up: Documenting GIPA at Community Level.

These are all good places to start to learn
You can also contact community development experts at the Global Network of People Living with HIV (GNP+) via infognp@gnpplus.net to help direct you in your search for more information and people with whom to work.