

# **Asia Pacific Network of People Living with HIV/AIDS**

## **FINAL REPORT OF THE APN+ HUMAN RIGHTS INITIATIVE**

### **A Documentation of AIDS-Related Discrimination in Asia**

#### **EXECUTIVE SUMMARY**

From July 2001 to October 2002, the Asia Pacific Network of People Living with HIV/AIDS (APN+) conducted the first regional documentation of AIDS-related discrimination in Asia. The project is an action-based, peer-led study that aimed to develop an understanding of the nature, pattern and extent of AIDS-related discrimination in several Asian countries. The project received funding from UNAIDS.

Ethical approval for the project was obtained from UNAIDS, Geneva; Pune University, India; University of Udayana, Indonesia; HAIN, the Philippines and Mahidol University, Thailand. In each country where the project was undertaken, people living with HIV were trained in discrimination, human rights, research methodology and interview techniques. A National Advisory Board was established in each country to oversee the project.

This study generated quantitative and qualitative data. Trained interviewers collected data from 764 positive people in four countries (India 302; Indonesia 42; Thailand 338; The Philippines 82). Completed questionnaires were analysed using a standard statistical package (SPSS). Case studies were also collected in order to explain the incidences, nature, and context of discrimination.

The survey indicated that the major area of discrimination in each country is within the health sector. Over half of those surveyed experienced some form of discrimination in the health sector. In all countries, the majority of people did not receive pre-test counselling before being tested for HIV. Those who were unprepared to take the HIV test were statistically more likely to face discrimination; people who were prepared experienced less discrimination within the health sector. A considerable number of respondents were refused treatment after being diagnosed with HIV and many experienced delayed provision of treatment or health services. Breaches of confidentiality by health workers were common.

In all sectors, women in the sample experienced more discrimination than men did. Women were much more likely than men to experience ridicule, harassment, physical assault and discrimination from family members. Women were also much more likely to have to change their place of residence, often several times, because of their HIV status.

Interviewers described the process of training and data collection as empowering in that it equipped them to respond to human rights violations in the future and provided them with skills and self-confidence in carrying out research.

National workshops were conducted in each country to report the findings and to develop strategies and interventions to counter AIDS-related discrimination; some of these included media awareness campaigns and legal challenges to systematic discrimination. The questionnaire has been modified to take account of the

experiences gained in this study, and it, together with a training outline, is now available for use by other positive people's groups.

## PREFACE

Widespread AIDS-related discrimination throughout Asia affects the quality of people's lives, their ability to access care and support and to contribute productively to society. Human rights violations of people living with HIV ultimately thwart efforts to prevent further HIV transmission.

In 1997, at a Strategic Planning Meeting of the Asia Pacific Network of People living with HIV (APN+), three Board Members (from Australia, Hong Kong and Taiwan), designed a peer-led initiative to respond to AIDS-related discrimination. The initiative aimed to train positive people and interview HIV-positive people in the field about the discrimination they had faced since their diagnosis. The following year, APN+ developed a questionnaire to be used as a survey instrument / data-collection tool in this study, and applied to UNAIDS for ethical approval to carry out the project in four Asian countries: India, Indonesia, the Philippines, Thailand. (Taiwan and Malaysia, because they did not qualify for UNAIDS funding, undertook to carry out the study independently.)

In the process of seeking ethics approval for the project, UNAIDS requested that APN+ also obtain ethics approval in each country in which the project was to be carried out. This was a challenge for country representatives, many of whom had never previously worked with academics. Identifying sympathetic academics and then waiting for ethics approval in each country caused long delays. UNAIDS then requested that APN+ develop the ethical protocol, based upon consultations with key stakeholders in each country in which the study was to be conducted. In 1999, APN+ carried out 82 key stakeholder interviews in the four countries and developed the protocol with the assistance of Dr Joe Thomas. Dr Siriwan Grisurapong (Thailand) and Dr Mike Tan (Philippines) assisted APN+ to translate the questionnaire and obtain ethics approval. When UNAIDS ethics approval was granted in May 2000, all but two of the HIV-positive people from the original working group were unavailable for the project, mostly due to ill health. APN+ therefore had to train several new team members and reignite passion for the project in each country.

This project drew the support and collaboration of a large number of individuals across Asia. The regional research team, at the end of the project, consisted of the following persons: Ms Geena Gonzales (APN+ Human Rights Convenor); Dr. Susan Paxton (Regional Principal Investigator); Mr. Brenton Wong (APN+ Coordinator); Mr. Paul Toh (APN+ Advisor); Mr. Abraham K.K. (Team Leader, India); Prof. K.S. Nair (Principal Investigator, India); Mr. Siradj Okta (Team Leader, Indonesia); Dr. Tuti Parwati Merati (Principal Investigator, Indonesia); Mr. Gamon Uppakaew (Team Leader, Thailand); Dr. Bang-on Thepthien (Principal Investigator, Thailand); Mr. Greg Gray (Project Liaison Officer, Thailand); Ms Malu Marin & Ms Amara Quesada (Principal Investigators, The Philippines)

By the time all the data were collected, five of the team leaders had passed away. APN+ continues to be greatly saddened by the loss of Jeramie Diaz, Archie Rivera and Mar Liwang (The Philippines), Ashok Pillai (India) and Suzana Murni (Indonesia), all of whose lives could have been extended if they had received timely and appropriate treatment and care. This report is dedicated to them. They each contributed enormously to driving the project forward in their respective countries and to ensuring that it progressed from a firm base. Their keen dedication and commitment is reflected in the quality of this research. They were each esteemed activists and are sorely missed.

## **DESCRIPTION OF PROJECT**

The APN+ Human Rights Initiative is a community-based action-research project. It provides empirical data on the types and extent of discrimination that people living with HIV experience. It identifies who is most vulnerable to such discrimination. This project was designed to map out the complex nature of AIDS-related discrimination in Asia.

It is the first time that human rights violations against people living with HIV have been systematically documented in the region.

The unique aspect of the project is that the documentation project was designed and implemented by people who are living with HIV. The consultative and participatory nature of the research methods was also a significant aspect of the study and increased the interviewees' awareness of their rights.

The project was important not only because of its output. The process of involving HIV-positive people in an ongoing discourse with NGOs and government was equally important. The project was initiated and driven by people living with HIV, and designed to build their capacity to respond to future human rights abuses in a self-reliant manner.

APN+ aimed to recruit 450 interviewees in India, 250 in Thailand, 80 in the Philippines and 80 in Indonesia. Countries were selected to participate in the study based on the availability, strength and commitment of HIV-positive people in each country, and the local support they could expect in carrying out the project.

APN+ collected three sets of data in the field: data on the overall national context; an extensive quantitative survey based on interviews with people living with HIV; and specific case studies to illuminate the nature of discrimination.

### **Goal**

The goal of the project was to increase the capacity of people living with HIV to advance a human rights based response to HIV/AIDS and to promote the adoption of policies and programs at national level that respond to HIV/AIDS whilst also protecting human rights and reducing stigma and discrimination.

### **Objectives**

1. To collect data on the context (legal, social, cultural and institutional), pattern, complex nature and extent of perceived and actual AIDS-related stigma and discrimination experienced by people living with HIV in Asia
2. To identify issues that need to be addressed and programs that can be implemented at country level to counter the types of discrimination highlighted in the research results
3. To increase the capacity of HIV-positive people to respond to future human rights violations

## **MAJOR PROJECT ACTIVITIES<sup>1</sup>**

### **1. Development of Survey Tool**

At its first meeting, the research team developed the study method and the questionnaire / data-collection tool, and discussed the logistical details of the study. The questionnaire was pilot tested and translated into local languages.

### **2. Development of Ethical Protocol**

To develop the ethical protocol for the project, APN+ carried out 82 Key Stakeholder Consultations: India (23), Indonesia (25), the Philippines (14), Thailand (20).

### **3. National Advisory Board Meetings**

In each country, a National Advisory Board (NAB) was constituted to advise the research team, oversee the implementation of the project and ensure that the study was carried out according to the ethical protocol.

### **4. Development of Human Rights Training Module**

A 3-day training module was developed as a prototype to be used throughout the region. Training includes: research protocols, ethical issues with vulnerable populations, understanding the relationship between human rights and public health, administering questionnaires, data collection techniques, interviewing skills, developing case studies. The module was field tested in each country.

### **5. National Training in Human Rights Documentation**

Team Leaders received regional Facilitator Training. In each country the National Team Leader, with the assistance of the National Principal Investigator, was responsible for coordinating the training of HIV-positive people in human rights research and documentation.

### **6. Data Collection**

Each trained researcher was assigned to conduct approximately 20 interviews. In Indonesia and the Philippines, researchers travelled to outlying provinces. In India and Thailand, researchers collected data within their own districts. During the data collection period, the research team met weekly, wherever possible.

### **7. Data Analysis**

The National Principal Investigator input the data from the questionnaires using SPSS statistical package. Audiotaped case studies were transcribed verbatim.

### **8. National Reports & Workshops**

Each country produced a report based on their country-specific findings. National workshops were held to present the findings. All key stakeholders (20-75 people per country) attended this. Participants planned appropriate interventions to address the critical human rights issues highlighted in the report, including strategies to lobby governments, NGOs, and other target groups to effect attitudinal, legislative and policy change.

### **9. Regional Consultation**

All members of the research team met after final data analysis to review the research findings, finalise the questionnaire and discuss the policy and program implications. Members of APN+, APCASO Human Rights Working Group, mainstream human rights NGOs and UNAIDS staff attended this consultation in order to discuss ways of ongoing collaboration.

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<sup>1</sup> Timelines for the project are given in Appendix 1.

## **METHODOLOGY**

An extensive survey was conducted among 764 positive people in four countries (India, Indonesia, the Philippines, Thailand). As well as the data from the questionnaires, specific case studies were collected to illuminate the nature of AIDS-related discrimination.

### **Development of Questionnaire / Data Collection Tool**

Twelve positive people from eight countries (India, Indonesia, the Philippines, Thailand, Hong Kong, Singapore, Sri Lanka and Australia) designed the questionnaire. It is intended to be completed by researchers during interviews with respondents and not to be self-administered.

Eight dimensions of discrimination, based on the human rights framework presented in the Universal Declaration of Human Rights, and the APCASO Compact on Human Rights were used as the major sections of the questionnaire.

They are:

- a) Right to health
- b) Right to privacy
- c) Right to liberty and security of person
- d) Freedom from inhuman and degrading treatment or punishment
- e) Right to employment
- f) Right to marry, found a family and form significant relationships
- g) Right to education
- h) Right to self-determination and association

The 133-item questionnaire attempted to document all conceivable cases of discrimination that a person living with HIV might face. Administering the questionnaire via interview took approximately one hour.

To test the efficacy of the research tool, over 50 pilot interviews were carried out in India, Philippines, Sri Lanka and Australia. The draft questionnaire was also submitted to UNAIDS and selected researchers for preliminary review. Based on the pilot testing and suggestions from reviewers, modifications were made to the questionnaire before data collection began.

### **Ethical Protocol**

In August 1998, UNAIDS informed APN+ that it could only give ethics approval after human research and ethics approval for the project was obtained from an academic establishment in every country in which the study was to be conducted, and after UNAIDS theme groups in each country also approved the project.

Team Leaders identified, albeit with great difficulty in some instances, sympathetic academics willing to put the documentation tool through their Research and Ethics Committee. Approval by UNAIDS theme groups was also pursued at the same time.

In August 1999, at the request of UNAIDS, the APN+ Human Rights Team conducted an extensive series of one-to-one consultations with key stakeholders in each country: people living with HIV, lawyers, academics, ethicists, government officials, workers in non-governmental AIDS organisations and UNAIDS staff. The aim of these consultations was to develop the ethical protocol for data collection.

The objective of this process was to identify risks associated with the study, inclusion and exclusion criteria, criteria for discontinuation of the study, strategies for recruiting vulnerable populations, and to develop a referral network. A semi structured interview

guide was used for data collection. In total, 82 people were formally consulted in four countries (India 23, Indonesia 25, the Philippines 14, Thailand 20).

Issues of justice, beneficence and respect for persons were the guiding principles in conducting this study. Justice required the presence of a reasonable system for referral to services and support programs. Beneficence required good research design, competent investigators, and a reasonable balance between risk and benefit. Respect for persons required informed consent from the participants of the study, demonstrable commitment to maintain confidentiality of the information and respect for the privacy of the respondents. An Ethical Code of Conduct (see Appendix 2) was developed to guide the study. This code of conduct was used in training the interviewers.

#### Confidentiality

Maintenance of confidentiality was the key concern of the research team as it was recognised that a breach could lead to loss of employment, loss of health care facilities, ridicule, social ostracism or physical violence.

Using a small group of HIV-positive interviewers was a safeguard against breaches of confidentiality, as they understood the potential for discrimination, were particularly sensitive to the needs of the study participants and were therefore unlikely to disclose respondents' status. As a further safeguard, no names, addresses or personal identification of respondents were recorded in the study.

#### Informed Consent

Oral informed consent was required from respondents; it was felt that written consent would be a real and unnecessary deterrent to potential interviewees in such a sensitive social research project. When interviews were audiotaped for the purposes of writing case studies, permission by the interviewee to do so was required.

A survey guide was prepared to assist interviewers. Interviewees were invited to submit any inquiries or complaints to the National Team Leader and Principal Investigator, whose names and addresses they were given. They were also asked if they wished to receive a copy of the final report.

An Information Sheet (in the local language) was provided to all respondents. Information concerning the research, particularly the potential risks, was explained to the respondents in their own language. They were informed that they were free to refuse to participate or withdraw from the study at any time without penalty. No monetary remuneration was given to study respondents.

The Informed Consent Form (see Appendix 3) was read out to the respondents prior to their participation in the study. The interviewer signed the consent form as proof of obtaining oral consent from the respondent to carry out the interview.

#### Referrals

Legal, medical and social referrals were identified by the local investigators prior to the data collection. At the end of the interview, respondents were offered referral services specific to each study location, if needed.

#### Ethics Approval

The questionnaire, research protocol, informed consent form and information sheet were translated into local languages in each country and checked for accuracy. Some instances of poor translation did lead to different interpretations of particular questions (for example, in some countries respondents were asked whether they had

ever applied for insurance whilst in other countries the question asked was whether they had ever been discriminated because they had applied for insurance), but these were minimal.

The research protocol was submitted to ethics review committees in all collaborating countries. In 1999, Research Ethics Committees of Pune University (India), University of Udayana (Indonesia), HAIN (the Philippines) and Mahidol University (Thailand) all approved the research protocol. UNAIDS gave ethical approval for the project to proceed in May 2000 and provided funding to commence the documentation the following year.

### **Study Sample**

According to estimates by the UNAIDS / WHO Working Group on Global HIV/AIDS and STI Surveillance, at the end of 2001, there were approximately 3,970,000 people living with HIV in India (0.8% of adults), 120,000 in Indonesia (0.1%), 9,400 in the Philippines (<0.1%) and 670,000 in Thailand (1.8%).

The study sample is not representative of the epidemiological profile of HIV infection in each country. Most people who are infected with HIV in the study areas are not aware of it. The people who have been tested for HIV are a skewed sample of actual infections. They may represent, for example, higher numbers of migrant workers, women attending antenatal clinics or military personnel than in the general population, because certain groups of people are more likely to be tested for HIV than others, with or without their consent.

Of the people who do test HIV-positive, most keep their status secret and do not have contact with other people living with HIV, for fear of the stigma and discrimination they may face if they reveal their status. It is understood that many people who are living with HIV do not access medical care and some do not reveal their status, even to their family. These factors made it difficult to select a representative study sample and hindered interviewers in reaching their interview quotas.

The sample size was determined by the maximum number of people living with HIV that interviewers could reach in each country and by the capacity and resources of interviewers to carry out the study. The targeted sample size was 860.

Data was collected from 764 people living with HIV who were aged sixteen years or older, using the structured questionnaire. The sample contains a mix of people of different ages, sexuality and economic, social and educational backgrounds. Although mode of transmission was not recorded in the questionnaire, particular attention was paid to recruit respondents from specific populations (women, transgenders, injecting drug users, ethnic minorities, sex workers) and from both rural and urban sites.

Although India has the highest burden of HIV infections in Asia, positive people are harder to reach than in a country such as Thailand where people are more open about their HIV status.

Researchers recruited respondents via "snowballing", through known positive contacts at local HIV peer-support groups, hospitals or AIDS service organisations. From the first pool of respondents, interviewers were referred on to other HIV-positive individuals by word of mouth. The sample was therefore, of necessity, a convenience sample of people living with HIV in each country.

### **National Advisory Boards**

A National Advisory Board (NAB) was established in each country, consisting of prominent members of AIDS service agencies, PLWHA leaders, academics, National AIDS Program administrators, UNAIDS in-country advisers and community leaders. The mission of the NAB was to advise the research team in all aspects of the project. The role of the NAB was:

- to monitor that the study was conducted according to the ethical protocol;
- to advise and monitor the referral system;
- to advise the team on data analysis;
- to advise the team on follow-up activities based on the study findings;
- to resolve any complaints about the study; and
- to advise the research team to abandon the project, partially or completely, if massive or systematic deviation occurred from the project protocol.

In each country all members of the National Advisory Board met at least twice: first to finalise the scope and mechanism of the data collection, including monitoring and reporting back; finally to approve the study findings and provide direction for future interventions to counter identified AIDS-related discrimination.

Within each country, an academic was appointed as the National Principal Investigator and a positive person as the National Team Leader. These two individuals worked collaboratively on the project.

National Team Leader's role was:

- to co-ordinate all in-country activities, including National Advisory Board meetings, recruitment and orientation of interviewers, overseeing data collection, organising National Workshop, writing National Report;
- to liaise at regular intervals with the APN+ Human Rights Convenor;
- to administer funding in-country

National Principal Investigator's role was:

- to guide the team in carrying out the project in an ethically sound manner;
- to analyse and manage data

During the course of the project, the Regional Principal Investigator visited all participating countries at least once to assist with the training and/or oversee data collection. In April 2002, Greg Gray, APN+ Advisor, was contracted to act as a Liaison Officer between the Thai team and APN+ because of communication difficulties.

### **Training**

Initial regional training in data collection, for team leaders and other APN+ Board Members who were interested in the project, was conducted in Hong Kong in 1998. Team Leaders and others were also trained in facilitation skills in Bangkok in May 2000.

A national training workshop was held for each data collection team. National Team Leaders, in consultation with Principal Investigators were responsible for coordinating the training and orientation of all data collectors in-country.

In total, 46 interviewers (27 women, 19 men) were trained, all people living with HIV: India, 14 (from Chennai, Calcutta, Goa, Manipur, Pune); Thailand 12 (Bangkok, Surat Thani, Chiang Mai, Chiang Rai); Philippines 12 (all Manila-based); Indonesia 6 (Jakarta, Sulawesi, Bali).

The training component of the study was essential to strengthen the capacity of HIV-positive people in data collection. It was seen as equally important as the development of the actual data collection instrument. The training explored stigma, discrimination and human rights and included interviewing techniques, particularly sensitising interviewers on how to deal with potentially difficult emotional situations.

Training was rigorous in relation to the procedures and mechanisms to ensure confidentiality and was vital in ensuring the interviewers understood the ethical implications and psychological risks for the research participants. Interviewers were also trained to offer legal, medical, and social referrals where necessary.

### **Data Collection**

Once in-country training was completed, the strong motivation of the interviewers carried the project forward very efficiently and the study gained great momentum. During the course of the interview, interviewers used the questionnaire as a trigger to probe areas of discrimination in greater detail, so as to build case studies. Guidelines for carrying out the study were provided to all interviewers.

Because the Australian HIV/AIDS and STDs Prevention and Care Project of AusAID assisted Indonesia with additional funding, it was the first country to start data collection, in July 2001. The Philippines followed in August 2001, India in February 2002 and Thailand in August 2002. In most countries, the data collection took four months to complete.

Staggering of data collection between countries proved to be advantageous in that countries that started later learnt from the experiences of the early starters. The questionnaire, for example, underwent some minor revisions in the process. The Indian version of the questionnaire contained two questions that had been overlooked in the first version, about respondents' annual income and the number of children they had.

No major problems were encountered in the implementation of the project on the ground. Some minor problems that did arise included some interviewers being slow to return completed questionnaires to Team Leaders, others being unable to reach targeted number of interviews. A few interviewers were inaccurate or careless in completing all sections of the questionnaire. In some instances, interviewers forgot to probe sufficient details of the discriminatory episode or to audiotape the interviews for the case studies and some respondents were impossible to track down later. Occasionally data collectors had difficulties in finding an appropriate, private space in which to conduct the interviews.

### **Data Analysis**

All quantitative data was input into SPSS and cleaned. Chi square and regression analyses were carried out, including  $r$  (correlation coefficient),  $B$  (standardised regression coefficient), Odds Ratio (OR), confidence interval (CI), Cronbach's alpha,  $p$ -value and standard deviation.

Audiotaped interviews were transcribed and translated. From these, case studies were selected that highlighted each dimension of discrimination identified by the quantitative findings.

## RESULTS

### Research Process

The spirit of the data collection teams, who were hand-picked by the original team leaders, was a tribute to them. Data collectors gained increased confidence, self-respect, motivation and spirit of activism by carrying out the project.

“I am very happy with the training because usually we sit and listen and that is it but we are going to do something with what we learn. We are being trained to interview people. We are being trained as community-based researchers. It’s very good”.

“In the past when we received training, we just listened. This time we have been trained to do research with our knowledge and that makes me feel very proud and strong”.

The team members in each country developed real ownership of the project and this resulted in strong team spirit. In each country, interviewers were empowered by the processes involved in implementing the project, from the data collection training to the interviews with peers in the field.

### Study Findings

Major study findings are given below; detailed in-country findings are provided in the respective National Reports, available from UNAIDS country offices.

Note that wherever there is no given value in a table, either the question was not asked in that country or the translation was such that a different question was asked. For example, the Thai questionnaire asked, “Did you request to go on the clinical trial” rather than “Did you ask to be taken off the trial”. In some instances, data (eg, the number of years since diagnosis) was entered into the computer in such a way that it could not be used and comparisons could not be made. Where instances of violations are noted in the text below, it should be mentioned that several questions were asked in two parts. For example, “Has your partner deserted you since you were diagnosed?” and “Was it because of your HIV status?” Only violations due to HIV status are reported here.

Although sample sizes are less than 100 in Indonesia and the Philippines, percentages have been used in most tables for easy comparisons.

### Study Sample

In total 764 interviews were conducted, usually in private rooms of the respondent’s choice. After cleaning the data there were 753 useable questionnaires.

Within each country, respondents were recruited from several regions:

India: Manipur, Nagaland, Tamilnadu, Kerala, Goa, Karnataka and Maharashtra.

Indonesia: Jakarta, West Java, Jogjakarta, East Java, Bali, West Sumatra, Riau, South Sulawesi, Papua, East Nusatenggara

Philippines: Manila, Angeles City, Olongapo City and Bacolod City

Thailand: Upper North (Chiangmai, Chiangrai, Prayao, Lampang, Lamphoon, Mae Hong Sorn); North-East (Nakorn Rachasrima, Chaiyaphoom, Burirum, Kornkaen, Nong-bua Lamphoo, Sakolnakorn, Ubonrachathanee, Yasothon,Srisaket); South (Satul, Songkhla, Nakornsrihamarat, Narathiwat, Ranong); Bangkok and Nonthaburi

The breakdown of the sample according to sex and country is given below.

**Table 1. Sample according to Country and Sex**

Country	Female	Male	Transgender	Unknown	TOTAL
India	126	159	2	4	291
Indonesia	20	20	1	1	42
Philippines	39	40	3	0	82
Thailand	163	175	0	0	338
<b>TOTAL</b>	<b>348</b>	<b>394</b>	<b>6</b>	<b>5</b>	<b>753</b>

Overall, forty-six percent of the sample was female, fifty-two percent male, one percent transgender and one percent sex not recorded. Mean age of respondents was 32.1 years (females, 30.6; males 33.3; transgender 37.0). Ages ranged from 16 to 58 years. In all countries except Indonesia, the mean age of female respondents was less than that of male respondents.

**Table 2. Mean Age of Respondents (years)**

COUNTRY	FEMALE mean (s.d.)	MALE mean (s.d.)	TRANSGENDER mean (s.d.)	TOTAL mean (s.d.)
India	28.4 (5.1)	32.4 (5.6)	42.0 (12.7)	30.7 (5.8)
Indonesia	27.7 (6.5)	24.8 (5.5)	31.0 (0)	26.4 (6.1)
Philippines	36.2 (9.1)	39.3 (6.8)	35.7 (5.9)	37.7 (8.0)
Thailand	31.2 (5.4)	33.8 (6.5)	-	32.6 (6.2)
<b>TOTAL</b>	<b>30.6 (6.3)</b>	<b>33.3 (6.7)</b>	<b>37.0 (8.0)</b>	<b>32.1 (6.7)</b>

Respondents were asked to describe their marital status. More than one in three respondents were married or living in a de facto relationship; 50% of females and 8% of males were widowed; 10% of females and 46% of males were single. The Philippines had the highest proportion of respondents (19%) who described themselves as being in a “significant relationship”. Indonesia, the youngest country cohort, had the highest rate of single people (50%). Of the six transgender persons, two were married, two were single and two were in a significant relationship. Only in India and the Philippines were respondents asked how many children they had. Of 55% of respondents in these two countries who had children, the average number was 1.8 (maximum 7).

**Table 3. Respondents’ Marital Status (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Marital status					
Married / De Facto	40	33	29	34	36
Widowed	24	12	16	35	27
Separated / Divorced	6	5	7	4	5
Single	30	50	29	26	29
Significant Relationship	0	0	19	1	2
TOTAL	100	100	100	100	100
Percent who have children	52%	-	70%	-	-
Mean no children / parent	1.7	-	2.0	-	-

Women were more likely than men to have received any secondary education (53% v 33%) and much less likely to have university education (11% v 22%). The Philippines cohort had the highest education level; 54% of respondents had a university education versus 11% from other countries. The Philippines also had the highest rate of unemployment (39%). Indian respondents were most likely to have had no formal education 13% v 2%).

**Table 4. Respondents' Education Level and Occupation (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Highest Education Level					
None	13	0	1	2	6
Primary	25	21	5	54	36
Secondary	33	52	37	27	32
Technical	6	2	1	11	8
University	22	22	55	6	18
No answer	1	3	1	0	0
TOTAL	100	100	100	100	100
Occupation					
Student	1	2	0	1	1
Unemployed	36	32	40	26	32
Self employed	16	20	5	12	13
Clerical/Sales	6	0	10	1	4
Professional/Manager	7	0	7	6	6
Other	13	39	38	0	11
NGO (Indonesia & India only)	10	7	-	-	5
Agriculture (India/Thai)	2	-	-	24	11
Labour (India/Thai)	9	-	-	30	17
TOTAL	100	100	100	100	100

The earliest version of the questionnaire had only six choices for occupation of respondents. This proved inadequate to describe the range of people's occupations. Subsequently, the list grew from country to country and not all respondents were provided with the same choices. Many people in the "other" category, for example, could be agricultural or unskilled workers, service workers, crafts people, counsellors, etc. The category "occupation" was not a useful demographic other than determining if the respondent was employed.

Respondents had been diagnosed an average of 3.9 years; the range of time since diagnosis was 0-19 years. The vast majority of respondents were diagnosed as HIV-positive within the past five years.

Respondents were asked about their current state of health and to describe any medication they were taking. There were no appreciable differences between men and women. The results are summarised in Table 5, below.

**Table 5. State of Health & Types of Medication (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
No years since diagnosis	3.2 yrs	2.3 yrs	4.4 yrs	4.8 yrs	3.9 years
Current health status					
Good	41	50	39	44	43
Just okay	44	26	41	41	41
Unwell	15	24	20	15	16
TOTAL	100	100	100	100	100

Currently taking medication	50	40	39	70	57
Type of medication*					
Antiretrovirals	8	2	22	30	22
Prophylaxis	15	14	4	50	31
Traditional medicine	5	10	9	6	6
Opportunistic infections	29	-	7	14	18
Other	8	14	12	4	7

\*indicates there may be more than one answer

Less than half the respondents said they were in good health but only in Thailand were 50% of people on prophylaxis to prevent opportunistic infections. The proportions of people in each country who are taking anti-retroviral medication are markedly different, from 30% of respondents in Thailand to 2% in Indonesia. However, it is not clear how many need prophylaxis or antiretroviral therapy under current guidelines.

### Human Rights Violations

By far, the major area of discrimination in each country was within the health sector. This discrimination often commenced when the person was first tested for HIV.

The reasons why people go for HIV tests vary greatly. In Indonesia, the majority response was “other”. This is because many respondents were tested as a pre-requisite for enrolling in drug rehabilitation programs and this was not anticipated in the questionnaire. Sex workers who had undergone mandatory testing also fell into this category, as did people tested while donating blood (1% of Indian respondents). Only in India and Thailand were respondents asked whether they were tested because they were pregnant.

Men were much more likely than women to be tested because they had an AIDS-defining illness (34% v 12%), whilst women were much more likely to be tested because their partner had tested positive (36% v 19%). In the Philippines, one in three respondents were tested for employment purposes whilst in Thailand this only accounted for 4% of responses. Thais were more likely to test because they “just wanted to know” than respondents from any other country were.

**Table 6. Context of HIV testing (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Reason for having test					
Insurance	0	0	0	1	0
Employment	7	8	35	4	9
STI clinic referral	10	3	1	0	4
Just wanted to know	16	18	14	33	26
Partner tested positive	28	8	21	29	29
AIDS-defining illness	24	7	4	32	23
Other	8	56	25	6	13
Pregnancy (India/Thai)	7	-	-	26	-
TOTAL	100	100	100	131*	-
Testing Site					
Hospital	57	37	51	82	67
Specialist clinic	4	2	9	9	9
Private lab	28	17	9	2	15
Private doctor's clinic	4	13	13	6	2
Other	7	31	18	1	7
TOTAL	100	100	100	100	100

Person who gave test result					
Doctor	56	37	76	55	56
Nurse	5	5	5	41	21
Social worker	15	22	3	2	9
Counsellor	7	3	0	0	3
Other	17	33	16	2	11
TOTAL	100	100	100	100	100

\* more than one answer

The majority of people were tested in a hospital, though whether it was a public or private hospital was not asked. Although most diagnoses were given by a health worker (usually a doctor), a high proportion of people said that other people outside the health sector, such as a family member or employer, first informed them of their result.

### Right to Privacy

In the Philippines and Thailand, the majority of people said they were unprepared to take the HIV-antibody test at the time it was done. Almost half of all respondents said that nobody explained the reasons for taking the test. One in every eight respondents was coerced into testing. Women were more likely than men to be unprepared for or coerced into an HIV test.

The majority of people in all countries, including Thailand, did not receive pre-test counselling. Overall, 60% of respondents received no post-test counselling and 30% (including the majority of Indonesians) received no information whatsoever before the test was taken. After the test results were given, only 52% of respondents received counselling and 21% received no information whatsoever about HIV/AIDS at the time they were told of their positive diagnosis.

Frequently, test results were given to respondents in front of a third person, usually a friend or family member. This happened more frequently with females (45%) than with males (39%). In the majority of these cases, the respondents said they did not want the third person to be with them at the time they received their test results. In Indonesia, if the respondent was admitted into a drug rehabilitation centre, the third persons present were parents, regardless of the client's age.

**Table 7. Violations during HIV-Antibody Testing (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Unprepared to take the test	33	38	53	56	46
Coerced into taking the test	14	17	15	9	12
Reason for HIV test not explained before tested	45	55	56	43	46
No pre-test counselling	61	71	78	58	60
No information given pre-test	13	54	38	47	30
No post-test counselling	48	57	67	40	48
No information given post-test	29	7	20	12	21
Result given in presence of someone else	57	58	31	29	42
Results given in presence of following person*:					
Friend	10	18	5	2	7
Family	26	22	11	9	18
Co-worker	5	0	1	0	2
Spouse	12	0	7	15	13
Other	4	19	7	3	5
Did not want person there	17	37	7	5	12

\*may be more than one answer

Breaches of confidentiality by health care workers were common. One in three people said that somebody else had been told of their HIV status without their consent. Over 20% of the sample said that they had not disclosed their HIV test results to anybody else, but less than 10% believed that nobody else knew about their HIV status.

Frequently, family members were told of a person's status against the person's wishes. Over half of the Thai respondents said that their status was well known in their community. Neighbours and members of the local community may account for the many of the "others" who are aware of respondents' status in Indonesia and the Philippines.

Case studies indicate that sometimes media, employers, landlords or community members were told of the person's status before the person was told. Breaches of confidentiality can have far-reaching consequences. One respondent described facing extreme hostility her family's village after her HIV status was accidentally disclosed by the media; she was requested to leave and did so in the middle of the night dressed as a man.

The questionnaire did not ask respondents to identify the person(s) who had breached their confidentiality. Interviewers asked if respondents knew other people who were tested without their consent. Over 20% of people said they did.

**Table 8. Breaches of Confidentiality (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Experienced breaches of confidentiality	29	29	36	40	35
People you told about status*					
Nobody	20	41	34	17	21
Relative(s)	44	23	43	72	56
Friend(s)	32	30	10	31	31

Colleague(s)	22	0	2	17	17
Other	6	13	11	8	8
People told without consent*					
Health care workers	6	18	9	6	7
Family members	12	13	12	22	17
Co-workers	4	5	6	11	8
Spouse	4	5	-	2	2
Sex partners	0	2	-	2	1
Media	1	2	-	1	1
Government officials	1	5	4	5	3
NGOs	1	-	2	1	1
Police	0	-	-	1	-
Other	10	10	12	-	5
Community (Thai only)	-	-	-	19	-
People aware of HIV status*					
Nobody	4	0	9	9	7
Immediate family	18	7	48	11	18
Family and friends	36	43	20	19	27
Only few friends	11	14	9	7	10
Widely known in the community	21	14	12	52	34
Open outside own community	3	22	2	3	4
Know other persons tested without knowledge or consent	19	41	20	20	21

\* more than one answer possible

### *Extract from Case Study, Indonesia*

Reni shared her status and that of her husband with her mother, whom she really trusted, but it turned out that her mother had already heard. Her mother had even been stigmatised by the community. Her mother had heard from a relation who was a doctor at the hospital. This doctor was aware of Reni's status and that of her husband as a result of this being revealed by the doctor during a doctors' meeting. This doctor/relation told the family, although Reni herself had not yet informed her family of her status or that of her husband because of concerns for the good name of the family.

### *Extract from Case Study, Philippines*

Marie said that when her husband was hospitalized, doctors wanted to draw blood from him so they could do a test. Her husband already knew that he was HIV-positive, so he refused but the hospital staff managed to get a sample of his blood after they told him they were just going to take his blood pressure. Marie and her husband endured humiliation when the entire hospital found out about her husband's HIV status. The nurses refused to attend to her husband anymore. Non-medical personnel such as hospital cleaners refused to enter her husband's room. The people in the hospital avoided her presence and would talk in whispers about her. The hospital then told the owner of the house that they rented about their HIV-positive status.

*"I felt that everyone was looking at me. I was very angry because they were disgust. When they passed by (me), they would walk sideway. They didn't want to be touched by me. They would pretend as if they were walking towards another direction. I saw that clearly and I would cry and cry. I was mad at them. The counsellor of the hospital herself told the owners of the house we were staying at that we had AIDS. She had wanted to tell them. I said, not now, because I still cannot handle it. Maybe my family will help out. Isn't that our decision to make? What happened was, we were still at the hospital, I was told over the phone that we had to move out... I wanted to talk to them. They didn't want to talk to me so I sent them a letter asking them for a meeting because I had a lease contract with them and we had an agreement. They were afraid to face me. Their son, who was a policeman, spoke to my house help. He shouted at her outside the house and told her, 'If you and your employer will not leave, I will shoot and kill all of you. You tell your employer to leave our house.'"*

When Marie gave birth in a government hospital, she reported that a big piece of red paper was put on top of her bed. Her older child, who was HIV-negative, experienced harsh treatment and ridicule by peers at school, treatment which was very stressful.

### Right to Health

Over half of the sample experienced some form of discrimination within the health sector. Most commonly this was from doctors or nurses. In Indonesia, women were twice more likely than men to experience discrimination from health workers.

Respondents who were unprepared to take the test were significantly more likely to have been denied medical treatment in the twelve months prior to the interview (10.4% v 16.0%,  $\chi^2(1)=4.66$ ,  $p=.031$ ), and to have ever been discriminated by a health care worker because of their HIV status (14.4% v 20.4%,  $\chi^2(1)=4.41$ ,  $p=.036$ ). Fifteen percent of respondents had been refused treatment or care and 15% experienced a delay in the provision of health care services. Many were turned away from health centres once their HIV status was known. Some respondents were persuaded or advised, usually by family members or friends, not to access health care services. In India, 15% of respondents have been forced to pay more than other people have paid for the same services because of their HIV-positive status. One Indian respondent claimed his child had died due to neglect by health care workers. A Filipina, when arriving at a hospital about to give birth, was told, "You're not fit to give birth here".

Almost one in ten respondents was denied private insurance either because they took an HIV-test or received a positive diagnosis; the vast majority was women. The survey did not ask whether respondents had ever applied for private health insurance. Presumably the proportion of people in these countries who did apply is low and the proportion that was subsequently denied insurance is not reflected in these statistics.

**Table 9. Right to Health  
(percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Experienced AIDS-related discrimination from health care worker	30	31	50	16	27
Refused treatment due to HIV-positive status	20	14	15	11	15
Experienced delay in treatment due to HIV status	20	15	22	10	15
Denied medical treatment in past 12 months due to HIV	14	3?	11	10	12
Persuaded or advised not to access health care services due to HIV status	11	10	5	6	9
Person gave this advice					
Family members	3	2	5	1	2
Friends	2	5	1	3	3
Health care workers	7	2	2	2	4
AIDS Service agencies	1	-	0	1	1
Other	1	-	7	-	1
Forced to pay additional charges for medical services/treatments	15	5	11	4	9
Denied/lost private insurance due to HIV status	1	0	4	6	4

### *Extract from Case Study, Indonesia*

Ratih has lived in Jakarta for a long time. Around September 1998, she found she had cancer, and was admitted to a hospital in quite a bad state of health. At that time, she was asked to have an HIV test in relation to her illness. She felt somewhat pressured; she believes if she had been given information about HIV through counselling, she would not have agreed to the test. She felt that the questions about her behaviour were very judgemental.

After the test, Ratih had to fetch the results from the hospital laboratory and read them herself, because there was no counselling. Since the result showed that she was HIV-positive, Ratih didn't want anyone else to know. But in fact the results were leaked widely, with the result that her oncologist refused further treatment. Even the catering staff at the hospital who usually delivered the food refused to enter her room any more, and passed the food through a window. Before her diagnosis, Ratih was placed in a ward with 6-7 other patients, but after it was known that she was HIV positive, Ratih was moved to single ward. She was due to have lung and heart tests, but the staff member was not willing for the test equipment to be used on Ratih so the tests were cancelled.

In total, 143 people were involved in clinical trials (India 39, Indonesia 2, the Philippines 31, Thailand 21). The average length of time spent on a clinical trial was 9 months. Half of these respondents participated in the clinical trial for up to 6 months and 18% for over 12 months. One in three trial participants were unaware of the purpose of or the risks associated with the trial before they agreed to participate in it. Thai respondents were more likely than others to receive treatment at the end of the trial (34% v 21%).

**Table 10. Violations Committed during Clinical Trials**

	India (N=39)	Indonesia (N=2)	Philippines (N=31)	Thailand (N=71)	Total (N=143)
Didn't know drug/trial name	19	1	8	18	45 (31%)
Didn't know purpose of trial	18	1	7	22	48 (34%)
Risks of trial not explained	24	1	8	14	47 (33%)
Ave. period on trial (months)	8mths	6 mths	9 mths	10 mths	9 months
Requested to stop participation	6	1	7	-	-
Request not honoured	3	1	2	-	-
Offered treatment at end	4	0	11	24	39 (27%)

### Violations of Right to Liberty and Security of Person

Violations of people's right to liberty and security of freedom were less common than discrimination within the health sector, probably because it is only within the health sector that most positive people are likely to disclose their HIV status.

Of the one in ten people who have been forced to change their place of residence due to their HIV status becoming known to their neighbours and/or landlord, over half of these people have had to move residence more than once (and up to nine times in one instance). Women were more than twice as likely to have changed their place of residence due to their HIV status than men were.

For many, finding an alternative place to live was a difficult challenge. Many women whose husbands had died, ended up in very destitute conditions with no money for food. One Indian woman said that after her husband passed away, her in-laws chased her out of her home and she had to sleep in the graveyard.

The most common violation of positive people's rights to security of person is facing ridicule, insult or harassment. This has happened to one in four people within the study sample (32% of women, 21% of men, 40% of transgenders). The questionnaire did not indicate from where this harassment came. In total, 30 women, nine men and one transgender person had been refused entry to, asked to leave or removed from a public establishment due to their HIV status.

The only area in which men experienced more discrimination than women did was when trying to travel to another country; 15 men, 8 women and 2 transgenders had been required to disclose their status when leaving or returning to their own country and 19 men, 17 women and 2 transgender persons had been denied entry into another country because of their HIV status. Of the Filipino respondents, 20% had to disclose their HIV status in order to enter another country.

Physical violence and segregation or quarantine, perhaps some of the most severe expressions of AIDS-related discrimination were the less common. Nevertheless, 4% of the study sample had been assaulted because they are HIV-positive. Women were almost twice as likely to have been threatened with physical violence or to have been physically assaulted because of their status than men were. In Indonesia, 12% of respondents had been detained, isolated or quarantined because of their HIV status.

**Table 11. Liberty and Security of Person  
(percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Refused entry to, removed from or asked to leave a public establishment because of HIV	6	5	11	5	6
Forced to change residence due to HIV status	15	7	7	5	10
Ridiculed, insulted or harassed because of HIV status	27	29	25	25	26
Threatened by physical violence due to HIV status	9	2	1	3	6
Physically assaulted because of status	8	2	4	2	5
Required to disclose status in order to leave or return to own country	4	0	14	1	4
Had to disclose status in order to enter another country	5	7	20	2	5
Quarantined, segregated, detained, isolated due to HIV	6	10	3	1	4

*Extract from Case Study, Indonesia*

From 1997, Dina worked in a red-light area that received special attention from the Social Welfare Department. One day a sample of Dina's blood was drawn; the official who drew the blood did not explain the reason for this.

Several months later, Dina decided to marry her partner. Dina was amazed at the attention paid to her marriage by the officials concerned. Several days after the wedding, Dina felt that she was receiving abusive treatment from her new neighbours.

Finally, Dina learned that her wedding photograph had been published in a newspaper, together with her name and details of her village. The newspaper presented it as news of the marriage of a person with HIV. Dina was very surprised, because this was the first she knew that she was HIV positive.

The neighbours asked Dina to move immediately, and if she didn't they threatened to report her to the owner of the house. The next day, the owner came and evicted Dina and her husband. They moved to another village, but a policeman demanded that they should not live in that village. Similar situations happened six times.

### Inhuman and Degrading Treatment or Punishment

Incidences of inhuman and degrading treatment or punishment are outlined in the Table 12, below.

**Table 12. Inhuman and Degrading Treatment or Punishment (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Experienced discrimination from friends	16	8	27	14	17
Excluded from social functions because of HIV status	9	3	6	18	13
Forcibly required to submit to medical or health procedure	5	7	8	9	8
Benefits, privileges or services denied due to HIV status	16	27	13	14	15
Charged, sued or brought to court related to HIV status	3	0	3	1	2

Eighteen percent of respondents experienced AIDS-related discrimination from friends (15% of males, 19% of females, 67% of transgenders) and 14% said they were excluded from social functions at some time. Respondents were asked how frequently these instances of violations occurred. The majority of people said that discrimination from friends was a rare occurrence.

One in every fourteen people said they were forcibly required to submit to a medical or health procedure. In total, 8 women and 4 men had been charged, sued or brought to court in relation to their HIV status.

Although 16% of respondents had been denied benefits, privileges or services because of their HIV status, the question itself provided little information as to the nature of such violations.

### Employment

Only in Thailand and India were respondents asked whether they had worked for an employer since their diagnosis; 48% of Thais and 70% of Indian respondents said they had. One of every nine people in the total sample (men 9%, women 14%) had experienced some form of discrimination within the workplace. Most common violations of people's right to work were having their duties changed or being harassed or made to feel discomfort on the job. In total, 16 women and 48 men had been tested for HIV because of employment yet 23 women and 29 men lost their jobs because of their HIV status.

The vast majority of people who experience AIDS-related discrimination in the workplace had no recourse for action; of the 4% who did have some recourse to address the discrimination they experienced, 92% were satisfied with the action taken. Once people did experience work-related discrimination, it was not an infrequent event but tended to happen "quite often".

**Table 13. Right to Employment (percentages)**

	India (N=291)	Indonesia (N=42)	Philippines (N=82)	Thailand (N=338)	Total (N=753)
Worked for an employer since diagnosis	70	-	-	48	-
Experienced AIDS-related workplace discrimination	12	15	21	6	11
Discrimination by employer because of HIV status	8	14	33	6	8
Discriminated by colleagues due to HIV status	8	-	16	10	5
Lost job because of HIV status	6	2	33	2	6
Job description or duties changed due to HIV status	3	5	44	7	7
Offered early retirement due to HIV status	1	0	16	1	2
Lost prospect for promotion because of HIV status	2	0	21	2	5
Experienced harassment or discomfort on job due to HIV	6	5	13	7	8
Earning capacity decreased due to your HIV status	3	5	49	28	20

In the Philippines, a much higher proportion of respondents experienced discrimination in the workplace than respondents in other countries. Although at the outset only 21% said they had experienced workplace discrimination, in fact the incidence of violations was much higher. Discrimination manifested in people losing their job (33%), their job description or duties being changed (44%) or losing prospects for promotion (20%) because of their HIV status. In many of these instances, the respondent did not immediately identify this as a form of discrimination or a violation of their right to employment. Half of the Filipino respondents said that their earning capacity had decreased because of their HIV status.

*Extract from Case Study, the Philippines*

Arla was working in a club when the news of her ex-partner dying of AIDS broke out. Her employer asked her to have an "AIDS" test to find out if she was positive or negative. When her test yielded a positive result, she was banned from entering at the club where she used to work as it could "frighten" away prospective customers and her status became known in the community, even though she only told her floor manager about it. Her co-workers and friends eventually shunned and avoided her.

Right to Marry, Found a Family and Form Significant Relationships

Over 15% of women had undergone mandatory testing whilst they were pregnant or because of the illness of a child. Almost one third of the sample (48% of females, 20% of males) was advised not to have children after diagnosis, but only one in five respondents was given information about prevention of parent-to-child transmission. In Thailand, 16% of women were coerced into an abortion; in India 11% of women were coerced into an abortion or sterilisation.

After diagnosis, 14% of the sample experienced discrimination from their family and were excluded from usual household activities such as cooking, sharing eating implements, sleeping in the same room as other family members. Women were more likely to experience discrimination from their family than men were (18% v 11%), often from in-laws. When people experienced discrimination from their family, it was

not an isolated incident, as was often the case in the health care sector, but tended to be a frequent or continuing occurrence.

Only in Thailand were men more likely to have been deserted by their spouse because of their HIV status (6% v 1%). However, women were more likely than men were to have lost financial support from their spouse (35% v 12%) or from other family members (12% v 6%) because of their HIV status. Many women faced a greatly increased financial burden after the death of their spouse. Eighteen respondents had their children involuntarily taken away from them due to their HIV status.

**Table 14. Right to Marry, Found a Family & Form Significant Relationships (percentages)**

	<b>India</b> (N=126)	<b>Indonesia</b> (N=20)	<b>Philippines</b> (N=39)	<b>Thailand</b> (N=163)	<b>Total</b> (N=348)
Mandatory HIV testing during pregnancy or because of an illness of child (women only)	21	15	5	15	16
Coerced into an abortion or sterilisation due to your HIV status (women only)	11	5	0	16	14
	<b>India</b> (N=291)	<b>Indonesia</b> (N=42)	<b>Philippines</b> (N=82)	<b>Thailand</b> (N=338)	<b>Total</b> (N=753)
Advised not to have a child since HIV-positive diagnosis	12	38	33	48	31
Given HIV information about parent-to-child transmission	7	29	28	24	18
Excluded from usual activities by family members	20	12	15	10	15
Deserted by partner because of HIV status	10	21	4	5	8
Financially dependent on partner who deserted	10	5	4	-	-
Lost financial support from other family members due to HIV status	12	0	14	3	8
Child(ren) involuntary taken away due to your HIV status	2	5	4	2	3

### Education

Overall, there were fewer violations within the sphere of education than in other areas. On the other hand it is probable that educational institutions are not aware of most students' status. Two men and 12 women said that they or their child(ren) had been denied admission into an educational establishment because of their HIV status; the majority of these were from Thailand.

### Right to Self-Determination and Association

A small proportion of respondents (6%) was excluded from associations, societies or clubs due to their status and/or restricted in their ability to meet with other people living with HIV/AIDS. Family members were usually responsible for discouraging positive people from meeting with their peers. Women faced more restrictions from family than men did.

Over 20% of respondents were not referred to any self-help group for people living with HIV and 27% did not know of any local groups. Over 40% of the respondents in this survey had participated in some form of decision-making committee. In the vast majority of instances, respondents found their participation useful.

**Table 15. Right to Self-Determination and Association  
(percentages)**

	<b>India (N=291)</b>	<b>Indonesia (N=42)</b>	<b>Philippines (N=82)</b>	<b>Thailand (N=338)</b>	<b>Total (N=753)</b>
Excluded from associations / societies / clubs due to status	5	0	7	6	5
Restricted in ability to meet with other people living with HIV/AIDS	2	2	5	4	3
Family restricted ability to join with associations/groups of people living with HIV/AIDS	4	7	4	4	4
Not referred to self-help group of people living with HIV	25	37	22	12	23
Participated in AIDS-related decision-making committees	14	27	56	62	41
Found participation useful	-	90	79	97	-

### Interviewer Observations

Over half of the sample needed referrals after the interview (India 28%, Indonesia 90%, the Philippines 33%, Thailand 61%). Most commonly referrals were for counselling. More than one in four respondents needed counselling referrals (India 15%, Indonesia 27%, Philippines 11%, Thailand 40%) and approximately one in ten needed legal advice (India 7%, Indonesia 11%, Philippines 14%, Thailand 9%).

### Cross Tabulations

There was no significant relationship between age, income or educational background, and the level of discrimination experienced by people living with HIV.

The only significant factor in experiencing discrimination was being prepared for the HIV test when the test was taken. People who were prepared to take the test were less likely to experience subsequent AIDS-related discrimination from health workers.

Respondents involved in clinical trials were more likely to have been coerced into HIV testing than others (24% v 9%) and were more likely than other respondents to have been refused medical treatment because of their HIV status (27% v 12%).

## **DISCUSSION**

This documentation, by necessity, utilised a convenience sample of people living with HIV. Interviewers cast their nets widely from peer support groups, testing sites, hospitals and AIDS service organisations to capture the experiences of as many positive people as possible. It cannot be assumed that these findings are

representative of the experiences of all people diagnosed with HIV in the study countries. It is possible that the people interviewed suffered greater amounts of discrimination and were therefore motivated to contact support organisations. On the other hand, it may be possible that people who do not have contact with any AIDS organisations may have experienced more discrimination than the respondents and may have been silenced to a greater extent and are harder to reach. Nevertheless, because of the large sample size, it can be assumed that these findings reflect the experiences of thousands of people living with HIV in the region.

Even in countries such as the Philippines, which has progressive anti-discrimination legislation in relation to AIDS, and Thailand, which has a very well-established epidemic and a model response, widespread and extreme discrimination against people living with HIV still occurs. Predominantly, discrimination comes not from threats of physical abuse by ignorant community members, employers, landlords or school principals, but from workers in the health sector.

There are remarkable similarities in the extent of discrimination between the country samples, particularly in the level of discrimination within the health sector, the lack of information provided to people before and after they are tested for HIV and the extent of discrimination against women.

The number of people who are tested without pre- or post-test counselling is extremely disturbing. Most of these people go on to experience discrimination within the very sector that tested them. This is particularly worrying considering the ever-increasing trend in many countries to test all pregnant women. Women are sometimes coerced into testing during a very vulnerable period of their lives and may then be subjected to refusal of treatment, abuse, breaches of confidentiality that may have severe consequences on the person's mental and physical health and, at least in Thailand, to sterilisation. They may then also experience extreme violations of their right to security of person by their family.

Most diagnoses were given by a doctor. When a social worker or nurse gave the result it was more likely to be accompanied by counselling. It would seem that a policy to ensure that positive people are referred to trained counsellors and that trained counsellors are always available to provide test results should be mandatory.

Questionnaire findings and case studies indicate that many instances of discrimination by family, work colleagues or community members are triggered by breaches of confidentiality by health care staff. It is therefore an urgent imperative that concerted, extensive and comprehensive HIV awareness raising, by people living with HIV, be carried out amongst health sector workers throughout the region. Health workers mirror the attitudes within a society and can also have a role in reinforcing those attitudes. Health care workers, particularly counsellors, nurses and doctors can be the vanguard of change, as they are the most significant players in the fight against discrimination.

The findings in relation to clinical trials are a cause for concern. An investigation into the quality of informed consent given to trial participants should be undertaken.

Overall, more women than men experienced discrimination, particularly in relation to discrimination by family, being forced to move residence, being harassed, ridiculed, threatened and physically assaulted. This is a reflection of the judgemental and blameful attitudes to HIV/AIDS, women's social status and the different expectations of men and women in society.

Overall, Thai HIV-positive people experience less discrimination within the health sector than people from other countries. Thais are more likely to receive counselling than their peers in other countries and they have greater rates of referral to self-help groups. Thailand also has a much higher percentage of positive people currently taking antiretroviral therapy. They were, however, more likely to be excluded from social functions or denied private health insurance than their peers in other countries. Thai women are also far more likely to be coerced into abortion or sterilisation.

In the Philippines, the proportions of people tested for employment and of those refused entry into another country were higher than in any other country. This reflects the fact that Philippines has a very high proportion of migrant workers. It is also of considerable note that the level of discrimination within the employment sector is highest in the Philippines. This country sample had the highest level of education yet also the highest level of unemployment. Many people were tested before entering a country for contract work and subsequently lost prospects of employment. There is need for regional organisations to place greater international pressure on receiver countries to overturn all policies that require HIV tests before employment.

The level of unemployment overall is disconcerting considering that most positive people have the responsibilities of parenthood and many are single or widowed.

These findings provide a broad sweep of the nature, pattern and extent of AIDS-related discrimination in Asia. The questionnaire proved to be a useful tool to examine the areas of discrimination that many people diagnosed with HIV subsequently face. By going through the interview process, many respondents realised that they had faced discrimination whereas beforehand they had not considered their experiences to be violations of their rights.

In all countries except India, most data collectors were female. This was by coincidence not design, and reflects the fact that more women are willing to be involved in HIV/AIDS advocacy issues.

This was a participatory action-based research project in which the process of undertaking the study was deemed to be as important as its product. In training people living with HIV to go out and interview others, all parties became more aware of the stigma, discrimination and human rights violations that people living with HIV face. The process educated those most vulnerable to AIDS-related discrimination and mobilised them to take action to challenge and change the status quo, and to become more involved in policy development on a national level.

## **RECOMMENDATIONS & NATIONAL INTERVENTIONS**

Participants at the national workshops, held in each country after data analysis was completed, developed action plans in response to the study findings. The regional consultation at the end of the project (May 2003) included training in advocacy strategies for all National Team Leaders.

In Indonesia, the report of findings was launched in September 2002 and used as an advocacy tool in the lead-up to World AIDS Day activities focussing on "Stigma and Discrimination". In the Philippines, interventions include the development of a proactive national anti-discrimination campaign specifically targeting institutions identified by the research as perpetrators of human rights violations (e.g. health care system, employment sector, media). A series of stakeholder's consultations with these institutions, human rights institutions and legal support networks are being conducted. These forums are being used to develop policies and programs to address human rights violations of people living with HIV/AIDS, including advocacy

re migrant workers' rights and monitoring whether employers are upholding the Philippines' anti-discrimination laws.

By carrying out this study, several Asian countries now have a system for ongoing monitoring of human rights violations.

#### **FINAL VERSION OF QUESTIONNAIRE**

Feedback from interviewers indicated that the questionnaire was still unnecessarily long and repetitive in places and therefore it was further slightly modified after the regional consultation in April 2003. The version provided in this report, (see Appendix 4), is that recommended for use internationally. Various alterations were made for this final version. For example, occupations are extremely diverse and do not provide an accurate description of a person's socio-economic status. Highest educational level and current annual income alone are sufficient for this therefore "occupation" was omitted and replaced by "annual income". A question on whether respondents were given information on parent-to-child transmission has been omitted as this question does not discriminate between informed, factual and supportive information and false or misleading information; even if the respondent received information, this does not tell us whether that was a positive experience.

Where frequency of violations is asked, this has been simplified to either "seldom" or "often". Once a violation is repeated, the frequency with which the violation occurs provides little information on the severity of the discrimination. The fact that an act of discrimination is occurring per se can be devastating for many people.

Additional questions in the final version include asking respondents whether they had worked for an employer since diagnosis, whether they have ever applied for private insurance, whether they know who has breached their confidentiality and an opportunity for respondents to provide any other information not covered in the questionnaire.

## **PROJECT OUTCOMES**

- Training module and data collection tool to document AIDS-related discrimination and human rights violations
- Over forty HIV-positive people in India, Indonesia, the Philippines and Thailand trained in research and documentation of AIDS-related discrimination and human rights violations
- Twelve HIV-positive people trained as facilitators
- Systematic collection and analysis of data on AIDS-related discrimination in each country
- Reports detailing the nature, extent and pattern of AIDS-related discrimination in four Asian countries
- National action plans outlining strategies to combat AIDS-related human rights violations
- Sustainable, ongoing human rights documentation processes in four Asian countries
- Enhanced skills and abilities of individuals and local organisations to carry out human rights advocacy efforts in the context of AIDS
- Enhanced skills and abilities of positive people to carry out research projects and situational analyses
- Development of policy and program guidelines to counter AIDS-related discrimination and the effects of human rights violations of people living with HIV
- Increased community awareness of the link between protecting human rights and HIV prevention and care
- More comprehensive regional human rights response to AIDS

## **CONCLUSION**

This model for AIDS-related human rights documentation can easily be adapted for other regions. The report can be used as an advocacy tool to lobby hospitals to improve counselling, testing and care facilities and safeguard the confidentiality of positive people; the report can be utilised to push for legal reform, to change workplace policies or to raise HIV awareness in the community. However, care must be taken in presenting results not to alienate people in those sectors who may themselves be working for change; as the results show, there are generally more cases where people are treated correctly and with compassion than the reverse.

APN+ strongly believes that protecting the rights of people living with HIV will enable members of society to examine their own vulnerability to HIV, and that this is the most effective way to improve public health outcomes for people living with HIV *and* for those who are now uninfected.

Although the progress of this project was slow, it was steady and ultimately, very successful. The positive people involved in the project are now a powerful force and interested in pushing for policy change and legal reform based on the data collected.

The project has contributed greatly to strengthening the resolve of people to fight discrimination in each country and has provided an informed and strategic direction.

## **Appendix 1**

### **Project Timelines**

#### **1997**

- April Project designed during APN+ Strategic Planning Meeting
- November Conducted basic human rights training for over 40 PLWHA, GNP+ Conference, Chiang Mai, Thailand

#### **1998**

- May Twelve people trained in documentation and interviewing  
Developed 133-item data collection tool / questionnaire
- June APN+ first submits questionnaire to UNAIDS
- August APN+ seeks ethics approval in each country

#### **1999**

- February APN+ resubmits questionnaire to UNAIDS for ethics approval
- April UNAIDS requests consultations with key stakeholders
- August Consultations with 82 Stakeholders in four countries  
*(with positive people, lawyers, academics, ethicists, government, workers in NGOs, AIDS service orgs, UNAIDS)*

#### **2000**

- February APN+ submits revised Ethical Protocol to UNAIDS ERC  
Human Rights Training Module developed
- May UNAIDS Ethics Approval received  
Facilitation training of Team Leaders carried out

#### **2001**

- May APN+ receives funding to commence data collection
- June National training begins in Indonesia
- July Data collection begins in Indonesia
- August Project start-up in The Philippines  
Data Analysis commences in Indonesia

#### **2002**

- February Project start-up in India
- August Project start-up in Thailand
- September Preparation for National Reports  
Start of National workshops to disseminate findings

#### **2003**

- May Regional consultation with research team

## **Appendix: 2** **Ethical Code of Conduct**

### **1. Introduction**

1.1 The principles given below are intended to apply to data collection on the study "Living with AIDS in Asia: A multi-city participatory action research on AIDS and Human Rights in Asia Pacific region". All those who are associated with the study are expected to uphold these principles while carrying out this study.

1.2 These principles will not replace the ethical requirements applicable to each country but will complement such principles.

1.3 All the associates of this study are expected to approach the participants of the study with mutual respect and confidentiality.

1.4 All the associates of this project must recognise the possibility of legal action if they infringe the rights and dignity of participants of this research.

### **2. General**

2.1 In all circumstances the associates of this study must consider the ethical implications and psychological consequences for the participants in this research. The essential principle is that the data collection for this study should be considered from the standpoint of participants of this study. All efforts must be taken to identify foreseeable threats to their psychological wellbeing, health, values or dignity and to eliminate these. All associates of this study should recognise that, in our multi-cultural and multi-ethnic society and where investigation involves individuals of different ages, gender and social background, we may not have sufficient knowledge of the implications of our study for the participants. It should be borne in mind that the best judge of whether an investigation will cause offence may be a member of the population from which the participants in the research are to be drawn.

### **3. Informed Consent**

3.1. Whenever data is being collected for this study the investigators should inform all participants of the objectives of the investigation.

3.2. Data collection from children or from those who have impairments that will limit understanding or communication such that they are unable to give their real consent requires special safeguarding procedures. In addition, when data is collected from persons under sixteen years of age, consent should be obtained from parents or from those 'in loco parents'.

3.3. An informed consent form should be administered. Before beginning the interview, the researcher should read out this form.

3.4. If data is collected from a detained person (for instance in drug rehabilitation centres) particular care should be taken over informed consent, paying attention to the special circumstances which may affect the person's ability to give free informed consent.

3.5 No participants should be pressurised to participate in this study.

### **4. Debriefing**

4.1. When data is being collected for this study, the investigators of this study will be provided with sufficient information to complete their understanding of the nature of

the research. If any unforeseen negative effects or misconceptions arise from this research it should be informed to the concerned parties.

4.2. All associates of this study have a responsibility to ensure that the participants receive any necessary debriefing in the form of active intervention or referral before they leave the data collection settings

## **5. Withdrawal from the Investigation**

5.1. At the onset of this study the data collectors should make plain to participants their right to withdraw from the research at any time.

5.2. The participant has the right to withdraw retrospectively any consent given, and to require that their data, including recordings, be destroyed.

## **6. Confidentiality**

6.1. Subject to the local legal requirements, including the Data Protection Act, data collected through this study should be kept confidential.

## **7. Protection of Study Participants**

7.1. All the associates of this study have a primary responsibility to protect participants from physical and mental harm during the investigation. Participants should not be exposed to emotional risk greater than in ordinary life. All the associates of this study should be aware of the possibility of mental conditions that could trigger off emotional stress during the data collection.

7.2. Participants should be informed of procedures for contacting the person in charge of this study.

## **8. Giving Advice and Referrals**

8.1. During the data collection, the data collectors may observe psychological or physical need for social support (such as counselling) or legal problems of which a participant is, apparently, unaware. In such a case, the investigator has a responsibility to inform the participants, if the data collectors believe that by not doing so the participants future wellbeing may be endangered.

8.2. During the normal course of data collection, if a participant solicits advice concerning educational, health or social support, caution should be exercised. The research associates are expected to offer appropriate sources of professional advice. (A list of such resources is presented separately)

## **9. Collective Responsibility**

9.1. All the associates of this study share responsibility for ethical treatment of research participants.

**Appendix 3**  
**Information Sheet and Informed Consent Form**

**INFORMATION SHEET A (For Questionnaire Respondents)**

(A copy of this information sheet is to be given to all the participants. The interviewers are also expected to read out the form if it is necessary)

**Introduction**

This information sheet briefly introduces the APN+ research study on AIDS and human rights. This study is being carried out by the Asia Pacific Network of People living with HIV/AIDS (APN+), with the financial support of UNAIDS.

**Purpose of the Study**

The study intends to collect information on AIDS-related discrimination and stigma experienced by people living with HIV/AIDS in selected Asian countries. The study will contribute towards a greater understanding of the nature of AIDS-related discrimination, and in particular, the extent, pattern, and context of such discrimination. This is the first time such information has been systematically documented in your country.

**Procedures of the Study**

APN+ would like to interview you as part of the study. All information collected is to be voluntary, anonymous, and confidential. No record will be made of your name, or other identifying details. If you agree to take part in the study, you have the right to withdraw at any time, and to request that any data the project has gathered from you be destroyed.

During the interview you will be asked about your experiences, as a person living with HIV, in areas such as health, employment, education, privacy, security, freedom from inhuman treatment, family life, and self-determination, via a detailed questionnaire.

The final report of the project will include the overall national context, statistical results from all the interviews with people living with HIV/AIDS, and specific case studies to illustrate the nature of discrimination. This report will be used as a tool for change, for example in challenging health or workplace policy, community attitudes, or for legal reform.

**Risks**

Although we are taking all the necessary steps to identify and reduce any psychosocial risk in participating in this study, there is a low risk of breaches of your confidentiality. In certain circumstances a breach of confidentiality could lead to stigmatisation, such as losing social status, deprivation of services, loss of job, media exposure, losing family and community support, being targeted by the authorities, or pressured by authorities to disclose the status of other participants.

All interviewers are HIV-positive and are trained in human rights documentation, and have signed agreements to protect the confidentiality of the participants. All data collected during this study will be kept confidential and stored in a locked filing cabinet in the office of the Principal Investigator (Name and contact details of P.I. in each country) until six months after the completion of the project, when all data will be destroyed.

**Discomfort**

There is the possibility that you may experience some emotional distress during the interview. You may decide to pause or stop the interview at any time, if necessary.

All the associates of this study have a primary responsibility to protect participants from physical and mental harm. In the event that you do need psychological or physical support (such as counselling or legal assistance), or advice concerning educational, health, or social support, a list of referrals to appropriate professional support services is available to you. A copy of the ethical principles guiding this project is also available on request.

**Inconvenience**

The interview process takes approximately 45 minutes to one hour.

**Benefits to Participants and Others**

APN+ hopes that the data collected in this study will contribute towards a greater understanding of the nature of AIDS-related discrimination experienced by people living with HIV; to understand the range of discriminatory attitudes and actions, and the pathways of AIDS-related discrimination and stigma. We believe that such data is essential in developing appropriate legal, social, cultural, and institutional responses to combat discrimination and human rights violations experienced by people living with HIV /AIDS.

**Alternatives to Participation**

If you prefer not to participate could you recommend somebody else who might want to participate in the study?

## **Informed Consent Form (For Questionnaire Respondents)**

(Before beginning the interview, the researcher will read out this form, and leave one copy of the form with the respondent.)

My name is \_\_\_\_\_.

I am collecting data for the APN+ Human Rights Initiative, described in the accompanying Information Sheet.

This study is being conducted by \_\_\_\_\_(Name and contact telephone number). If you have any questions about any aspects of the study, please feel free to contact them.

Before you answer any questions I would like you to know that:

- a) Your participation in this study is entirely voluntary;
- b) You are free to refuse to answer any questions;
- c) You are free to terminate this interview at any time.

The data collected in this interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from individual interviews may form part of the final research report, but under no circumstances will your name or any identifying characteristics be included in the report.

May I seek your consent to interview?

(If the respondent declines to be interviewed, please thank the respondent and discontinue the interview.)

Thank you for agreeing to take part in this study.

I will now declare that oral consent for the interview has been given by you.

Has oral consent been obtained?

Yes / No

Name of the interviewer:

Signature of Interviewer:

Date of Interview:

## **Appendix 4**

### **APN+ Human Rights Initiative Questionnaire**

Data for this study should be collected from people living with HIV/AIDS, who are eighteen years or older. In selecting the respondents, have a good mix of people of different age, sex, social background and mode of infection. They could be selected through local PWA groups, hospitals, and AIDS Service Organisations/ Non Governmental Organisations.

It may be necessary to translate the questionnaire into the local language. The translation should be done in two stages. As a first step you (or a translator) translate the questionnaire into the local language and ask another independent translator to translate the local language version back into English. Finally, you along with the other person try to clarify the discrepancies in translation.

#### **Instructions for the interviewer**

Please do not attempt to administer this instrument to other respondents without first familiarising yourself with the attached interview guide and completing the questionnaire once by yourself.

When you interview respondents, remember to ensure their privacy. Conduct the interview in a private place, preferably alone with the respondent.

Begin by administering the information sheet and consent form. Please make sure you read out this section and get the respondent's oral consent to participate in this study. You must get the informed consent before the interview. If the respondent refuses consent for the interview, please thank him/her and terminate the interview.

Boldly mark the number corresponding to the correct answer to each question in the third column. Some questions will not be applicable to everybody or a respondent may not want to respond. If the answer is "other" please provide a description. The timeframe of the questions is since the respondent has known his or her HIV status.

During an interview, if you feel that some follow-up questions are important, please note them down promptly in the space available besides each question for notes. You may remark on any significant observations about issues that arise in the interview and suggest modification of any questions, additional questions and difficulties in canvassing responses to the survey. If respondents have experienced instances of severe discrimination and are willing to discuss this in detail, you can probe the questions at the time of the survey or make a time to return for an in-depth interview later. Before case studies can be audiotaped, respondents must give further consent to this.

Sometimes while interviewing respondents you may face adverse reactions such as emotional outbursts, anger or hostility to the interviewer. If you feel you cannot continue, you should stop the interview.

Familiarise yourself with the list of local resources and contacts, which you have already prepared. If you need additional support or need to make referrals for medical, emotional or legal support, the local resource list would be helpful.

At the end of the entire interview, check each questionnaire for completeness and accuracy and note down all the questions and concerns expressed by the respondent.

APN + Human Rights Team

## **Section 1 Location/ Country Specific Information**

- 1.1 Interview Schedule No. [     ] ]
- 1.2 Country           [            ] ]
- 1.3 Interviewer Code No. [            ] ]
- 1.4 Date of Interview
- 1.5 Where is the interview being carried out?  
       [1] Hospital  
       [2] Residence  
       [3] Public place  
       [4] Private room  
       [5] Other

## **Section 2 Demographic Information**

<b>Q</b>	<b>Question and filters</b>	<b>Coding</b>	<b>Notes / Skip to</b>
2.1	How old are you?	(                    Years)	
2.2	Sex	[1] Male [2] Female [3] Transgender	
2.3	What is your current marital status?	[1] Married/ De Facto [2] Widowed [3] Separated/ Divorced [4] Single [5] Significant Relationship	
2.4	Is this city/ location your normal place of residence?	[1] Yes [2] No [8] No Response	
2.5	How long have you been living in this city/location?	Years:	
2.6	What is your highest level of education?	[1] None formal [2] Primary [3] Secondary [4] Technical [5] University [6] Postgraduate	
2.7	What is your occupation?	[1] Student [2] Unemployed [3] Self employed [4] Clerical [5] Sales [5] Admin./ Managerial [6] Professional [7] Other	
2.8	How many, if any, children do you have?		
2.9	What is your annual income? (record amount per month)		

### Section 3 Right to Health

3.1	How would you describe your current health status?	[1] Good [2] Just okay [3] Unwell	
3.2	Are you currently taking any medication for HIV infection?	[1] Yes [2] No _____ [9] Not Applicable	Skip to 3.4 “
3.3	If yes, what medication are you taking?	[1] Antiretrovirals [2] Prophylaxis [3] Traditional medicines [4] Medicine for Opportunistic Infections [5] Other	
3.4	Have you ever experienced discrimination by any hospital or health care workers because of your HIV status?	[1] Yes [2] No [3] Don't Know [9] Not Applicable	Skip to 3.6 “ “
3.5	If yes, how often has this happened to you?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
3.6	In the past year, have you been denied medical treatment or care because of your HIV status?	[1] Yes [2] No _____ [3] Don't Know	
3.7	Has a health care worker ever refused to treat you because of your HIV status?	[1] Yes [2] No [3] Don't Know	
3.8	Have you ever experienced any delay in the provision of treatment or health services?	[1] Yes [2] No [9] Not Applicable	Skip to 3.10 “
3.9	If yes, was it due to your HIV status?	[1] Yes [2] No	
3.10	Have you ever been persuaded or advised into not accessing health care services?	[1] Yes [2] No _____ [9] Not Applicable	Skip to 3.13 “
3.11	If yes, was it due to your HIV status?	[1] Yes [2] No	
3.12	Who advised or persuaded you into not accessing health care services?	[1] Family members [2] Friends [3] Health care workers [4] AIDS Service agencies [5] Other	
3.13	Have you been forced to pay <i>additional</i> charges for medical services/treatments (eg. dental care, surgical procedures) once you tested positive for HIV?	[1] Yes [2] No [9] Not Applicable	
3.14	Have you ever participated in any AIDS-related medical studies or clinical trials?	[1] Yes [2] No _____ [3] Don't know	Skip to 3.23 “
3.15	If yes, were the following aspects of the study explained to you?		
3.16	The name of the drug or the	[1] Yes	

	study/trial	[2] No	
3.17	Purpose of the study/trial	[1] Yes [2] No	
3.18	Risks and consequences of the study/trial	[1] Yes [2] No	
3.19	How long were you on the trial/study?	Months:	
3.20	Did you ever make a request to stop being a participant?	[1] Yes [2] No	Skip to 3.22
3.21	If yes, was your request honoured?	[1] Yes [2] No	
3.22	Were you offered treatment at the end of the trial?	[1] Yes [2] No [9] Not Applicable	
3.23	Have you ever been denied private insurance or benefits because you took an HIV test?	[1] Yes [2] No [9] Not Applicable	
3.24	Have you ever lost or been denied private insurance once your HIV status was known?	[1] Yes [2] No [9] Not Applicable	

#### **Section 4 Privacy**

4.1	In what year did you find out your HIV status?	Year:	
4.2	Why was the test taken?	[1] Insurance [2] Employment [3] Pregnancy [4] STD clinic referral [5] Referred from hospital [6] I just wanted to know [7] Partner tested positive [8] Other	
4.3	Were you prepared to take the test at that time?	[1] Yes [2] No	
4.4	Were you coerced into taking the test?	[1] Yes [2] No	
4.5	Was it explained to you what the test was about before you were tested?	[1] Yes [2] No _____ [9] Not Applicable	Skip to 4.7 “
4.6	If yes, what information did you get before you took the test?	[1] Counselling [2] Advice/Info [3] Literature [4] Other [5] Nothing	
4.7	Where were you tested?	[1] Hospital [2] Specialist clinic [3] Private lab [4] Private doctor's clinic [5] Other	
4.8	Who informed you of the results?	[1] Doctor [2] Nurse [3] Social worker [4] Other	

4.9	Was there someone else with you when you got your result?	[1] Yes [2] No _____	Skip to 4.12
4.10	If yes, who was it?	[1] Friend [2] Family member(s) [3] Co-worker [4] Spouse [5] Other	
4.11	Did you want them to be with you?	[1] Yes [2] No	
4.12	What information did you get when you received your test result?	[1] Counselling [2] Advice/Info [3] Literature [4] Other [5] Nothing	
4.13	Have other people been told about your HIV status without you wanting them to know?	[1] Yes [2] No _____ [9] Don't Know	Skip to 4.15 “
4.14	If yes, who has been told without your consent?	[1] Health care workers [2] Family members [3] Co-workers [4] Spouse [5] Sex partners [6] Media [7] Government officials [8] NGOs [9] Police [10] Other	
4.15	Have you told anyone about your status?	[1] Yes [2] No _____	Skip to 4.17
4.16	If yes, who?	[1] Friend(s) [2] Relative(s) [3] Colleague(s) [4] Other	
4.17	How widely is your HIV status known to others?	[1] Nobody else knows [2] Only immediate family [3] Family members and a few friends [4] Only a few friends [5] Widely known in the community [6] Not known in community but open elsewhere	
4.18	Have you, since your diagnosis, been excluded from usual activities by your family members?	[1] Yes [2] No [9] Not Applicable	Skip to 4.20 “
4.19	If yes, how often have such incidents occurred?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
4.20	Have you, since your diagnosis, been excluded from any social functions because of your HIV?	[1] Yes [2] No [9] No Response	Skip to 4.22 “
4.21	If yes, how often have such incidents occurred?	[1] Seldom [2] Quite often [3] Very often	

		[4] Constantly	
4.22	Have friends ever discriminated against you because of you HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 5.1 “
4.23	If yes, how often do you feel this has happened?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	

### **Section 5 Liberty and Security of Person**

5.1	Have you ever been refused entry to, removed from or asked to leave any public establishment because of your HIV status?	[1] Yes [2] No [8] No Response	
5.2	Have you been forced to change your place of residence once you were diagnosed HIV-positive?	[1] Yes [2] No [9] Not Applicable	
5.3	If yes, how many times have you changed your place of residence?		
5.4	Have you ever been ridiculed, insulted or harassed because of your status?	[1] Yes [2] No [8] No Response	
5.5	Have you ever been threatened by physical violence because of your HIV status?	[1] Yes [2] No [8] No Response	
5.6	Have you ever been physically assaulted because of you status?	[1] Yes [2] No	
5.7	Have you ever been forcibly required to submit to any medical or health procedure?	[1] Yes [2] No [3] Don't Know	
5.8	Have you ever been required to disclose your status in order to leave or return to your country?	[1] Yes [2] No [9] Not Applicable	
5.9	Have you ever had to disclose your HIV status in order to enter another country?	[1] Yes [2] No [9] Not Applicable	
5.10	Have you ever been quarantined, detained, isolated or segregated because of your HIV status?	[1] Yes [2] No [8] No Response	

### **Section 6 Inhuman and Degrading Treatment or Punishment**

6.1	Apart from you, do you know of any other person tested without their knowledge or consent	[1] Yes [2] No [3] Don't Know	
6.2	Have there been any benefits, privileges or services given to others that were denied to you	[1] Yes [2] No [9] Don't Know	

	because of your HIV status?		
6.3	Have you ever been charged, sued or brought to court on an offence or an act related to your HIV status?	[1] Yes [2] No [9] No Response	

**Section 7 Right to Employment**

7.1	Have you ever experienced any AIDS-related discrimination in your work environment?	[1] Yes [2] No [9] Not Applicable	Skip to 7.14 “
7.2	Has your employer ever discriminated against you because of you HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 7.4 “
7.3	If yes, how often has this happened?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
7.4	Have you ever felt discriminated against by your colleagues because of your HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 7.6 “
7.5	If yes, how often has this happened?	[1] Seldom [2] Quite often [3] Very often [4] Constantly	
7.6	Have you ever lost your job because of your HIV status?	[1] Yes [2] No [9] Not Applicable	
7.7	Has your job description or duties changed because of you HIV status?	[1] Yes [2] No [9] Not Applicable	
7.8	Have you been offered early retirement?	[1] Yes [2] No [9] Not Applicable	Skip to 7.10 “
7.9	If yes, was it due to your HIV status?	[1] Yes [2] No	
7.10	Have you ever lost your prospect for a promotion because of your HIV status?	[1] Yes [2] No [9] Not Applicable	
7.11	Have you ever experienced harassment or discomfort on the job because of HIV?	[1] Yes [2] No [9] Not Applicable	Skip to 7.15 “
7.12	Did you have any ways to address these abuses or any recourse for action?	[1] Yes [2] No _____ [3] Don't Know	Skip to 7.15 “
7.13	If yes, were you satisfied with the recourse of the action taken?	[1] Yes [2] No	
7.14	Has your earning capacity decreased due to your HIV status ?	[1] Yes [2] No [9] Not Applicable	

**Section 8 Right to Marry, Found a Family and Form Significant Relationships**

8.1	Have you ever undergone mandatory HIV testing during pregnancy or because of an illness of your child (women only)?	[1] Yes [2] No [9] Not Applicable	
8.2	Has your partner deserted you because of your HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 8.5 “
8.3	If yes, were you financially dependent on your partner?	[1] Yes [2] No	
8.4	Have you ever lost any financial support from other family members due to your HIV status?	[1] Yes [2] No [9] Not Applicable	Skip to 8.8 “
8.5	What were the repercussions?		
8.6	Has your child (or children) ever been involuntary taken away from you?	[1] Yes [2] No [9] Not Applicable	Skip to 8.10 “
8.7	If yes, was it due to your HIV status?	[1] Yes [2] No	
8.8	Have you ever been advised not to have a child since you were diagnosed to be HIV positive?	[1] Yes [2] No [9] Not Applicable	Skip to 8.12 “
8.9	If yes, were you given information about mother to child HIV transmission?	[1] Yes [2] No	
8.10	Have you been coerced into an abortion or sterilisation due to your HIV status (women only)?	[1] Yes [2] No [9] Not Applicable	

**Section 9 Right to Education**

9.1	Have you or your child(ren) ever been dismissed, suspended, prevented from continuing with your /their education because of your status?	[1] Yes [2] No [9] Not Applicable	
9.2	Have you or your child(ren) ever been denied admission into any educational institution because of your status?	[1] Yes [2] No [9] Not Applicable	

**Section 10 Right to Self-Determination and Association**

10.1	Have you ever been excluded from any associations / societies / clubs / self-help groups due to your HIV status?	[1] Yes [2] No [9] Not Applicable	
10.2	Have you ever been restricted in your ability to meet with other people living with HIV/AIDS?	[1] Yes [2] No [9] Not Applicable	
10.3	Has your family ever restricted in your ability to join with associations/groups of people living with HIV/AIDS?	[1] Yes [2] No [9] Not Applicable	
10.4	Have you ever been referred to any self-help group of people living with HIV by	[1] Yes [2] No	

	an AIDS / health care worker or others?	[9] Not Applicable	
10.5	Have you ever participated in any AIDS-related decision-making committees?	[1] Yes [2] No [8] No Response	
10.6	Do you know of any local self-help group of people living with HIV?	[1] Yes [2] No	
10.7	Do you intend to join a peer self-help group in the near future?	[1] Yes [2] No	
10.9	If not, why not?		

Thank you very much for your participation You have now completed the survey. Are there any further issues you want to talk about? If you are willing to permit a detailed interview about your experiences of discrimination we do request your informed consent to tape it.

### **Section 11 Observation and comments (by the interviewer)**

11.1	Does this respondent need a referral?	[1] Yes [2] No
11.2	If Yes	[1] Legal [2] Counselling [3] Other
11.3	Is follow-up required?	[1] Yes [2] No
11.4	Is this respondent a potential candidate for case studies?	[1] Yes [2] No
11.5	If yes, appointment for next meeting	
11.6	Other observations	
11.7	Interviewer	
11.8	Field edited by	