

# Baseline survey

of GIPA and stigma and discrimination in the Greater Mekong Region

## Report on qualitative surveys in Lao PDR, Thailand, Vietnam, and Guangxi and Yunnan Provinces, China

October 2005

APN+

POLICY Project



**USAID**  
FROM THE AMERICAN PEOPLE





# **Baseline survey of GIPA and stigma and discrimination in the Greater Mekong Region**

## **Report on qualitative surveys in Lao PDR, Thailand, Vietnam, and Guangxi and Yunnan Provinces, China**

October 2005

APN+

**POLICY Project**



## Table of Contents

<b>Acknowledgements.....</b>	<b>3</b>
<b>Acronyms .....</b>	<b>4</b>
<b>Executive summary.....</b>	<b>5</b>
<b>1. Introduction .....</b>	<b>8</b>
<b>2. Methodology .....</b>	<b>10</b>
2.1 Possible limitations of the methodology .....	12
<b>3. Interviewee profiles.....</b>	<b>14</b>
<b>4. Format of this report .....</b>	<b>16</b>
<b>5. Overview of survey results (country by country).....</b>	<b>17</b>
5.1 Yunnan.....	17
5.2 Guangxi.....	18
5.3 Lao .....	20
5.4 Viet Nam.....	21
5.5 Thailand .....	22
<b>6. Challenges and opportunities.....</b>	<b>24</b>
6.1 Possible interventions .....	24
6.2 Possible indicators .....	26
<b>7. Survey results .....</b>	<b>29</b>
7.1 GIPA.....	29
7.2 Stigma and discrimination .....	41
<b>Viet Nam.....</b>	<b>53</b>
7.3 Improving conditions for PLHAs .....	56
<b>8. Overall observations .....</b>	<b>62</b>
<b>Annex 1.....</b>	<b>65</b>
<b>Annex 2.....</b>	<b>82</b>
<b>Annex 3.....</b>	<b>89</b>
<b>III. Questionnaire for Civil Society Leaders and NGOs.....</b>	<b>94</b>
<b>IV. Questionnaire for People Living with HIV/AIDS.....</b>	<b>95</b>

# Acknowledgements

The original concept for the survey was developed by Patchara Rumakom, Program Specialist, USAID Regional Development Mission/Asia, Felicity Young, Deputy Director, POLICY Project and Chris Hermann, Consultant, POLICY Project. The questionnaires were developed by Chris Hermann and reviewed by Greg Gray, Regional Coordinator, APN+ and David Lowe, Consultant, POLICY Project. Technical oversight of all aspects of this work was provided by David Lowe. Local consultants to conduct the surveys were identified by APN+ with the assistance of their in-country affiliates and broader networks, with input from the POLICY Project country programs in China and Vietnam. The local consultants who undertook the surveys were:

- Lao PDR: Dr Bounsuane and Mr Kham Souan
- Thailand: Dr Wassann Im-em and Khun Prairat
- Vietnam: Nguyen Thi Diu and Nguyen Thi Tuyet Lan
- Guangxi: Dr Xie Yong Hong and Ren Guoliang
- Yunnan: Mae Zhou and Ying Cong

This report was written by Chris Hermann and Tim Leach, Consultants, POLICY Project.

The POLICY Project and APN+ wish to thank all people who contributed to this study.

# Acronyms

ARVs	Anti-retroviral therapies
CBO	Community based organisation
CDC	Centre for Disease Control
GIPA	Greater involvement of people living with HIV/AIDS
IEC	Information, education and communication
MSF	Médecins Sans Frontiers
MTCT	Mother-to-child-transmission
NGO	Non-government organisation
PHB	Public Health Bureau
PLHA	Person living with HIV/AIDS
PLHAs	People living with HIV/AIDS
USAID	United States Agency for International Development
VCT	Voluntary counselling and testing
WHO	World Health Organisation
WAD	World AIDS Day

# Executive summary

1. The methodology employed in relation to this research has been appropriate and has elicited useful baseline information. In particular, interviewing different groups of stakeholders has enabled group views to be cross-referenced with the perceptions of other stakeholders, indicating significant divergence of views in relation to the extent to which GIPA is being implemented and the prevalence of stigma and discrimination.
2. The central role in this research of people with HIV, and the partner organisation APN+, has modelled good GIPA practice, and has no doubt added to the effectiveness of the process, to the willingness of different groups, particularly PLHAs, to participate, and to the quality of the outcomes.
3. Despite substantial efforts to standardise country reports (or provincial reports in the case of China), there are significant variations between reports. Efforts will need to be made in relation to future surveys of this kind to minimise variation in report writing.
4. Many PLHAs do not disclose their status due to fear of discrimination. It is important, therefore, that studies such as this one look beyond actual experiences of discrimination and also research stigma and fear of discrimination.
5. Many PLHAs experience stigma and discrimination in many facets of their lives – at the hands of government, from health service providers, from NGOs, in the workplace, from family and friends and in general community life. Significant levels of stigma and discrimination were reported in all surveyed countries. This reality should fuel advocacy responses in support of GIPA and the significant reduction of stigma and discrimination.
6. Implementation of GIPA varies across countries, but the overall implementation of the principles remains extremely limited. Survey data demonstrates that there is solid support for the principles in theory, but there is clearly a long way to go before GIPA becomes a reality. ‘Engagement’ of PLHAs in HIV responses is piecemeal, often ‘one off’ rather than comprehensive or enduring, more likely to involve participation in an already-developed government program than assistance with program design, and is more likely to involve volunteerism than employment.
7. There is a solid basis for building on GIPA developments to date. There is commitment from all sectors (government, the health sector, NGOs and civil society) to inclusion of PLHAs in theory, and this is an important first step. There is some acknowledgement that PLHA perspectives are relevant and useful, so the challenge is to upscale this acknowledgement to something more meaningful. This will only happen if there is a long-term commitment to capacity building and developing the skills of PLHAs.

8. While health service providers, NGOS and civil society representatives are often critical of government failures in relation to GIPA, the survey results suggest these sectors could significantly enhance their own commitment to implementation of GIPA.
9. Perceived or actual capacity of PLHAs to contribute to development of policy or service responses to HIV is a significant barrier to greater engagement. This suggests an undervaluing of the consumer perspective in developing and implementing HIV programs – a failure to acknowledge that the very experience of being HIV-positive is of great use in helping to shape epidemic responses. It also suggests that greater engagement might be assisted through measures to train and support PLHAs, and to boost their confidence.
10. Perceptions of stigma and discrimination are different for PLHAs than for government officials, health service providers, civil society leaders and NGOs. PLHAs report higher rates of stigma and discrimination than other groups, and in circumstances where other stakeholders deny it.
11. Fear of discrimination prompts many PLHAs to keep their HIV status a secret. This results in significant under-measuring of stigma. While occurrences of discrimination might be prevented through such secrecy, the stigma that discourages disclosure continues unchallenged. Most interviewee groups thought that discrimination would be greater if more people were openly positive. Maintaining secrecy of status can have direct negative impacts on PLHAs. In the longer term, a greater degree of openness by PLHAs about their status will challenge HIV-related stigma and result in reduced levels of discrimination.
12. PLHA experiences of stigma and discrimination vary between urban and rural environments. Many respondents across different groups believe the situation for rural PLHAs is worse than for PLHAs living in main centres.
13. While many groups consider the rates of stigma and discrimination to be reducing, this is often not the view of PLHAs. This presents an obvious challenge for policy and decisions makers, as well as for those involved in the delivery of services to PLHAs. The survey results offer no basis for assuming that stigma and discrimination will be reduced without continued and concerted effort.
14. Different sectors acknowledge their different roles in combating HIV. This offers a useful basis for the development of partnership responses to HIV, where each sector seeks to meet its own responsibilities while acknowledging the capacities and expertise of other members of the partnership.
15. The survey results suggest a range of possible interventions that might be pursued by POLICY, APN+ and country level PLHA groups to capitalise on the expressed positive views of different stakeholders, and to facilitate a shift from GIPA as theory to GIPA in practice.

16. The survey results suggest a range of possible indicators that might be used to assess changes in the extent to which GIPA is being implemented, and changes in levels of HIV-related stigma and discrimination.

A summary of the survey results, country by country, is provided in section 5.

# 1. Introduction

The POLICY Project, funded by USAID, is supporting a variety of activities to facilitate development of an enabling environment necessary for more effective responses to the HIV/AIDS epidemic in the Great Mekong Region. This work is being undertaken within the context of USAID's HIV/AIDS Strategic Plan for the Greater Mekong Region 2003-2006. An enabling environment includes the implementation of appropriate policy and legal frameworks. Central to POLICY's work is advancing the implementation of the Greater Involvement of People Living with HIV/AIDS (GIPA) concept and reducing the stigma and discrimination that people living with HIV/AIDS (PLHAs) experience.

The Asia Pacific Network of People Living with HIV/AIDS (APN+) is the peak body representing and advocating on behalf of PLHAs in Asia and the Pacific. The membership of APN+ consists of national PLHA organisations. Promoting implementation of the GIPA principle and reducing stigma and discrimination is central to the work of APN+ and its members. The POLICY Project, with USAID funding support, has been providing capacity building and organisation support to APN+ over the last three years.

As with any development project, it is important to determine the progress and results with respect to support for GIPA and the reduction of stigma and discrimination. POLICY and USAID decided that given the nature of these areas of work, a qualitative survey of current conditions in five locations would be an appropriate way to assess progress and results being made over time. This report presents a summary of the baseline surveys conducted in Lao PDR, Thailand, Vietnam, and Guangxi and Yunnan Provinces, China<sup>1</sup>. The objective was to establish a country-by-country (or provincial) description of current conditions and a summary of common patterns or trends across the places surveyed, where they are found. A subsequent survey, planned for 2007, will generate a second description of conditions, with greater attention on what has changed over the intervening period of time.

This baseline survey project was jointly conducted by APN+ and the POLICY Project.

One additional outcome of the survey is that it is an example of at least one approach to monitoring and assessing progress on GIPA and stigma and discrimination. Considerable thought and effort has gone into the issue of developing appropriate indicators of change that can be monitored over time.<sup>2</sup> This baseline survey in four Mekong countries contributes to such work in that the results might be helpful in suggesting indicators appropriate for GIPA and stigma and discrimination that are attuned to prevailing conditions in the Region.

---

<sup>1</sup> The POLICY Project is currently operating country programs in Vietnam and Guangxi and Yunnan Provinces, China.

<sup>2</sup> One example is the "HIV/AIDS-related Stigma and Discrimination Indicators Development Workshop Report", February 10, 2004. USAID Inter-Agency Working Group on Stigma and Discrimination.

The survey results will also help identify priority areas of activity for POLICY, as well as others working on these issues, over the near-term.

Finally, and perhaps most important, the results constitute information that can be readily used for advocacy purposes, directed at government policy makers and officials about actions needed to advance GIPA and reduce stigma and discrimination.

## 2. Methodology

This regional baseline is based on interviews with 209 respondents, spread over five sites. A key informant approach was used and interviews were conducted with five different groups, described as follows:

- Senior government officials responsible for managing key elements of the national HIV/AIDS program (or provincial program in the case of Guangxi and Yunnan Provinces)
- Health workers providing services to HIV/AIDS clients at major public and private health facilities
- International and local directors or representatives of NGOs that support HIV/AIDS-related programs or services
- Civil society leaders who are active advocates or spokespersons for the needs and interest of PLHAs
- PLHAs.

The following table presents the distribution of respondents.

Location	Government Officials	Health Workers	Civil Society	NGO Rep's	PLHAs	Total
Guangxi	4	10	4	4	20	<b>42</b>
Yunnan	5	10	3	3	20	<b>41</b>
Lao	5	10	5	5	21	<b>46</b>
Thailand	3	9	5	5	18	<b>40</b>
Viet Nam	2	10	3	5	20	<b>40</b>
<b>Total</b>	<b>19</b>	<b>49</b>	<b>20</b>	<b>22</b>	<b>99</b>	<b>209</b>

Questionnaires quite similar in content were developed for each group of respondents covering:

- Knowledge about and support for GIPA
- Actions taken to implement GIPA
- Stigma and discrimination in medical services for PLHAs
- Testing procedures and confidentiality
- The economic, social, and human rights consequences of stigma and discrimination.

The questionnaires concluded with several questions concerning what actions government, medical services, NGOs and civil society could take to improve conditions for PLHAs. The questionnaires were developed by a consultant commissioned by the POLICY Project, in consultation with APN+. Annex 1 contains the questionnaires.

The interviews in each location were conducted by a two-person team consisting of an experienced research consultant and one PLHA.<sup>3</sup> POLICY worked with its partner organisation, APN+, to identify the team members who were contracted by APN+.

<sup>3</sup> The Guangxi team consisted of four members to speed up the process since identifying qualified consultants was difficult in this province and caused some delay.

POLICY provided technical backstopping by developing detailed instructions and guidelines for the team members.

After extensive review, the questionnaires were field pre-tested in Thailand after being translated into Thai and then back-translated to English to ensure the Thai translation was accurate. The pre-testing found no serious problems with the questionnaires, i.e. people could understand and respond to the questions. This translation/back-translation process was followed in the other countries as well.

Instructions concerning the interview process were prepared for the survey teams to try to achieve as much uniformity as possible. The instructions also explained how to go about selecting interviewees from each of the groups. For the PLHAs interviews, the teams were encouraged to seek a gender balance across their interviewees. In general, a good mix of respondents was willing to be interviewed. The guideline was to interview:

- Three to five government officials
- Five civil society leaders
- Five NGO representatives
- Ten health workers
- Twenty PLHAs.

As the above table shows, this distribution was achieved for most categories of interviewees in each place where the survey was conducted.

Those who were interviewed were purposively selected. There was no attempt at random selection because the number of people who would fit the criteria for the key informant groups is fairly small, with the exception of PLHAs. For that group, random selection was impractical given the constraints of the survey and the difficulty of identifying a sufficiently large population of PLHAs willing to be interviewed since so many conceal their HIV status.

The guidelines emphasized ethical considerations, including the right of anyone to decline to be interviewed or to stop the interview at any time, and the importance of maintaining confidentiality of the respondents in that no comments were attributable to identified individuals. This was explained to all respondents at the outset of the interview. This did not prove to be a problem for the respondents. Annex 2 contains the guidelines provided to consultants.

In addition to the survey instructions, specific questionnaire guidelines discussing the purpose of each set of questions were prepared to help the consultants clearly understand why these questions were being asked. Annex 3 includes these instructions.

The instructions to the consultants also discussed the use of the interview data to prepare a report following the same structure as the questionnaires. This proved perhaps the most problematic instruction for the teams.

## 2.1 Possible limitations of the methodology

As with all qualitative work, there are questions regarding the reliability and accuracy of the information collected. For logistical and cost reasons it was only possible to interview relatively small numbers of people from each of the categories (eg. government officials, PLHAs). It is not possible to say whether the views of interviewees are representative of other people from the same category who were not interviewed. A quantitative approach would have provided a greater degree of certainty in relation to the validity of responses, but far less in-depth data. The nature of the problems that are being addressed with respect to GIPA and stigma and discrimination are suited to the more in-depth exploration that a qualitative interview allows. Given limited time and resources, a very practical, fairly low-cost approach to creating a baseline was the most viable option. In general, the qualitative surveys did generate sufficient descriptive information to capture prevailing conditions as reported by different groups of key informants, plus changes in recent years, in some cases. This will enable POLICY and USAID to assess and report on progress made on what are very difficult matters to measure in a pure textbook sense.

Due to time and budget constraints, surveys were conducted only in the capital cities of Vientiane, Bangkok, Hanoi, and Kunming (Yunnan Province). The Guangxi survey was conducted in the capital city of the province and a number of other urban centres. For all surveys, many of the PLHA respondents were from various parts of the country or province, so the samples actually reflect a broader range of experiences than just those of people living in the capital city.

The five reports by local consultants on the results of their survey work vary in quality. Despite the detailed instructions provided to those conducting interviews, report writers have taken differing approaches to their work. Useful lessons can be learned from this outcome, and those involved in future surveys of this kind may need to pay close attention to trying to minimise these variations for future reports.

### Variations in report-writing style

The most significant difference in reports is that some reports have tended to present overall pictures of local responses, while others have taken care to distinguish views across various categories of interviewees, as was requested. The result is that for some countries, while an overview of the situation can be gained from the report, it is not always possible to determine how the views of, say, government officials, are different from the views of, for example, people with HIV. These reports offer readers the reviewers' perspectives (based on the interview data) but are not specific as to the views of interviewee groups. Two reports (Guangxi and Thailand) also collapsed views of civil society leaders and NGO representatives.

Occasionally, data is provided in the negative – for example, a report might declare that 70per cent of PLHA respondents did *not* experience a particular form of discrimination. It is not necessarily possible to conclude from this, however, that the other 30per cent *did* experience such treatment. They may, for example, have chosen not to answer.

Not all reports detail responses to all parts of the questionnaires, and some report responses suggest a misunderstanding of some questions.

### **Challenges for interviewees**

It is possible that some respondents may have felt some degree of inhibition in their ability to fully answer questions. For example, people employed in government departments or health care facilities may have been mindful that their comments would reflect on their employers and colleagues. In such circumstances, it is easy to appreciate why interviewees would be reluctant to be overly critical of their sectors. And even where confidentiality is guaranteed to the extent that no views are attributable to named individuals, views are linked to small groups and individual views might be inferred. This is more likely to be the case where only small numbers of respondents in the one category were interviewed. Maintaining anonymity regarding ones views is a greater challenge when views across a category are uniform – for example, where country reports declare that all interviewees in a particular category held a particular view. Nonetheless, the risk of linking views to individuals is minimised as the report does not reveal the identity of interviewees.

### **Meeting the category criteria for interviewees**

Generally, interviewers were able to find a sufficient number of respondents who matched the proposed criteria. Not all targets were met (notably in relation to government officials), but numbers of interviewees generally met targets, and at least eighteen PLHAs were interviewed in each country or province (with the target being surpassed in one).

‘Health care workers’ and ‘civil society leaders’ are broad categories. Within the category of ‘health care workers’, reviewers interviewed doctors, nurses (clinical and mental health), nurses’ aids/assistant nurses, counsellors and social workers. The views of ‘civil society leaders’ include feedback from interviews with, amongst others, people working in the media, business leaders and religious leaders.

### **Language issues**

Not surprisingly, there are challenges associated with multiple translations of data. As outlined above, considerable efforts were made to ensure that the survey instrument was correctly translated. Even so, the questions were probing and the responses detailed and sometimes complex. When considering the reports in English, there are occasional difficulties in comprehending the data. Given the project constraints, there have been limited opportunities to clarify some of these uncertainties and some data has been lost as a consequence. Overall, however, the reports have effectively conveyed interviewees’ feedback and the reports are a rich source of information.

### 3. Interviewee profiles

Country surveys (or provincial surveys, in the case of China) were conducted with interviewees as follows:

#### Yunnan<sup>4</sup>

The Yunnan study interviewed five senior government officials (from a national HIV/AIDS agency, Ministry of Health, Health Education Department and Public Security Bureau), ten health service providers who work directly with PLHA services (five doctors and five nurses), three directors of HIV/AIDS NGOs (international and national), three civil society leaders and twenty PLHAs. Amongst the PLHAs there was a mix of men and women and the group included sex workers, men who have sex with men, injecting drug users and five couples.

#### Guangxi<sup>5</sup>

Interviews were conducted with four government officials (from the Guangxi PHB, Guangxi CDC, Pingxiang government and Ningming government), seven people from NGOs and civil society (including people from three different international NGOs), ten health service providers (from Guangxi CDC HIV/AIDS Department, Guangxi CDC/MSF clinic, Pingxiang CDC counselling centre and Ningming CDC) and twenty PLHAs from the cities of Nanning, Liuzhou, Pingxiang, Hezhou and Qinzhou, as well as from the counties of Ningming, Heng and Lingshan.

#### Lao<sup>6</sup>

The Lao study interviewed five government officials from the National HIV/AIDS Program, Ministry of Health, Lao Women's Union, Youth Union and the Health Education Centre. Ten health service providers were interviewed, including two doctors from each of the two main public hospitals, assistant doctors, nurses and counsellors. The study interviewed five people from NGOs, including representatives of four international NGOs and one local NGO, and five civil society leaders (three media representatives, a religious organisation and a business manager).

#### Viet Nam<sup>7</sup>

Interviews were conducted with forty people. Of this group, twenty were PLHAs, ten were health service providers, five were from NGOs, three were civil society leaders and two were government officials. The surveys were conducted in Hanoi but interviewees were from a range of locales including Hanoi, Quang Ninh, Hai Phong, Bac Ninh and Hai Duong.

---

<sup>4</sup> Zhou Hongmei and Yingcong, Stigma and Discrimination Survey in Kunming, China

<sup>5</sup> Xie Yonghong, Liu Wei, Ren Guoliang and Wang Pien, Greater involvement of people living with HIV/AIDS (GIPA) and stigma and discrimination survey

<sup>6</sup> Bounsouane and Kham Souan, Report of Survey "Greater Involvement of People Living with AIDS" and Stigma and Discrimination Lao PDR (31 January – 16 February 2005)

<sup>7</sup> Nguyen Thi Diu and Nguyen Thi Tuyet Lan, Viet Nam Report

## **Thailand<sup>8</sup>**

The Thai study interviewed eighteen PLHAs, of whom just more than half were men. The study also interviewed nine health service providers from five different hospitals (public and private) and with varying degrees of experience working with PLHAs (from four months to ten years), ten NGO/civil society representatives and three government officials (including an employee of the Ministry of Health's Office of AIDS, TB and STI, a HIV researcher from a government university and a member of the Provincial AIDS Committee). The three government officials had all been working in HIV/AIDS for eight years.

---

<sup>8</sup> Wassana Im-em & Khun Prairat, GIPA and Stigma and Discrimination Survey Thailand

## 4. Format of this report

This report looks at the survey responses in three main areas:

- Knowledge and implementation of GIPA
- Stigma and discrimination
- Improving conditions for PLHAs.

This reflects the three broad areas of questioning (see Annex 1).

Section 5 provides an overview of the survey results, country by country, for each of the three broad areas of questioning. This section provides a summary for the reader who may not require a more detailed description of the survey results.

Section 7 provides a more detailed description of the survey results for each country and region. Within the three broad areas of questioning, section 7 provides data on the responses by the four main groupings of respondents:

- Government officials
- Health service providers
- NGOs/civil society leaders
- PLHAs.

NGO and civil society responses are grouped together as this was the approach taken by a number of country report writers and data cannot always be broken down between these two groupings.

The report should be read in association with the designated questions, attached at Annexure 1.

# 5. Overview of survey results (country by country)

## 5.1 Yunnan

### GIPA

On the basis of interviews, it would appear that while there is some engagement of PLHAs in HIV planning and service delivery, it is clearly limited. Government processes were seen as more inclusive by government officials than by PLHAs. PLHAs reported greater engagement in NGO activities than in government processes. Health service providers were not able to report significant engagement of PLHAs.

There was, however, recognition across all groups of the value of PLHA input. There was solid support across all groups for the greater involvement of PLHAs in the planning and delivery of HIV services and policies, and for government policies to bring about this change.

Suggested barriers to greater engagement included government attitudes, government policies, societal attitudes and a lack of skills and knowledge amongst PLHAs. This lack of capacity amongst PLHAs was reported across all interviewee groups.

Interviewees suggested a range of strategies for promoting greater involvement: identifying and training appropriate PLHAs, development of appropriate government policies and community education.

PLHAs were known as peer educators/outreach workers, as working for CBOs or self-help groups, as working with NGOs or as managing programs or activities for PLHAs. No interviewees were able to report knowledge of PLHAs as employees of government or of a health care facility.

### Stigma and discrimination

Government officials had heard of many forms of unfair treatment of/discrimination towards PLHAs, including in relation to testing, infringement of personal liberties, discrimination at work and unfair treatment from family and friends. Government officials acknowledged that there would no doubt be more experiences and reports of discrimination were it not for the fact that most PLHAs are highly secretive about their status.

Health service providers generally denied discrimination within the health care sector, although they did note that patients with HIV were often isolated from other patients (to reduce infection risks and to promote confidentiality). Health service providers reported a fear of occupational infection and noted that there were many challenges associated with caring for PLHAs. Interviewees were keen for more training.

Health service providers agreed that discrimination was minimised through PLHAs being secretive about their status. Interviewees did not report discrimination in

relation to personal liberties or the workplace, but acknowledged problems for PLHAs within their families and friendship networks.

NGO/civil society representatives believed that unfair treatment was generally uncommon, but that it did sometimes occur in relation to testing, infringement of personal liberties and workplace discrimination. Problems within families were thought to be widespread.

PLHA interviewees confirmed that a key strategy for avoiding discrimination is to prevent anyone knowing they are HIV positive. Some reported unfriendly health service provider attitudes, and some reported that they cut themselves off from others to avoid stigma and discrimination.

### **Improving conditions**

Government officials and health service providers considered that stigma and discrimination is declining. Most civil society/NGO representatives agreed. By contrast, most PLHAs thought rates of stigma and discrimination were unchanged. There was some agreement across groups as to initiatives that might improve conditions for PLHAs. Groups agreed that government needs to pay attention to policy issues. NGOs and donors were encouraged to support HIV responses with funding, to conduct training, to offer technical assistance and utilise mass media opportunities.

The community or broader society was expected to facilitate positive communication about HIV, including between PLHAs.

## **5.2 Guangxi**

### **GIPA**

There was strong government support for engagement of PLHAs in government responses and interviewees reported various attempts at fostering this involvement as well as some instances of actual participation. The 'culturally low level' (i.e., poor education) of many PLHAs was seen as a barrier to greater participation. Officials saw a role for government in expanding PLHA participation, including through policy development and legislative initiatives.

Health service providers said that HIV positive people were employed within health care facilities and supported discussion of PLHA needs. There was less support for directly seeking PLHA views on service issues.

NGOs reported some engagement of PLHAs in government activities, but thought improved legislative frameworks might facilitate greater participation. Half of the NGO interviewees reported involvement of positive people in their own programs and there was solid support for increasing this. Civil society representatives thought that governments could do more to foster positive involvement, but generally did not themselves employ PLHAs and did not have HIV workplace policies.

PLHAs reported some engagement in HIV programs, and were unanimous in their view that they should be involved.

### **Stigma and discrimination**

Government officials reported discrimination in relation to health services and testing, but not in relation to infringement of liberties or within the workplace. They did suggest discrimination occurred within families and social networks.

Health service providers claimed to be comfortable providing services to PLHAs, but many were concerned about risks to their own health in providing services to PLHAs, and said there were some difficult issues to be dealt with in providing these services. They were satisfied that they knew how to provide services to PLHAs, but a need for additional training was expressed.

NGOs and civil society representatives had heard of discrimination within the health sector and in relation to testing, infringements of liberties, discrimination within the workplace and within families.

A minority of PLHAs said they had experienced poor treatment or discrimination as a consequence of their status. Most had experienced inappropriate treatment in relation to testing and some had experienced discrimination within the community, including having to leave a public place, having to move residence and being subject to ridicule, insult or threat.

### **Improving conditions**

Most Guangxi groups considered stigma and discrimination to be on the decline, but PLHA thought improvements to be minimal.

It was suggested by various groups that in order to improve conditions for PLHAs, government should be responsible for:

- Policy development
- Financial support
- Continuing to demonstrate support for PLHAs through practical gestures such as shaking the hands of PLHAs in public
- Addressing treatments issues
- Training medical staff
- Supporting PLHAs to organise self-help groups.

NGOs were encouraged to:

- Expand their propaganda efforts
- Model good work practices, including by expanding involvement of PLHAs
- Increase funding, particularly in relation to ARVs
- Conduct education and skills development programs.

Community was seen as having responsibility for:

- Training
- Care
- Education
- Encouraging and accepting PLHAs
- Advocacy.

## 5.3 Lao

### **GIPA**

Amongst government officials, there was support for involvement of PLHAs in HIV responses, but a degree of caution about special treatment of PLHAs as compared with treatment of those with other health conditions. There were also concerns about the capacity of PLHAs to contribute to responses. Government officials reported some current involvement of PLHAs in relevant programs.

Health service providers tended to think that government could do more to promote GIPA, but there was limited evidence of health service providers themselves engaging PLHAs in meaningful ways. Some health service providers found it challenging to work with PLHAs and, again, there were concerns about the capacity of PLHAs to participate fully in responses.

NGOs and civil society interviewees were similarly in favour of greater government efforts to engage PLHAs, and also identified the need to enhance PLHA participation within their own sectors. Perception of PLHAs' capacity was again an issue, as it was for many PLHAs who, while reporting some involvement in HIV responses, sought more engagement.

### **Stigma and discrimination**

Government tended to see stigma and discrimination as decreasing in the face of increased knowledge of HIV. Officials tended to see it as a thing of the past or a rural phenomenon. Health service providers did not report having directly witnessed stigma and discrimination, although some had heard stories of such occurrences. Health service providers thought there might be some problems for PLHAs within their families. NGO responses acknowledged the possibility of stigma and discrimination within the health sector, but there were no concrete examples offered. NGO representatives considered there may be some stigma and discrimination in other areas of life (outside the health sector), but did not consider it to be extensive (a view shared by civil society representatives).

PLHAs reported some discrimination within the health sector and isolated cases of discrimination within families and workplaces, but did not generally report high levels of stigma or discrimination.

### **Improving conditions**

All interviewees tended to consider that stigma and discrimination levels were on the decline, but rural occurrences were considered more likely.

Government was seen as having an important role in improving the lives of PLHAs. It was variably seen as having a role in community awareness and propaganda, providing funding, policy development, expanding health care, generating greater incentives for health service providers to care for PLHAs, offering free treatments, fostering greater participation of PLHAs and offering more training for PLHAs.

NGOs and donor agencies were seen as having the following roles: financial and technical assistance, recruiting more PLHAs, conducting education campaigns and supporting better treatments for PLHAs.

Interviewees thought that civil society/community was responsible for accepting PLHAs, undertaking training to become more informed about HIV issues, becoming involved in the fight against HIV, and creating supportive work environments for PLHAs.

PLHAs called for increased communication and awareness, support and training for health service providers (as well as greater incentives for health service providers to undertake HIV work), and an increased role for positive organisations.

## **5.4 Viet Nam**

### **GIPA**

The Viet Nam report notes that a majority of PLHA interviewees had been involved in a limited way in HIV programs. Involvement had evolved from PLHAs being recipients of programs to more meaningful forms of engagement. PLHAs had not, however, been asked about their needs or how health services need to be tailored, and their involvement continued to fall short of what might be expected from a full application of GIPA. Reasons for the limited nature of involvement were given as lack of understanding of GIPA on the part of government and other groups, lack of a legal framework to promote GIPA, and difficulties engaging female sex workers in programs given their mobile lives.

The report notes that health service providers and social workers have some very good ideas about how to promote positive engagement, but these need to be communicated to government. Other factors that might facilitate greater involvement included support from family and community, improved HIV/AIDS worker attitudes, and promotion of the distinction between HIV and illicit drug use (i.e., separating HIV from socially stigmatised risk practices). Health service providers thought it important to raise awareness of GIPA amongst government officials, health workers, community leaders and amongst PLHAs. PLHAs needed support to facilitate their engagement – they needed to be supported to understand the importance of positive involvement, to be supported emotionally and to be helped to overcome fear of stigma. PLHAs also needed economic and medical assistance.

Interviewees from Viet Nam knew of PLHAs having taken part in various national HIV programs, contributing to the making of HIV ordinances, working as counsellors in hospital, working for NGOs, working as peer educators, VCT counsellors, outreach workers distributing condoms and needles, providers of home-based care and as organisers of self-help groups.

### **Stigma and discrimination**

Most PLHAs interviewed face stigma and discrimination. Positive interviewees reported discrimination from family, community, within the workplace and within health care settings. PLHAs avoid discrimination by avoiding the health care they require (by self-care, travelling to facilities far from their homes etc.) Many PLHAs said that discrimination, while continuing within the health system, had reduced. PLHAs continued to avoid discrimination by keeping their status a secret.

Discrimination within families, in particular, was reported as widespread.

### **Improving conditions**

The Viet Nam report notes that most PLHAs face stigma and discrimination, but that there have been some improvements. The report notes improving attitudes amongst health service providers and the community more generally following communication of HIV information and training.

The report describes the quality of care for PLHAs as poor, notes the importance of greater access to ARVs and acknowledges the role of greater community awareness in reducing stigma and discrimination. The report suggests a role for PLHAs in 'living positively', showing the community that they can contribute meaningfully to HIV responses.

## **5.5 Thailand**

### **GIPA**

The Thai report notes some engagement of PLHAs in relevant programs. It canvasses a range of reasons why this engagement is not greater: reluctance of PLHAs to publicly disclose their status, NGOs being so busy that they cannot allocate time to working with PLHAs, difficulties in bringing PLHA groups in Thailand together, lack of understanding of GIPA principles, government working structures that impede participation, perceptions of PLHAs as lacking the necessary capacity to contribute, and perceptions of PLHAs as being clients of but not participants in service planning and delivery. The report describes some forms of current PLHA input, but this input does not appear to be comprehensive across the country or across all areas of potential contribution. The report says that PLHAs do not, for example, participate in monitoring or evaluation of HIV programs.

The report suggests that many health care facilities do not implement GIPA, either because GIPA is not understood or because workers do not feel it to be necessary. Some NGOs saw implementation of GIPA as requiring long-term funding commitments or, at the very least, suggested that in environments where they must account for every dollar, attention to GIPA was not an output that funders tended to value.

### **Stigma and discrimination**

Most interviewees in the Thai study were of the view that stigma and discrimination is on the decline, although many forms of discrimination were in fact documented. People with HIV tended to keep quiet about their status in an effort to reduce the risk of stigma and discrimination.

PLHAs reported discrimination within health care settings. There were reports of having been denied treatment, of having received poor services and of experiencing poor attitudes on the part of health service providers. Half of PLHA interviewees had been tested without their consent. A number of PLHAs reported poor counselling associated with testing and some HIV-positive women had been told to have an abortion. Health care facility practices identified and separated PLHAs. Health care workers acknowledged some of these issues. Some reported a fear of occupational infection.

In relation to work, HIV testing is still a requirement for many jobs and PLHAs are significantly disadvantaged by this requirement. It means, for example, PLHA cannot change jobs, are pushed into self-employment or illegal means of supporting themselves. Employed PLHAs tend to keep their status hidden at work, if at all possible.

The report suggests a range of factors influencing levels of stigma and discrimination, including the degree of ill health and perceived ‘guilt’ associated with infection.

To avoid stigma and discrimination, some PLHAs isolate themselves.

### **Improving conditions**

The Thai report suggests the extent of community stigma and discrimination has reduced as a result of better information and knowledge, and increased contact with PLHAs. It was suggested, however, that the improvements might not have been experienced in rural areas.

Health service provider attitudes have improved as a result of greater focus on HIV and more informed and assertive patients with HIV. Despite this, there is much in the report to suggest that fear of stigma and discrimination continue to shape the way PLHAs look after their health – they travel distances to health care facilities rather than risk exposure in their own locales, they do not claim entitlements because this requires disclosure, etc.

The report suggests NGOs can play an important role in improving conditions for PLHAs: by expanding their networks and reach, offering ongoing training for PLHAs and supporting programs that help PLHAs to support themselves, trying to reduce the allocation of funds to organisations that provide poor HIV services (or that present poor images of PLHAs), employing PLHAs, providing care and support, and moving from a view of PLHAs as clients to a view of PLHAs as partners in problem solving.

The report suggests the role of community and civil society is to continue to disseminate information to people, to take opportunities to distribute HIV information through schools and to build mutual understanding (communities must understand PLHAs and PLHAs must understand why communities react they way they do).

The report suggests government must play a role in promoting collaboration and reducing duplication in HIV responses, in promoting a whole of government approach (rather than just a Ministry of Health-based response), doing more to advise PLHAs of the government health services available, conducting better IEC, ensuring the National AIDS Council operates more effectively, and in doing more generally to support PLHAs (eg. by supporting them economically and facilitating peer support).

## 6. Challenges and opportunities

It is reasonable to conclude from the survey results that significant effort will be required if the slow pace of GIPA implementation is to be hastened, and if the disturbing levels of HIV-related stigma and discrimination are to be reduced. Different sectors will have their own particular responsibilities for meeting these challenges, but there are clearly some ways in which stakeholders might be supported through the work of POLICY, APN+ and country level PLHA groups.

The first sub-section below outlines some future interventions for consideration. The list is not exhaustive; there are many different strategies that might be employed, and each will need to be tailored to fit the requirements of the particular country or province.

Whatever strategies are pursued, it will be important to measure their effect, and any overall changes in implementation of GIPA and in levels of stigma and discrimination. This will not be easy, but the second sub-section below suggests some different measurements that stakeholders might consider.

### 6.1 Possible interventions

POLICY, APN+ and its affiliates should consider:

- Capitalising on the expressed positive views of government officials to encourage them to put such views into practice by making more concerted efforts to engage PLHAs in their activities.
- Assisting government to formulate policies, ordinances and rules of implementation that advance GIPA in government programs and services.
- Assisting government to develop mechanisms, including communication channels with PLHAs and other stakeholders, to monitor and facilitate implementation of GIPA.
- Assisting government to develop programs that support PLHA representatives to participate in government processes through mentoring, skills development, training, capacity building, and provision to PLHA representatives of technical assistance and financial support. This work should be done in partnership with national PLHA networks (at the country level) and APN+ (at the regional level).
- Supporting advocacy efforts aimed at:
  - Promoting employment of PLHAs, even on a part-time basis, to work on HIV/AIDS activities implemented by government, NGOs, or civil society
  - Changing laws which restrict the employment of PLHAs by government
  - Encouraging greater participation of PLHAs in the HIV-related work of government, the health care sector, NGOs and civil society.

- In partnership with organisations such as the International Labour Organisation (ILO), providing assistance to agencies and organisations to develop and implement HIV/AIDS workplace policies and programs.
- Supporting long-term strategies for developing the organisational and individual capacity of PLHAs. (This requires a concerted effort, over time, by governments and funding agencies, in recognition of the fact that many PLHAs in developing countries have had limited education opportunities and skills development will take time.)
- Providing practical guidance to government and other sectors on how to implement GIPA.
- Conducting an assessment of the current and projected need for services by PLHAs, and using this to advocate to government for increasing the number of facilities where quality services are offered.
- Strengthening referral systems for PLHAs and acknowledging the sexual and reproductive health rights of PLHAs.
- Conducting anti-stigma and discrimination training for all health care workers who provide services to PLHAs, or have direct contact with PLHAs, and their supervisors; as well as encouraging making non-discriminatory behaviour by these staff a part of their appraisal systems.
- Helping develop mechanisms for measuring the experiences relating to stigma and discrimination of PLHAs within the health care sector.
- Developing a mechanism at the service delivery level to enable an ongoing dialogue between PLHAs and health services (eg. PLHA consultative forums), with the opportunity for NGOs and other organisations supporting PLHAs to have input to this dialogue.
- Supporting health care facilities to reduce the likelihood of HIV-related stigma and discrimination within the workplace and to respond appropriately to reported experiences of unfair treatment.
- Informing appropriate government officials about continuing problems with testing and counselling services, and encouraging them to take the necessary remedial actions through advocacy activities.
- Providing or facilitating the training health workers need to improve the quality of their services to PLHAs, particularly in the areas of the provider – client relationship, pre- and post-test counselling, and assisting positive people cope with the social and psychological difficulties they encounter.
- Encouraging the employment of PLHAs as peer counsellors for newly diagnosed people and for those starting ARV treatment, and establishing ARV ‘buddy’ systems to increase adherence and compliance with ARV treatment.

- Developing innovative initiatives to raise public awareness about the lives of PLHAs and the stigma and discrimination they experience.
- Supporting PLHA-driven initiatives that seek to assert the rights of PLHAs to live free from stigma and discrimination.
- Supporting government initiatives to provide legal and policy protections for PLHAs, including anti-discrimination legislation and other protections.
- Helping to reduce, through awareness and training, the fears health staff experience in relation to PLHAs, and promoting more positive attitudes in their delivery of services to PLHAs. PLHAs should be involved in all aspects of this training.
- Expanding efforts to develop PLHA networks and support groups that can serve as advocates for the interests and needs of PLHAs.

## **6.2 Possible indicators**

These indicators could be used to measure movement in the implementation of GIPA and the prevalence of stigma and discrimination, when the survey is repeated in 2007.

### **Indicators of improvement in attitude and knowledge about GIPA**

- A government policy that clearly encourages the implementation of GIPA across all programs and services pertaining to HIV/AIDS.
- A decrease in government expressions that reflect perceptions of PLHAs solely as beneficiaries or clients and an increase in recognition of PLHAs as partners in HIV/AIDS activities, beginning with policy and program development and continuing through to implementation and evaluation.
- Additional initiatives that support PLHA engagement in government processes, including through programs that provide PLHAs with mentoring, skills development, training, capacity building, technical assistance and financial support.

### **Indicators of improved action to implement GIPA**

- An increase in the number of government agencies, NGOs, and/or civil society organisations that employ (directly or by contract) PLHAs to work on HIV/AIDS-related activities.
- An increase in the number of government agencies, NGOs, and/or civil society organisations that engage PLHAs and/or representatives of PLHA organisations in the discussion, planning, implementation, or review of activities on a periodic basis.

- An increase in the number of government agencies, NGOs and/or civil society organisations that establish HIV/AIDS workplace policies and programs for their staff.
- An overall increase in the number of PLHAs employed within government agencies, NGOs and/or civil society organisations (through recruitment of PLHAs or through the disclosure by current employees of HIV-positive status).
- An increase in the development and implementation of systems to obtain feedback from PLHAs on the quality of HIV services being provided, and on their service and policy needs more generally.
- An increase in the establishment of forums that facilitate exchange of views between government officials, health service providers, NGOs, civil society representatives and PLHAs.

### **Indicators of improvement in treatment of PLHAs by health service providers**

- An increase in the number of health facilities with staff adequately trained to provide medical services for PLHAs.
- Increased development by health care facilities of systems designed to seek feedback on HIV-related services from PLHAs.
- Increased development by health care facilities of systems to monitor services for actual or potential discrimination against PLHAs.
- An overall decline in discrimination against PLHAs by health staff based on PLHA and health care worker reports.

### **Indicators of improvement in relation to testing and counselling**

- An increase in reports by PLHAs tested for HIV in the preceding 18 months that they:
  - a) Were informed that they were being tested prior to testing
  - b) Provided informed consent for testing
  - c) Received adequate pre- and post-test counselling
  - d) Were afforded confidentiality in relation to test results
  - e) Received their results within a reasonable period of time
  - f) Felt they were shown care and empathy by doctors and nurses.
- An increase in reports by health workers providing services to PLHAs that, as a result of better training and ongoing contact with PLHAs, they are providing better quality medical and psychological support services, they understand more clearly how to care for PLHAs, and that they understand ARV therapy more clearly. PLHA reports need to confirm such improvements.

### **Indicators of improvement in relation to stigma and discrimination**

- A decrease in concern and fear reported by PLHA respondents relating to the consequences of others knowing their HIV status.
- A decrease in the number of social problems reported by PLHAs that have resulted from others learning of their HIV status.
- An increase in the number of PLHA respondents who report no serious problems at work from co-workers who may be aware of their HIV status.
- An increase in the number of reports by PLHAs of caring and respectful treatment by health workers.

# 7. Survey results

## 7.1 GIPA

### 7.1.1 Government officials responses on GIPA

#### Yunnan

In Yunnan, all government officials thought it was important to involve PLHAs in their work. Officials thought that the personal experiences of PLHAs meant they had a unique contribution to make. One government official noted that the sort of contribution a PLHA could make would depend upon his/her individual capacity.

All Yunnan government officials interviewed had invited PLHAs or representatives of PLHA organisations to attend meetings or workshops concerning government programs.

When asked if a PLHA or PLHA organisation had asked to participate in their unit's activities, government officials from Yunnan replied in the negative. They cited as possible reasons a lack of dialogue between government officials and PLHAs on the one hand, and strict government regulations relating to employment on the other. Presumably this latter reason in fact only prohibits employment with the unit rather than participation in the work of the unit.

All government officials from Yunnan said that PLHAs had participated in activities or events with themselves or with others from their unit: either World AIDS Day events or regular or irregular meetings for the exchange of ideas.

Most Yunnan government officials thought it was difficult to include PLHAs in government processes and suggested various reasons why this might be the case:

- Government lack of experience of such collaboration
- Inadequate HIV knowledge amongst some government officials resulting in negative attitudes towards PLHAs, which in turn discouraged PLHAs from disclosing their status and becoming engaged in government processes.

Yunnan government officials thought some of these problems might be overcome through:

- Strategies to change the attitudes of government officials
- Broad public information campaigns
- Development of relevant policies.

All Yunnan government officials interviewed said that they had participated in activities or events organised by others that had involved PLHAs. All considered the PLHA contribution to those events useful in building better understanding of PLHAs, reducing fear of PLHAs and offering an opportunity to hear PLHA perspectives. It was also noted by Yunnan interviewees that these events are useful opportunities to demonstrate practical things such as the non-transmissibility of HIV through casual contact (like sharing food).

Government officials from Yunnan knew of PLHAs working as peer educators, outreach workers and NGO employees, and as managers of services designed to assist PLHA. They did not know of PLHAs working in health facilities or government agencies. Government officials from Yunnan noted that PLHAs were not amongst official employees as the official employment requirements (for HIV positive and negative Chinese) are strict. Some PLHA had been employed in a non-official capacity within HIV units.

All government officials from Yunnan thought that it would be a good idea to develop official policy or standard practices to expand participation by PLHAs, but that it might take some time. All were committed to trying to involve PLHAs in their work over the next 12 months.

Government officials indicated there were no HIV workplace policies in Yunnan and no need for any as HIV workplace issues are addressed through the National Medical Practice Standard.

When asked about practical ideas for expanding PLHA participation, three Yunnan government officials suggested providing training for PLHAs to build their living skills and self-confidence. Another government official suggested that PLHAs need to speak out more. A fifth suggested that capable PLHAs might be found through voluntary counselling and testing (VCT) programs and then supported to make greater contributions.

Government officials from Yunnan agreed that appropriately healthy and qualified PLHAs should be allowed to manage government programs and activities designed to assist PLHAs.

## **Guangxi**

All Guangxi government officials agreed that participation of PLHAs in government HIV activities was important, necessary, and useful for the government in developing HIV prevention and control policies and plans. All Guangxi government officials reported that PLHAs had been invited to participate in relevant conferences, projects or services.

Half of all Guangxi government officials interviewed reported that requests for involvement in their work had been received from PLHAs or a PLHA organisation. All government officials from Guangxi reported that they or others from their unit had participated in an activity with PLHAs or a PLHA organisation.

All respondents considered the involvement of PLHAs to be difficult on the basis of the 'culturally low level' of many PLHAs. This is taken to be a reference to the fact that most PLHAs in China come from the working class and have had limited educational opportunities.

Guangxi officials reported events or activities organised by others (government departments, NGOs or donors) that involved PLHAs or a PLHA organisation.

All officials knew of PLHAs working as peer educators or as employees of NGOs. Most knew of PLHAs working in health facilities. Half of the interviewees knew of a PLHA who had established a community based organisation (CBO) or self-help group (but not in Guangxi). Most responded that they did not know of PLHAs managing other projects (i.e. non-CBO or self-help group) or activities designed to help PLHAs through services or advocacy.

All government officials from Guangxi agreed that the government should support greater engagement of PLHAs through policy development and implementation.

Government officials from Guangxi did not employ any PLHAs, but all reported that they had plans to engage PLHAs in their upcoming work. Respondents said that there are current work-place guidelines covering employment of people with HIV.

Most officials from Guangxi suggested some practical measures to promote more PLHA engagement in the work of government or that would at least encourage more feedback from PLHAs on government services. These suggestions included formulation of laws that address the needs of PLHAs, relevant policy development and reduction of discrimination.

When asked whether a PLHA with the necessary health and qualifications should be able to head up a government HIV program, most government officials from Guangxi agreed that it was necessary and important, but that it depended upon the willingness of PLHAs.

## **Lao**

Government officials from Lao agreed it would be a positive thing to involve PLHAs in their work, as it would demonstrate that the Lao government did not discriminate against PLHAs.

Lao officials said that PLHAs had been invited to participate in specific events rather than to discuss government programs. They suggested that barriers to the strengthening of GIPA included low levels of education and skills deficits amongst PLHAs.

Some Lao government officials had observed PLHA attendance at NGO meetings but had not seen it as being useful because the PLHA representatives had remained silent.

Some Lao government officials agreed that extended participation of PLHAs should be government policy. There was, however, a view amongst some Lao interviewees that 'special' approaches to PLHAs were not appropriate, as this was not done for people with other health conditions.

While Lao officials were open to greater PLHA participation, the country survey report does not mention that officials had proactive strategies to produce this outcome.

Government officials from Lao advised they did not have a workplace policy on HIV, and that workplace policies should be more general and not specific to PLHAs. There

was a desire to ensure PLHAs were not favoured over other groups of people eg. people with TB or malaria. It was suggested that Lao people were generally overcoming their prejudices against PLHAs and that PLHAs would be accepted in the workplace.

Several Lao officials agreed that it would be appropriate for an adequately qualified and sufficiently healthy PLHA to manage a HIV program. One respondent could not imagine PLHAs having the skills to manage such programs, given that the skills and education levels of PLHAs are generally lower than what this type of job would require.

Several government officials from Lao knew of PLHAs working as employees of government (including the Ministry of Health and the Department of Public Administration), but none could comment on their involvement as health service staff, as working as peer educators/outreach workers or as NGO employees, as having organised a CBO or self-help group or as managing activities of projects designed to assist PLHAs.

## **Thailand**

The Thai report notes a range of views, but it is not always possible on the basis of this report to attribute particular views to particular categories of respondents. The report notes that the number of PLHAs working with government officials has increased significantly, but that government structures do not permit full involvement of PLHA. The report notes the view that some government officials do not understand how to implement GIPA principles, and that some government officials see PLHAs as lacking the capacity to make greater contributions.

Thai government officials tended to perceive PLHAs as lacking capacity to fully participate, due to their 'background'. This background made PLHA participation particularly problematic in activities such as academic forums. The government's working structure also militated against greater involvement.

Most government officials from Thailand also saw PLHAs in association with welfare support, which may have coloured their view of the potential of PLHAs to contribute to HIV strategies and program planning and implementation.

Thai government officials acknowledged that the government did not have a clear policy on how to implement GIPA.

### **7.1.2 Health workers responses on GIPA**

#### **Yunnan**

There were no PLHAs working in the Yunnan health worker's units, although they thought qualified PLHAs might be useful as peer-educators and counsellors. When asked if staff discussed the perceived special needs of PLHAs, Yunnan interviewees suggested the discussions were informal rather than formal: such needs had been discussed informally in the context of PLHA being service targets.

All interviewees from Yunnan thought it would be good to seek the advice of PLHAs, but this did not usually occur in practice. One Yunnan hospital had sought advice in writing from HIV-positive patients and a second hospital asked for this feedback orally.

Seven Yunnan interviewees said they thought the Ministry of Health should actively encourage PLHAs to be involved in its HIV-related activities.

Yunnan interviewees did not know of PLHAs as employees of health facilities or government departments, but did not know of PLHAs as peer educators, staff of NGOs, organisers of CBOs or self-help groups, and as managers of activities designed to assist PLHAs.

## **Guangxi**

Most health service providers from Guangxi responded that there were PLHAs working at their facility.

Most Guangxi health service providers said that discussions about the special needs of PLHAs had occurred within their facility, nominating the cost of treatment, employment and marriage as important issues for PLHAs.

While Guangxi health service providers did ask PLHA clients how services could be improved, most said that they did not think it was a useful practice. Most Guangxi health service providers said the Ministry had solicited the views of PLHAs in the context of planning HIV services.

The majority of health service providers knew of PLHAs as peer educators, employees of government agencies or NGOs, or as managers of PLHA advocacy groups or services. A minority knew of PLHAs as organisers of a CBO or self-help group. Most had no knowledge of PLHAs as health service employees.

## **Lao**

All interviewees in Lao thought it was important and useful to employ people with HIV in their units.

Staff in Lao noted that meetings with PLHAs to discuss services and operations had occurred, and that issues raised related mainly to appropriate supplies and materials for treatments.

Many Lao interviewees said it was not necessary to seek the views of PLHAs, as their views were already known (concerns relating to shortages of medical equipment and materials, as well as the need for staff incentives).

Several Lao health workers thought it would be a good idea for the Ministry of Health to encourage involvement of PLHAs as a demonstration that it does not discriminate against PLHA, although one thought PLHAs generally lacked the skills and knowledge to contribute. Lao health workers thought that government responses generally to the needs of PLHA were inadequate, and referred specifically to

inadequate access to ARVs, insufficient medical instruments and an absence of treatments sites for PLHAs. Interestingly, health care workers tended to see these failings as evidence of inadequate implementation of GIPA.

Lao interviewees knew of HIV-positive peer educators, employees of government and as organisers of self-help groups, but not as managers of projects to assist PLHAs.

### **Viet Nam**

Most interviewees from Viet Nam perceived it was important for PLHAs to participate in HIV program activities because their voices reflected the needs of the broader positive community.

Health service providers thought greater engagement of PLHAs would be facilitated by family and community support for PLHAs, positive attitudes amongst health service providers as well as amongst PLHAs themselves.

Health service providers from Viet Nam thought that participation of PLHAs in HIV programs and services would generate many positive physical and emotional outcomes for PLHAs, help prevent the spread of HIV, build a positive image of PLHAs and reduce stigma and discrimination.

Health care workers considered it was important to raise awareness of GIPA across all sectors of Viet Nam. They also thought there was a need to promote communication with and amongst PLHA and to provide counselling as this would help positive people understand the value of participating in HIV responses, help PLHAs to meet their emotional challenges and help reduce fear of stigma and discrimination.

### **Thailand**

The report suggests that most health service providers tend to see PLHAs as clients of services rather than as contributors to service planning and implementation. However, some facilities – particularly specialist services – do actively promote positive involvement.

Some nurses interviewed did not see PLHAs as having the background or training necessary for significant involvement in services, other than at lower levels. Some supported greater engagement of PLHAs on the bases that it would facilitate their access to valuable information and their contact with other PLHAs.

## **7.1.3 NGOs and civil society leaders responses on GIPA**

### **Yunnan**

Yunnan respondents said the government had involved a few PLHAs in government processes, but that it could improve in this regard. They thought that governments tended to use the language of inclusion, but were significantly less effective when it came to action. Respondents said the government did not understand the value of PLHA involvement, and tended to see HIV as a medical problem rather than understand its social and economic dimensions.

Yunnan interviewees did not know of specific cases of PLHAs being invited to participate in government processes designed for their benefit, but thought it might possibly have occurred.

Despite this possible lack of involvement, most Yunnan respondents answered that PLHAs had participated in government activities, but said that PLHA participation had not necessarily led to government action.

Yunnan respondents supported official government policy as a means of facilitating greater involvement, but noted that there were additional challenges associated with implementing the policy once developed.

Interviewees suggested the following factors as limiting the capacity of PLHAs to participate in government processes designed to assist PLHAs: fear of PLHAs amongst government officials, government policies and official positions, the question of the capacity/personal qualifications of PLHA, and the fact that PLHAs often spoke as individuals but not as a group.

All Yunnan NGO interviewees said that they engaged PLHAs in the work of their organisation to support PLHAs. They all agreed that engagement should be greater, although one emphasised the focus must remain on a person's capacity to do the job rather than his/her status.

All Yunnan NGO respondents answered that they would try to expand the engagement of PLHAs in their work over the next 12 months.

All Yunnan NGO respondents answered that they did employ PLHAs, noting that since they ran HIV programs the employment of people with HIV would obviously be beneficial.

Respondents answered that they have useful and necessary workplace policies covering HIV, as well as other safety issues.

Civil society representatives from Yunnan said that governments and NGOs both fail to do enough to engage PLHAs in their work, but that the situation had improved.

When asked why engagement was not greater, Yunnan civil society representatives cited lack of understanding of GIPA, the limitations of existing policies, inadequate funding and a shortage of information exchange between HIV sectors.

The Yunnan civil society respondents said they planned to expand the role of PLHAs in their business or organisation. They said that PLHAs were invited to participate in relevant activities, but were not formal employees. They did note, however, that employment of people with HIV would be useful if appropriate positions became available.

Yunnan civil society interviewees did not have HIV-related workplace policies but thought it would be useful. When asked for suggestions as to how to promote greater involvement of positive people in government or NGO and civil society processes,

civil society representatives from Yunnan suggested: mass publicity campaigns, advocacy in support of sound government policy, skills building and capacity development amongst PLHAs.

Yunnan civil society respondents knew of PLHAs as peer educators and outreach workers, as working for NGOs, organising CBOs or self-help groups or managing activities for PLHAs. Respondents did not know of PLHAs working in health facilities or for government.

## **Guangxi**

Most Guangxi interviewees said they hoped for greater PLHA participation and that it would be useful.

Half of the Guangxi respondents answered that they knew of a government unit that invites PLHAs to participate in some part of its work intended for the benefit of PLHAs. Most Guangxi interviewees said that such participation had occurred.

All Guangxi respondents suggested that expanded participation of PLHAs be pursued through legislation.

Guangxi interviewees suggested the following factors as limiting the ability of PLHAs to participate in government processes designed for their benefit: limited understanding of HIV, wrong societal guidelines and serious discrimination against PLHAs.

When NGO representatives were asked if they engaged PLHAs in any of their work designed for the benefit of PLHAs, half of the Guangxi interviewees answered yes. Half also answered yes to the question whether such engagement should be greater and half had plans to expand involvement. Only a quarter of Guangxi respondents answered yes to the question on whether current engagement took the form of employing PLHAs.

A quarter of Guangxi respondents said they had an HIV workplace policy and that it was useful.

A number of civil society interviewees thought that not enough was being done by NGOs and government to engage PLHAs in their work in support of PLHAs. Several Guangxi interviewees thought that more effort was needed.

Civil society interviewees from Guangxi answered that PLHAs were not employed in their business or organisation, but that it would be useful if they were.

Guangxi civil society interviewees indicated that they had no workplace policy on HIV.

The Guangxi data suggests that there is majority support for greater PLHA participation, but the data does not include any practical steps suggested by civil society interviewees to pursue this goal.

Most Guangxi respondents knew of PLHAs as peer educators or outreach workers and half of the respondents knew of PLHAs as staff of government agencies or NGOs, as organisers of a CBO or self-help group or as managers of activities or projects designed to assist PLHAs by providing services or supporting advocacy. No Guangxi interviewees knew of PLHAs as health facility workers.

## **Lao**

Lao NGO/civil society representatives said that government did not do enough to involve PLHAs in government processes, and that it should do more.

Lao NGO/civil society representatives suggested that the lack of involvement might be attributable to a lack of understanding of the benefits of PLHA involvement or a lack of skills and knowledge on the part of PLHAs. Many said that government failed to appreciate that the application of GIPA could reduce stigma and discrimination.

Some Lao respondents knew of government having involved PLHAs in its processes, but thought this practice was infrequent.

All Lao interviewees thought that expanded participation should be official government policy.

Lao interviewees thought that a lack of understanding of GIPA might be a barrier to greater positive participation, with one suggesting government officials still held discriminatory views.

One Lao NGO had a plan to train PLHAs to be peer educators and a Lao business operator planned a micro-finance program to be managed by PLHAs.

Lao respondents said PLHAs were employed for specific purposes, but that their skills levels made it difficult to expand employment opportunities. Lao respondents said they had no HIV workplace policy, but that one would be useful.

Lao interviewees had no specific plans to increase engagement of PLHAs in their work. This view seemed to be based significantly on the perceived limited nature of PLHA experiences, knowledge and skills.

Lao respondents suggested government should develop policies to increase the number of health facilities for PLHAs and provide free treatment. NGOs should increase their employment of PLHAs, respondents said.

Lao respondents did not know of PLHAs working in any capacities other than (for a minority of respondents) peer education and with a self-help group.

## **Thailand**

Some NGO representatives interviewed tended to see PLHAs as beneficiaries of services rather than as people requiring capacity building. There was also a tendency to associate PLHAs with concepts of welfare.

## **7.1.4 PLHA responses on GIPA**

### **Yunnan**

Interviewees from Yunnan had not participated in government processes relating to HIV, but were keen to do so as it would open useful communication channels with government officials and help indicate how PLHAs might be further involved. Interviewees were concerned, however, that they did not have the requisite skills.

Interviewees from Yunnan agreed that such participation in government processes is important for various reasons: such involvement helps PLHAs, promotes government responses, improves care and support services, improves prevention and reduces stigma and discrimination.

Interviewees were asked if they knew of a PLHA who participated in government processes involving meeting with officials about the interests and needs of PLHAs. All interviewees from Yunnan said they did not know of such PLHA participation, although two knew of a PLHA who had had some discussions with government officials.

When polled if they had ever been asked by a government official or service provider about their interests or special needs, all interviewees from Yunnan replied no.

Only one respondent from Yunnan knew of a way to communicate with government officials about the needs and interests of PLHAs – through NGOs.

The overwhelming majority of PLHA respondent from Yunnan said that government officials were not interested in their views, ideas or needs. One said that government officials had actively discriminated against the respondent.

Half of the Yunnan interviewees answered that they had discussed their interests and needs with an NGO.

Over three-quarters of Yunnan interviewees answered yes to the question whether they had been invited by an NGO to attend a meeting or workshop concerning PLHA needs.

Interviewees from Yunnan knew of PLHAs as peer educators, NGO staff members, and organisers of self-help groups or managers of activities for PLHAs. Interviewees did not know of PLHAs as health sector employees or government employees.

### **Guangxi**

Some, but not all PLHAs reported engagement in government processes to some extent.

Only a minority of PLHAs from Guangxi knew of PLHA participation in government processes involving meeting with officials about the interests and needs of PLHAs.

All PLHAs from Guangxi said it was very important that they be involved in government processes intended for their benefit.

Most PLHA interviewees from Guangxi said they had been asked by a government official or service provider about their interests or special needs, or about how services could be improved.

Most Guangxi interviewees answered that government officials were interested in their views, citing the provision of free treatment as evidence that government officials were at least interested in their needs.

A minority of interviewees from Guangxi said they had discussed their interests and needs with an NGO. A minority of interviewees had been asked by an NGO to attend a meeting or workshop relating to PLHA needs.

Half of the interviewees from Guangxi knew of PLHAs working as peer educators or outreach workers. A minority of Guangxi interviewees knew of PLHAs in all of the other suggested roles.

## **Lao**

While many interviewees from Lao had participated in government processes, these were mostly related to short-term activities (like WAD) rather than anything more extensive. Many PLHAs were keen to be involved in government processes, but expressed concerns that their skills or experience might be barriers to such engagement.

Some PLHAs from Lao suggested that involvement in government processes would help improve national programs, but many interviewees saw the benefits of such engagement in terms of reducing stigma and discrimination.

Interviewees from Lao did not know of a PLHA who had participated in a government process in which he/she had discussed PLHA needs with officials.

Several Lao interviewees looked to PLHA organisations to communicate with government officials about their needs.

Lao PLHAs generally thought government officials were disinterested in their views or needs, as government focus was on prevention rather than care.

Some Lao respondents had been approached by an NGO but said there had been no follow-through on the part of the NGO. Some PLHAs said they had attended an NGO meeting but had felt uncomfortable (others present were thought to have higher levels of skill and knowledge).

PLHAs from Lao knew of positive people working for NGOs, but not within the government sector. They generally did not know of PLHAs as peer educators or as health facility employees.

## **Viet Nam**

Interviewees from Viet Nam reported an increase in involvement in prevention and care plans. While they had originally been seen as targets only, they had increasingly become involved in the delivery of information and programs and were now participating in more significant roles. Most had taken part in HIV programs (including as speakers). These experiences had been relatively recent, so many PLHAs thought they lacked experience and capacity in relation to contributing to responses.

Thirteen out of twenty respondents had participated as speakers in workshops and four out of twenty respondents had worked as peer educators. Most engagement in HIV responses appeared to be through NGOs.

Most PLHAs from Viet Nam emphasised the necessity of people with HIV participating in prevention and care programs. The majority noted their capacity to meaningfully contribute to the HIV responses in a whole variety of ways, rather than being seen merely as service targets.

Most interviewees from Viet Nam had not been asked about their needs or how their health services might be improved.

## **Thailand**

Most PLHAs from Thailand thought it very important that their life experiences be used to help guide programming and planing, although some remained comfortable with a welfare model of service delivery.

PLHAs from Thailand thought it rare for government to encourage PLHA participation in government programs.

Some PLHAs from Thailand perceived that HIV/AIDS NGOs were too busy to put much time or effort into working with PLHAs.

PLHAs from Thailand reported their engagement in terms of problem analysis and brainstorming but did not specifically report participation in the other forms canvassed by the questions.

## 7.2 Stigma and discrimination

### 7.2.1 Government officials responses on stigma and discrimination

#### Yunnan

All government officials from Yunnan had heard of PLHAs being denied medical services, being unnecessarily referred to another health facility and being isolated from others within a health care service. Officials did not know of PLHAs being told not to make use of available health services, being charged more for medical assistance or having to wait unreasonably. Government officials did not see separating PLHAs from others as less favourable treatment but, rather, as a strategy for managing infection and protecting HIV confidentiality.

Yunnan interviewees knew of practices of PLHAs being tested without consent, being coerced into testing and of someone else being present while testing was conducted. They did not think these practices were widespread. Responses seem to indicate that non-voluntary testing is deemed more appropriate for certain groups of people, specifically sex workers and injecting drug users. The presence of others while testing was being conducted was, it was suggested, a consequence of testing in a busy public laboratory rather than a disregard for confidentiality.

Yunnan respondents did not know of cases of test results being revealed without the permission of the person tested, or of excessive waiting times for test results.

Government officials were asked about violations of PLHAs' rights to personal liberty and security.<sup>9</sup> Respondents suggested these occurrences were not widespread. Three respondents reported having heard of cases of PLHAs having to move house because of HIV-related discrimination and two had heard of PLHAs having been ridiculed or harassed in public. It was suggested these incidents occurred in less tolerant rural areas.

All government officials from Yunnan had heard of PLHAs having experienced discrimination at the hands of their friends.

All of the Yunnan interviewees had heard of isolated cases of work-related discrimination: being forced to take a test, unfair treatment at work, lost promotion opportunities/being encouraged to leave work, and a loss of earning capacity. Such

---

<sup>9</sup> The question asked specifically about the following kinds of violation:

- Refused entry, removed from or asked to leave a public establishment because of their HIV status (restaurants, bars, barber shops, or other types of businesses open to the public)
- Having to change residence, some times, several times
- Ridiculed, insulted, or harassed in public
- Threatened with violence or assaulted
- Forced to reveal his/her HIV status
- Quarantined, detained, isolated or segregated, e.g., during travel, when seeking health care
- Discriminated against by friends or friends
- Excluded from social events because of his/her HIV status
- Unjustifiably denied benefits, privileges or services given to others
- They or their child(ren) are denied access to education

problems were thought not to be widespread but this was partly attributed to the fact that PLHAs remain secretive about their status. The government officials stated societal attitudes towards PLHAs were capable of generating significant discrimination.

Interviewees from Yunnan advised that there had been cases of PLHAs not having access to treatment and women not being advised of the facts of mother-to-child-transmission. They said that this occurred in rural rather than urban areas and was a reflection of poorer health services in rural areas rather than being specific to PLHAs.

Yunnan government officials thought it appropriate to encourage women to be tested during a pregnancy or when their child was sick, and that it was the responsibility of health care workers to so advise. Similarly, health workers had a responsibility to advise HIV-positive women of the risk their child might acquire HIV during pregnancy or birth. Government officials said that it was a woman's right to make the final decision about having a child in the context of being HIV+.

Yunnan Government officials thought it common for PLHAs to be excluded from family functions, to be avoided by family or friends, to be abandoned by partners, or to lose financial support from partners or family.

## **Guangxi**

Government interviewees from Guangxi reported that they knew or had heard of cases of discrimination in relation to PLHAs being denied medical services and necessary information (half of the interviewees), being redirected unnecessarily to another health facility (most of the interviewees) and of inappropriate waiting times (half of the interviewees). Most interviewees were unable to report discrimination in relation to PLHAs being told not to make use of facilities, being isolated or being made to pay more than others.

Guangxi government officials reported discrimination in relation to testing without being informed (most interviewees) and coerced testing (most interviewees). Most interviewees suggested there was not a problem in relation to the inappropriate revealing of test results, or excessive waiting times between testing and results. When asked about the presence of others during testing, half the Guangxi interviewees said they had heard of this and half said they had not.

When asked if PLHAs had experienced violations of their personal liberties and security, government officials from Guangxi overwhelmingly answered in the negative. Officials said that they had not heard of PLHAs experiencing discrimination in the workplace, although stories of discrimination within families and social networks were reported by half of the respondents.

## **Lao**

Lao government officials had heard of some minor forms of discrimination against PLHAs, but nothing of great significance and thought that most instances had occurred well in the past. Government officials said discrimination against PLHAs was being reduced through government communication and campaigns. They could

not recall cases of PLHAs being denied medical services, having to wait inappropriately or being required to pay higher prices.

Government officials from Lao recalled some past instances where the rights of PLHAs to personal liberty and security had been violated - being required to change residence, being discriminated against by friends - but had never heard of PLHAs being ridiculed, refused entry to a public place or threatened with violence. Lao government officials seemed to think of this sort of behaviour as a thing of the past, although conceded that people in remote villages might continue to hold negative views about PLHAs – they might, for example, resent PLHAs being employed within the civil service.

Some Lao interviewees had heard of deteriorating relations within families as a consequence of a person's HIV-positive status.

## **7.2.2 Health Service Providers responses on stigma and discrimination**

### **Yunnan**

Yunnan interviewees said they were providing ARVs and that they had seen positive results as a consequence. Interviewees knew about how HIV is transmitted but were eager for further HIV information more generally, particularly in the area of treatment.

Yunnan health service providers had been concerned about being infected with HIV through their work. They had also experienced fear of being stigmatised because of their work with PLHAs. Access to information and contact with PLHAs had helped to manage these anxieties.

Most Yunnan interviewees had not received counselling training, but looked forward to such opportunities. In relation to counselling, Yunnan interviewees said they provided simple advice about the purpose of the test, how HIV is transmitted and how to prevent transmission. The meaning of positive and negative results is explained when providing test results.

Health service providers from Yunnan said it took on average two days between testing and receiving the result, and that this was reasonable.

Yunnan interviewees said that as a general rule test results are given to the person who was tested. Interviewees noted that sometimes a person might be sent for testing by others, such as parents or family, who request that the result be kept from the patient.

Yunnan interviewees said that disclosure of test results to others in the absence of the patient's authority was not appropriate, although health care workers would advise a PLHA's family of the results if asked to do so by the PLHA.

While interviewees from Yunnan said it was up to an individual PLHA to determine who should know about his/her status, respondents noted that in-patients tend to know

of the status of other in-patients. This no doubt is because all PLHAs are cared for in a dedicated ward.

Yunnan interviewees acknowledged that colleagues discuss patient cases (including status). While this might not sound professional, interviewees said, it was sometimes unavoidable.

Yunnan interviewees said that PLHAs are separated from other patients – in fact, all infectious patients are grouped in particular wards. The respondents thought this separation was conducive to protection of confidentiality and control of infection.

One third of interviewees from Yunnan said that PLHAs had been refused services, but only because of a patient's incapacity to pay or because the facility could not fund the relevant treatments.

Yunnan interviewees said referral to other facilities was rare and occurred only in cases where their own service could not meet particularly patient needs.

Yunnan respondents said they did experience some problems in providing services to PLHAs. Problems included: dealing with injecting drug users' tempers, patients being difficult due to pain, and difficulties managing the psychological situation for many PLHAs.

Half of the interviewees from Yunnan said they had heard of PLHAs being discriminated against by family and friends, excluded from social events, unjustifiably denied benefits etc., or being denied education for themselves or their children. Interviewees had not heard of the other suggested forms of societal discrimination, but noted that most PLHAs in Yunnan keep their status a secret to minimise the chances of such adverse treatment occurring.

Health service providers in Yunnan did not know of discrimination in the workplace but, again, this was attributed in part to the fact that workers with HIV kept their status secret. Loss of earnings was more likely the result of ill health than discrimination, interviewees said.

Yunnan respondents thought that discrimination within the family was common.

## **Guangxi**

Most Guangxi health service providers interviewed were providing ARV treatment and described the impact as positive, facilitating a shift in the patient's views from hopeless to hopeful.

A minority of health service providers from Guangxi claimed to have sufficient knowledge about HIV, yet all claimed to understand transmission routes. All would like further training.

All Guangxi respondents said they were comfortable providing services to PLHAs, but 40 per cent said they were concerned about their own health, citing fear of tuberculosis, work pressure and psychological stress.

All Guangxi interviewees had received useful training in HIV counselling from the World Health Organisation (WHO).

All interviewees suggested clients were provided with adequate pre- and post-test counselling. Interviewees indicated that a negative test result prompted information about window periods, while a positive test result led to the provision of information on how to see a doctor, nutrition, managing energy levels and fatigue, maintaining safe sex practices and preventing transmission.

Most interviewees from Guangxi suggested that the waiting period for test results was a reasonable 1-2 days, while a minority advised that the wait was an unreasonable 1-3 months. Some suggested the waiting time was 10-15 days.

All Guangxi interviewees advised they sought the patient's permission for disclosure if others were present. Fifty per cent provided results with family or friends present.

All Guangxi interviewees agreed that it was not acceptable to disclose a person's HIV status without that person's written consent. All interviewees advised that information about status was not shared with other staff and that it was not leaked to family or friends.

Guangxi interviewees unanimously agreed that there was no discussion of status outside of professional meetings.

All health service providers from Guangxi indicated that patients with HIV were not separated in the course of providing services. One interviewee, however, thought it might be better to separate HIV patients from others.

All interviewees from Guangxi advised that there had been no cases of a PLHA being refused service.

All health service providers from Guangxi suggested that they had had difficulties in providing services to PLHAs and cited economic challenges, dealing with marriage and procreation matters, and the expense of transferring between health services, if referred, as difficult issues arising in the course of their work with PLHAs.

## **Lao**

Interviewees said there were insufficient ARVs for PLHAs in Lao, with treatments being available from limited points. Doctors interviewed, however, were providing ARVs and considered the benefits to be positive.

Lao doctors who were interviewed said they had adequate knowledge about transmission but saw a role for future training on ways to provide better treatment and care for PLHAs. Lao doctors did not express any discomfort working with PLHAs. It was a different story for nurses, however. Some nurses from Lao sought additional incentives to work with PLHAs. This was not, they said, attributable to any discrimination on their part but due to the fact that working for PLHAs was

particularly demanding and carried risks of infection in circumstances where there would be no compensation for occupational transmission.

Some Lao nurses had received useful training relating to testing, counselling and dealing with giving positive results. Lao doctors advised that they provided pre-test counselling and the report writers describe their reported practice as friendly and respectful.

Lao doctors said that no patients had complained of the time delays involved in obtaining test results.

Lao doctors advised that they would never disclose information about a person's status without that person's consent. Test results were always given in private.

Several Lao interviewees said that PLHAs were separated within facilities; this was done for the comfort of other (non-HIV) patients or because it was preferable for PLHAs.

All Lao interviewees said that PLHAs were never refused services. Lao interviewees advised that patients were seen in the order they arrived, regardless of HIV status. They said patients were not referred to other services because there were no services to which they might be appropriately referred.

## **Thailand**

Some health service providers interviewed saw plans on the part of PLHAs to have families as possibly leading to problems. A number of pregnant PLHAs were told to have an abortion, and said they did not receive adequate information to help them with this decision.

There were reports of overly zealous attempts to prevent occupational infection (including use of gloves and masks in unnecessary situations), although one health service provider said that workers were now more sensitive and discussed infection control steps with positive clients.

Some health service providers acknowledged that testing without consent had occurred and, while appreciating that this violated the rights of PLHAs, also argued that it was a necessary step to protect workers from occupational infection.

Some respondents said that non-voluntary testing of emergency patients was performed while others said that universal precautions were applied.

There were also reports of hospital practices that effectively disclosed the HIV status of patients – for example, conducting all operations for PLHAs on the same day, or at the end of the operating list, and lengthy periods of sterilisation of theatres following operations on PLHAs.

Thai respondents said they would like further information about how to care for PLHAs, and specifically on ARVs. Most said they lacked the training to enable them to give appropriate counselling and support to PLHAs.

Some health service providers said they would prefer not to work with PLHAs.

### **7.2.3 NGOs and civil society leaders responses on stigma and discrimination**

#### **Yunnan**

Two of the respondents from Yunnan had heard of PLHAs being denied medical services or being sent unnecessarily to another facility, although they believed this to be uncommon. They suggested it may have resulted because of fear on the part of the health care workers or a concern on the part of the hospital that it could not bear the costs of providing the services. All respondents knew of PLHAs being isolated from other patients, but believed this to be consistent with infection control practices and conducive to protecting the confidentiality of PLHAs. Respondents had not heard of examples of the other suggested forms of health care discrimination.

In relation to testing, Yunnan respondents acknowledged rare cases of inadequate explanation of the test's purpose and of people being coerced into testing. They considered the incidence of these problems to be reducing. These types of problems were seen as a consequence of the relative newness of the epidemic (they considered that China has had to learn, like other countries, how to handle these issues). Respondents had known PLHAs to not receive counselling before being tested, but noted that counselling procedures were also relatively new in China. Testing procedures were now working properly in the two main HIV hospitals, respondents said.

Yunnan interviewees said that there had only been rare cases of test results being given in circumstances that caused embarrassment, of results being revealed without a person's permission and/or of excessive delays between testing and the result. Privacy policies were generally new, but respondents agreed that test results should be given to the person tested and that results should be accompanied by counselling.

Yunnan interviewees said that most PLHAs kept their status a secret so as to avoid discrimination. Respondents could not confirm experiences of societal discrimination other than discrimination by family and friends – they had all heard of this type of experience.

In the context of employment, interviewees from Yunnan had heard of workers being forced to take a test (as a result of government policy). Interviewees thought loss of earnings were more likely to result from ill health than discrimination. Respondents thought the other types of workplace discrimination were uncommon but, again, suggested this was linked to many PLHAs being secretive about their status.

Respondents suggested that negative family responses to PLHAs might be, in part, the result of the fact that families of PLHAs also experience discrimination (and perhaps take it out on the positive family member), and that it is families that must often bear the economic cost of a person's positive status.

Yunnan respondents thought discrimination from family and friends to be common, but that it would be reduced if the population's understanding of HIV could be increased. Poor treatment of PLHAs was still based on associating HIV with criminality and 'dirty' behaviour, interviewees suggested.

## **Guangxi**

All Interviewees from Guangxi had heard of PLHAs being denied medical services. Most interviewees had heard of PLHAs being told to go to another facility even though services were available, being told to not make use of available health care services and being isolated from others at health care facilities.

A minority of Guangxi interviewees had heard of PLHAs having to wait unfairly until others were served and being required to pay higher or additional charges for services.

In relation to testing, Guangxi interviewees had heard of all of the sorts of negative experiences outlined in the question, most commonly PLHAs not receiving counselling when being given test results.

Guangxi interviewees had heard of all or almost all of the listed types of violations of personal liberty or security: most commonly PLHAs having to change residence, being excluded from social events or having access to education denied to them or their children. Interviewees had not heard of PLHAs being quarantined, detained, isolated or segregated.

Guangxi interviewees had heard of all of the listed types of workplace discrimination, most commonly unfair treatment and harassment and of people losing jobs or opportunities for promotion.

Most Guangxi respondents thought discrimination by family and social networks to be very common, particularly being excluded from family functions because of HIV status, being avoided by family members or friends, or PLHAs being visited much less than prior to their status being known.

## **Lao**

Lao NGO/civil society interviewees agreed that patients were seen by health service providers in the order they arrived.

Respondents thought that PLHAs were not asked to wait inappropriately or to pay higher prices for treatment.

Lao respondents said there were no problems with HIV testing in Lao, and no forced testing.

Interviewees had generally not heard of discrimination at the hands of health service providers, but suspected it might occur due to ignorance.

Lao respondents had heard of stigmatisation and discrimination within village communities with a range of consequences including a need for PLHAs to relocate,

but no one reported having heard of PLHAs being ridiculed or threatened with violence or being forced to disclose status. One respondent reported a child being forced to change schools.

Respondents from Lao generally did not report workplace-related problems for PLHAs. One interviewee said that employment of PLHAs within his/her unit would generate bad feelings towards that workplace.

#### **7.2.4 PLHA responses on stigma and discrimination**

##### **Yunnan**

Three Yunnan interviewees had had information about their status disclosed by health care workers to their family without their permission. One had been refused service in a hospital. One Yunnan respondent had been asked to pay additional charges for medical services.

Three of the twenty Yunnan interviewees are taking ARVs, and said that this had had an impact on their lives. One of these interviewees said the impact had been negative in that he had had to go to such efforts to fund the treatments that it had caused his health to deteriorate. The other two were receiving free treatments but complained of painful side effects.

Three of the Yunnan interviewees were tested without their consent in the context of being treated in hospital.

Over half of the Yunnan interviewees received their results from CDC health workers. Others received their results from staff of detoxification centres, AIDS project staff or prison officials.

Most interviewees thought the waiting periods for test results were reasonable.

While all interviewees received post-test counselling, eight did not receive pre-test counselling. Interviewees understood what they were told in post-test counselling, but were still left worried. Interviewees noted that pre- and post-test counselling is available through the CDC.

Most Yunnan interviewees had someone accompany them for the test and three-quarters thought this was a good idea.

Eight Yunnan interviewees were advised of their results with others present and did not appreciate this – either because they did not want to worry their family or friends or simply because they did not like their status being disclosed to others.

Four Yunnan interviewees answered that their status had been revealed without permission – their status had been revealed to other health service staff, family members, partners or leaders. As a consequence, they had felt their privacy and rights to be violated.

Yunnan interviewees advised that they were generally keeping their status a secret. Hence much discrimination had been avoided.

No interviewees from Yunnan had been forced to submit to medical examination, denied entitlements or benefits or been denied education because of their status.

In relation to employment, six of the Yunnan interviewees were working but they had not disclosed their status to their colleagues.

Forty per cent of female Yunnan interviewees said they had been advised about mother-to-child transmission issues.

Yunnan interviewees had mixed responses to the question about exclusion from family. Four of the twenty interviewees had not disclosed their status to their families. Most Yunnan interviewees said they had not been excluded, although one reported exclusion by his mother. Others reported that the care and support increased after disclosure. Some interviewees feared rejection and excluded themselves from family socialising.

Overall, Yunnan interviewees did not report a drop in visits from family and friends, but again noted that few people knew of their status.

Ten Yunnan interviewees were (five) couples, all being HIV-positive. Only one Yunnan respondent had lost a partner as a result of disclosure.

Yunnan interviewees generally answered no to the question whether they had experienced a drop in financial support from family.

No interviewees from Yunnan said that they had been denied access to education or that they had heard of this occurring to others.

## **Guangxi**

A fifth of Guangxi interviewees answered that they had experienced unfair or bad treatment from a health service provider, and a quarter had been forced to pay additional costs for treatment.

Most interviewees from Guangxi answered that they had had reasonably good access to the health services they need, citing Médecins Sans Frontiers (MSF) as the source of services. Forty-five per cent of interviewees from Guangxi are receiving ARVs

Only 70per cent of interviewees from Guangxi were informed they were being tested for HIV, although no PLHAs from Guangxi claimed to have been forced to have a HIV test.

In relation to waiting times for test results, responses from Guangxi PLHAs varied enormously from 2-3 days (for 25%) to 7 months (5%). Interviewees indicated that wait periods of 2-3 days for the CDC or of 7 days for a county CDC or hospital were reasonable, while longer waits were unreasonable. Four interviewees waited 10-15 days, 3 waited 1-2 months, 2 waited 3-4 months and 1 waited 7 months.

Half the Guangxi interviewees were informed of their results by a doctor, 35per cent were informed by the CDC and a few were advised by phone, internet or by word sent through family.

Almost all PLHAs from Guangxi said they received counselling, but the data does not indicate at what point the counselling was provided.

A sizeable minority of Guangxi interviewees said that they were accompanied for testing, and that it is good for couples to be tested together.

Most interviewees from Guangxi said that health care workers had disclosed their status with their permission.

In relation to societal discrimination, 15per cent of interviewees from Guangxi said they had been asked to leave a public place, while 30per cent of Guangxi interviewees had been forced to change residence. A minority of PLHAs from Guangxi had been subjected to ridicule, insult or threat.

No interviewees from Guangxi had been forced to disclose their HIV status, and none reported being quarantined, detained, isolated, segregated or forced to submit to a medical examination.

Ninety per cent of interviewees from Guangxi also answered that they had not been denied benefits, privileges or services because of their status.

No interviewees from Guangxi said that they had been denied access to education or that they had heard of this occurring for others.

No female interviewees from Guangxi reported mandatory testing during pregnancy or a child's illness.

Eighty per cent of female interviewees from Guangxi answered that they had not been given information about mother-to-child transmission, and 95per cent of female interviewees from Guangxi answered that they had not been offered treatment to reduce mother-to-child transmission.

Fifty-five per cent of respondent from Guangxi said they had not been visited less frequently by family or friends since disclosing their status, although 40per cent of Guangxi interviewees have separated from their partner. Seventy per cent of Guangxi interviewees indicated that they had lost financial support as a consequence of their infection.

## **Lao**

Lao interviewees did not report being denied any services or overcharged, although some said they had received 'bad looks' from health care staff.

Regardless of the accessibility of health care services, some Lao respondents suggested they would prefer to have a separate and specialist department to provide them with quality treatment.

Most Lao respondents were receiving ARVs and felt better as a consequence. All complained that ARVs are available from only one site and that this meant treatment involved expensive travel.

Lao respondents did not report any cases of being tested without permission and none reported being forced to have a test.

Lao PLHAs were advised of test results by a doctor or by a laboratory technician in a private space. They reported being satisfied with these processes.

Several interviewees from Lao reported receiving proper counselling pre- and post-test.

Most Lao interviewees were accompanied by parents or relatives when they attended testing. Some said they would prefer to go to a testing site alone. Most Lao PLHAs said they were informed of the result in the presence of parents or relatives and many thought it was good for the family to know of their status. Some thought it better not to tell anyone (including family) of their status.

PLHAs from Lao did not report unauthorised disclosures of HIV status by health service providers.

In relation to societal discrimination, Lao interviewees said they had heard of a PLHA having to move residence in the past, but none had personally experienced such a need.

No interviewees had been forced to disclose their status, and none reported being isolated or detained. No interviewees had been forced to submit to medical examination.

Some interviewees had heard of the exclusion of children with HIV from education, however this was not reported as a current phenomenon.

One interviewee from Lao had been forced to leave a position with a restaurant because the restaurateur believed patrons would not accept HIV-positive staff.

Of eight female PLHA interviewed in Lao, two had had children, and neither had been forced to undergo testing. Female interviewees had received information about mother to child transmission (MTCT) through radio, TV, posters, and education from health centres. Lao respondents said they had been advised not to have children following diagnosis.

Interviewees from Lao said they had not been excluded from family activity, but that family concerns for their health had encouraged family members to ask that they engage less actively.

Many Lao respondents said their friends visited them less frequently.

Lao respondents did not report having personally been left by their partners as a consequence of disclosure, but said it did occur.

## **Viet Nam**

Many of the interviewees from Viet Nam reported discrimination at the hands of health care providers. Interviewees complained of doctor attitudes and extended delays in obtaining services. Interviewees blamed this discrimination on an absence of supportive mechanisms for doctors in charge of treatment and care, and on a lack of support from hospital leadership.

Many interviewees reported behaviours that demonstrated an expectation of discrimination, including reluctance to go to community health stations, decisions to self-treat rather than go to specialist services, refusing to go to hospital, etc.

Some of the interviewees from Viet Nam reported taking ARVs and experiencing good health as a consequence. These interviewees were purchasing the drugs in Thailand, requiring the assistance of family to cover treatment costs.

Many interviewees had been tested without their consent, in circumstances such as being admitted to hospital for antenatal care or delivery or other services, or prior to surgery. There was a report of a pregnant PLHA experiencing stigma and discrimination when seeking antenatal care and of being required to pay more for medical services. There were also reports of doctors avoiding contact with PLHAs and of delaying services.

Some interviewees said they had not experienced any discrimination from health service providers, and that overall levels of stigma and discrimination had reduced significantly due to increased knowledge amongst health service providers.

Interviewees from Viet Nam suggested that negative HIV results could be obtained in a day, but that positive results took a week.

Interviewees from Viet Nam reported many cases of testing without consent, and that the victims of such testing had not received any pre-or post-test counselling. PLHAs reported that counselling was provided at the VCT centre, but that the counselling was insufficient. The generally poor view of counselling was fuelled by the inadequacy of the information and the attitude of the doctors (said to range from unsympathetic to fearful).

Interviewees from Viet Nam reported that HIV results had been disclosed to doctors other than the PLHA's own doctor. Status had been disclosed on one occasion to a person's employer and on another occasion to a person's landlord.

Most interviewees from Viet Nam had not disclosed their status to anyone outside their immediate family and had not therefore experienced discrimination at the hands of others.

One respondent reported that their son had been denied a service on the basis of the parent's status. Another had had to leave their accommodation when the respondent's landlord discovered they were HIV-positive. Many interviewees feared public discrimination if their status was discovered.

Interviewees from Viet Nam did report exclusion from education services, but one had managed to resolve the problem satisfactorily.

Some interviewees from Viet Nam had been placed under great pressure within the workplace to disclose their status, but had resisted.

While most interviewees were unemployed, some reported HIV-related discrimination within the workplace. One reported being transferred to a much less interesting position after their employer was advised of their status. Some interviewees had felt compelled to resign their positions following (or fearing) discrimination within the workplace.

In relation to the reactions of family and friends, the experiences of Viet Nam interviewees varied enormously – while almost all had experienced discrimination from family members, some had enjoyed strong family support. Those who had experienced negative family reactions reported the negative impact upon them in emotional and spiritual terms, and some said that the extent of discrimination depended on the degree of their illness – the more obvious or serious the illness, the greater the likelihood of stigma and discrimination. Others reported that with increased understanding, discrimination had reduced.

Some interviewees from Viet Nam have experienced less contact with family and friends following disclosure, although the Viet Nam report notes some of this is due to the behaviour of people with HIV themselves (i.e., cutting themselves off from social contact).

## **Thailand**

Thai PLHAs reported a reluctance to disclose their status – they felt there would be little to gain and feared stigma and discrimination as a result.

Half of the Thai respondents had had an HIV test without their consent and most did not receive pre-test counselling. Where post-test counselling was received, respondents considered it inadequate. Respondents said they did not understand the information provided in post-test counselling because they were in no state to hear it. Instead, they thought there should be a follow-up opportunity to obtain this information once the news of their status had been adsorbed.

Most interviewees said they were advised of their positive results in a private room with no one else present. Waiting periods for test results were said to vary between 30 minutes and two weeks.

Respondents said they had not had an opportunity to meet with other positive people in connection with their diagnoses, although this was said to be changing with greater opportunities for peer support.

Some Thai respondents said that attitudes had improved and that they were now receiving better and more sympathetic treatment, while others reported recent discrimination from hospitals.

A number of pregnant PLHAs had been told to have an abortion and were not given adequate information to help with the decision. Women were not usually given any guidance from health service providers on how to disclose their status to their partners.

A few PLHAs had been refused proper treatment, particularly at private clinics. Some reported disclosure of their status by health service providers and a lack of sympathy in treatment and care.

There were reports of hospital systems that identified positive patients – this was a greater problem in the past but still continues in some places.

Most PLHAs feared disclosing their status at work. In Thailand a test is required in many cases before a person can take up a new job, and this has serious implications for a PLHA's ability to change or seek employment. Health service providers who were identified as positive were forced to leave their positions.

Of those PLHAs who had disclosed at work, some had had sympathetic reactions and some had had negative reactions.

Most Thai PLHAs interviewed were receiving ARVs. PLHAs said that access to ARVs was important because it helped prevent visible signs of infection, and this reduced the number of people who could identify a PLHA. This in turn reduced experiences of stigma and discrimination.

PLHAs said they lacked adequate knowledge to support their treatments, and that this information was difficult to obtain from general health facilities. Some PLHAs said that their treatments decision had been taken by doctors rather than by themselves. Fear of others becoming aware of their HIV status prompts many PLHAs to avoid their local treatments facility. Positive government officials were not pursuing HIV-related entitlements (such as subsidised health care) for fear of the consequences of disclosure.

When it came to family and friends, PLHAs reported very different experiences. Several said that reactions depended upon how a person had become infected – women who had been infected by their husbands received generally more sympathetic responses.

Some PLHAs had experienced discrimination from their family and social networks – being asked to eat separately, being forbidden to touch children etc. Some had received solid support from family and friends, but in some cases the families themselves had experienced stigma and discrimination.

Some PLHAs had had to move residence when they became symptomatic, for fear of discrimination.

## **7.3 Improving conditions for PLHAs**

### **7.3.1 Government officials responses on improving living conditions**

#### **Yunnan**

Government interviewees from Yunnan agreed that discrimination against PLHAs was decreasing, and attributed this to such matters as:

- Changes in the government's attitude
- Appropriate policy development
- Practices like condom distribution, which had previously been difficult, but which were now more common and more open
- IEC and publicity campaigns
- The voices of PLHAs being commonly heard
- More people providing care and support to PLHAs.

When asked what were the two or three most important and useful actions that government could take to reduce unfair or unkind treatment of PLHAs, government officials in Yunnan suggested:

- Development, promotion and enforcement of policies to promote equality of PLHAs
- Promoting understanding of HIV within the community.

As for the role of NGOs, Yunnan government officials suggested:

- Introduction of successful models of HIV programming from abroad
- Provision of more economic support
- Advocacy
- Policy development
- Facilitating effective communications between government and risk groups
- Training and coordination of networks.

For the role of community and civil society, Yunnan government officials suggested:

- Communication with government in relation to PLHA problems
- Creating an atmosphere of acceptance for PLHAs
- Working to create more job opportunities for PLHAs
- Involvement of PLHAs in activities.

#### **Guangxi**

All government officials from Guangxi reported that discrimination was decreasing and the situation for PLHA improving. They attributed this to:

- Greater understanding and acceptance of HIV and PLHAs following mass communication initiatives
- Appropriate law reform.

When asked about the future role for government, officials suggested the following:

- Shaking hands with PLHAs
- Appropriate policy development

- Greater financial contribution to prevention and training.

Government officials in Guangxi suggested NGOs should work with compassion and expand propaganda efforts.

The role for community and civil society should involve specific programs, communication with the community, greater propaganda efforts, greater encouragement for PLHAs to take part in community training, the bringing of care to community and family and acceptance of PLHAs.

## **Lao**

Government officials from Lao reported an overall decrease in discrimination. This was attributable to:

- Establishment of HIV networks from the central to peripheral level
- Communication and information sharing with the support of NGOs and international agencies.

Lao government officials suggested that the government focus on continuing to increase community awareness and ongoing support for community propaganda. They said that NGOs and international agencies should focus on financial and technical support.

Government officials from Lao said that civil society must participate in training to increase awareness and accept PLHAs as normal people.

### **7.3.2 Health service providers responses on improving living conditions**

#### **Yunnan**

Yunnan respondents thought stigma and discrimination to be declining. They thought this might be the result of mass communication campaigns, which had increased knowledge and subsequently reduced fear.

Yunnan respondents thought the government should increase its propaganda efforts and implement relevant policies, as well as provide more economic support for PLHAs.

Health service providers from Yunnan suggested that NGOs could bring PLHAs together, train them in living skills and inform them of their entitlement to live free of discrimination. They also thought NGOs could generate opportunities for PLHAs to learn how to be self-supportive and economically independent. Respondents said that donors should invest in medical treatment.

Yunnan respondents suggested that the community and civil society should provide a venue for PLHAs to communicate with each other, and that the community should care for and support PLHAs, respect confidentiality and treat PLHAs as equal.

## **Guangxi**

All health service providers in Guangxi suggested that discrimination was reducing as a consequence of a proper focus on PLHAs, more people understanding the routes of transmission, families and doctors acting as role models for the broader population, greater acceptance of patients and better treatment services.

Guangxi health service providers thought the best things government could do would include:

- Shaking hands with PLHAs
- Addressing treatments issues
- Providing skills training for medical staff
- Developing policies to support PLHA employment
- Supporting PLHAs to organise self-help groups.

Health service providers from Guangxi suggested the following role for NGOs and international donors: increase funding, provide free ARVs, combat discrimination, prevent risk behaviours, conduct health education and offer skills training for medical staff.

For community/civil society, health service providers from Guangxi suggested the following:

- Community education about HIV
- Education from different perspectives
- Thinking about families
- Participation of PLHAs
- Offering PLHAs respect and financial support
- Enhanced treatment.

## **Lao**

Health service providers from Lao said stigma and discrimination were decreasing.

Interviewees suggested government should continue to set clear HIV policies, increase funds to health services, expand health care facilities, and offer further incentives to health care workers.

Lao health service providers said NGOs should focus on financial and technical support at central, provincial and district level.

### **7.3.3 NGOs and civil society leaders responses on improving living conditions**

#### **Yunnan**

Most respondents from Yunnan thought that stigma and discrimination were declining, and based this view on improving government attitudes, more policies aimed at solving HIV-related problems and mass information and education campaigns reaching the general population. Three respondents, however, thought that

stigma and discrimination remained unchanged and that people continued to associate HIV with sex work, injecting drug use and homosexuality. These minority respondents called for more careful distribution of information to the public, as misinformation could make the situation even worse.

Interviewees from Yunnan suggested the government's role should involve policy development and dissemination to the broader society, to be accompanied by policy enforcement (including legislation).

Yunnan interviewees suggested NGOs should advocate with government for the implementation of GIPA principles, conduct education and training, set up networks to improve communication between PLHAs and their families, make good use of mass media and bring international best practice to the attention of the government.

Yunnan interviewees suggested that the community needed to encourage everyone to talk about HIV, to provide care and support to PLHAs, make available basic medical services, improve the quality of life for PLHAs, and make use of the education system for expanding HIV knowledge.

## **Guangxi**

Guangxi interviewees noted some changes in stigma and discrimination, suggesting these were the result of propaganda efforts and policy development. New laws would be required to address HIV employment issues, they thought.

Guangxi interviewees suggested the government's role should be in policy development, improving medical conditions, propaganda, taking steps to reduce discrimination, addressing employment issues and increasing capital allocation.

Interviewees from Guangxi suggested that NGOs and international donors focus on greater participation of PLHAs, involvement of PLHAs in management, allocation of more funds to support patients, addressing HIV employment issues and skills training. Interviewees further suggested that NGOs and donors might provide more money, work to reduce discrimination and assist in the provision of free treatment for PLHAs.

Guangxi responses for the role of civil society and community included strengthening community health education, caring for PLHAs, more community propaganda, advocacy with government and broadening community actions.

## **Lao**

All Lao NGO representatives, and most Lao civil society representatives, thought that stigma and discrimination were reducing.

Lao NGO and civil society representatives said that government should facilitate greater PLHA participation and offer training opportunities to enable PLHAs to be more self-sufficient. Some said that government should expand health care and offer free treatments, continue education initiatives, involve PLHAs in service work where possible and set appropriate policy.

Lao NGOs and civil society representatives thought that NGOs should continue to provide financial and technical support to government, and employ PLHAs where possible.

Lao respondents called for a continued community fight against HIV and for companies to fund HIV treatments for employees rather than dismiss PLHAs. Community awareness initiatives should increase and a National Solidarity Fund could be established, it was suggested.

### **7.3.4 PLHA responses on improving living conditions**

#### **Yunnan**

Most Yunnan interviewees said that stigma and discrimination levels remained unchanged – they continued to hear HIV discussed only in negative ways, as a disease that follows bad behaviour. A minority of Yunnan interviewees said that levels had reduced a little, and cited more understanding from their peers as a basis for this view.

Yunnan respondents had differing answers to the question about changing attitudes of health service providers. Some said health service providers were improving and behaving in a friendlier manner; some said that health service providers continued to behave badly and that even CDC counsellors acted impatiently towards PLHAs; most said they did not have ongoing relationships with health service providers or with the health sector (possibly because they kept their status generally hidden).

Six PLHAs from Yunnan said they could not personally do more to address stigma and discrimination, as they were not open about their status. Some others said that they had a role to play in supporting each other to live positively.

PLHAs from Yunnan said that the government should enact laws or develop policies to reduce stigma and discrimination. They hoped the government would reduce or eliminate the costs associated with treatment, and suggested the government provide more job opportunities for PLHAs.

Interviewees suggested NGOs could provide more economic support and training for PLHAs. They could also use mass media to conduct education/publicity campaigns.

When asked what could be done by their community to generate greater support for PLHAs, respondents from Yunnan suggested the community create more opportunities for distribution of HIV information.

#### **Guangxi**

PLHAs from Guangxi suggested that discrimination had decreased (as evidenced by friendlier health staff), but only a little.

Guangxi interviewees thought that attitudes might be improved through continuing programs to increase HIV knowledge, strategies to encourage health service providers to not discriminate, and government penalties imposed on health sector workers who did discriminate (eg. by demotion or salary reduction).

When asked what they thought should be done to help others in the community be more understanding of PLHAs, interviewees from Guangxi suggested community care, mass education and attention to employment issues.

PLHAs from Guangxi suggested government's role should include education and media campaigns, population care, working with medical staff to reduce discrimination and provision of treatments for PLHAs.

PLHAs from Guangxi suggested NGOs and international donors focus on provision of financial support, assistance with employment, provision of treatments and technical assistance with HIV control.

## **Lao**

Lao interviewees suggested that discrimination was reducing in urban areas, but that it might be continuing in rural areas. Improvements had been the result of increased communications and awareness.

Interviewees from Lao noted improvements in the work of health service providers. They said health care workers needed support, training and greater incentives.

To build further support for PLHAs, Lao interviewees suggested more education campaigns and community awareness would promote greater understanding. They considered outcomes would be improved if PLHA organisations had a greater role and if governments searched for new and more ways to support PLHAs.

## **Viet Nam**

Most interviewees from Viet Nam considered that increased information and communication about HIV had resulted in a decrease in discrimination.

Some interviewees from Viet Nam reported improved doctor attitudes following training.

PLHAs from Viet Nam called on government to provide additional beds for PLHAs in hospitals, improved quality of health care for PLHAs, increased community awareness to further reduce stigma and discrimination and free access to ARVs.

PLHAs from Viet Nam called for greater NGO involvement in building the capacity of PLHAs and the community.

Interviewees from Viet Nam acknowledged that they must live positively, demonstrating to the community that they have capacity to contribute, and be willing to assert themselves as necessary. Some interviewees thought that it would help the cause if PLHAs dissociated themselves from sex work and drug use.

## **Thailand**

Thai PLHAs noted their need to work together, bringing the multitude of PLHA groups together for constructive networking.

## 8. Overall observations

### On the methodology:

- Conducting interviews with different groups of stakeholders is a useful methodology for surveys relating to implementation of GIPA and the experience of stigma and discrimination. The data indicates that members of a group often share a view, but that other groups often challenge this view. In this way, each category of interviewee can provide a useful counterbalance to (or check upon) the evidence of other groups. For example, government performance in the implementation of GIPA was usually rated more favourably by government officials than by other groups. Health service providers often denied discrimination in circumstances where multiple other groups confirmed it. This multiple group criticism is harder to deny or ignore than the criticism of a single group, and helps validate the complaints of PLHA groups.
- Involvement of people with HIV, and the partner organisation APN+, models good GIPA practice. It would be difficult to conduct surveys such as these if the researchers could not claim to be implementing GIPA through their own work. The engagement of PLHAs no doubt added to the effectiveness of the process, to the willingness of different groups, particularly PLHAs, to participate, and to the quality of the outcomes.
- Extra efforts will need to be made in relation to future surveys of this kind to minimise variation in report writing across countries or provinces.
- Many PLHAs do not disclose their status due to fear of discrimination. For this reason, questions that relate only to their actual experience of discrimination might not elicit the full picture. Questions should also be directed to fears of disclosure and the consequences of such fears.

### On the data:

- Many PLHAs experience stigma and discrimination in many facets of their lives – at the hands of government, from health service providers, from NGOs, in the workplace, from family and friends and in general community life. Stigma and discrimination were reported in all surveyed countries. This reality should fuel advocacy responses in support of GIPA and the elimination of stigma and discrimination.
- Implementation of GIPA varies across countries, but the overall implementation of the principles remains extremely limited. Survey data demonstrates that there is solid support for the principles in theory, but there is clearly a long way to go before GIPA becomes a reality. Engagement of PLHAs in HIV responses is piecemeal. Engagement is often ‘one off’ rather than comprehensive or enduring, and PLHAs are more likely to be invited to participate in a government program than to help design one. There is a continuing reluctance to seek or respond to the views of PLHAs in relation to

service design and delivery. PLHA engagement is not likely to involve employment – this is especially the case with government and the health care sector.

- There is a solid basis for building on GIPA developments to date. There is commitment to inclusion of PLHAs in theory, and this is an important first step. There is some acknowledgement that PLHA perspectives are relevant and useful, so the challenge is to upscale this acknowledgement to something more meaningful. There is a need for programs that help build PLHA contributions from humble beginnings (as, say, a speaker at WAD) to more proper participation in program design and delivery.
- While health service providers, NGOS and civil society representatives were often critical of government failures in relation to GIPA, these sectors had also generally failed to implement GIPA.
- Perceived or actual capacity of PLHAs to contribute to development of policy or service responses to HIV is a significant barrier to greater engagement. This suggests an undervaluing of the consumer perspective in developing and implementing HIV programs – a failure to acknowledge that the very experience of being HIV-positive is of great use in helping to shape epidemic responses. It also suggests that greater engagement might be assisted through measures to train and support PLHAs, and to boost their confidence.
- Perceptions of stigma and discrimination are different for PLHAs than for government officials, health service providers, civil society leaders and NGOs. PLHAs report higher rates of stigma and discrimination than other groups, and in circumstances where it is denied by other stakeholders. While this may not be surprising, it suggests that many incidences of stigma and discrimination go unreported and/or are unnoticed by those who do not feel the direct brunt of these phenomena. It also confirms the importance of speaking directly to PLHAs to gauge levels of stigma and discrimination, rather than relying on the views of others – even where those others are committed to the rights and wellbeing of PLHAs.
- Fear of discrimination prompts many PLHAs to keep their HIV status a secret. This results in significant under-measuring of stigma. While occurrences of discrimination might be prevented through such secrecy, the stigma that discourages disclosure continues unchallenged. Most interviewee groups acknowledged that discrimination would be greater if more people were openly positive. Maintaining secrecy of status can have direct negative impacts on PLHAs - reluctance to access essential health services, failure to claim benefits and entitlements, and unwillingness to seek all-important peer support contribute to poorer health outcomes overall for PLHAs.
- PLHA experiences of stigma and discrimination vary between urban and rural environments. Many respondents across different groups suggested the situation for rural PLHAs was worse than for PLHAs living in main centres.

- While many groups consider the rates of stigma and discrimination to be reducing, this is often not the view of PLHAs. This presents an obvious challenge for policy and decisions makers, as well as for those involved in the delivery of services to PLHAs. There is little basis for assuming that stigma and discrimination will be reduced without continued and concerted effort.
- Interviewees perceive that different sectors have different roles in combating HIV. This offers a useful basis for the development of partnership responses to HIV, where each sector seeks to meet its own responsibilities while acknowledging the capacities and expertise of other members of the partnership.

# Annex 1

## Qualitative Survey Questionnaires

Separate questionnaires were developed for each category of respondent. Each of the questionnaires is reproduced below.

### **GIPA and S&D Questionnaire for Government Officials**

We would like to start by hearing your views and experiences about involving people with HIV in government processes, such as meetings, workshops, planning and assessment, services and other activities that are intended to assist PLHAs.

#### **1. GIPA**

1.1 Do you think that involving PLHAs in some part of your unit's work that responds to the HIV epidemic is important?

- If yes, could you please explain what you think the advantages/benefits are? (Interviewer: prompt by asking if the benefits include helping those with HIV/AIDS, improving the national program and national response to the epidemic)
- If no, could you please explain why this is not useful?

1.2 Has your unit ever invited individual PLHAs or representatives of PLHA organizations to come to meetings or workshops concerning government HIV/AIDS programs or services? If no, why not?

1.3 Has an individual PLHA or a PLHA organization(s) ever requested that they participate in some part of your unit's work?

1.4 Has an individual PLHA or a PLHA organization ever participated in any activity or event with you and others in your unit?

- If no, why do you think they have not done so?
- If yes, how often were they involved? In what type of activities? Only for specific parts of the activity or process, or for the entire activity?

1.5 Do you think that it is difficult to include PLHAs in these government processes?

- If yes, what are the barriers/problems that create difficulties? (Interviewer: prompt with educational level, lack of experience, lack of resources, lack of representativeness of PLHAs broadly)
- How could these problems be overcome?

1.6 Have you ever participated in any type of activity or event organized by other parts of government, by NGOs, or by donors where PLHAs were present and participated in the discussions?

- If yes, was their participation useful to the outcome of the activity? If no, could you please tell us why not?
- If no, do you think that PLHAs can offer any valuable insights that would contribute to the planning process? If no, could you please tell us why you think so?

1.7 Do you think that expanded participation by PLHAs should be an official government policy or a standard practice for programs and services to assist PLHAs?

1.8 Will your unit try to involve PLHAs in some part of your work in the next 12 months? If no, why not?

1.9 Does your unit employ anyone who is HIV positive? If no, why not? Do you think that employing a HIV positive person would be helpful to your unit's work? If no, why not?

1.10 Does your department or agency have a work place policy on HIV? If no, do you think one is needed and it would be useful?

1.11 What practical ideas or suggestions do you have for how you could get greater involvement of PLHAs in some part of your work or to provide feedback on services your unit provides?

1.12 In your opinion, how do other stakeholders feel about greater involvement of PLHAs in government processes and services? Stakeholders include other government officials, NGOs, health workers, medical professionals, donors, and academics.

1.13 Do you think that a person with HIV who is still healthy enough to work effectively and has the proper qualifications should be allowed to manage a government program or activities that provides services and assistance to PLHAs? If no, why not?

1.14 Beyond participating in activities and events designed to assist PLHAs, do you know of PLHAs who:

- Work as peer educators or outreach workers
- Work as staff in health facilities
- Work as staff for government agencies or NGOs
- Have organized a CBO or self-help group
- Manage activities or projects designed to assist PLHAs by providing services or supporting advocacy in the interests of PLHAs

## **2. Stigma and Discrimination**

I would like to broaden our discussion about the treatment PLHAs receive in our society. There are several areas where PLHAs often experience difficulties in life and I would like to ask whether you know about any of these problems.

2.1 Some PLHAs report that they experience unfair or improper treatment at health facilities because of their HIV status. We would like to ask you about this.

Do you know of or have you heard of cases where a PLHA experienced some form of discrimination due to his/her HIV status? This includes:

- Being denied medical services and information they need or should receive
- Being told to go to another facility even though services were available
- Having to wait incorrectly until others were served to receive health services
- Being told to not make use of available health care services
- Being isolated from others at health care facilities
- Being required to pay higher or additional charges for services

If yes, could you please tell me what you know or have heard about regarding such problems? Do you think such problems are common or widespread?

2.2 Studies have found that some PLHAs encounter difficulties with the HIV testing process when they were first tested. Some PLHAs report that they were forced to be tested and/or that results were disclosed without the person's permission, violating their rights of fair treatment and confidentiality.

Do you know or have you heard of any incorrect practices at testing facilities that reflect unfair or inequitable treatment? This includes:

- Being tested without being informed first
- Being coerced into being tested
- Someone being present when the individual was tested
- Revealing test results to others without the permission of the person tested
- Experiencing an excessive amount of time between being tested and receiving results

If yes, could you please tell me what you know or have heard about regarding such problems? Do you think this is very common or widespread?

2.3 Another problem that some PLHAs experience is violation of their personal liberty and security, as well as receiving inhumane or degrading treatment. They report that they experience treatment that violates their human rights because of their HIV status.

Do you know of or have you heard of actions against PLHAs that violate their right of personal liberty and security? This includes:

- Refused entry, removed from or asked to leave a public establishment because of their HIV status (restaurants, bars, barber shops, or other types of businesses open to the public)
- Having to change residence, some times, several times
- Ridiculed, insulted, or harassed in public
- Threatened with violence or assaulted
- Forced to reveal his/her HIV status
- Quarantined, detained, isolated or segregated, e.g., during travel, when seeking health care
- Discriminated against by friends or friends
- Excluded from social events because of his/her HIV status
- Unjustifiably denied benefits, privileges or services given to others
- They or their child(ren) are denied access to education

If yes, could you please tell me what you know or have heard about regarding this problem? Do you think this is very common or widespread?

2.4 Some PLHAs experience unfair and illegal treatment regarding employment. Employers and fellow workers create difficulties for these PLHAs in the work place even when the individual is still healthy and able to work hard.

Do you know about or have you heard of cases where PLHAs experienced discrimination in the work place? This includes:

- Denied employment or lost job because of HIV status
- Being forced to take a HIV test
- Being refused employment because of their HIV status
- Unfair treatment, harassment, or made to feel unwelcome due to actions of the employer and fellow workers because of his/her HIV status
- Losing his/her job, losing opportunities for promotion, or being encouraged to stop/leave work
- A significant loss of earning capacity because of discrimination in the work place.

If yes, could you please tell me what you know or heard about regarding this problem? Do you think this is very common or widespread?

2.5 Some PLHAs experience problems regarding their family and social relationships. Some families reject the individual when they learn that he or she is HIV positive and view them as a “bad person” because of it.

Do you know or have you heard about cases where a PLHA has suffered problems with his/her family or experienced other social problems? This includes:

- Lack of access to treatment
- Women being required to be tested during pregnancy or illness of her child
- Women not being given information about mother to child transmission
- Women being advised to not have another child after diagnosis
- Being excluded from family functions because of his/her HIV status
- Avoided by family members or friends, or visited much less than before
- Deserted by his/her partner

- Losing financial support from his/her partner or family

If yes, could you please tell me what you know or heard about regarding this problem? Do you think this a common or widespread problem?

### **3. Improving Conditions for PLHAs**

3.1 Do you think that there are any changes or trends in attitudes and behaviours toward PLHAs? Is stigma and discrimination toward PLHAs decreasing, getting worse, or about the same over the past few years? Could you please tell what the basis is for your views regarding changes in stigma and discrimination toward PLHAs?

3.2 What are the two or three most important and useful actions that government could take to reduce unfair or unkind treatment of PLHAs?

3.3 What are the two or three most important and useful actions that NGOs and international donors could take to reduce unfair or unkind treatment of PLHAs?

3.4 What could be done in the community or civil society generally to promote understanding and acceptance of PLHAs?

## **GIPA and S&D Questionnaire for Health Service Providers**

### **1. GIPA**

We would like to begin by hearing your views and experience with involving PLHAs in developing or improving services for them.

1.1 Are there any HIV positive people on the staff of this facility? Do you think it would be a good thing to employ PLHAs? If no, why not?

1.2 In your health facility, when the staff meet to discuss services and operations, particularly those that PLHAs require, is there any discussion about what the perceived special needs are of PLHA clients?

1.3 Do you think it would be useful to ask your PLHA clients for their views about how services could be improved for them and take into consideration their views to make changes in services for them? If no, why not?

1.4 Do you or your fellow workers ever ask PLHA clients how services could be improved for them? If no, why not? If yes, how often do you ask, how do you go about asking this, do you have a process or system for asking such questions?

1.5 Do you know whether the Ministry of Health encourages PLHAs to participate in its planning of services that assist PLHAs? Do you think the Ministry should do this? (Whether yes or no) Could you please briefly explain why you say that?

1.6 Beyond participating in activities and events designed to assist PLHAs, do you know of PLHAs who:

- Work as peer educators or outreach workers
- Work as staff in health facilities
- Work as staff for government agencies or NGOs
- Have organized a CBO or self-help group
- Manage activities or projects designed to assist PLHAs by providing services or supporting advocacy in the interests of PLHAs

## **2. Stigma and Discrimination**

2.1 Do you provide ARVs at your facility? If so, do you think this has a positive effect on your clients? Why do you say this?

2.2 Do you think that you have sufficient knowledge about HIV/AIDS? Do you fully understand how HIV is transmitted and how it is not transmitted? Would you like further training about HIV/AIDS and how to provide services to PLHA clients?

2.3 Are you comfortable when you provide services to a PLHA client? Do you have some concerns about your own health – are you afraid that you will be infected by them? If yes, what are your specific concerns?

2.4 Have you ever received special training regarding the counselling needed for HIV testing services, including how to manage the psychological stress the client experiences, especially if found to be positive? Would this be useful to you?

2.5 When someone comes to be tested for HIV, what do you tell them before conducting the test? (Interviewer: you must judge whether this is correct and sufficient counselling.)

2.6 When you give someone their test results, what do you tell the client after informing him/her that they: a) test positive for HIV, or b) test negative for HIV? (Interviewer: you must judge whether this is correct and sufficient counselling.)

2.7 On average, how long is the time between testing a client and providing him/her with results? Do you think this is a reasonable, acceptable amount of time, or is it too long?

2.8 Do you or your co-workers ever inform a client of his/her HIV status with a family member in the room? With a friend? Do you do so with the permission of the client?

2.9 Do you or your co-workers think that it is acceptable to reveal the HIV status of a PLHA client to family members – their spouse, parents, brothers, sisters – without the permission of the PLHA client? Is it acceptable if the PLHA client gives you permission to do so?

2.10 In your health facility, do all the staff know about the HIV status of your PLHA clients? Is this revealed to other clients at the facility? Is it revealed to family members or community leaders? If so why?

2.11 Other than during professional case review meetings where the client's confidentiality is protected, do you or your co-workers discuss among yourselves the HIV status of clients at your facility?

2.12 Does your facility separate PLHA clients from others? If so, how do you do that? If yes, do you think this is a good practice? Why?

2.13 Are PLHA clients served in the order of their coming to the facility, in a regular queue, or must they wait until other clients have been served first?

2.14 Has a PLHA ever been refused services at your facility? If yes, could you please explain why?

2.15 Do you or your co-workers ever refer PLHA clients to other facilities? If yes, could you please explain what type of referrals and the reason for doing so?

2.16 Do you or your co-workers ever experience problems in providing services to PLHAs? If yes, could you please tell what those problems were?

### **3. Knowledge of Stigma and Discrimination**

I would like to broaden our discussion about the treatment PLHAs receive in our society. There are several areas where PLHAs often experience difficulties in life and I would like ask whether you know about any of these problems.

3.1 A problem that some PLHAs experience is violation of their personal liberty and security, as well as receiving inhumane or degrading treatment. Some report experience with treatment that violates their human rights because others know of or suspect they are infected with HIV.

Do you know of or have you heard of actions against PLHAs that violate their right of personal liberty and security? This includes:

- Refused entry, removed from or asked to leave a public establishment because of their HIV status (restaurants, bars, barber shops, other types of businesses open to the public)
- Having to change residence, some times, several times
- Ridiculed, insulted, or harassed in public
- Threatened with violence or assaulted
- Forced to reveal his/her HIV status
- Quarantined, detained, isolated or segregated, e.g., during travel, when seeking health care
- Discriminated against by friends or family
- Excluded from social events because of his/her HIV status
- Unjustifiably denied benefits, privileges or services given to others
- They or their child(ren) are denied access to education

If yes, could you please tell me what you know or have heard about regarding this problem? Do you think this is a common or widespread problem?

3.2 Some PLHAs experience unfair and illegal treatment regarding employment. Employers and fellow workers create difficulties for these PLHAs in the work place even when the individual is still healthy and able to work hard.

Do you know about or have you heard of cases where PLHAs experienced discrimination in the work place? This includes:

- Denied employment or lost a job because of HIV status
- Unfair treatment, harassment, or made to feel unwelcome due to actions of the employer and fellow workers because of his/her HIV status
- Losing his/her job, losing opportunities for promotion, or being encouraged to stop/leave work
- A significant loss of earning capacity because of discrimination in the work place.

If yes, could you please tell me what you know or heard about regarding this problem? Do you think this is a common or widespread problem?

3.3 Some PLHAs experience problems regarding family and social relationships. Some families reject the individual when they learn that he or she is HIV positive and view them as a “bad person” because of it.

*Do you know or have you heard about cases where a PLHA has suffered problems with his/her family or experienced other social problems? This includes:*

- Women being required to be tested during pregnancy or illness of her child
- Women not being given information about mother to child transmission
- Women being advised to not have another child after diagnosis
- Being excluded from family functions because of his/her HIV status
- Avoided by family members or friends, or visited much less than before
- Deserted by his/her partner
- Losing financial support from his/her partner or family

If yes, could you please tell me what you know or heard about regarding this problem? Do you think this is a common or widespread problem?

## **4. Improving Conditions for PLHAs**

4.1 Do you think that there are any changes or trends in attitudes and behaviours toward PLHAs? Is stigma and discrimination toward PLHAs decreasing, getting worse, or about the same over the past two years? Could you please tell what the basis is for your views regarding changes in stigma and discrimination toward PLHAs?

4.2 What are the two or three most important and useful actions that government could take to reduce unfair or unkind treatment of PLHAs?

4.3 What are the two or three most important and useful actions that NGOs and international donors could take to unfair or unkind treatment of PLHAs?

4.4 What could done in the community or civil society generally to promote understanding and acceptance of PLHAs that would unfair or unkind treatment of PLHAs?

## **GIPA and S&D**

### **Questionnaire for NGOs and Civil Society Leaders**

We would like to start by hearing your views and experiences with how government, NGOs and civil society goes about involving people who are infected in its various process, e.g., planning meetings, workshops, assessments, services and other activities, that are intended to assist PLHAs.

#### **1. GIPA**

1.1 To what extent does government involve PLHAs in its processes that respond to the HIV epidemic? Should the government try to involve PLHAs more in such activities?

1.2 Why do you think government does not encourage greater participation in its processes that intend to assist PLHAs? Is there a lack of understanding of the importance of their involvement? Not enough awareness among government officials?

1.3 Do you know of any government unit that invites PLHAs to participate in some part of its work that are intended to benefit them? If yes, does this occur frequently?

1.4 Have PLHAs ever participated in such government activities? If no, why not? If yes, did their participation lead to government taking action on what they said as a result?

1.5 Do you think that expanded participation by PLHAs should be an official government policy or a standard practice for programs and services to assist PLHAs?

1.6 Other than a lack of understanding or disinterest, what other factors limit the ability of PLHAs to participate in government process that are designed to assist PLHAs?

1.7 For NGOs:

1.7.1 Does your organization engage PLHAs in any elements of its work that the organization supports to assist PLHAs?

1.7.2 Do you think that the involvement of PLHAs should be greater in your Organization's work?

- 1.7.3 Will your organization try to expand the involvement of PLHAs in its work in the next 12 months? If no, why not?
- 1.7.4 Does your organization employ PLHAs? If no, why not? Do you think it would be beneficial to your organization to employ PLHAs?
- 1.7.5 Does your organization have a work place policy on HIV? Do you think this is needed and would it be useful? If no, why not?
- 1.8 For Civil Society leaders:
- 1.8.1 Do you think that NGOs and government do enough to engage PLHAs in elements of their work and processes that are designed to assist them?
- 1.8.2 Should they do more?
- 1.8.3 Why do you think they do not engage PLHAs more intensively or frequently in such work?
- 1.8.4 Does your own business or organization plan to expand the role of PLHAs in its activities?
- 1.8.5 Does your business or organization employ PLHAs? If no, why not? Do you think it would be beneficial to your organization to employ PLHAs?
- 1.8.6 Does your business or organization have a work place policy on HIV? Do you think this is needed and would it be useful? If no, why not?
- 1.9 What practical ideas or suggestions do you have for how to achieve greater involvement of PLHAs in government, NGO, and civil society processes and activities that are designed to assist them?
- 1.10 Beyond participating in activities and events designed to assist PLHAs, do you know of PLHAs who:
- Work as peer educators or outreach workers
  - Work as staff in health facilities
  - Work as staff for government agencies or NGOs
  - Have organized a CBO or self-help group
  - Manage activities or projects designed to assist PLHAs by providing services or supporting advocacy in the interests of PLHAs

## **2. Stigma and Discrimination**

I would like to broaden our discussion about the treatment PLHAs receive in our society. There are several areas where PLHAs often experience difficulties in life and I would like ask whether you know about any of these problems.

2.1 Some PLHAs report that they experience unfair or improper treatment at health facilities because of their HIV status. We would like to ask you about this.

Do you know of or have you heard of cases where a PLHA experienced some form of discrimination due to his/her HIV status? This includes:

- Being denied medical services
- Being to go to another facility even though services were available
- Having to wait unfairly until others were served to receive health services
- Being told to not make use of available health care services
- Being isolated from others at health care facilities
- Being required to pay higher or additional charges for services

If yes, could you please tell me what you know or have heard about regarding this problem? Is this a common or widespread problem?

2.2 Studies have found that some PLHAs encounter difficulties with the testing procedure when they were first tested. This typically involved inadequate explanation and no counselling as part of the testing procedure, followed by violation of the person's privacy by revealing their HIV status to others without permission.

Do you know of or have you heard of any incorrect practices at testing facilities? This includes:

- Lack of adequate explanation about the purpose of the test
- Being coerced into taking the test
- Not receiving counselling before being tested
- Someone being presented when tested or when test results are given that causes embarrassment or problems.
- Not receiving counselling when results are given
- Revealing test results to others without the permission of the person tested
- Experiencing an excessive delay between being tested and receiving results

If yes, could you please tell me what you know or have heard about regarding this problem? Do you think this is a common or widespread problem?

2.3 Another problem that some PLHAs experience is violation of their personal liberty and security, as well as receiving inhumane or degrading treatment. Some experience treatment that violates their human rights because others know of or suspect they are HIV positive.

Do you know of or have you heard of actions against PLHAs that violate their right of personal liberty and security? This includes:

- Refused entry, removed from or asked to leave a public establishment because of their HIV status (restaurants, bars, barber shops, other kinds of business open to the public)
- Having to change residence, some times, several times
- Ridiculed, insulted, or harassed in public
- Threatened with violence or assaulted
- Forced to reveal his/her HIV status
- Quarantined, detained, isolated or segregated, e.g., during travel, when seeking health care
- Discriminated against by friends or family
- Excluded from social events because of his/her HIV status
- Unjustifiably denied benefits, privileges or services given to others

- They or their child(ren) are denied access to education

If yes, could you please tell me what you know or have heard about regarding this problem? Do you think this is a common or widespread problem?

2.4 Some PLHAs experience unfair and illegal treatment regarding employment. Employers and fellow workers create difficulties for these PLHAs in the work place even when the individual is still healthy and able to work hard.

Do you know about or have you heard of cases where PLHAs experienced discrimination in the work place? This includes:

- Being forced to be tested for HIV
- Being refused employment because of their HIV status
- Unfair treatment, harassment, or made to feel unwelcome due to actions of the employer and fellow workers because of his/her HIV status
- Losing his/her job, losing opportunities for promotion, or being encouraged to stop/leave work
- A significant loss of earning capacity because of discrimination in the work place.

If yes, could you please tell me what you know or heard about regarding this problem? Do you think this is a common or widespread problem?

2.5 Some PLHAs experience problems regarding family and social relationships. Some families reject the individual when they learn that he or she is diagnosed as having HIV and view them as a “bad person” because of it.

Do you know or have you heard about cases where a PLHA has suffered problems with his/her family or experienced other social problems? This includes:

- Lack of access to treatment
- Women being required to be tested during pregnancy or illness of her child
- Women not being given information about mother to child transmission
- Women being advised to not have another child after diagnosis
- Being excluded from family functions because of his/her HIV status
- Avoided by family members or friends, or visited much less than before
- Deserted by his/her partner
- Losing financial support from his/her partner or family

If yes, could you please tell me what you know or heard about regarding this problem? Do you think this is a common or widespread problem?

### **3. Improving Conditions for PLHAs**

3.1 Do you think that there are any changes or trends in attitudes and behaviours toward PLHAs? Is stigma and discrimination toward PLHAs decreasing, getting worse, or about the same over the past few years? Could you please tell what the basis is for your views regarding changes in stigma and discrimination toward PLHAs?

3.2 What are the two or three most important and useful actions that government could take to reduce unfair or unkind treatment of PLHAs?

3.3 What are the two or three most important and useful actions that NGOs and international donors could take to reduce unfair or unkind treatment of PLHAs?

3.4 What could be done in the community or civil society generally to promote understanding and acceptance of PLHAs that would reduce unfair or unkind treatment?

## **GIPA and S&D**

### **Questionnaire for People Living with HIV/AIDS**

#### **1. GIPA**

We would like to start by hearing your views and experiences about involving people living with HIV in government processes, such as meetings, workshops, services, and other activities that are intended to assist PLHAs.

1.1 Have you or your PLHA organization ever participated in government processes that concerned the interests and needs of PLHAs?

- If yes, how much did you/they participate in the process – only for specific parts of it, or for the entire process?
- If no, have you or has your organization ever been asked to participate in a government process or event concerning the interests or needs of PLHAs?
- If no, would you be interested in participating in such processes? If not, why?
- Do you think that you have the necessary skills or experience to participate in such government processes?
- If not, what help could be given to you to support you participating more fully?

1.2 Do you think that it is important that PLHAs or representatives of PLHA organizations participate in government processes that are intended to assist PLHAs?

- If yes, what are the benefits of including PLHAs in these government processes? (Interviewer: prompt with helps other PLHAs, improves the national program/response, improves care and support services, expands access to treatments, reduces stigma and discrimination, improves prevention programs)
- If no, could you please tell us why not?

1.3 Do you know of any one who is HIV positive who participated in a government process where they met with officials about the interests and needs of PLHAs?

- If yes, did the meeting or event result in the government doing anything for PLHAs?

1.4 Has any government official or service provider ever asked you what your interests or special needs are, or how services could be improved for you?

1.5 Do you know of any way that PLHA organizations can communicate their interests and needs to government officials?

1.6 Do you think government officials are interested in the views, ideas or needs of people who are HIV positive? Why do you say this?

1.7 Has a representative from a NGO ever talked to you about your interests and needs?

1.8 Did an NGO invite you to attend a meeting or workshop concerning the interests and needs of PLHAs? Did you attend? If not, why not?

1.9 Beyond participating in activities and events designed to assist PLHAs, do you know of PLHAs who:

- Work as peer educators or outreach workers
- Work as staff in health facilities
- Work as staff for government agencies or NGOs
- Have organized a CBO or self-help group
- Manage activities or projects designed to assist PLHAs by providing services or supporting advocacy in the interests of PLHAs

## **2. Stigma and Discrimination**

We would like to broaden our discussion about the treatment PLHAs receive in our society. There are several areas where PLHAs often experience difficulties in life and we would like ask whether you are aware or experienced personally any of these problems.

### **2.1 Access to Health Services**

2.1.1 Have you ever been treated unfairly or badly by any health care worker(s) due to your HIV status? This includes being denied medical care or services, or experiencing an unjustified delay in receiving treatment/care. If yes, would you please describe what happened if you are comfortable doing so?

2.1.2 Have you ever been forced to pay additional charges for medical services due to your HIV status?

2.1.3 Do you feel that you have reasonably good access to the health services you need, including information, e.g., about PMTCT, safe sex practices, opportunistic infections? How could access to these services be improved or made more easily available to you.

2.1.4 Are receiving ARVs? If so, how long have been receiving ARVs? Has access to ARV treatment had an impact on you life? Could you please explain how this has affected your life?

### **2.2 Testing and Privacy**

2.2.1 were you tested for HIV without being told first?

2.2.2 were you forced into having a HIV test? If yes, by whom and why were you forced to be tested, e.g., forced to do so when applying for a job?

2.2.3 How did you receive your results and who informed you of the results?

2.2.4 How long was the time between being testing and receiving your results? Do you think this was a reasonable, acceptable amount of time, or was the time too long?

2.2.5 Did you first receive counselling about the test before it was done and information about what the results would mean? Did you receive counselling before being told your result? Did you receive counselling after you received the results? If yes, did you understand what was said to you?

2.2.6 Was any friend or family member with you when you went to be tested for HIV? If yes, was this a good thing?

2.2.7 When you received your test results, was any one else present and heard the results? If yes, who was present? If yes, was this a good thing?

2.2.8 Has a health care worker ever told anyone else about your HIV status without your permission? If yes, who did they tell, e.g., family members, community leaders? Did this cause you problems? If yes, what happened?

### **2.3 Personal Liberty and Security**

2.3.1 Have you ever been refused entry, removed from, or asked to leave a public place (restaurant, bar, barber shop, other kind of business) because of your HIV status? If yes, would you please describe the event.

2.3.2 Have you ever been forced to change your residence because of your HIV status? If yes, how many times? What were the circumstances that caused you to move?

2.3.4 Have you ever been ridiculed, insulted, threatened with violence, or assaulted because of your HIV status? If yes, by whom?

2.3.5 Have you ever been forced to disclose your HIV status? If yes, by whom and why were you forced to do so?

2.3.6 Have you ever been quarantined, detained, isolated, or segregated because of your HIV status? If yes, would please describe the event.

### **2.4 Inhumane and Degrading Treatment**

2.4.1 Have you ever been forced to submit to medical examination because of your HIV status? If yes, why?

2.4.2 Have you been denied benefits, privileges or services given to others because of your HIV status? If yes, would you please describe what happened?

2.4.3 Have you or your child(ren) ever been denied access to education because of your HIV status? Do you know of any one else who has experienced this?

## **2.5 Right to Employment**

Screen: Ask if they have ever worked for an employer since being diagnosed. If no, go to the next section – 2.6

2.5.1 Have you experienced bad or unkind treatment from your employer or fellow workers at work because of your HIV status? If yes, would you please describe what happened?

2.5.2 Have you ever lost your job, lost the opportunity for promotion, or been encouraged to stop/leave work because of your HIV status? If yes, what were the reasons for this?

2.5.3 If you have not been sick because of HIV, do you think that your earning capacity has decreased as a result of having HIV?

2.5.4 Have you ever been forced to be tested for HIV as a requirement for employment. Do you know of any one who was forced to do so?

## **2.6 Family and Relationships**

2.6.1 Have you undergone mandatory HIV testing during pregnancy or illness of your child? (women only)

2.6.2 Were you given information about mother to child transmission? (women only)

2.6.3 Was treatment offered to reduce the chance of transmission from mother to child?

2.6.4 Were you advised to not have any more children after being diagnosed? If yes, by whom? (women only)

2.6.5 Have you been excluded from usual family activities since becoming HIV positive?

2.6.6 Have friends or family member avoided you or visit much less frequently since being diagnosed?

2.6.7 Has your partner left you because of your HIV status?

2.6.8 Were you financially dependent on your former partner?

2.6.9 Have you lost financial support from your family?

### **3. Improving Conditions for PLHAs**

3.1 Do you think that there are any changes or trends in attitudes and behaviours toward PLHAs? Is stigma and discrimination toward PLHAs decreasing in your community, getting worse, or about the same over the past few years? Could you please tell us what the basis is for your views?

3.2 Over the past year, have you seen any improvement in the way you are treated when you go for health care? Are health workers kinder and more understanding or do they still react to you unfairly or unkindly? What do you think could be done to encourage them to treat HIV+ people more fairly and correctly?

3.3 What do you think should be done to help others in the community to be more understanding of those who are HIV positive? Should government do more? Can NGOs do more? Do PLHA organizations/networks have a role to play?

3.4 What are the two or three most important and useful actions that government could take to reduce the unfair or bad way that some people treat PLHAs?

3.5 What are the two or three most important and useful actions that NGOs and international donors could take to reduce the unfair or bad way that some people treat PLHAs??

3.6 What could be done by your community to promote understanding and acceptance of PLHAs that would reduce the unfair or bad way that some people treat PLHAs?

# Annex 2

## Consultants' Guidelines for the GIPA and Stigma and Discrimination Survey

These guidelines were provided to the consultants who conducted the interviews in each of the five sites to maximize a standardized approach to the selection of respondents and the administration of the questionnaires.

### 1. Background: Rationale for the Survey

The POLICY project and its partner organization, the Asia Pacific Network of People Living with HIV/AIDS (APN+) have been requested by USAID to establish a baseline for greater involvement of people living with HIV/AIDS (GIPA) and stigma and discrimination (S&D) toward people who are HIV positive. USAID's Mekong Regional Program for HIV/AIDS and POLICY's participation in that program are designed to identify the policies and legislation needed to create a supportive policy environment that makes prevention information, health services, and care accessible to those who are HIV positive and those who are experiencing the symptoms of AIDS. APN+ supports organizations and associations of people living with HIV/AIDS (PLHAs) to advocate for rights, programs, and services that meet the needs of PLHAs.

Confronting the issues of stigma and discrimination is an essential element of creating an effective response to the HIV/AIDS epidemic. Experience worldwide demonstrates that stigma and discrimination are major impediments to HIV positive people gaining access to essential prevention information and health services. In all countries, stigma and discrimination result in isolating HIV positive people from their families, friends and general society which only worsens their wellbeing and magnifies the effects of the epidemic on society as a whole.

Stigma and discrimination are particularly important in the concentrated epidemics that are expanding in the countries of the Mekong Region. If stigma and discrimination can be decreased, the chances of the epidemic reaching the general population also decreases. In other words, reducing stigma and discrimination through effective implementation of policies and legislation can play a vital role in containing concentrated epidemics and preventing the development of generalized epidemics. Better information about the stigma and discrimination HIV positive people currently confront helps create a clearer understanding of the problem, in turn, leading to identification of corrective actions.

GIPA is closely associated with decreasing stigma and discrimination. PLHAs' participation in processes and events that are intended to assist them brings an important perspective to these processes and activities. Their personal knowledge of what PLHAs need and their life experiences give additional direction to activities such as strategy development, program planning and assessments of the effectiveness of services related to HIV/AIDS.

While the importance of GIPA is widely acknowledged to be an effective means to improving the national response to the HIV/AIDS epidemic and officially endorsed by the United Nations and its members, actual practice lags far behind. Either engagement of PLHAs in government and non-government activities and programs is often lacking, or PLHA participation is largely tokenism. The consequence of this is that government and non-government strategies, programs and activities are developed that lack this critical perspective, resulting in less than optimal assistance and services for PLHAs.

The involvement of PLHAs in government and non-government activities can vary widely. Attachment 1 provides some of the accepted ways in which the level of PLHA involvement varies from very limited to very extensive.

The information the survey you are working on will generate information on GIPA and S&D that will be useful for several purposes: for national HIV/AIDS program managers, for USAID as a measure of the results of its programs, and for POLICY and APN+ for advocacy pertaining to GIPA and S&D. Therefore, your efforts will contribute to improving the overall response to the HIV/AIDS epidemic in your country as well as across the Mekong region.

## **2. Purpose of the Survey**

The survey will establish a qualitative baseline reflecting current conditions regarding GIPA and stigma and discrimination confronted by people who are HIV positive. This will allow assessing the results of activities sponsored by USAID in the Mekong region, in cooperation with national and provincial governments, to promote GIPA and to reduce stigma and discrimination. These activities are implemented by the POLICY project, APN+, and other USAID partners. Therefore, the assessment of results will allow USAID and its partners, including local governments, to determine how their activities can be made more effective.

## **3. What will be done**

You have been contracted to conduct a series of interviews using questionnaires developed by the POLICY project that have been reviewed by APN+ and USAID. Approximately 40 to 50 interviews with a mix of key informants will be completed. The information from these interviews will be summarized in a report prepared by the two consultants working on this task. Both consultants will participate in each interview and in the review and analysis of your findings.

## **4. Where will the survey be done**

The survey will be limited to the national or provincial capital city.

## **5. How to Prepare**

Prior to starting the interview process, the two consultants hired in each country/province should interview each other. This will make you familiar with the

question and help clarify any questions either of you might have about a particular question. If you have any questions about the content of the questionnaires, contact Chris Hermann (contact information is below)

## **6. Who Will Be Interviewed – Selection**

Individual interviews will be conducted and five categories of key informants will be interviewed; they are:

- Senior government officials responsible for managing key elements of the national HIV/AIDS program
- Health workers providing services to HIV/AIDS clients at major public and private health facilities
- International and local directors or representatives of NGOs that support HIV/AIDS-related programs or services
- Civil society leaders are active advocates or spokespersons for the needs and interests of PLHAs
- PLHAs

Who you select to be interviewed and exactly how many people from each group are interviewed will vary somewhat across the five locations where this survey is being conducted. What we would like is that, in general, the same types of people and mix of people be included in your sample. The following provides general guidance about identifying individuals you should try to interview.

- **Government Officials**

**Interview three to five officials** responsible for national HIV/AIDS programs. If possible this should include:

- the director or deputy director of the national HIV/AIDS agency/authority
- a senior official in the Ministry of Health responsible for a key element of the national HIV/AIDS program
- one or two senior officials in government, e.g. a MP, a senior Party official, who is actively involved with the national HIV/AIDS program
- one or two senior officials of other Ministries, e.g., Defense, Interior, Labor, Education, that have ongoing programs pertaining to HIV/AIDS prevention education, services, etc.

- **Health Care Workers**

**Interview 10 health care workers** who directly provide services to PLHAs working in at least two different facilities. Their medical training, e.g., midwife, nurse, doctor, is not very important, and interviewing a mix of health professionals is desirable. Also, if there are private health facilities that provide services for PLHAs, try to conduct some interviews with the staff who deliver those services. Most important is the fact that they regularly provide health care services to PLHAs, i.e., they are current practitioners and have regular contact with PLHAs. Supervisors who do not work directly with PLHAs should not be interviewed.

**It is important** that you should first contact the director of the health facility to explain the purpose of the survey and make clear this is approved by a senior official of the national HIV/AIDS program. You will receive a signed letter showing this approval and you should allow anyone who asks to read it. Get the directors approval and ask him/her to identify the staff who you should interview.

- **NGO Representatives**

**Interview five directors** or the persons responsible for the organizations' HIV/AIDS activities. Try to include a mix of local NGOs (e.g., two or three locals) and international NGOs (e.g., two or three internationals). Identify those NGOs that are most active in supporting HIV/AIDS-related programs or services, most active in advocacy for PLHA interests, or who have the largest HIV/AIDS program. In other words, these should be leading NGOs regarding HIV/AIDS. The NGOs you select may support other programs in addition to HIV/AIDS activities. In other words, they do not have to be exclusively working on HIV/AIDS

**Do not confuse NGOs with foreign donor funded projects.** NGOs are non-profit organizations that typically receive grant funding from various sources (including foreign donors). They are typically registered with the government as a NGO, and they are not part of government, though they usually work in coordination with government agencies.

- **Civil Society Leaders**

**Interview five civil society leaders** who are active advocates who advance the interests of PLHAs, who call for more effective government responses, who raise awareness among the public about HIV/AIDS, and/or who call for greater protection of the rights of PLHAs. This typically includes religious leaders, former politicians or other opinion leaders, people in the mass media (e.g., newspapers, radio, TV), people in the entertainment industry (popular actresses, actors, singers), influential labor leaders, or prominent leaders in the business community. The objective here is to interview people who are prominent, influential leaders on issues pertaining to HIV/AIDS who **are not** in government and who are not directors or managers of NGOs. They might be associated with government or NGO programs as an advocate on HIV/AIDS issues, but they are **not part of government or a NGO**. Again, a mix people from different parts of society is desirable for this group.

- **PLHAs**

**Interview up to 20 PLHAs.** The PLHA consultant on the team might be the best source for initial contacts. If PLHA self-help groups or associations exist, try to work through their network of members. Use a "snow balling" approach, i.e., after interviewing one respondent, ask if he or she could recommend someone else who might be willing to be interviewed. As with the other groups, it is desirable to interview a mix of people, for example:

- men versus women (not all men, not all women, but an equal mix)
- women who were not engaged in high risk behaviors who became positive from their husband versus women who did engage in high risk behaviors

- people who are poor versus those who are better off,
- people from different high risk groups (e.g., sex workers, MSMs, IDUs).

## **7. Ethical Issues**

There are important ethical practices that you must follow during the course of your work. The most important are confidentiality of respondents and their responses, and informed consent.

Confidentiality of the respondents identity and his/her responses is a key concern, especially for PLHAs because of the social damage, e.g., loss of employment, violation of confidentiality could cause. For other respondents, you must also protect their confidentiality by not reporting who was interviewed, i.e., no names.

As an introduction to the interview, you will read the informed consent statement (see Attachment 2) that makes clear:

- the purpose of the survey and the individual interviews
- the identity of respondents and their responses will be totally confidential,
- no names will appear in any report,
- notes or other materials from the interview will not be released to others
- the information from the interviews will be used in such a way that the anonymity of respondents will be maintained, e.g., “a senior government official reported that...”

You must obtain the respondent’s oral consent before proceeding. You must also emphasize that the interview is totally voluntary and that the respondent may choose to stop the interview at any time.

## **8. The Interview Process**

After explaining the purpose of the interview and obtaining the respondent’s oral agreement, begin the interview. Some general practices to follow include:

- Be polite and respectful at all times, try to establish a friendly setting to make the respondent feel at ease.
- Give the respondent sufficient time to think and respond fully. Do not try to hurry through the questionnaire.
- If the answer does not correspond to the meaning of the question, help clarify the question for the respondent.
- If the respondent seems confused, ask if they understand the question and clarify any misunderstanding.
- Do not prompt or lead the respondent by suggesting answers, but do probe simple yes/no answers by asking why they think that way.
- It can be helpful to repeat the respondent’s answer to make sure you understand clearly. Sometimes this prompts the respondent to provide some additional relevant information.
- A valid response to any question is to say that “I do not know” or “I have no experience with that”. Do not try to force the respondent to answer every question if they cannot.

- Write answers in a notebook, number the responses the same as the questions are numbered.
- Many of the questions have probing questions attached to them. These are important to capture the fuller perception or experience of the respondent. Allow sufficient time for the respondent to provide this additional information.
- If the respondent appears uncomfortable answering a question, remind them that they do not have to answer or talk about events that cause them distress.
- If the respondent appears to be experience increasing stress as you proceed through the questionnaire, ask if they would prefer to take a break or stop the interview entirely. Remind them that this is their right.
- The interview team can decide how to work through the questionnaire. One interviewer could take the lead in asking questions, while the other asks probing questions. You can alternate these roles.
- When interviewing PLHAs, it is recommended that the PLHA consultant lead the interview process to reduce the stress these questions might cause the respondent.
- Try to answer any questions a respondent asks you. If you do not know, simply say that and offer to consult with someone who you can ask.
- Try to respond to referrals for medical or other types of assistance and services that you know of that the respondent might ask about.

## **9. Report Preparation**

An important part of your assignment is to summarize the information you have obtained from the interviews. You need to summarize this information in your report. For each category of respondent, read through all of their answers looking for common responses, question by question. You are looking for patterns or common themes in the responses to each question. You are looking for responses reported by several/many/most respondents. You need to describe those responses in your report, question by question, for each group of respondents, e.g., for government officials, for health workers, etc.

For some questions, the answers might be very different and there is no common theme or pattern to the responses. You need to report this as well. You would say, for example, the answers to question X by PLHAs ranged from “this” to “that”. This is also very useful information.

Even when common themes or patterns can be found in the responses to a question, it is also useful to note some of the exceptional responses. This information can also be useful in describing some of the variation in the respondents’ answers.

In all cases, include what you think are particularly important or insightful statements or observations respondents made. You should do this whenever possible for each question. This information often helps a report become more interesting and thought provoking.

The length of the report will vary, but 15 to 20 pages should be sufficient. More than 25 pages and you are probably providing too much detail.

## **10. Contact Information**

For Logistical and Administrative Issues:

**APN+**

Greg Gray

Phone: (66) 1-554-0986

e-mail: [ggray@apnplus.org](mailto:ggray@apnplus.org)

For Technical Issues:

**The POLICY Project**

Chris Hermann

Phone: (66) 7-983-5228

e-mail: [chermann@asiaaccess.net.th](mailto:chermann@asiaaccess.net.th)

*Please send your completed reports to Greg Gray and Chris Hermann using these e-mail addresses*

## **11. Payment**

Please follow the instructions provided by APN+ with your contract agreement.

# Annex 3

## Questionnaire Guidelines

These guidelines were provided to the consultants who conducted the interviews in each of the five sites to explain the purpose of each question and to indicate areas which may require probing during the interview. The purpose of the guidelines was to ensure there was a common understanding of the information the questions were seeking.

### I. Questionnaire for Government Officials

#### 1. GIPA

As discussed in the introduction to these guidelines, GIPA is an important element of overcoming stigma and discrimination toward those who are HIV positive. GIPA is equally important for improving the effectiveness of policies, strategies, programs and services designed to assist PLHAs. Their participation in such processes adds a very constructive perspective to the development of government policies, programs and services for PLHAs. The experience of living with HIV/AIDS with all its personal and social difficulties is something those who are HIV negative often cannot fully appreciate.

The questions in this section are intended to obtain information about the respondent's understanding of GIPA, his/her acceptance of this concept, and actions planned or taken that lead to GIPA. The reason for asking these questions is that GIPA has become a widely accepted concept in principal; however, actual practice lags far behind for a variety of reasons. Some of the questions in this section attempt to identify some the reasons for not pursuing the implementation of GIPA more aggressively.

**Questions 1.1 through 1.4** concern the respondent's acceptance of the GIPA concept and any actual experience of being part of an activity or process where PLHAs participated.

As with all of the questions that have associated probing questions attached to them, its important to have the respondent explain their responses, e.g., why do you say that, what is the reason for that, etc.

**Questions 1.5 through 1.9** try to elicit information about the respondent's personal views regarding GIPA in the context of the government agency or unit that they manage. One can understand the concept of GIPA and know that the correct answer is to questions about GIPA, but this might not reflect their own personal views about the concept. You might find some contradictions between these questions and preceding questions. If so, you might take a minute or two to ask the respondent about preceding responses that are not consistent with responses to this set of questions. Do not put the person in an embarrassing situation, but ask him/her to please clarify your understanding of what they are telling you.

**Regarding question 1.10,** HIV/AIDS workplace policies is a strongly promoted practice by such organizations as UNAIDS, the ILO, and various donor agencies. The most extensive effort to establish such policies has been made in South Africa to date, but increasingly this is becoming an accepted practice both in government and the private sector in other countries.

**Questions 1.11 through 1.14** are designed to give the respondent the opportunity to express more openly their thoughts about GIPA. Its important to allow them sufficient time tell you what they think, but keep in mind that the entire interview should take no more than one hour.

**Question 1.15** reflects another widely accepted principal concerning the degree or level of involvement of PLHAs in activities and process. Too often, reported GIPA is little more than tokenism, i.e., a PHLA is present at an event or participates in an activity because people know this is considered “correct”. However, the PLHAs participation does not significantly influence the outcome or their role is marginal as opposed to giving leadership or making a substantial contribution to decisions.

## **2. Stigma and Discrimination**

The questions in this section are based on various research findings concerning the stigma and discrimination that PLHAs typically experience, as well as other efforts to develop indicators on these topics. The five topics covered in this section are common or recurrent categories of stigma and discrimination reported by PLHAs. By asking government officials about these topics, you are, in effect, testing their awareness of the problems and difficulties PLHAs experience. You are encouraged to probe their responses by asking “Why do you think that” and similar questions.

**Question 2.1** is included because one of the most common problems PLHAs encounter is improper, rude or discriminatory treatment at health facilities.

**Question 2.2** addresses a second common problem PLHAs report concerning improper testing procedures. Confidentiality is often not protected, violating standard testing protocols and the rights of the person tested.

**Question 2.3** covers various types of social discrimination and violation of human rights that PLHAs encounter

**Question 2.4** pertains to the problems some PLHAs experience regarding discriminatory actions affecting their employment. People are HIV positive are often able to work effectively for a number of years even without ARV treatment, yet employers and co-workers discriminate against because of their HIV status.

**Question 2.5** covers various social problems and violation of rights PLHAs encounter when their HIV status is known. Social isolation is not only experienced by the PLHA but also by their children even when their child is HIV negative. Such discrimination only worsens the impact of the epidemic on society.

### **3. Improving Conditions for PLHAs**

**Question 3.1** is asked to all categories of respondents. What this question will tell us is how perceptions of changes in stigma and discrimination, or the lack of changes, varies among different respondents.

**Questions 3.2, 3.3, and 3.4** attempt to identify actions that respondents think could be taken by different elements of society – government, NGOs, civil society – to improve the situation of PLHAs, particularly regarding decreasing the stigma and discrimination that they experience.

## **II. Questionnaire for Health Workers**

### **1. GIPA**

The questions in this section pertain to the involvement of PLHAs in the provision of services that they require at the health facilities they use. Such involvement could provide an excellent opportunity to make services more responsive to their needs. However, a number of barriers often block such PLHA involvement.

**Question 1.1** examines perceptions of health staff about the utility of involving PLHAs in the operation of the facility and its services. This includes engaging PLHAs as peer counselors, especially after someone has been found to be HIV positive.

**Questions 1.2, 1.3 and 1.4** ask about the staff's perception of adjusting services or operations to better meet the needs of PLHAs, whether they recognize that PLHAs have special needs, and whether they recognize that it's their responsibility to try to meet those needs.

**Question 1.5** pertains to the respondents acceptance of the GIPA concept and recognizes that such involvement can contribute substantially to developing or improving programs and services designed to assist PLHAs.

**Question 1.6** reflects another widely accepted principle concerning the degree or level of involvement of PLHAs in activities and process. Too often, reported GIPA is little more than tokenism, i.e., a PLHA is present at an event or participates in activity because people know this is considered "correct". However, the PLHAs participation does not significantly influence the outcome or their role is marginal as opposed to giving leadership or making a substantial contribution to the outcome.

### **2. Stigma and Discrimination**

**Question 2.1** pertains to the health workers perceptions about the benefits ARV treatment provides to PLHA clients. This includes social and psychological benefits in addition to the physical improvement and extension of a healthy life ARVs make possible.

**Questions 2.2, 2.3, and 2.4** ask about how comfortable health workers are in providing services to PLHAs. Many have not received any special training and might not be particularly knowledgeable about HIV/AIDS and the psychological and social problems PLHAs experience. Providing accurate and detailed information to health workers about HIV/AIDS, counseling skills, care requirements for those who are positive, and ARV therapy are important means of improving services to PLHAs and reducing discriminatory practices. Question 2.4 pertains to training about voluntary counseling and testing (VCT) that health staff involved with testing should receive.

**Questions 2.5** pertains to the counseling that should be provided prior to testing. Prior to testing, counseling should include the following:

- What are the ways in which HIV is transmitted, including mother to child transmission,
- Whether the client thinks that they have a chance of being HIV positive based on the routes of transmission,
- That it is a good thing to be tested if he/she thinks that they are at risk of being HIV positive (assuming that the person has voluntarily decided to be tested),
- The test is highly accurate but not 100 percent accurate every time,
- The test results will be kept confidential,
- A confirmatory test is needed if the initial test shows a positive result, and
- Further counseling will be provided when the client receives his/her results

There are additional messages that could also be considered correct, you must judge whether any additional messages are helpful to the client. If four or more of correct messages are covered, then the counseling can be considered adequate. Please record briefly what messages the respondent reports as part of pre-testing counseling.

**Question 2.6** pertains to the counseling that should be provided when test result is given to the client. Counseling when the test result is given should include the following:

If positive results:

- A confirmatory test should be done.
- The client needs to practice safe sex with all partners and that condoms must be used to protect his/her partner(s) whenever they have sexual intercourse.
- The client will remain healthy for a number of years – a positive result is not an immediate death pronouncement.
- He/she will be able to maintain a useful and productive life during those years, including working, taking care of the family, etc.
- It is very important that they adopt a very health life style, including eat properly, get adequate rest, maintain a positive outlook on life to make the most of his/her life, avoid behaviors detrimental to good health (e.g., heavy smoking and drinking).
- They need to take even common illnesses seriously and seek proper medical care.
- Many people can prevent the onset of serious illnesses by keeping themselves in good health.
- He/she needs to decide whether to inform their spouse/partner about their HIV status.

- ARV treatment can extend his/her life and help to maintain the quality of their life. If ARV treatment is available locally, they should be informed about where to go to determine if they should start treatment.
- There are groups of others who are HIV positive that can help the client come to terms with their HIV status, providing social and psychological support.
- Religion can help the person come to terms with his/her HIV status, as well as being a source of support and encouragement to make the most of his/her life.
- He/she should come back to the facility whenever they have further questions or experience any health problems.

There are additional messages that could also be considered correct, you must judge whether any additional messages are helpful to the client. If the respondent cites six or more of these messages, the counseling can be considered sufficient. Please record the messages that the respondent reports as part of their post-test counseling.

**Question 2.7** pertains to a common problem with testing using older technologies that require a return visit to the facility to obtain results. A varying percentage of those who are tested will not return to obtain their results.

**Questions 2.8 through 2.11** concern protecting the client's confidentiality regarding his/her test results. Women tend to experience somewhat greater problems maintaining the confidentiality of their results than men.

**Question 2.12, 2.13, and 2.14** concern discriminatory practices that some PLHAs experience at health facilities. Such practices violate the client's right to correct treatment equal to those who are HIV negative.

**Question 2.15** pertains to problems some PLHAs experience in obtaining services. In some cases, they are referred to other facilities even when the needed service is available at the clinic or hospital where they first went. There are also perfectly legitimate reasons for referring clients and it will be useful to know what referrals are made.

**Question 2.16** asks about the problems health workers experience when providing services to PLHAs. This question could reveal stigma-related problems associated with working directly with HIV positive clients.

### **3. Knowledge of Stigma and Discrimination**

This section asks the same questions used in other questionnaires, but from the perspective of health workers. See preceding comments for Section 2 (Stigma and Discrimination) of the Government Officials questionnaire.

### **4. Improving Conditions for PLHAs**

This section asks the same questions used in other questionnaires, but from the perspective of health workers. See preceding comments about Section 3 of the Government Officials questionnaire.

### **III. Questionnaire for Civil Society Leaders and NGOs**

#### **1. GIPA**

**Question 1.1** asks about the respondents knowledge of PLHAs being involved in government processes intended to benefit PLHAs and whether they think government needs to make a more concerted effort to engage these people in their activities. This question pertains to both the efforts of government and the respondent's acceptance of the GIPA concept.

**Question 1.2** pertains to a perceived lack of understanding on the part of government about the benefits that GIPA can provide, e.g., better programs and services for PLHAs.

**Questions 1.3 and 1.4** concern the respondent's knowledge of PLHA participation in government processes, possible constraints to greater involvement, and the extent of participation, i.e., whether PLHA involvement was taken seriously.

**Question 1.5** also concerns the respondent's view about the perceived utility of greater PLHA involvement in government processes. There might be valid reasons for not having an official policy about GIPA; therefore, ask probing questions to the respondent's answer.

**Question 1.6** pertains to other constraints that limit GIPA, such as PLHAs lacking the necessary skills and experience to participate constructively in government processes.

**The set of questions for NGOs (1.7) and Civil Society Leaders (1.8)** shifts the focus to GIPA in their respective organizations or businesses. GIPA includes more than government processes, it is equally applicable to the private sector.

**Question 1.9** is aimed at identifying ways that GIPA could be advanced from the perspective of the respondents.

**Question 1.10** pertains the level of involvement of PLHAs in activities designed to assist them.

#### **2. Stigma and Discrimination**

This section asks the same questions used in other questionnaires, but from the perspective of NGO directors and Civil Society Leaders. See preceding comments for Section 2 (Stigma and Discrimination) of the Government Officials questionnaire.

#### **3. Improving Conditions for PLHAs**

This section asks the same questions used in other questionnaires, but from the perspective of NGO directors and civil society leaders. See preceding comments for Section 3 of the Government Officials questionnaire.

## **IV. Questionnaire for People Living with HIV/AIDS**

### **1. GIPA**

**Question 1.1** asks about actual participation in government processes that are designed to assist PLHAs, whether efforts have been made to involve them, interest in participating, constraints to such participation, and how participation could be facilitated.

**Question 1.2** pertains the respondent's knowledge about the importance of GIPA.

**Question 1.3** also pertains to participation in government processes and includes a probing question to get a rough idea of the extent of that involvement.

**Question 1.4** asks about the level of effort government has made to promote GIPA from the perspective of the respondent.

One of the constraints to GIPA is the lack of open channels of communication with government agencies that provide services to assist PLHAs. **Question 1.5** addresses this issue.

**Question 1.6** asks for the opinion of the respondent about government interest in GIPA from what they have seen and heard.

**Questions 1.7 and 1.8** shift the focus to the support for GIPA by NGOs and possible constraints to PLHAs participating in NGO processes.

**Question 1.9** concerns the level of participation of PLHAs.

### **2. Stigma and Discrimination**

**Sections 2.1 and 2.2** ask about the experience of PLHA in obtaining health services. The differences between their responses compared to the health workers responses will identify divergence in their experiences and perceptions and identify areas of agreement between health workers and their clients.

**Section 2.1** asks a series of questions concerning the respondent's experiences and perceptions about the quality of health services they use. Question 2.1.1 asks about improper treatment the respondent might have experience. Their description of such experiences will provide useful examples.

**Question 2.1.2** asks about improper charges that some PLHAs report.

**Question 2.1.3** asks about the ease of access to essential services and information. The respondent's views about how access could be improved is important for this study, encourage them to respond to this question if they find it hard to do so by telling what some others have said and whether they share that view.

**Question 2.1.4** concerns ARV treatment that might not be available in some locations. The question about benefits from treatment includes social and psychological benefits as well as physical health.

**Section 2.2** covers many of the same topics asked to health workers about their testing and counseling practices, but this time from the perspective of clients, i.e., PLHAs. See comments on Section 2, Stigma and Discrimination of the Health Worker questionnaire

**For question 2.2.5**, you can use the “correct” messages presented about concerning pre- and post-test counseling for questions 2.5 and 2.6 of the Health workers questionnaires. You can ask whether they were informed about these topics.

The probing questions in this section are important to the study because it will provide examples of PLHAs experienced when they were tested. Improvement in testing practices is an important concern for APN+ and the POLICY project.

**Section 2.3 through 2.6** are an expanded version of similar questions asked to other respondents. See comments on Section 2, Stigma and Discrimination of the Government Officials questionnaire.

### **3. Improving Conditions for PLHAs**

This section asks the same questions used in other questionnaires, but from the perspective of PLHAs. See preceding comments about Section 3 of the Government Officials questionnaire.

