

**MTAAG+**

Positive Malaysian Treatment Access  
& Advocacy Group



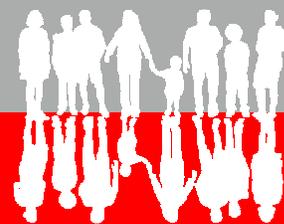
**THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX**

**MALAYSIA**

**December 2012**

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# Malaysia



This study was supported by a process and tools developed by the founding partnership of the People Living with HIV Stigma Index



The International Partnership of the People Living with HIV Stigma Index can be contacted at [plhivstigmaindex@gnpplus.net](mailto:plhivstigmaindex@gnpplus.net)

Published by:

**Positive Malaysian Treatment Access & Advocacy Group (MTAAG+), Malaysia**

21, Jalan 21/24, 46100 Petaling Jaya, Selangor, Malaysia.

Telephone: +6012-3278812

Email: [mtaagplus@gmail.com](mailto:mtaagplus@gmail.com)

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# Stigma Index



## ACRONYMS

<b>AIDS</b>	Acquired immunodeficiency syndrome
<b>ARV</b>	Antiretroviral therapy
<b>CAKNA</b>	Terengganu <i>Cakna</i> Community
<b>DIC Pahang</b>	Drug Intervention Community Pahang
<b>GNP+</b>	Global Network of People Living with HIV
<b>HIV</b>	Human immunodeficiency virus
<b>HDN</b>	Health and Development Networks
<b>IBBS</b>	Integrated Bio-Behavioural Surveillance
<b>ICW</b>	International Community of Women Living with HIV/AIDS
<b>IDU</b>	Injecting drug user
<b>IKHLAS</b>	IKHLAS Drop-in Centre for Drug Users
<b>INTAN Lifezone Johor</b>	<i>Pertubuhan Kebajikan Intan Zon Kehidupan Johor</i>
<b>IPPF</b>	International Planned Parenthood Federation
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>KAWAN</b>	Kawan ('friend' in Malay) Drop-in Centre for street community
<b>MOH</b>	Ministry of Health
<b>MSM</b>	Men having sex with men
<b>MTAAG+</b>	Positive Malaysian Treatment Access & Advocacy Group
<b>NGO</b>	Non-governmental Organization
<b>NSEP</b>	Needle exchange program
<b>NSP</b>	National Strategic Plan (NSP) on HIV and AIDS
<b>PLHIV</b>	People living with HIV
<b>PVT</b>	Prevention of vertical transmission
<b>PTF</b>	PT Foundation
<b>SAHABAT</b>	<i>Persatuan Perantaraan Pesakit-Pesakit Kelantan</i>
<b>SRH</b>	Sexual and reproductive health
<b>STI</b>	Sexually transmitted infection
<b>SW</b>	Sex worker
<b>UN</b>	United Nations
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>VCT</b>	Voluntary Counselling and Testing
<b>WHO</b>	World Health Organization

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### **The Study Team for Coordination support:**

Edward Low (MTAAG+), Nazarious Celsus Dorus (MTAAG+), Yang Yun Fei (MTAAG+).

### **The Translators of the Questionnaire:**

Nazarious Celsus Dorus (Malay version) and Teo Loo Sin (Mandarin version).

### **The Regional Team Leaders for Data Collection:**

Alias Abdullah, South region (Johor), Najib Harun, East Coast region (Kelantan, Terengganu and Pahang), Bennerdict Monteiro, Central region (Selangor and Federal Territory), Nurul, North region (Kedah, Penang and Perak), Faizal Jamil, East Malaysia (Sabah and Sarawak).

### **For Data Entry and Data Analysis:**

Nazarious Celsus Dorus, Thilaga and Jason Yeo (University Putra Malaysia).

### **The Report Team Consultant and Report Writer:**

Assoc. Prof. Dr. Mary Huang Soo Lee (University Putra Malaysia) and Lim Shiang Cheng (University Putra Malaysia).

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**Most importantly we would like to acknowledge the invaluable role of people living with HIV who participated in this study as interviewees. We thank them for their time and for sharing their stories. We trust that these findings, and the advocacy that arises from it, will contribute to improving the health and quality of their lives and that of people living with HIV in general.**

# Stigma Index



## EXECUTIVE SUMMARY

The PLHIV Stigma Index Study in Malaysia was conducted by The Positive Malaysian Treatment Access and Advocacy Group (MTAAG+) to document and measure the extent of HIV-related stigma and discrimination experienced by people living with HIV in order to contribute to strengthening the evidence base for advocacy, policy change and programme interventions.

### Methodology

The study was conducted by using a standard questionnaire that was developed by GNP+, ICW, IPPF and UNAIDS. The questionnaire was administered by trained PLHIV through face-to-face interviews. Data collection started in September 2010 and ended in January 2011. A total of 421 PLHIV throughout Malaysia participated in the study, with 14.6% from rural areas, 42.1% from small towns and 43.3% from the cities.

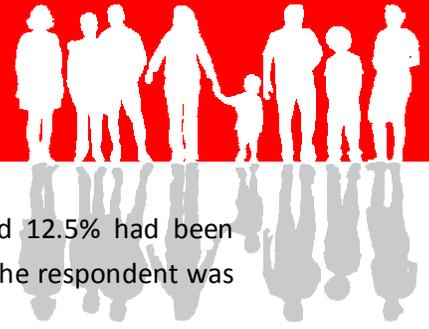
### Major Findings

Majority of the respondents who participated were male (70.2%), between 30 to 39 years old (47.4%), single (49.1%), with secondary school education (65.5%) and employed full time (39.1%) at the time of the study, had an annual household income that less than USD 3,000 (39.4%) and did not have any food insecurity problems (93.3%). Most of the respondents (79.7%) only discovered their HIV status in the last ten years, especially after the Malaysian government started to provide free first line HIV treatment in 2006. Majority of the respondents also identified themselves as belonging to key populations, with 52.7% being IDUs, 23.2% prisoners, 10.7% MSM, 6.7% were gay or lesbian, 6.4% were sex workers and 4.3% were transgender.

### Experience of stigma and discrimination

Almost half of people living with HIV taking part in the study (46.7%) said that they were aware of being gossiped about in the 12 months preceding the study mainly because of their HIV status and other reasons (i.e. sexual orientation and/or membership of a key population). Respondents reported that in the last year they had been excluded from social gatherings (17.2%), religious activities (7.8%), and 13.6% reported exclusion from family activities. Verbal insults had been experiences by 23.2%

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of respondents, 13.4% had experiences physical harassment, and 12.5% had been physically assaulted (87.5%). In nearly all cases the HIV+ status of the respondent was part of the contributory cause, for the treatment they had received.

In the previous twelve months 12% of respondents had lost, or been denied, accommodation, 15.6% had suffered discrimination in relation to jobs or incomes, with 12.4% being refused employment , and 6.4% having been refused promotion or having the nature of their job changed. Stigma in relation to accessing educational opportunities had happened to 6.4% of respondents, and 6.9% of respondents had experiences stigma and/or discrimination when accessing healthcare services. When respondents were asked why they felt these things had happened to them most of them stated that they believed it was their HIV+ status (sometimes alongside other reasons) that had caused this stigma and discrimination.

Overall, the study found that majority of the respondents (more than 60%) experienced internalised stigma. A total of 64.9% of respondents harboured feelings of shame about themselves, 73.1% felt guilty, 71.6% blamed themselves for their HIV status, and 62.1% had low self-esteem. However most did not feel that they should be punished (69.5%) nor were they suicidal (80%) because of their HIV status. In terms of marriage and having children; about half of the respondents cited that they decided not to get married (43.4%) or have (more) children (59.2%).

In the area of rights, laws and policies pertaining to PLHIV, it was found that majority of the respondents had very little knowledge with regards to their rights. This finding (that the respondents may not have been aware that their rights were being violated) may account for 79% reporting they had never experienced any violations of their rights and 64.9% did not think that their rights had been abused. The findings showed that a proportion of respondents reported that they were forced to undergo medical procedures against their will including HIV testing (13.1%), were denied health or life insurance (9.8%), had been being arrested or charged in court due to their HIV status (1.2%), had been forced to disclose HIV status in order to enter another country (2.1%) or apply for residence (2.1%) and 4.3% had been detained, quarantined, isolated or segregated due to being HIV+

About half of the respondents (47.3%) said that they knew some HIV-related organizations/ PLHIV support groups where they could seek help when they experienced stigma and discrimination; 53.7% of the respondents also provided support (especially psychological) to their peers even though they were not member of

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any PLHIV support group or network. On the other hand, only a small number had been involved in any HIV-related policy development (6.9%), though a larger number had been involved in a programme that provided assistance to PLHIV (24.3%).

For the recommendations to organisations for PLHIV, a quarter of the respondents (26.3%) felt that it was for these organisations to address stigma and discriminations and to raise the awareness and knowledge of the public about AIDS, while the other quarter (25.8%) said that these organizations should provide various types of support to PLHIV, including emotional, physical and referral support.

## **Experience of testing, disclosure, treatment and having children**

Generally, the study showed that most of the respondents had voluntarily tested for HIV (59.0%) as they wanted to know about their status (29.8%) or they were being referred for testing due to suspected HIV-related symptoms (24.1%). However, it should be noted that only 40% of the respondents received both pre- and post-HIV test counselling, while 41.2% were tested without pre-test counselling.

Pertaining to disclosure of HIV status, most respondents only revealed their status to the people closest to them or the people they trusted such as spouses/partners (37.3%), family members (38.8%), other people living with HIV (50.3%), injecting drug partners (39.5%), health care workers (37.4%) and social workers/counsellors (50.3%) and the reactions of these people were either supportive or very supportive.

However, it should be noted that the fear of disclosure among PLHIV remained and some of the people were discriminatory or very discriminatory after they found out respondents' HIV status.

Majority of the respondents (59.4%) were on ARV at the time of the study and most of them were confident that they had access to ARV (65.6%) or medication to prevent or treat opportunistic infections (53.0%). Nonetheless, respondents still had some problems in relation to ARV treatment including insufficient knowledge about the treatment (such as adherence and side effects), problems relating to distances travelled to access healthcare (hospital was too far away), frequency of visits to hospital (due to drug prescriptions of less than a month) and the limited therapy combinations available.

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With regards to the experience of having children and reproductive option, 40% of the respondents had a child or children and slightly more than one third (37.9%), especially women living with HIV had received counselling on reproductive option. On the other hand, 43.4% of the women living with HIV were found to be HIV positive when they were pregnant and almost all (82.6%) had received ARV treatment to prevent vertical transmission during pregnancy.

## Recommendations

Some recommendations from this study are outlined below.

1. Recognizing and advocating the rights of People Living with HIV regardless their sexual orientations and involvement in potentially high risk behaviours.
2. Creating and intensifying public understanding and awareness of HIV and AIDS to reduce risk taking as well as stigma and discrimination are essential.
3. Up-scaling, monitoring and evaluation of Voluntary Counselling and HIV testing to meet the needs of providers and clients, in an equitable and acceptable manner, within the resources available and in line with national guidelines.
4. Reviewing existing labour legislation and encouraging more companies to adopt the Code of Practice on Prevention and Management of HIV/AIDS at the Workplace to promote a non-discriminatory work environment.
5. Encouraging PLHIV to play a role of effecting change by involving them actively in developing and implementing stigma and discrimination reduction efforts including the development of laws, policies and guidelines.
6. Continue to provide psychosocial and socioeconomic support including training opportunities for PLHIV to become peer educators, capacity and network building, counselling, training, and income generation.
7. To conduct a repeat assessment to assess the overall situation of stigma and discriminations faced by PLHIV in Malaysia and to include those PLHIV who were not supported by peer groups in the study.

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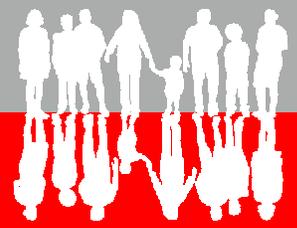
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## INTRODUCTION

### HIV-related stigma and discrimination

That people living with HIV (PLHIV) face stigma and discrimination in all areas of life is a known fact and what is even sadder is the fact that it is imposed on people who are already generally excluded or have unequal status in society. They generally also have the fewest resources to cope with the consequences. At the same time, fear of stigma and discrimination, prevents people from seeking information, adopting preventive behaviour, getting tested, disclosing their serostatus and accessing treatment. In some instances it prevents families from giving or accepting care. PLHIV, on the other hand may not take their drugs at the correct time or in a correct way in order to conceal their status.

UNAIDS in 2006, categorized HIV stigma and discrimination along with inequity and human rights abuses as primary obstacles to scaling up services in HIV and AIDS and achieving universal access to comprehensive HIV prevention, treatment, care and support by 2010. In Malaysia, we are reminded that we are on tract to achieve all the eight-millennium development goals except the one related to halting and begin to reverse the spread of HIV/AIDS. We are well aware that “Visibility and openness about AIDS are prerequisites for successful mobilization of government, communities and individuals to respond to the epidemic. Concealment encourages denial that there is a problem and delays urgent action. It causes people living with HIV to be seen as a ‘problem’, rather than as a solution to containing and managing the epidemic” (UNAIDS 2005). That studies on stigma and discrimination in Malaysia are far and few between and in general the issue of confidentiality make systematic sampling of PLHIV a rather arduous affair.

### Country context

HIV was first identified in Malaysia in 1986. The total cumulative reported cases in Malaysia as of December 2011 stood at 94,841 HIV cases, 17,686 AIDS cases and

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14,986 AIDS deaths<sup>1</sup>. The HIV epidemic in Malaysia has been classified as at the concentrated stage with high prevalence amongst some key populations<sup>2</sup>, i.e. injecting drugs user (IDU), men who are having sex with men (MSM) and sex worker (SW), and low prevalence (0.5%) in the general population. The findings from the Integrated Bio-Behavioural Surveillance (IBBS) and Venue-Day-Time-Sampling (VDTS) estimated the HIV prevalence for IDU at 22.1%, female sex worker at 10.5%, transgender, at 9.7% and MSM at 3.9%.

Although the current trend bears testimony to the fact that the HIV epidemic in Malaysia is still driven by IDU and sexual transmission amongst key populations, it should be noted that the number of HIV-infected women among the general population has increased from 5% of total new infections in 1998 to 21% in 2011. As of December 2011, 9,494 women and girls in Malaysia have been diagnosed with HIV. Two thirds are in their reproductive age, between 20 to 39 years and, 86% contracted the disease through heterosexual intercourse and 40% of them are housewives. By 2011, the ratio of female to male for newly infected cases increased from 1:99 in 1990 to 1:10 in 2000 and to 1:4 in 2011.

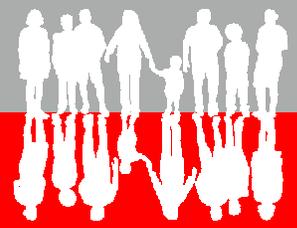
The main mode of HIV transmission has changed from injecting drug use to sexual transmission over the past ten years. Sexual transmission, especially heterosexual transmission, has become the main driving force in the epidemic in 2011 and the proportion of newly infected cases through heterosexual transmission has increased from 5.2% of total infections in 1990 to 18.8% in 2000, and 45.2% in 2011. This is partly due to the fact that the Government introduced the needle exchange program (NSEP) with the help of NGOs such as *SAHABAT*, *CAKNA*, Drug Intervention Community Pahang (DIC Pahang), Intan Lifezone Johor, *Kelab Rakan Melaka*, *IKHLAS*, *KAWAN*, AIDS Action Research Group (AARG) and *Cahaya Harapan* under Malaysian AIDS Council

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<sup>1</sup> Ministry of Health, Malaysia (2012). *Global AIDS Response Progress Report 2012 – Malaysia*.

<sup>2</sup> The term ‘key populations’ or ‘key populations at higher risk of HIV exposure’ refers to those most likely to be exposed to HIV or to transmit it – their engagement is critical to a successful HIV response i.e. they are key to the epidemic and key to the response. In all countries, key populations include people living with HIV. In most settings, men who have sex with men, transgender persons, people who inject drugs, sex workers and their clients, and sero negative partners in sero discordant couples are at higher risk of HIV exposure to HIV than other people. There is a strong link between various kinds of mobility and heightened risk of HIV exposure, depending on the reason for mobility and the extent to which people are outside their social context and norms. (Source: *UNAIDS terminology guidelines 2011: [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118\\_terminology-guidelines\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf)*)

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(MAC) thus contributing to drastic reduction in infections acquired through the sharing of needles among drug users.

The number reported AIDS-related deaths has declined since the Malaysian government provided free first line antiretroviral therapy (ARV) therapy<sup>3</sup> and subsidized the fees for second line and other HIV related services in 2006<sup>4</sup>. Currently, the ARV treatment initiation threshold in Malaysia is based on the latest guidelines by World Health Organization, which is at CD4 350 cells/mm<sup>5</sup>. Despite the fact that free first line ARV treatment is available in all major government hospitals, only a total of 14,002 PLHIV were on treatment in 2011, and this accounts for only 37.5% of the PLHIV who need it. The government has identified the fear of being discriminated and self-stigma as the main reason that hinders the PLHIV from accessing treatment and care<sup>6</sup>.

In view of stigma and discrimination being the main challenges in HIV prevention, treatment, care and support programmes in Malaysia, the latest National Strategic Plan (NSP) on HIV and AIDS 2011 - 2015 has included countering stigma and discrimination as a priority in order to respond more effectively to the epidemic. The NSP 2011 - 2015 is targeted toward *“creating and maintaining a conducive and enabling environment for government and civil society to play meaningful and active roles in decreasing stigma and discrimination”*. Nevertheless, much needs to be done by the healthcare sectors, NGO, faith-based organizations and private sectors to lessen stigma and discrimination among PLHIV and most at risk population.

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<sup>3</sup> Antiretroviral therapy is defined as *“HIV treatment in suppressing viral replication, reducing the amount of virus in the blood to undetectable levels, and slowing the progress of HIV disease”*. The usual antiretroviral therapy regimen combines three or more different drugs, such as two nucleoside reverse transcriptase inhibitors and a protease inhibitor, two nucleoside analogue reverse transcriptase inhibitors and a nonnucleoside reverse transcriptase inhibitor, or other combinations. More recently, entry inhibitors and integrase inhibitors have joined the range of treatment options. (Source: UNAIDS terminology guidelines 2011 - [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118\\_terminology-guidelines\\_en.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/JC2118_terminology-guidelines_en.pdf))

<sup>4</sup> Ministry of Health (MOH), Malaysia. (2010). *UNGASS Country Progress Report 2010: Malaysia*. Kuala Lumpur, Malaysia.

<sup>5</sup> Ibid 1.

<sup>6</sup> Ibid 1

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## About MTAAG+

The Positive Malaysian Treatment Access and Advocacy Group (MTAAG+) is a national network to mobilize the Positive Community to take ownership of their lives and circumstances. It was founded by a group of 7 PLHIV empowered and inspired through attending a regional treatment workshop in Pattaya in September 2004. It was officially registered as an organization on 21 December 2005. Since the organization was registered, it has partnered and worked with other organizations such as the Australia Federation of AIDS Organisations (AFAO), Malaysian AIDS Council (MAC), Third World Network (TWN), TIDE Foundation, International Treatment Preparedness Coalition (ITPC), Global Network of People Living with HIV (GNP+), International Community of Women Living with HIV/AIDS (ICW), Joint United Nations Programme on HIV/AIDS (UNAIDS), International Planned Parenthood Federation (IPPF), Health and Development Networks (HDN) and local partner organisations.

MTAAG+ has been actively involved in national advocacy and information sharing efforts, particularly in access to ARV and literacy (including among illiterate people living in rural areas) for the past few years. It advocates and organizes ongoing campaigns to protest against the adverse impact of restrictive drug patents and Free Trade Agreements on PLHIV in Malaysia, in order to urge the Malaysian Government to ensure continuing access to affordable ARV. In addition, MTAAG+ also provides treatment literacy under community driven projects such as Hospital Peer Support Groups and reaching out to illiterate groups for treatment in rural areas. Through these support programmes, MTAAG+ is able to complement the counselling services offered by the healthcare providers. The range of this support includes moral support, further information on HIV transmission, treatment options, treatment side effects, providing signposting to (and working in partnership with) hospitals and clinics that offer treatment, as well as providing information and support on methods of safer sex practices for people living with HIV.

On the other hand, as an organization driven by and for PLHIV, MTAAG+ feels that issues of stigma, discrimination, denial and ignorance continue to have an impact on HIV treatment, care and support programmes. This prompted MTAAG+ to initiate the PLHIV Stigma Index study to document the extent and causes of stigma and discrimination felt by PLHIV in Malaysia in 2010. MTAAG+ believes that such a study needs to be systematically carried out at this stage of the epidemic so that Malaysia

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has empirical data to advocate for support, remove all misconceptions (generally based on ignorance) about the epidemic and hopefully move on to more effective policy and programs.

## Objectives

The general objective of this study is to collect information on stigma, discrimination and the rights of PLHIV that will help in advocacy efforts. The specific objectives include:

1. To document the various experiences of people living with HIV in Malaysia.
2. To compare the situation of people living with HIV in Malaysia with other countries
3. To measure changes over a period of time as part of the process of monitoring the stigma situation in the country
4. To provide an evidence base for policy information for policy change and programmatic interventions.
5. To empower PLHIV to take charge of their own issues and at the same time provide them with a tool to advocate for changes needed according to the index data.

These objectives are in line with those laid out in the *“The People Living with HIV Stigma Index User Guide”* (at page 4) adapted for the Malaysian situation<sup>7</sup>.

## Methodology

### Study population and exclusion criteria

The study population was people living with HIV in Malaysia who were 18 years and above. Since this was a study on stigma and discrimination the local team decided it was pertinent to only interview PLHIV who had revealed their status to at least some family and friends. Therefore PLHIV who had not revealed their HIV-positive status to family and friends were excluded in order to ensure that the study did not have

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<sup>7</sup>Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). *The People Living with HIV Stigma Index: User Guide*. [www.stigmaindex.org](http://www.stigmaindex.org)

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respondents who had not faced any form of discrimination because they had not revealed their status to others.

## Sampling

Because of confidentiality and thus the unavailability of a complete sampling frame, a snowball method<sup>8</sup> of recruitment of respondents was utilized. The proportion of respondents by gender and mode of transmission was guided by the distribution of reported infected cases in the country.

## Study Instrument - Questionnaire

The questionnaire used in this study was the standard questionnaire developed by and for people living with HIV by the founding partnership of the People Living with HIV Stigma Index; the GNP+, ICW, IPPF and UNAIDS.

This English version of this questionnaire extended over 23 pages and was divided in various sections, namely:

1. Referrals and follow-up
2. Information about respondent
3. Experience of Stigma and Discrimination for other people
4. Access to work and Health and Education Services
5. Internalised stigma
6. Rights, Law and Policies,
7. Effecting change
8. Testing/Diagnosis
9. Disclosure and confidentiality
10. Treatment
11. Having children and Problems and challenges.

The questionnaire was translated into *Bahasa Malaysia* and Mandarin to improve understanding of the survey intent and delivery of answers.

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<sup>8</sup> Snowball sampling “a non-probability sampling technique where existing study subjects recruit future subjects from among their friends, peers or acquaintances”. (Source: Goodman, L.A. (1961). “Snowball sampling”. *Annals of Mathematical Statistics* 32 (1): 148–170. doi:10.1214/aoms/1177705148.)



## Recruitment and Training of the Survey Team

The questionnaire was administered by trained PLHIV through face-to-face interviews. Five regional training sessions were conducted in 2010 and each training session lasted two days. In Peninsular Malaysia, the first training session was held in Johor Bahru for the Southern region on 3-4 July 2010, followed by one in Kuala Terengganu for the east coast region on 7-8 August 2010, in Kuala Lumpur for the central region on 21-22 August 2010, and in Alor Setar for the northern region on 28-29 August 2010. In East Malaysia, the training was held in Kuching on 10-11 July 2010.

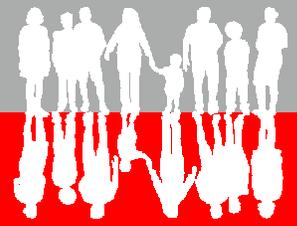
At each of the training sessions on Peninsular Malaysia, ten to fifteen enumerators who were people with HIV were trained on how respondents should be recruited and how interviews should be conducted. Majority of these enumerators were members of PLHIV support groups or affiliated with HIV-related organizations. In East Malaysia six people living with HIV were trained to recruit only 13 respondents from Sabah and Sarawak. Fewer respondents were recruited from East Malaysia mainly because of there were fewer HIV related organizations or PLHIV support groups in Sabah and Sarawak from whom enumerators could recruit respondents.

## Data Collection

Data collection for the study started immediately after the completion of the regional training workshops, which started in September 2010 and ended in January 2011. The plan was to recruit 500 PLHIV as respondents, but only 421 respondents (84.2%) from different parts of the country were eventually interviewed within the timeframe given. It was not easy to identify PLHIV in Malaysia and attract them to participate in this study in view of the fact that most of them would prefer to keep their status confidentially and did not wish to participate in any study. Most of the respondents recruited in this study belonged to or were supported by support groups or HIV related organizations.

In this study 14.6% of the respondents were recruited from rural areas, 42.1% from small towns and 43.3% from the cities. In the central region, the respondents were mainly recruited from Kuala Lumpur and Selangor. Interviews were conducted in Perak and Kedah to represent the northern region. The respondents from southern region were all from Johor Bahru while respondents from east coast region were from

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Kelantan, Terengganu and Pahang. There study also included 13 respondents who were from Sabah and Sarawak.

The interviews took place in different places depending on the arrangement of the NGOs, and the request or the availability of the respondents. Some of the interviews were conducted at the NGOs' shelter homes or drop-in centres. Some were carried out during the NGOs' outreach activities or through the hospital peer support groups. It should be noted that the study was also conducted in the prison in Kelantan.

## Limitations of Study

Although 421 respondents took part in the study, only 419 respondents were included in the analysis because two questionnaires had 25% or more missing values. In addition, there were also some missing values in most of the questionnaires collected and this made analysis of data rather challenging. The missing data can be attributed to several factors; the methodology of the stigma index allowing for participants to not answer any question or questions which they felt were perhaps too personal (especially questions about identifying themselves as being part of a key population), respondents (and interviewers) not feeling that the question applied because of a previous response, inadvertently skipping a question, and because there was not enough time to complete the questionnaire (many interviews were conducted during outreach activities and consequently pressured in relation to time) or the respondent just lost interest. However the recording of the reasons for missing data was not analysed. Despite these challenges the response rate overall to the questionnaire was very high.



## Section 1: Demographic details of those who took part as interviewees

A total of 419 people living with HIV took part in this study as interviewees. Majority of them (294 or 70.2%) were male, 107 or 25.5% female and 18 or 4.3% were transgender (Table 1). Only 418 respondents made known their ages with almost half in the 30 to 39 age range. The distribution by age was also in favour of this age group for the males, females and transgender alike. Respondents aged 40 to 49 forms the second largest group and less than 10% were below 25 years or above 50 years. Very few of them (five or 1.2%) were young people aged 18 to 19 years. Only 6.8% reported experiencing a physical disability and it was almost the same irrespective of gender. Almost two thirds of the respondents had some secondary school education and in fact 18.4% had tertiary education<sup>9</sup>. In this study more males (20.3%) had tertiary education than females (14.2%) or the transgender (11.1%).

Of the 419 respondents, 412 disclosed their employment status and all of them only provided one response. Of these most were working at the time of the study; they were either employed full time (39.1%) or part time (9.7%). About one third of the respondents (31.3%) reported that they were self-employed. A total of 19.9% of the respondents were unemployed at the time of the study and most of them were females. In view of the fact that some of the respondents were unemployed at the time of the study, the following analysis is based on the 355 respondents who provided information on their household incomes. About two fifths of these respondents came from the lowest income group, with annual household incomes at about USD 3,000. A total of 26.8% of these respondents had a household income between USD 3,000 to USD 6,000 annually and one third (33.8%) were from the highest income group.

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<sup>9</sup>Tertiary education refers to post secondary education. In Malaysia, provided by colleges, universities and polytechnics and generally culminates in receipt of certificates, diplomas, degrees, masters and Doctorates.

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**Table 1: Socio-economic status**

<b>Gender (N = 419)</b>				
<b>Characteristics</b>	<b>Male No. (%)</b>	<b>Female No. (%)</b>	<b>Transgender No. (%)</b>	<b>Total No. (%)</b>
	<b>294 (70.2)</b>	<b>107 (25.5)</b>	<b>18 (4.3)</b>	<b>419 (100)</b>
<b>Age Groups in Years (N = 418)</b>				
18 to 19	2 (0.7)	3 (2.8)	0 (0)	5 (1.2)
20 to 24	13 (4.4)	10 (9.4)	3 (16.7)	26 (6.2)
25 to 29	31 (10.5)	19 (17.9)	0 (0)	50 (12.0)
30 to 39	143 (48.6)	48 (45.3)	7 (38.9)	198 (47.4)
40 to 49	83 (28.2)	21 (19.8)	6 (33.3)	110 (26.3)
>50	22 (7.5)	5 (4.7)	2 (11.1)	29 (6.9)
<b>Total</b>	<b>294 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>418 (100)</b>
<b>Physical Disability (N = 413)</b>				
Yes	22 (7.6)	5 (4.7)	1 (5.6)	28 (6.8)
No	267 (92.4)	101 (95.3)	17 (94.4)	385 (93.2)
<b>Total</b>	<b>289 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>413 (100)</b>
<b>Educational Level (N = 414)</b>				
None	3 (1.0)	3 (2.8)	2 (11.1)	8 (1.9)
Primary	38 (13.1)	18 (17.0)	3 (16.7)	59 (14.3)
Secondary	190 (65.5)	70(66.0)	11 (61.1)	271 (65.5)
Tech/Tertiary	59 (20.3)	15(14.2)	2 (11.1)	76 (18.4)
<b>Total</b>	<b>290 (100)</b>	<b>106 100)</b>	<b>18 (100)</b>	<b>414 (100)</b>
<b>Employment Status (N = 412)</b>				
Full-time employment	111 (38.5)	42 (39.6)	8 (44.4)	161 (39.1)
Part-time employment	31 (10.8)	5 (4.7)	4 (22.3)	40 (9.7)
Full time self-employed	52 (18.1)	13 (12.3)	2 (11.1)	67 (16.3)
Part time self-employed	49 (17.0)	11 (10.4)	2 (11.1)	62 (15.0)
Unemployed	45 (15.6)	35 (33.0)	2 (11.1)	82 (19.9)
<b>Total</b>	<b>288 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>412 (100)</b>
<b>Annual Household Income (USD) (N = 355)</b>				
Lowest income (0.00 to 3019.02)	81 (32.9)	51 (53.1)	8 (61.5)	140 (39.4)
Middle income (3019.03 to 6038.04)	67 (27.3)	26 (27.1)	2 (15.4)	95 (26.8)
Highest income (6038.05 and above)	98 (39.8)	19 (19.8)	3 (23.1)	120 (33.8)
<b>Total</b>	<b>246 (100)</b>	<b>96 (100)</b>	<b>13 (100)</b>	<b>355 (100)</b>

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About 40% of the respondents came from lowest income group (annual household income less than USD 3000/RM 9,000); majority of respondents (93.3%) reported no food insecurity problems (Table 2). Only 28 (6.7%) reported moderate or severe food insecurity problems and majority of them were males. Of 28 respondents reporting food insecurity, 22 (75%) were injecting drug users, mostly from small town/urban areas.

**Table 2: Food insecurity**

Characteristics	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
Not Food Insecure	272 (92.5)	101 (94.4)	18 (100.0)	391 (93.3)
Moderately Food Insecure	1 (0.3)	0 (0)	0 (0)	1 (0.3)
Severely Food Insecure	21 (7.2)	6 (5.6)	0 (0)	27 (6.4)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

Table 3 shows that more than two thirds of the respondents have known their status between one and nine years and one in five have known their status for over nine years. The number of those who have known their status more than ten years may be partially explained by the fact that before 2005 PLHIV had to pay for their own medication; before that only children and women whose status were detected during antenatal check-ups and Government employees received free medication. The absence of treatment availability was indeed a barrier to people going for testing in many countries. Therefore if PLHIV could not afford treatment they had to seek assistance from the Malaysian AIDS Council, other NGOs or religious organizations for assistance. Irrespective of gender the distribution of respondents by number of years they had known their status was similar, that is with two thirds having known between one to nine years, 15% less than one year and one in five (20%) having known for ten or more years.

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**Table 3: Number of years respondents have known they are HIV-positive**

Characteristics (years HIV+)	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
< One	44 (15.1)	17 (16.0)	1 (5.6)	62 (14.9)
One to four	92 (31.6)	50 (47.2)	10 (55.5)	152 (36.6)
Five to Nine	81 (27.8)	31 (29.2)	5 (27.7)	117 (28.2)
Ten to fourteen	28 (15.8)	4 (3.8)	1 (5.6)	51 (12.3)
> Fourteen	28 (9.7)	4 (3.8)	1 (5.6)	33 (8.0)
<b>Total</b>	<b>273 (100)</b>	<b>106(100)</b>	<b>18 (100)</b>	<b>415 (100)</b>

Respondents were asked whether they at the time of the study or in the past they belonged to any key population. For the key populations such as refugees or asylum seeker, internally displaced person, indigenous people and migrant workers, the sample size of the group was less than 1% and it was too small for further analysis, therefore, their experiences are not included in this study. Further study or focus group discussions may be needed in order to ensure that the experiences and needs of people from these groups are included in our understanding and advocacy work around stigma and discrimination.

As shown in Table 4, more than half of respondents (52.7%) reported themselves as injecting drug users (IDUs). Most were male (90%), with at least secondary education (82%), came from small towns or villages (51.2%). Only one fifth (26.4%) were employed full time and most belonged to the lowest (36.3%) or middle income groups (35.2%).

As interviews were conducted in prison, it was not surprising that a total of 23.2% of respondents (92.8% men) were prisoners; ex-prisoners were not included in this study. The prisoners in this study shared similar background with IDUs, i.e. most had secondary education (83.5%), 50% were from small towns or villages. In addition, they also had low earning power, most having very low (32.5%) or middle income (38.6%).

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**Table 4: Key populations\***

Characteristics	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
MSM	45 (15.3)	0 (0)	0 (0)	45 (10.7)
Gay or Lesbian	22 (7.5)	6 (5.6)	0 (0)	28 (6.7)
Transgender	0 (0)	0 (0)	18 (100.0)	18 (4.3)
Sex worker	11 (3.7)	5 (4.7)	11 (61.1)	27 (6.4)
Injecting Drug User	199 (67.7)	20 (18.7)	2 (11.1)	221 (52.7)
Refugee or Asylum Seeker	1 (0.3)	1 (0.9)	1 (5.6)	3 (0.7)
Internally Displaced Person	1 (0.3)	0 (0)	1 (5.6)	2 (0.5)
Member of an indigenous Group	1 (0.3)	0 (0)	1 (5.6)	2 (0.5)
Migrant Worker	2 (0.7)	0 (0)	1 (5.6)	3 (0.7)
Prisoner	90 (30.6)	6 (5.6)	1 (5.6)	97 (23.2)
	<b>294</b>	<b>107</b>	<b>18</b>	<b>419</b>

\* Respondent may belong to more than one group

A total of 6.4% of respondents reported that they were sex workers. Of these 27 respondents, most were male and transgender (each accounting for 40.7% of all sex workers) and five (18.5%) were female. Two thirds had received secondary education; almost half (48.1%) were from urban areas and the lowest income group (43.5%).

A total of 10.7% of the respondents declared themselves as men having sex with men (MSM), followed by 6.7% who said that they were gay or lesbian and 4.3% as transgender. Most of the respondents who were MSM, gay or lesbian had higher education, with two thirds of them (69.9%) having tertiary education. In addition, most of them (68.5%) were fully employed and thus earned more. Majority of them (67.8%) reported annual household incomes in excess of USD 18,000. Majority of the transgender (83.3%) had secondary education and half of them (50%) came from lowest income group.

There were 411 respondents who revealed their relationship status at the time of the study; 49.1% were single, 23.8% who were married or had a cohabitating relationship and 12.4% reported as widows or widowers (Table 5). The other respondents were either divorced/separated (6.8%), in a relationship but not living together (5.8%) or

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married or cohabitating but partners were away (2.1%). The men were either single (59.6%), married or cohabitating (20.7%). One third of the women were also in a married or cohabitating relationship (34.0%), and another one third were widowed (27.4%). Almost all transgender (93.3%) said they were single at the time of the study.

When respondents were asked about the length of their current relationship, less than half (187 respondents) answered the question. Of those who answered the majority (73.3%) had been in a relationship for less than 10 years. One third of the respondents (31%) had been in a relationship for one to four years, 26.2% in a relationship between five to nine years, and 10.6% had been in a relationship for more than 15 years.

**Table 5: Relationship status, length of current relationship and sexual status**

Characteristics	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Relationship status (N = 411)</b>				
Married or cohabitating	60(20.7)	36 (34.0)	1(6.7)	97(23.8)
Married or cohabitating but partner is away	6(2.1)	3(2.8)	00	9(2.1)
In a relationship but not living together	12(4.1)	12 (11.2)	00	24(5.8)
Single	173(59.6)	15(14.2)	14(93.3)	202(49.1)
Divorced/Separated	17(5.9)	11 (10.4)	0	28(6.8)
Widow/Widower	22(7.6)	29 (27.4)	0	51(12.4)
<b>Total</b>	<b>290(100)</b>	<b>106(100)</b>	<b>15(100)</b>	<b>411(100)</b>
<b>Length of current relationship (N = 187)</b>				
0 - 1 year	21 (17.9)	8 (13.1)	1 (11.1)	30 (16.1)
1 - 4 years	37 (31.6)	17 (27.9)	4 (44.4)	58 (31.0)
5 - 9 years	25 (21.4)	22 (36.1)	2 (22.3)	49 (26.2)
10 - 14 years	16 (13.7)	13 (21.3)	1 (11.1)	30 (16.1)
15+ years	18 (15.4)	1 (1.6)	1 (11.1)	20 (10.6)
<b>Total</b>	<b>117 (100)</b>	<b>61 (100.0)</b>	<b>9 (100.0)</b>	<b>187 (100.0)</b>
<b>Sexually active (411)</b>				
Sexually active	118 (40.7)	44 (41.5)	10 (66.7)	172 (41.8)
Not sexually active	172 (59.3)	62 (58.5)	5 (33.3)	239 (58.2)
<b>Total</b>	<b>290 (100)</b>	<b>106 (100)</b>	<b>15 (100)</b>	<b>411 (100)</b>

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The study revealed that less than half of the respondents (41.8%) were sexually active at the time of the study and that sexual status of respondents was not related with their relationship status. Although a total of 42.4% respondents who were sexually active were in a marriage or cohabitating relationship, it should be noted that majority of the others were single (39.5%), their partners were away (6.4%), divorced or separated (4.1%) or widowed (4.1%) (Table 6). For those who were not sexually active, more than half (56.1%) were single, followed by 18.4% who were widowed and 10% who were in a marriage or cohabitating relationship.

**Table 6: Cross tabulation of sexual status and relationship status**

Relationship Status	Sexually Active (%)				Not Sexually Active (%)				Total (%)
	Male	Female	TS	Total	Male	Female	TS	Total	
<b>Married/ cohabitating</b>	45 (38.1)	27 (61.4)	1 (10.0)	<b>73 (42.4)</b>	15 (8.7)	9 (14.5)	0.0	24 (10.0)	<b>97 (23.8)</b>
<b>Married/ cohabitating but partner is away</b>	3 (2.5)	3 (6.8)	0.0	<b>6 (3.5)</b>	3 (1.7)	0.0	0.0	3 (1.3)	<b>9 (2.1)</b>
<b>In a relationship but not living together</b>	8 (6.8)	3 (6.8)	0.0	<b>11 (6.4)</b>	4 (2.3)	9 (14.5)	0.0	13 (5.4)	<b>24 (5.8)</b>
<b>Single</b>	55 (46.7)	4 (9.1)	9 (90.0)	<b>68 (39.5)</b>	118 (68.6)	11 (17.8)	5 (100)	134 (56.1)	<b>202 (49.1)</b>
<b>Divorced/ Separated</b>	4 (3.4)	3 (6.8)	0.0	<b>7 (4.1)</b>	13 (7.6)	8 (12.9)	0.0	21 (8.8)	<b>28 (6.8)</b>
<b>Widow/ Widower</b>	3 (2.5)	4 (9.1)	0.0	<b>7 (4.1)</b>	19 (11.1)	25 (40.3)	0.0	44 (18.4)	<b>51 (12.4)</b>

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## Section 2: Experience of stigma and discrimination

HIV-related stigma and discrimination refers to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. The HIV-related stigmatization and discrimination cause the rights of PLHIV to be neglected, with some being shunned by family, peers and the wider community, received poor treatment in healthcare and education settings, insecure and some even at risk of family dissolution and violence. This section describes the findings of the study related to stigma at family, community and institutional settings and internalised stigma.

### 2.1 Experience of HIV-related stigma and discrimination

In this section, respondents were asked about the types of stigma and discrimination experienced by them in the 12 months preceding the interview. The types of stigma and discrimination included exclusion from social gatherings, religious activities, and family activities, experiences of verbal or physical harassments or assaults.

As shown in Table 7, about half of the respondents (46.7%) said that they were aware of being gossiped about in the past 12 months. About one third (28.2%) of the respondents said that they experienced it a few times (28.2%) and 14.3% reported that they often faced this problem. Slightly more female respondents (48.6%) said that they had experienced being gossiped about than male (46.3%) and transgender (44.4%) respondents.

Respondents were also asked about being excluded from social gatherings, religious, and family activities. Though majority of the respondents reported that they had never being excluded from social gatherings (82.8%), religious activities (92.1%), and family activities (86.4%) and in addition, most of them also did not experience any verbal (76.8%) or physical (86.6%) harassment and had never being physically assaulted (87.5%), this still means that a large number had suffered stigma, discrimination, and physical abuse.



**Table 7: Types of stigma and discrimination experienced**

Types of stigma and discrimination	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Exclusion from social gatherings or activities (N = 418)</b>				
Never	248 (84.6)	84 (78.5)	14 (77.8)	346 (82.8)
Once	9 (3.1)	3 (2.8)	0	12 (2.9)
A few times	27 (9.2)	15 (14.0)	4 (22.2)	46 (11.0)
Often	9 (3.1)	5 (4.7)	0	14 (3.3)
<b>Total</b>	<b>293 (100)</b>	<b>107(100)</b>	<b>18 (100)</b>	<b>418 (100)</b>
<b>Exclusion from religious activities or places of worship (N = 416)</b>				
Never	267 (91.8)	100 (93.4)	16 (88.8)	383 (92.1)
Once	3 (1.0)	2 (1.9)	0	5 (1.2)
A few times	15 (5.2)	3 (2.8)	1 (5.6)	19 (4.6)
Often	6 (2.0)	2 (1.9)	1 (5.6)	9 (2.1)
<b>Total</b>	<b>291 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>416 (100)</b>
<b>Exclusion from family activities (N = 418)</b>				
Never	257 (87.4)	89 (83.9)	15 (83.3)	361 (86.4)
Once	5 (1.7)	2 (1.9)	0	7 (1.7)
A few times	19 (6.5)	13 (12.3)	2 (11.1)	34 (8.1)
Often	13 (4.4)	2 (1.9)	1 (5.6)	16 (3.8)
<b>Total</b>	<b>294 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>418 (100)</b>
<b>Being gossiped about (N = 419)</b>				
Never	158 (53.7)	55 (51.4)	10 (55.5)	223 (53.2)
Once	12 (4.1)	6 (5.6)	0	18 (4.3)
A few times	81 (27.6)	32 (29.9)	5 (27.8)	118 (28.2)
Often	43 (14.6)	14 (13.1)	3 (16.7)	60 (14.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Verbal harassment (N = 419)</b>				
Never	228 (77.6)	81 (75.7)	13 (72.2)	322 (76.8)
Once	11 (3.7)	2 (1.9)	0	13 (3.1)
A few times	43 (14.6)	18 (16.8)	4 (22.2)	65 (15.6)
Often	12 (4.1)	6 (5.6)	1 (5.6)	19 (4.5)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Physical harassment (N = 417)</b>				
Never	257 (88.0)	89 (83.2)	15 (83.3)	361 (86.6)
Once	6 (2.1)	3 (2.8)	0	9 (2.1)
A few times	25 (8.5)	12 (11.2)	0	37 (8.9)
Often	4 (1.4)	3 (2.8)	3 (16.7)	10 (2.4)
<b>Total</b>	<b>292 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>417 (100)</b>
<b>Physically assaulted (N = 416)</b>				
Never	256 (87.6)	93 (87.7)	15 (83.3)	364 (87.5)
Once	11 (3.8)	2 (1.9)	1 (5.6)	14 (3.4)
A few times	19 (6.5)	9 (8.5)	0	28 (6.7)
Often	6 (2.1)	2 (1.9)	2 (11.1)	10 (2.4)
<b>Total</b>	<b>292 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>416 (100)</b>

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For those respondents who reported that they had ever received any physical assault, one third (32.2%) said that they were assaulted by a person outside the household who was known to them and another third (30.9%), especially male and transgender respondents, reported that they were assaulted by an unknown person (Table 8). More female respondents (37.5%) cited their household members having assaulted them. Another 11.8% reported that they were assaulted by their husbands, wives or partners.

**Table 8: Person who physically assaulted respondents**

Physically Assaulted by Whom	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
Husband/Wife/Partner	3 (6.2)	4 (25.0)	1 (33.3)	8 (11.8)
Another member of the household	11 (22.4)	6 (37.5)	0	17 (25.0)
Person(s) outside the household who is/are known to respondent	17 (34.7)	5 (31.2)	0	22 (32.3)
Unknown person(s)	18 (36.7)	1 (6.3)	2 (66.7)	21 (30.9)
<b>Total</b>	<b>49 (100)</b>	<b>16 (100)</b>	<b>3 (100)</b>	<b>68 (100)</b>

When those respondents who had ever experienced stigma and discriminations were asked about the reasons of they experienced that, about or less than 20% said that was solely due to their HIV status, followed by one of the respondents who reported being stigmatized or discriminated due to other reasons and another third who said that were mainly because of their HIV status and other reasons.

Table 9 shows the reasons given for being discriminated against or stigmatised. Additionally respondents were asked whether they thought this stigma and discrimination was because of HIV+ status only, whether their HIV+ status was a contributory factor, or whether it was for something that they did not perceive as being due in any way to their HIV+ status.



**Table 9: Reasons for being stigmatised or discriminated against**

Types of stigma and discrimination	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Exclusion from social gatherings or activities (N = 88)</b>				
Because of HIV status	18 (29.0)	6 (25.0)	0	24 (27.3)
For another reason(s)	10 (16.1)	9 (37.5)	1 (50.0)	20 (22.7)
Both because of HIV status and other reason	22 (35.5)	7 (29.2)	1 (50.0)	30 (34.1)
Not sure why	12 (19.4)	2 (8.3)	0	14 (15.9)
<b>Total</b>	<b>62 (100)</b>	<b>24 (100)</b>	<b>2 (100)</b>	<b>88 (100)</b>
<b>Exclusion from religious activities or places of worship (N = 48)</b>				
Because of HIV status	5 (14.3)	3 (25.0)	0	8 (16.7)
For another reason(s)	7 (20.0)	4 (33.3)	0	11 (22.8)
Both because of HIV status and other reason	16 (45.7)	3 (25.0)	1 (100.0)	20 (41.7)
Not sure why	7 (20.0)	2 (16.7)	0	9 (18.8)
<b>Total</b>	<b>35 (100)</b>	<b>12 (100)</b>	<b>1 (100)</b>	<b>48 (100)</b>
<b>Exclusion from family activities (N = 71)</b>				
Because of HIV status	11 (22.4)	7 (36.8)	0	18 (25.4)
For another reason(s)	11 (22.4)	4 (21.1)	1 (33.3)	16 (22.5)
Both because of HIV status and other reason	21 (42.9)	6 (31.6)	1 (33.3)	28 (39.4)
Not sure why	6 (12.3)	2 (10.5)	1 (33.4)	9 (12.7)
<b>Total</b>	<b>49 (100)</b>	<b>19 (100)</b>	<b>3 (100)</b>	<b>71 (100)</b>
<b>Being gossiped about (N = 199)</b>				
Because of HIV status	25 (18.0)	15 (28.9)	1 (12.5)	41 (20.6)
For another reason(s)	39 (28.1)	14 (26.9)	1 (12.5)	54 (27.1)
Both because of HIV status and other reason	51 (36.6)	13 (25.0)	2 (25.0)	66 (33.2)
Not sure why	24 (17.3)	10 (19.2)	4 (50.0)	38 (19.1)
<b>Total</b>	<b>139 (100)</b>	<b>52 (100)</b>	<b>8 (100)</b>	<b>199 (100)</b>
<b>Verbal harassment (N = 106)</b>				
Because of HIV status	15 (20.8)	9 (31.0)	1 (20.0)	25 (23.6)
For another reason(s)	20 (27.8)	7 (24.2)	3 (60.0)	30 (28.3)
Both because of HIV status and other reason	30 (41.7)	8 (27.6)	1 (20.0)	39 (36.8)
Not sure why	7 (9.7)	5 (17.2)	0	12 (11.3)
<b>Total</b>	<b>72 (100)</b>	<b>29 (100)</b>	<b>5 (100)</b>	<b>106 (100)</b>
<b>Physical harassment (N = 69)</b>				
Because of HIV status	7 (15.6)	8 (38.1)	0	15 (21.7)
For another reason(s)	13 (28.9)	6 (28.6)	1 (33.3)	20 (29.0)
Both because of HIV status and other reason	19 (42.2)	4 (19.0)	1 (33.3)	24 (34.8)
Not sure why	6 (13.3)	3 (14.3)	1 (33.4)	10 (14.5)
<b>Total</b>	<b>45 (100)</b>	<b>21 (100)</b>	<b>3 (100)</b>	<b>69 (100)</b>
<b>Physically assaulted (N = 71)</b>				
Because of HIV status	6 (11.8)	4 (23.5)	0	10 (14.1)
For another reason(s)	18 (35.3)	6 (35.3)	1 (33.3)	25 (35.2)
Both because of HIV status and other reason	15 (29.4)	5 (29.4)	1 (33.3)	21 (29.6)
Not sure why	12 (23.5)	2 (11.8)	1 (33.4)	15 (21.1)
<b>Total</b>	<b>51 (100)</b>	<b>17 (100)</b>	<b>3 (100)</b>	<b>71 (100)</b>

# Stigma Index



For those respondents who felt that they experienced stigma and discrimination for reasons other than their HIV status, about half (48.2%) said that it was mainly due to their IDU status, followed by 13.8% who reported that it was because of their sexual orientation (MSM, gay or lesbian, transgender) and 2.9% who cited that it was due sex work (Table 10). It should be noted that 32.5% of the respondents who reported that they were being stigmatized due to reasons other than sexual orientation and involvement in potentially high risk behaviour. These reasons included gender (some respondents said that they were being stigmatized mainly because of being women), the perceived 'high risk' behaviours of the husbands (especially those respondents whose husband were drug users), their widowed status and poverty. For those respondents who cited that they were being stigmatized or discriminated because of their HIV status, most reported that the community or family members stayed away from them due to the fear of contagion and pre-occupation with HIV transmission.

**Table 10: Other reasons for being stigmatised or discriminated against**

Other reason	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Stigma Experienced for some other reasons (N = 419)</b>				
Sexual Orientation	43 (14.6)	4 (3.7)	11 (61.1)	58 (13.9)
Sex worker	3 (1.0)	4 (3.7)	5 (27.8)	12 (2.9)
Injecting Drug User	185 (63.0)	17 (16.0)	0	202 (48.2)
Refugee/Asylum seeker	0	1 (0.9)	0	1 (0.2)
Migrant Worker	1 (0.3)	0	0	1 (0.2)
Prisoner	8 (2.7)	1 (0.9)	0	9 (2.1)
Other reasons	54 (18.4)	80 (74.8)	2 (11.1)	136 (32.5)
<b>Total</b>	<b>294</b>	<b>107</b>	<b>18</b>	<b>419</b>

Table 11 shows the reasons given by respondents who experienced HIV-related stigma and discrimination. Slightly more than one third of the respondents (37.9%) said that most people stigmatised PLHIV due to the fear of contagion. Most people were afraid of getting HIV infection from PLHIV. In addition, 21.6% of the respondents were of the opinion that most people did not understand how HIV was transmitted and thus their fear of getting infected by PLHIV contributed to HIV/AIDS-related stigma and discrimination. Furthermore, 10% of the respondents said that the society or community disapproved of their lifestyles or behaviours (such as sexual orientation, drug use, sex work) and as such stigmatised them.

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One in ten (10%) respondents associated HIV-related stigma and discrimination with a perception that HIV infection is a result of shameful behaviour, religious beliefs or “moral” judgement, or that they (the respondent ) looked sick with the symptoms of HIV; 14.2% of the respondents were unsure of why they experienced HIV-related stigma and discrimination.

**Table 11: Reason for experiencing HIV related stigma and discrimination**

Reason	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Reason for experiencing HIV related stigma and discrimination (N = 240)</b>				
People are afraid of getting infected with HIV from me	73 (41.5)	17 (30.9)	1 (11.2)	91 (37.9)
People don't understand how HIV is transmitted and are afraid I will infect them with HIV	39 (22.1)	12 (21.8)	1 (11.1)	52 (21.6)
People think that having HIV is shameful and they should not be associated with me	13 (7.4)	5 (9.1)	2 (22.2)	20 (8.3)
Religious beliefs or "moral" judgements	2 (1.1)	0	0	2 (0.8)
People disapprove of my lifestyle or behaviour	16 (9.1)	7 (12.7)	1 (11.1)	24 (10.0)
I look sick with symptoms associated with HIV	11 (6.3)	4 (7.3)	2 (22.2)	17 (7.2)
I don't know/I am not sure of the reason(s)	22 (12.5)	10 (18.2)	2 (22.2)	34 (14.2)
<b>Total</b>	<b>176 (100)</b>	<b>55 (100)</b>	<b>9 (100)</b>	<b>240 (100)</b>

When comparing the stigma and discrimination experienced by key populations, more MSM reported they had been excluded from social gatherings or activities (37.4%), religious (22.4%), or family activities (30.6%) than those respondents from other groups. This was also the case in relation to being gossiped about (65.3%), receiving

# Stigma Index

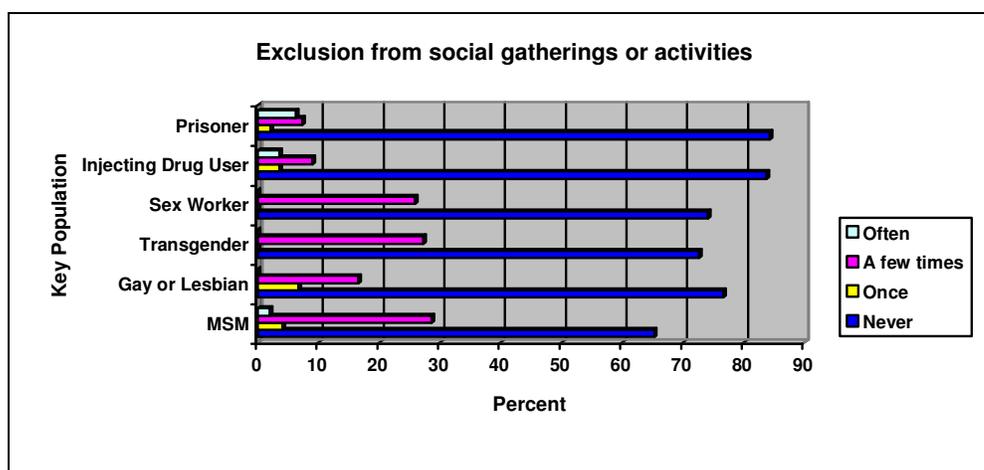


verbal (46.9%) and physical harassment (30.6%). This is illustrated in the Figures 1 to 6 below. Most (40.0% - 64.7%) said that they had been excluded from various activities or being harassed because of their HIV status and other reasons, especially their sexual orientation.

Amongst IDUs and prisoners fewer reported they were excluded from social gatherings or activities (16.2% and 15.7% respectively), religious activities (6.4% and 9.3% respectively), family gatherings (10.9% and 10.4% respectively), verbal harassment (22.1% and 22.7%) and physical harassment (11.8% and 12.7%). About half of the IDUs (47.3%) and prisoners (49.5%) also reported they had been gossiped about by the community members. Fewer IDUs or prisoners reported they were excluded from the social or religious activities. It was also reported by most of the IDUs that were accepted by their family members especially their wives or female partners; this might due to the subordinate status of women in Asian culture.

Among the sex workers, transgender, gays or lesbians, about 10% to 30% of them reported ever being stigmatized, discriminated or excluded from various activities. The most common issue experienced by 50% to 60% of these key populations was being gossiped about. At the same time 11% to 18% of the key population, especially IDUs and prisoners mentioned that they had been physically assaulted, and most of them were assaulted by an unknown person or a person outside their households.

**Figure 1: Key populations and exclusion from social gatherings or activities**



# Malaysia



Figure 2: Key populations and exclusion from religious activities

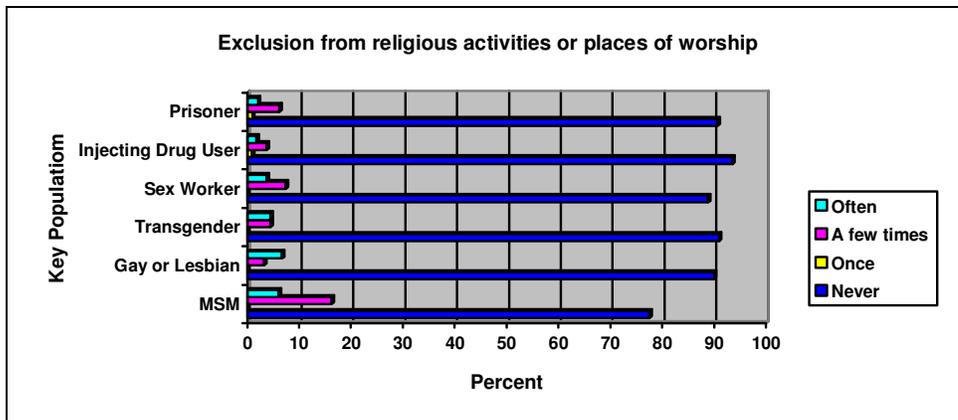


Figure 3: Key populations and exclusion from family activities

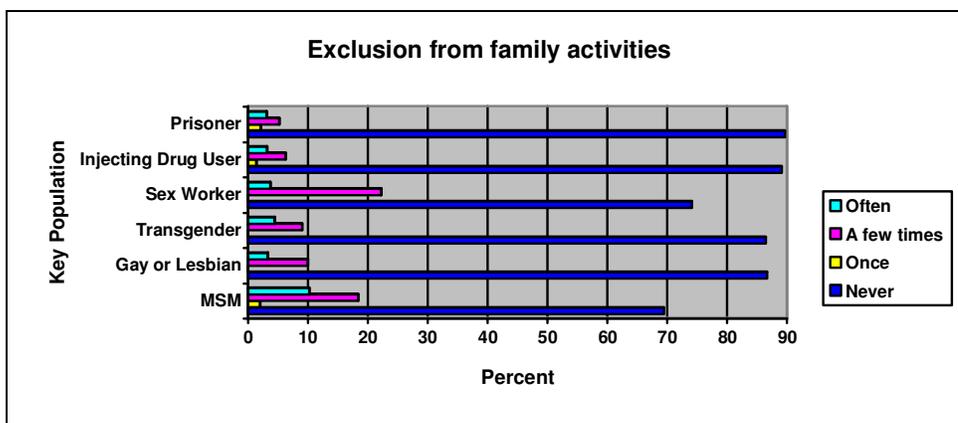
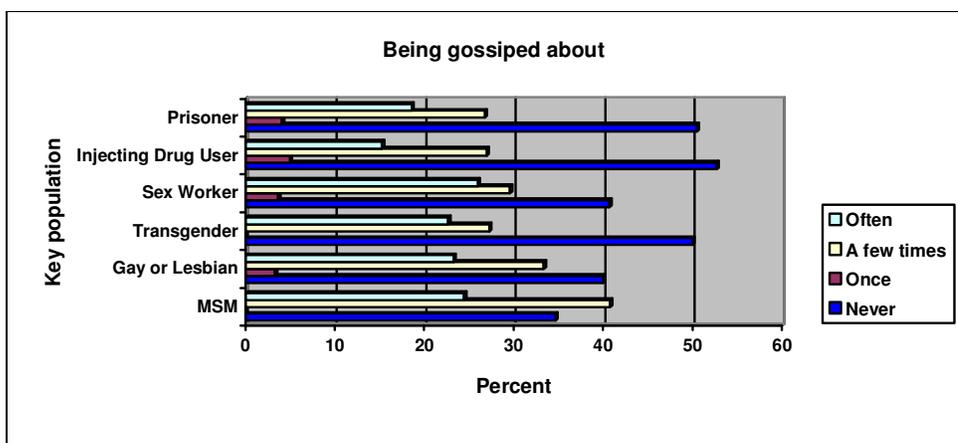


Figure 4: Key populations and being gossiped about



# Stigma Index



Figure 5: Key populations and verbal harassment

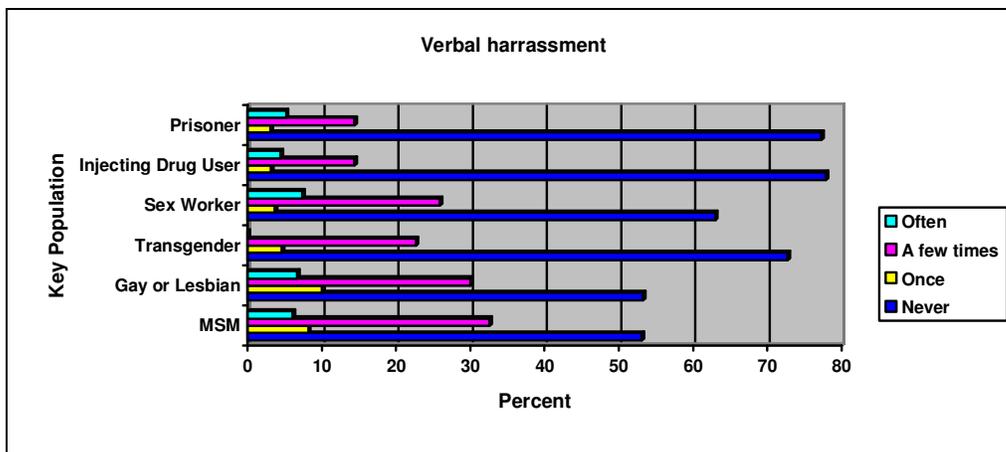


Figure 6: Key populations and physical harassment

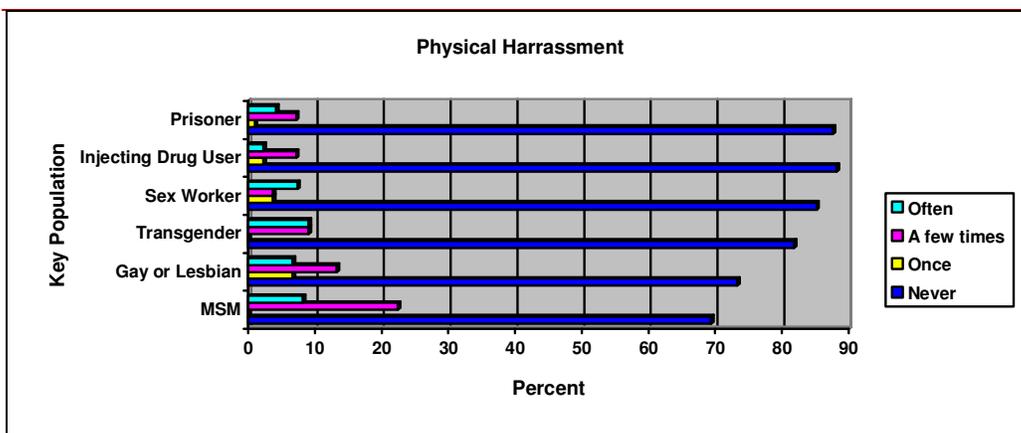
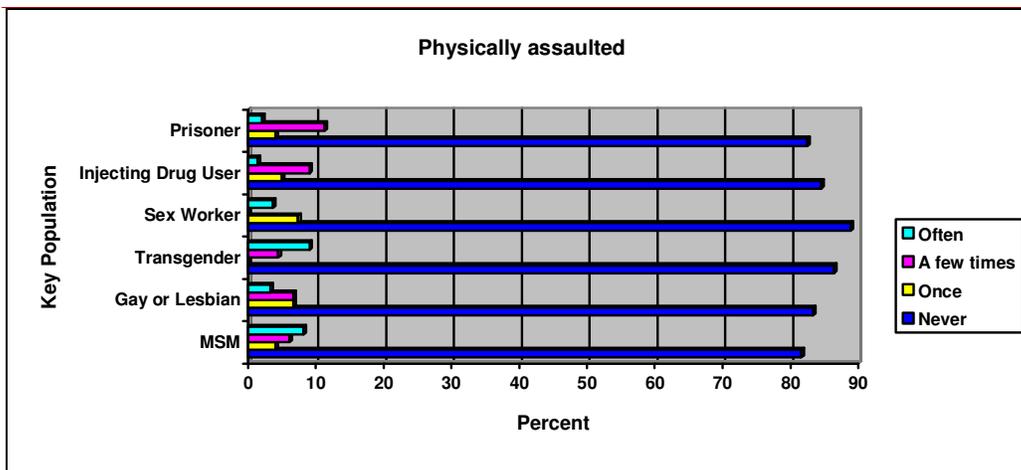


Figure 7: Key populations and physically assault



# Malaysia

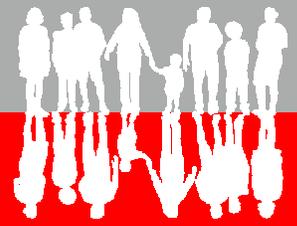


As shown in Table 12, nearly 1 in 5 respondents had experienced psychological pressure or manipulation by their husband/wife or partner, sexual rejection, or being discriminated against by other PLHIV. It should be noted that some of them still experienced the problems, especially women living with HIV. More female respondents reported that they had been subjected to psychological pressures from their husbands or partners (21.9%) and their household members (19%) compared to male and transgender respondents.

**Table 12: Impact/result of HIV status**

Impact/result of HIV status	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Psychological pressure or manipulation by husband/wife or partner (N = 394)</b>				
Never	225 (82.7)	82 (78.1)	15 (88.2)	322 (81.7)
Once	5 (1.8)	9 (8.6)	0	14 (3.6)
A few times	29 (10.7)	12 (11.4)	2 (11.8)	43 (10.9)
Often	13 (4.8)	2 (1.9)	0	15 (3.8)
<b>Total</b>	<b>272 (100)</b>	<b>105 (100)</b>	<b>17 (100)</b>	<b>394 (100)</b>
<b>Sexual Rejection (N = 392)</b>				
Never	241 (87.0)	88 (90.7)	17 (94.4)	346 (88.3)
Once	6 (2.2)	2 (2.1)	0	8 (2.0)
A few times	18 (6.5)	6 (6.2)	1 (5.6)	25 (6.4)
Often	12 (4.3)	1 (1.0)	0	13 (3.3)
<b>Total</b>	<b>277 (100)</b>	<b>97 (100)</b>	<b>18 (100)</b>	<b>392 (100)</b>
<b>Being discriminated against by other PLHIV (N = 416)</b>				
Never	250 (85.9)	92 (86.0)	17 (94.4)	359 (86.3)
Once	11 (3.8)	4 (3.7)	0	15 (3.6)
A few times	24 (8.2)	8 (7.5)	1 (5.6)	33 (7.9)
Often	6 (2.1)	3 (2.8)	0	9 (2.2)
<b>Total</b>	<b>291 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>416 (100)</b>
<b>Wife/husband/partner or other household members being discriminated against because of respondents HIV+ status (N = 410)</b>				
Never	243 (84.7)	85 (80.9)	17 (94.4)	345 (84.1)
Once	3 (1.0)	3 (2.9)	0	6 (1.5)
A few times	28 (9.8)	11 (10.5)	0	39 (9.5)
Often	13 (4.5)	6 (5.7)	1 (5.6)	20 (4.9)
<b>Total</b>	<b>287 (100)</b>	<b>105 (100)</b>	<b>18 (100)</b>	<b>410 (100)</b>

# Stigma Index



## 2.2 Access to accommodation, work, and health and education services

In this section, access to accommodation, work, health and education services were measured by seven indicators. They include:

- lost of accommodation
- lost jobs or income
- refused employment or a work opportunity
- changed of job descriptions or the nature of work
- respondents themselves or their children being dismissed
- suspended or prevented from attending an educational institution and
- being denied health services, family planning, sexual and reproductive health services.

Generally, nearly 1 in 5 respondents reported that they had experienced problem in accessing accommodation, work, education and healthcare services. As shown in Table 13, 12% of the respondents reported that they had been forced to change their place of residence or had been unable to rent accommodation in the 12 months preceding the survey. Slightly more transgender respondents (16.7%) reported the problem in accessing accommodation than male (12.8%) female (8.4%) respondents. When those respondents who had ever lost accommodation were asked about the reason, 52.1% of them said it were mainly due to other reasons and one third of them (33.3%) claimed that it was both because of their HIV status and other reasons. The study also found that most respondents who were ever forced to change their place of residence were those aged 18 to 19 years old (20.0%), MSM (20.4%), stayed in urban areas (14.0%), with primary school education (22.0%) and came from the middle income group (16.2%).

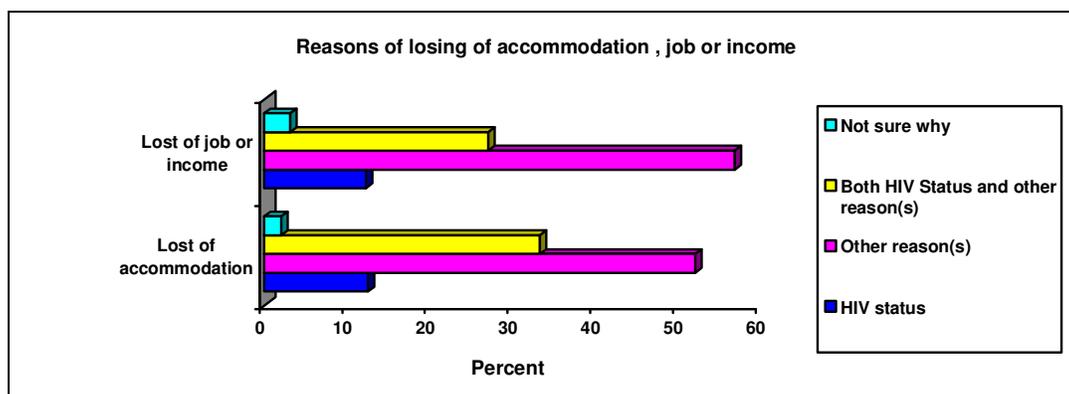
A total of 15.6% of the respondents reported that they had lost their jobs or source of income in the 12 months preceding the study. As shown in Figure 8, more than half (56.9%) stated it was for reasons 'other' than HIV and almost one third (27.1%) reported "HIV status and others" as the reasons. For those respondents who stated HIV status as the reason of losing their jobs, most of them (42.3%) said that it was because of discrimination by their employer or co-workers, followed by one third of them (34.6%) who reported that was due to a combination of discrimination and poor health.



**Table 13: Access to accommodation and work**

Accommodation and work	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Lost of accommodation (N = 419)</b>				
Never	258 (87.7)	98 (91.6)	15 (83.3)	371 (88.6)
Once	14 (4.8)	3 (2.8)	2 (11.2)	19 (4.5)
A few times	15 (5.1)	5 (4.7)	1 (5.5)	21 (5.0)
Often	7 (2.4)	1 (0.9)	0	8 (1.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Lost of jobs (N = 419)</b>				
Never	242 (82.3)	97 (90.7)	15 (83.3)	354 (84.5)
Once	15 (5.1)	4 (3.7)	0	19 (4.5)
A few times	29 (9.9)	6 (5.6)	2 (11.1)	37 (8.8)
Often	8 (2.7)	0	1 (5.5)	9 (2.2)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Refused employment or a work opportunity (N = 419)</b>				
Yes	43 (14.6)	8 (7.5)	1 (5.6)	52 (12.4)
No	251 (85.4)	99 (92.5)	17 (94.4)	367 (87.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Job description/nature of work changed or being refused promotion (N = 419)</b>				
Never	275 (93.6)	104 (97.2)	16 (88.8)	395 (94.3)
Once	10 (3.4)	3 (2.8)	1 (5.6)	14 (3.3)
A few times	6 (2.0)	0	0	6 (1.4)
Often	3 (1.0)	0	1 (5.6)	4 (1.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

**Figure 8: Reasons for lose of accommodation, job or income**



# Stigma Index



The study also found that 12.4% of the respondents had been refused employment or a work opportunity in the previous twelve months. Most of the respondents who reported that they had experienced this problem were male (14.6%), aged 30 to 39 years old (16.1%), MSM (34.7%), from urban areas (15.1%), with tertiary education (28.9%) and from the middle income group (18.2%).

With regards to changes of job description or being refused promotion, nearly 6% of the respondents reported they had experienced this problem in the previous twelve months; more commonly reported by transgender (11.1%), those aged 30 to 39 years old (6.5%), MSM (24.5%), from urban areas (7.3%), had been to college or university (17.1%) and from the middle income group (9.1%). More than a third of the respondents (37.5%) who experienced change in job descriptions or were refused promotion felt that it was because of discrimination by their employers or co-workers. There was another one third (29.2%) who said that it was poor health that prevented them from doing what they were employed to do.

Table 14 shows the distribution of respondents by access to health and education services. Of the sample of 419 respondents, 308 (73.5%) reported that the question on whether they had been dismissed, suspended or prevented from attending education institutions was applicable to them and majority of them (96.1%) said that they had never experienced this problem. More male reported they had been dismissed, suspended or prevented from attending education institutions than female respondents.

Similarly, for 168 respondents who had children, 5.4% said that their children had ever been prevented from attending educational institution and all of them were male respondents.

With regards to the access of healthcare services including family planning and sexual and reproductive health services, 27 respondents (6.4%) reported that the statement was not applicable to them. Of the remaining number 6.9% had experienced some problems in accessing healthcare services.



**Table 14: Access to health and education services**

	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Being dismissed, suspended or prevented from attending an educational institution (N = 308)</b>				
Never	205 (95.3)	80 (97.6)	11 (100.0)	296 (96.1)
Once	5 (2.3)	2 (2.4)	0	7 (2.3)
A few times	3 (1.4)	0	0	3 (1.0)
Often	2 (1.0)	0	0	2 (0.6)
<b>Total</b>	<b>215 (100)</b>	<b>82 (100)</b>	<b>11 (100)</b>	<b>308 (100)</b>
<b>Children prevented from attending educational institution (N = 168)</b>				
Never	74 (89.2)	82 (100)	3 (100)	159 (94.6)
Once	2 (2.4)	0	0	2 (1.2)
A few times	5 (6.0)	0	0	5 (3.0)
Often	2 (2.4)	0	0	2 (1.2)
<b>Total</b>	<b>83 (100)</b>	<b>82 (100)</b>	<b>3 (100)</b>	<b>168 (100)</b>
<b>Denied health services, family planning, sexual and reproductive health services (N = 392)</b>				
Never	254 (92.0)	97 (96.0)	14 (93.3)	365 (93.1)
Once	9 (3.3)	3 (3.0)	0	12 (3.1)
A few times	10 (3.6)	1 (1.0)	1 (6.7)	12 (3.1)
Often	3 (1.1)	0	0	3 (0.7)
<b>Total</b>	<b>276 (100)</b>	<b>101 (100)</b>	<b>15 (100)</b>	<b>392 (100)</b>

## 2.3 Internalised stigma and fears

In addition to experiencing stigma and discrimination from external forces, some PLHIV also experience internalised stigma<sup>10</sup>. Due to internalised stigma, PLHIV may isolate themselves from the community or may not access essential health care services. Respondents were asked about thoughts of shame, guilt, self-blame, low self-esteem, feeling a need to be punished, suicidal feelings.

<sup>10</sup> It is a contention of this study, and the people living with HIV Stigma Index that internalised stigma is a direct result of the stigma and discrimination visited upon PLHIV individually (or in society) rather than any inherent pathology that can be attributed to people living with HIV.

# Stigma Index

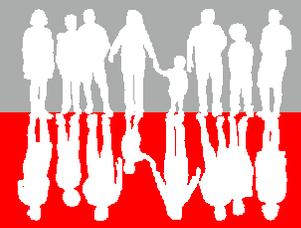


The study found that majority of the respondents (more than 60%) experienced internalised stigma (Table 15). A total of 64.9% of the respondents harboured feelings of shame (women (80.4%) compared to men (61.2%) and transgender (33.3%). Among the key populations, it was found that higher proportion of MSM (73.3%) and prisoners (73.2%) felt ashamed compared to other groups (Figure 9).

**Table 15: Internalised stigma**

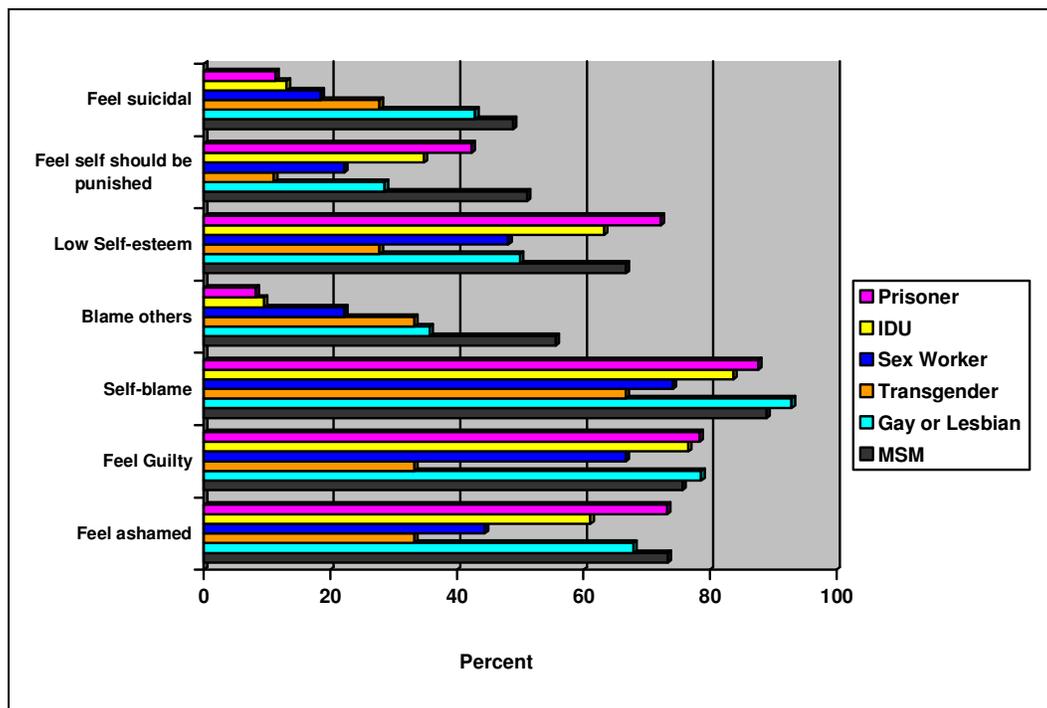
Types of Internal Stigma	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Feel ashamed (N = 419)</b>				
Yes	180 (61.2)	86 (80.4)	6 (33.3)	272 (64.9)
No	114 (38.8)	21 (19.6)	12 (66.7)	147 (35.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Feel guilty (N = 419)</b>				
Yes	215 (73.1)	51 (47.7)	6 (33.3)	272 (64.9)
No	79 (28.9)	56 (52.3)	12 (66.7)	147 (35.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Self-Blame (N = 419)</b>				
Yes	235 (79.9)	53 (49.5)	12 (66.7)	300 (71.6)
No	59 (20.1)	54 (50.5)	6 (33.3)	119 (28.4)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Blame others (N = 419)</b>				
Yes	50 (17.0)	60 (56.1)	6 (33.3)	116 (27.7)
No	244 (83.0)	47 (43.9)	12 (66.7)	303 (72.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Low self-esteem (N = 419)</b>				
Yes	182 (61.9)	73 (68.2)	5 (27.8)	260 (62.1)
No	112 (38.1)	34 (31.8)	13 (72.2)	159 (37.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Feel him/herself should be punished (N = 419)</b>				
Yes	99 (33.7)	27 (25.2)	2 (11.1)	128 (30.5)
No	195 (66.3)	80 (74.8)	16 (88.9)	291 (69.5)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Feel suicidal (N = 419)</b>				
Yes	55 (18.7)	24 (22.4)	5 (27.8)	84 (20.0)
No	239 (81.3)	83 (77.6)	13 (72.2)	335 (80.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

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In addition the majority of respondents (64.9%), especially the male respondents (73.1%) also felt guilty and (71.6%) reported that they blamed themselves because of their HIV status. The situation of self-blame was more common among the key populations, especially gay or lesbian (92.9%), MSM (88.9%), prisoners (87.6%) and IDUs (83.7%).

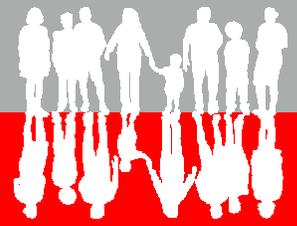
**Figure 9: Key populations and internalised stigma**



The study showed that most of the respondents blamed themselves because of their HIV status but not others. Only 27.7% said that they blamed others. However, it should be noted that more than half of the women (56.1%) and MSM (55.6%) said they blamed others (in this instance their partners) because of their HIV status.

In this study, two thirds (62.1%) of the respondents reported that they had low self-esteem, especially among male (61.9%) and female (68.2%) respondents. Generally, most of the transgender (72.2%) did not feel that their self-esteem was low. However, the other groups of key populations such as MSM (66.7%), gays or lesbians (50%), sex workers (48.1%), IDUs (63.3%) and prisoners (72.2%) also had low self-esteem.

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Although majority of the respondents felt ashamed, guilty, blamed themselves and had low self-esteem, most of them did not feel that they should be punished (69.5%) or feel suicidal (80%) because of their HIV status. Among the key populations, a higher proportion of MSM (51.1%) and prisoners (42.3%) said that they should be punished. In addition, almost half of the MSM (48.9%) and gays or lesbians (42.9%) also indicated that they had suicidal feelings.

In this study despite that fact that most of the respondents experienced internalised stigma, this has not become a barrier to their attendance at social gatherings, to working or studying nor do they isolate themselves.

As shown in Table 16, the majority of the respondents (67.5%) reported attending social gathering(s) as usual after they found out about their HIV status. In addition, two thirds of the respondents (70.6%) also reported that they had not isolated themselves from their families or friends because their HIV status.

Generally, a higher percentage of transgender (88.9%) reported isolating themselves than the male (70.1%) and female (69.2%) respondents. The findings of the study among the key populations showed similar results except with the MSM community. A higher proportion of the MSM reported that they choose not to attend social gathering(s) (60%) and isolated themselves (46.7%) due to their HIV status (Figure 10).

With regards to the questions on employment, work and promotion opportunity, only a small proportion of the respondents reported they decided to stop working (13.1%) or not apply for a job or promotion (11.0%). Similarly, majority of the respondents (88.1%) also reported that they had not withdrawn themselves from education or training due to their HIV status (Table 16).



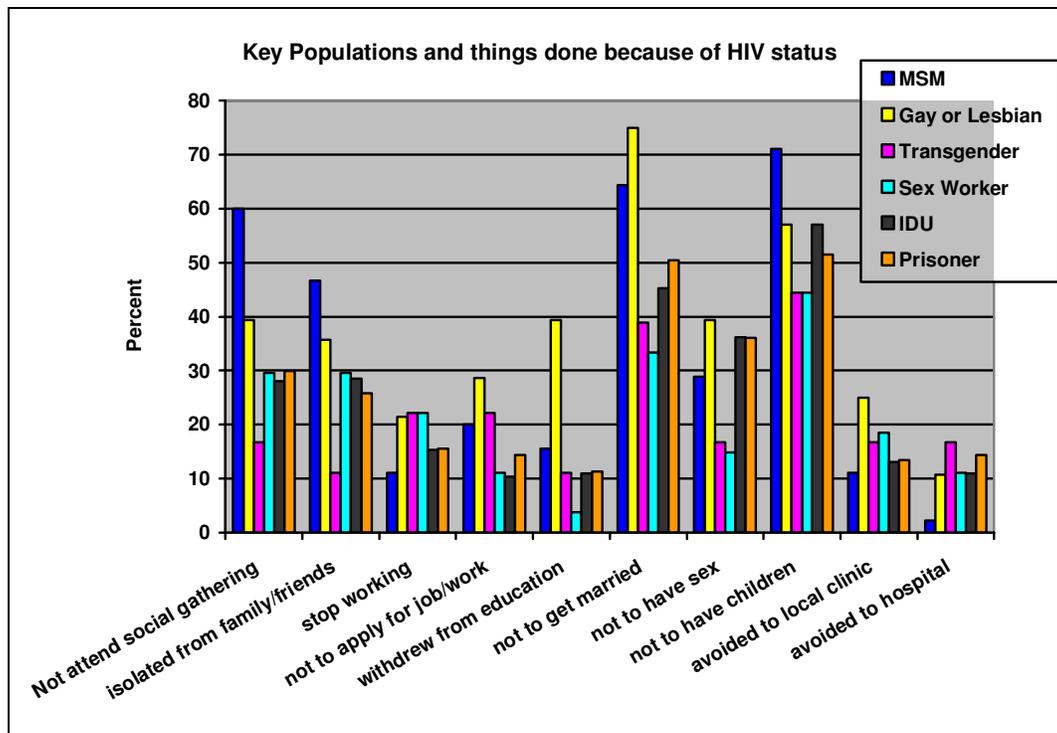
**Table 16: Things NOT done because of internalised stigma**

	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Not to attend social gathering(s) (N = 419)</b>				
Yes	96 (32.7)	37 (34.6)	3 (16.7)	136 (32.5)
No	198 (67.3)	70 (65.4)	15 (83.3)	283 (67.5)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Isolated him/herself from family and/or friends (N = 419)</b>				
Yes	88 (29.9)	33 (30.8)	2 (11.1)	123 (29.4)
No	206 (70.1)	74 (69.2)	16 (88.9)	296 (70.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Took the decision to stop working (N = 419)</b>				
Yes	39 (13.3)	12 (11.2)	4 (22.2)	55 (13.1)
No	255 (86.7)	95 (88.8)	14 (77.8)	364 (86.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Decided not to apply for a job/work or for a promotion (N = 419)</b>				
Yes	31 (10.5)	11 (10.3)	4 (22.2)	46 (11.0)
No	263 (89.5)	96 (89.7)	14 (77.8)	373 (89.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Withdrew from education/training - did not take education/training opportunity(N = 419)</b>				
Yes	33 (11.2)	15 (14.0)	2 (11.1)	50 (11.9)
No	261 (88.8)	92 (86.0)	16 (88.9)	369 (88.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Decided not to get married (N = 419)</b>				
Yes	141 (48.0)	34 (31.8)	7 (38.9)	182 (43.4)
No	153 (52.0)	73 (68.2)	11 (61.1)	237 (56.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Decided not to have sex (N = 419)</b>				
Yes	98 (33.3)	37 (34.6)	3 (16.7)	138 (32.9)
No	196 (66.7)	70 (65.4)	15 (83.3)	281 (67.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Decided not to have (more) children (N = 419)</b>				
Yes	173 (58.8)	67 (62.6)	8 (44.4)	248 (59.2)
No	121 (41.2)	40 (37.4)	10 (55.6)	171 (40.8)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Avoided going to a local clinic when needed to (N = 419)</b>				
Yes	35 (11.9)	21 (19.6)	3 (16.7)	59 (14.1)
No	259 (88.1)	86 (80.4)	15 (83.3)	360 (85.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Avoided going to hospital when needed to (N = 419)</b>				
Yes	25 (8.5)	13 (12.1)	0	38 (9.1)
No	269 (91.5)	94 (87.9)	18 (100.0)	381 (90.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

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Figure 10: Key populations -things NOT done due to stigma and discrimination



On the question of marriage and having children, about half of the respondents cited that they decided not to get married (43.4%) or have (more) children (59.2%). A higher proportion of men (48.0%) indicated their decision on not to get married compared to women (68.2%) and transgender (61.1%). Although more female respondents said that they wished to marry, most of them (62.6%) reported that they would not have any or anymore children because of their HIV status.

About one third (32.9%) of the respondents said that they decided not to have sex because of their HIV status. Slightly higher proportion of women (34.6%) indicated their decision of not having sex than men (33.3%) and transgender (16.7%). The similar trend of decision on marriage, having children and sex were showed among the key populations (Figure 10). Most of the key populations indicated that they decided not to get married (45% to 75%) or having children (51.1% to 71.1%) except the sex workers. Only a third (33.3%) of the sex workers cited that they decided not to get married and 44.4% of them said that they did not want to have children. However, the study found that sex was important to most of the key populations. Only 14.8% to 39.3% of the key populations indicated that they decided not to have sex because of



their HIV status. With regards to the access to healthcare services, majority of respondents reported that they would go to local clinics (85.9%) or hospitals (90.9%) whenever they needed to.

Table 17 shows what the respondents were fearful of. About half of the respondents indicated that they feared being gossiped about (49.9%) and sexual rejection (54.4%). However, most of them were less worried about being abused or harassed verbally (66.6%) or physically (82.6%).

**Table 17: Things that respondent fearful of because of HIV status**

Things fearful of	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Being gossiped about (N = 419)</b>				
Yes	141 (48.0)	57 (53.3)	11 (61.1)	209 (49.9)
No	153 (52.0)	50 (46.7)	7 (38.9)	210 (50.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Being verbally abused, harassed and/or threatened (N = 419)</b>				
Yes	91 (31.0)	43 (40.2)	6 (33.3)	140 (33.4)
No	203 (69.0)	64 (59.8)	12 (66.7)	279 (66.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Being physically harassed and/or threatened (N = 419)</b>				
Yes	38 (12.9)	31 (29.0)	4 (22.2)	73 (17.4)
No	256 (87.1)	76 (71.0)	14 (77.8)	346 (82.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Being physically assaulted (N = 419)</b>				
Yes	36 (12.2)	29 (27.1)	2 (11.1)	67 (16.0)
No	258 (87.8)	78 (72.9)	16 (88.9)	352 (84.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Fear of sexual rejection (N = 419)</b>				
Yes	170 (57.8)	47 (43.9)	11 (61.1)	228 (54.4)
No	124 (42.2)	60 (56.1)	7 (38.9)	191 (45.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

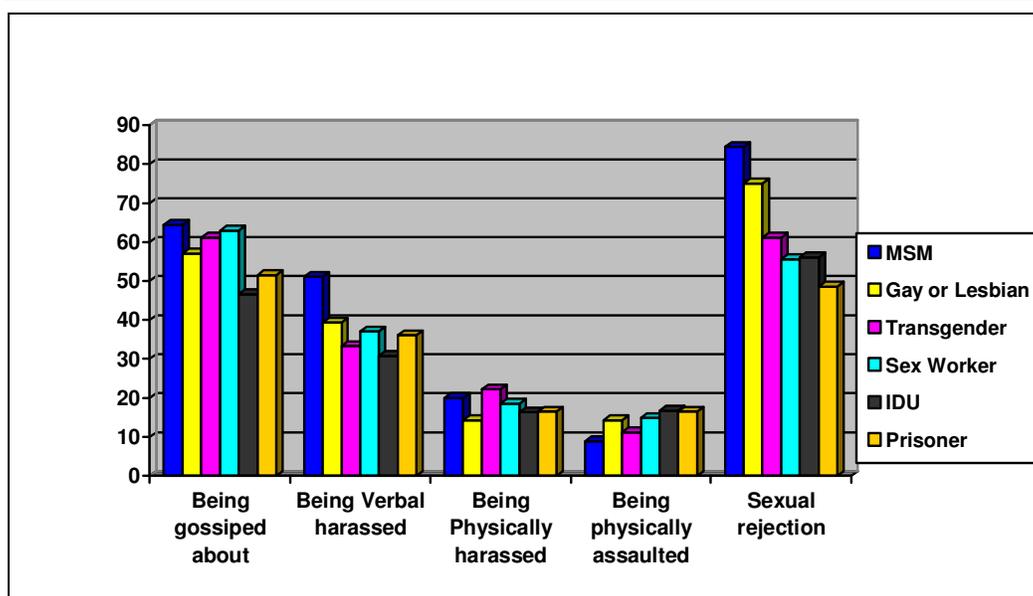
On the other hand, the key populations also indicated the similar things that they were fearful of (Figure 11). Majority of them said that they feared being gossiped about (46.6% to 64.4%) and sexual rejection (48.5% to 84.4%). It should be noted that a higher proportion of the key populations, especially MSM (84.4%), gay or lesbian (75%)

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and transgender (61.1%) said that they feared being rejected by their partners sexually because of their HIV status as compared to the rest (54.4%). With regards to the fear of verbal or physical harassment and physical assaulted, most of the key populations also claimed that they were less worried about that.

**Figure 11: Key populations and things fearful of**



## 2.4 Rights, laws and policies

This section explored respondents' awareness of the Declaration of Commitment on HIV and their knowledge of national laws and policies, as well as violation of rights experienced in various settings. In this study in Malaysia, the national policy on HIV is referred to as the "Five Year National Strategy Plan on HIV and AIDS".

Despite the Declaration of Commitment on HIV/AIDS being adopted by Member States of UN including Malaysia in 2001 to affirm human rights and fundamental freedom for all and respect for the rights of people living with HIV to reduce vulnerability to HIV/AIDS, only 13.9% of the respondents (n=58) had heard about it (Table 18). Out of these 58 respondents, about one third of them (36.2%) had ever read or discussed the contents of this Declaration. With regards the five years National Strategy Plan on HIV and AIDS, almost all respondents (91.1%) were not aware of it. However, for the 37 respondents

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(8.9%) who had ever heard of it, about half of them (54.1%) had discussed it with others.

**Table 18: Knowledge of HIV related laws and policies**

HIV related laws and policies	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Heard of Declaration of Commitment on HIV/AIDS (N= 418)</b>				
Yes	40 (13.6)	14 (13.2)	4 (22.2)	58 (13.9)
No	254 (86.4)	92 (86.8)	14 (77.8)	360 (86.1)
<b>Total</b>	<b>294 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>418 (100)</b>
<b>Discussed the content of the Declaration of Commitment on HIV/AIDS (N = 58)</b>				
Yes	13 (32.5)	6 (42.9)	2 (50.0)	21 (36.2)
No	27 (67.5)	8 (57.1)	2 (50.0)	37 (63.8)
<b>Total</b>	<b>40 (100)</b>	<b>14 (100)</b>	<b>4 (100)</b>	<b>58 (100)</b>
<b>Heard of national law/policy/guidelines on HIV/AIDS (N = 418)</b>				
Yes	28 (9.5)	7 (6.6)	2 (11.1)	37 (8.9)
No	266 (90.5)	99 (93.4)	16 (88.9)	381 (91.1)
<b>Total</b>	<b>294 (100)</b>	<b>106</b>	<b>18</b>	<b>418</b>
<b>Discussed the content of the national law/policy/guidelines on HIV/AIDS (N = 37)</b>				
Yes	17 (60.7)	3 (42.9)	0	20 (54.1)
No	11 (39.3)	4 (57.1)	2 (100)	17 (45.9)
<b>Total</b>	<b>28 (100)</b>	<b>7 (100)</b>	<b>2 (100)</b>	<b>37 (100)</b>

In order to assess the violation of rights among PLHIV, a number of indicators were used, such as whether they were forced to submit to medical procedures including HIV testing, denied insurance, being arrested, forced to disclose HIV status or being detained or quarantined.

About 1 in 5 of respondents (21%) reported they had experienced one or more of the violations asked about in this study (Table 19). A total of 13.1% of respondents said that they were forced to undergo medical procedures against their will including HIV testing denied health or life insurance (9.8%), being arrested or charged in court due to their HIV status (1.2%), forced to disclose HIV status in order to enter another country (2.1%) or apply for residence (2.1%) and being detained, quarantined, isolated or segregated (4.3%).

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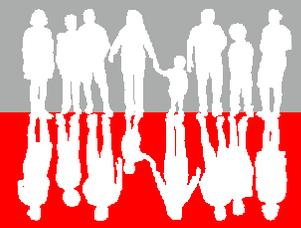


**Table 19: Violations experienced because of HIV status**

Violations experienced	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Forced to submit to a medical or health procedure (including HIV testing) (N = 419)</b>				
Yes	41 (13.9)	11 (10.3)	3 (16.7)	55 (13.1)
No	253 (86.1)	96 (89.7)	15 (83.3)	364 (86.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Denied health insurance or life insurance because of HIV status (N = 419)</b>				
Yes	30 (10.2)	10 (9.3)	1 (5.6)	41 (9.8)
No	264 (89.8)	97 (90.7)	17 (94.4)	378 (90.2)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Arrested or taken to court on a charge related to HIV status (N = 419)</b>				
Yes	4 (1.4)	0	1 (5.6)	5 (1.2)
No	290 (98.6)	107 (100)	17 (94.4)	414 (98.8)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Had to disclose my HIV status in order to enter another country (N = 419)</b>				
Yes	8 (2.7)	0	1 (5.6)	9 (2.1)
No	286 (97.3)	100	17 (94.4)	410 (97.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Had to disclose my HIV status to apply for residence or nationality (N = 419)</b>				
Yes	7 (2.4)	1 (0.9)	1 (5.6)	9 (2.1)
No	287 (97.6)	106 (99.1)	17 (94.4)	410 (97.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Violations experienced</b>				
<b>Detained, quarantined, isolated or segregated (N = 419)</b>				
Yes	14 (4.8)	4 (3.7)	0	18 (4.3)
No	280 (95.2)	103 (96.3)	18 (100)	401 (95.7)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>None of the above things happened to me (N = 419)</b>				
Yes	230 (78.2)	86 (80.4)	15 (83.3)	331 (79.0)
No	64 (21.8)	21 (19.6)	3 (16.7)	88 (21.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

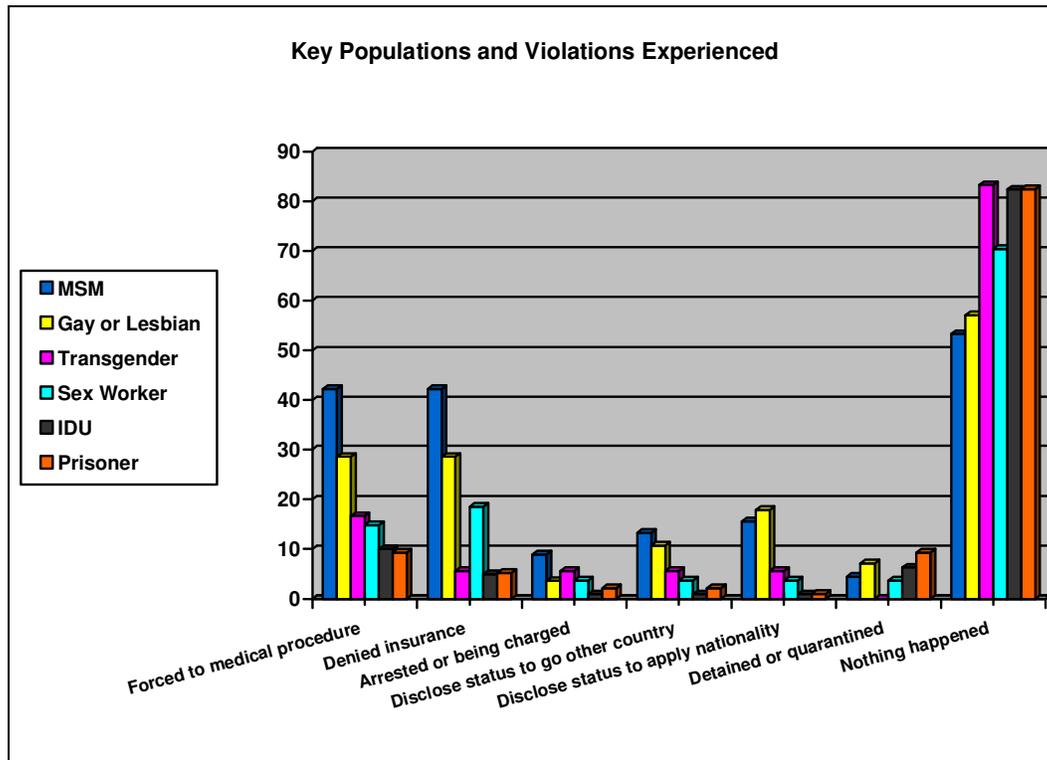
It should be noted that a higher proportions of the key populations, especially MSM and Gay or Lesbian stated that their rights had been violated (Figure 12). A total of 42.2% of MSM and 28.6% of gay or lesbian cited that they had been forced to submit to a health procedure and denied insurance. In addition, 13% to 15% of the MSM also

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reported that they were forced to disclose their status in order to enter another country or apply for residency.

**Figure 12: Key populations and violations experienced**



Respondents were also asked whether they felt their rights as PLHIV had been abused. A total of 8.1% of respondents said their rights were being violated, with a further 27% of those interviewed not being sure (Table 20). For those respondents who were unsure about whether their rights were being abused or violated, they were asked whether any action was taken to address the issue. Only a quarter of the respondents (26.5% or 39 respondents) reported that there was action taken. Out of these 39 respondents who took some action; 35.9% were trying to get legal redress, 33.3% tried to seek redress from a politician and another one third (30.8%) from government employee(s). Almost all (94.9%) reported that the process had begun in the 12 months previous to the study. However, most of them (87.2%) said that the matter was not dealt with or resolved.

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**Table 20: Action taken against an abuse of rights - all violations**

Rights being abused and action taken	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Rights as PLHIV being abused (N = 419)</b>				
Yes	24 (8.1)	9 (8.4)	1 (5.6)	34 (8.1)
Not sure	74 (25.2)	35 (32.7)	4 (22.2)	113 (27.0)
No	196 (66.7)	63 (58.9)	13 (72.2)	272 (64.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Action attempts to redress for any abuse of rights as PLHIV (N = 147)</b>				
Yes	32 (32.7)	4 (9.1)	3 (27.3)	39 (26.5)
No/Not sure	66 (67.3)	40 (90.9)	11 (72.7)	108 (73.5)
<b>Total</b>	<b>98 (100)</b>	<b>44 (100)</b>	<b>14 (100)</b>	<b>147 (100)</b>
<b>Attempts to get legal, government employee, or political redress for any abuse of rights as PLHIV (N = 39)</b>				
Through legal system	12 (37.4)	1 (25.0)	1 (33.3)	14 (35.9)
Through government employee	10 (31.3)	1 (25.0)	1 (33.3)	12 (30.8)
Through Politician	10 (31.3)	2 (50.0)	1 (33.4)	13 (33.3)
<b>Total</b>	<b>32 (100)</b>	<b>4 (100)</b>	<b>3 (100)</b>	<b>39 (100)</b>
<b>Process begun in the last 12 months (N = 39)</b>				
Yes				37 (94.9)
No				2 (5.1)
<b>Total</b>				<b>39 (100)</b>
<b>Outcome of the process (N = 39)</b>				
Dealt with	2 (6.3)	1 (25.0)	0	3 (7.7)
In process	2 (6.3)	0	0	2 (5.1)
Nothing happened	28 (87.4)	3 (75.0)	3 (100)	34 (87.2)
<b>Total</b>	<b>32 (100)</b>	<b>4 (100)</b>	<b>3 (100)</b>	<b>39 (100)</b>

For those respondents who said that they did not try to get legal redress for the abuse of their rights, most of them (50%) said that it was mainly because they had no confidence that the outcome would be successful and 20% of them said that they did not have sufficient financial resources to do it (Table 21).



**Table 21: Reason for not attempting legal redress**

	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Reason for not attempting legal redress (N = 20)</b>				
Insufficient financial resources to take action	3 (25.0)	1 (12.5)	0	4 (20.0)
addressing the problem appeared too bureaucratic	1 (8.3)	0	0	1 (5.0)
Felt intimidated or scared to take action	0	1 (12.5)	0	1 (5.0)
Advised against taking action by someone else	1 (8.3)	0	0	1 (5.0)
No/little confidence of a successful outcome	5 (41.7)	5 (62.5)	0	10 (50.0)
None of the above	2 (16.7)	1 (12.5)	0	3 (15.0)
<b>Total</b>	<b>12 (100)</b>	<b>8 (100)</b>	<b>0 (100)</b>	<b>0 (100)</b>

## 2.5 Effecting change

In this section on effecting change, respondents were asked about the actions taken for change or taken to resolve an issue of stigma or discrimination. About one fifth (19.1%) of the respondents said that they had confronted, challenged or educated someone who was stigmatizing or discriminating them (Table 22). The study also found that a higher proportion of transgender respondents (44.4%) tried to challenge those people who were stigmatizing them than male (20.4%) and female (11.2%) respondents.

With regards to the awareness of organizations or groups that PLHIV can go for help when they experienced stigma and discriminations, about half of the respondents (47.3%) said that they knew where to seek help. The types of organizations that the respondents knew of included:

- PLHIV support groups (68.7%),
- Local NGOs (58.6%) and
- The Malaysian AIDS Council (44.9%)
- Network of PLHIV (31.3%)
- Human rights organization (16.2%)
- National NGOs (14.1%) of them who knew some

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**Table 22: Effecting change**

Effecting change	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Confronted, challenged or educated someone who stigmatised/discriminated (N = 419)</b>				
Yes	60 (20.4)	12 (11.2)	8 (44.4)	80 (19.1)
No	234 (79.6)	95 (88.8)	10 (55.6)	339 (80.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Know of organizations or groups for help (N = 419)</b>				
Yes	133 (45.2)	51 (47.7)	14 (77.8)	198 (47.3)
No	161 (54.8)	56 (52.3)	4 (22.2)	221 (52.7)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Types of organizations or groups for help that respondent know of* (N = 198)</b>				
PLHIV support group	90 (67.7)	33 (64.7)	13 (92.6)	136 (68.7)
Network of PLHIV	43 (32.3)	8 (15.7)	11 (78.6)	62 (31.3)
Local NGO	78 (58.6)	26 (58.7)	9 (64.3)	116 (58.6)
Faith-based organization	17 (12.8)	4 (7.8)	1 (7.1)	22 (11.1)
A legal practice	10 (7.5)	2 (3.9)	2 (14.3)	14 (7.1)
A human rights organization	23 (17.3)	5 (9.8)	4 (28.6)	32 (16.2)
National NGO	21 (15.8)	5 (9.8)	2 (14.3)	28 (14.1)
National AIDS council or committee (The Malaysian AIDS Council)	61 (45.9)	16 (31.4)	12 (85.7)	89 (44.9)
International NGO	16 (12.0)	2 (3.9)	2 (14.3)	20 (10.1)
UN organization	15 (11.3)	1 (2.0)	1 (7.1)	17 (8.6)
Others	2 (1.5)	0	0	2 (1.0)
<b>Total</b>	<b>133 (100)</b>	<b>51 (100)</b>	<b>14 (100)</b>	<b>198 (100)</b>
<b>Sought help from any above organisations or groups (N = 419)</b>				
Yes	29 (9.9)	8 (7.5)	0	37 (8.8)
No	265 (90.1)	99 (95.5)	18 (100)	382 (91.2)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

*\* Respondents could choose more than one answer*

For the respondents (1%) who reported other groups actually referred to the support services that provided by some hospital nurses voluntarily on an individual basis.

# Malaysia



Despite the fact that most of the respondents were aware of these HIV-related organizations, majority of them (91.2%) had never sought help from any of these organizations to resolve the issue of stigma and discrimination. For those respondents who had ever sought help, most of them said that they experienced internalised stigma such as low self-esteem, felt guilty or ashamed, being harassed, mistreated or being gossip about, being isolated from family members or others (especially PLHIV who was prisoner), rejected for insurance application, work related stigma and discriminations or being mistreated in healthcare facilities (Table 23).

**Table 23: Issues of stigma and discrimination from qualitative responses**

<b>Issue of Stigma and Discrimination</b>
<b>At Family/Community Level</b> <ul style="list-style-type: none"><li>• Being mistreated by other people</li><li>• Being harassed and gossiped</li><li>• Not to react to what other gossip</li><li>• My family is afraid of staying with me.</li><li>• Not accepted by family</li><li>• My wife's family discriminate me even though she accepts me</li><li>• Isolation of crockery ( for fear that I could infect people)</li><li>• Can't get married although wanted to</li><li>• I have been laughed at for being single</li></ul>
<b>At Healthcare Facilities</b> <ul style="list-style-type: none"><li>• Nurse told her that she will be given death injection</li><li>• Treated badly in Hospital during appendicitis because HIV+</li><li>• HIV-Treatment/HAART (highly active anti retroviral therapy)</li></ul>
<b>At Work</b> <ul style="list-style-type: none"><li>• Work related stigma and discrimination</li></ul>
<b>At other Institution</b> <ul style="list-style-type: none"><li>• Isolating people in institution or prison</li><li>• New Life and Medical Insurance policy application</li></ul>
<b>Internalised Stigma</b> <ul style="list-style-type: none"><li>• Feeling guilty, ashamed and frustrated</li><li>• Feeling isolated and low self esteem</li></ul>

# Stigma Index



When respondents were asked about where they get help to resolve the issues of stigma and discrimination, majority of the respondents said that they sought help from local NGOs, support groups, family members, religion, and individuals (Table 24).

**Table 24: Action taken to address the issue of stigma and discrimination**

Where/who to get help	How to resolve the matter
<p><b>Local NGOs</b></p> <ul style="list-style-type: none"> <li>• DIC Pahang</li> <li>• MAYCARE Penang</li> <li>• PT Foundation</li> <li>• Pendamai</li> <li>• HIV/AIDS organisation</li> </ul> <p><b>Support Group</b></p> <ul style="list-style-type: none"> <li>• Hospital peer support social worker</li> <li>• Positive Living MSM Support Group</li> <li>• Peer Support DIC Pahang</li> </ul> <p><b>Family Members</b></p> <ul style="list-style-type: none"> <li>• Younger sister and elder brother</li> <li>• Partner</li> </ul> <p><b>Religion</b></p> <ul style="list-style-type: none"> <li>• Someone from my church</li> </ul> <p><b>Individual Support</b></p> <ul style="list-style-type: none"> <li>• Lots of moral support from staff nurse Connie</li> <li>• Matron Fu</li> <li>• Mrs Chong and Mrs Chee</li> <li>• Mr Daniel and Mrs Anne</li> <li>• The Supervisor of the rehab centre</li> </ul> <p><b>None or nobody</b></p>	<p><b>At Family/Community Level</b></p> <ul style="list-style-type: none"> <li>• Raise the matter to relevant party</li> <li>• I told them my views</li> <li>• Talk nicely to the person only</li> <li>• A specialist to explain to my wife's family</li> <li>• Giving information on HIV and modes of transmission</li> <li>• Giving speeches in <i>Kampung</i> (village)</li> <li>• Reported the discrimination</li> <li>• Referred to Legal Aid</li> <li>• They explain to my family</li> <li>• Go to Komuniti Intan (Local NGO)</li> <li>• Place to stay in DIC Pahang</li> <li>• Legal Advice</li> <li>• Learning and understanding about insurance</li> <li>• Support from Tzu Chi (NGO)</li> </ul> <p><b>Internalised Stigma</b></p> <ul style="list-style-type: none"> <li>• Accept reality</li> <li>• Advice, counselling and sharing experience</li> <li>• Counselling and giving hope</li> <li>• Getting full information on HIV/AIDS</li> <li>• Get advice on what needs to be done</li> <li>• Gives ideas and strength</li> <li>• Just let it go</li> </ul> <p><b>Nothing has been done/Run away from problem</b></p>

# Malaysia



Most of the help received to address these issues were information and counselling and most PLHIV learned to accept their status and live positively. For those respondents who had ever experienced stigma and discrimination from other people or agencies, most of them learned to educate the person who stigmatized or discriminate them by giving information on HIV and AIDS, sought support from healthcare professionals to explain HIV to their family members, and obtained the support from local NGOs and legal system. However, it should be noted that some of the respondents said that they did not receive support from anybody or any organization or were not taking any action despite the fact that they were being stigmatized or discriminated against.

When respondents were asked about whether they had been supported other PLHIV in the 12 months preceding the study, it was found that more than half of respondents (53.7%) had provided support to their peers, especially those who identified as transgender (77.8%) and men (57.5%); this is shown in Table 25. Less female respondents (39.3%) indicated their support for other people with HIV. In terms of the types of support provided, almost all respondents said that they gave emotional support such as counselling, sharing personal stories and experiences. About one third of participants (31.6%) said that they also provided physical support for other people with HIV including money or food or running errands for them. In addition, 18.2% said they referred other people with HIV for related services.

**Table 25: PLHIV peer support to other PLHIV**

PLHIV Support Group	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Supported other PLHIV (N = 419)</b>				
Yes	169 (57.5)	42 (39.3)	14 (77.8)	225 (53.7)
No	125 (42.5)	65 (60.7)	4 (22.2)	194 (46.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Types of support provided* (N = 225)</b>				
Emotional support	165 (97.6)	39 (92.9)	14 (100)	218 (96.9)
Physical support	51 (31.2)	14 (33.3)	6 (42.9)	71 (31.6)
Referral	34 (20.1)	6 (14.3)	1 (7.1)	41 (18.2)
<b>Total</b>	<b>169 (100)</b>	<b>42 (100)</b>	<b>14 (100)</b>	<b>225 (100)</b>

*\* Respondents could choose more than one answer*

# Stigma Index



Table 26 showed that most of the respondents (68.3%) were not members of PLHIV support groups. On the other hand, only a quarter of the respondents (24.3%) said that they were involved in programmes or projects that provided assistance to PLHIV. In addition, 6.9% were involved in efforts to develop legislation, policies or guidelines related to HIV. Majority of the respondents (76.4%) said that they did not have any power to influence decisions in the project or matters that relate to PLHIV, including legal including rights in local or national government policies that affect PLHIV, local or national projects that benefit PLHIV nor in the international agreements or treaties.

**Table 26: Involvement in PLHIV programmes or activities**

Involvement	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Member of a PLHIV support group and/or network (N = 419)</b>				
Yes	104 (35.4)	24 (22.4)	5 (27.8)	133 (31.7)
No	190 (64.6)	83 (77.6)	13 (72.2)	286 (68.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Involvement in programme/project that provides assistance to PLHIV (N = 419)</b>				
Yes	80 (27.2)	14 (13.1)	8 (44.4)	102 (24.3)
No	214 (72.8)	93 (86.9)	10 (55.6)	317 (75.7)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Involvement in developing legislation/policies/guidelines related to HIV (N = 419)</b>				
Yes	23 (7.8)	4 (3.7)	2 (11.1)	29 (6.9)
No	271 (92.2)	103 (96.3)	16 (88.9)	390 (93.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Have power to influence decisions in the following aspects* (N = 419)</b>				
Legal/rights matters	50 (17.0)	8 (7.5)	4 (22.2)	62 (14.8)
Local government policies	33 (11.2)	2 (1.9)	1 (5.6)	36 (8.6)
Local projects	42 (14.3)	7 (6.5)	5 (27.8)	54 (12.9)
National government policies	28 (9.5)	2 (1.9)	2 (11.1)	32 (7.6)
National projects	49 (16.7)	5 (4.7)	3 (16.7)	57 (13.6)
International agreements/treaties	25 (8.5)	3 (2.8)	1 (5.6)	29 (6.9)
None of these things	216 (73.5)	93 (86.9)	11 (61.1)	320 (76.4)
<b>Total</b>	<b>294</b>	<b>107</b>	<b>18</b>	<b>419</b>

\* Respondents may choose more than one answer

# Malaysia



When respondents were asked about their recommendations to organisations for PLHIV, a total of 26.3% of them felt that the most important thing was for these organisations to address stigma and discriminations and to raise the awareness and knowledge of the public about AIDS (Table 27). Another quarter (25.8%) said that these organizations should provide various types of support to PLHIV, including emotional, physical and referral support. Other respondents (18.2%) suggested that the organizations should educate them on how they could live with the virus and some (17.7%) felt that there was a need for more advocacy work for the rights of all PLHIV and marginalised communities (12.0%).

**Table 27: Recommendations to PLHIV organisations from respondents**

Recommendation	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Recommendation to PLHIV organisations (N = 407)</b>				
Advocating for the rights of all PLHIV	57 (19.9)	10 (9.7)	5 (27.8)	72 (17.7)
Providing support to PLHIV by providing emotional, physical and referral support	66 (23.0)	34 (33.0)	5 (27.8)	105 (25.8)
Advocating for the rights and/or providing support to particularly marginalized groups	41 (14.3)	3 (2.9)	5 (27.8)	49 (12.0)
Educating PLHIV about living with HIV	53 (18.5)	21 (20.4)	0	74 (18.2)
Raising the awareness and knowledge of the public about AIDS	69 (24.1)	35 (34.0)	3 (16.6)	107 (26.3)
<b>Total</b>	<b>286 (100)</b>	<b>103 (100)</b>	<b>18 (100)</b>	<b>407 (100)</b>



## Section 3: Experience of testing, disclosure, treatment and having children

This section includes the responses to questions on testing and diagnosis, disclosure and confidentiality, treatment and having children. Respondents were also asked to supplement the quantitative responses that they had made with their views in general with regards to the challenges and problems faced in these four areas. These open-ended questions did come at the end of the interview and for reasons already discussed in the limitations section the response rate to these questions was not as high as was hoped.

### 3.1 Testing and diagnosis

HIV testing and diagnosis in Malaysia takes place predominantly through government and private health facilities, where free services are provided in government clinics with some level of counselling available. On the other hand, free Voluntary Counselling and Testing are also available through selected non-government organisations (NGOs) such as PT Foundation (PTF). It should be noted that HIV screening is also routinely done for blood donors, pregnant women, IDUs, residents in drug rehabilitation centres, prisoners serving custodial sentences, individuals diagnosed with tuberculosis or a sexually transmissible infection (STI), individuals named as a contact of somebody with confirmed HIV infection, and patients with a clinical presentation suggestive of an HIV-related diagnosis. However, the quality of the services has never been evaluated and the availability of pre- and post-counselling is uncertain. Similarly, HIV testing is required for all Muslim couples before marriage and the counselling services may not accompany testing but it basically depends on the places where the couples go for testing.

As shown in Table 28, the study found that most (29.8%) of the respondents cited that the reasons they went for HIV testing was because they wanted to know about their status or they were being referred for testing due to suspected HIV-related symptoms (24.1%). It should be noted that a total of 17.2% of the respondents said they had their HIV testing because of other reasons and most of them (63 out of 71 respondents) cited that was a mandatory testing in prison or rehabilitation centres.



**Table 28: Reasons for testing**

Testing	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Reason for HIV testing* (N = 419)</b>				
Employment	28 (9.5)	2 (1.9)	0	30 (7.2)
Pregnancy	5 (1.7)	22 (20.6)	0	27 (6.4)
To prepare for a marriage/ sexual relationship	26 (8.8)	7 (6.5)	1 (5.6)	34 (8.1)
Referred by a clinic for STI	20 (6.8)	3 (2.8)	6 (33.3)	29 (6.9)
Referred due to suspected HIV-related symptoms	77 (26.2)	19 (17.8)	5 (27.8)	101 (24.1)
Husband/wife/partner/family member tested positive	17 (5.8)	29 (27.1)	1 (5.6)	47 (11.2)
Illness or the death of husband/wife/partner/family member	7 (2.4)	20 (18.7)	0	27 (6.4)
Just wanted to know	100 (34)	15 (14)	10 (55.6)	125 (29.8)
Other	64 (21.8)	8 (7.5)	0	71 (17.2)
<b>Total</b>	<b>294</b>	<b>107</b>	<b>18</b>	<b>419</b>
<b>Own decision to be tested for HIV (N = 415)</b>				
Own decision	165 (56.9)	66 (61.7)	14 (77.8)	245 (59.0)
Own decision but it was under pressure from others	28 (9.7)	17 (15.9)	1 (5.6)	46 (11.1)
Was made to take an HIV test	56 (19.3)	9 (8.4)	0	65 (15.7)
Tested without knowledge	41 (14.1)	15 (14.0)	3 (16.6)	59 (14.2)
<b>Total</b>	<b>290 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>415 (100)</b>
<b>Received counselling when tested for HIV (N = 413)</b>				
Received both pre- and post- HIV test counselling	94 (32.7)	57 (53.3)	14 (77.7)	165 (40.0)
Only pre-test HIV counselling	4 (1.4)	1 (1.0)	1 (5.6)	6 (1.5)
Only post-test HIV counselling	132 (45.8)	36 (33.6)	2 (11.1)	170 (41.1)
Did not receive any counselling	58 (20.1)	13 (12.1)	1 (5.6)	72 (17.4)
<b>Total</b>	<b>288 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>413 (100)</b>

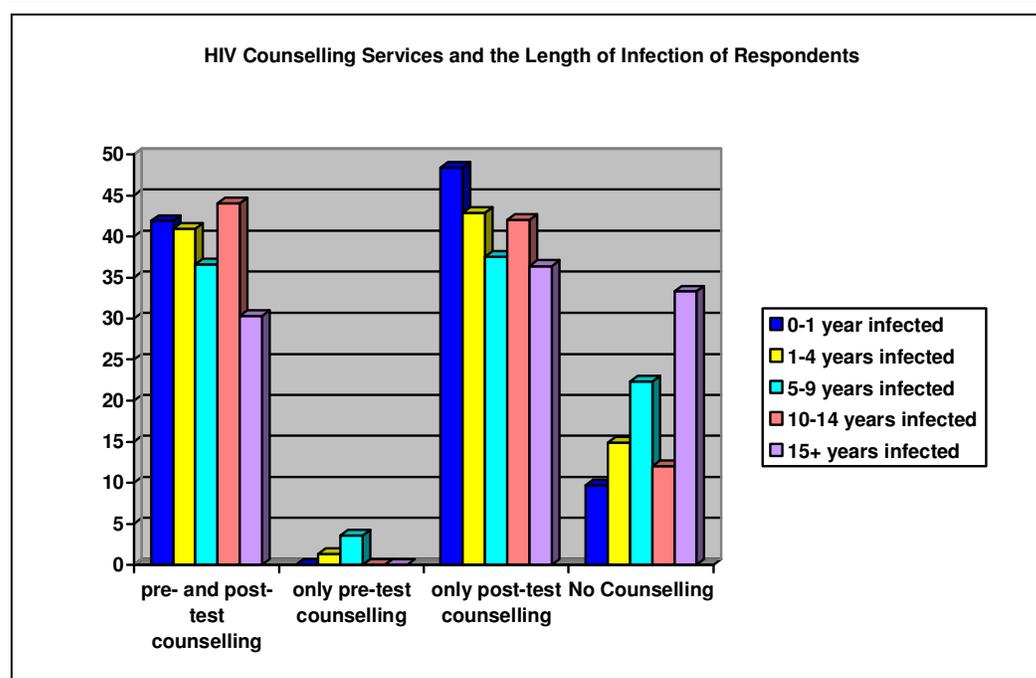
\* Respondents may choose more than one answers

# Stigma Index



Most of the respondents reported that they were tested because they just wanted to know their status; therefore, it was not surprising that more than half of them (59%) said that it was their own decision to be tested. It should be noted that two fifths of the respondents (41.2%) cited that they were tested without pre-test counselling but they received post-test counselling. On the other hand, 40% of the respondents received both pre- and post-HIV test counselling. When comparing the counselling services by the years of infection among respondents, it is evident that the quality of counselling services has not improved over the years (Figure 13). About half of the respondents (42.9% to 48.4%) who had only discovered their HIV status in the last five years still stated that they did not receive pre-test counselling. However it is also evident the numbers who received no counselling at all has declined significantly from more than one third of those who were diagnosed more than 15 years ago to only about 8% in the case of those diagnosed in the last years. Nonetheless almost one in ten are still not given any form of counselling before or after testing resulting in a lost opportunity to help people to make informed evidence based choices around their sexual and reproductive health rights.

**Figure 13: HIV counselling services and the length of infection of respondents**

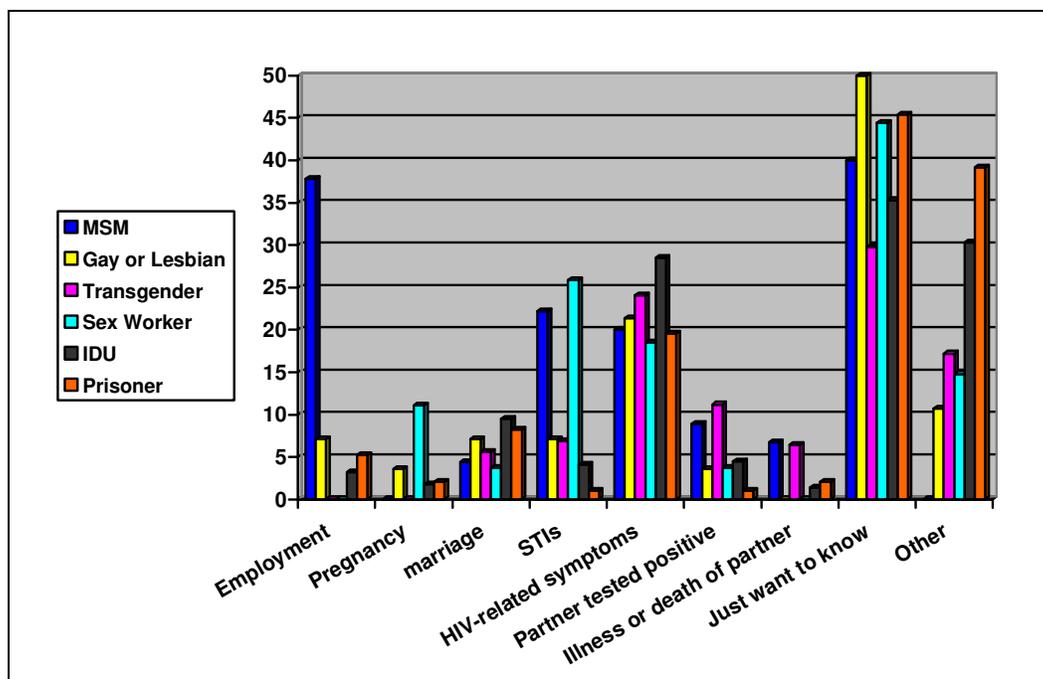


# Malaysia

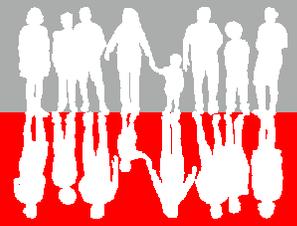


With regards to HIV testing among key populations, the majority also stated that it was because they just wanted to know (35.3% to 55.6%) (Figure 14). On the other hand, some said that they were referred for testing due to suspected HIV-related symptoms (18.5% to 38.9%). Some transgender (33.3%), MSM (22.2%) and sex workers (25.9%) reported that they found out about their status when they were referred to a clinic because of an STI. It should be noted that a total of 37.7% of MSM reputed being tested due to employment requirements. In general MSM are better educated and therefore the types of employment they sought would be in the formal sector where medical examinations are routine. The other key population groups do not experience this as much because the types of work they are involved in would generally be in the sectors where medical examinations were not necessary.

**Figure 14: Key populations and reason for HIV testing**



# Stigma Index



Respondents were asked about the problems they faced during testing and diagnosis. Below are excerpts from some of the interviews with the respondents:

*“I was forced to undergo the test” ~ Male, 40 - 49 years old, IDU*

*“The test was done badly at somewhere out of Kuala Lumpur, I don’t have any information and support” ~ Female, 40 - 49 years old*

*“I was scared.” Male, 30 - 39 years old, IDU*

*“I couldn’t accept the positive result after my husband’s death” ~ Female, 40 - 49 years old*

*“No counselling was given before nor after testing” ~ Male, 30 - 39 years old, IDU / prisoner*

*“Patient has insufficient knowledge on HIV.” ~ Male, 40 - 49 years old, IDU/ prisoner*

*“Scared to accept the fact of being HIV positive.” ~ Male, 30 - 39 years old*

*“Visiting to the hospital was too frequent.” ~ Male, 25 - 29 years old, MSM*

*“I have a problem of returning to the hospital for tests and diagnosis.” ~ Male, 20 - 24 years old, Gay or Lesbian*

*“Employers should not have the right to test me.” ~ Male, 25 - 29 years old, MSM*

*“Accessibility & availability of information.” ~ Male, 25 - 29 years old, MSM*

*“Most IDUs do not see testing & diagnosis as important.” ~ Male, 50+ years old, IDU*

## 3.2. Disclosure and confidentiality

Disclosing HIV status is not an easy process. The process of disclosing varies from one person to another, sometimes depending on psychosocial circumstances. Generally, the study found that most of the respondents only revealed their status to the people closest to them, such as spouses/partners (37.3%), family members (38.8%), other people with HIV (50.3%), injecting drug partners (39.5%), health care workers (37.4%) and social workers/counsellors (50.3%) (Figure 15).

# Malaysia

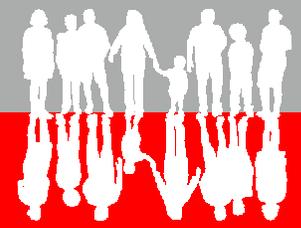
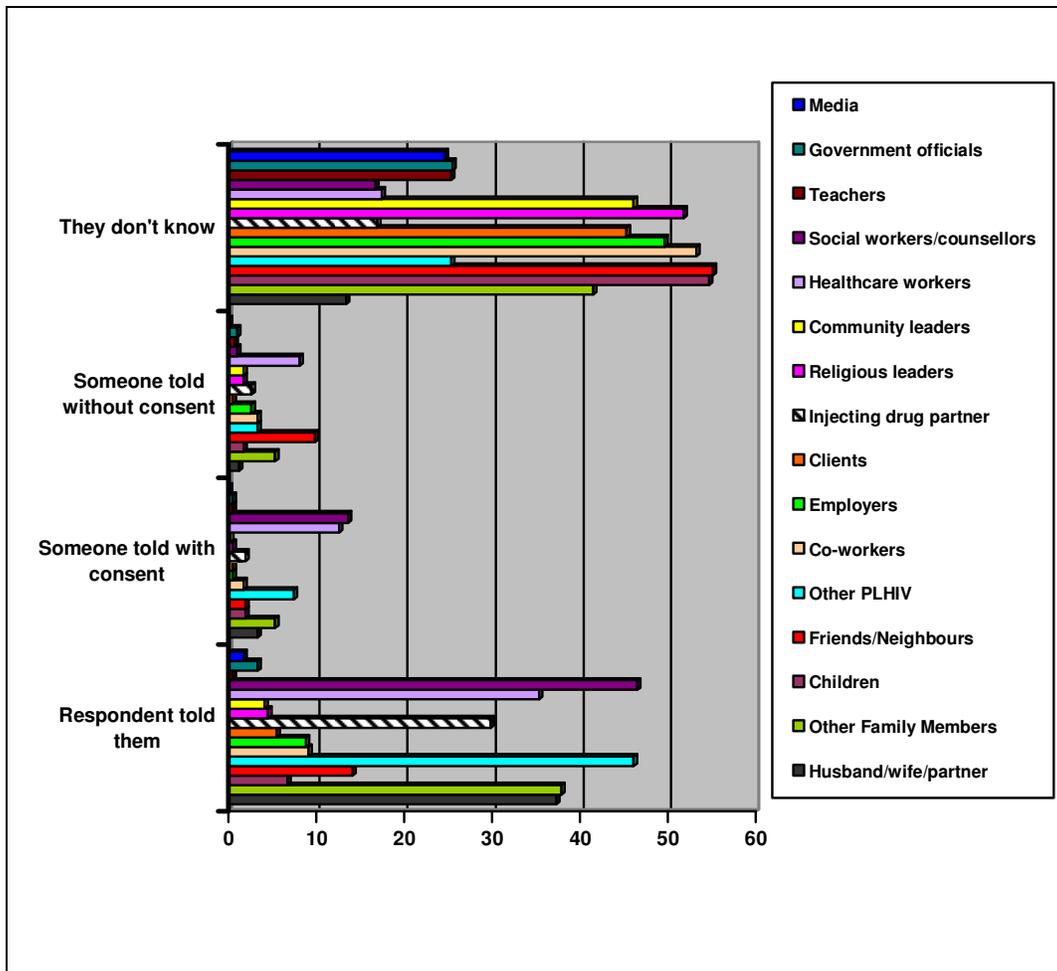


Figure 15: People that respondents disclosed their status to



On the other hand, (41.5%) chose to keep their status from other family members whom they were not close to, children (54.7%), friends/neighbours (55.1%), co-workers (53.2%), employers (49.6%), clients (45.3%), religious leaders (51.8%) and community leaders (46.1%). A number of respondents also stated that some other people help them to disclose their status to certain parties with their consents as they did not know how to describe or tell these people about their status. For example, more than 10% of the respondents reported that someone else help to disclose their status to the healthcare workers (12.6%) and social workers or counsellors (13.6%) with their consent. However, a number of respondents reported that someone else had disclosed their status without their consents to the other family members (5.3%), friends or neighbours (9.8%) and healthcare workers (8.1%).

# Stigma Index



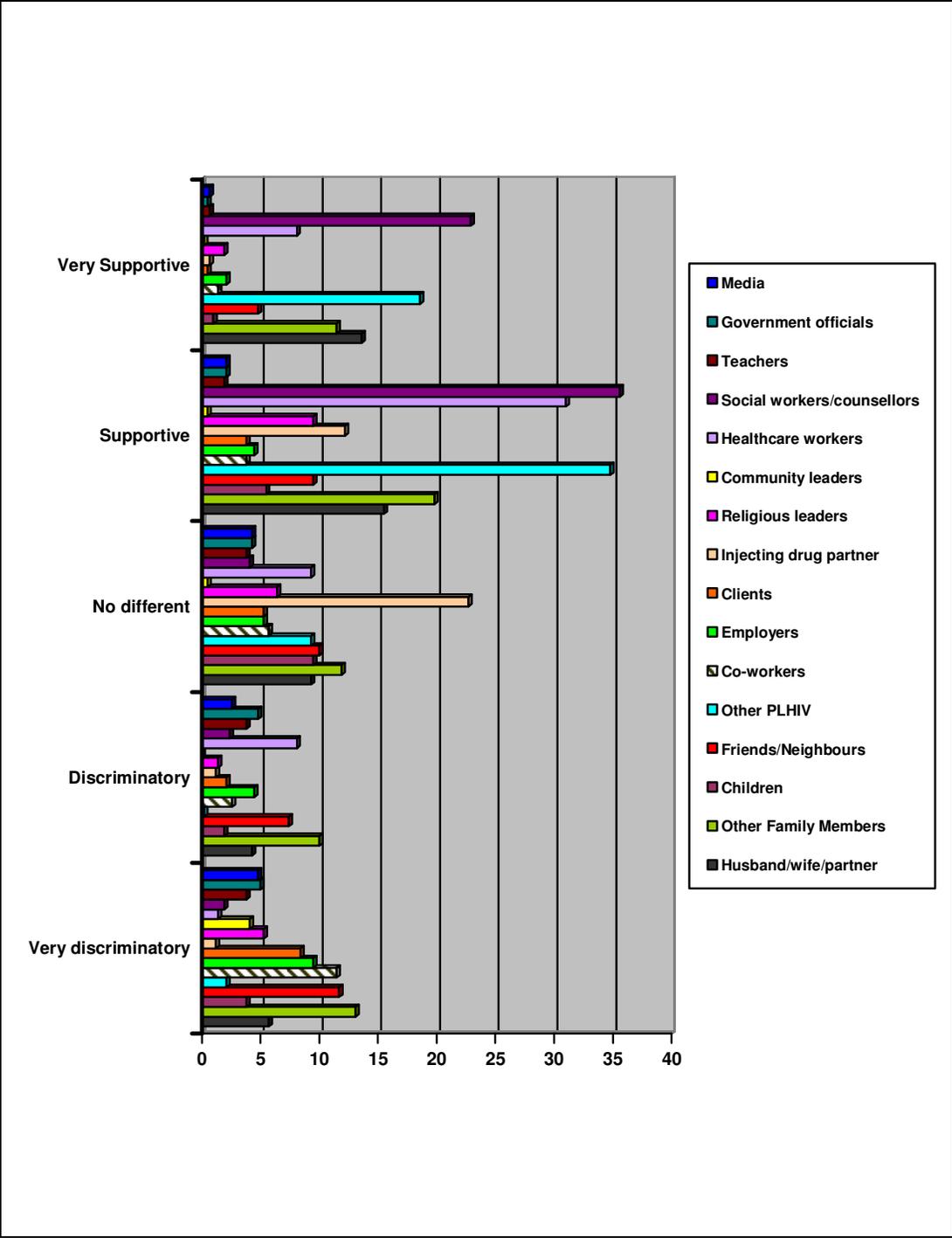
When respondents were asked about the reactions of these people when they first knew about their HIV status, majority of the respondents reported supportive or very supportive reactions from only 31.0% of healthcare workers and 35.6 % of counsellors. Disaggregated this support or very supportive reaction was found in 8.1% of the healthcare workers and 22.9% of the social workers. (Figure 16). More support was experienced from other PLHIV, 34.6% were supportive and 18.6% were very supportive). Their husbands/wives/partners (15.5% were supportive and 13.6% were very supportive) and other family members (19.8% were supportive and 33.7% were very supportive). For injecting drug users, a total of 22.7% of them said that their peers' attitudes were no different after they were told about respondents' HIV status, while 12.2% said that their peers were supportive.

On the other hand, respondents also disclosed that some of the people were discriminatory or very discriminatory after they found out respondents HIV status. For example, some of the family members (13.1% were very discriminatory and 10.0% were discriminatory), friends or neighbours (11.7% were very discriminatory and 7.4% were discriminatory), co-workers (11.5% were very discriminatory and 2.6% were discriminatory) and employers (9.5% were very discriminatory and 4.5% were discriminatory).

# Malaysia



Figure 16: The reactions of people that respondents disclosed their status to



# Stigma Index

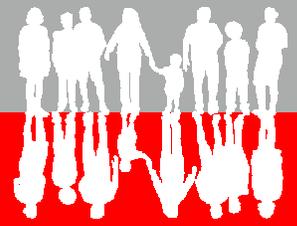


Table 29 explored whether respondents were under pressure or forced to disclose their HIV status and in this study most (81.1%) of the respondents had never disclosed their status due to the pressure from other PLHIV or other individuals (70.4%). With regards to the ethical issues among the healthcare providers, especially in terms of protection of client's information and maintain the confidentiality, a total of 41.2% of the respondents believed that the health professional had never disclosed their status without their consent, while the other half (48.2%) said that they were unsure about this. Similarly, when half of the respondents (52.7%) believed that their medical records would be kept completely confidential, but the other two fifths (42.2%) was either unsure or not confident that it would be kept confidential. As shown in Table 3b, slightly more than one third (37.0%) of the respondents reported that the disclosure of HIV status was an empowering experience for them. However, the other one third (31.7%) did not agree with the statement.

Respondents were also asked what problems they faced after disclosing status. Majority of the respondents did not answer this question. However, some of them expressed their fear of disclosure as stated as the quotes below:

*"I am afraid of others will know my status."* Female, 30 - 39 years old

*"It should be kept confidential to protect the patient."* Male 30 - 39 years old, IDU/  
Prisoner

*"My status was disclosed without consent."* Male, 40 - 49 years old, IDU

*"I am afraid others will find out my status."* Male, 30 - 39 years old, IDU

*"It is a challenge to talk to the doctor."* Male, 30 - 39 years old, IDU

*"I am afraid to expose my status and be isolated."* Male, 30 - 39 years old,  
IDU/Prisoner

*"I am afraid of being discriminated against."* Female, 30 - 39 years old

*"I have lost my job."* Male, 40 - 49 years old, MSM



**Table 29: Issues related to disclosure**

Disclosure	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Pressure from other PLHIV to disclose HIV status (N = 419)</b>				
Often	26 (8.8)	2 (1.9)	3 (16.7)	31 (7.4)
A few times	24 (8.2)	9 (8.4)	1 (5.6)	34 (8.1)
Once	10 (3.4)	4 (3.7)	0	14 (3.3)
Never	234 (79.6)	92 (86.0)	14 (77.7)	340 (81.2)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Pressure from other individuals not living with HIV to disclose HIV status (N = 419)</b>				
Often	36 (12.2)	7 (6.5)	1 (5.6)	44 (10.5)
A few times	41 (13.9)	19 (17.8)	4 (22.2)	64 (15.3)
Once	10 (3.4)	6 (5.6)	0	16 (3.8)
Never	207 (70.4)	75 (70.1)	13 (72.2)	295 (70.4)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Health professional disclosed status without consent (N = 417)</b>				
Yes	30 (10.2)	12 (11.3)	2 (11.1)	44 (10.6)
No	136 (46.4)	31 (29.3)	5 (27.8)	172 (41.2)
Not sure	127 (43.4)	63 (59.4)	11 (61.1)	201 (48.2)
<b>Total</b>	<b>293 (100)</b>	<b>106 (100)</b>	<b>18 (100)</b>	<b>417 (100)</b>
<b>Confidentiality of medical records (N = 419)</b>				
I am sure that my medical records will be kept completely confidential	153 (52.0)	54 (50.5)	14 (77.7)	221 (52.7)
I don't know if my medical records are confidential	124 (42.2)	50 (46.7)	3 (16.7)	177 (42.3)
It is clear that my medical records are not being kept confidential	17 (5.8)	3 (2.8)	1 (5.6)	21 (5.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Disclosure of HIV status as an empowering experience (N = 419)</b>				
Yes	106 (36.1)	36 (33.6)	13 (72.2)	155 (37.0)
No	95 (32.3)	37 (34.6)	1 (5.7)	133 (31.7)
Not applicable	93 (31.6)	34 (31.8)	4 (22.1)	131 (31.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

# Stigma Index



On the other hand, a number of respondents expressed their concerns with regards to the confidentiality of their medical records. Below are excerpts from some of the interviews with the respondents:

*“I am afraid my medical report will be exposed.”* Male, 40 - 49 years old, IDU/ prisoner

*“I feel that my medical record is unsafe”* Male, 50+ years old, IDU and prisoner

*“I only trust Sg Buloh ID Clinic doctors.”* Male, 20 - 24 years old, Gay

## 3.3 Treatment

In this study, the respondents had known their HIV status from a few months to more than 10 years. However, majority of the respondents still perceived their health as “excellent” (5.5%), “very good” (12.9%) or “good” (39.1%), especially the female and transgender respondents (Table 30). Two fifths of the respondents felt that their health status at the time of the study was fair (32.7%) or poor (9.8%). It should be noted that a higher proportion of the male respondents had a perception of ill-health.

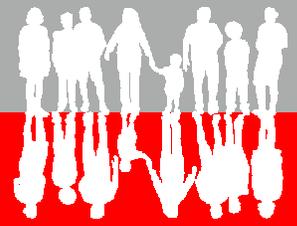
Almost two thirds of the respondents (59.4%) reported that they were on ARV therapy and most of them (65.6%) were confident that they had access to ARV. However, one third of the respondents either did not know about access to ARV (17.9%) or did not have access to ARV (16.5%). In fact, the first line ARV treatment is provided at no cost and the second line is partially subsidized by the Malaysian Government since 2006. In addition, the government had also revised the initiation threshold of ARV treatment from the CD4 level of 200 to 350 cells/mm<sup>3</sup> in 2010. However, if ARV drugs and routine tests were available at very low cost, it does not mean that PLHIV have access to the treatment as some of health expenditures were not for ARV drugs, and treatment alone. There are indeed other hidden cost such as transportation cost as well as opportunity cost (cannot go to work and therefore loss of income).



**Table 30: Health status and access to treatment**

Health status and treatment	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Current Health (N = 419)</b>				
Excellent	14 (4.8)	6 (5.6)	3 (16.7)	23 (5.5)
Very good	32 (10.9)	14 (13.1)	8 (44.4)	54 (12.9)
Good	109 (37.1)	53 (49.6)	2 (11.1)	164 (39.1)
Fair	103 (35.0)	30 (28.0)	4 (22.2)	137 (32.7)
Poor	36 (12.2)	4 (3.7)	1 (5.6)	41 (9.8)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Currently taking ARV (N = 419)</b>				
Yes	165 (56.1)	70 (65.4)	14 (77.8)	249 (59.4)
No	129 (43.9)	37 (34.6)	4 (22.2)	170 (40.6)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Have access to ARV (N = 419)</b>				
Yes	187 (63.6)	76 (71.0)	12 (66.7)	275 (65.6)
No	55 (18.7)	12 (11.2)	2 (11.1)	69 (16.5)
Don't know	52 (17.6)	19 (17.8)	4 (22.2)	75 (17.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Currently taking medication to prevent/treat opportunistic infections (N = 419)</b>				
Yes	101 (34.4)	24 (22.4)	5 (27.8)	130 (31.0)
No	193 (65.6)	83 (77.6)	13 (72.2)	289 (69.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Have access to medication to prevent/treat opportunistic infections (N = 419)</b>				
Yes	163 (55.4)	49 (45.8)	10 (55.5)	222 (53.0)
No	56 (19.1)	19 (17.8)	3 (16.7)	78 (18.6)
Don't know	75 (25.5)	39 (36.4)	5 (27.8)	119 (28.4)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Constructive discussion with health care professional(s) on HIV related treatment option (N = 419)</b>				
Yes	167 (56.8)	67 (62.6)	12 (66.7)	246 (58.7)
No	127 (43.2)	40 (37.4)	6 (33.3)	173 (41.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Constructive discussion with health care professional(s) regarding SRH, emotional well-being, etc (N = 419)</b>				
Yes	135 (45.9)	58 (54.2)	12 (66.7)	205 (48.9)
No	159 (54.1)	49 (45.8)	6 (33.3)	214 (51.1)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

# Stigma Index



On the other hand, one third of the respondents (31%) reported that they were taking medication to prevent or treat opportunistic infections at the time the interview was conducted. More than half of the respondents (53%) also said that they had access to medication to prevent or treat opportunistic infections.

Nonetheless, most of the respondents also reported that they had a constructive discussion with health care professional on HIV related treatment option (58.7%) and SRH as well as emotional well-being (48.9%).

With regards to the problems and challenges in relation to ARV treatment, majority of the respondents said they had problems in adhering with the treatment.

*"I have to take the medicines according to time"* Male, 40 - 49 years old, IDU/prisoner

*"Can't take it at the given time"* ~ Male, 30 - 39 years old, IDU

*"Too many problems in timing"* ~ Female, 30 - 39 years old

*"Too difficult to remember the time"* ~ Male, 25 - 29 years old, MSM

In addition, a lot of respondents reported that they had problems in accessing ARV treatment, with most of them stating economic factor as the main barrier. Furthermore, a number of respondents also stated health care factors or structural factors such as long distance, frequency of visits to hospital as the hospital is only able to supply one month ARV medication at a time and there is also limited choice of drugs.

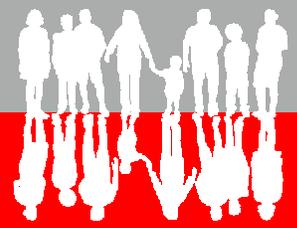
*"Access and availability of ARV."* ~ Male, 50+ years old, IDU/prisoner

*"I have problem in taking ARV in prison. I am not on ARV now and I want advice."* ~ Male, 30 - 39 years old, IDU/prisoner

*"Hospital is too far and travelling is costly."* Female, 25 - 29 years old

*"Medication sometimes does not reach my village".* ~ Female, 25 - 29 years old

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*"I can't afford the medicine."* ~ Female, 30 - 39 years old

*"2nd line medication have to be paid."* ~ Male, 40 - 49 years old, IDU and prisoner

*"2nd line medication is too expensive."* ~ Male, 40 - 49 years old, IDU and prisoner

*"Afraid have to pay one day"* ~ Female, 30 - 39 years old

*"Prescription for more than 1 month needed."* Male, 30 - 39 years old, ID/ prisoner

*"Availability of drug choice and drug resistant treatment"* Male, 50+ years old, MSM

*"No comment as there is no choice."* ~ Male, 30 - 39 years old

Nevertheless, many respondents reported that they experienced a lot of side effects in taking ARV treatment. Most of them also had insufficient knowledge about the treatment and they were afraid of the side effects and did not how to manage it.

*"I experienced bad side effect - vomiting."* Female, 40 - 49 years old

*"My skin becomes dark and itchy."* ~ Female, 30 - 39 years old

*"Lots of side effect."* ~ Male, 30 - 39 years old, IDU

*"Patient has insufficient knowledge."* Male, 40 - 49 years old, IDU/prisoner

*"No knowledge about medication."* Male, 30 - 39 years old

# Stigma Index



## 3.4 Experience of having children

In this section, respondents were asked about their experience of having children and their reproductive option. Female respondents were also asked about their experience of receiving ARV for prevention of vertical transmission (PVT).

As shown in Table 31, two fifth of respondents reported that they had children. Majority of the women (76.6%) cited that they have children (many were widowed) compared to men (28.2%) and transgender (16.7%). Out of 168 respondents who had a child/children, 13.1% of them said that their children were HIV-positive.

Slightly more than one third of the respondents (37.9%) reported that they had received SRH counselling. with (63.6%) of female respondents said that they had received it compared to male (29.9%) and transgender (16.7%) respondents. About one third (30.8%) were advised by a health care professional not to have a child because of HIV status and most of them were women (49.5%). Although in Malaysia the ability to obtain ARV was not based on the use of certain forms of contraception, some of the respondents still thought it was a condition (9.3%) and another 20% of them were unsure.

Table 32 shows that nearly half of the respondents (43.4%) were found to be HIV positive when they were pregnant. Out of these 46 respondents who reported being pregnant, majority of them (82.6%) cited that they had received ARV treatment to prevent vertical transmission during pregnancy. However, a small proportion of the women cited that they did not receive such treatment as they did not know about it (10.9%), or they were refused such treatment (4.3%), or did not have access to it (2.2%). For those who received ARV during pregnancy, almost all of them (92.1%) had also received information about healthy pregnancy.



**Table 31: Experience of having children**

Experience of Having children	Male No. (%)	Female No. (%)	Transgender No. (%)	Total No. (%)
<b>Have a child/children (N = 419)</b>				
Yes	83 (28.2)	82 (76.6)	3 (16.7)	168 (40.1)
No	211 (71.8)	25 (23.4)	15 (83.3)	251 (59.9)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Have a HIV-positive child/children (N = 168)</b>				
Yes	10 (12.0)	11 (13.4)	1 (33.3)	22 (13.1)
No	73 (88.0)	71 (86.6)	2 (66.7)	146 (86.9)
<b>Total</b>	<b>83 (100)</b>	<b>82 (100)</b>	<b>3 (100)</b>	<b>168 (100)</b>
<b>Received counselling on reproductive options (N = 419)</b>				
Yes	88 (29.9)	68 (63.5)	3 (16.7)	159 (37.9)
No	124 (42.2)	19 (17.8)	7 (38.9)	150 (35.8)
Not applicable	82 (27.9)	20 (18.7)	8 (44.4)	110 (26.3)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Advised by health care professional not to have a child because of HIV status (N = 419)</b>				
Yes	76 (25.8)	53 (49.5)	0	129 (30.8)
No	112 (38.1)	53 (49.5)	0	165 (39.4)
Not applicable	106 (36.1)	1 (0.9)	18 (100)	125 (29.8)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Coerced by health care professional into sterilization (N = 419)</b>				
Yes	4 (1.3)	16 (15.0)	0	20 (4.8)
No	174 (59.2)	90 (84.1)	0	264 (63.0)
Not applicable	116 (39.5)	1 (0.9)	18 (100)	135 (32.2)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>
<b>Ability to obtain ARV conditional on the use of certain forms of contraception (N = 419)</b>				
Yes	21 (7.1)	18 (16.8)	0	39 (9.3)
No	76 (25.9)	62 (58.0)	0	138 (33.0)
Not applicable	142 (48.3)	1 (0.9)	15 (83.3)	158 (37.7)
Don't know	55 (18.7)	26 (24.3)	3 (16.7)	84 (20.0)
<b>Total</b>	<b>294 (100)</b>	<b>107 (100)</b>	<b>18 (100)</b>	<b>419 (100)</b>

# Stigma Index



**Table 32: Prevention of vertical transmission (PVT)**

<b>HIV positive when pregnant (N = 106)</b>	<b>No. (%)</b>
Yes	60 (56.6)
No	46 (43.4)
<b>Total</b>	<b>106 (100)</b>
<b>Ever received ARV for PVT (N = 46)</b>	
Yes - I have received such treatment	38 (82.6)
No - I did not know that such treatment existed	5 (10.9)
No - I was refused such treatment	2 (4.3)
No - I did not have access to such treatment	1 (2.2)
<b>Total</b>	<b>46 (100)</b>
<b>Received information about healthy pregnancy (N = 38)</b>	
Yes	35 (92.1)
No	3 (7.9)
<b>Total</b>	<b>38 (100)</b>

The main problems and challenges seen by most of the respondents in relations to having child were the fear of transmitting the diseases to the child and the future of the child.

*“Risk of infecting child” ~ female, 30 - 39 years old*

*“Care and support of the child if anything happen.” ~ Male, 25 - 29 years old, MSM*

*“Afraid child will be infected.” ~ Male, 25 - 29 years old, IDU*

*“Afraid children will be infected and discrimination.” ~ Male, 40 - 49 years old, IDU and prisoner*

*“I am afraid the kids will be infected. The main challenge of having kids is taking care of their welfare and health.” ~ Female, 25 - 29 years old*

*“The future of my kids, if I have any.” ~ Male, 30 - 39 years old, IDU*

In addition, some of the respondents also concerned about the cost of raising a child and some of them said that they could not afford it.

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*"The kids' future and expenses."* ~ Female, 30 - 39 years old

*"Unable to work to raise them."* ~ Male, 50+ years old, IDU

*"I afraid cannot take care of them because I am not working."* ~ Male, 40 - 49 years old, IDU and prisoner

Some of the respondents felt that they had insufficient information to help them to make the decision on whether to have a child or not and most of them could only decide based on the healthcare professional advice.

*"Patient has insufficient knowledge to decide."* ~ Male, 40 - 49 years old, IDU and prisoner

*"Health workers have to give knowledge to patients."* ~ Male, 40 - 49 years old, IDU and prisoner

*"Doctor does not encourage."* ~ Transgender, 30 - 39 years old

Nonetheless, for some respondents, the fear of disclosure of their status to their children was the main challenge for them in relation to decide whether to have a child.

*"Ashamed if the children ask about her status."* ~ Female, 25 - 29 years old

*"Difficulty in explaining to children."* ~ Female, 40 - 49 years old

*"Kids will feel insulted by friends because of my status."* ~ Male, 30 - 39 years old, IDU and prisoner



## CONCLUSION AND RECOMMENDATIONS

### Conclusion

HIV-related stigma and discrimination continues to be a problem and challenge throughout the world. It not only affects the lives of PLHIV and those around them, but is also an obstacle to the progress and implementation of HIV prevention, treatment, care and support programmes in a way which is consistent with the best principles of Positive Health Dignity and Prevention<sup>11</sup>.

In Malaysia, despite stories about breach of confidentiality, stigma, and discrimination, and issues with rights to treatment, access and employment, little has been documented properly in a way which is systematic and can provide the much needed 'evidence' to properly inform programmatic and policy responses. The PLHIV Stigma Index study in Malaysia, as the first such study that documents the extent and causes of stigma and discrimination felt by PLHIV from a PLHIV perspective, can give valuable insight and data to inform the work of all those involved in the response

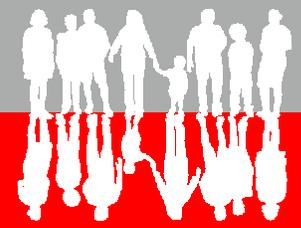
The PLHIV Stigma Index Study in Malaysia was initiated by The Positive Malaysian Treatment Access and Advocacy Group (MTAAG+), an organization driven by PLHIV and for PLHIV to take ownership of their lives and circumstances. The study was conducted by using a standard questionnaire and administered by trained PLHIV through face-to-face interviews; 421 respondents from different areas throughout Malaysia participated in this study<sup>12</sup>.

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<sup>11</sup> Positive Health, Dignity and Prevention highlights the importance of placing the person living with HIV at the centre of managing their health and wellbeing. It helps inform and expand understanding on how to enhance and nurture the leadership of people living with HIV, as they define and guide existing programmes that allow them to live in dignity, maintain or improve their health, and make choices that have beneficial results for themselves and their partners, families, and communities. For further information see the Policy Guidance provided by UNAIDS and GNP+ at [http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110701\\_phdp.pdf](http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2011/20110701_phdp.pdf)

<sup>12</sup> Though only 419 were included in the analysis due to missing data.

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The majority of the respondents who participated in this study were male, 30 to 49 years old, had secondary school education, stayed in small towns or cities and working, at the time of study, with an average annual income of less than USD 6,000. More than two thirds of respondents have known their status between one and nine years. Most of the respondents also revealed that they belonged to certain key populations and majority were IDU and MSM.

Most respondents reported they were single. For those who were in a relationship at the time of the study, about three quarters had a relationship of less than 10 years. Despite the fact that most of the respondents were single or not in any relationship at the time of the study, more than two thirds were sexually active.

Almost half of people living with HIV taking part in the study (46.7%) said that they were aware of being gossiped about in the 12 months preceding the study, mainly because of their HIV status and other reasons (i.e. membership of a key population). Respondents reported that in the last year they had been excluded from social gatherings (17.2%), religious activities (7.8%), and 13.6% reported exclusion from family activities. Verbal insults had been experiences by 23.2% of respondents, 13.4% had experiences physical harassment, and 12.5% had been physically assaulted (87.5%). In nearly all cases the HIV+ status of the respondent was the major or contributory cause, for the treatment they had received. It should be noted that the true degree of stigma and discrimination that exists toward people who are HIV+ in Malaysia may be masked by the fact that many respondents had only revealed their status to the people closest to them such as their spouses/partners, family members or their peers.

For those respondents who reported that they had been excluded for certain activities or being harassed, most of them said that it was mainly because of their HIV status (due to the fear of contagion) and reasons such as the view that others had of people from key populations - especially in this case those who used drugs, were from the MSM community, or were transgender.

Most women who were experiencing stigma cited their gender, the membership of a key population (IDU) of their partner, their widowed status and poverty as the reasons.

# Stigma Index



Nearly – in 1 in 5 of the respondents had problem caused by stigma and discriminatory attitudes in accessing accommodation, work, health and educational services.

Against this background it is perhaps not surprising that the majority of the respondents experienced internalised stigma; feeling ashamed of themselves, feeling guilty, self-blame and had low self-esteem. However despite having internalised stigma, they did not feel that they should be punished nor did they feel suicidal.

Most of the respondents stated that they had decided not to get married and/or have children as they worried about transmitting the disease to their children and the future of the children. Although most of them decided not to marry, the study found that sex was still an important aspect of the respondents' lives, especially amongst the key populations. This is important to program planners who often assume that safe sex programs should only be directed at married people.

In addition to experiencing internalised stigma, fear of being gossiped about and sexual rejection were the biggest fears and a challenge for most of the respondents.

Awareness of the Declaration of Commitment on HIV and the knowledge of national laws and policies, were found to be unknown to most of the respondents and as a result many were not aware of their rights. As such it is not surprising that the majority reported that they had never experienced any violation in this study. Therefore it is understandable that no action needs to be taken to address these issues. For the few who felt that their rights were violated and action had been taken, the issues were also not addressed nor resolved.

In order to address the issue of stigma and discriminations towards PLHIV, PLHIV themselves must also play a vital role in effecting change. However, in this study, only one fifth of the respondents said that they had confronted, challenged or educated someone who was stigmatizing or discriminating them. Furthermore, almost all had never sought help from any HIV related organizations to resolve the issue of stigma and discrimination and most did not belong to any PLHIV support group. In terms of support to other PLHIV, slightly more than half of the respondents reported providing support to their peers, especially emotional support. It must be borne in mind that more than three quarters of the PLHIV interviewed in this study are from communities who are inherently discriminated against (drug users or prisoners) by the Malaysian

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people even if they do not carry the virus. Now that they have discovered that they have the virus it does not change matters - in fact they have now to face double discrimination if they choose to reveal their status.

The last section of this study focused on respondents' experiences of testing and diagnosis, disclosure and confidentiality, treatment and having children. As shown in the study, most of the respondents tested for HIV voluntarily as they wanted to know their status or due to suspected HIV-related symptoms. However, about 20% of the respondents said that they had been tested mandatorily in prisons or rehabilitation centres.

HIV testing and counselling is freely available in all government health facilities, including primary health clinics. However, the quality of the services is not standardized and evaluation of the services has not been conducted. As such, it was not surprising to find that only about two fifths of the respondents received both pre- and post-HIV test counselling, while another two fifths were tested without pre-test counselling. Furthermore, a number of respondents felt that the tests were not done properly and they could not accept that they tested positive.

With regards to disclosure of HIV status, majority of the respondents chose to keep their status confidential and only disclosed to the people they were close to such as their partners, family members or their peers and those people who provided them support such as healthcare workers, social workers and counsellors. Most of these people were supportive or very supportive when they first knew about respondents' status. However, some of the other people in the community or work place can be very discriminating. Majority of the respondents stated that the fear of encountering stigma or being discriminated against was their biggest concern when deciding whether or not to disclose their status.

Although majority of the respondents chose to disclose their status to healthcare workers and most cited that the healthcare workers were supportive, more than half were unsure whether the health professionals would keep their status and medical records confidential and this was cited as one of their challenges.

In Malaysia, the Government is committed to providing ARV therapy to all those who need it, by making it affordable and accessible to all at government health centres.

# Stigma Index



First line ARV treatment is being provided free of charge and the second line ARV treatment at subsidized rates for those who need it. The study found that most of the respondents were confident that they had access to ARV and medication to prevent or treat opportunistic infections. In fact, the major problems and challenges faced by respondents were not the direct costs of the medications. Problems that were reported included adherence with the treatment, and the source of the treatment. Also of concern were the costs (of time and money) associated with the need to make frequent visits (having to collect their medication more than one a month) to the hospital for medication and diagnostic and monitoring costs.

With regards to the reproductive options and experience of having children, only slightly more than one third of the respondents reported that they had received counselling on this and most had been advised by health care professional not to have a child because of their status. In addition, PVT is provided for all the women who were found HIV positive when they were pregnant.

## Recommendations

Although the study found that most of the PLHIV in Malaysia did not report much stigmatization and discrimination we should be mindful of the fact that most of them had only kept the status amongst their close family members and the peers. In addition, many had internalized stigma, high rates of being fearful about the ways they were perceived and treated in the community. As such, more needs to be done and concerted effort is required to promote positive living among PLHIV. Some recommendations from this study are outlined below.

1. Recognizing and advocating for the rights of People Living with HIV regardless their sexual orientations and involvement in potentially high risk behaviours. By recognizing the rights of PLHIV, it will create systems that give them the right to live, to dignity, to work, to non-discrimination, and to health and education. Furthermore, it enables a person to make choices that would - in his or her own way - make life meaningful and rewarding, physically, mentally, and emotionally.
2. Creating and intensifying public understanding and awareness of HIV to enable more appropriate health seeking behaviour based on accurate information as well as to counter HIV-related stigma and discrimination are essential. The fear and

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preoccupation with HIV transmission and the perception of the public that HIV is a disease that is related with high risk behaviours among key populations should be addressed through education.

3. Up-scaling, monitoring and evaluation of Voluntary Counselling and HIV testing. It should be noted that HIV testing without pre-test counselling will increase the fear and internalised stigma which may prevent a person from undergoing HIV testing. In addition, it will also increase the stigma and discrimination among the healthcare providers towards patients. As such, it is important to improve the quality of VCT services to meet the needs of providers and clients, in an equitable and acceptable manner, within the resources available and in line with national guidelines. In addition, it is important that the quality be monitored, improved and evaluated at each level with the active involvement of all stakeholders.
4. Reviewing existing labour legislation and encouraging more companies to adopt the Code of Practice on Prevention and Management of HIV/AIDS at the Workplace developed by the Ministry of Human Resources in 2001 to address the issue of stigma & discrimination of PLHIV at workplace and promote a non-discriminatory work environment.
5. Encouraging PLHIV to play a role of effecting change by involving them actively in developing and implementing stigma and discrimination reduction efforts including the development of laws, policies and guidelines.
6. Continue to provide psychosocial and socioeconomic support including training opportunities for PLHIV to become peer educators, capacity and network building, counselling, training, and income generation.
7. In view of the fact that this study was conducted as an introductory activity on the overall situation of stigma and discriminations faced by PLHIV in Malaysia, it only focused on PLHIV who were known to support groups or HIV-related organizations. Therefore, it is proposed that a repeat assessment to be conducted and those PLHIV who were not supported by peer groups should also be included.



## References

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# Malaysia



## MTAAG+

Positive Malaysian Treatment Access & Advocacy Group

### Disclaimer:

The People Living with HIV Stigma Index is designed as a research tool by which people living with HIV capture data on their experiences and perceptions regarding stigma and discrimination.

In this regard, the results can be said to comprise a snapshot of the level of HIV-related stigma and discrimination in a certain place and time. Through its implementation, the tool also serves to educate and empower people living with HIV on human rights related to HIV.

Survey questions therefore focus on experiences and perceptions and do not represent factual investigations, with follow up questions, into particular allegations, incidents or events nor are the answers to the questions subject to independent verification. As research participants interviewees have a right to anonymity and to confidentiality regarding their responses.

In addition to the empowerment function, appropriate uses of the data are for advocacy and in order to inform stigma/discrimination reduction programming and policy responses in the national response to HIV.

The data is not available as a source of allegations of individual instances of wrong-doing.

