

GIPA Report Card User Guide

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KEY PROCESS STEPS TO IMPLEMENT THE GIPA REPORT CARD

About the GIPA principle

The Greater Involvement of People Living with HIV (GIPA) is a principle that aims to realise the rights and responsibilities of people living with HIV to self-determination and meaningful participation in decision-making processes that affect their lives. By promoting and strengthening the involvement of PLHIV, the application of the GIPA principle enhances the quality and effectiveness of HIV responses.

About the GIPA Report Card

The GIPA Report Card is a means of generating evidence about the application of the GIPA principle in-country based on the views and experiences of people living with HIV. The evidence will contribute to monitoring and evaluating governments' and organisations' application of the GIPA principle, with the aim of enhancing the programmatic, policy and funding actions taken to realise the greater involvement of people living with HIV in a country's HIV response.

Depending on each country and the partners involved, the GIPA Report Card will be realised in different ways. In each case, people living with HIV must be at the center of the process, guiding the implementation of the GIPA Report Card. While multiple variations will occur (either cultural, regional or others), a number of key process components are recommended to effectively implement the GIPA Report Card. The following recommended processes are described below:

1. Getting started: preparation and planning
2. Doing the interviews
3. Developing the GIPA Report Card
4. Getting the results out

1. GETTING STARTED: PREPARATION AND PLANNING

A team of 2-3 people may be needed to develop the GIPA Report Card from start to finish. Collaboration with people living with HIV (PLHIV) networks at state/provincial, regional and national levels will be needed to gain wide ownership of the process. Through the collaboration, identify a small team of PLHIV with the skills needed to develop the GIPA Report Card.

Consultants will need the following skills and resources:

- Writing and communication skills
- Research experience is a plus, but not mandatory
- Have some experience in the local or national people living with HIV movement in your country
- Consistent computer, internet and printer access
- Printing or photocopier access
- Digital recorders for recording interviews

Key documents your team will need to get started:

- GIPA Report Card User Guide
- GIPA Report Card Questionnaire
- Community Member and Interviewee Information Sheet
- Interviewee Consent Form
- GIPA Report Card Briefing Paper
- Report Template (electronic version available from the Global Network of People Living with HIV/AIDS (GNP+): gipareportcard@gnpplus.net, +31 20 423 4114)

Once the team is formed and has become familiar with all the documents then the process can begin.

1.1 COMMUNICATING WITH PARTNERS

Connecting with the various partners who may be interested in participating in the development of the GIPA Report Card and who may also be involved as interview respondents is an important step in moving forward. Identifying partners and meeting with them will help your team to communicate and build an understanding among partners of the GIPA Report Card and the intended process. Speaking with the PLHIV networks, the UNAIDS country office, the National AIDS Programme, Ministry of Health, and other civil society organisations will help to garner support for the GIPA Report Card and will also help with communication efforts once you start seeking interview respondents. This may also assist your team with practical issues, as your connections may help to support the GIPA Report Card if your partners are willing to assist with logistical or other supports.

Suggested partners are:

UNAIDS, National AIDS Programme, Ministry of Health, GIPA staff or officers in the government, Non-Governmental Organisations delivering care and support to people living with HIV, and all PLHIV networks.

1.2 WORKSHOP ON RESEARCH SKILLS FOR GIPA REPORT CARD TEAM

The GIPA Report Card is primarily a research project. Some basic research skills are required by the team to implement the project effectively. The GIPA Report Card team should take part in a focused skills development workshop to build research skills, such as understanding different research approaches, how to conduct interviews, research ethics, analysing data and using research data to mobilise policy change.

Suggested Resources:

- Some useful resources: cbr.cbrc.net/modules.php?name=Topics&area=Library
- Online ethics tutorial: www.pre.ethics.gc.ca/english/tutorial

- Guideline for ethics in international settings: ethics.cahr-acrv.ca/CAHRreportFinal.pdf
- 'How-to' on conducting interviews: cbr.cbrc.net/files/1075145804/InterviewingFocusGrpTechniques.pdf

1.3 WRITING THE LITERATURE AND POLICY REVIEW

A vital component to the GIPA Report Card is the Literature and Policy Review, which will provide an overview on how the GIPA principle and PLHIV involvement is discussed in policies and guidance documents. A Literature and Policy Review generally looks at key documents on a specific topic and analyses them for a specific purpose. In this case government and organisational HIV policies will be analysed for how they integrate the GIPA principle and discuss the involvement of people living with HIV. The Literature and Policy Review provides the final GIPA Report Card a broad perspective and understanding of how the GIPA Principle is or is not being written about in policy documents in your country.

Key documents to be gathered include national, state and district strategic plans; organisational by-laws from Non-Governmental Organisations and PLHIV networks; GIPA Principle guidance documents; country United Nations General Assembly Special Session on HIV/AIDS (UNGASS) reports and civil society shadow UNGASS reports; Country Coordinating Mechanism (CCM) Terms of Reference; organisational pamphlets and other information.

When the Literature and Policy Review is finalised make sure to include a bibliography of all referenced documents. Suggested format for the bibliography is in APA style, use the following online style guides for assistance:

- www.library.uq.edu.au/training/citation/apa.pdf
- www.wisc.edu/writing/Handbook/DocAPA.html

A Literature and Policy Review should be:

- Informative (the review should contain a neutral description of how the GIPA principle and PLHIV involvement is discussed in current policies and other selected documents across the country);
- Evaluative (the review should include critical statements analysing the described policies and selected documents by indicating relations, contradictions, gaps, and inconsistencies);
- Integrative (the review should be able to compare and contrast how the GIPA principle is or is not discussed in to the policies and other selected documents).

SOMETHING TO REMEMBER When reading the entire collected documents make sure to look for cases where the GIPA principle is or is not included. Look for cases where people living with HIV are involved in participatory mechanisms (e.g. if people living with HIV were consulted in the development of the National AIDS Plan) and if there are specific people living with HIV with designated governance, staff and volunteer positions.

1.4 MATERIALS TRANSLATION

Make sure to devote an appropriate amount of time and financial resources to accurately translate the *GIPA Report Card Questionnaire*, *Community Member and Interviewee Information Sheet*, and *Interviewee Consent Form* and other materials. Some of the technical language in the documents may take time to translate; therefore the translation process should be organized well in advance. If funds are limited, the materials could be translated verbally to the respondents during the interview.

1.5 SETTING CRITERIA FOR WHOM TO INTERVIEW

It is important to have an idea of the types of people your team will want to interview. It is recommended that the interviews be targeted to key individuals including the UNAIDS Country Coordinator and manager of the National AIDS Programme. The GIPA Report Card should aim to include a total of twenty-five (25) interview respondents. Examples of whom to target for interviews are:

- Executive Director of National and State level PLHIV Networks
- Board Chair of National and State level PLHIV Networks
- PLHIV CCM Representatives
- PLHIV working in the United Nations
- PLHIV working in Government Ministries
- GIPA Officers
- PLHIV Representatives on National HIV Programme Committees for the National AIDS Plan

However, there may be other key individuals your team would like to interview. Think about what experiences are important to capture among the people living with HIV that will be interviewed. Setting criteria can help ensure that your team selects the appropriate individuals to interview and ultimately will get valuable data for the final report. This is an important area to consult your partners on. Below are some suggested criteria:

- Representative of and/or working with key populations
- Engagement in organisations and mechanisms related to the country's HIV response, such as:
 - PLHIV networks
 - Country Coordinating Mechanisms
 - UNAIDS secretariat and Co-sponsors
 - Development agencies
 - Civil Society Organisations
 - National AIDS Councils
 - Donor organisations
- Various levels and lengths of involvement in country's HIV response

1.6 INTERVIEW LOGISTICS

Decide on safe and quiet location for the interviews, and make arrangements for travel depending on if you will need to travel to meet people or have them meet you. Take time to arrange for suitable venues in which the interviews can be conducted and also establish a safe place to store all your interview data and completed questionnaires.

Be sure to use a locked filing cabinet for hard copies of your study materials and a password protected folder on a computer (with password protected backup on USB stick or disk) where you can store individual electronic files. It is also recommended to remove all personal data from questionnaire forms and store this separately with the consent forms using the same number codes on each for the same person.

Depending on project funding, your team will need to decide an appropriate honorarium amount. It is customary to compensate interviewees for the time they have taken to participate in the interview.

1.7 GETTING YOUR INTERVIEW RESPONDENTS

Through the questionnaire your team will gather respondent's observations, ideas, feelings and thoughts on how the GIPA principle and the meaningful involvement of PLHIV is taking place in your country.

The minimum number of interview respondents suggested is twenty-five (25); a majority of whom are living with HIV. We also recommend interviewing one (1) UNAIDS Country Coordinator (or equivalent) and one (1) National AIDS Programme Manager (or equivalent). Depending on your country and resources for the project this number can vary depending on what your team decides is appropriate, however less than twelve (12) respondents is not recommended.

Now you will need to get the word out so that people living with HIV will be available to take part in the interview process. There are various ways to get

the information out to potential individuals you might want to interview. One simple way to do this is by using the *Community Member and Interviewee Information Sheet*. You could send out invitations with the information sheet attached describing the GIPA Report Card and indicating that your team is looking for interested parties on PLHIV network list-servs.

- Be proactive and directly contact people you think are important to be interviewed.
- Make a poster about the GIPA Report Card and post it in PLHIV networks offices.
- Make sure to give your respondents appropriate time to schedule an interview time, be flexible; your team will want to make sure you get the right people interviewed!
- Get references from others, such as Board members from PLHIV networks, UNAIDS staff, Country Coordinating Mechanism members and others.
- When contacting the UNAIDS Country Coordinator and National AIDS Programme Manager, or equivalents to arrange interview dates and times, make sure to be flexible and allow plenty of time in advance.
- Contact your countries UN Plus representative (if applicable) to get the word out to colleagues in-country. UN Plus is the United Nations System HIV-Positive Staff Group. For more information, please visit their website www.unplus.org
- Make sure to set a timeline within which people will need to respond by and make sure to add dates and contact information on all communication materials.

SOMETHING TO REMEMBER You will not be able to interview everyone who contacts you, or everyone who fits your criteria. Your team will want to ensure that the persons selected as interview respondents have a certain amount of knowledge to be able to effectively contribute to the GIPA Report Card. It may be important to liaise with partners to discuss your potential interview respondents in order to ensure that you get broad and knowledgeable perspectives.

2. DOING THE INTERVIEWS

Your team will be gathering various kinds of information during the interviews, including **quantitative data** (data that can be measured in a unit or 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).

Interviews should be conducted one-on-one, and not in groups. The best way to collect qualitative data is to do your interview face-to-face, meaning that the respondent being interviewed and the interviewer from your team are meeting face-to-face.

Having interview respondents self-administer the questionnaire will likely result in your team not gathering enough data from the interview to contribute to the final report. However, based on your budget and location you may have to have certain interview respondents do their interview via email.

The interview should take between 45 minutes to one hour.

From start to finish the interview process could go as follows:

- A. Before the interview the interviewer makes sure that the interview respondent understands the intent of the project. The interview respondent is provided with a verbal overview of the project and goals of GIPA Report Card by the local team member. A copy of the *GIPA Report Card Briefing Paper and the Community Member and Interviewee Information Sheet* are provided.
- B. The interview respondent agrees to participate and signs the consent form. Contact information (email address, phone number), full name, and signature are provided. Contact information is kept separate from the interviews just in case the team does any follow-up evaluation interviews.

- C. The interview respondent is provided with a copy of the questionnaire and is guided through it by the interviewer. It is recommended to record responses with a digital recorder. Alternatively, they can be manually transcribed using a computer; however, this method is not recommended. If neither of these other options is available, the interviewer can ask the respondent to clearly write down all responses into the questionnaire. If possible use two (2) digital recorders to safeguard against low batteries or loss.
- D. When the questions are finished the interview respondent is asked if they any questions, or if they would like to provide any more information. The interview respondent is given some time to reflect on their answers and see if they have any more information.
- E. Finally, the interview respondent is then thanked for their time when the discussion questions have concluded and they are provided with a monetary honorarium for their time.

SOMETHING TO REMEMBER: Having all your responses inputted electronically will help with developing your report, and will also ensure that responses are legible, as some interview respondent's poor handwriting may obscure the intent of their responses.

As a majority of the questions are seeking respondents to "Agree" or "Disagree" replies or are just generally asking for comments, please feel free to ask prompt questions to help garner more information. Below are a series of example questions that are intended to help the team member performing interviews through the interview process and get the interview respondent to provide some context to their replies. Example prompt questions:

- Please explain further...
- Why? Or why not?
- Please tell me a little bit more...
- Why was that process effective or not effective?
- How could have things been made better?

- Why do you think people living with HIV were not involved in that process?
- What made people living with HIV involvement successful in that process?
- If people living with HIV were not involved what were the barriers to involvement?
- How were barriers overcome? Or how could barriers have been overcome?

GIPA KNOWLEDGE COMPONENT

Conducting a workshop on the GIPA principle and the meaningful participation of PLHIV is highly recommended. This can be done for the interview respondents and also among the wider community during the GIPA Report Card implementation process. The process of implementing the GIPA Report Card should be viewed as an opportunity to support the advocacy aims of the end result of the project. The GIPA Report Card should not only be seen as a research project, and in fact, the process of doing the research can be used to build technical knowledge of the GIPA principle and how to advocate on its application within country policies and programmes.

Key resources:

GIPA Report Card Briefing Paper

Key areas to cover in the workshop(s):

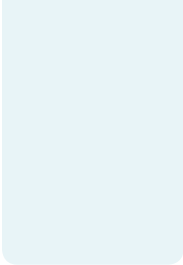
- The origins of the GIPA principle
- The benefits of acting on the GIPA principle for organisations, governments and PLHIV in order to influence policy, programmes and funding actions
- The GIPA principle in practice, including examples of how to meaningfully involve PLHIV in policy development and programming
- Developing indicators for measuring the application of the GIPA principle

3. DEVELOPING THE GIPA REPORT CARD

The GIPA Report Card will only be successful if the final report is rooted in data collected through the interviews and the Literature and Policy Review. For the final GIPA Report Card to have integrity, meaning and to be used effectively as evidence to inform advocacy efforts, the final report must accurately reflect what the interview respondents indicated and the information gathered in the review.

Here is a suggested step-by-step guide to developing the final report:

- Ensure when planning that plenty of time is devoted to the final report, as this is the most important part of the process. The final report will be the GIPA Report Card.
- Listen to all of the interviews or read all of the questionnaires (depending on how you recorded your data).
- Gather quotes from the interviews which convey an overall consensus or highlight differing opinions on key topic areas from the questionnaire.
- Synthesize the questionnaire responses into the Report Template and include the collected quotes where appropriate.
- Include the already developed Literature and Policy Review at the beginning of the final report. Also, make sure to include the bibliography at the end of the report draft.
- Once each section is finalized, summarize overall themes from the findings into a one-page country overview or executive summary. Include the overview or executive summary at the front of the final report.
- When the draft is completed ensure that a number of people from the team act as editors and review the draft. The editor's role is to ensure that the final report is accurate and reflects what was said in the interviews.
- Once the draft report has undergone a review process and revisions then it is ready to be disseminated!



Contact GNP+ – gipareportcard@gnpplus.net, +31 20 423 4114 – for an electronic copy of a *Report Template*.

4. GETTING THE RESULTS OUT

The results of the GIPA Report Card should have wide ownership among all the partners, interview respondents and the community of people living with HIV. It is important that results are shared with all partners and the people who were interviewed and there are multiple ways to disseminate the results and final GIPA Report Card. Please also share the results with the regional networks of people living with HIV and the Global Network of People Living with HIV/AIDS (GNP+).

Community Member and Interviewee Information Sheet

What is this project about?

The GIPA Report Card is an advocacy tool, which aims to increase and improve the programmatic, policy and funding actions taken to realise the greater involvement of people living with HIV in a country's HIV response.

Who is running this project?

The GIPA Report Card was developed and is being implemented by people living with HIV. The development and implementation of the tool has been led by the Global Network of People Living with HIV/AIDS (GNP+) with support from UNAIDS. [INSERT FURTHER DETAILS ABOUT THE ORGANISATION IMPLEMENTING AND MANAGING THIS SPECIFIC PROJECT]

The contact information of your local researcher will be at the bottom of this sheet.

How will selected interviewees participate in this project?

We are asking a diverse range of people living with HIV to participate in a one-on-one interview that will consist of 14 questions lasting approximately 45 minutes to one hour. We are looking for people living with HIV with experience in their country's HIV response. The interview will involve a discussion about personal experiences and perspectives regarding the application of the GIPA principle, as well as barriers to involvement and the personal initiative to be involved, including safe space for disclosure, clarification on why one is getting involved and strategies to deal with stigma, discrimination and burnout.

How are interview participants selected to participate?

The information in this sheet is only for information purposes, it does not indicate you have been selected to participate in an interview. Interviewees will be selected by using criteria to ensure those interviewed have a diverse range of experiences within the country HIV response and also represent local HIV prevalence trends. If you are interested in participating or know someone who might be please contact the researcher.

What will happen to the information provided during the interview?

All the information gathered will be put into a final report which can then be used to further develop the GIPA Report Card tool and may also be used towards advocacy efforts and to support more effective application of the GIPA principle. The information provided during interviews will be used to report on the successes and challenges faced within your country in regards to the application of the GIPA principle within policies and programmes.

How will interviewee participation be confidential?

Interviewees will be asked to give their name and organisational information during the interview; however this will not be included in the report. There will be no way of connecting them with the information provided.

Will interviewees be compensated for participation?

Yes, each selected interviewee will be given [AMOUNT TO BE DETERMINED WITHIN THE GIVEN CONTEXT] for their time participating in the one-on-one interview.

Who can I contact if I have more questions about the GIPA Report Card?

If you have any general questions about the project please feel free to contact:

[INSERT NAME, POSITION, ORGANISATION AND DETAILS]

For more information on participating in interviews please contact:

[INSERT RESEARCHER'S NAME AND CONTACT DETAILS]

THANK YOU!

Interviewee Consent Form

Interview number	
Interview date	

Title of Research Project

GIPA REPORT CARD [INSERT NAME OF COUNTRY]

Background & Purpose of Research

The [INSERT NAME OF THE ORGANISATION] is implementing the GIPA Report Card, which aims to increase and improve the programmatic, policy and funding actions taken to realise the greater involvement of people living with HIV in a country's HIV response.

Investigators

This project is being coordinated and supported by [NAME OF ORGANISATION(S)]

The GIPA report card was developed and is being implemented by people living with HIV. The development and implementation of the tool has been led by the Global Network of People Living with HIV/AIDS (GNP+) with support from UNAIDS. [FURTHER DETAILS OF THE ORGANISATION IMPLEMENTING THIS PARTICULAR PROJECT].

I understand that if I have any questions about the research procedures, I can contact the project coordinator [INSERT NAME AND CONTACT DETAILS]

Invitation to Participate

I understand that I am being asked to participate in a research study to increase understanding of how people living with HIV are meaningfully engaged in various levels of the HIV response including programmatic, funding and policy within my county.

Procedures

I understand that my participation in the study will involve taking part in a one-on-one interview lasting approximately 45 minutes to one hour. I will be asked 14 questions looking at the experiences of people living with HIV with experience in their local country response. The interview will involve a discussion about personal experiences and perspectives regarding the application of the GIPA principle, as well as barriers to involvement and the personal initiative to be involved, including safe space for disclosure, clarification on why one is getting involved and strategies to deal with stigma, discrimination and burnout. I understand that the interview may be audio recorded and transcribed and that all information I share will be coded in such a manner that I cannot be identified. The data will be used only for research purposes and the development of a report on the meaningful involvement of people living with HIV in my country.

Voluntary Participation

I understand that my participation in this research study is purely voluntary and that I am free to withdraw from the interview at any time. I can choose not to participate in any discussions or answer any questions in the interview that I do not want to.

Risks & Benefits

I understand that as a participant, I might recall emotionally upsetting experiences during the interview. However, I have the right not to participate in any discussions or answer any questions which make me feel uncomfortable.

GIPA Report Card Briefing Paper

About the GIPA principle

The Greater Involvement of People Living with HIV (GIPA) is a principle that aims to realise the rights and responsibilities of people living with HIV to self-determination and meaningful participation in decision-making processes that affect their lives. By promoting and strengthening the involvement of people living with HIV (PLHIV), the application of the GIPA principle enhances the quality and effectiveness of HIV responses.

About the GIPA Report Card

The GIPA Report Card is an advocacy tool, which aims to increase and improve the programmatic, policy and funding actions taken to realise the greater involvement of people living with HIV in a country's HIV response. It is seen as a means of monitoring and evaluating governments' and organisations' application of the GIPA principle, particularly in light of the 2001 United Nations General Assembly's Special Session on HIV and the Declaration of Commitment.

The need for developing a GIPA Report Card was identified at a PLHIV Think Tank Meeting in 2005. The process for developing this GIPA Report Card involved a literature review; and telephone interviews with men and women living with HIV from all regions, who are either working in organisations and networks of PLHIV, or for nongovernmental organisations, donor agencies or United Nations agencies, or who have previously worked extensively on the application of the GIPA principle. Subsequently, the draft GIPA Report Card was developed and has been piloted in four countries: Kenya, India, Lesotho, and Trinidad and Tobago. Recommendations from the implementation of the GIPA Report Card in the four countries have informed an updated version of the GIPA Report Card and its accompanying tools. The GIPA Report Card will continue to be adapted and improved over time based on experiences of implementing of the tool in-country.

Who is running this project?

The GIPA Report Card is a prime example of the application of the GIPA principle. The tool was developed by consultants living with HIV and is managed by the Global Network of People Living with HIV/AIDS (GNP+) with support from UNAIDS. The tool is being implemented by people living with HIV networks in-country.

GIPA Report Card Objectives

The objectives of the GIPA Report Card are to:

1. Provide information on the current level of application of the GIPA principle, which will serve as a baseline against which future application of the GIPA principle can be measured;
2. Hold governments, NGOs, United Nations agencies, donors, organisations of PLHIV and other stakeholders accountable to their commitments relating to the application of the GIPA principle;
3. Increase and improve the meaningful participation of PLHIV in different sectors within the broader national response to the HIV epidemic in a country;
4. Assist in developing indicators to monitor and evaluate the quality and impact of PLHIV engagement; and
5. Provide follow-up recommendations to enhance stakeholders' (governments, NGOs, United Nations agencies, donors, organisations of PLHIV) identification of opportunities and entry points for the application of the GIPA principle within their organisation or institutions and in their policies and programmes, including cost estimates.

The GIPA Report Card is to be owned, developed and implemented by PLHIV through a bottom-up process, including broad and diverse consultation.

GIPA Report Card Outline

It is envisaged that ultimately the GIPA Report Card questionnaire will cover a broad range of the issues relating to the various stakeholders: governments, NGOs, multilaterals, United Nations agencies, organisations of PLHIV and other stakeholders. It is proposed that the GIPA Report Card addresses the following three levels:

1. **Macro/Institutional level** (government policy level such as UNGASS follow-up processes and programmes, and institutions such as CCMs): There must be laws and policies for protecting PLHIV who become involved, including access to affordable health care such as life prolonging medication, and capacity building as required.
2. **Meso/Organisational level** (organisational level, focusing on government ministries, NGOs and organisations of people living with HIV): Pre-conditions for safe involvement include: sensitivity training for colleagues; information about the opportunities for the application of the GIPA principle; appropriate training for the tasks to be undertaken and optimal use of existing skills.
3. **Micro/Individual level** (barriers and/or facilitators to involvement): It has to be a personal initiative to be involved, and should be accompanied by a safe space for disclosure, counselling and support, clarification on why one is getting involved and strategies to deal with stigma, discrimination and burnout.

Evidence-based advocacy

The GIPA Report Card is a means of generating evidence about the application of the GIPA principle in-country based on the views and experiences of people living with HIV. The evidence will contribute to monitoring and evaluating governments' and organisations' application of the GIPA principle, with the aim of enhancing the programmatic, policy and funding actions taken to realise the greater involvement of people living with HIV in a country's HIV response.

For more information, please visit:
www.gnpplus.net

The Global Network of People living with HIV/AIDS (GNP+) is a global network for and by people living with HIV. GNP+ advocates to improve the quality of life of people living with HIV. For more information, please visit www.gnpplus.net

