

**Challenging,
Changing, and
Mobilizing:**

**A Guide to
PLHIV
Involvement in
Country
Coordinating
Mechanisms**



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Acknowledgments

When the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) was first announced in 2001, people living with HIV/AIDS (PLHIV) across the world were excited and encouraged by this new funding mechanism that promised to deliver large amounts of additional resources to communities and individuals desperately in need of them. Many PLHIV have been involved in the work and processes of the Global Fund from the very beginning, with varying degrees of effectiveness. This handbook considers strategies to increase PLHIV involvement and influence in the Global Fund's future efforts. It is a resource for all of us living with HIV who care desperately about making activities related to the Global Fund as inclusive and effective as possible.

We would like to take this opportunity to acknowledge the funders of this handbook for recognizing the importance of improving effective PLHIV involvement. In particular, we give thanks to USAID, which, since March 2003, has supported much of the work that has gone into producing the handbook through the POLICY Project, including covering the cost of numerous consultations, and staff and consultant time and travel. We would also like to thank Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ) for its support for our meeting at the 15th International AIDS Conference in Bangkok in July 2004. Lastly, we would like to thank the Global Fund Secretariat for financing the initial studies on PLHIV participation on CCMs and for the staff time donated to help make the studies happen. The views expressed in this document, however, do not necessarily reflect those of the funding agencies.

Thanks and acknowledgments are also due to the many PLHIV from around the world who were involved in this lengthy but rewarding process. The challenges of working across continents, languages and time zones were not inconsiderable, but we believe the result of this collaboration is a handbook that will play a vital role in improving the delivery of Global Fund resources to all people affected by HIV.

We have not attended any CCM meetings, but we really want to attend meetings to know what is going on. If we are involved we can support and add our voice to the work of the CCM. It is really important that the CCM has positive people to ensure an understanding of the real situation of people living with HIV/AIDS in Viet Nam. It is PLWHA who understand the real difficulties and needs of PLWHA, and through us so will the CCM.

—PLHIV groups Vietnam

PLHIV have a right to be members of their national CCM, not just because it is a requirement of the Global Fund, but because the experience and expertise of people who live with HIV/AIDS makes a vital contribution to our shared response to HIV/AIDS.

— PLHIV, Australia

Contents

Acknowledgments	2	
Common Words, Phrases, and Abbreviations Used in This Handbook and in Global Fund Documents	5	
Section 1. Background to the Handbook	8	1
<ul style="list-style-type: none"> • Who wrote the handbook? • Who is the handbook for? • What is the aim of the handbook? • Models of good practice and universal principles • History of the handbook: why PLHIV might need it • About the CD that accompanies the handbook • Country-specific information 		
Section 2. About the Global Fund	18	2
<ul style="list-style-type: none"> • What is the Global Fund? • Guiding principles of the Global Fund • History of PLHIV involvement in the Global Fund • Global Fund structure and PLHIV participation 		
Section 3. CCM Basics	27	3
<ul style="list-style-type: none"> • What is a CCM? • The top 10 problems faced by CCMs • Why it is important for a CCM to include PLHIV stakeholders • CCM responsibilities • The role of the Principal Recipient (PR) • What is a Sub-Recipient (SR) • What is the Local Fund Agent (LFA) • Finding out more about the Global Fund grant cycle process 		
Section 4. Being HIV Positive Is not a Profession	37	4
<ul style="list-style-type: none"> • Acquiring the skills, knowledge and experience to be an effective CCM member • Monitoring and Evaluation (M&E) and why it matters 		
Section 5. Roles and Responsibilities	42	5
<ul style="list-style-type: none"> • Moving from tokenism to meaningful involvement on CCMs • Key roles and responsibilities of PLHIV CCM members • Deliberate choice: Why join a CCM? • Roles and responsibilities of PLHIV constituency members towards their CCM representatives 		

6	Section 6. Communication and Coordination	54
	<ul style="list-style-type: none">• How to work together at the country level and beyond• Examples of PLHIV communication channels• Using the media and others to get our messages across• Talking to governments• How institutions in partnership with PLHIV can help enhance PLHIV communications	
7	Section 7. Guidelines for Improving CCMs through Greater PLHIV Involvement	69
	<ul style="list-style-type: none">• Current Global Fund guidelines• The new inclusive model: PLHIV-developed guidelines• Guidelines for improving CCMs through greater PLHIV involvement	
8	Section 8. Additional Technical Resources and Information	76
	<ul style="list-style-type: none">• National laws• Relevant issue-based organizations and related documents and declarations• Useful contacts• International and regional networks for PLHIV• Other resources• Planning summary page	
Q	Feedback Questionnaire	96

Common Words, Phrases, and Abbreviations Used in This Handbook and in Global Fund Documents

Frequently Used Abbreviations

APN+	Asia Pacific Network of People Living with HIV/AIDS
ARV	Antiretroviral
AusAID	Australian Agency for International Development
CBO	Community Based Organization
CEO	Chief Executive Officer
CCM	Country Coordinating Mechanism
CCP	Country Coordinated Proposal
CIDA	Canadian International Development Agency
COI	Conflict of Interest
CRP	Coordinated Regional Proposal
DFID	Department for International Development
DOTS	Directly Observed Treatment, Short course
FBO	Faith-Based Organization
GF	Global Fund
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People Living with HIV/AIDS
GFO	Global Fund Observer
GNP+	Global Network of People Living with HIV/AIDS
GTZ	Deutsche Gesellschaft für Technische Zusammenarbeit
HAART	Highly Active Antiretroviral Therapy
HDN	Health and Development Networks
HIVOS	Humanist Institute for Co-operation with Developing Countries
ICASO	International Council of AIDS Service Organizations
ICW	International Community of Women Living with HIV/AIDS
IDU	Injection Drug Users
IEC	Information, Education, and Communication
INGO	International Nongovernmental Organization
JICC	Kenyan CCM
LFA	Local Fund Agent
M&E	Monitoring and Evaluation
MDGs	Millennium Development Goals
MSM	Men Who Have Sex with Men
MOH	Ministry of Health
MTCT	Mother-to-Child Transmission
NACP	National AIDS Control Program
NEPHAK	National Empowerment Network of People Living with HIV/AIDS in Kenya
NGO	Nongovernmental Organization

OI	Opportunistic Infection
PMTCT	Prevention of Mother-to-Child Transmission
PR	Principal Recipient
PLHIV	Person or People Living with HIV/AIDS *
RBM	Roll Back Malaria
SIDA	Swedish International Development Cooperation Agency
SR	Sub-Recipient
STB	Stop TB
STI	Sexually Transmitted Infection
TB	Tuberculosis
TERG	Technical Evaluation Reference Group
ToR	Terms of Reference
TRP	Technical Review Panel
TWG	Transitional Working Group
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCT	Voluntary Counseling and Testing
WHO	World Health Organization
UN	United Nations
UNDP	United Nations Development Program
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	U.S. Agency for International Development

*The terminology used here was discussed at great length by PLHIV involved in the handbook's development. The majority agreed that the term "PLHIV" is more appropriate than terms such as "PLHA" because everyone living with AIDS is also living with HIV, but not all those living with HIV are living with AIDS. As the Nigerian reviewers so eloquently stated:

The word PLHIV tries to use a common name for all infected persons and does away with the unnecessary segregation of people with AIDS from those with HIV, which has led to some extra stigma being attached to the word AIDS. It was reasoned that since it's impossible to have AIDS without HIV, then HIV is what we all have in common.

Other key words used in the handbook include the following:

Stakeholder/stakeholder group: individuals or organizations that have a vested interest in a given product, activity, or issue. Key stakeholders in this report include PLHIV and their families and communities; NGOs in the HIV/AIDS field; care and service providers in both the private and public sectors; and public health policymakers and agencies at national, regional, and local levels.

Constituency: a group or people, often with similar backgrounds, ties, interests, and priorities, which is represented on a decision-making body. Representatives are often elected by the entire group, but they may also be selected through other mechanisms (by appointment, for example).

Constituent: a member of a constituency. Frequently, a constituent has a voice (by vote) in choosing his or her representative.

Sector: a sociological, economic, or political subdivision of society. The term “public sector” refers primarily to the government, as compared to the “private sector” or “nonprofit sector.”

Accountability: refers primarily to responsibility for a decision or policy. Individuals or organizations that are “accountable” are expected to address any problems or issues that arise and are generally held responsible for the successful implementation of a policy or decision.

Accessibility: refers primarily to openness and/or ease of use and understanding.

Tokenism: refers primarily to policies and practices that make only symbolic efforts, to effect change or inclusion. For instance this might include inviting PLHIV to participate in a meeting when they cannot speak the working language. This may outwardly give the impression that those organizing the meeting are making an effort to consult with PLHIV, but in reality PLHIV are invited to be ‘seen and not heard’.

Additionality: Refers to the guiding principle of the Global Fund that states that it will raise significant new and additional resources to fight the three diseases. This means the money that the Global Fund receives from donors should not be taken from existing development budgets. At the country level, if for example a country receives a grant from the Global Fund to provide ARVs, that money should be used to scale up existing programs or fund new ones, but not to replace existing government funding for ARVs that could then be reallocated by the government.



I. Background to the Handbook



Who wrote the handbook?

This handbook is the product of numerous consultations and input of over 400 people living with HIV (PLHIV) from more than 30 countries in every region of the world, with the vast majority of those involved living in developing countries and countries in transition. Each draft has been sent out for comments and feedback, and responses have been translated where necessary and incorporated wherever possible. The handbook is an example of collaboration and pooling together of HIV positive individuals' rich and diverse expertise across borders, regions, languages, and networks. Most of those who worked on this handbook began with some prior knowledge of the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and, even more important, of Global Fund Country Coordinating Mechanisms (CCMs). Many contributors, in fact, are themselves CCM members, founding members, or board members of the Global Fund. Others gained experience throughout the lengthy consultation process. Together we were able to draw on our collective expertise and from the lessons learned through our individual interactions with CCMs to shape the content of this book. A list of some of the key individuals involved can be found in Section 8.

Who is the handbook for?

This handbook was created primarily for PLHIV who are already working on HIV/AIDS issues in their country and who have some prior knowledge of the Global Fund. It is anticipated that many in the target audience will already be involved in some aspect of work that is related to the Global Fund, perhaps through membership on a CCM, as members of networks represented on a CCM, or as sub-recipients of Global Fund grants. Some may not be directly involved at present, but may have an interest in learning more about the Global Fund and in advocating for inclusion of a network or organization on the CCM in a specific country or region.

But isn't the Global Fund about three diseases—HIV, tuberculosis (TB), and malaria—not just HIV?

Yes, that is correct: the Global Fund was set up to assist people living with and affected by any of these three diseases and aims to involve representatives from all relevant groups in its processes. People living with HIV are often excluded from initiatives that affect our lives; we therefore recognize the importance of involving people with and affected by TB and malaria in the work of the Global Fund. However, we do feel it is important to highlight that while TB and malaria are curable diseases, HIV is not. For this reason, along with many others, such as the disproportionate stigma and discrimination that many PLHIV face, living with HIV is a significantly different experience from having either TB or malaria.



That said, in many parts of the world, TB and malaria profoundly affect communities that are also impacted by HIV. Many people living with HIV also develop TB and malaria, and in some countries TB is the most common illness and cause of death for PLHIV. For this reason, we need to learn much more about how to coordinate HIV prevention and treatment initiatives with those of TB and malaria.

However, this handbook will focus solely on HIV because the work that has gone into it reflects our experiences as PLHIV. We hope that some of the lessons to be learned from this handbook can also be helpful for communities affected by TB and malaria.

What is the aim of the handbook?

The aim of the handbook is to increase and improve the meaningful participation of PLHIV on CCMs across the world. This development will undoubtedly enhance the ability of the Global Fund to be an effective force in serving the communities most in need and will also contribute to facilitating PLHIV access to Global Fund resources.

There are already many useful resources available nationally (though not in every country) and internationally to assist PLHIV in developing various types of skills and knowledge; however, none is specific to PLHIV who are involved in Global Fund CCM processes. We realized during the consultations that we could fill hundreds of pages with useful and relevant information, so instead of duplicating material that already exists, we will refer to it where appropriate. To the greatest extent possible these resources have been included on the CD that accompanies this handbook.

What is different about this handbook?

This handbook focuses on specific issues, needs and problems faced by PLHIV in relation to CCMs. In addition to background information, other sections include the following:

- information about the Global Fund and the history and importance of PLHIV involvement in its processes;
- basic information on CCMs and discussion on why PLHIV should participate;
- skills, knowledge, and experience required of PLHIV involved in CCM processes;
- roles and responsibilities of PLHIV involved in CCM processes;
- communication and coordination needs of PLHIV groups and networks involved in CCM processes;
- guidelines developed by PLHIV for CCM good practice;
- additional knowledge, information, skills, and resources PLHIV might need or find useful to enhance participation in CCM processes; and
- country examples of PLHIV involvement on CCMs.

Models of good practice and universal principles

Throughout the handbook, we will be suggesting models for good practice that PLHIV from around the world have agreed on. We do not want to be prescriptive about what should and should not be done, especially since what works in one country will not necessarily work in another. PLHIV in each country will likely adapt the suggestions in this book to suit local context. In Section 8, we have provided a summary page where PLHIV groups and networks can collate responses to the questions posed in the handbook and gain an overall view of the needs and planned actions. Some may find this useful as a template to assist in the development a strategic plan for PLHIV involvement on the CCM.

There are some universal principles that are always relevant, regardless of national differences. Such principles include, for instance, the need to achieve gender balance in PLHIV representation, and the inclusion of people living with HIV (known as the GIPA Principle), in all HIV/AIDS-related activities.

What is the GIPA Principle?

The Paris Declaration, sometimes also known as the Declaration on the Greater Involvement of People living with HIV/AIDS (GIPA) was signed in Paris, France, on December 1, 1994. Governments pledged

We, the heads of government or representatives of the 42 states assembled in Paris on 1 December 1994 are resolved to step up the international cooperation through the following measures. We shall do so by providing our commitment and support to the development of the joint and co-sponsored United Nations program on HIV/AIDS, as the appropriate framework to reinforce partnerships between all involved and give guidance and world-wide leadership in the fight against HIV/AIDS. The scope of each initiative should be further defined and developed in the context of the joint and co-sponsored programme and other appropriate fora.

1. Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all—national, regional and global—levels, this initiative will, in particular stimulate the creation of supportive political, legal and social environments.

This commitment to involve PLHIV became known as the GIPA Principle. The full text of the Paris Declaration is included in the materials on the CD accompanying this handbook or can be downloaded from the UNAIDS website, www.unaids.org, in the annex of “From Principle to Practice: GIPA, 1999.”

The greater participation of PLHIV would help mitigate stigma and discrimination, since it would change the way PLHIV are traditionally viewed, offering an image that shows them as capabilities, abilities, and knowledge.

—PLHIV, Honduras



Why is it important for PLHIV to advocate for gender balance?

Women all over the world face gender inequalities in personal relationships, in the community, within the workforce and in political circles. In this context, many barriers exist to women attaining decision-making or influential positions. Ensuring gender balance in PLHIV structures and decision-making processes, and within CCM representation, can help address these problems.

Since women bear a disproportionate burden of the impact of HIV, PLHIV communities should give importance to HIV positive women's voices. In many instances, HIV positive women's opinions are rarely sought and as a consequence their specific issues are not listened to or acted upon. Often HIV positive women's issues are lumped together with men's issues and represented as the issues of PLHIV as a whole, even though huge differences may apply.

Many HIV positive women experience acutely the impact of gender inequality in their daily lives. Ensuring the involvement of women living with HIV in the design of specifically targeted interventions that aim to mitigate the impact of gender inequality is a minimum requirement for effective programming.

PLHIV can help change gender imbalance and show leadership in the CCM by requiring gender-balanced representation. This goal has been achieved, for example, by the Global Fund Board delegation for communities living with the three diseases as well as during the consultations for this handbook. An important thing to keep in mind is that women and men often have different ways of working. In many contexts, this results in women experiencing difficulties in their attempts to participate with confidence in mixed-gender groups. PLHIV groups and networks should be mindful of these cultural barriers to women's participation and explore ways of overcoming or accommodating them.

The need for HIV positive women to be on CCMs cannot be overemphasized as they constitute more than 50% of those living with HIV. They have invaluable input to contribute as they know best the challenges HIV poses. We have a lot to share with everyone and know what is good for us.

—PLHIV, Swaziland

History of handbook: Why PLHIV might need it

To understand why this handbook is needed, it is best to consider its history and evolution.

Cape Town, South Africa:

Challenges to PLHIV involvement on CCMs identified

The seeds of this handbook were sown in March 2003, when a group of more than 150 treatment activists, including many PLHIV, met for several days at the International Treatment Preparedness Summit in Cape Town, South Africa. Over the course of the meeting, it became apparent there was great interest in the Global Fund and widespread anticipation and expectation among participants that this new funding mechanism would make a massive difference in the lives of people living with and affected by HIV, TB and malaria. At the same time, however, these same people were experiencing enormous difficulties in actually becoming part

of this bold new global partnership or even accessing accurate information about it in their countries. Among the comments and observations from participants in Cape Town were the following:

- CCMs hand-picked only “government-friendly” PLHIV to become members;
- CCMs selected non-English-speaking PLHIV for the one available PLHIV seat when the meetings were conducted in English only, and translation and interpretation were not provided;
- CCMs did not allow PLHIV to become members, or if they did, only with the requirement that they would sign proposals;
- CCMs did not want to, know how to, or take the time to listen to PLHIV or seek their effective inclusion;
- CCMs were government agencies or departments in all but name—and thus were essentially government-run;
- no training at the CCM level was considered or provided for PLHIV, thus making it difficult for them to be effective advocates and representatives;
- funding had been approved, but it had yet to reach beneficiaries and those responsible (usually the CCM) had little sense of urgency; and
- programs were designed by donors and governments, not by those at the local level who have the most experience and awareness of what is needed and how services might best be provided.

A multi-country study to document the situation

At the Cape Town Summit, a call was made to document the failures of CCMs to engage in meaningful partnerships with our communities. Shortly after, the Global Fund Secretariat commissioned the Global Network of People Living with HIV/AIDS (GNP+) to oversee 13 country studies focusing on the involvement of PLHIV in the CCM process. A series of interviews were conducted with key players and stakeholders in each of the countries, including but not limited to the CCM’s chairperson, PLHIV CCM members, other CCM members and PLHIV not on the CMM. This work was done by a group of HIV positive consultants who were mainly from the countries in question, although on two occasions they were from neighboring countries.

The countries examined in this study were Bolivia, Cameroon, Chile, El Salvador, Haiti, Honduras, India, Malawi, Moldova, Nepal, Nigeria, Peru, and Ukraine. The outcome of the study may be found in the report “A Multi-Country Study of the Involvement of People Living with HIV/AIDS in the Country Coordinating Mechanisms” on the CD accompanying this manual or on the GNP+ website at www.gnpplus.net.



What the study found

The following direct quotes from PLHIV and others involved with CCMs were among those gathered by interviewers during the research process:

I stay quiet and sign what has been decided without understanding why it has been decided as discussions and decisions are not in my language.

I was told to be a CCM member. It's because one member has to be HIV+. That's why they selected me!

I feel my voice is not heard on the CCM.

I don't understand much about what is going on within the CCM as I do not speak English, so there is not much I can share with other PLHIV outside the CCM.

No equal opportunities, no equal involvement of different stakeholders, no involvement of the groups that are most affected, such as PLHIV, sex workers, MSM, IDUs, etc. The CCM needs to be reformed.

I do not know what selection process they followed. I received a letter saying you have been selected to serve on the CCM board as a PLHIV representative.

I feel pressure from others on the CCM to force me to agree with their decisions.

The country priority is not the priority of PLHIV. PLHIV representatives are very silent and their voices are not heard.

At times we feel powerless because other members are not supportive when we raise issues. One PLHIV representative on the CCM is not sufficient to represent our issues. We need more PLHIV representatives in the CCM process.

In spite of us not being involved in the CCM processes, at least we are aware that the Global Fund exists to fight HIV/AIDS, TB, and malaria.

As the above quotes show, the study demonstrated low levels of understanding about CCM functions among those interviewed. Generally, there was little understanding of the roles and responsibilities of CCM members—including those of PLHIV members. Even though all the studies took place in countries that had been awarded Global Fund grants, the majority of PLHIV, including the few who were CCM members, knew little or nothing about the Global Fund. The few PLHIV who had heard of the Global Fund believed it was the government that owned and controlled grant funds.

Improved access to technical assistance and training, including organizational support for PLHIV groups and networks, was identified as an urgent need in order for PLHIV to fully participate in the CCM process. Another area of identified need was the provision of easily accessible information, including materials that had been translated into local languages, related to the Global Fund and CCMs. Overall, the study reinforced and confirmed messages that had come out of the Cape Town meeting, illustrating that the problems raised there were not limited to one or two countries or regions, but were common to all countries where the Global Fund was operating.

Impact of this multi-country study: follow-up activities leading to the handbook and guidelines

The multiple interviews that were conducted with stakeholders during the studies prompted people—especially those living with HIV—to ask questions and demand answers. This in turn encouraged or put pressure on some CCMs and on the Global Fund Board to begin to make changes and initiate reforms. Among the follow-up activities that grew out of the studies was the development of this handbook and the *Guidelines for Improving CCMs Through Greater PLHIV Involvement* (see Section 7) as a step towards our common goal: the real and meaningful involvement of PLHIV in the response to the global HIV/AIDS epidemic through CCMs and beyond.

Another follow-up activity was a meeting organized during the 11th International Conference for People Living with HIV/AIDS in Kampala, Uganda, in October 2003. At that meeting, many of the people who conducted the country surveys came together with other PLHIV to validate the results. It was obvious from the studies that most CCMs were not working in the way that had been envisaged when the Global Fund was set up; although some were being more inclusive of PLHIV than others, all needed improvement. The majority of people attending the conference knew little about the Global Fund or its in-country processes. Participants at the Kampala meeting agreed there was clearly the need for a guide or manual to assist communities of PLHIV to participate effectively in their CCM processes.

The study also resulted in a policy paper being submitted to the Global Fund Board with recommendations for strengthening PLHIV participation on CCMs.

Country consultations to develop a resource for PLHIV

Over the months that followed, five country consultations were held to bring together people who had been involved in the studies, along with other representatives from national PLHIV networks. The aim was to seek broad input into the process of putting together a resource or handbook, which would be a first step in addressing those gaps and needs that had been so clearly identified by the studies. During the consultations, participants were asked to analyze the role and performance of PLHIV in the CCM process in their country, and based on this, to recommend key points to consider and focus on in the handbook. Consultations took place in Honduras, Malawi, Nepal, Nigeria, and Ukraine.

Further PLHIV consultations to develop the handbook

In June 2004, the Global Fund Board delegation of communities living with the diseases met to review the country reports and discuss the next steps for developing the handbook. A second workshop in July 2004 brought together 20 PLHIV in Bangkok, Thailand, to review the findings from these consultations and make more detailed recommendations. Participants included PLHIV from four of the five consultation countries, with the exception of Honduras; overall, a total of 18 countries were represented. Suggestions and decisions were made about the content and layout of the handbook and for the wording of the *Guidelines for Improving CCMs Through Greater PLHIV Involvement*.

In the months following the Bangkok meeting, a draft handbook was produced, which was sent out for consultation and field-testing among PLHIV groups and networks in Haiti, Honduras, Kenya, Malawi, Nigeria (where meetings were held in both Lagos and Abuja), and Ukraine. In addition to the group consultations, numerous individual PLHIV reviewed the draft before it was finalized—reviewers included PLHIV from Chile, Columbia, India, Nepal,



the Netherlands, the Netherlands Antilles, Peru, Uganda, the United Kingdom, and the United States. In line with the wishes of the group, the final editing and design of the handbook was done by PLHIV with professional skills in these areas.

Comments from PLHIV reviewers of the initial handbook draft

After reading the draft, I felt so empowered and ready to represent PLHIV with confidence at any level.

– PLHIV from Kenya

The country team working on the draft handbook strongly feels that it's a great resource for PLHIV.

– PLHIV from Malawi

The group in Honduras consider the handbook to be a tremendous tool for them and they are sure it will be a great tool for all PLHIV in countries where the Global Fund is working.

– PLHIV from Honduras

This draft handbook is of very great use, even outside the CCM. A lot of sensitive topics raised by the handbook were discussed freely at the meetings and a lot of recommendations were made for the Nigerian Network and the Global Network.

– PLHIV from Nigeria

Other useful resources

The following resources are among the most highly recommended and may prove particularly useful alongside this handbook. (Unfortunately, all but one are available only in English.)

- Positive Development: Setting up Self-help Groups and Advocating for Change. A Manual for People Living with HIV. Available online at www.gnpplus.net/programs.html. This publication is available in Arabic, Bahasa Indonesian, Chinese (Mandarin), English, French, Hindi, Khmer, Portuguese, Russian, Spanish, Swahili, and Vietnamese.
- The Global Fund CCM Toolkit (soon to be published). It will be available online at www.theglobalfund.org. This publication is aimed at all members of CCMs and contains a wealth of useful information.
- Getting Comfortable: Understanding the Ryan White Care Act Planning Bodies. Available online in PDF format at www.aids-alliance.org/img/gv2/nonstandard_files/aids_alliance/getting_comfortable.pdf. This was published in the United States as a guide for “consumer representatives” working on issues related to the U.S. government’s primary domestic HIV/AIDS funding program. Many of the issues and skills discussed are relevant to CCM members.
- The Aidspan Guide to Building and Running an Effective CCM (published November 2004). Available online at www.aidspan.org/guides or by sending an e-mail request to guides@aidspan.org. Aidspan is an NGO that produces various guides on the Global Fund as part of its activities (see Section 8).

- The HIV/AIDS NGO/CBO Support Toolkit was produced by the International HIV/AIDS Alliance and can be found on the Alliance website at www.aidsalliance.org/ngosupport. This publication is a valuable resource for PLHIV groups, covering many key topics such proposal development, monitoring and evaluation, and program implementation.

There are two additional key documents that are referred to in this handbook and are recommended for all interested or involved in Global Fund issues. Both are included on the CD, and are available on the Global Fund website at www.theglobalfund.org in the six official UN languages (Arabic, Chinese, English, French, Russian, and Spanish).

- The Global Fund Framework Document
- Revised guidelines on the Purpose, Structure and Composition of Country Coordinating Mechanisms (produced by the Global Fund)

About the CD that accompanies the handbook

One concern voiced when this handbook was field-tested by PLHIV networks was that too many of the documents referred to are only made available on the accompanying CD. This is problematic for PLHIV living in places where there are few or no computers.

The national PLHIV network in Kenya suggested a way to overcome this obstacle, without making the handbook so lengthy that it becomes impractical. The solution is for each country to nominate an organization to print the materials and act as the distribution point for those who require them. In countries such as Kenya, where there is a national network of PLHIV, it could be this office that takes on the task. In other countries where PLHIV groups are small or have limited resources, PLHIV could approach other organizations and request assistance printing and distributing, among them larger NGOs such as CARE, the National Red Cross or Red Crescent Society, or the International HIV/AIDS Alliance. UN agencies including UNAIDS or UNDP could also be approached. If a CCM Secretariat exists, it too could be requested to make these documents available.

Country-specific information

Some PLHIV who reviewed this handbook requested more information on the status of Global Fund grants in their individual countries. However, it is impossible to provide country-specific information in this handbook; not only does the Global Fund have grants in over 120 countries, but the status of each grant and the progress of the activities being funded changes from day to day. Up-to-date information on a country-by-country basis can be found on the Global Fund website at www.theglobalfund.org. (This option may not be appropriate for those without reliable or fast Internet access. In such cases, information may be obtained by contacting some of the people listed in the “Useful contacts” part of Section 8.)



2. About the Global Fund

The Fund will promote partnerships among all relevant players within the country and across all sectors of society. It will build on existing coordination mechanisms and promote new and innovative partnerships where none exist.

The Global Fund Framework Document

What is the Global Fund?

The Global Fund is a financing mechanism, set up in 2001, that seeks to combat AIDS, TB, and malaria by channelling large amounts of additional resources to the countries and communities most in need.

How did the Global Fund begin?

Over the past two decades, the HIV epidemic has swept across the world, killing millions and infecting millions more. Few governments have been willing or able to invest appropriate resources to confronting this global crisis, especially since the disease disproportionately affects poor nations. Kofi Annan, the Secretary General of the United Nations, was the first high-profile person to make a public call for a "war chest" or global fund to be organized to fight AIDS. His voice was soon joined by many others, including PLHIV, who were keen to see a new and innovative approach to tackling AIDS (and subsequently tuberculosis and malaria, two other deadly diseases wreaking havoc worldwide).

Below is a brief history of the Global Fund from 2000, when it was no more than an idea in a few people's minds, to midway through 2004, by which time it had pledged over US\$3 billion in grants to 128 countries. There are plenty of sources for additional information on the Fund's history, including the Global Fund website at www.theglobalfund.org, so we will not go into great detail here. The timeline below should, however, give an idea of how rapidly the Global Fund came into existence and how fast it has begun to make a difference in people's lives.

In this context, it is important to remember and acknowledge the tremendous work and activism of PLHIV and their allies since 1984. For years, PLHIV and others have advocated tirelessly for additional resources to be channelled into combating the global HIV pandemic. Without the efforts of these colleagues and friends, many of whom are now dead, this greatly enhanced level of resources to fight HIV, TB, and malaria that the Global Fund represents would never have become available.

2000

- July** In his closing speech at the 13th International AIDS Conference in Durban, South Africa, former South African President Nelson Mandela calls for “total inclusiveness in the struggle against AIDS.” He goes on to say, “Let us not, however, underestimate the resources required to conduct this battle. Partnership with the international community is vital.”
- The G8 (see box) endorses new AIDS, TB, and malaria targets at a summit in Okinawa, Japan. Ministers agree that existing bilateral and multilateral efforts are not sufficient to channel the additional resources needed to scale up the response to these epidemics. They make a commitment to support innovative partnerships, including those comprising NGOs, the private sector, and multilateral organizations, to fight the three diseases.

What is the G8?

The Group of 8 (G8) consists of eight of the world’s wealthiest or most influential nations, including Canada, France, Germany, Italy, Japan, Russia, the United Kingdom, and the United States. G8 heads of state meet annually to discuss major economic and political issues facing their domestic societies and the international community as a whole. Other government officials, including finance and foreign ministers, meet separately during the year.

2001

- April** At the African Summit in Abuja, Nigeria, UN Secretary General Kofi Annan makes a public call for a “war chest” or global fund to be set up to fight AIDS. African leaders support this idea, and the vision is expanded to include other diseases of poverty, such as TB and malaria.
- June** Participants in the United Nations Special Session on AIDS (UNGASS) in New York endorse the need for a global fund. The Declaration of Commitment, which calls for the establishment of a global health fund, is agreed. It is drafted with the input of many PLHIV and nongovernmental representatives after much successful lobbying and advocacy on their part.
- July** At the G8 meeting in Genoa, Italy, members voice unanimous support for the new (as yet non-existent) fund and make over US\$1.5 billion in pledges.
- August** A Transitional Working Group (TWG)—which includes Joseph Scheich, International Coordinator of GNP+ among its members—is formed to begin drawing up the policies and principles (the Framework Document) on which the Global Fund will base its work. A technical support Secretariat is set up in Brussels, Belgium.
- September** Consultations on the formation of the new fund take place among December stakeholders in all regions.

2002

- January The Global Fund is formally created at its first board meeting in Geneva and registered in Switzerland.
- April At the second board meeting, the first round of proposals totalling US\$600 million over two years to programs in 36 countries is approved.
- August Charles Roy, alternate board member for the delegation of communities living with the diseases, dies on August 24.
- December Initial disbursements of grants commence.

2003

- January Joseph Scheich, ex-TWG member and board member for the delegation of communities living with the diseases, dies on January 15.
- At the fourth board meeting, the second round of proposals, totalling US\$900 million over two years to 72 countries, is approved.
- March Representatives from PLHIV and civil society organizations meet in Paris to discuss the future of the Global Fund. Sharing concerns that wealthy countries are not contributing enough to the Global Fund, they agree to work together to promote more adequate funding, and the “Fund the Fund” advocacy initiative is born.
- May “It Starts with Us,” a fundraising campaign initiated by PLHIV, is launched publicly to highlight the fact that the Global Fund is in dire need of additional funds. Along with “Fund the Fund,” it is one of many examples highlighting how PLHIV and other civil society groups have taken a lead in the response to the HIV/AIDS crisis.
- Brigitte Symalvwe, member of the communities living with the diseases board delegation, dies of cerebral malaria and HIV.
- June Additional pledges are made by the G8 during a summit in Evian, France.
- October At the Global Fund’s sixth board meeting in Chiang Mai, Thailand, Round 3 proposals are approved, totalling US\$623 million over two years.

2004

- June At the eighth board meeting, Round 4 proposals are approved, totalling US\$968 million over two years to 69 countries.
- June The communities living with the diseases delegation receives a vote on the Global Fund Board (previously it had been one of several non-voting members, along with WHO, UNAIDS, and the World Bank). This is a historic and emotional moment in the history of the Global Fund, and it is hoped that this victory for PLHIV representation will be replicated elsewhere, including on CCMs.
- July The first Global Fund Partnership Forum is held in Bangkok, Thailand, with 400 participants, including many PLHIV. The issue of PLHIV participation on CCMs and the need for more stringent requirements to ensure this participation is hotly debated.

November At the ninth board meeting in Arusha, Tanzania, only days before this handbook goes to press, the board approves several CCM requirements. Among the requirements, all CCMs must show evidence of membership of people living with and/or affected by the diseases. CCM members representing the nongovernmental sector must now be selected by their own sector, based on a documented, transparent process. CCMs are also required to put in place and maintain a transparent, documented process to ensure the input of a broad range of stakeholders, including CCM members and non-members, in proposal development and grant oversight processes.

This decision marks a victory for many PLHIV and their advocates, who have worked long and hard to make this happen.

Guiding principles of the Global Fund

The purpose of the Global Fund is to attract, manage and disburse additional resources through a new public-private partnership that will make a sustainable and significant contribution to the reduction of infections, illness and death, thereby mitigating the impact caused by HIV/AIDS, tuberculosis and malaria in countries in need, and contributing to poverty reduction as part of the Millennium Development Goals.

– Framework Document

The work of the Global Fund is guided by a set of principles, which can be found in the Framework Document. Among its principles, the Global Fund

- operates as a financial instrument, not an implementing entity;
- raises significant new and additional resources to fight the three diseases;
- supports programs that evolve from national plans and priorities;
- focuses on creation, development, and expansion of government/private/NGO partnerships;
- strengthens participation of people infected and directly affected by the three diseases in the development of proposals;
- aims to eliminate stigmatization of and discrimination against those infected and affected by HIV/AIDS, especially for women, children, and vulnerable groups;
- has an integrated and balanced approach to prevention, treatment, care, and support;
- evaluates proposals through an independent review process;
- operates transparently and accountably; and
- promotes country ownership and self determination.

What is different about the Global Fund from a PLHIV perspective?

From a PLHIV perspective, what is particularly inspiring about the establishment of the Global Fund is its commitment to promoting the UNGASS goals by creating the potential for real and meaningful involvement of PLHIV in its processes. The Global

Fund's vision, laid out in what is known as the Framework Document (see the CD that accompanies this handbook), builds on the UNGASS Declaration (see www.unaids.org) in an attempt to transform some of these goals into reality.

The Global Fund operates in a way that allows PLHIV to be far more than passive beneficiaries of its grants. Instead, PLHIV, along with other key stakeholders in the global battle against the three diseases, have the opportunity to play active parts in the Global Fund's governance structures and in-country processes. This is achieved by bringing PLHIV into broad partnerships involving representatives drawn from all sectors, including those who represent vulnerable or hard-to-reach populations.

For those of us who are men who have sex with men (MSM) or working with MSM in sub-Saharan Africa, it is important that CCMs take special note of the recommendation that membership should be drawn from all sectors. This should include MSM groups. Even though there is denial of our existence, we still exist.

– Alliance Rights Nigeria

What is the UNGASS Declaration?

The UNGASS Declaration of 2001 is the product of lengthy negotiations during the United Nations General Assembly Special Session on AIDS (UNGASS), which took place in New York in 2001.

What does the UNGASS Declaration say?

The declaration is far-reaching and covers many areas of concern to those involved in the response to HIV/AIDS (see the accompanying CD). In one section of particular relevance to PLHIV, governments committed to:

Foster stronger collaboration and the development of innovative partnerships, between public and private sectors, and by 2003 establish and strengthen mechanisms that involve the private sector and civil society partners and people living with HIV/AIDS and vulnerable groups in the fight against HIV/AIDS.

Elsewhere, the declaration states:

By 2003 ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS...that involve partnerships with civil society and the business sector and the full participation of people living with HIV/AIDS...

The UNGASS declaration contains a set of targets that governments have agreed to and should be accountable to. It is the most powerful international statement that supports and encourages the involvement of PLHIV, providing an international advocacy template for PLHIV and communities. As we look in more detail at how the Global Fund works, we will see how these UNGASS goals are being addressed through the fund's mechanisms. One of the core indicators that PLHIV can use for monitoring and evaluating the Global Fund in countries is to see how its activities are consistent with the UNGASS goals.

History of PLHIV involvement in the Global Fund

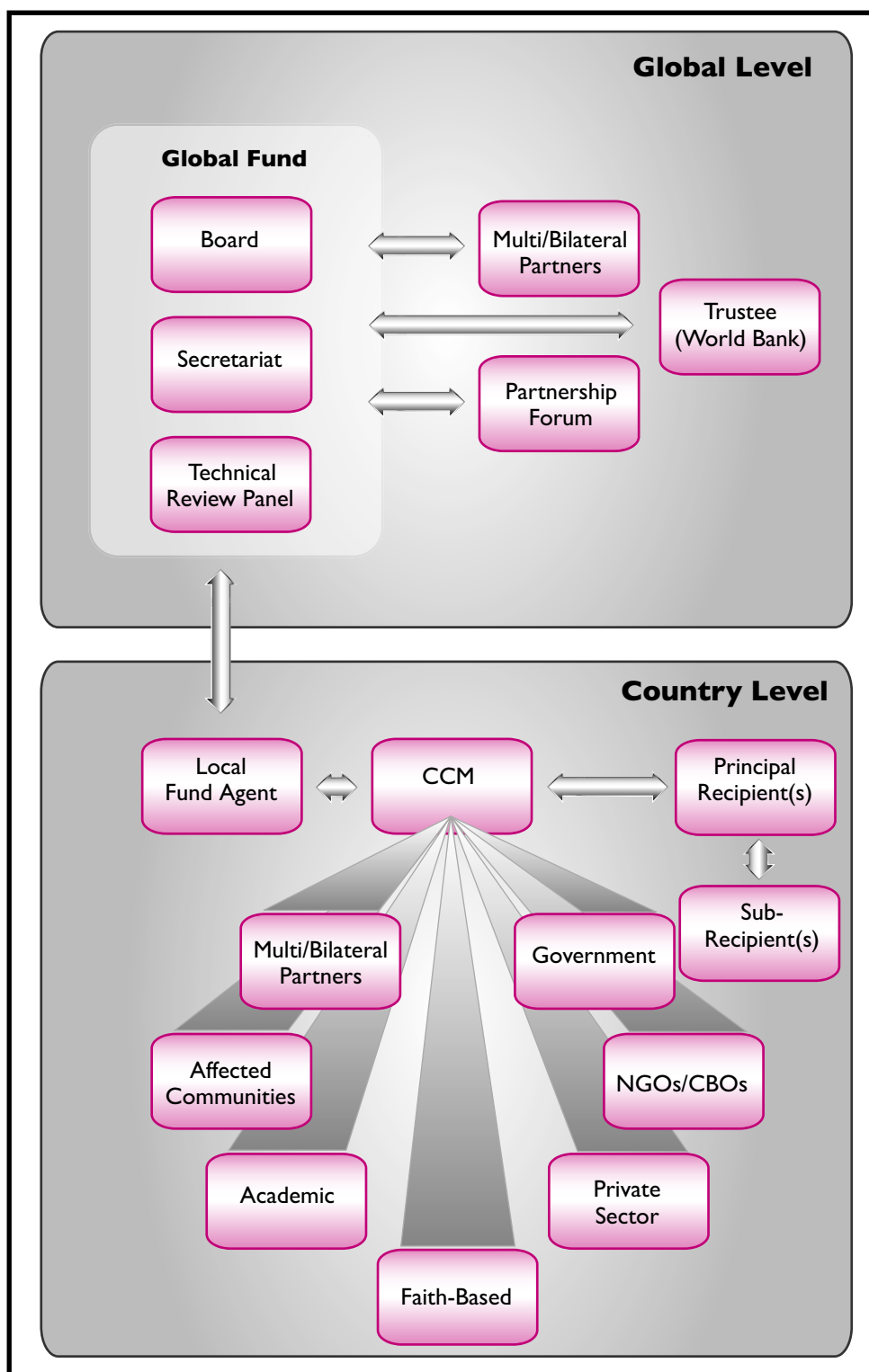
PLHIV have played a crucial role in the Global Fund since its inception, and their input has been of immense influence in helping shape how the Global Fund operates today. One of the ways PLHIV have been able to maximize their influence at the global level is through participation on the Global Fund Board. The board is made up of 23 members, each with a delegation of up to 10 people. The delegation of communities living with the diseases (or "Communities delegation," as it is sometimes referred to) is one of the most focused and active of the delegations—for obvious reasons, since the Global Fund is about our lives. The Communities delegation includes PLHIV representatives from all regions, although the working language of the delegation is English. Delegation members are selected because of their knowledge, experience and credibility in their communities. They play a vital role in supporting, assisting and advising the board member in his or her work. In 2004 the Communities delegation was successful in advocating for and achieving voting rights at the board. Another essential role for PLHIV is at the country level, through the CCMs. In general, PLHIV have been less successful in achieving influence in this arena—hence, the need for this handbook.

Being aware of the history of how the Global Fund came into being and becoming familiar with the wording of the Framework Document and the UNGASS Declaration is a useful strategy for being prepared to argue for greater involvement of PLHIV on CCMs. One basic strategy to use against those who resist PLHIV representation on CCMs is to refer directly to relevant parts of the Framework Document spelling out this obligation.



Global Fund structure and PLHIV participation

The activities of the Global Fund are far-reaching and span every country in some form or another. The organogram below attempts to describe the various different entities involved in Global Fund processes and to illustrate how they all play a part in its work.



Where do PLHIV fit into this picture?

Although for the purposes of the handbook we are focusing on CCMs, there are multiple other possibilities for PLHIV to be involved in the work of the Global Fund at different stages of the process. Some of the ways to participate include the following:

- At the board level, either as a board member or delegation member. PLHIV can be board or delegation members for any delegation—not only for the delegation of communities living with the diseases. For instance, at recent board meetings, the Western Pacific Region delegation headed by China included a PLHIV member. Both the Southern NGO delegation and the Northern NGO delegation also had PLHIV members.
- At the board committee level. The board committees are where much of the detailed discussion happens before the committee recommendations go to the board. The current Resource Mobilization and Communications Committee is chaired by a PLHIV, and PLHIV sit on all but one of the board Committees
- On the Technical Review Panel (see next section on CCMs)
- On the Technical Evaluation Reference Group (TERG; a small group that meets in Geneva to focus on these issues and that has PLHIV representation)
- On a CCM
- As a member of a network that nominates and works alongside the PLHIV CCM member
- As a staff member or volunteer in a CCM Secretariat
- As a staff member or volunteer in the Global Fund Secretariat
- As a staff member or volunteer with one of the Global Fund's development partners
- As a staff member of an Local Fund Agent (LFA; see Section 3 for information about LFAs)
- As a staff member or volunteer of a Principal Recipient (PR; see Section 3 for information about PRs)
- As a staff member, volunteer or service user of a sub-recipient (SR; see Section 3 for information about SRs)
- As a beneficiary of Global Fund-supported programs or services
- As a participant in the Global Fund's Partnership Forum (see box below)
- By being in contact with members of a regional delegation, the Southern NGO delegation and the Communities delegation, and providing input and feedback when necessary

What is the Partnership Forum?

The Global Fund Partnership Forum is an event that takes place every two years. It brings together stakeholders, many of whom do not usually play a part in the Global Fund's governance processes, and allows participants the opportunity for reflection on all aspects of the Global Fund's operations, seeking input and recommendations for the board about how the Global Fund could improve.

The first-ever Partnership Forum took place in Bangkok in 2004. Four hundred participants from around the world, including a large percentage of PLHIV, met for two days to review and discuss the work of the Global Fund and to make recommendations on how that work could be improved.

In addition to the main Partnership Forum event, six regional meetings took place in advance of the Bangkok gatherings. At these meetings, the themes of the Partnership Forum were discussed and recommendations to be shared in Bangkok were drafted by participants. An independent English language online discussion forum, “Partners GF,” with a membership of approximately 750 people, was moderated by Health and Development Networks (HDN), which had also run a similar discussion forum called Break-the-Silence when the Global Fund was first being set up. The online discussion focused on the main issues of interest and debate that would be covered at the actual event—among them the composition and functioning of CCMs.

Although the main Partnership Forum event will be convened only every two years, the Partnership Forum itself was conceived as an ongoing process. Therefore, opportunities exist for input between the biannual meetings, for instance through the Global Fund regional meetings that take place every year and through meetings attached to other events, such as international conferences. The Partnership Forum is a key structure of the Global Fund for PLHIV to become involved in and by which to make their voices heard.

The report from the First Global Fund Partnership Forum is available on the CD accompanying the handbook and on Global Fund website at www.theglobalfund.org/en/about/forum/report/

The Global Fund is unique: PLHIV must grasp the opportunity it offers

What is truly unique about the Global Fund is the potential it offers for PLHIV to have a say in its affairs. If PLHIV are able to take full advantage of this opportunity, the Global Fund will prove to be an incredible tool for increasing control over our own lives and allowing others in our communities to improve theirs as well. To fully take advantage, we must be involved consistently and be as vocal as possible, demanding to be heard when necessary. In addition, we must be proactive in seeking out those opportunities for involvement that have not yet arisen. For the majority of this handbook, we will focus on one aspect of this potential for involvement: PLHIV involvement through the CCMs and in-country processes.

3. CCM Basics



The Fund will work with a country coordination and partnership mechanism that should include broad representation from governments, NGOs, civil society, multilateral and bilateral agencies and the private sector

–The Global Fund Framework document

A brief note of Section 3

All this information is quite technical. Reading it through with others helped to answer our questions, but this would be challenging if one had to read and understand it all by oneself.

– PLHIV, Nigeria

People unfamiliar with the Global Fund may find Section 3 to be complicated and technical. However, although the systems and processes used by the Global Fund seem daunting to everyone at first, they can often be explained clearly and concisely by someone with experience and familiarity with the Global Fund.

The language the Global Fund uses is often full of jargon and abbreviations. We have tried to provide the terms and language used to help PLHIV become comfortable with them and use them when needed. Yet, it is important to continue to remember that beyond the technical aspects and jargon, it is clear PLHIV have a very important role that others cannot fill: we provide the face and the reality behind the impersonal technical terms. If we use our power, value, knowledge, and experience effectively, we can truly make an impact on the CCMs and a difference in the lives of people living with HIV/AIDS.

PLHIV are an essential element of the Global Fund because they are spokespeople for the multiple needs that affect them.

– PLHIV, Honduras

*The Global Fund is about **not** doing business as usual. This philosophy is crucial to the concept of the fund and informed the manner by which it was set up. We must be careful not lose sight of this. We must remember that the Global Fund is not the World Bank or a bilateral fund.*

– PLHIV, United States

What is a CCM?

The concept of the Country Coordinating Mechanism (CCM) lies at the very heart of the Global Fund vision. A properly functioning CCM is a true manifestation of multi-stakeholder country ownership, of public-private partnership and of the GIPA Principle in action. A CCM is a group of individuals representing a wide range of different sectors within a country who come together to assess the country's needs vis-à-vis AIDS, TB, and malaria or any combination of these three diseases. This group is expected to not only build on existing coordination mechanisms and partnerships within a country, but also to expand these to include new partners such as PLHIV. A CCM should also ensure representation from outside the capital city, including rural and urban areas. PLHIV who worked on this handbook believed that CCMs should also demonstrate gender balance in their membership.

Once a country's needs have been assessed, taking into account what is already happening on the ground, what projects and interventions are planned, and what gaps exist, it is the responsibility of the CCM to prepare a Country Coordinated Proposal (CCP) and submit this to the Global Fund following a call for proposals. Calls for proposals are issued on average once or twice a year, and CCMs have approximately four months from the first announcement to submit a CCP to the Global Fund Secretariat in Geneva, Switzerland. During this time, the CCM is likely to be extremely busy engaging in the necessary consultation and analysis to develop the CCP. To create a balanced CCP, it is essential to draw on the knowledge and expertise of all sectors and groups with an interest in the country's response to the diseases—including PLHIV.

The top 10 problems faced by CCMs

In many countries, CCMs have proved disappointing so far from the perspective of PLHIV and other key stakeholders. Concerns have been raised about issues ranging from composition, communications strategy, and interaction between civil society and government. Some of the major complaints about CCMs in various countries are listed below (note that each concern does not necessarily apply to all CCMs that have been criticized).

1. The CCM's role and operating methods are not clearly defined, nor are they clearly understood by CCM members and outsiders.
2. The CCM is dominated by government members. Civil society and people living with the diseases are under-represented and have little influence.
3. CCM members who are supposed to represent NGOs were not chosen by the NGO sector and do not properly represent them.
4. CCM members were not involved in choosing the CCM chairperson or in selecting the Principal Recipient.
5. The CCM chairperson also serves as Principal Recipient, a situation that represents a conflict of interest.
6. There is no genuine involvement by all CCM members in the CCM decision-making process. Decisions are made in advance by the CCM chairperson and a few others allied with him or her.

7. CCM members are asked to sign a proposal to the Global Fund even though they had no input in its preparation and little prior knowledge of its content.
8. The CCM does not have access to sufficient money, practical resources, or expertise to operate effectively.
9. The CCM chairperson and other influential members do not share information within and outside the CCM.
10. CCM members are unable or unwilling to determine whether projects funded through the Global Fund grant are being implemented effectively.

Source: Aidspace

Who should be part of a CCM?

According to the Global Fund, a CCM should include representatives from the following sectors:

- PLHIV networks and associations;
- domestic nongovernmental organizations (NGOs) and community-based organizations (CBOs);
- international NGOs (INGOs);
- faith-based organizations (FBOs);
- academic institutions, such as research institutes and universities;
- the private sector, including business coalitions on AIDS;
- government departments such as the ministries of Health and Finance;
- multilateral organizations such as UNAIDS, United Nations Development Program (UNDP), WHO, and the World Bank; and
- bilateral development organizations such as AusAID (Australia), CIDA (Canada), DFID (United Kingdom), GTZ (Germany), HIVOS (the Netherlands), SIDA (Sweden) and USAID (United States).

Although not specifically mentioned by the Global Fund, there are plenty of other groups whose contribution could be valuable in a CCM. Such groups might include women's and young people's organizations or those representing vulnerable populations such as injection drug users (IDUs), men who have sex with men (MSM), sex workers, migrants, and or/refugees and displaced persons.

Currently, PLWHA representatives in the JICC (CCM) in Kenya are grouped as NGOs and do not represent the PLHIV constituency; this makes their representation rather tokenistic. The recently constituted Network of People living with HIV/AIDS in Kenya (NEPHAK) will develop criteria to identify PLHIV to formally represent the constituency in the JICC.

— PLHIV, Kenya

Why it is important for a CCM to include PLHIV stakeholders

We are the “experts” when it comes to living with HIV. We need to be consulted when it comes to designing interventions for HIV/AIDS.

– PLHIV Network, Kenya

In making funding decisions, the Fund will support proposals that...strengthen the participation of communities and people, particularly those infected and directly affected by the three diseases, in the development of proposals.

– Global Fund Framework Document

3

The result of a properly functioning and inclusive CCM is likely to be a well-balanced CCP that has been prepared with the genuine engagement of all relevant stakeholders within a country, including groups and networks of PLHIV. With this input across sectors, the CCP will have more chance of success. It is also more likely that PLHIV organizations and other key groups will be identified as implementers as well as beneficiaries of Global Fund grants, and that the money will actually reach the populations most in need. A truly inclusive and participatory CCM promotes and demonstrates genuine “country ownership” in action rather than “government ownership.”

No PLHIV members on the CCM? The time for excuses is over!

Nothing for us without us. We want to participate in the design and implementation of the country proposals.

– PLHIV, Kenya

When the Global Fund was created, CCMs were set up in haste, usually by governments, in a rush to submit proposals for the first round of Global Fund grants. As a result of the need for speed, the need for inclusiveness was often overlooked, resulting in the existence of many CCMs that did not include PLHIV. Unfortunately, this situation has not improved: an analysis of CCM representation in Round 4 found that the overall percentage of PLHIV on CCMs had actually decreased compared to the previous round.

Over time, there are fewer and fewer acceptable excuses that can reasonably be made by CCMs for not including PLHIV in their membership. Regardless of the country and its specific circumstances, PLHIV should be on the CCM—and as we will discuss later, inclusion alone is not enough. We need to look beyond inclusion to what it actually means to participate in a meaningful way.

Reform in action: The Bolivian example

The Fund will support programs that stimulate and are integral to country partnerships involving government and civil society.

– Global Fund Framework Document

While preparing proposals for Rounds 1 and 2 of Global Fund grants, the Bolivian government decided who could join the CCM, and PLHIV were excluded. Proposals were written in almost total secrecy and were rejected both times. Before Round 3 was launched, PLHIV groups decided to challenge this situation. They did so in several ways, including the following:

- They developed their capacity and learned skills with the assistance of REDLA (the Latin American regional network for PLHIV) and ICASO (the International Council of AIDS Service Organizations).
- They sent letters denouncing the fact that PLHIV were not involved in the CCM to national and international networks and to the Global Fund. These letters were intended to embarrass the CCM and proved extremely effective.
- PLHIV leaders communicated their demands through the media.
- PLHIV lobbied international organizations such as UNAIDS.

The Bolivian PLHIV strategy was successful: four of the 30 or so CCM members are now PLHIV. The PLHIV members are elected by the PLHIV network, not appointed by the government, and PLHIV also are represented on the CCM Executive Committee and subcommittees. And perhaps most important, Bolivia's application for Round 3 was accepted.

As a last resort, use whatever means necessary!

– PLHIV, Ukraine and Belarus

PLHIV involved in creating this handbook felt strongly that if, despite repeated efforts, a CCM remains unresponsive to requests to include PLHIV members, community members should use whatever means necessary to achieve this goal. The example from Bolivia is a good illustration of moving beyond the stage of simply asking to be included, toward targeted advocacy and action.

CCM responsibilities

The responsibilities of CCMs go beyond writing a CCP to involvement throughout all stages of the Global Fund grant cycle. For this reason it is important to understand the stages of the cycle after the CCP is submitted.

What is the Technical Review Panel (TRP)?

Once a proposal has been submitted to the Global Fund Secretariat, it is screened to ensure it meets basic criteria for proposal acceptance. It then goes to the Technical Review Panel (TRP). The TRP is a group of 26 international experts, including one PLHIV, whose collective technical knowledge and experience spans every aspect of AIDS, TB, and malaria. The TRP is independent of both the Global Fund Secretariat and the Global Fund Board. It meets for two weeks, soon after the closing date for each funding round. During this time, the TRP reviews each proposal based solely on technical and scientific merit, and then makes recommendations to the Global Fund Board on which of the proposals should be approved for funding. Proposals are subsequently placed in one of the four following categories:

- Category 1: The proposal is funded
- Category 2: The proposal is funded if certain adjustments and clarifications are provided
- Category 3: The CCM is encouraged to resubmit in the next round
- Category 4: The proposal is rejected

The role of the Principal Recipient (PR)

After a proposal is approved by the Global Fund Board, the CCM is responsible for identifying and confirming one or more organizations to act as Principal Recipient (PR). The PR receives the money that the country is granted from the Global Fund. A PR may come from the governmental or nongovernmental sector. Often, governmental-sector PRs are ministries of health; an example of a nongovernmental PR might be a large national NGO. In most countries, there is more than one PR, with some countries having one or more governmental PRs and one or more nongovernmental PRs.

It is the PR, not the CCM, which enters into a legally binding grant agreement with the Global Fund Secretariat. Before the agreement is signed, the PR is expected to prove to the Local Fund Agent (LFA; see below) that it has the capacity to carry out all the tasks involved in managing the resources and supervising program implementation. The PR will identify and appoint multiple sub-recipients (SRs) to carry out different aspects of implementation.

Changing the PR in Ukraine: PLHIV speak out!

In Ukraine, there were serious problems and lack of coordination with the three Principal Recipients that initially had been selected to handle the Global Fund grant money. PLHIV groups, along with other NGOs, succeeded in provoking an unscheduled visit from the Global Fund Secretariat. During this visit, Secretariat staff met extensively with PLHIV, sub-recipients, and service users from the programs and was informed of various problems related to the grant's implementation. As a result, the Global Fund made a decision to halt the distribution of funds to Ukraine, and a temporary PR was identified for a period of 11 months to handle the Global Fund grant.

This example illustrates how PLHIV should not be afraid to take action to remove obstacles to reaching their goals, which in the Ukraine were ensuring that ARVs [antiretroviral therapies] reached our PLHIV communities. We believe PLHIV should not be afraid to contact the Global Fund Secretariat with legitimate complaints and concerns and to keep doing so until action is taken. Finally, it is essential that PLHIV communities are able to be vocal and articulate the difficulties that are being experienced with Global Fund programs at the country level.

– PLHIV, Ukraine

What is a sub-recipient (SR)?

The PR provides funds to multiple sub-recipients (SRs), which are selected to implement parts of the grant. Over the first two years of the grant, the CCM maintains responsibility for overseeing and monitoring implementation of the funded programs and is expected to request and receive regular progress reports from the PR(s). Four months before the end of the initial two-year funding period, assuming a program has been successful, the CCM generally makes a request to the Global Fund Secretariat for an additional three years of funding.

SRs often do not have the capacity to take on the responsibility of a PR, but are usually more involved in grassroots, community-level work. Organizations of PLHIV are sometimes selected as SRs, although this is a rare occurrence that will hopefully become more common. SRs report directly to the PR or to one of the PRs if there is more than one in a country. Different methods are used to select SRs in different countries.

Choosing nongovernmental sub-recipients: The Zambian model

Zambia has four PRs: the Ministry of Health, the Ministry of Finance, the Churches Association of Zambia, and the Zambian National AIDS Network (ZHAN). The role of ZHAN is to identify SRs from among NGOs, CBOs, PLHIV organizations, and the private sector. ZHAN did this by issuing a call for proposals, publicized through the media (newspapers, television, radio and the Internet). It then evaluated the proposals received to determine which organizations should be selected as SRs for the Global Fund grant.

Guidelines for selection of sub-recipients

We need specific guidelines to help PLHIV be part of the selection process for sub-recipients.

– PLHIV network, Nigeria

The issues of how to ensure that sub-recipients are selected in a fair manner and that PLHIV groups and organizations are included both in the selection process and as recipients were raised by PLHIV during the handbook review process. CCMs need to make a commitment to set up fair and transparent processes for

this to happen; a suggestion was made that the Global Fund Secretariat produce recommendations on how CCMs can develop high-quality grant guidelines for sub-recipients, including PLHIV organizations and networks. Fund Portfolio Managers and LFAs should insist that rigorous guidelines be in place to govern the selection of sub-recipients prior to the signing of grant agreements.

What is the Local Fund Agent (LFA)?

Once a country has a grant approved, a Local Fund Agent (LFA) will need to be identified. Since the Global Fund does not have country offices, the Global Fund contracts with a nationally based LFA to assess the financial and administrative capacity of the Principal Recipient(s) to manage the grant and supervise program implementation. LFAs also verify the PRs' disbursement requests, progress updates, and annual audit reports. The CCM does not choose the LFA; instead, the LFA is selected by the Global Fund Secretariat through a tender process.

3

Finding out more about the Global Fund grant cycle process

There are many documents that give detailed explanations of the various stages of a Global Fund grant cycle, of the roles of the various actors involved, and of their relationships with each other. A good place to start is the Global Fund website at www.theglobalfund.org. A soon-to-be-published toolkit for CCMs, which the Global Fund is producing, and The Aidspace Guide to Building and Running an Effective CCM also explain in great depth the role of the CCM at all stages of the grant cycle. An additional useful resource is a publication from the Global Fund Secretariat, Guidelines on the Purpose, Structure and Composition of Country Coordinating Mechanisms, which can be found on the Global Fund website and on the accompanying CD.

Additional assistance may possibly be obtained by contacting CCM members themselves or Fund Portfolio managers: the names and contact details for nearly all CCM members and managers are available on the Global Fund website. Alternatively, it may be useful to be in touch with a member of the Global Fund Board delegation for communities living with the diseases. Contact details for these individuals may be found in Section 8 of this handbook.

Corruption, coercion, manipulation, and conflict of interest

Issues that arose many times during the country consultations for this handbook were corruption, coercion, and manipulation. PLHIV reported these problems in relation to Global Fund money and other resources at all levels and in all sectors. Examples ranged from high-level government corruption to coercion and manipulation in NGOs and in PLHIV groups and networks. Many questions were asked about how to deal with these issues, but there is not enough space in this handbook to cover the topic with the detail it merits. If there were easy answers to these questions, then the unfortunate realities of corruption, coercion, and manipulation would probably not exist in our societies. Sadly, this is not the case.

A related issue that arose, especially in relation to CCMs, concerns conflict of interest. Some CCMs have been accused of allowing potential conflicts of interest such as when the CCM chairperson is a government official, the PR is a

government ministry, or the sub-recipients are government-friendly NGOs. In some countries, NGO members of the CCM are also the PRs and sub-recipients, which can provoke accusations of conflict of interest if the process of selection for PR and sub-recipients is not clearly articulated, transparent, and open to all.

Many CCMs are developing policies to ensure conflicts of interest do not occur within the CCM. Meanwhile, the Global Fund Board is considering making certain requirements of CCMs that will limit the potential for conflict of interest—for instance, insisting that the CCM chairperson should not be employed by the PR. In November 2004, the Global Fund Board agreed to revise the CCM Guidelines: according to a new provision, when the PR and chairperson or vice chairperson of the CCM are the same entity, the CCM must have a written plan in place to mitigate against possible abuses of power stemming from this inherent conflict of interest.

Each Global Fund agreement contains a section that specifically discusses corruption and conflicts of interest. CCM members and constituencies can use this information to hold others accountable.

In Chile we have not confronted corruption, but Vivo Positivo (the national PLHIV network) and PAHO (the Pan American Health Organization) are currently creating a code of ethics for CCM members. This will consist of principles that can guide CCM operating procedures to avoid conflict of interests. An external ethics committee is being created, which will be able to act upon request of any CCM member. All of this will be submitted to the CCM for approval in the near future.

— PLHIV, Chile



Working with the Global Fund and other donors, you may find reference to the “Three Ones.” What are they?

The Three Ones are principles for the coordination of national AIDS responses. They comprise the following:

- **One** agreed HIV/AIDS Action Framework that provides the basis for coordinating the work of all partners;
- **One** National AIDS Coordinating Authority, with a broad-based multisectoral mandate; and
- **One** agreed country-level Monitoring and Evaluation System

On April 25, 2004, UNAIDS, the United Kingdom, and the United States co-hosted a high-level meeting at which key donors reaffirmed their commitment to strengthening national AIDS responses led by the affected countries themselves. They endorsed the “Three Ones” principles to achieve the most effective and efficient use of resources and to ensure rapid action and results-based management.

There has been a marked shift in the global response to the complex AIDS crisis, which continues to worsen. National responses are broader and stronger and have improved access to financial resources and commodities. In addition to the increased commitments by affected countries themselves, the advent of the Global Fund to Fight AIDS, Tuberculosis and Malaria, the new AIDS programs of the World Bank, expanding commitments from donor countries (especially the United States), and the work of private sector foundations has contributed to a rise in the amount of funding on AIDS from US\$2.8 billion in 2002 to an estimated US\$4.7 billion in 2003.

While more resources are needed, there is an urgent need for greater support and collaboration with heavily affected countries and to avoid duplication and fragmentation of resources. It is this challenge that the “Three Ones” are specifically designed to address. Built on lessons learned over two decades, the “Three Ones” will help improve the ability of donors and developing countries to work more effectively together, on a country-by-country basis.

Source: UNAIDS

You can find more about the Three Ones on the UNAIDS website at www.unaids.org.

4. Being HIV Positive Is not a Profession



Acquiring the skills, knowledge, and experience to be an effective CCM member

A lack of understanding of technical and political issues is an obstacle to effective participation.

– PLHIV, Honduras

Having a potentially deadly virus does not by itself qualify us to do our work and represent others successfully. Beyond their HIV status, those representing PLHIV on CCMs need skills, knowledge and experience to do their jobs effectively. What kind of people are we looking for to represent us? What background, experience, skills, and personal qualities will they need?

1. Organizational affiliation

Our representatives should be active members of one or more of the following groups:

- an association of PLHIV
- a nongovernmental organization of PLHIV
- a network of PLHIV

2. Personal qualities

PLHIV who are members of CCMs should be:

- living with HIV and open about their status;
- ready to work in the interest of the PLHIV constituencies and related constituencies such as young people, women, MSM, IDU, sex workers, migrants, and refugees;
- perceived as credible and honest, and have the trust and confidence of their community;
- willing to confront their own prejudices and able to demonstrate a lack of bias toward women, MSM, IDUs, sex workers, foreigners, and other vulnerable groups;
- motivated to defend the rights of all PLHIV, irrespective of who they are (e.g., economic status, education, religion, and culture);
- open to working with other groups and sectors such as government, academics, the private sector, etc.;
- capable of standing up for other PLHIV beliefs and priorities in the face of fierce criticism and opposition from others;
- able to work within a team and be flexible, tolerant, and accepting of criticism;

- willing to listen to others and to empathize and see things from other peoples' perspectives, however different or challenging they may seem;
- ready to be a leader and not a "victim"; and
- willing and able to support fully the principle of gender equality.

3. Time commitment

PLHIV representatives should be:

- able to devote the necessary time required to effectively represent PLHIV on the CCM (an absolute minimum of one day to review papers in advance of each CCM meeting, one day to consult with the PLHIV constituency before the meeting, one day for the CCM meeting, and one day after each CCM meeting to provide feedback to the constituency);
- able to devote adequate time to familiarize themselves with existing donors, funders, and services in the country, so that the Country Coordinated Proposal (CCP) can adequately address the gaps in services and not duplicate existing efforts; and
- willing to devote time to learning new skills and information.

4. Education and experience

To be effective on the CCM, it is recommended that PLHIV representatives have:

- a minimum of two years relevant work experience in the HIV/AIDS field;
- in-depth understanding of a broad range of HIV and related social issues;
- confidence to speak up in meetings;
- experience in negotiation;
- ability to think creatively;
- sufficient education to be able to take part effectively in planning, monitoring, and evaluating programs—with minimal training if required;
- ability to report back to PLHIV constituencies in an effective manner, both verbally and through concise, well-written reports; and
- ability to read and understand the CCM documentation with ease.

5. Technical skills

The following important technical skills needed by PLHIV CCM members may require capacity building or reinforcement of existing capacity:

- language (for both national and international forums);
- competency in technologies such as computers, Internet, and e-mail;
- understanding of monitoring and evaluation of projects and programs;
- management skills;
- proposal and report writing;
- priority setting and strategic planning; and
- understanding of current scientific data and evidence

Monitoring and evaluation and why it matters

The use of monitoring and evaluation (M&E) is an important way to judge the impact of projects or interventions by measuring progress against previously agreed plans and criteria.

By using M&E tools, PLHIV groups can show the effectiveness of their projects and generate the evidence they need to successfully seek funds in the future. Through M&E, the process, success, and impact of a project can be demonstrated and the problems can be identified and rectified. PLHIV initiatives that are initiated and “owned” by PLHIV often work better than other interventions that do not involve PLHIV in their planning and implementation. However, there is often very little documented evidence to actually prove the viability of these approaches. Only by using M&E can PLHIV show with confidence what works, how it works, and why it works.

In the context of the Global Fund, M&E is a critical function. The Global Fund uses a system called “Results-Based Funding”. This means that if sub-recipients cannot provide evidence of successful programs to the Principal Recipient (PR) and if the PR cannot in turn supply evidence of success to the CCM, the Local Fund Agent (LFA) and the Global Fund Secretariat, then funding may be delayed or temporarily terminated. M&E can also help to highlight problems with the PR’s administrative capabilities or with corruption or conflict of interest. For this reason, the CCM should constantly monitor the performance of the PR and receive the reports sent by the PR to the Global Fund Secretariat. If a PR appears to be performing poorly, the CCM may decide to nominate another PR at the end of the two-year period. Such a possibility indicates why it is crucial that PLHIV are involved through the CCM with monitoring and evaluation of the PR(s).

Areas of disagreement among PLHIV

Language is one area where the PLHIV who produced this handbook have failed to reach consensus during consultations. Some people, especially those from countries where the language of government administration is not one of the official UN languages,* feel strongly that people sitting on CCMs need to be able to speak English to read and understand Global Fund documents, and communicate with CCM members and Global Fund staff. Others feel all CCM meetings should take place in a local language.

*Many Global Fund documents are available in the six United Nations languages: Arabic, Chinese (Mandarin), English, French, Russian, and Spanish, and are available on the Global Fund website at www.theglobalfund.org.

We debated the language issue extensively, but eventually the majority felt it made better sense to have a representative who could easily read and understand all CCM documents and be sufficiently literate to write a report back to the constituency.

– PLHIV, Nigeria

We agreed that a working knowledge of English, which is the “international medium of communication” and an official language in Kenya, was relevant. A second language such as Kiswahili or French and a university degree would be an added advantage, though not essential.

– PLHIV, Kenya

4

Education is another area where there are differences of opinion among those consulted during research for this handbook. Some people feel a university degree is essential. Others feel a CCM member should have completed his or her secondary education. Still others believe that formal education is irrelevant because the most important prerequisite is an understanding of the needs of PLHIV and the ability to lobby around these issues. All agreed that once a person is sitting on the CCM, the skills and knowledge required become apparent.

A friend from Africa was taken out of school very young to care for her sick family. Later she was diagnosed with HIV. She became an activist and has made incredible achievements in the HIV/AIDS field, yet she did not finish her education.

– PLHIV, United Kingdom

A degree does not make a person qualified and capable of improving on the CCM processes regarding inclusion and participation of PLHIV. Experience, skills, expertise, and commitment are what are necessary.

– PLHIV, Malawi

Language Classes in Vietnam

The capacity of PLHIV to engage with international and national actors relies to a large extent on English-language ability. In Asia, English is becoming the regional language for communication in business as well as development and HIV/AIDS. In Vietnam, the United Nations Volunteer program has organized a program to match volunteer English tutors with people living with HIV/AIDS. This program has begun on a small scale with volunteers each teaching about four hours a week to 5-10 people living with or affected by HIV/AIDS. This program aims to raise awareness and create a forum in which more people can become involved as well as improve English skills among PLHIV.

Anyone interested in learning more about this program should contact dang.phuong.lan@undp.org

Accessing technical assistance and resources

When we look at all the qualities, skills, knowledge, and experience we require from our CCM representatives, it can seem quite overwhelming. It is also apparent that many PLHIV who are sitting on CCMs will need to develop at least some new skills and strategies—as will those PLHIV who are working with and supporting them.

Specific recommendations as to where to find technical assistance and resources to acquire or improve these skills is difficult to provide because sources vary from country to country. There are numerous resources in English and on the Internet, but many PLHIV do not have

Internet access or do not communicate in English. It is likely, however, that focused research will uncover resources translated into local languages and adapted for local cultures. International organizations can also assist in identifying the relevant materials and in training for the appropriate skills. Donors and large NGOs may also be able to provide financial assistance to support training costs and translations of already developed material.

Bali Statement: PLHIV and ARV Provision Policies

The following text is taken from the Bali Statement, which was issued in November 2004 by representatives of 33 peer support groups for PLHIV from 24 towns in 20 provinces throughout Indonesia. The statement was issued in response to the government's plans for provision of ARVs. The full statement can be found on the CD accompanying the handbook.

4. We urge the government to involve our groups, because we are in the front line of the AIDS programs, especially in increasing access to antiretroviral therapy and other treatment for our members. This matter is too important to be considered solely the responsibility of the government or the health sector. The community, in particular our groups, must be involved in planning, implementing, monitoring and evaluating all elements of this program. We strongly urge that our groups be included as members in the national, provincial and district/municipal AIDS commissions.

5. In return, our groups are ready to be fully involved in the program. We will work to our utmost to understand all aspects of the program and seek ways that our members can contribute to its success. However, although we are ready to contribute to the program based on our expertise and experience in living with HIV, we admit that we are not doctors. We still need and request understanding and support from all parties, especially from the medical profession. We also hope all parties concerned, in particular the central and regional governments, will provide our groups with more financial, moral, material and technical support.

Are we practicing what we preach? A challenge to all PLHIV

PLHIV participation must first be promoted and practiced by ourselves.

– PLHIV, Honduras

Many of us talk about GIPA (Greater Involvement of People Living with HIV/AIDS); however, GIPA is not just something others need to implement. The question of what steps we are taking to implement GIPA in our own PLHIV communities is a crucial one. Leadership is about mentoring others and giving them the chance to develop and become leaders too. It's about involving others living with HIV from all backgrounds, from all religions, lifestyles, and countries and of all ages. Are we really being inclusive in the work we do as PLHIV? We should all ask ourselves how we can involve more PLHIV in the work we are doing and take both collective and individual steps toward making that happen.

Readers of this handbook are encouraged to think about how they and their groups, organizations, or networks can improve GIPA in their work. At the same time, they could also consider if there are steps to take that could improve gender balance in the work of PLHIV in their countries.

5. Roles and Responsibilities



Moving from tokenism to meaningful involvement on CCMs

When big organizations like the World Bank are speaking, they are listened to and the rapporteur takes extensive notes. But when we speak, the JICC (CCM) members do not take us seriously and most of our comments and suggestions are not included in the meeting notes. Being there to be seen and not heard is not acceptable.

— PLHIV, Kenya

The manipulation of information by the governmental and nongovernmental organizations working in AIDS makes effective PLHIV participation difficult. The political will does not exist to make it happen.

— PLHIV, Honduras

Our goal is for many more PLHIV to be meaningfully involved with the CCM process in any country where the Global Fund is operating or potentially operating. (It is important to keep in mind that nearly all countries have agreed to the UNGASS Declaration, which committed them to increase the meaningful involvement of PLHIV in all processes. The accompanying CD has a list of all countries that agreed to the UNGASS Declaration.)

Meaningful involvement does not mean having one or more HIV positive individuals attending CCM meetings but not really participating. Rather, it's about having a number of appropriately skilled representatives of PLHIV networks and groups actively engaged. It's about each of these PLHIV members recognizing and being confident in the value of their contribution—and their contribution being valued by other CCM members.

In addition, these representatives need to be supported by and engaged in working with members of the networks and organizations that nominated them to the CCM and whose views they articulate. Being part of a CCM is a collaborative effort that extends far beyond the confines of a CCM meeting. Therefore, all PLHIV involved in different roles need to be able to meet certain criteria to do their jobs effectively and thoroughly.

Some definitions of “meaningful participation or involvement” from PLHIV who were interviewed for the studies or involved in the consultations include the following:

- PLHIV are able to design their own projects for the Global Fund and be represented at every level and in the CCM subgroups;
- PLHIV participate at all levels from design to implementation to monitoring and evaluation;
- PLHIV are not only beneficiaries but also staff, directors, and on the board of trustees on HIV organizations, NGOs, international NGOs, and donors;
- PLHIV needs in treatment, support, and care will be met as a result of the work;
- PLHIV can successfully and consistently influence decision makers;
- PLHIV are involved heavily in process and decision-making on the CCM and there is an effective communication system between the CCM and PLHIV networks;
- PLHIV actively contribute to decision-making and policy development and implementation; and
- PLHIV are provided with all the technical information they need for effective performance in dealing with issues affecting their lives and the lives of those they represent.

The points above include basic priorities that are likely to be appropriate around the world. PLHIV in each country and region may have additional definitions and priorities that they believe represent “meaningful participation” on their local CCMs. Similarly, many of the obstacles to effective participation are likely to differ in each country and region, as will the strategies that can and should be developed to overcome these obstacles.

Key roles and responsibilities of PLHIV CCM members

What follows are some key roles and responsibilities for PLHIV involved in CCM processes, together with some questions for you and your peers to think about and discuss.

I. Represent a constituency

A CCM member or alternate member should recognize that his or her participation on the CCM is as a representative of the wider PLHIV community and not as an individual representing his or her own interests.

Do you and/or your CCM members do this? Yes No

If yes, how can you and/or he/she do this better?

If no, how could this be changed?

What could you do to help?

2. Be professional

If PLHIV want to be accepted as professionals we have a responsibility to behave in a professional manner on the CCM and elsewhere. This involves consistently attending and being on time for meetings. It means sending apologies in advance of the meeting if attendance is impossible and ensuring an alternate is there if allowed by the CCM rules. It means behaving and dressing appropriately. It also means using appropriate language during meetings and in all interactions with CCM members and others involved in the work of the CCM.

Keeping one's temper in the face of potential ignorance and prejudice is not always easy, but it is almost always necessary if we want to be perceived as professionals. Even when we are feeling highly emotional about something we strongly believe in, arguing politely and calmly is usually a more effective strategy than making emotional statements. Being professional means completing tasks on time and doing a thorough and a high-quality job when asked to do something by the CCM or our constituencies.

Do you and/or your CCM member act professionally? Yes No

If yes, how can you and others improve your professionalism?

If no, what steps can you take to change this?

What can you do to help?

3. Facilitate better understanding of PLHIV issues within the CCM

PLHIV on the CCM should be educators, facilitating a better understanding of PLHIV issues among CCM members. Our representatives may be the first PLHIV that some members have worked with on a professional level, or even, in some cases, the first PLHIV they have met. There is a lot that can be taught and communicated, and prejudices can be turned on their heads just through casual everyday interactions. PLHIV should seize these chances whenever they occur.

Do you and your CCM members act as educators? Yes No

If yes, could you and others do better?

If no, what steps could you take to change this?

What could you do to help?

4. Seek out and articulate different opinions

• Understanding the needs of the community

CCM members must always remember that a key part of their job is to know and be aware of the changing needs of the communities living with HIV, on whose behalf they are participating in the CCM. They must be proactive in seeking input from community members and take the lead in relaying information obtained during CCM meetings.

- **Maintaining a balanced relationship with different PLHIV communities**

It is important that PLHIV CCM members always maintain balanced relationships between the different PLHIV communities and groups that exist within a country. For instance, separate groups may exist for women, youth, IDUs, migrants, sex workers and MSM. There may be groups that are based in towns or cities while others are based in rural locations. Sometimes there may be little communication or cooperation between the various groups or occasionally rivalry or open hostility. Whichever group the CCM member belongs to, he or she should respect and advocate on the CCM for the interests of all PLHIV constituency groups and make a conscious effort not to show favoritism or exclude any groups; on the contrary, the CCM member should be reaching out to bring others into the process.

- **Articulating the issues of the wider PLHIV community at the CCM**

It is important that a PLHIV representative is able to speak to the CCM from a position of authority, and thus accurately and effectively articulate the issues of the wider PLHIV community. Only by engaging in the various activities outlined above will they be able to do so with legitimacy and with the respect of their community.

Articulating these needs and issues will also depend on being aware of the existing resources and programs in the country, becoming familiar with current HIV best practice and being able to understand research data to credibly argue for the appropriate interventions to be funded. These efforts will also help ensure that the Global Fund can fulfil its mandate of “additionality” and not duplicate existing efforts in each country.

Are these activities happening in your country? Yes No

How could this situation be improved?

Discuss some steps PLHIV could take to make this happen?

5. Consult and report on a systematic and regular basis

- **Ensuring the agenda for CCM meetings is prepared far enough in advance to allow for consultation with constituency members**

It is important that PLHIV are able to meet and discuss the issues they would like to propose for the CCM agenda before it is developed. Once the agenda has been agreed by the CCM, PLHIV need to meet again to discuss and strategize on agenda items and agree on clear positions and perspectives. In many countries, adequate time is not allowed for these stages of consultation among constituencies. While we know it might not always be possible to change this, PLHIV members should be advocating for the timely preparation of an agenda to become normal procedure within the CCM. It is likely that other stakeholder groups will also want the opportunity to discuss the upcoming agenda items in advance, so it is probable that efforts to achieve this goal will attract many allies.

- **Representing the views of the constituencies at CCM meetings**

CCM members need to accurately represent the views of their constituencies at CCM meetings through processes of prior consultation and feedback such as those described elsewhere in this section. PLHIV CCM members should also take on the task of communicating any specific questions or concerns of other CCM members to the constituencies for discussion and response.

- **Reporting in a timely manner the outcomes of CCM meetings and processes to members of constituencies**

The decisions made during CCM meetings or other meetings connected with the CCM (such as CCM working groups or executive group meetings) are often relevant to PLHIV constituencies. These decisions may require urgent discussion within the PLHIV network and immediate action may be necessary; therefore, it is important that the PLHIV CCM member is able to report back promptly to his or her constituencies.

In many countries, PLHIV have requested that PLHIV CCM members provide a written report shortly after the meeting to the national PLHIV network or group, the regional network, and the Global Fund board member for the communities living with the diseases delegation.

- **Monitoring and evaluating the CCM performance and reporting back to constituencies and the Global Fund**

Like all structures in the Global Fund, CCMs need to be held accountable. One method of doing this is by monitoring and evaluating CCM performance against the recommendations laid out in the guidelines for CCMs produced by the Global Fund (see Section 3). If a CCM is falling short in any way, the PLHIV member should alert the constituency as part of an effort to ensure that appropriate action can be taken. Another method might be to measure Global Fund activities in individual countries against the UNGASS targets (see Section 2).

Do you and/or your CCM members do all these things? Yes No

Could you improve this? How?

6. Participating in proposal development

It is the right and the responsibility of each and every CCM member to actively support and participate in the development of the Country Coordinated Proposal (see Section 3). Only by this engagement can we ensure that PLHIV needs and related issues are given the attention they deserve in the proposal that the CCM produces. Concerns of vulnerable populations deserve particular attention—these populations include women, young people, IDUs, MSM, migrants, and sex workers.

It is important for PLHIV CCM members to advocate within the CCM for the development of clear and transparent criteria and selection processes for Principal Recipients (PR) and sub-recipients (SRs). This will greatly assist in articulating these criteria to PLHIV constituencies. The CCM member should always provide information to constituencies as soon as calls for proposals are made. They should then, if possible, assist constituency members to develop their own proposals for submission to the CCM.

Do your CCM members give information to the constituencies when the call for proposals is made? Yes No

Do you and/or your CCM members participate in proposal development? Yes No

If yes, how can you/they become more involved?

If no, what steps can you/they take to change this?

What should PLHIV CCM members put in their written reports to constituents?

A simple meeting report might include the following information:

- date of the meeting
- time of the meeting
- location of the meeting
- who attended the meeting
- agenda (this could be attached separately)
- background information on the PLHIV discussion and consultation that took place in advance of the meeting and on the positions that were agreed. This will help inform those PLHIV who were not part of the process.
- isolating and summarizing each agenda item one-by-one and making comments on each of them including:
 - how the discussion went;
 - who else on the CCM took the same or a similar position as the PLHIV member (it is useful to know who potential allies are for future advocacy);
 - what decision was finally taken on this agenda item and how the PLHIV CCM member voted;
 - any agreed action points for the CCM in relation to this item; and
 - any proposed action points for PLHIV constituencies in relation to this item.
- list any other important issues that arose during the meeting and whether or not there will or should be any follow-through on them (a) by the CCM as a whole and/or (b) by PLHIV constituencies.
- list, in order of importance and/or urgency, the key items that PLHIV constituencies need to discuss; and
- give the date of the next meeting, if it is already agreed.

Deliberate choice: why join a CCM?

PLHIV involvement will bring a human face and voice within the Global Fund. They can share firsthand experiences of programs and their effectiveness.

– PLHIV, Malawi

We want to influence decisions on distribution of resources especially for treatment.

– PLHIV, Kenya

It is clear that being a CCM member requires much time, energy, and dedication. Any group member who is involved or thinking about becoming involved on a CCM will first need to consider carefully the pros and cons to make an informed and responsible decision about participation. One of the requirements of

becoming a CCM member is willingness to disclose one's HIV status. Another potential barrier is lack of time to prepare and consult with other PLHIV or lack of confidence to speak in large groups.

It is useful for the group, organization, or network as a whole to be clear about the advantages and disadvantages of participation. Those considering CCM participation are encouraged to make lists of reasons to join a CCM and also why not to join—and then study them closely, sharing thoughts and concerns with others in the community.

Make lists for and against joining a CCM. Then discuss your thoughts with your group.

Reasons to join

5

Reasons not to join

Making decisions in CCM meetings

Making decisions during CCM meetings is not as straightforward as it might initially seem, even if a lengthy consultation process has been held in advance. This is because decisions often must be negotiated between different stakeholders on the CCM and some degree of compromise is likely to be required by everyone to reach consensus.

For this reason, it is useful for PLHIV CCM members to arrive at CCM meetings with a range of possible options that have been explored and agreed on with constituencies. If the PLHIV member has a Plan A, B, C, and D, then chances of success will be higher, given the various potential scenarios that can arise, than if they have just one agreed option to put forward.

In addition, a strategy of preparing agreed options will reduce the risk of conflict between PLHIV CCM members and their constituencies. If the constituencies agree on only one option in advance, the CCM member may find it necessary to compromise on a decision point during the meeting without prior consultation

with the community. This could result in criticism of the CCM member if other PLHIV do not agree with the stance he or she has taken.

However, it is realistic to expect that there will be times when the PLHIV CCM member will need to make a decision on the spur of the moment, and there should be enough trust and confidence placed in him or her for constituency members to accept this. There will undoubtedly be some points of discussion or decisions made during a CCM meeting that are general in nature and do not necessarily require extensive consultation with constituency members. These could be, for example, questions over the timing or location of meetings. The PLHIV CCM member will need to make a judgment as to whether or not such issues merit consultation. A simple way to judge this is to ask the question, “Would the constituencies be surprised by this decision and would they want to express an opinion on it?”

During the Global Fund board meetings, the PLHIV board member for the “communities” delegation sits at the table with the other board members. Four or five PLHIV members of the delegation sit behind him or her to give support. Often, the PLHIV member at the table will send a note asking a question to the others if a topic arises to which the member does not know the best way to respond. Having other delegation members supporting the PLHIV board member at the table helps ensure consultation and representation, and can help the board member feel less intimidated.

– Ex-board member of the Communities delegation

Roles and responsibilities of PLHIV constituency members toward their CCM representatives

1. Take an interest and keep up-to-date about what’s happening in the CCM

We realize that PLHIV often have multiple commitments—such as jobs, child care and caring for other family members—in addition to issues related to their own health. However, PLHIV who are able to attend constituency gatherings to obtain feedback from CCM meetings and give input for future meetings generally find them to be time well spent. In the long-term, participation in such meetings could have huge benefits for individual PLHIV and their communities by helping develop a truly balanced CCP that reflects the needs of PLHIV women, men, and children throughout the country.

2. Facilitate the input of other PLHIV

We all need to find ways to consult with other network members who cannot be at meetings and to inform CCM members of their views. One way to facilitate the input of others is to help organize local consultation meetings or by hosting a small discussion group for those who will not be able to make it to the general meeting. For those who have access, e-mail discussion is another relatively low-cost way to consult with other members. It is important to include substantial consultation with PLHIV who live outside the capital city, too, since their views are often not solicited. Some

PLHIV may not be linked into existing organizations and networks, but if possible, it's still important to get their opinions to help inform the process.

Do you or your constituencies seek input of other PLHIV? Yes No

If yes, how can it be done better?

If no, can you come up with some ways to make this happen?

3. Ensure effective hand over and induction

Inductions should be done for all PLHIV CCM members and their alternates to strengthen their knowledge and understanding of Global Fund issues, systems, and procedures and maximize their potential for effectiveness. Although there should be some form of induction organized by the CCM itself, it is important that PLHIV constituencies are able to think about what will be needed and design their own induction programs, preferably in consultation with each other. In addition to learning about the Global Fund, this might include visiting different PLHIV groups as well as groups representing vulnerable communities including IDUs, MSM, migrants, and sex workers. Meetings with NGOs, UN agencies, and bilateral development agencies might also need to be set up so that the new member can learn about their work and relationships can be initiated. Discussions or other forms of communication with specific PLHIV in-country and abroad may need to take place, and it is always helpful to make connections with relevant Global Fund Board delegation members.

In addition to induction, whenever a new CCM member and/or alternate takes on his or her role, a smooth and effective hand over from the previous CCM member (if there was one) is very important. One of the things that will greatly assist with a hand over is for each CCM member to have kept carefully documented records, which he or she can pass on to the new member. New and old members should aim to spend a substantial amount of time together so the new member can be fully briefed. Other PLHIV who have been close to the CCM process should also be involved in the hand over.

Do you have a hand over or induction process in your country? Yes No

Is your CCM member keeping documented records? Yes No

If either of these is not happening, what could be the first steps toward making them happen?

4. Elect an alternate

There may be times when a PLHIV CCM member is unable to attend meetings or fulfil other responsibilities because of illness or other circumstances. For this reason, it is desirable and in the interests of PLHIV constituencies to select an alternate. The alternate ideally should have the same or similar skills and competencies as the CCM member and the two should work together as a team as much as is practically possible. This will ensure that the alternate is able to take over his or her duties, if necessary, with minimal disruption. As with the process for selecting the CCM member, the selection of the alternate should be democratic and transparent. All the roles and responsibilities recommended for PLHIV CCM members in this handbook should also apply to alternates.

It is extremely helpful if the alternate is able to attend all CCM meetings and be part of the pre- and post-consultation meetings with other PLHIV. Alternates have played crucial roles at the Global Fund Board level, serving on board committees and supporting the delegation process.

Do you have an alternate CCM member? Yes No

If not, how can you plan for this?

5. Establish Terms of Reference

People normally have terms of reference (ToR) for their jobs, so for a position that carries as much responsibility as being a CCM member, we believe this should also be the case. ToR lay out a set of tasks and responsibilities for the member and can be used as a tool by them to ensure they are working within their mandate. ToR can also be useful in assisting others to assess the performance of the member. The ToR should always be established by the constituencies, preferably through a process of consultation. Often it's easier for a small working group to draft the ToR and then bring it to the wider group for discussion and agreement. The CCM member will also need to agree to the ToR.

Do you have ToR for your CCM member? Yes No

If not, how can you plan for this?

6. Give support

As PLHIV, we know a lot about creating supportive environments in the face of the hostility many of us have faced. We have years of experience in organizing self-help groups, in providing peer support, and in taking care of each other. We need to make sure we extend this support to our PLHIV CCM members—they have major responsibilities and cannot be expected to do their jobs alone. No one should be expected to become a CCM member without expecting to be able to turn to peers and other community members for support and advice. It is essential that our CCM members can identify one or more PLHIV to share their fears and problems with.

Does anyone in your constituency take on this role? Yes No

If not, how could you put this system in place?

7. Hold CCM member(s) accountable and keep them accessible

If a CCM member is being ineffective in his or her role—and this can happen in many different ways and for many different reasons—the situation needs to be addressed as quickly as possible. It is the responsibility of constituency members to recognize problems related to a CCM member and to explore all possible remedies and solutions; furthermore, it is their responsibility to do this in a constructive and respectful way.

Do your constituency members hold members accountable? Yes No

If no, what do you need to do to make it possible?

8. Give positive feedback

We all need positive feedback and to know that our efforts are appreciated. It helps us to remain motivated, even when we are feeling stressed, overwhelmed, or inadequate. A CCM member may experience these feelings frequently, and it is important that we all remember to acknowledge the important work that our CCM representatives are doing. We need to tell them that we appreciate their efforts.

Do you and your constituency members give each other and the CCM member positive feedback? Yes No

What forums might you use to acknowledge the work of PLHIV CCM members and others involved?

5

Sharing the burden

Being a CCM member can be stressful and time-consuming. Some of the people who took part in the consultations around this handbook recommended that PLHIV networks should establish a small **Constituency Advisory Group** for CCM members in their country. This group would offer support and guidance to the member during the periods between larger meetings that take place in the PLHIV community. This group could also assist by monitoring the progress and performance of the CCM member, giving him or her constructive feedback and assistance in identifying training needs. In addition, the Constituency Advisory Group could take on the role of monitoring and evaluating all PLHIV activities related to the CCM in that country.

Do you think a group like this would be useful in your country? Yes No

What steps would you need to take to set up a group like this?

6. Communication and Coordination



PLHIV should develop user-friendly communication and coordination mechanisms.

– PLHIV, Ukraine

The networks are there but exchange of information is very rare. We need to strengthen the bonds between the different constituencies to facilitate the exchange of information.

– PLHIV, Malawi

Issues and problems that highlight the need for effective communications and coordination among PLHIV have been touched upon throughout this handbook. It is undeniable that the involvement of PLHIV on CCMs will inevitably be compromised without efficient and open methods of communication and coordination that are straightforward and accessible.

Several potential problems could arise without good communication and coordination among PLHIV. For example, their lack would likely make it unrealistic to expect appropriate and consistent consultation, the establishment of conditions ensuring the democratic election of CCM members, or thorough reporting back to constituencies. Ultimately, not only the community of PLHIV but the whole country as well is negatively affected by the absence of our meaningful involvement.

It is only fair to acknowledge some of the barriers and challenges to coordination and communication that the majority of PLHIV face. For instance, at a local level access to e-mail or phone lines can be rare and unreliable, and it is often problematic or dangerous for PLHIV to meet because of the real fear of stigma and discrimination. In spite of this, PLHIV from all parts of the world have over the years shown remarkable courage and resourcefulness in overcoming these obstacles and their achievements should be applauded and offer inspiration to us all.

A Latin American success story: REDLA+

One example of a successful communications strategy emphasizing communications and information sharing about the Global Fund among PLHIV is a regional project implemented by REDLA+, an umbrella organization consisting of individual PLHIV and associations, NGOs, and national networks of PLHIV from across Latin America.* With funding from the GTZ Back-up Initiative (more information about this initiative may be found in Section 8), REDLA+ has been able to engage in a number of activities that promote and facilitate awareness and participation in the Global Fund throughout the region. Some of these activities include the following:

- establishment of the Spanish Electronic Forum, ESVIHSA, which is a vehicle for the exchange of ideas about the Global Fund across Latin America;
- the development of a bulletin in Spanish and English for communities involved in implementation of Global Fund grants; and
- the development of communication resources to improve the participation of communities of PLHIV in implementation of Global Fund grants in the region.

For many PLHIV in Latin America, one of the barriers to participation in Global Fund processes has been the lack of information, resources, and discussion opportunities available in Spanish. REDLA+'s communication work has assisted greatly in addressing this gap and thereby promoting PLHIV involvement in the region.

* REDLA+ also works with PLHIV groups in the Spanish-speaking Caribbean

5

How to work together at the country level and beyond

• Creation, expansion, and strengthening of PLHIV networks

PLHIV are at different stages of network development in each country. There are no established groups or networks of PLHIV in some nations, while others have multiple networks and others lie somewhere in-between. Although some might assume that countries with multiple networks will find it easier to coordinate activities and communications, in reality this is not always the case.

In Uganda there are a few very large PLHIV networks and many small community-based PLHIV initiatives. Whenever there is consultation with PLHIV the views and input of the large networks are sought, while the smaller groups are not represented and their members not consulted. This can lead to a distorted overview of the real needs of PLHIV and the work of the smaller groups is undermined. To avoid situations like this, we must emphasize the need for democratic, transparent, and all-inclusive participation through strong partnerships and coalitions. We are now in the process of developing a strategic framework for the PLHIV constituency in Uganda.

– PLHIV, Uganda

How developed are the PLHIV networks in your country?

What are the problems you are facing?

Can you think of some immediate and more long-term steps to improve the current situation?

• Commitment and engagement

Effective communication and coordination can only be achieved with the commitment and engagement of all PLHIV groups and networks that want to be involved. For this to happen, people first need to understand the value of coming together and to be clear about what their goals are. It may mean putting aside differences and inter-group politics and finding a way to reach consensus on CCM issues. PLHIV should bear in mind that fragmentation and division within our communities can easily play into the hands of those who wish to undermine our efforts. Building coalitions increases our potential for effective advocacy and involvement, so it is important that PLHIV are able to show a united front whenever possible.

We are together; we promise that we will support and respect the efforts of groups and PLHIV within the Indonesian Network of PLHIV. We will not compete with each other, or consider PLHIV who are involved in our groups as objects.

–PLHIV, Indonesia

There are many reasons—aside from the Global Fund and CCMs—for PLHIV to come together. In many nations, PLHIV had support groups and networks long before the Global Fund ever existed; certainly at that time they were not coming together to discuss CCMs. Nowadays, however, it is important that the Global Fund and CCMs are among the issues PLHIV networks discuss because of the potential radical impact of a successful grant in our countries.

It is essential that information on the Global Fund and on its vision and relevance to PLHIV are communicated to network members during meetings. If this does not happen it will be difficult to ensure that increasing numbers of PLHIV become fully engaged and committed to being involved in the CMM processes. Lastly, we all need to feel our participation can really make a difference; therefore, the sustained engagement of network members will rely on ensuring those who want an active role have specific tasks to perform and receive acknowledgment for their contribution.

Would it be useful to organize an information session on the Global Fund for PLHIV in your country?

How would you do this?

What materials would you need? Where could you obtain them?

- **Making links and creating alliances**

Being involved in the Global Fund effort is all about building new, non-traditional partnerships. It is important that PLHIV networks reach out to make links and create alliances with others who share their concerns—and who can assist and work alongside them in their advocacy efforts or in other areas, such as the provision of technical assistance. These allies might include other civil society groups such as communities with or affected by TB and malaria, NGOs, faith-based organizations, the private sector, UN agencies, or the media—in fact any of those groups that might be sitting on the CCM—and others that may not yet be represented.

Which groups in your country would it be helpful to develop alliances with?

How could you go about this?

Alliances with people with or affected by TB and malaria

At the beginning of the handbook, we talked about how the Global Fund was created to combat not only HIV but also TB and malaria. Links among communities affected by these diseases are not as strong as one might expect, even though many of us living with HIV also have or have had TB and/or malaria at some time in the past—and TB is the major killer of PLHIV in many parts of the world. However, there are few groups or organizations that exist specifically for people with TB and none, so far as we are aware, for people with malaria.

There are several likely reasons for the absence of links and alliances between PLHIV and those with TB and malaria. Most center on the fact that treatment options and attention paid to the diseases vary significantly, and each disease is viewed quite differently around the world. For one thing, unlike HIV, TB and malaria are almost always curable as long as the appropriate medications are available and taken correctly. In addition, TB and malaria do not carry with them the same degree of fear, stigma, and discrimination that HIV does. As a consequence of this, people with TB or malaria have not historically felt the same need as PLHIV to form groups for support and advocacy purposes. Despite this lack of community organization around TB and malaria, PLHIV should try nonetheless to seek out people who are engaged on these issues, establish connections with them, and work collaboratively on Global Fund issues wherever possible.

• **Organization of democratic elections**

We have already referred to the importance of holding elections for PLHIV CCM members. To be effective in representing and communicating PLHIV constituencies' needs and agenda, members should always be selected by the community through an all-inclusive and democratic process. Elections for CCM members can happen in a multitude of different ways, but should always be based on what is realistic in each country. Below are descriptions of two processes, one from Latin America and one from Eastern Europe.

6

Chile: the Vivo Positivo CCM election process

Vivo Positivo is the one national PLHIV network in Chile. At very short notice, the Chilean Ministry of Health asked Vivo Positivo to participate in designing the Country Coordinated Proposal for the Global Fund.

Vivo Positivo's structure has one decision-making body, known as the Council. The membership of the Council is made up of representatives from the different community-based organizations that form the network. After receiving the invitation from the government, the executive coordinator of Vivo Positivo made a presentation to the Council, explaining what participation in the Global Fund process would mean for PLHIV in Chile, and the Council decided Vivo Positivo should accept the government's offer. The Council established terms of reference (ToR) and criteria for the selection of PLHIV representatives; these ToR included the need for skills in project design and development, knowledge of national and international HIV politics, and experience in policy development.

Using these criteria, five people were proposed by Council members for the three seats that had been made available for PLHIV to take part in the proposal preparation process. The three who were chosen were selected by a large majority and the selection process was documented in the minutes of the Council meeting.

Once the country proposal process was complete, another election was held by the Council to decide on who should take up the two PLHIV seats that were available on the CCM. The two successful candidates were among the three who had been previously selected for the proposal phase. They were both men, as the woman who had been involved in the proposal stage was leaving the organization.

At the time of the selection process, the Council met weekly—but only with local representatives present, which meant that representatives from outside the capital did not take part. Although the final decision was not formally validated by the regional representatives, all of the organizations that form the network were fully briefed and there was no opposition to the final decisions.

Ukraine: Moving toward regional CCM representation of PLHIV from Kiev to Odessa

There are three seats for PLHIV on the Ukrainian CCM. Originally there was only one seat, but the allotment was increased to three as a result of PLHIV activism. All three PLHIV representatives are activists who have worked in PLHIV organizations for over three years. Prior to joining the CCM, they all had knowledge, skills, and experience in the areas of scaling-up access to treatment, care and support, including project proposal development, management, and monitoring and evaluation. The original PLHIV CCM members all lived and worked in Kiev, the Ukrainian capital.

When the CCM adopted a process of annual rotation of members, it became necessary to re-elect one PLHIV representative. The criteria for the new PLHIV CCM member stated that the person should be an activist, have at least two years' experience working in a PLHIV organization, understand the needs of PLHIV and be able to advocate for them on the CCM.

At the general meeting of the All-Ukrainian PLHIV Network, which was attended by 200 PLHIV from different regions of the country, the PLHIV CCM member who was stepping down was identified. Then, by a majority of votes, the representative of the network's regional office in Odessa was elected as the new member. As a result, the voices of PLHIV in regions outside Kiev are now more effectively heard on the CCM.

(Note: As of October 2004 this new member had been unable to officially join the CCM because the PR in Ukraine was recently changed and the CCM temporarily suspended its activities. The Ukrainian CCM is currently being restructured.)

The process for electing provincial and board representatives to the newly formed National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK) took 11 months. Even though it is not directly related to CCM elections, lessons can be learned and applied from our experience. First, a task force was created. One of its tasks was to appoint a chief executive officer (CEO) and to

work with the CEO to form the NEPHAK Secretariat. Together, the CEO and the task force mobilized PLHIV throughout the entire country, with the help of the government and other partners on the ground, such as Action Aid Kenya, Family Health International, POLICY Project, and others.

PLHIV elections were held at the provincial level to determine who would attend the national PLHIV conference (two participants per district). This took place very peacefully—Kenya is now becoming very democratic. During the national conference in August 2004, the 11 people from each province (Kenya has nine provinces) were allowed to vote for the NEPHAK board member and the alternate representing the province.

We invited the Electoral Commission of Kenya to preside over the elections. All partners and visitors were requested to attend as observers. The NEPAK constitution was adopted by all the delegates before a renowned Kenyan lawyer. The process was very professional and successful and the results were published in the media. I am proud of it.

— PLHIV, CEO of NEPHAK, Kenya

Do you have a fair and transparent election process in place to identify your PLHIV CCM member?

Yes No

If yes, is it an effective process?

If no, what are the barriers to making this happen?

How could you plan an election in your country?

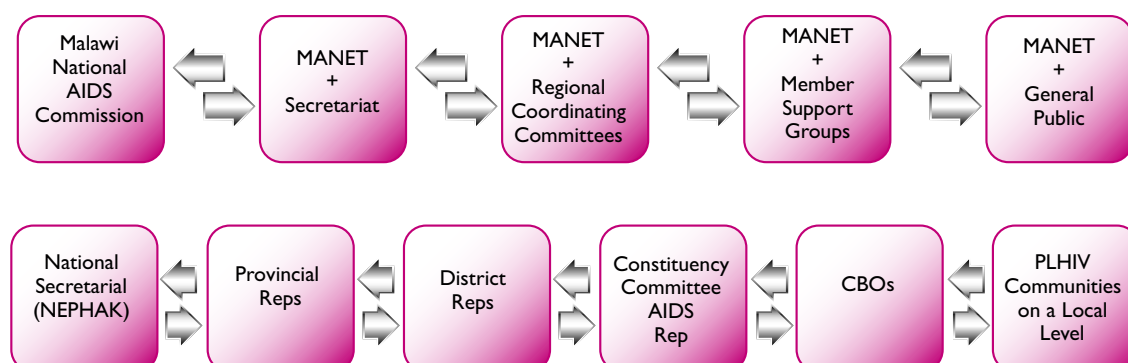
How could it be improved?

• Planning, time, and resources

It is relatively easy to identify what needs to happen to ensure effective and consistently PLHIV representation on CCMs, but little can ultimately be achieved without planning, time and—very important—resources. Many PLHIV groups and networks find themselves in a “chicken and egg” situation: to plan we need resources, but to receive resources we need to plan. PLHIV also need resources to enable them to build the capacity and develop the skills they need to do this work.

We should never underestimate how much PLHIV groups all over the world have managed to do with minimal resources; however, PLHIV can do far more and be far more effective partners if our organizations are adequately resourced. The question of where to find assistance is always hard to answer and different opportunities exist in different countries. We have listed some potential sources of funding for PLHIV groups and networks on the CD that accompanies this handbook, but PLHIV in each country will also need to do some local research.

Examples of PLHIV communication channels



The space below is provided for PLHIV in other countries to devise locally appropriate PLHIV communications maps.

Communication Maps

How we communicate with others will affect public relations and how PLHIV are perceived

• Communicating our messages

A key element in achieving good public relations is knowing how to get messages across effectively. The style of communication used by a group is important in establishing how it is perceived by others. To communicate messages effectively, groups and networks of PLHIV should reach agreement and be clear among themselves about exactly what they want to say and why they need to say it.

Target audiences

Once a message has been clearly articulated and agreed, it is important to establish to which audience the message will be communicated and to determine the appropriate tone of the message. Some messages will need to be confrontational, others polite or formal, and others should have a friendly or familiar tone.

Specific target audiences for a message might include:

- the public;
- the government;
- CCM members;
- the Global Fund Secretariat;
- national PLHIV groups;
- PLHIV in other countries; and
- UN agencies

Can you think of any other potential audiences? Add them here:

Then, depending on the specific audience, you will need to decide on the most effective way of communicating your message.

Suggested methods for communicating an effective message might include:

- making phone calls;
- writing letters;
- placing articles or announcements in newspapers;
- having members participate in TV or radio interviews;
- working through other organizations; for instance, asking a UN agency to communicate the message to a wider audience, perhaps through a statement of support; and
- writing and distributing press releases.

Are there other ways of delivering your message?

Add them here:

Building support

Building support for your messages is another useful strategy. Often, messages can be made much more forceful with evidence and support from others.

Below are some examples from PLHIV of how they have gathered support for their messages.

Utilizing already established documents or country agreements and/or treaties (whether provincial, national or international), like UNGASS or the Global Fund country proposal as evidence for your message can be very effective.

– PLHIV Global Fund Board delegation member, United States

We have found that support letters from international organizations are especially effective when dealing with governmental structures.

– PLHIV, Ukraine

Can you think of other ways to get additional support for your messages?
Add them here:

6

Suggested messages

Suggested messages to get across in each country about PLHIV involvement on the CCM might be related to:

- the need for more PLHIV to be included on the CCM;
- the need for the community, rather than the government, to select the PLHIV CCM member;
- the need for grant money to move from the Principal Recipient to the sub-recipients (this is a concern that was brought to our attention by several PLHIV during the consultations for this handbook); and
- the need to increase the number of people living with HIV, TB, and malaria who will receive medication from Global Fund grants.

Do your PLHIV groups or networks have other messages to communicate?
Add them here:

Using the media and others to get our messages across

The communications strategy the PLHIV network in Bolivia used to gain a place on the CCM (see Section 3) is a good example of how PLHIV can use the media and collaborate with certain key allies to achieve their goals. We also recommend reading the section on working with the media in the Positive Development manual.

Agua Buena Human Rights Association in Costa Rica uses e-mail to constantly and effectively challenge or ask questions of donors and governments, including the Global Fund, through letters such as the following, which are sent electronically to thousands of people:

5 October, 2004

For Immediate Release...

Progress Toward ARV Access in Peru Slower than Expected

From Richard Stern

Although 700 Peruvians Living with AIDS (PLWA) have begun to receive antiretroviral (ARV) therapy this year, the number falls far short of the 5,000 that had been agreed upon by the Health Ministry and the Global Fund.

The original goal for ARV access for 2004 had been decided upon by combining funds from a \$23,000,000 Global Fund grant with additional resources provided by the Peruvian Health Ministry. Medications purchased by the Global Fund have arrived in the country but are not yet being disbursed. The 700 people who do receive treatment are seen at five major public hospitals in Lima but three of these five hospitals are now "saturated" and cannot accept additional patients. Peru's Global Fund grant was approved in February of 2003.

Medications to begin treatment for up to 2,000 more PLWA are already in the country, but disbursement has been delayed by cumbersome bureaucratic procedures...

...According to AIDS activist Guillermo Murillo, who has just returned from Peru, "It is particularly tragic when medications are in-country, but people are still dying because they cannot access them. Bureaucratic obstacles should be quickly overcome to save lives. Why isn't PAHO (the Pan American Health Organization) speaking out on this issue? Why are Peruvian health care authorities unaware of WHO guidelines for scaling up in resource poor settings? Why are treatment interruptions not being addressed?"

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Another example of getting an important message across is from Rajiv Kafle, a PLHIV activist in Nepal. Frustrated at the lack of progress being made to resolve problems with the Global Fund grant, Kafle e-mailed this letter to multiple recipients throughout the world.

From: Rajiv Kafle

An open letter to Richard Feachem and the Board of Directors of the Global Fund

October 14, 2004

...The government as the principal recipient of the Global Fund grant [for Nepal] ha[s] to come to an agreement with the management support agency (in this case the UN system) soon. Otherwise, the Global Fund [will] pull back the grant to Nepal that was approved in January 2003. Coincidentally, I had attended that board meeting in January 2003 and was asked by a journalist if I was happy that my country was receiving the grant. I had answered “no” because I thought that the money may not reach the right people.

However, over the next year, we did a lot of advocacy to reallocate the money so that it might best reach those who need help the most. In response to our efforts, the government had even started an ARV program hoping that it would receive Global Fund money to continue it. But now the chances look grim. This is a challenge for the Fund too: if it pulls back from Nepal, many who have started ARVs will die...

... I recently went to meet the director of the National Center for AIDS Control. I wanted to inform him about an event we were organizing next week. I also wanted to hear his views about the Global Fund contract.... He took out a piece of paper and gave it to me. It was a draft agreement that the Global Fund required approval of before it would release the funds. However, this agreement still had to be approved by the cabinet. The director told me that the bureaucracy involved in this process was massive and that the government may not be able to meet the fund’s deadline. And in a rather hopeless tone he asked me, “How is the Global Fund different from any other mechanism?” I said nothing. And I left him thinking that I will surely write a letter to Richard Feachem and ask him the same question.

6

• **The way we act: challenging stereotypes**

Beyond the other messages we are putting across, good public relations involves changing the way PLHIV are perceived by others. PLHIV have been labelled in many negative ways that indicate the level of misunderstanding and stigma still prevalent in many societies. PLHIV continue to be viewed as, among other things, “victims,” “prostitutes,” “fallen women,” “promiscuous,” “sexual deviants,” “dirty junkies,” “dangerous foreigners,” and “bad mothers.” Our job is to find ways to move beyond all these dangerous and inaccurate stereotypes. Given how institutionalized social stigma and discrimination against PLHIV and vulnerable communities continues to be, this is not an easy task—but it is an essential one nonetheless. This means that whatever PLHIV do in the public eye, we must constantly be aware that we are under scrutiny. So, the more PLHIV act in a professional manner, the more likely it is that we will be treated as professionals and taken seriously—and the more we will be contributing to dismantling some of the false stereotypes that haunt PLHIV. At the same time, we must continue to raise our voices against social, economic, and political discrimination that affects members of all vulnerable communities, not just those living with HIV.

Talking to governments

Talking to governments is an excellent opportunity for PLHIV to challenge inaccurate stereotypes. Any PLHIV who is participating on a CCM will without a doubt interact with high-level government officials. Dealing with such officials is not like attending a local, informal support group, so a certain level of formality is usually required. PLHIV representatives should be clear about certain things, such as:

- what language to use;
- protocol and etiquette;
- bureaucratic procedures;
- appropriate dress code; and
- acceptable body language.

If you want a question answered, sometimes it is not enough to just make a call or ask for a meeting. You need to write a letter, register it, and preferably give a copy to the mass media or to a higher authority. Sometimes you also need a letter of support from an international organization. For meetings, you always need to make an appointment in advance, indicating the purpose of your visit.

– PLHIV, Ukraine

It is hard to make precise recommendations in this handbook because protocols and procedures vary enormously from country to country. However, it is important for PLHIV CCM member and others in their constituencies to get these basics correct by becoming informed of the rules, procedures and customs commonly observed in the country.

This is a topic PLHIV might wish to discuss in a group or network to help prepare the CCM representative. It may be useful to solicit advice from others who have more experience working with governments, such as staff of local NGOs or those who work in local UNAIDS or bilateral development partner offices.

List some of the basic ground rules that your group can come up with for talking to governments:

How institutions in partnership with PLHIV can help enhance PLHIV communications

Groups and networks of PLHIV work with many institutions that can be influential in assisting them to improve their communication capabilities. Below we list some suggestions from PLHIV involved in creating the handbook.

CCM Secretariats can

- establish and maintain constant communication with PLHIV constituencies;
- give sufficient advance notice of CCM meetings; and
- provide financial and logistical support PLHIV constituencies for communication, including capacity building.

The Global Fund Secretariat can

- produce and publish guidelines and manuals on Global Fund processes and procedures;
- increase the number of Global Fund documents that are translated from English into the other five official UN languages;
- simplify Global Fund publications, tools, and instruments;
- make deliberate efforts to establish direct communication with constituencies at the country level;
- document and disseminate information on best practices concerning PLHIV involvement with the Global Fund;
- publish hints on effective communication to and from the various constituencies, including PLHIV in-country communications with the Global Fund Secretariat;
- make available contact information for all Global Fund Board members and all CCM members at country level; and
- employ skilled PLHIV in senior leadership positions, which will help increase trust and improve honest dialogue between PLHIV communities and the Secretariat.

International organizations can

- offer support and help mobilize resources;
- provide training in specific communications-related areas;
- provide support for quarterly meetings to facilitate information sharing;
- circulate up-to-date information to organizations and networks that cannot access electronic media or other information sources. For instance, UNAIDS or government could organize monthly meetings;
- help PLHIV networks to establish and maintain media relationships for ongoing monitoring of progress in Global Fund grants and keeping those involved accountable;
- show public support for PLHIV initiatives;
- employ skilled PLHIV in senior leadership positions, not just as peer educators, which will help increase trust and improve honest dialogue between PLHIV communities and the organization in question; and
- appoint PLHIV to their boards of directors.

7. Guidelines for Improving CCMs Through Greater PLHIV Involvement



Current Global Fund guidelines

The Global Fund has developed its own resource, “Guidelines on the Purpose, Structure and Composition of Country Coordinating Mechanisms,” which outlines recommendations for how a CCM should operate. These guidelines can be found on the Global Fund website at:

http://www.theglobalfund.org/pdf/5_pp_guidelines_ccm_4_en.pdf.

These guidelines have been under much discussion at the Global Fund Board, in the board committees, and recently at the Partnership Forum. At the 8th board meeting in June 2004, the board debated whether it should adopt a more prescriptive stance toward CCMs and considered adding some requirements to the existing recommendations for CCM membership and operating procedures. Although some changes were made to the guidelines at this meeting, no requirements were agreed on.

In November 2004, days before this handbook went to press, the Global Fund Board revised this decision, transforming some of the previous recommendations into requirements. Among the requirements, all CCMs must show evidence of membership of people living with and/or affected by the diseases (although PLHIV should be aware that the wording suggests it could be acceptable for CCMs to show evidence of membership of people affected by but not necessarily living with the diseases). CCM members representing the nongovernmental sector must now be selected by their own sector, based on a documented, transparent process. CCMs are also required to put in place and maintain a transparent, documented process to ensure the input of a broad range of stakeholders, including CCM members and non-members, in proposal development and grant oversight processes.

This decision marks a significant victory for many PLHIV and their advocates, who have worked long and hard to make this happen.

The new inclusive model: PLHIV-developed guidelines

The guidelines listed below are different: they are ours. They have been drawn up and agreed on by a large group of PLHIV who have first-hand experience of the challenges and obstacles to PLHIV involvement on CCMs, thus giving the guidelines value, legitimacy, and credibility. These guidelines can be used as an advocacy tool to assist all stakeholders in the Global Fund processes to help ensure that PLHIV concerns and issues are addressed as fully as possible. (The guidelines can also be adapted for use when working with other multisectoral or coordinating bodies at the local, district, provincial, or regional level.) We hope these guidelines will be copied and distributed as widely as possible.

Who should receive the guidelines?

The following individuals, organizations, and entities would benefit greatly from receiving copies of the PLHIV guidelines for CCMs:

- CCM chairperson and members
- government officials
- UN agencies
- local NGOs
- national NGOs
- international NGOs
- faith-based organizations
- other PLHIV groups
- academic institutions
- private sector representatives
- MSM groups
- sex worker organizations
- schools
- organization working with and for migrants
- drug users' groups
- women's organizations
- legislators at the national, regional, and local levels
- the media
- local community members
- trade unions

We have left some space for you to add your own ideas of where and to whom the guidelines should go.

Adapting the guidelines

These guidelines are a work in progress. We are confident they can and will be added to as CCMs evolve and working partnerships across sectors continue to grow and mature. Some of the guidelines may not be appropriate in each country; therefore, we recommend that PLHIV consult with each other to draw up additional guidelines that are locally relevant. It is important to ensure, however, that the guidelines adopted are agreed on by everyone involved in the consultation process.

Sharing locally developed guidelines with the Global Fund and others

We strongly encourage the sharing of guidelines developed by all PLHIV at the local level. PLHIV in other countries will undoubtedly benefit, as will the Global Fund Board, Secretariat, and donors. Guidelines developed by local PLHIV networks can also be shared with the Global Fund Board delegation for communities living with the diseases (see Section 8 for contact details). Circulating this information widely can help ensure that vital input from PLHIV at the local level is fed into the deliberations of the Global Fund Board Committees and of the Global Fund Partnership Forum (see Section 2).

Guidelines for improving CCMs through greater PLHIV involvement

Guidelines for CCMs

- CCMs should ensure membership from as wide a range as possible of different groups, including PLHIV.
- PLHIV should constitute at least 10 percent of CCM membership, with a minimum of two PLHIV per CCM.
- Selection processes for all CCM representatives should be fair, wide-reaching, and transparent.
- PLHIV CCM members and alternates should be selected through an all-inclusive and democratic process that is totally independent of the CCM.
- Alternates should be allowed to attend CCM meetings.
- CCMs should ensure gender balance among their membership. PLHIV CCM members should ensure that gender balance is maintained when selecting an alternate.
- All CCM members should receive HIV orientation and awareness training, including discussion of the GIPA Principle, UNGASS, and the Three Ones.
- CCMs should rotate the positions of chairperson and vice chairperson equally between civil society and government.
- The length of term for a CCM member should normally be one to two years and never more than three.
- The preliminary agenda for a CCM meeting should be disseminated no later than two weeks in advance of the meeting.
- Each CCM decision should be reached through group consultation and consensus wherever possible.
- CCM meetings should be accurately documented and minutes circulated widely within two weeks of the meeting.

- To enhance communication and transparency, CCMs should publish regular updates through newsletters and by e-mail.
- PLHIV and other CCM members, including alternates, should be paid travel costs and per diems where appropriate.
- When necessary, PLHIV and other members of a CCM should have the right to seek outside guidance in specific areas, such as policy, finance, and legal issues.
- CCMs should support PLHIV in acquiring the relevant skills and capacity they require to fully participate on the CCM.
- During meetings, interpretation and translation of documents should be made available to PLHIV and others who cannot communicate in the official working language of the CCM.
- PLHIV CCM members should actively participate in executive committees and subcommittees.
- PLHIV CCM members should be consulted in the planning and scheduling of CCM meetings and in agenda development.
- CCMs should support PLHIV networks to hold meetings for discussion of CCM issues if such meetings are not already taking place.
- CMM Secretariats should employ PLHIV on their staff teams.
- Inductions should be done for all PLHIV CCM members to strengthen their knowledge and understanding of Global Fund issues, systems, and procedures.

7

Guidelines for the Global Fund Board and Secretariat

- The Global Fund Secretariat should facilitate and encourage contact among PLHIV members of CCMs in different countries.
- The Global Fund Secretariat should ensure PLHIV members of CCMs have access to and contact details for the appropriate person(s) in the Global Fund Secretariat and on the board Delegations, including board members.
- During country visits, Global Fund staff should, as a matter of course, meet with PLHIV networks.
- During country visits, Global Fund staff should, as a matter of course, contact the PLHIV CCM member(s) if they are not present at any of the scheduled meetings.
- The Global Fund Secretariat should lead by example, employing significant numbers of PLHIV across all teams of the Secretariat, with the eventual goal to have PLHIV constitute 10 percent of all staff. The Global Fund should use affirmative action when recruiting and seek to ensure that PLHIV are not only administrators or assistants, but also employed in key leadership positions.
- The Global Fund Secretariat should make available terms of reference and selection criteria for Local Fund Agents (LFAs).

Guidelines for PLHIV CCM members and constituencies

- PLHIV CCM members should have alternates to replace them if, for some reason, they are unable to participate in the work of the CCM.
- CCM members and alternates should be selected through an all-inclusive and democratic process. The process for selecting PLHIV to sit on CCMs should be agreed on and conducted by national PLHIV networks, ensuring inclusion of all groups. The process should be totally independent of the CCM.
- PLHIV representatives in the CCM should be appropriately skilled and belong to an organization or network of PLHIV that operates within a province, state, or country.
- Terms of Reference (ToR) should be established for PLHIV CCM members and alternates by their constituencies.
- Inductions should be organized by the PLHIV constituency for the PLHIV CCM members and alternates, in addition to the induction provided by the CCM.
- PLHIV CCM members and alternates should exhibit qualities of good interpersonal and public relations to communicate effectively.
- Geographic, gender, and vulnerability representation should be ensured by allowing a rotation of representation after each term, as well as by advocating for more than one PLHIV member per CCM.
- If there are currently no PLHIV on a CCM, networks should advocate changing this situation. They should be proactive about attending CCM meetings and demanding a place at the table.
- Every decision scheduled to be taken by a CCM needs prior discussion by the network of PLHIV. A primary position and back-up positions should be agreed on in advance. Every decision should be made with group consultation and consensus, therefore reflecting a credible and united PLHIV perspective.
- PLHIV CCM members should be well-prepared to speak on agenda items prior to a CCM meeting, after thorough consultation with their networks.
- PLHIV CCM members should be prepared (and comfortable doing so) to ask probing questions and demand honest answers during CCM meetings.
- PLHIV CCM members should be in direct contact with PLHIV CCM members in other countries and with the Global Fund Board delegation for communities living with the three diseases, via the relevant regional focal points for the delegation.
- PLHIV CCM members should present clear written and verbal updates to their PLHIV networks on a regular basis.
- PLHIV networks should develop user-friendly communication and coordination mechanisms. They should publish and disseminate regular updates for their members via newsletters and e-mail to enhance communication and transparency.
- PLHIV CCM members should regularly attend network meetings so they can report on the CCM activities and consult with members on upcoming CCM issues.

- PLHIV networks should always allow adequate time to discuss CCM issues in meetings.
- PLHIV networks should identify and build relationships with the Global Fund Secretariat staff covering their region and communicate with them on a regular basis.
- PLHIV CCM members should be aware when Global Fund regional meetings are taking place well in advance of the date and ensure attendance of themselves and/or other representatives of PLHIV networks.
- PLHIV networks should develop partnerships with international and national NGOs, and regional and international PLHIV networks (such as the International Community of Women with AIDS [ICW] and GNP+). This should help improve access to technical support and increase collaboration, thus ensuring local input into global advocacy efforts.
- PLHIV CCM members should ensure that PLHIV issues are given priority and adequately reflected in the Country Coordinated Proposals.
- National PLHIV networks should, wherever possible, plan meetings two weeks before every board meeting to devise strategies on their Global Fund and CCM-related work. The outcomes of these meetings should be communicated to the relevant representatives of the Global Fund Board delegation for communities living with the diseases.

This space is provided for comments and feedback on the guidelines, including suggestions for additional guidelines.



8. Additional Technical Resources and Information



This section provides information on topics not included so far in the handbook but which may be of significance for PLHIV involvement on CCMs. It also includes contact details for key individuals and organizations. Much of the contact information in this section is subject to change, so details of where the information can be updated are included wherever possible. Many of the documents referenced are included on the CD accompanying this handbook. The resource section in GNP+'s Positive Development is particularly useful.

Some of the publications and documents mentioned in this section, such as Positive Development, are available in multiple languages. Unfortunately, others are available only in English. It is likely, however, that focused research will uncover resources translated into local languages and adapted for local cultures. International organizations can also assist in identifying the relevant materials and in training for the appropriate skills.

National and international laws

There is no country in the world without people who are vulnerable to HIV, such as migrants, refugees, sex workers, MSM, IDUs, women and young people. Yet there are different laws in every country that affect each of these groups, providing or denying them varying degrees of protection under the law. Such discrepancies and the repressive nature of some of the laws themselves result in a wide range of marginalization among populations especially vulnerable to HIV around the world.

For instance, in some countries women have no property inheritance rights when their husband dies. They and their children are often left homeless, destitute, and reliant on the goodwill of the deceased's family—all factors that leave them more vulnerable to HIV infection. Persecution, imprisonment, or mandatory "rehabilitation" of drug users and sex workers is common in several countries. As a result, many stay underground and cannot access information on safer sex and safer drug use that can help prevent HIV transmission. In places with particularly harsh anti-drug policies, drug users face the death penalty or may be killed with impunity by police. In some countries, it is illegal for men to have sex with men; seeking specific information on safer sex for MSM, if indeed that information exists, can result in intimidation or even imprisonment. Many countries bar HIV positive individuals from other nations from entering for any reason, even if they meet all other entry requirements.

The Global Fund was established to ensure that resources reached those populations most in need. Therefore, PLHIV groups and networks that play a part in the Global Fund processes need to be not only working with all vulnerable groups but also aware of the national laws relevant to these groups and the general laws covering HIV. In addition to national laws, there are also international laws that can be helpful in the planning, lobbying, and advocacy efforts of PLHIV networks. Finding this information may take some time and research; some excellent places to begin include the following:

1) POLICY Project

The Policy Project's Human Rights Matrix can be found online at www.policyproject.com/matrix/.

The Human Rights Matrix lists the international human rights documents that are important to reproductive and maternal health, family planning, and HIV/AIDS. The matrix also permits a user to access information about a country's human rights obligations. Using the matrix efficiently requires the following steps:

- a) Select a country and see the RH/MH/FP/HIV/AIDS-related human rights documents that this country's government has signed.
- b) Select a right and see what RH/MH/FP/HIV/AIDS-related human rights documents have to say about this right.
- c) Select a document and see which rights are listed in this document and the document's exact language about this right.

Included in the matrix is a link, www.policyproject.com/matrix/matrix2.cfm?SpecificRights=R5, to documents concerned with the right to non-discrimination on grounds of disability (including HIV status). Among the documents linked to are the following:

Legally Obligorating Documents

- Additional (San Salvador) Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights
- African (Banjul) Charter on Human and People's Rights
- Arab Charter on Human Rights
- Convention on the Rights of the Child
- European Convention for the Protection of Human Rights and Fundamental Freedoms
- International Covenant Economic, Social and Cultural Rights
- International Covenant on Civil and Political Rights

Standard Setting Documents

- Beijing Platform for Action
- Cairo Programme of Action
- UN Special Session on HIV/AIDS (UNGASS) Declaration of Commitment
- Universal Declaration of Human Rights

2) UNAIDS

The website of the Joint United Nations Program on HIV/AIDS (UNAIDS), at www.unaids.org, has information on national legislation regarding HIV in its country-by-country section.

3) GNP+

GNP+'s Positive Development Manual, online at www.gnpplus.net/programs.html, also has a useful section on legislation in various countries.

4) Other CCM members

Other CCM members may also be able to help identify relevant laws in their countries.

Relevant issued-based organizations and related documents and declarations

We have referred to several key documents and declarations in this handbook, among them the Global Fund Framework document and the CCM guidelines ("Guidelines on the Purpose, Structure and Composition of Country Coordinating Mechanisms"), both of which are available on the CD accompanying this handbook; the Paris (GIPA) and UNGASS Declarations; and the human rights documents mentioned above. However, there are numerous other documents and declarations relevant to the participation of PLHIV on CCMs and other related issues. We have included some of these on the CD in several subject folders. There are also issue-based organizations that can provide advice and information on key topics and help identify other relevant resources and information. A few of them are listed under the subject headings below.

Tuberculosis and malaria

Stop TB

The Global Partnership to Stop TB is made up of organizations and individuals committed to both short- and long-term measures to control and eventually eliminate TB. Like the Global Fund, it has a Partnership Forum that meets every two years. As the links between TB and HIV become more evident, especially given the large number of co-infected individuals, increasing numbers of PLHIV are becoming involved in efforts around TB. Several PLHIV were among those who attended the most recent Partnership Forum in Delhi, India, in May 2004. Additional information about TB may be found by contacting the Stop TB Secretariat, which is based in Geneva, Switzerland. Information on the Global Partnership to Stop TB can be found on its website, www.stoptb.org.

Roll Back Malaria

A good starting point for obtaining information on malaria is the Roll Back Malaria (RBM) partnership, which, like the Global Fund and Stop TB, is based in Geneva, Switzerland. RBM was launched in 1998 by the World Health Organization, UNICEF, UNDP and the World Bank. RBM's goal is coordinate efforts to halve the burden of malaria by 2010. The partnership is made up of more than 90 members, many from the nongovernmental sector, who work together to fight malaria. Additional information about RBM, including a list of members, can be found at its website, www.rbm.who.int/partnership.

Treatment

The International Treatment Preparedness Coalition is a global coalition of people living with HIV and their advocates who are working and advocating on HIV treatment issues. The coalition can be contacted via

Gregg Gonsalves
Director of Treatment and Prevention
Advocacy
Gay Men's Health Crisis
119 West 24th Street
New York, NY 10011
USA
Tel.: +1 212 367 1169.
E-mail: greggg@gmhc.org

World Health Organization

Avenue Appia 20
1211 Geneva 27
Switzerland
Tel: +41 22 791 21 11
Fax: +41 22 791 3111

The World Health Organization's 3 by 5 initiative is major effort to get three million PLHIV in the developing and middle income countries on ARVs by the end of 2005. It is a step towards the goal

of providing universal access of HIV/AIDS prevention and treatment services for all who need them as a human right. You can find out more about “3x5” on the organization’s website at www.who.int/3by5/en.

Médecins Sans Frontières

Médecins Sans Frontières runs a Campaign for Access to Essential Medicines. More details can be found online at www.accessmed-msf.org.

Women’s issues

ICW – see below

Young people’s issues

Young Positive

Contact details for this new organization of young people living with HIV can be obtained from GNP+ (see below).

United Nations Children’s Fund

UNICEF Headquarters
UNICEF House
3 United Nations Plaza
New York, NY 10017
USA
Tel: +1 212 326.7000
Web: www.unicef.org

Sex Workers’ issues

The Network of Sex Work Projects was founded in 1991 as an informal alliance to participate in independently financed projects in partnership with member organizations and technical support agencies. The Network has recently established a secretariat, which was based in Cape Town in 2002 and moved to Rio de Janeiro in 2003. A board has been established to enable the network to act as a legally constituted international organization to promote sex workers’ health and human rights.

Network of Sex Work Projects

Rua Visconde de Pirajá
03 apt 803
Ipanema
22410-001 Rio de Janeiro
RJ Brazil
Tel: +55 21 2522 5944
Fax: +55 21 2523 9602
E-mail: secretariat@nswp.org
Web: www.nswp.org

Drug users’ issues

Asian Harm Reduction Network (AHRN)

PO Box 235 Phrasingh Post Office
Chiang Mai
Thailand 50200
Tel: +66 53 894112
Fax: +66 53 894113
E-mail: ahrn@loxinfo.co.th

Central and Eastern European Harm Reduction Network (CEEHRN)

Pamenkalnio St. 19-6,
Vilnius
Lithuania
Tel. +370 52691 600
Fax: +370 52691 601
E-mail: info@ceehrn.org

Latin American Harm Reduction Network: RELARD

Dr. Fabio Mesquita
Tel: +55 13 467 6623
Fax: +55 13 289 1857

Human rights

Human Rights Watch

350 Fifth Avenue, 34th floor
New York, NY 10118-3299 USA
Tel: +1 212 290-4700
Fax: +1 212 736-1300
E-mail: hrwnyc@hrw.org

Prisoners

Canadian HIV/AIDS Legal Network

417 Saint-Pierre Street, Suite 408
Montréal, Québec H2Y 2M4
Canada
Tel: +514 397-6828
Fax: +514 397-8570
E-mail: info@aidslaw.ca

Migrants, refugees, and displaced people

Coordination of Action Research on AIDS and Mobility (CARAM)
Asia Secretariat

8th Floor, Wisma M L S 31,
Jalan Tuanku Abdul Rahman
50100 Kuala Lumpur
Malaysia
Tel: +603-2697-0708 / +603-2697-0219
Fax: +603-2697-0282
E-mail: caraminfo@yahoo.com or
infom@caramasia.org
Web: www.caramasia.org

United Nations High Commissioner for Refugees

Case Postale 2500
CH-1211 Genève 2 Dépôt
Switzerland
Tel: +41 22 739 8111
Web: www.unhcr.org

Gay, lesbian, bisexual, and transgender

International Lesbian and Gay Association (ILGA)

Administrative Office
Rue Marché-au-Charbon, 81
B 1000, Brussels
Belgium
Tel: +32-2-5022471
Fax: +32-2-5022471
Email: ilga@ilga.org

Stigma and discrimination

The Seven Sisters Network

Web: www.7sisters.org

The Coalition of Asia Pacific Regional Network on HIV/AIDS (the Seven Sisters) is a broad-based alliance of organizations working with affected communities and vulnerable populations such as drug users, sex workers, transgender communities, MSM, HIV positive people and mobile populations. APN+, one of the members of the 7 Sisters, recently conducted a peer-led study to document the discrimination faced by PLHIV in the region.

Useful Contacts

Key people at the Global Fund Secretariat

Many PLHIV who are active in their countries have found it productive to develop good working relationships with the Fund Portfolio Manager for their country or other staff members of the Global Fund Secretariat. Below are some suggestions of who might be useful to get to know.

- The **Fund Portfolio Manager** for the country. Each country that has been awarded a Global Fund grant has a Fund Portfolio Manager assigned to it. Within the Secretariat, the Fund Portfolio Managers are organized into teams, known as clusters, each of which focuses on a particular region or sub-region. Each cluster has a leader, who is him or herself a Fund Portfolio Manager. Each Fund Portfolio Manager will be responsible for several countries; therefore, since they and the countries to which they are assigned change on a regular basis, they are not listed here. Regularly updated information on each country's Fund Portfolio Manager can be found on the Global Fund website at www.theglobalfund.org by selecting a specific country.
- The **CCM Development Coordinator**, Doris D'Cruz Grote, is an excellent person to contact at the Global Fund Secretariat. The CCM Development Coordinator is the focal point for all issues related to CCMs. In 2004, one of the coordinator's many responsibilities was to initiate and oversee 20 detailed CCM studies. These studies are broader than the GNP+ surveys, which focus only on the involvement of PLHIV. They are available on a separate CD accompanying this handbook. Doris D'Cruz Grote may be reached via e-mail at doris.dacruzgrote@theglobalfund.org
- The **Civil Society Relations Manager** is another key person in the Secretariat. This individual is responsible for liaisons with civil society groups, including PLHIV, and thus works closely with GNP+, ICW, and the regional networks of PLHIV as well as with the Communities and NGO delegations on the Global Fund Board. At the time this handbook was going to press, the Secretariat was in the process of recruiting a new Civil Society Relations Manager, who will start in early 2005. He is Mick Matthews and his e-mail address will be mick.matthews@theglobalfund.org
- The person responsible for **In-Country Support for Civil Society and the Private Sector**, Ntombekhaya Matsha, is another key person, especially for those involved in the implementation of Global Fund grants. Her e-mail address is ntombekhaya.matsha@theglobalfund.org

Key people on the Global Fund Board

The Global Fund Board has the final say in all matters of policy related to the Global Fund. Good relations and lines of communication with board members and their delegations can help facilitate the flow of ideas and opinions from the community level to the board meetings. The board has members from governments, NGOs, communities, and the private sector. Although it is extremely helpful for PLHIV to develop good relations with each board member or delegation member in their region, the natural points of contact for PLHIV are usually with the nongovernmental delegations, especially if they want to have their views represented at board meetings.

Global Fund delegations include the Developing Country NGOs Delegation, the Developed Country NGOs Delegation, and the Communities Living with the Three Diseases Delegation. Each of these three nongovernmental delegations consists of 10 members, including one board member, one alternate, and one communications focal point. All three of the nongovernmental delegations include some PLHIV, but every member of the communities living with the three diseases delegation is living with HIV. Many members of the Communities delegation have also had TB and/or malaria. The current NGO board members, alternates, and focal points are listed below along with their contact details.

**Communities
(NGO representative of
communities living with the
diseases) delegation**

Board member

Ms. Anandi Yuvaraj
Program officer of India HIV/AIDS
Alliance
E-26, 1st Floor, Greater Kailash Part-I
New Delhi-110048
India
Tel: +91 11 51 633 081/ 84
Fax: +91 11 51 633 085
E-mail: ayuvaraj@allianceindia.org

Alternate

Mr. Rodrigo Pascal
Executive Coordinator
Vivo Positivo REDLA+
San Isidoro 367
Santiago, Chile
Tel: +56 2 635 93 96
Fax: +56 2 635 39 51
E-mail: rpascal@vivopositivo.org

Focal Point

Mr. Stuart Flavell
Director
Global Network of Positive People living
with HIV/AIDS (GNP+)
P.O.Box 11726
1001 GS, Amsterdam
Netherlands
Tel: +31 20 320 82 56
Fax: +31 20 423 42 24
E-mail: gnp@xs4all.nl

**Developed Country NGO
delegation**

Board Member

Dr. Hélène Rossert-Blavier
Director General
AIDES Federation
14 rue Scandicci
93 500 Pantin
France
Tel: +33 1 41 83 4606
Fax: +33 1 41 83 4609
E-mail: hrossert@aides.org

Alternate

Mr. Jairo Pedraza
International Program Director
Cicatelli Associates
2-12 Seaman Ave.,
3H New York, NY 10034
USA
Tel: +1 212 569 6023
Fax: +1 212 942 8530
E-mail: jpgfna@aol.com

Focal Point

Mr. Richard Burzynski
Executive Director
International Council of AIDS Service
Organizations
ICASO – Central Secretariat
65 Wellesley Street East, Suite 403
Toronto, ON
Canada M4Y 1G7
Tel: +1 416 921 0018 ext.15
Fax: +1 416 921 9979
E-mail: richardb@icaso.org

Developing Country NGO delegation

Board Member

Ms. Rita Arauz Molina
President
Fundacion Nimehuatzin De los semaforos
de ENEL 1c. arriba,
1c. al sur 1/2c. abajo No.611
Managua
Nicaragua
Tel: +505 278 0028
Fax: +505 278 6534
E-mail: nimehuatzin@cablenet.com.ni

Alternate

Ms. Razia Essack-Kauaria
Secretary General
Red Cross Society
P.O. Box 345
Windhoek
Namibia
Tel: +264 61 23 5226
Fax: +264 61 22 8949
E-mail: secgen@redcross.org.na

Focal Point

Ms. Lucy Ng'ang'a
Program Director
Eastern African Nation Network
of AIDS Service Organisations
Njiro Road
Themi Hill Plot 45
Arusha
Tanzania
Tel: +255 27 250 7521
Fax: +255 27 254 8224
E-mail: eannaso@eannaso.org

Other Global Fund Board Delegation Focal Points

Voting Members

Canada (Germany, United Kingdom, Switzerland)

Ms. Ranu Sharma
Program Officer
Program Against Hunger, Malnutrition and
Disease
Canadian International Development
Agency
200 Promenade du Portage
Gatineau, Quebec
Canada K1A 0G4
Tel: +1 819 953 1379
Fax: +1 819 953 5348
E-mail: ranu_sharma@acdi-cida.gc.ca

Eastern Europe (Romania)

Dr. Radu Constantiniu
General Director
Ministry of Health
1-3 Cristian Popisteanu Str., Sector 1,
010024 Bucuresti
Romania
Tel: +4021 307 2608
Fax: +4021 307 2607
E-mail: raducons@ms.ro

Eastern Mediterranean Region (Pakistan)

Mr. Muhammad Raza
Director/Secretary CCM
Health Services Academy
12D West Bewal Plaza
Fazal Haq Road Blue Area
Islamabad
Pakistan
Tel: +92 51 922 1321
Fax: +92 51 922 2034
E-mail: hsaacademy@yahoo.com

**Eastern & Southern Africa
(South Africa)**

Mr. Ray Mabope
Special Adviser to the Minister of Health
Ministry of Health
Private Bag x339
Pretoria
South Africa
Tel: +27 12 312 08 60
Fax: +27 12 325 55 26
E-mail: raymabope@health.gov.za

European Commission (Belgium)

Mr. Henrik Hansen
Human and Social Development
Directorate General for Development
European Commission
Rue de Genève 12
1140 Brussels
Belgium
Tel: + 32 22 99 30 30
Fax: + 32 22 96 36 97
E-mail: henrik.hansen@cec.eu.int

France (Luxemburg, Spain)

Mr. Frédéric Goyet
Chargé de Mission
SIDA et maladies transmissibles
Bureau de la Santé DCT/HSA
Ministry of Foreign Affairs
20 rue Monsieur
75007 Paris
France
Tel: +33 1 53 69 31 86
Fax: +33 1 53 69 37 19
E-mail: frederic.goyet@diplomatie.gouv.fr

Italy

Mr. Giorgio Guglielmino
Head of Division I
Directorate General for Development
Cooperation
Ministry of Foreign Affairs
Piazza della Farnesina 1
00194 Rome
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Tel: +39 06 36 915 489
E-mail: giorgio.guglielmino@esteri.it

Japan

Dr. Yasuhisa Nakamura
Deputy Director
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1-2-2, Kasumigaseki
Chiyoda-ku
100-8916 Tokyo
Japan
Tel: +81 3 3595 2403
Fax: +81 3 3501 2532
E-mail: kasai-takeshi@mhlw.go.jp

**Latin America & Caribbean
(Barbados)**

Ms. Barbara Vandyke
Pan Caribbean Partnership Against
HIV/AIDS (PANCAP)
Caribbean Community Secretariat
(CARICOM)
57 High Street, Kingston
Georgetown
Guyana
Tel: +592 223 5028
Fax: +592 226 4127
E-mail: bvandyke@caricom.org

**Point Seven (Sweden - Denmark,
Ireland, Netherlands, Norway)**

Mr. Bengt Gunnar Herrström
Deputy Director
Dept. for Global Development (GU)
Ministry for Foreign Affairs
103 39 Stockholm
Sweden
Tel: +46 8 405 5482
Fax: +46 8 723 1176
E-mail: bengt-gunnar.herrstrom@foreign.ministry.se

Private Foundations

Mr. Todd Summers
Progressive Health Partners
1350 Connecticut Ave, Suite 900
Washington, DC 20036
USA
Tel: +1 202 207 13 36
Fax: +1 202 478 16 31
E-mail: todd@phpartners.com

Private Sector

Dr. Kate Taylor
 Director
 Global Health Initiative
 World Economic Forum
 91-93 Route de la Capite
 Cologny
 1223 Geneva, Switzerland
 Tel: +41 22 869 14 96
 Fax: +41 22 786 27 44
 E-mail: kate.taylor@weforum.org

Southeast Asia (India)

Ms. Meenakshi Datta Ghosh
 Additional Secretary and Project Director
 National AIDS Control Organization
 Ministry of Health and Family Welfare
 9th Floor, Chandralok Building
 36 Janpath
 New Delhi- 110001
 India
 Tel: +91 11 2332 5331 / 2301 9066
 Fax: +91 11 2301 3793
 E-mail: mdg@nacoindia.org

USA

Ms. Pamela J. Pearson
 Acting Director, Office of Diplomatic
 Initiatives
 Office of the U.S. Global AIDS
 Coordinator (S/GAC)
 Room 1004, Department of State
 Washington, DC 20520
 USA
 Tel: +1 202 663 2471
 Fax: +1 202 647 5792
 E-mail: pearsonpj@state.gov

**West and Central Africa
(Cameroon)**

Dr. Maurice Fezeu
 MD/ Health Economist, Health Sector
 Expert
 Consultative and follow-up committee for
 the Management of HIPC resources
 CNR Building: 10th floor; door 1002
 Yaounde
 Cameroon
 Tel: +237 992 48 65
 Fax: +237 222 02 33
 E-mail: mauricefe@yahoo.fr

Western Pacific Region (China)

Dr. Xing Jun
 Deputy Director
 Division of Multilateral Relations
 Department of International Cooperation
 Ministry of Health
 1 Xiwai Nanlu
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 China
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 Fax: +86 10 6879 2279
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8

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Board members and delegation members change from time to time. Updated lists of board members are posted on the Global Fund website and contact information for all delegation members is available from the delegation Focal Points, whose e-mail addresses are available on the website at www.theglobalfund.org/en/about/board/contact/ or from the Board

Relations Manager at the Global Fund Secretariat, who can be reached via e-mail at dianne.stewart@theglobalfund.org.

International and regional networks for PLHIV

• The Global Network of People living with HIV/AIDS (GNP+)

The Global Network of People living with HIV/AIDS (GNP+) is a global network for and by people with HIV/AIDS. The mission of GNP+ is to work to improve the quality of life of people living with HIV/AIDS. The central secretariat of GNP+ is based in Amsterdam, the Netherlands.

GNP+ works with six affiliated regional networks of PLHIV. Each of these networks sends two persons to represent its respective region at the GNP+ board meetings. These 12 AIDS activists and advocates constitute GNP+'s governing body.

GNP+ achieves its mission through advocacy, capacity-building, and communications programs that draw from strategies based on

- lobbying for inclusion, visibility, access, and rights;
- linking by networking, mentorship, dialogue, and education; and
- sharing of capacities, knowledge, strength, and resources.

Among other activities, GNP+ organizes international conferences for PLHIV. GNP+ also carries out the role of Communication Focal Point for the Global Fund delegation for communities living with the three diseases, and its members have played a key role in the Global Fund since its inception.

Becoming a member of GNP+
Membership in GNP+ is open to all PLHIV. Registration forms for membership can be obtained from the GNP+ Secretariat or regional offices (see contact details below).

Contact details:

GNP+ Central Secretariat
 P.O. Box 11726
 1001 GS, Amsterdam
 Netherlands
 Tel: +31 20 423 4114
 Fax: +31 20 423 4224
 E-mail: info@gnpplus.net

Network of African People Living with
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 Kenya
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 Fax: +254 20 331 897
 E-mail: nep@wananchi.com

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 with HIV/AIDS (APN+)
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 Fax: +662 255 1128
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Caribbean Regional Network of People
 Living with HIV/AIDS (CRN+)
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 E-mail: crnplus@tstt.net.tt

European Network of People Living with
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**Latin America Network of
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 Fax: +202-332-7087
 Email: info@gnpna.org

• **The International Community
 of Women living with HIV/
 AIDS (ICW)**

ICW is an international network of women living with HIV/AIDS with 2,700 members in 120 countries and an International Support Office based in London. It is also establishing regional offices, the first of which is the Southern Africa Regional Coordinating Office, set up in Swaziland in April 2004. ICW has an international governance structure with trustees based in nine countries. Some ICW members are on the CCMs in their countries, and ICW is represented on the Global Fund Board delegations. ICW advocates strongly for the inclusion of women and girls living with HIV in all areas.

Membership of ICW

Membership in ICW is open to all women living with HIV. Membership information and forms can be found on the ICW website at www.icw.org

Contact details

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• The International Council of AIDS Service Organizations (ICASO)

ICASO is not an organization of PLHIV, but rather network of NGO s working in HIV/ AIDS. There are many linkages between the members of ICASO and networks of PLHIV. As with GNP+ and ICW, ICASO members have been deeply involved with the Global Fund from the start, and ICASO acts as the Communication Focal Point for the Developed Country NGO Delegation on the Global Fund Board. ICASO has produced many useful guides and publications, some of which are about the Global Fund. These can be accessed via the ICASO website at www.icaso.org.

Contact details:

International Secretariat
 Contact person: Richard Burzyiski
 E-mail: richardb@icaso.org
 Web: www.icaso.org

Contact details for the ICASO regional offices can also be obtained from the International Secretariat or via the ICASO website.

Contact details for people involved in creating the manual

As mentioned at the beginning of the handbook, over 400 people have been involved in some way or another in the creation of this handbook. Such a large number means that it is impossible to list everyone's contact details. Instead, we are listing two organizations and contact persons that where any questions, comments and suggestions can be sent.

Francoise Welter
 The Global Network of People living with HIV/AIDS (GNP+)
 E-mail: fwelter@gnpplus.net

Philippa Lawson
 POLICY Project
 E-mail: plawson@futuresgroup.com

Other resources

Global Fund-related information and discussion groups on the Internet

Aidspan is a small U.S.-based NGO that promotes awareness and support for the Global Fund. Aidspan produces a regular electronic newsletter, Global Fund Observer (GFO), which shares detailed and candid analysis and information on Global Fund policies and activities. More information about Aidspan and GFO can be found online at www.aidspan.org/.

Health & Development

Networks (HDN) is involved in a number of activities focused on HIV/AIDS, including the moderation of various electronic discussion fora. In the early days of the Global Fund, HDN ran a forum called “Break the Silence” where members could discuss their views on the Global Fund. More recently, HDN moderated another electronic discussion forum about the Global Fund called “PartnersGF,” which allowed those who could not attend the Partnership Forum in Bangkok to add their views regarding the process. More information about HDN can be found at its website, www.hdnet.org/home2.htm.

REDLA+ houses the regional Secretariat for GNP+ in Latin America and runs an e-mail discussion in Spanish known as ESVIHSIDA. Information on REDLA+ and on the discussion group can be found on its website, www.redla.org.

Supporters of this handbook

Deutsche Gesellschaft für Technische Zusammenarbeit (GTZ) BACKUP Initiative

GTZ has nearly 20 years of experience in HIV/AIDS programs in more than 40 countries worldwide. Recognizing HIV/AIDS as one of the major obstacles to development, GTZ has incorporated HIV/AIDS as an integral part of its activities. The organization supports multisectoral HIV/AIDS programs in all relevant sectors of societies and offers comprehensive prevention, care and treatment programmes at the national level. GTZ provides private and public clients with advisory services on the introduction and implementation of HIV/AIDS interventions at the workplace.

To accelerate the fight against HIV/AIDS, GTZ BACKUP Initiative assists partner countries in accessing and implementing global finance. GTZ is committed to fostering the involvement and greater participation of those infected with or affected by HIV/AIDS in planning and implementation processes. Therefore, GTZ BACKUP Initiative supports global, regional and national networks of people living with HIV/AIDS.

Much of its focus is on strengthening CCMs and organizations that are members of CCMs. GTZ also focuses on strengthening partnerships to make better use of Global Fund resources and provides assistance for development of skills and knowledge of implementing stakeholders. Among bilateral donors, GTZ scores high marks for its support of PLHIV in Global Fund processes—including assistance with this handbook. Additional information may be found at GTZ’s website, www.gtz.de/backup-initiative/.

POLICY Project

Building on more than 25 years of experience in population and development, the POLICY Project works with host-country governments and civil society groups to achieve a more supportive policy environment for family planning/reproductive health (FP/RH), HIV/AIDS, and maternal health. POLICY's approaches to better reproductive health policies and programs are characterized by multisectoral engagement, community and organizational empowerment, and promotion of human rights and gender equality.

The POLICY Project brings to its work a strong background in program management and support, capacity development, advocacy, training, strategic planning, policy formulation, research, and monitoring and evaluation. POLICY staff also contribute their expertise in public health, gender analysis, law and human rights, economics and health finance, community mobilization, and data analysis and modeling.

POLICY is proud of its unique organizational structure that places emphasis on using highly skilled, experienced in-country staff and on building the capacity of local counterparts. The organization's U.S.-based staff of 60 works closely with some 130 local professionals and 200 partner organizations in more than 30 countries across Africa, Asia and the Near East, Eastern Europe and Eurasia, and Latin America and the Caribbean.

What does POLICY do?

To improve the policy environment, the POLICY Project endeavors to

- broaden and strengthen political and popular support for FP/RH, HIV/AIDS, and safe motherhood policies and programs;

- improve the operational environment for these programs, including better planning and financing;
- ensure that accurate, up-to-date information informs policy decisions; and
- build in-country and regional capacity to participate in policy development.

POLICY embraces multisectoral approaches that involve partnering with and providing technical assistance to government agencies, civil society groups, private sector organizations and research institutions to develop policies and plans that guide the implementation of responsive, sustainable programs and services. A key component of POLICY's approach to improving programs and services is to build in-country capacity of partners to participate in policymaking processes. This approach empowers communities, encourages broad-based participation, and ensures program effectiveness and sustainability. Additional information about the POLICY Project may be found on its website at www.policyproject.com. The POLICY Project is supported by the U.S. Agency for International Development (USAID).

Planning summary page

Based on discussions regarding different sections of this handbook, the grid below can be used to provide an overall picture of the needs and planned actions in each country regarding PLHIV involvement on CCMs. It may be useful as a template for developing a strategic plan. (will be laid out across two pages)

Area of work	Planned actions	Who needs to be involved	Time frame	Plans to monitor progress and document results
Skills and experience for PLHIV CCM members and alternates				
Roles and responsibilities for PLHIV CCM members and alternates				
Roles and responsibilities for constituency members				

Area of work	Planned actions	Who needs to be involved	Time frame	Plans to monitor progress and document results
Group and network development				
Creating alliances with other groups				
Communication strategies				

Feedback Questionnaire: PLHIV Views on the Handbook



Readers' opinions and assessment of this handbook are important to us. Without them we cannot make changes and improvements to how we do things in the future.

All readers are asked to take a few minutes to photocopy this form (or tear it out of the handbook), fill it out, and then send it to:

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P.O. Box 11726,
1001 GS,
Amsterdam,
Netherlands
Fax: +31 20 423 4224
E-mail: info@gnpplus.net

Section 1

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 2

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 3

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 4

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 5

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 6

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 7

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Section 8

Do you agree with the following statements?

Rate each answer from 1 – 5. 1 = strongly disagree; 5 = strongly agree

The content was easy to read 1 2 3 4 5

The content will help me in my work 1 2 3 4 5

What was the most useful aspect of this section?

What was the least useful aspect of this section?

What would have helped to improve this section?

Overall usefulness of the handbook

How would you rate the usefulness of the handbook?

1 = very poor; 2 = poor; 3 = fair; 4 = good; 5 = very good

1 2 3 4 5

Overall design and layout of the handbook

How would you rate the design and layout of the handbook?

1 = very poor; 2 = poor; 3 = fair; 4 = good; 5 = very good

1 2 3 4 5

Language and education of PLHIV CCM members

As you may remember from Section 4, PLHIV who collaborated on this handbook did not reach agreement on the issues of language and education of PLHIV members. Please tell us what you think about these issues.

Is there any other feedback you would like to give about this handbook?
Please do so below.

About you

Are you a PLHIV? Yes No

If yes, what HIV-related activities are you involved in?

If no, what is your connection with HIV?

What country do you live in?

Were you involved with a CCM before reading this handbook? Yes No

Were you involved in any other way with the Global Fund
before reading this handbook?

Yes No

If no, do you plan to become involved in the CCM in your country? Yes No

Tell us how this handbook was used in your country

Please mark the appropriate boxes (you can mark more than one).

- ☐ I read it on my own
- ☐ I did some or all of the exercises
- ☐ After I read it, I discussed the contents with other PLHIV
- ☐ I read it with other PLHIV from my group/network
- ☐ We did some or all of the exercises
- ☐ Our CCM member(s)/alternate used this handbook
- ☐ This handbook was shared with non-PLHIV
- ☐ I/we would recommend other PLHIV to read the handbook

Thanks to:

Allan Dunaway
Alliance Rights Nigeria
All Ukrainian PLWHIVA Network
Alice Wanjuu
Anjan Amatya
Angeline Siparo
Arthur Ovsepyan
Anandi Yuvaraj
Anatoliy Bondarenko
Andrew Doupe
Anne Eckman
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Asia Pacific network of People living with HIV/
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Association of Positive Youths in Nigeria
Association of Positive Women in Nigeria
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Centre for the Right to Health
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Caribbean Network of PLHIV (CRN+)
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Network of People living with HIV/AIDS in Nigeria (NEPWHAN)	Tita Isaac
NAP+ (Network of African People living with HIV)	Tommy Thompson
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Odir Miranda	Unique AIDS Control Program
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Oswaldo Rada	Women Against AIDS and infectious diseases
Pablo Anamaria	Women and Children of Hope
Pablo Magaz	Women Fighting AIDS in Kenya (WOFAK) Women of Hope Organisation
Paisan Suwannawong	Xiomara Hernandez
PATAM, Nigeria	Yawo Gouna
Paul Ehmer	
Philippa Lawson	

And many more who helped with the handbook but preferred to stay anonymous or whose names we did not have permission to mention.

And remembering:

Joseph Scheich
Charles Roy
Brigitte Symalwwe
Igor Menshikov
David O. Sira
Ruvinus Obiero

And all those friends and fellow activists
we have lost along the way.



Deutsche Gesellschaft für
Technische Zusammenarbeit (GTZ) GmbH

After reading the draft, I felt so empowered and ready to represent PLHIV with confidence at any level.

— PLHIV from Kenya

The country team working on the draft handbook strongly feels that it's a great resource for PLHIV.

— PLHIV from Malawi

The group in Honduras consider the handbook to be a tremendous tool for them and they are sure it will be a great tool for all PLHIV in countries where the Global Fund is working.

— PLHIV from Honduras

This draft handbook is of very great use, even outside the CCM. A lot of sensitive topics raised by the handbook were discussed freely at the meetings and a lot of recommendations were made for the Nigerian Network and the Global Network.

— PLHIV from Nigeria

For more information contact:

POLICY Project

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