



**FINAL REPORT**

# Malaysia Stigma Evaluation Survey 2025



Malaysian AIDS Council (MAC)

## **MALAYSIA STIGMA EVALUATION SURVEY (MySES)**

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President / Executive Director  
Malaysian AIDS Council  
Date: XX XXXX 2026

## ACRONYMS

AA	Alcoholic Anonymous
AIDS	Acquired Immunodeficiency Syndrome
AO	AIDS Officers
ART	Antiretroviral Therapy
CD4	Cluster of Differentiation 4
FMS	Family Medicine Specialists
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ID	Infectious Diseases
MAC	Malaysian AIDS Council
MAF	Malaysian AIDS Foundation
MBCH	Malaysian Business Consortium on HIV/AIDS
MOH	Ministry of Health
MSM	Men Having Sex with Men
MySES	Malaysia Stigma Evaluation Survey
NGO	Non-Governmental Organisation
PLHIV	People Living with HIV
PWID	Persons who Inject Drugs
SPSS	Statistical Package for the Social Sciences
STI	Sexually Transmitted Infection
USM	Universiti Sains Malaysia
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation
WLHIV	Women Living with HIV

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# MALAYSIA STIGMA EVALUATION SURVEY (MySES)

## 1.0 INTRODUCTION

The WHO declared HIV/AIDS a ‘global epidemic’ and a major global public health concern. According to the WHO, HIV/AIDS have so far claimed 32.7 million lives since the start of the epidemic. Approximately 38 million people worldwide are living with HIV, with millions unaware of their status (Payagala & Pozniak, 2024).

The Human Immunodeficiency Virus (HIV), which can lead to Acquired Immune Deficiency Syndrome (AIDS), was first discovered in Malaysia, in 1986 (Apenteng et al., 2020). According to recent epidemiological data, while new infections are generally declining in the Asia-Pacific region, a significant number of new cases and AIDS-related deaths continue to be reported daily in Malaysia, necessitating aggressive structural interventions (UNAIDS, 2024a). Malaysia is one of ten countries that account for more than 95% of new HIV infections (Adnan et al., 2024).

Stigma and discrimination are two of the worrying issues faced by people living with HIV/AIDS (PLHIV) and key populations. The key populations include persons who inject drugs (PWID), transgender (TG), female sex workers (FSW), and men having sex with men (MSM). According to the UNAIDS, the fear of stigma and discrimination is the primary cause of why many of this population are reluctant to get tested, to disclose their HIV status, or to go for treatment (UNAIDS, 2024b). Stigma and discrimination can lead to death when the PLHIV refuses to be tested and treated. Other consequences of stigma and discrimination experienced by PLHIV include loss of income and livelihood; loss of marriage and childbearing options; loss of hope while displaying feeling of worthlessness; loss of reputation; and loss of employment (Global Network of People Living with HIV, 2018; Global Information and Education on HIV and AIDS, 2019). This external stigma and discrimination lead to self- stigma or internal stigma, which consequently breaks PLHIV confidence to seek help and medical care. It is vital to understand this phenomenon in order to come up with a more effective prevention and coping strategies.

There are many factors contributing to HIV-related stigma, including stereotyping, low levels of HIV knowledge, and socially sensitive concerns that often lead to discrimination and late presentation for care (Ahmad et al., 2024). In fact, HIV-related stigma and discrimination are the main barriers to HIV care, treatment and prevention among PLHIV and key populations in Malaysia and globally.

Consequently, such stigma continues to act as a primary stumbling block for widespread HIV awareness, testing interventions, and comprehensive care initiatives within society which could made it difficult to take preventive steps to reduce the spreads of the disease (Dessie & Zewotir, 2024). Society still has a strong stigma about HIV even after the antiretroviral therapy was introduced. Consequently, with an estimated 40.8 million people living with HIV globally as of 2024, the disease remains a major global health concern despite significant advances in antiretroviral therapy and treatment (World Health Organization, 2024).

From the above arguments, it is clear that the prevention and treatment of HIV is negatively affected by HIV-related stigma and discrimination (Ahmad et al., 2024). There are many forms and manifestations of stigma and discrimination. The most prevalent manifestations include negativity, prejudice, and systemic discrimination against PLHIV, which act as severe deterrents to seeking early information, diagnosis, and sustained HIV treatment (Lo Hog Tian et al., 2024). Such stigma and prejudice disproportionately affect marginalized groups associated with higher risks of HIV, such as men who have sex with men (MSM), sex workers, and people who inject drugs, compounding structural barriers to equitable care (Sasset et al., 2025). Modern conceptual frameworks illustrate that internalized and enacted HIV-related stigma not only deteriorate psychosocial health but directly undermine clinical benchmarks such as medication adherence and viral suppression (Crawford et al., 2024).

According to Lo Hog Tian et al. (2024), the stigma, prejudice, and abuse faced by PLHIV are also experienced by communities with high HIV risks. This situation could negatively affect their livelihood and social wellbeing of these already vulnerable communities, making them particularly susceptible to HIV infection. Many were hesitant to attend HIV education programmes provided by healthcare providers. Some are reluctant to visit a medical facility for diagnosis and getting early treatment, if they were tested positive. As a result, they were cut off from care and support networks. Such a situation could hinder prevention activities where undiagnosed patients

could unknowingly spread the virus. Many PLHIV were unwilling to inform their family members or partners about their HIV status for fear of exposing their risky behaviour and lifestyles that are often considered as sinful (Global AIDS Monitoring Report, 2019). Furthermore, some kept their diagnosis a secret to prevent their family from facing the same stigma and discrimination. Hence, eradicating stigma and prejudice is critical to encouraging more people to come forward for early screening and treatment, thereby breaking the infection chain (Aziz et al., 2025).

Despite the continuous HIV awareness programmes in the country, the stigma against PLHIV in Malaysia's general population perceived to be relatively high. According to the Global AIDS Monitoring Report (2020), 30% or about one-third of Malaysian mentioned that they would not buy food items like vegetables from an HIV-positive seller and 26% agreed that HIV-positive children should not attend school with other children. Such negativity reflects that more initiatives should be taken to eliminate stigma against PLHIV.

More than 70 countries have adopted the “People Living with HIV Stigma Index” to understand and capture data related to stigma and discrimination among the PLHIV (Global Network of People Living with HIV (GNP+), 2016). Current global assessments continue to indicate that stigma and discrimination, particularly in health-care settings, frequently result in PLHIV being denied health access or delaying treatment out of fear of mistreatment (UNAIDS, 2024a). Currently, in Malaysia, the last officially sanctioned national study was completed in 2021 to examine this stigma and discrimination issues faced by PLHIV. For effective management of prevention and treatment of HIV/AIDS in the country, comparisons understanding of the same issues among the PLHIV population is urgently needed. At the same time, the general population will also benefit from a more accurate and current information about the HIV/AIDS.

The proposed national PLHIV stigma survey is also in line with Malaysia’s other initiatives on stigma reduction, including the Stigma Reduction Quality Initiative at healthcare settings currently ongoing at selected 10 government health facilities.

The Malaysia Stigma Evaluation Survey (MySES) 2025 is the second officially sanctioned national study to examine stigma and discrimination issues faced by people living with HIV (PLHIV) in the country. MySES is a community-based initiative involving all key stakeholders. The main strategic outcome of this study is more affirmative policies on preventing the spread of

HIV through selected and effective programmes; and eventually minimising and eliminating the socio-economic impact of the epidemic to Malaysians. The Malaysian AIDS Council (MAC) is the custodian of MySES and will be entrusted to repeat the study every three to five years in the future.

### **Study Objectives**

The general objective of this national study was to establish data on stigma and discrimination experienced by PLHIV in Malaysia. The specific objectives of the study were:

1. To gather and analyse data on the experiences of stigma and discrimination experienced by PLHIV.
2. To document a more up-to-date national data with regards to stigma and discrimination.
3. To recommend for policy advocacy and intervention strategies in addressing HIV stigma and discrimination.

### **Methodology**

#### **Research Design**

This quantitative study used an online survey questionnaire. Secondary data provided the background and rationale for conducting the study.

#### **Study Instrument (Questionnaire)**

The survey instrument, titled “*Malaysia Stigma Evaluation Survey (MySES)*” was developed by the following working groups:

- a. A group of researchers with vast experience in HIV/AIDS and related studies;
- b. Members (partner organisations) from Malaysian AIDS Council (MAC);
- c. PLHIV communities from the key populations;
- d. Selected service providers from both the non-governmental organisations and governmental organisations serving the PLHIV; and

- e. Individual practitioners and activists who have served the PLHIV community directly.

Recent global framework updates, including the standardized People Living with HIV Stigma Index 2.0 (UNAIDS & GNP+, 2023), alongside inputs from the local PLHIV community, provided the basis for the development of the survey instrument. Direct input and participation from the PLHIV community was sought to ensure that all issues were being thoroughly examined and addressed. Development of this questionnaire took cognisance of the local cultural context and at the same time to be in line with the Stigma Reduction Quality Initiative at the Healthcare Settings.

The questionnaire covers seven (7) sections as follows:

#### Introduction to the Study

*[The section includes the primary aim or purpose of the study, including respondents' consent for participation]*

#### 1. Section A: Background of Respondents

*[The section aims to capture the demographic profiles of the study respondents]*

#### 2. Section B: Disclosure

*[The section gathers information about the respondents' disclosure of their HIV status]*

#### 3. Section C: Personal Experiences

*[The section captures personal experiences related to stigma and discrimination]*

#### 4. Section D: Internal Stigma

*[The section identifies the different form of internal stigmas by the respondents themselves]*

#### 5. Section E: Experiences with Services (Healthcare, Workplace and Insurance)

*[The section documents respondents' experiences when seeking services such as healthcare, workplace or insurance]*

## 6. Section F: Human Rights

*[The section documents the different form of awareness and actions by the respondents in respond to stigma and discrimination]*

## 7. Section G: Experiences on Stigma and Discrimination due to Appearance or Behaviour

*[The section captures respondents' stigma and discrimination experiences due to their appearance or behaviours].*

The questionnaire was prepared in two languages – English and Bahasa Melayu. A backward and forward translation was conducted in order to ensure the validity and reliability of the two versions of the questionnaire. The translation process involved a language expert and two subject experts familiar with HIV/AIDS. The English version will be the official reference, in case of any doubt regarding the meaning of any of the questions in the questionnaire.

### **Respondents**

The inclusion criteria of respondents in the study are as follows:

- a. PLHIV who are Malaysian citizen, non-residents and permanent residents.
- b. PLHIV of all genders (male, female, transgender and non-binary).
- c. PLHIV from all races / ethnicities.
- d. PLHIV from key population (including PWID, Transgender, MSM, Female Sex Workers).
- e. Other PLHIVs who are not in treatment and HIV care (identified via referral from peers - snowball technique).
- f. Respondents who do not meet the inclusion criteria will be excluded from the study.

### **Study Location**

The respondents were PLHIV living in the urban or rural areas of Peninsular Malaysia, Sabah and Sarawak.

## Population and Sample

In 2023 there were 71,927 People Living with HIV (PLHIV). A vast majority, 90 percent, were male and 10 percent were female. Children below 19 represented less than four percent of the population. AIDS related death was 882 in 2023 (Malaysian AIDS Council, 2023).

The sampling frame for PLHIV in the country is consistent with the 2021 Malaysian Stigma Evaluation Survey. The online survey was chosen as it has many apparent advantages besides being cost effective and efficient, which restricts movement. The survey relied on purposive sampling with cooperation of outreach workers to assist in identifying PLHIV residing around the country. This sample also allow respondents a greater degree of privacy and anonymity. The survey relied on purposive sampling with the active cooperation of outreach workers to assist in identifying PLHIV residing around the country.

## Sampling

Samples for this study were drawn from the PLHIV population and were identified from the following sources:

1. Partner organisations (POs) under MAC / ID clinics / caseworkers that provide care and support to PLHIV.
2. Services providers (centers / agencies / civil societies) who deal or provide direct services to PLHIV.
3. Through referrals by other PLHIVs, additional respondents were identified by snowballing technique.

In 2023, the official estimate of the number of PLHIV population was 71,927. This final sample size for this study was determined as follows:

$$n = N / [1 + N * (e)^2]$$

Where: n = Desired sample size  
N = The population size  
e = Level of precision or sampling error (sampling error in this study is 5 percent)

Source: (Yamane, 1967)

Given the population (N) = 71,927 and using 95% confidence level and 5 percent error level, the calculated sample size = 398. The survey gathered 719 respondents exceeding the 398 thresholds.

The survey was designed to be self-administered; thus, it was possible to do it online, which is cost-effective and faster analysis as data collected will be in a ready format for final tabulation.

## **Enumerators**

Although the survey was done online, trained enumerators were accessible to respondents who may require assistance. Enumerators had on their devices, such as mobile phones, tablets or laptop computers; the same questionnaire for face-to-face interviews.

Selected outreach workers, case workers, members of PLHIV support groups or affiliated HIV-related organisations and civil societies who were registered with MAC were trained as enumerators. These were individuals familiar to the respondents and it was hoped that they can encourage more PLHIV to participate in the survey. With their greater knowledge about HIV, the enumerators were expected to show more empathy and better understanding on the predicament of PLHIV.

On 7<sup>th</sup> October 2025, a physical training session was conducted with the selected enumerators and stakeholders on the data collection process of the survey. In the session, all questions in the questionnaire were thoroughly discussed to ensure that all enumerators were sure of the meaning and purpose of every question. Similarly, inclusion criteria of respondents were emphasised. Overall, feedbacks from the training were very positive. Some minor adjustments of the questionnaire were made from the feedback, including questions related citizenship, premarital screening and questions related to insurance. Comparisons were also made to the 2021 survey and how we can improve from the previous practice.

## **Questionnaire Development**

The initial draft was developed by experts in the field and with inputs from the PLHIV community as was discussed in section 3.2 earlier. The draft required further refinement with

comments from other stakeholders.

On 8<sup>th</sup> October 2025, a face-to-face workshop was held at the Citadines Connect Hotel in Penang to further improve the initial draft. The one-day workshop involved 25 representatives from the Malaysian AIDS Council (MAC), caseworkers and outreach workers from the partner organisations providing direct services to PLHIV, and representatives from the Ministry of Health.

The aims of the session included the following:

- a) To ensure the correct meaning of each question.
- b) To ensure and emphasise on the “voluntarily” nature for respondents’ participation in the survey.
- c) To ensure the translation accuracy of each question in both English and Bahasa Melayu languages.
- d) To determine the consistency of terminology used throughout the questionnaire.
- e) To scrutinise questions that differentiated between internal and external stigmas.
- f) The need to provide introductory explanation for each section for respondents’ better understanding of the scope of the questions.
- g) To emphasise on the duration PLHIV confirmed positive thus eligible to participate as respondent.
- h) Added more questions related to appearances and behaviours.
- i) Added more questions related to workplace discrimination.
- j) Other related matters including formatting, technical aspects of running the survey via online, and logistics issues.

The final Bahasa Melayu and English questionnaires were finally validated using *turn-it-in* to determine its similarity index. The *turn-it-in* reported a satisfactory score with similarity index of only 10%.

## **Data Collection**

The actual data collection phase started on 28 November 2025 and was completed on 31 December 2025.

## **Data Analysis**

Data gathered were then analysed using Google Form and SPSS Version 25.0.

## **Ethical Considerations**

1. Consent from all respondents' participation was mandatory and was recorded via digitally signed consent form.
2. All data collected were used only for study purposes and hence confidentiality of the personal details of the respondents and the data were given due priority.

## **Plans for Dissemination of Findings**

The survey findings were presented to the Ministry of Health (MOH) Malaysia, civil societies and relevant stakeholders that provide direct services to the PLHIV population. Study findings were jointly published by the authorised entities.

## **2.0 STUDY FINDINGS**

The total number of respondents needed for the study was statistically estimated to be 398. After the closing date, a total of 1,555 respondents took part in the survey. However, after initial analyses, it was found that not all submitted questionnaires could be used for the purpose of this study. While a total of 1,555 individuals initially engaged with the survey link, rigorous data cleaning excluding incomplete responses, duplicate entries, and those failing inclusion criteria (e.g., HIV-negative individuals) resulted in a final, valid sample size of 719 respondents.

The main reasons why 54 percent of the questionnaires could not be used include:

1. Not all pertinent questions were fully answered by the respondents.
2. There were redundancies and inconsistencies in many of the responses.
3. Many chose to answer all questions in the questionnaire despite instructions to skip questions not relevant to their cases. This raised doubts as to the ability of the respondent to respond to other questions coherently.

## Testing Facilities

Given the many of testing facilities available throughout the country, it was decided that these testing centres were grouped into four main categories: government health clinic, government hospital, private clinic and private hospital, which should encompass all the facilities available and used for this study.

Table 1: HIV Testing Facilities Respondents Confirmed HIV Positive

<b>Health Facilities</b>	<b>Numbers (%) N=719</b>
Government Health Clinic,	437 (60.8%)
Government Hospital	208 (28.9%)
Private Clinic	59 (8.2%)
Private Hospital	15 (2.1%)
Total	719

The study finding reveals that in a majority (60.8%) of the cases, the respondents were confirmed HIV positive at government health clinic, The rest of the respondents were confirmed at government hospital (28.9%), and around 11% for private clinic and private hospital.

## Year Confirmed HIV

Figure 1 below shows when the respondents were confirmed of their HIV status. The highest number of cases were confirmed in the five- year period (2020-2025). Cumulatively, total number confirmed over the years depicted an increasing trend, although this do not necessarily represent the actual national trend (Figure 1 and Figure 2).

5. Bilakah anda disahkan positif HIV (tahun) ? / When did you achieve confirmation on your HIV-positive status (year)?

719 responses

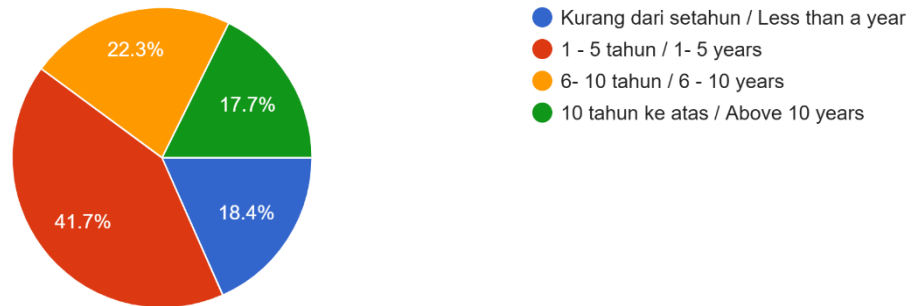


Figure 1: Year Confirmed HIV-Positive

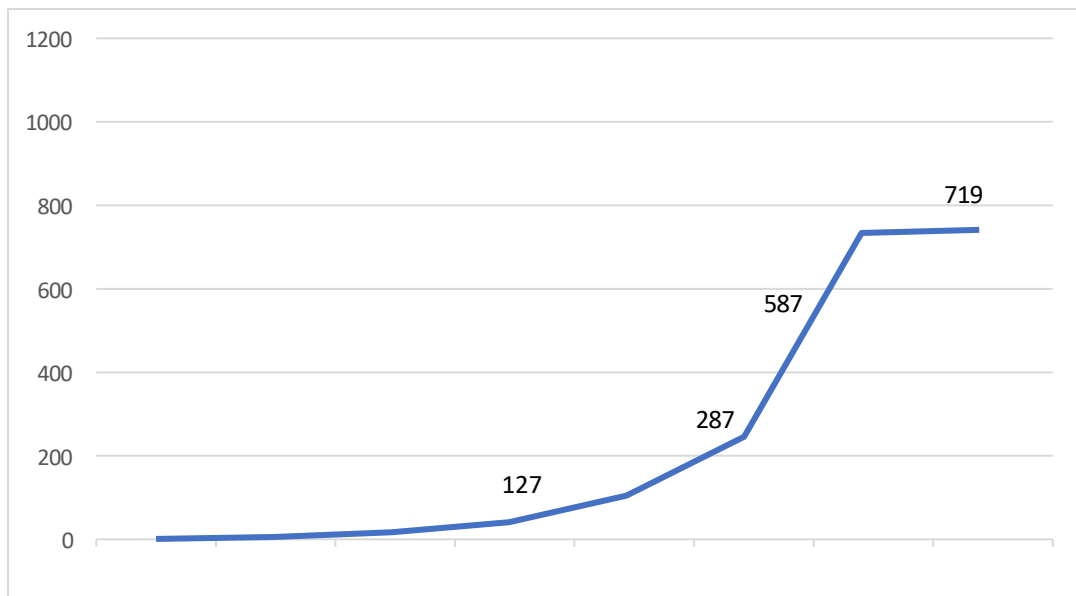


Figure 2: Year Confirmed HIV-Positive (Cumulative)

### Section A: Background of Respondents

This section profiles the respondents with respect to their nationality or resident status, their ages, gender, education and employment, among others. Table 2 below, classifies whether the respondents were citizens or non-citizens or permanent residents.

Table 2: Citizenship of Respondents

Citizenship Status	Numbers (%) (N=719)
Malaysian	710 (98.7%)
Permanent Resident	2 (<1%)
Non-Malaysian	6 (<1%)
Stateless	1 (<1%)

Almost all (99%) of the respondents were Malaysian with the remainders either non-citizen or permanent resident based on the survey.

### Age

The survey result reveals their ages ranged from 19- to above 60-year-olds. Most of the respondents age was between 19 to 40 years with (74.8%) followed by 41 to 60 year old with (23.8%), 61 years old and above (1.3%) and 15 - 18 years old (<1%).

Table 3: Age of Respondents

Age Group (Years)	Male	Female	Transman	Transwoman	Total (N=719)
<b>15-18</b>	1 (0.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.1%)
<b>19-40</b>	503 (78.7%)	23 (37.7%)	2 (100.0%)	10 (58.8%)	538 (74.8%)
<b>41-60</b>	130 (20.3%)	34 (55.7%)	0 (0.0%)	7 (41.2%)	171 (23.8%)
<b>61 and above</b>	5 (0.8%)	4 (6.6%)	0 (0.0%)	0 (0.0%)	9 (1.3%)
<b>Total</b>	<b>639 (100%)</b>	<b>61 (100%)</b>	<b>2 (100%)</b>	<b>17 (100%)</b>	<b>719 (100%)</b>

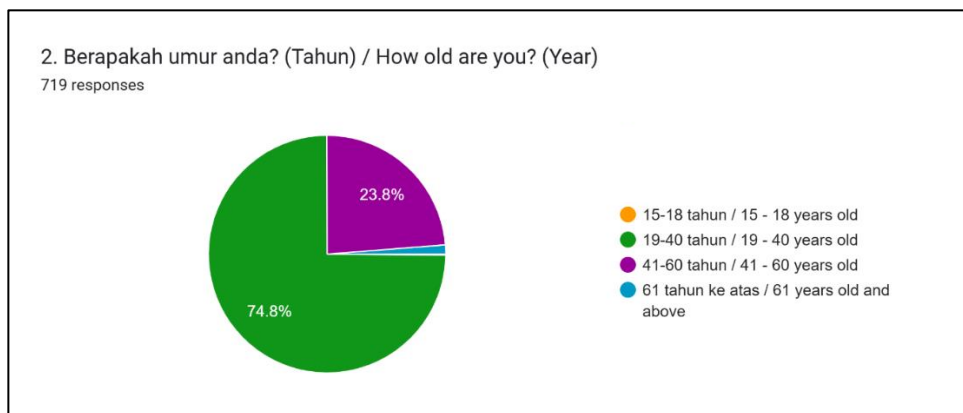


Figure 3: Age of Respondents by Age Group

## Distribution of Respondents by State and Region

The Table 4 below shows distribution of respondents according to their state of residences, including the three Federal Territories (FT) of Kuala Lumpur, Putrajaya and Labuan. The highest number of respondents were from the Johore State (89), Selangor (132), and Kuala Lumpur (88). Five states with the least number of respondents were Perlis (7), Putrajaya (4) and Labuan (2), representing less than 1% of total respondents.

Table 4: Distribution of Respondents by States and Key Population

State	MSM	Sex Worker	PWID	None of the Above	Transgender	Total (N=719)
<b>Johor</b>	62 (11.8%)	0 (0.0%)	7 (22.6%)	17 (11.9%)	3 (18.8%)	<b>89 (12.4%)</b>
<b>Kedah</b>	26 (5.0%)	0 (0.0%)	0 (0.0%)	2 (1.4%)	2 (12.5%)	<b>30 (4.2%)</b>
<b>Kelantan</b>	21 (4.0%)	0 (0.0%)	6 (19.4%)	13 (9.1%)	0 (0.0%)	<b>40 (5.6%)</b>
<b>Kuala Lumpur</b>	72 (13.7%)	1 (20.0%)	0 (0.0%)	10 (7.0%)	5 (31.3%)	<b>88 (12.2%)</b>
<b>Labuan</b>	2 (0.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	<b>2 (0.3%)</b>
<b>Melaka</b>	24 (4.6%)	0 (0.0%)	2 (6.5%)	5 (3.5%)	1 (6.3%)	<b>32 (4.5%)</b>
<b>Negeri Sembilan</b>	16 (3.1%)	1 (20.0%)	5 (16.1%)	5 (3.5%)	1 (6.3%)	<b>28 (3.9%)</b>
<b>Pahang</b>	13 (2.5%)	1 (20.0%)	1 (3.2%)	5 (3.5%)	3 (18.8%)	<b>23 (3.2%)</b>
<b>Penang</b>	34 (6.5%)	0 (0.0%)	1 (3.2%)	16 (11.2%)	0 (0.0%)	<b>51 (7.1%)</b>
<b>Perak</b>	16 (3.1%)	0 (0.0%)	0 (0.0%)	1 (0.7%)	0 (0.0%)	<b>17 (2.4%)</b>
<b>Perlis</b>	6 (1.1%)	0 (0.0%)	1 (3.2%)	0 (0.0%)	0 (0.0%)	<b>7 (1.0%)</b>
<b>Putrajaya</b>	4 (0.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	<b>4 (0.6%)</b>
<b>Sabah</b>	44 (8.4%)	1 (20.0%)	0 (0.0%)	14 (9.8%)	0 (0.0%)	<b>59 (8.2%)</b>
<b>Sarawak</b>	50 (9.5%)	0 (0.0%)	0 (0.0%)	12 (8.4%)	1 (6.3%)	<b>63 (8.8%)</b>
<b>Selangor</b>	107 (20.4%)	1 (20.0%)	3 (9.7%)	21 (14.7%)	0 (0.0%)	<b>132 (18.4%)</b>
<b>Terengganu</b>	27 (5.2%)	0 (0.0%)	5 (16.1%)	22 (15.4%)	0 (0.0%)	<b>54 (7.5%)</b>
<b>Total</b>	<b>524 (100%)</b>	<b>5 (100%)</b>	<b>31 (100%)</b>	<b>143 (100%)</b>	<b>16 (100%)</b>	<b>719 (100%)</b>

For the purpose of this study, the 13 states and three Federal Territories were grouped into five regions. Four regions are on the peninsula and one on the Borneo Island. Other studies with different objectives may vary their groupings of the 13 states and three Federal Territories, slightly. The four regions in Peninsular Malaysia are the Northern Region (Kedah, Perlis, Penang and

Perak), the East Coast Region (Kelantan, Terengganu and Pahang), the Southern Region (Johor, Negeri Sembilan and Melaka), and the Klang Valley (Selangor and the two Federal Territories of Kuala Lumpur and Putrajaya). On the Borneo Island, Sabah and Sarawak and the Federal Territory of Labuan, are one region classified as East Malaysia. The Federal Territories of Kuala Lumpur and Putrajaya used to be part of the Selangor state. Kuala Lumpur is the nation's capital while Putrajaya is the nation's new administrative seat. Similarly, Labuan was previously part of Sabah.

Table 5: Distribution of Respondents by Region

<b>Regions</b>	<b>Numbers (%) N=719</b>
<b>Northern Region</b> Kedah Perlis Penang Perak	105 (14.6%)
<b>East Coast Region</b> Kelantan Terengganu Pahang	117 (16.2%)
<b>Southern Region</b> Johor Negeri Sembilan Melaka	149 (20.7%)
<b>The Klang Valley</b> Selangor Kuala Lumpur Putrajaya	224 (31.1%)
<b>East Malaysia</b> Sabah Sarawak Labuan	124 (17.2%)
<b>Total</b>	719 (100%)

This study indicated that more than a quarter of the respondents were from the Klang Valley with 31.1%. According to key population most of the respondents residing in Klang Valley

are from the MSM category (25.4 %) which represent more than a quarter of the respondent population.

## Gender

There were ten times more male (88.9%) than female (8.5%) in this study. This ratio is fairly close to the national average of male (85%) and female (14%) PLHIV population (MOH, 2020). There were 19 transgenders (2 transmen and 17 transwomen) which amounted to 2.6% of total number of respondents (Figure 4).

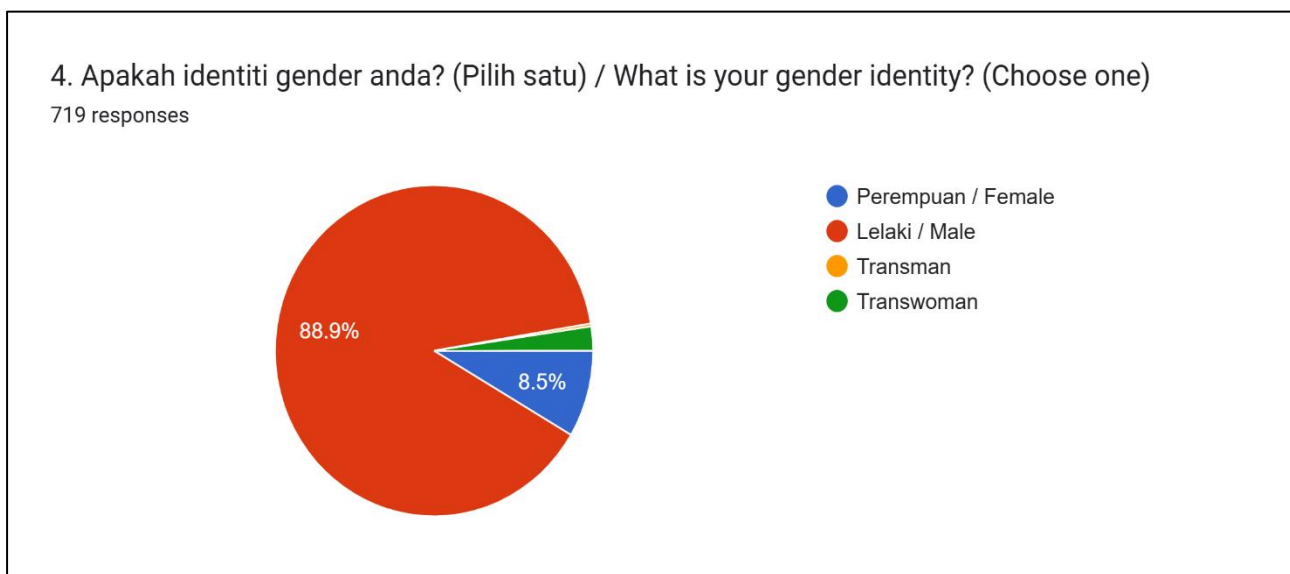


Figure 4: Gender Identity

## Key Population

UNAIDS identified five key population groups: Men Having Sex with Men (MSM), Persons who Inject Drugs (PWID), transgender, sex worker, prisoners and other incarcerated people. However, the last group, prisoners and other incarcerated people, were not considered in this study for the main reason that it was not possible to get this key population to participate.

This study reveals that of the 719 respondents, the majority (72.9%) were MSM. Five transmen, transwomen and female claimed they were MSM. PWID formed the next largest group (4.3%), while the rest were Transgender (2.2%) and Sex Worker (<1%). Less than quarter (19.9%) of all respondents, claimed did not belong to any of the key population groups. This last group is categorised as Non-Key Population; with (90%) of the female respondents belonged to this group.

Table 6: Key Population to Gender Identity

<b>Gender Identity</b>	<b>MSM</b>	<b>Sex Worker</b>	<b>PWID</b>	<b>Non-key Population</b>	<b>Transgender</b>	<b>Total</b>
<b>Male</b>	519 (81.2%)	3 (0.5%)	28 (4.4%)	88 (13.8%)	1 (0.2%)	<b>639 (100%)</b>
<b>Female</b>	1 (1.6%)	1 (1.6%)	3 (4.9%)	55 (90.2%)	1 (1.6%)	<b>61 (100%)</b>
<b>Transman</b>	2 (3.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	<b>2 (100%)</b>
<b>Transwoman</b>	2 (11.8%)	1 (5.9%)	0 (0.0%)	0 (0.0%)	14 (82.4%)	<b>17 (100%)</b>
<b>Total (N=719)</b>	<b>524 (72.9%)</b>	<b>5 (0.7%)</b>	<b>31 (4.3%)</b>	<b>143 (19.9%)</b>	<b>16 (2.2%)</b>	<b>719 (100%)</b>

*\* This is raw self-reported data and respondents may have misunderstood the terminology,*

To justify what might appear to be discrepancies in the data, in epidemiological surveillance, standard categories have historically struggled to separate gender identity from sexual behavior. Traditional HIV surveys often incorrectly aggregated transgender women into the MSM (Men who have Sex with Men) transmission category because risk algorithms assigned categories based on sex assigned at birth rather than self-reported gender identity (Truong et al., 2019). Academic research now frequently studies these intersections directly for example, evaluating "transgender women who have sex with men" which validates that an individual can legitimately select a transgender gender identity while simultaneously reporting behaviors that place them in MSM sexual networks (Pitasi et al., 2020). Key populations also are not mutually exclusive silos. Academic literature emphasizes that key populations including sex workers, MSM, transgender persons, and people who inject drugs frequently present intersecting individual and network-level risks that complicate epidemiological measurement (Schwartz et al., 2019). Because these highly marginalized populations lack standard probabilistic sampling frames, field surveys often rely on peer-led sampling methods that capture these real-world demographic overlaps (Schwartz et al., 2019). Consequently, preserving these intersecting responses (rather than arbitrarily deleting them) is necessary to maintain the data's integrity and accurately reflect the complex risk environments these populations navigate.

### **Status of Sex Partners**

This study reveals that most (44.9%) of the PLHIV did not have regular sex partners followed by that their sex partners were not HIV-positive (26.7%). The rest (15.4%) claimed that

their sex partners were HIV-positive and some (12.9%) claimed unsure of the status of their sex partners. Among the male respondents, less than half (48%), claimed to have no regular sex partners, while among the female respondents, more than half (50.8%) claimed that their sex partners were either not HIV-positive or were HIV-positive. The majority among the transgenders, claimed that their sex partners were not HIV-positive (36.8%) and they do not have a regular partner (52.6%). (Table 7).

Table 7: Status of Sex Partners

<b>Gender Identity</b>	<b>No Regular Partner</b>	<b>Not Sure of Partner's HIV Status</b>	<b>Partner Not HIV-Positive</b>	<b>Partner HIV-Positive</b>	<b>Total</b>
<b>Male</b>	307 (48.0%)	91 (14.2%)	162 (25.4%)	79 (12.4%)	<b>639 (100%)</b>
<b>Female</b>	6 (9.8%)	1 (1.6%)	23 (37.7%)	31 (50.8%)	<b>61 (100%)</b>
<b>Transman</b>	1 (50.0%)	0 (0.0%)	1 (50.0%)	0 (0.0%)	<b>2 (100%)</b>
<b>Transwoman</b>	9 (52.9%)	1 (5.9%)	6 (35.3%)	1 (5.9%)	<b>17 (100%)</b>
<b>Total (N=719)</b>	<b>323 (44.9%)</b>	<b>93 (12.9%)</b>	<b>192 (26.7%)</b>	<b>111 (15.4%)</b>	<b>719 (100%)</b>

## Education

More than half (66.3%) of all respondents, the majority were among the male respondents, claimed to have completed tertiary education. 31% of the respondents claimed they completed secondary education, with more than half (62.2%) were among the female respondents population. Overall, only a few (2.1%) of the respondents completed primary education and fewer (1%) claimed they had no formal education.

Almost half (47.4%) of the transgender respondents claimed to have secondary and another half (52.6%) claimed to have tertiary education (Table 8).

Table 8: Level of Education

<b>Gender Identity</b>	<b>Secondary Education</b>	<b>Primary Education</b>	<b>No Formal Education</b>	<b>Tertiary Education</b>	<b>Total</b>
<b>Male</b>	175 (27.4%)	8 (1.3%)	4 (0.6%)	452 (70.7%)	<b>639 (100%)</b>
<b>Female</b>	38 (62.3%)	7 (11.5%)	0 (0.0%)	16 (26.2%)	<b>61 (100%)</b>
<b>Transman</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (100.0%)	<b>2 (100%)</b>
<b>Transwoman</b>	10 (58.8%)	0 (0.0%)	0 (0.0%)	7 (41.2%)	<b>17 (100%)</b>
<b>Total (N=719)</b>	<b>223 (31.0%)</b>	<b>15 (2.1%)</b>	<b>4 (0.6%)</b>	<b>477 (66.3%)</b>	<b>719 (100%)</b>

## **Employment**

Almost seven in ten of the respondents (67.3%), the majority were males, claimed that they had full-time work. Another 14.6% claimed to be self-employed. Smaller number of others claimed to be working part-time (3.8%), or were still studying (5.3%). While the overall unemployment was relatively high (9%), it was proportionally highest (40.9%) among the female respondents. The majority (73.6%) of the transgenders worked full-time while some of them were self-employed (15%) or (10.5%) work part time (Table 9).

Table 9: Employment Status by Gender Identity

Gender Identity	Self-Employed / Business Owner	Part-Time Worker	Full-Time Worker	Student	Unemployed	Total
Male	93 (14.6%)	25 (3.9%)	444 (69.5%)	37 (5.8%)	40 (6.3%)	<b>639 (100%)</b>
Female	9 (14.8%)	0 (0.0%)	26 (42.6%)	1 (1.6%)	25 (41.0%)	<b>61 (100%)</b>
Transman	0 (0.0%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)	<b>2 (100%)</b>
Transwoman	3 (17.6%)	2 (11.8%)	12 (70.6%)	0 (0.0%)	0 (0.0%)	<b>17 (100%)</b>
<b>Total (N=719)</b>	<b>105 (14.6%)</b>	<b>27 (3.8%)</b>	<b>484 (67.3%)</b>	<b>38 (5.3%)</b>	<b>65 (9.0%)</b>	<b>719 (100%)</b>

Among the working respondents, most of them are working in the private sector (60.8%), followed by public sector (25%) and NGO sector (14.2%). More than half of the female respondents (62.3%) are working in the NGO and private sector.

### Social Network / Support Group

Overall, only 27.5% of the respondents belonged to a social network or support group for PLHIV. Proportionally, more among the female (27.8%) than male (26.2%) respondents belonged to a support group / social network. The majority (68%) of the transgender respondents did belong to some social network / support group. The respondents preferred individual (60.5%) and online (55.4%) type of support especially for the female respondents (68.8%).

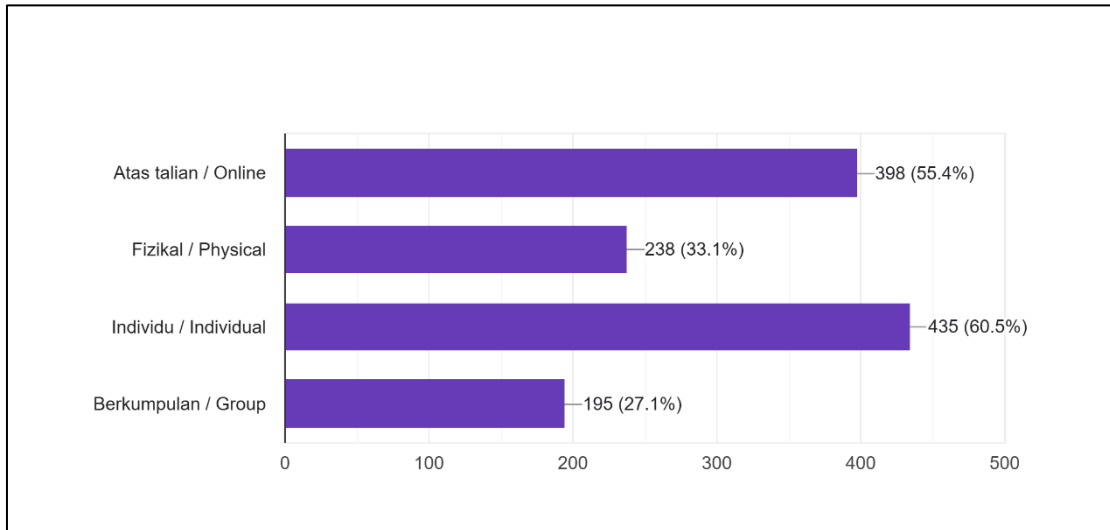


Figure 5: Type of Support

## Section B: Disclosure

After being tested positive for HIV, more than half decided (53.3%) of all respondents chose to reveal their status to others individuals. More male (54.6%) than female (37.7%) respondents chose to share their status. A majority (57.9%) of the transgender respondents also chose to disclose their HIV status (Table 10).

Table 10: Sharing of Status

Gender Identity	No	Yes	Total
Male	290 (45.4%)	349 (54.6%)	<b>639 (100%)</b>
Female	38 (62.3%)	23 (37.7%)	<b>61 (100%)</b>
Transman	0 (0.0%)	2 (100.0%)	<b>2 (100%)</b>
Transwoman	8 (47.1%)	9 (52.9%)	<b>17 (100%)</b>
<b>Total (N=719)</b>	<b>336 (46.7%)</b>	<b>383 (53.3%)</b>	<b>719 (100%)</b>

The survey results reveal that in more than half of the cases, the respondents only chose their close friends (74.9%), to share their status with. While less than half of the respondents chose to share their status with NGOs (47%), other or extended family members (44.1%), their spouses (37.3%), employers (26%) and coworkers (15.9%), less than one in twenty of the respondents shared them with their children.

The data suggest 17.6% of the total respondents claimed that their status was disclosed without their consents. Proportionally, these percentages of without consent disclosure were the same among the male (13%) and female (13%) respondents. However, proportionally it was more among the transgender respondents (21%). The non-binary respondent had no issue with disclosure without consent (Table 11).

Table 11: Claimed Disclosure Without Consent

<b>Gender Identity</b>	<b>No</b>	<b>Yes</b>	<b>Total</b>
<b>Male</b>	526 (82.3%)	113 (17.7%)	<b>639 (100%)</b>
<b>Female</b>	52 (85.2%)	9 (14.8%)	<b>61 (100%)</b>
<b>Transman</b>	2 (100.0%)	0 (0.0%)	<b>2 (100%)</b>
<b>Transwoman</b>	12 (70.6%)	5 (29.4%)	<b>17 (100%)</b>
<b>Total (N=719)</b>	<b>592 (82.3%)</b>	<b>127 (17.7%)</b>	<b>719 (100%)</b>

### **Section C: Personal Experiences including Harassment**

Almost one in ten of all the 383 respondents (42 respondents), who disclosed their HIV status, claimed they faced several discriminatory experiences. The most common was given discriminatory remarks or gossiped about by family and non-family members (14.7%).

Other personal discriminatory experiences claimed by the respondents, included being excluded from social gatherings (5.8%), and that their partners or spouses too experienced some form of discrimination (3.9%). Among the harassment that they faced, verbal (5.8%) and online (3.6%) abuse has clock in the highest. Followed by physical abuse (1.8%) and blackmail (0.8%).

From a housing application perspective, (96.9 %) vast majority have not been refused housing application and also a majority (94.2%) did not faced discrimination when pursuing higher education. Those who did experience discrimination during medical check-up (3.3%), scholarship application (1.5%) and during intake (1%).

### **Section D: Internal Stigma**

Internalised stigma is common among PLHIV and is rooted in the fear of HIV. These were strong negative feelings claimed by PLHIV after being diagnosed HIV-positive. The study reveals that most respondents felt guilty (73.7%), ashamed (75.1%), worthless (62.2%), and insulted (57.7%). Some of the most dominant negative feelings include they also found it difficult to share their HIV (87.3%) status, and preferred to hide it instead (88.9%) with proportionally similar across gender (Table 12).

Table 12: Feelings After Being Diagnosed HIV-Positive

<b>Feelings</b>	<b>Male</b>	<b>Female</b>	<b>Transman</b>	<b>Transwoman</b>	<b>Numbers (%) (N=719)</b>
Chose to Hide HIV Status	572	53	2	12	639 (88.9%)
Difficult to Share with Others About HIV Status	563	50	2	13	628 (87.3%)
Felt Guilty	493	27	2	8	530 (73.7%)
Felt Ashamed	497	32	2	9	540 (75.1%)
Felt Worthless	413	25	2	7	447 (62.2 %)
Felt Insulted	377	27	2	9	415 (57.7%)

Having those negative feelings led to other related feelings. The survey reveals that the most frequent feelings, in more than half of the cases, the respondents claimed were: loss of confidence to have relationships with others (64.2%), loss of desire to have children (58.5%), and loss of self-assurance (61.5%). The other feelings claimed were loss of confidence to cope with stress (50.9%), loss of direction to achieve personal or professional goals (49.4%), loss of dignity (45.9%); and loss of confidence to contribute to community (40.3%). These internalised stigma and strong negative feelings about themselves were similarly proportionally about the same across gender. However, in the case of having lost faith to practice religion, the incidence was 27 times more among the male than the female respondents. (Table 13).

Table 13: Internal Stigma Experiences

<b>Possible Experiences</b>	<b>Male</b>	<b>Female</b>	<b>Transman</b>	<b>Transwoman</b>	<b>Numbers (%) (N=719)</b>
Loss of Confidence to Have Close Relationship	430	22	1	9	462 (64.2%)
Loss of Desire to Have Children	387	25	2	7	421 (58.5%)
Loss of Self- Assurance	402	29	2	9	442 (61.5)
Loss of Confidence to Cope with Stress	335	23	1	7	366 (50.9%)

Loss of Direction to Achieve Personal or Professional Goals	331	15	2	7	355 (49.4%)
Loss of Dignity	305	18	2	5	330 (45.9%)
Loss of Confidence to Contribute to Community	271	14	1	4	290 (40.3%)
Loss of Faith to Practice Religion	135	5	0	4	144 (20 %)

The respondents were also asked how else the internal stigma have affected them, after being diagnosed HIV-positive. Most (53.4%) of them claimed they chose not to have sex and, one in third cases, chose not to attend social gathering.

Other responses 1 in four included isolating themselves from family and friends (25.6%), while others chose not to apply for jobs (18.4%) and in an extreme case (7.9%) chose not to seek health care, or treatment for their HIV infections. Similarly, all these incidences were proportional in numbers across gender (Table 14). No cases from transgender chose not to seek healthcare in reacting after being diagnosed HIV-positive.

Table 14: Reactions/Responses After Being Diagnosed HIV-Positive

Reactions/ Responses	Male	Female	Transman	Transwoman	Numbers (%) (N=719)
Chose Not to Have Sex	355	20	1	8	384 (53.4%)
Chose Not to Attend Social Gathering	204	16	0	6	226 (31.4%)
Isolate from Family and Friends	173	6	0	5	184 (25.6%)
Chose Not to Apply for Any Job	117	14	0	2	133 (18.4%)
Chose Not to Seek Health Care	50	7	0	0	57 (7.9%)

## Section E: Experiences with Services (Healthcare, Workplace and Insurance)

### Treatment Literacy

Section E discusses the experiences of HIV patients with their healthcare providers. When asked why the respondents took the HIV tests, majority (69.5%) of them claimed they did it voluntarily, followed by (18.6%) after undergoing a procedure. The other 1 in 10 respondents took their HIV test after being advised to do so by concerned others including their employers, or outreach workers, or NGOs, tested without their knowledge, pressured by others or was born with HIV.

One third among the female respondents found out their status, while undergoing other procedures (32.7%), while among the male (63.8%) and transgender (63.1%) respondents found out their status, when they voluntarily took the HIV test. Three respondents who claimed to have known their HIV positive status since childhood, or were born with it, were women (Tables 19a).

On the other reasons, among the males, 36% and 32%, found of their status while donating blood and while they were undergoing routine premarital HIV screenings, respectively. Among the female respondents, four in ten, found out while they were undergoing routine premarital HIV screenings, and one in three, while they were undergoing routine antenatal test (Table 15).

Table 15: Reasons for HIV Screening / Testing

Gender Identity	Forced	Suggested	Tested Without Knowledge	Underwent Voluntary	Underwent Procedure	Born / Acquired HIV in Childhood	Total
<b>Male</b>	11 (1.7%)	21 (3.3%)	36 (5.6%)	459 (71.8%)	112 (17.5%)	0 (0.0%)	<b>639</b> <b>(100%)</b>
<b>Female</b>	2 (3.3%)	1 (1.6%)	6 (9.8%)	29 (47.5%)	20 (32.8%)	3 (4.9%)	<b>61</b> <b>(100%)</b>
<b>Transman</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (100.0%)	0 (0.0%)	0 (0.0%)	<b>2</b> <b>(100%)</b>
<b>Transwoman</b>	1 (5.9%)	3 (17.6%)	1 (5.9%)	10 (58.8%)	2 (11.8%)	0 (0.0%)	<b>17</b> <b>(100%)</b>
<b>Total (N=719)</b>	<b>14</b> <b>(1.9%)</b>	<b>25 (3.5%)</b>	<b>43 (6.0%)</b>	<b>500 (69.5%)</b>	<b>134 (18.6%)</b>	<b>3 (0.4%)</b>	<b>719</b> <b>(100%)</b>

Table 16: Reasons for Voluntary HIV Screening / Testing

Characteristics	Male	Female	Transman	Transwoman	Numbers (%)
I was at risk of having HIV	255	11	2	6	274 (54.8%)
Out of curiosity	236	7	1	3	247 (49.4%)
Requirement Screenings (Marriage, Employment, Incarceration)	44	3	0	2	49 (9.8%).
Community based Programme	52	2	0	5	59 (11.8%).
Recommendation of service provider	140	17	0	7	164 (32.8%).
Because of Deteriorating Health	88	3	1	4	96 (19.2%)

*Note: Can answer more than one*

Of the 500 respondents, who volunteered to take the test, about half (54.8%) of them claimed they did the test voluntarily as they believed they were at risk and they just wanted to know out of curiosity (49.4%) and about one third respondents were recommended by their healthcare providers as part of other health screenings (32.8%). One in five who were sick at the time (19.2%) were encouraged by their family members to take the test. Others volunteered as it was a requirement for employment, marriage or incarceration (9.8%) and part of a community-based programme (11.8%).

According gender, among the male respondents, most took the test because they believed they were at risk (51%) and wanted to know out of curiosity (47.2%), or were recommended as part of healthcare screening (28%). The highest proportion among of the female respondents, took the test, when recommended by their healthcare providers as part of other health care screenings (3.4%); and another (2.2%) took it because they believed they were at risk.

A good majority of the respondents did not hesitate to take the HIV test (81.5%). This included 93.4% among the female, 80.5% among the male and 82.3% among the transgender respondents.

Out of the 133 who hesitated, the most frequent reasons for hesitation to take the HIV test were: 35 respondents were worried of being badly treated by healthcare workers or status being disclosed (26.3%), 23 respondents not ready to deal with the HIV infection (17.3%), 17

respondents claimed to have had previous bad experiences with them (12.7%) and 11 respondents (8%) worried others would find out their status. More of these claims were made by the male respondents, in comparison with the other genders. Only 9 female and transgender respondents (11.3%) had hesitated to take the test.

## ART Treatment

Only 12 out of 719 (1.7%) respondents did not receive ART treatment after finding out that they were HIV-positive (Table 17). Nine in ten of the 719 respondents (91.5%), who chose to start the ART treatment, did it because they were told of the benefits. Of the remaining respondents, 4.2% said they plan to start treatment later, less than 1% claimed to have been pressured to start for health reasons, while one female respondent claimed was pressured her partner / family members, to start treatment and other related reasons.

Table 17: Reasons for Starting ART Treatment

<b>Started ART Treatment</b>	<b>Male</b>	<b>Female</b>	<b>Transman</b>	<b>Transwoman</b>	<b>Numbers (%) (n=719)</b>
Was Told of the Benefits	575	54	2	16	647 (91.5%)
Decided to Wait and Start Treatment Later	27	3	0	0	30 (4.2%)
Other Reasons	27	5	0	1	42 (4.5%)
Did not Receive ART	10	2	0	0	12 (1.7%)
Total	639	61	2	17	719 (100%)

*Note: (row % of total respondents, column %).*

Almost half (46.9%) of the 707 respondents (12 respondents did not receive ART) chose to start on the ART treatment on the same day they were diagnosed HIV-positive. Among the rest of the respondents, almost one third (27.1%) claimed to have started their HIV treatment in less than 30 days after being diagnosed, (13.5%) of the respondents elected to start the treatment between a month to six months later, and another 12.3% of the respondents could not recall when they start treatment.

According to gender almost half of the male population (47.2%) took the test the same day. Two fifth of the female respondents started during one to six months or could not remember when they started treatment. All of the transmen took same day treatment while (41.1%) transwomen took it the same day (Table 18).

Table 18: Time Started ART Treatment

<b>Gender Identity</b>	<b>Same Day</b>	<b>&lt; 30 Days</b>	<b>1–6 Months</b>	<b>Do Not Remember</b>	<b>Total</b>
Male	297	181	82	69	629
Female	26	9	12	12	59
Transman	2	0	0	0	2
Transwoman	7	2	2	6	17
<b>Total</b>	<b>332 (46.9%)</b>	<b>192 (27.1%)</b>	<b>96 (13.5%)</b>	<b>87 (12.3%)</b>	<b>707</b>

At the time of this survey, only 4 out of the 707 (<1%) of the respondents claimed they were not undergoing the ART treatment anymore with 3 of them being males and 1 transwoman. Among the four reasons gathered (<1%) a response included feeling healthy due to high CD4 volume, claimed to have surrendered, could not tolerate the side effects of the medication, have stopped treatment because the treatment and medication were expensive while 3 response mentioned that they are not confident they can follow the medication schedule all their life (respondents can choose more than one).

Out of the 707 respondents, 632 or 9 out 10 (89.4%) did not miss a (ART) treatment purposely because there were worried about someone learning about their HIV status. Among those who miss on purpose, are 10.1% of the male population, 6.5% of the female population, and 31.5% of the transgender population.

### **Viral Load Test**

In response to the question whether they had been told of their undetectable viral load (“good viral load”) in the last 12 months, (71.2%) of the respondents said they had taken the test and were informed of the results. Less than 1% across gender claimed to have not been tested in the last 12 months and claimed do not know what viral load test was and the implications. Others (11.1%) were tested but were still waiting for their results while 13.2% of the respondents claimed did not take the test as virus was still detectable (Table 19). More 70% of the male, female, and transgender population reported undetectable viral load.

Table 19: Undetectable Viral Load (Good Viral Load)

<b>Gender Identity</b>	<b>Do Not Know What Viral Load Is</b>	<b>Awaiting Viral Load Result</b>	<b>No Viral Load Test in Past 12 Months</b>	<b>Viral Load Detectable</b>	<b>Yes (Viral Load Undetectable)</b>	<b>Total</b>
Male	16	68	13	88	454	639
Female	1	9	1	7	43	61
Transman	0	0	0	0	2	2
Transwoman	1	3	0	0	13	17
<b>Total</b>	<b>18</b>	<b>80</b>	<b>14</b>	<b>95</b>	<b>512</b>	<b>719</b>

### **Experience with Healthcare Service Delivery**

Majority of the respondents (96.9%), who decided to take the sought HIV treatment from Government Health Facilities. Four respondents (<1%) opted for private health facilities and eight (1.1%) of them opt for HIV treatment from NGO.

Similarly, nearly all of the 707 respondents gave very good feedback on the services provided by the mainly government health facilities staff. More than 95% of them claimed the staff spent enough time with them, their privacy and confidentiality were protected by the staff, that they were involved in all decisions regarding their treatments; and they were treated with respect just like all other patients (99%). While 43.8%, (45.4% of male population), of the respondents claimed being advised not to have sex, 2% of the respondents (12 males and 2 females) claimed they were denied treatment because they were HIV-positive.

While getting the non-HIV related treatments, 500 of the 719 (69.5%) respondents, did not disclosed their status during non-HIV related healthcare services. Among those who disclosed, were from 29.6% from the male population, 36.1% from the female population and 42.1% from the transgender population (Figure 33).

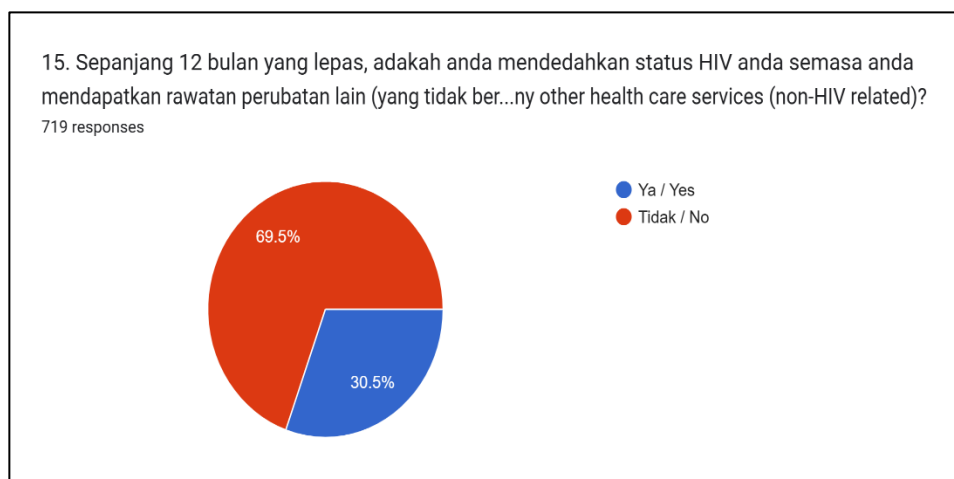


Figure 6 Disclosure Status during Non-HIV Treatment

Of the 219 respondents, four males and one female were denied treatment. Furthermore, 11.1% of the male population claimed they were advised not to have sex. Other respondents claimed that healthcare providers avoided physical contact, or became overcautious like wearing extra gloves (20.5%). Other experiences, shared by respondents, including distribution by gender are as listed in Table 20. Only (1.5%) of the total transgender population were involved in these experiences.

Table 20: Experience with Health Facility Staff

Treatment by Health Facility Staff	Male	Female	Transman	Transwoman	Total (N=219)
<b>Advised Not to Have Sex</b>	72 (88.9%)	7 (8.6%)	1 (1.2%)	1 (1.2%)	<b>81 (37.0%)</b>
<b>Avoid Physical Contact and Over Cautious (Wear Extra Gloves)</b>	41 (91.1%)	4 (8.9%)	0 (0.0%)	0 (0.0%)	<b>45 (20.5%)</b>
<b>Badly Talked at or Gossiped About</b>	23 (92.0%)	2 (8.0%)	0 (0.0%)	0 (0.0%)	<b>25 (11.4%)</b>
<b>Disclosing HIV Status Without Having Given Consent</b>	21 (84.0%)	3 (12.0%)	1 (4.0%)	0 (0.0%)	<b>25 (11.4%)</b>
<b>Verbally Abused</b>	4 (80.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	<b>5 (2.3%)</b>
<b>Denied Health Services</b>	4 (80.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)	<b>5 (2.3%)</b>

<b>Denied Dental Care in Case of Requiring Dental Treatment</b>	13 (86.7%)	2 (13.3%)	0 (0.0%)	0 (0.0%)	<b>15 (6.8%)</b>
<b>Physically Abused</b>	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	<b>0 (0.0%)</b>

*Note: Respondents can choose more than one option*

### Special Section for Women

This special section is for the 22 women who voluntarily informed the non-HIV health facility staff of their HIV status, while undergoing treatments related to antenatal and postnatal care for the last 12 month. 5 respondents claimed they were advised not to get pregnant (22.7%) while 6 respondents told can only receive art drug only if use contraception (27.2%), and 2 respondents pressured to accept ART treatment during pregnancy to reduce chances of transmitting HIV to others (9%) and another 2 respondents told can receive art drugs only if baby given formula milk, not breast fed (9%). None of the women claimed to been sterilised without their knowledge nor forced to have an abortion, while getting their antenatal or postnatal care (Table 21).

Table 21: Treatment by Health Facility Staff

<b>Responses of Health Facility Staff</b>	<b>Numbers (%)</b>
<b>Advised Not to Get Pregnant</b>	5 (22.7%)
<b>Pressured To Take ART Drugs During Pregnancy to Reduce HIV Transmission Rather Than to Counsel on Available Options</b>	2 (9.1%)
<b>Told Can Only Receive ART Drug Only if Use Contraception</b>	6 (27.3%)
<b>Told Can Receive ART Drugs Only if Baby Given Formula Milk, not Breast Fed</b>	2 (9.1%)
<b>Was Sterilised Without Knowledge</b>	0 (0.0%)
<b>Forced to Have an Abortion</b>	0 (0.0%)

*Note: Respondents can choose more than one option.*

### Workplace Discrimination

From an employment or workplace perspective, less than one in ten (6.9%) claimed they have experienced loss of income of refused employment application after HIV status was known

while 3.9% claimed their job description were changed, or they were denied promotion.

Table 22: Personal Discriminatory Experiences (Why Employment Application Rejected)

Gender Identity	Not Applicable	HIV Status Known	Other HIV/ Health-Related Reasons	Employment-Related Reasons	Other Reasons	Total
Male	573 (89.7%)	47 (7.4%)	6 (0.9%)	4 (0.6%)	9 (1.4%)	639 (100%)
Female	59 (96.7%)	2 (3.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	61 (100%)
Transman	2 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (100%)
Transwoman	16 (94.1%)	1 (5.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	17 (100%)
<b>Total (N=719)</b>	<b>650 (90.4%)</b>	<b>50 (7.0%)</b>	<b>6 (0.8%)</b>	<b>4 (0.6%)</b>	<b>9 (1.2%)</b>	<b>719 (100%)</b>



Figure 7: Workplace Discrimination

There were only 37 (5.1%) respondent reported discrimination at workplace. Out of the 37, 56.8% claimed that their HIV status was known without their consent. Among them 19 males, and 2 females were identified while not transgender population was reported.

Out of the 37 who experienced discrimination 51.4% claimed they were treated differently compared to their colleague, while 32.4% claimed they were previously fired from their

employment. Other significant form of discrimination included a rescinded permanent offer (18.9%), denied promotion (13.5%), changed department (13.5%), and denied employee benefits (13.5%).

Workplace discrimination may come at various stages of respondents' employment period. Given the options on the possible situations, 25 (67.6%) respondents claimed they were discriminated during employment, six (16.2%) claimed after receiving the job offer, four (10.8%) respondents, on the other hand, claimed to experience discrimination before receiving the job offer another four (10.8%) respondents claimed they felt discriminated during their job interviews.

### Insurance Coverage Discrimination

This section is on issues of stigmas and discrimination affecting HIV-positive respondents, related to their experiences in getting insurance coverage. 60.9% of the respondent have no experience in applying for insurance, 20.6% did not faced any issue applying for insurance. 82 respondents (11.4% ) admit they faced discrimination when applying for insurance particularly on health insurance (84.1%), life insurance (54.9%), general insurance (18.3%) and employee insurance (14.6%) (Figure 34). Out of those discriminated 93.9% were male, 3.6% were female and 2.4% were transgender.

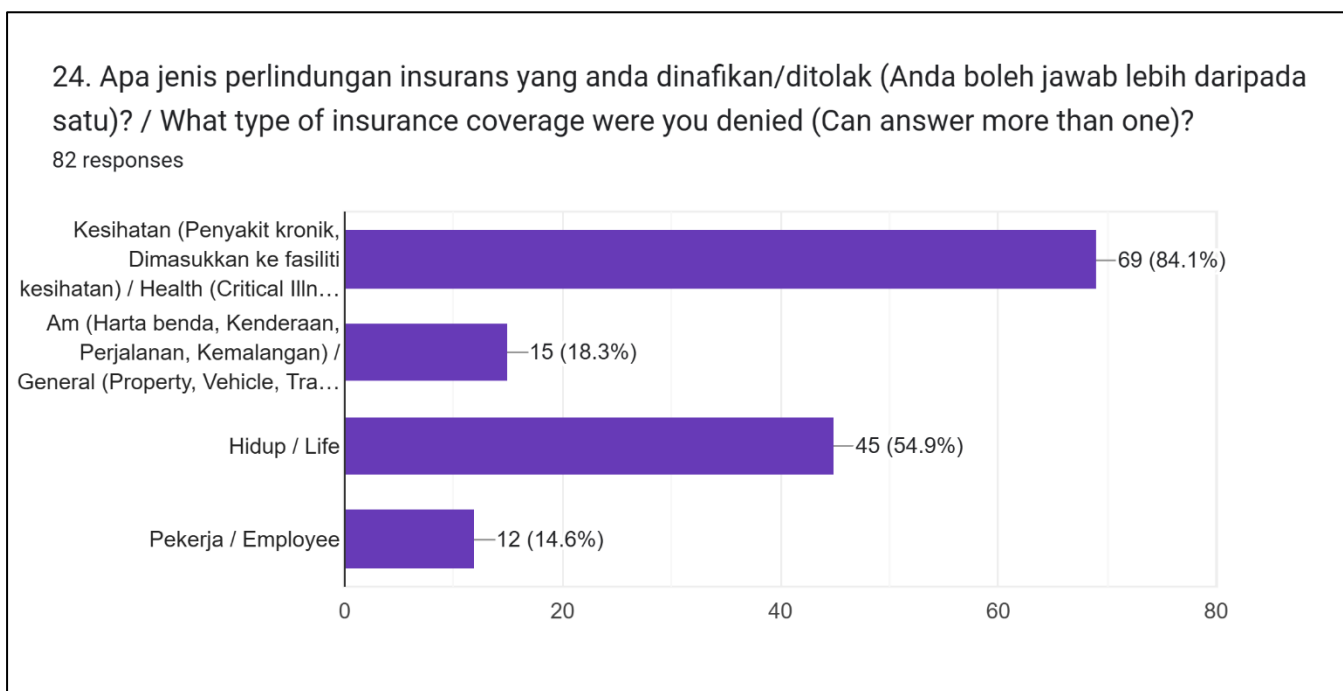


Figure 8: Type of Insurance Coverage

## Section F: Human Rights

Only 24 (3.4%) of the PLHIV respondents claimed being forced to be tested for HIV or to disclose their HIV status happened to them in the last 12 months (Table 23).

Table 23: Forced to Test for HIV

<b>Forced to test for HIV</b>	<b>Numbers (%) (N=719)</b>
Yes	24 (3.3%)
No	695 (96.7%)

79.2% or 19 respondents who chose not to take any action on this issue gave several reasons, including did not know their basic rights (26.3%), worried that taking action will expose their HIV status (21.1%) or did not know where to go or how to take action (15.8%), and insufficient financial resources to take action (10.5%). 5 respondent who took action, 3 of them manage to resolve the matter while the two was either in the midst of resolving and were not resolved.

On awareness about any laws protecting the rights of people living with HIV, a majority (61.8%) of the respondents said they were unaware of such laws. Only 33.7% of the respondents believed that there were laws to protect them, while the remaining 4.6% believed that there were no such laws.

This last question asked, what actions the respondents have taken, in the last 12 months, on issues related to stigma and discrimination in their effort to protect their rights. The preferred actions of the respondents provide emotional or financial support to help other PLHIV to deal with stigma and discrimination (47.5%) while speaking to the media seems the less preferred action (14.4%). These actions are well spread across gender especially for providing emotional or financial support to help other PLHIV to deal with stigma and discrimination which shows almost half of the male, female and transgender population.

Table 24: Actions Taken in the Last 12 Months

<b>Actions in the Last 12 Months</b>	<b>Male</b>	<b>Female</b>	<b>Transman</b>	<b>Transwoman</b>	<b>Total (N=719)</b>
<b>Provide Emotional or Financial Support to help other PLHIV to Deal with Stigma and Discrimination</b>	304 (47.6%)	31 (50.8%)	2 (100.0%)	5 (29.4%)	<b>342 (47.6%)</b>
<b>Challenge or Educate Those Who Discriminate Against Other PLHIV</b>	199 (31.1%)	10 (16.4%)	1 (50.0%)	5 (29.4%)	<b>215 (29.9%)</b>
<b>Participated in Campaigns Working to Address Stigma and Discrimination Against PLHIV</b>	140 (21.9%)	17 (27.9%)	2 (100.0%)	7 (41.2%)	<b>166 (23.1%)</b>
<b>Encouraged Community Leader to Take Action About Stigma and Discrimination Against PLHIV</b>	133 (20.8%)	13 (21.3%)	1 (50.0%)	6 (35.3%)	<b>153 (21.3%)</b>
<b>Challenge or Educate Those Who Discriminate Against Me</b>	142 (22.2%)	9 (14.8%)	1 (50.0%)	4 (23.5%)	<b>156 (21.7%)</b>
<b>Encouraged Government or Political Leaders to Take Action About Stigma and Discrimination Against PLHIV</b>	96 (15.0%)	13 (21.3%)	1 (50.0%)	4 (23.5%)	<b>114 (15.9%)</b>
<b>Spoke to The Media About Stigma and Discrimination Against PLHIV</b>	90 (14.1%)	10 (16.4%)	0 (0.0%)	3 (17.6%)	<b>103 (14.3%)</b>

*Note: Respondents can choose more than one option*

## Section G: Experiences on Stigma and Discrimination Due to Appearance or Behaviour

This section deals with public's perception of the PLHIV due to their appearances and behaviours and to understand the extent of stigma and discrimination experienced by them. The most common experiences (14.8%) claimed by the respondents were discriminatory remarks made at them or gossiped about. Apart from this, less than 6% from the total population, claimed to be denied employment (5%) or denied job promotion (3.8%), been excluded from social gatherings or activities (4.3%), spouses or partners have been discriminated (3.3%), were perceived as habitual drug users (PWID) (5.8%), perceived as giving sexual services in exchange for money (4.5%).

Overall, (12.8%) respondents claimed to have experienced harassment. There were twice the number verbal harassments compared to physical harassments. Cases of respondents being blackmailed were lower, by comparison. In all cases, these incidences happened more to the male respondents than to the females and transgenders (Table 25).

Table 25: Form of Harassments

Harassments		Male	Female	Transman	Transwoman	Numbers (%) (N = 719)
<b>No</b>		320 (50.1%)	32 (52.5%)	0 (0.0%)	5 (29.4%)	<b>357 (49.7%)</b>
<b>Not Applicable</b>		258 (40.4%)	26 (42.6%)	2 (100.0%)	8 (47.1%)	<b>294 (40.9%)</b>
<b>Yes</b>	<b>Verbal</b>	51 (8.0%)	3 (4.9%)	0 (0.0%)	4 (23.5%)	<b>92 (12.8%)</b>
	<b>Physical</b>	25 (3.9%)	2 (3.3%)	0 (0.0%)	1 (5.9%)	
	<b>Blackmailed</b>	6 (0.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	

*Note: Respondents can choose more than one option*

### **3.0 RECOMMENDATION AND CONCLUSION**

#### **Recommendations**

Notwithstanding the current government's relentless multi-approach efforts to contain the spread of HIV/AIDS, a "global epidemic", in the country, more needs to be done. Hence, the study suggests the following recommendations:

1. Awareness programmes and targeted interventions for eliminating the common myths of HIV among general population should be continued. This is important in order to reduce stigma and discrimination against PLHIV by the general population.
2. More psychosocial supports, including peer-to-peer support groups, network building, and counselling to PLHIV and their spouse/partners are needed. Proactive measures are vital in order to allow PLHIV to have access to the needed support system and at the same time obtaining the current information about treatment and care of HIV/AIDS.
3. Capacity building for stigmatised individuals and groups, which include training, legal services, and counselling must be developed. This is to enable PLHIV lead a more normal life.
4. Empower PLHIV to understand and assert their basic human rights. This is possible if PLHIV are well linked to the related groups, especially leading NGOs that deals directly with HIV/AIDS issues.
5. The government, non-governmental organisations, and PLHIV support groups, should work together towards ensuring an accessible supply of ART drugs and adequate nutrition.
6. A comprehensive program needs to be developed to address reproductive health issues of females who are living with HIV. This will also encourage female PLHIV to obtain the needed support and adequate knowledge about their health, treatment and care.

7. Strengthen capacity of health facility staff in relation to rights of PLHIV, confidentiality, testing, treating and providing specialized care at the government and private hospitals or other health facilities, including the university health facilities. This has to continue as health facility staff's unbiased acceptance will encourage more and more PLHIV to come forward for treatment and care. The health facilities staff and patient relationship must remain professional regardless of the patients' appearance or socio-economic status.
8. Facilitate the inclusion of stigma and discrimination reduction in national HIV strategic planning, funding and activities. This requires continued partnership between government health agencies and NGOs.
9. Advocate eradicating stigma and discrimination to be part of HIV prevention agenda at the national level and in the service delivery system. This is vital in order to invite more PLHIV to come forward for treatment and care voluntarily.
10. Develop HIV prevention strategies via all mass media, in consultation with PLHIV to ensure sensitivities of PLHIV are given due considerations.
11. Develop a system to measure stigma and discrimination using standardized measures or tools to monitor, address and evaluate the progress over time.
12. Conduct a periodic national stigma and discrimination survey to document the more current findings for continued improvement of the services related to HIV/AIDS treatment and care.

## **Conclusion**

Negative feelings or internal stigma among PLHIV is an expected experience, if not unavoidable. It is a psychological response, particularly and especially when HIV/AIDS is still a taboo in the country. More could be done especially for the education of the general population. Greater awareness about HIV/AIDS could reduce fear and misunderstanding on the danger and potential spread of the disease.

Data shows that less than one in three of the PLHIV respondents belonged to any social network / support group. This begs some answers as to why the rate is low, whereas such social network / support group can help PLHIV reduce their internal stigmas or other negative feelings. If there are enough of such social networks / support groups but PLHIV unaware of their existence, then the level of awareness must be enhanced. If the social network / support group are not yet regulated, then when establishing new ones, they must have clear structures and protocols, particularly in maintaining anonymity of their members, among others. Existing ones need to be registered and regulated as well. The Malaysian AIDS Council (MAC) and Non-governmental Organisations with the support of the Ministry of Health can be the lead agencies to look into this issue.

The level of workplace discrimination is not alarming at this point in time, so is the level of stigma and discrimination faced by PLHIV while getting non-HIV treatment and care. Nevertheless, the level of awareness on the predicament of PLHIV still have plenty of room for improvement. There are enough laws in the country to protect citizens' rights against any form of discrimination.

Government health facilities were the choice facilities by the general public because they are affordable. More than nine in ten of the respondents reported very satisfied with service delivery by the many health care facilities throughout the country. This is a positive sign as the treatment and care services provided by the government health care facilities are seen as one of the most trusted in the country.

A major concern of PLHIV is privacy and confidentiality, which was satisfactorily observed by the health care facility staff. The usual advice not to have sex is a non-issue, in fact should be appreciated, as this is one way of controlling the spread of HIV/AIDS infections.

In conclusion, evidences of this study demonstrate that there are HIV related stigma and discrimination faced by PLHIV in the country, although, as shown by this study, such incidences were low and not alarming. Although much have been done to combat this stigma and discrimination, many barriers still exist. The need to fully and effectively overcome these barriers is urgent; otherwise PLHIV will continue to not disclose their status. That in itself is a major setback in the fight against the spread of HIV/AIDS. This study has highlighted the importance of addressing the adversity of stigma and discrimination of HIV/AIDS; and that there is still room for more efforts to ensure greater success for Malaysia's development and social well-being of the general population.

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# COMPENDIUM

## COMPENDIUM I: SPECIAL SECTION FOR WOMEN

### INTRODUCTION

This section focuses on the 61 women respondents who took part in the national survey, MySES 2025. Data for the analyses was extracted from the 719 valid respondents of the main study. The objectives of this special section were:

- To determine whether the women respondents experienced different levels of stigma and discrimination from the main sample of the study.
- To determine if the women were treated with a professional manner by the health facility staff who provided their antenatal and postnatal care and other health services.

### SECTION A: BACKGROUND OF RESPONDENTS

The female respondents in the 2025 survey trended older, with the majority (55.7%) belonging to the 41-60 age group, followed by 37.7% in the 19-40 age bracket.

Almost all women respondents (91.8%) belonged to the Non-Key Population group. A small minority were Persons Who Inject Drugs (PWID) at 4.9%, and 1.6% were sex workers. It can be inferred that the vast majority of these women contracted HIV/AIDS from their spouses or sex partners.

**Table 1: Key Population**

<b>Key Population</b>	<b>Numbers (%) (N=61)</b>
<b>Sex Workers</b>	1 (1.6%)
<b>People who Inject Drugs (PWID)</b>	3 (4.9%)
<b>Men Having Sex with Men (MSM)</b>	0 (0%)
<b>Transgender</b>	1 (1.6%)
<b>Non-Key Population</b>	56 (91.8%)

Most of the women (62.3%) claimed they had secondary education, 26.2% claimed tertiary education, and 11.5% had primary education. Employment remains a critical issue; while 42.6% of the women claimed to work full-time, a significant 41.0% were unemployed.

**Table 2: Level of Education**

<b>Level of Education</b>	<b>Numbers (%) (N=61)</b>
<b>Secondary Education</b>	38 (62.3%)
<b>Tertiary Education</b>	16 (26.2%)
<b>Primary Education</b>	7 (11.5%)
<b>No Formal Education</b>	0 (0.0%)

**Table 3: Employment Status**

<b>Employment Status</b>	<b>Numbers (%) (N=61)</b>
<b>Full-time Worker</b>	26 (42.6%)
<b>Self-employed</b>	9 (14.8%)
<b>Part-time Worker</b>	0 (0.0%)
<b>Student</b>	1 (1.6%)
<b>Not Employed</b>	25 (41.0%)

Slightly more women respondents (27.8%) claimed to belong to a social network or support group compared to the male respondents (26.2%).

## **SECTION B: DISCLOSURE**

More than one-third (37.7%) of the women respondents chose to share their status after being confirmed HIV-positive. However, 9 women (14.8%) claimed that their HIV status was disclosed to others without their consent.

**Table 4: Sharing of Status**

<b>Sharing of Status</b>	<b>Numbers (%) (N=61)</b>
<b>Yes</b>	23 (37.7%)
<b>No</b>	38 (62.3%)

## **SECTION C & D: INTERNAL STIGMA AND HARASSMENT**

At least half of the women respondents felt ashamed, guilty, worthless, or insulted after knowing they were HIV-positive. Consequently, over 80% of the women found it difficult to share their status with others and chose to hide it.

**Table 5: Feelings after Knowing HIV Status**

<b>Feelings after Confirmed HIV-positive</b>	<b>Numbers (%) (N=61)</b>
<b>Chose to Hide HIV Status</b>	53 (86.9%)
<b>Felt Difficult to Share with Others</b>	50 (82.0%)
<b>Felt Ashamed</b>	32 (52.5%)
<b>Felt Guilty</b>	27 (44.3%)
<b>Felt Worthless</b>	25 (41.0%)
<b>Felt Insulted</b>	27 (44.3%)

In nearly half (47.5%) of the cases, the women claimed to have lost self-assurance. Others claimed a loss of desire to have children (41.0%), a loss of confidence to cope with stress (37.7%), and a loss of confidence to have close relationships (36.1%). In response to these negative internal feelings, roughly one in three women (32.8%) chose not to have sex, while 26.2% chose not to attend social gatherings. Furthermore, 23.0% chose not to apply for job opportunities. Regarding external harassment, the rates remained relatively low. Only 3 women (4.9%) reported facing verbal harassment, and 2 women (3.3%) reported physical harassment.

#### **SECTION E: EXPERIENCES WITH SERVICES (HEALTHCARE, WORKPLACE AND INSURANCE)**

The vast majority of women reported positive experiences with healthcare staff during their routine treatments. However, of the women who disclosed their HIV status while getting non-HIV care at health facilities, 7 women were advised not to have sex, 4 reported staff avoiding physical contact, and 3 claimed their status was disclosed without consent.

#### **Antenatal and Postnatal Care**

A special block captured data for 22 women who underwent antenatal and postnatal care. While 7 (31.8%) reported being treated normally like other patients, concerning deviations from standard care were noted.

**Table 6: Treatment by Health Facility Staff (Maternal Care)**

<b>Responses of Health Facility Staff</b>	<b>Numbers (%) (n=22)</b>
<b>Advised Not to Get Pregnant</b>	5 (22.7%)

<b>Told Can Only Receive ART Drug if Use Contraception</b>	6 (27.3%)
<b>Pressured To Take ART Drugs During Pregnancy to Reduce HIV Transmission</b>	2 (9.1%)
<b>Told Can Receive ART Drugs Only if Baby Given Formula Milk</b>	2 (9.1%)
<b>Was Sterilised Without Knowledge</b>	0 (0.0%)
<b>Forced to Have an Abortion</b>	0 (0.0%)

### **Workplace**

While the overall rates of workplace discrimination were low, 2 female respondents (3.3%) reported that their employment applications were rejected specifically because their HIV status became known.

### **Insurance**

Out of the total 82 respondents nationwide who reported being denied insurance coverage due to their status, 3.6% were women (representing roughly 3 female respondents).

## **SECTION F: HUMAN RIGHTS AND ADVOCACY**

Women living with HIV demonstrated strong advocacy and peer support behaviors. When asked about actions taken in the past 12 months to protect their rights, more than half of the women actively provided support to others.

**Table 7: Actions Taken in the Last 12 Months**

<b>Actions Taken in the Last 12 Months</b>	<b>Numbers (%) (N=61)</b>
<b>Provide Emotional/Financial Support for PLHIV</b>	31 (50.8%)
<b>Participated in Campaigns Addressing Stigma</b>	17 (27.9%)
<b>Encouraged Government/Political Leaders to Take Action</b>	13 (21.3%)
<b>Encouraged Community Leader to Take Action</b>	13 (21.3%)
<b>Spoke to The Media About Stigma and Discrimination</b>	10 (16.4%)

## **DISCUSSION AND CONCLUSION**

The following are key observations made regarding the women respondents based on the 2025 study:

1. The majority of female respondents belonged to the 41-60 age group (55.7%).
2. Almost all women respondents (90.2%) did not belong to any Key Population group (such as PWID, sex workers, or transgender).
3. Most of them (62.3%) had secondary education, while 26.2% had tertiary education.

4. There is a persistent gendered economic gap; 41.0% of the women were unemployed, and only 42.6% claimed to be working full-time.
5. Slightly more female respondents (27.8%) belonged to support groups compared to male respondents (26.2%).
6. The women shared severe internal stigmas; 86.9% chose to hide their status, and 52.5% reported feeling ashamed.
7. In maternal healthcare settings (N=22), no women were involuntarily sterilized or forced to have abortions.
8. However, coercive maternal practices remain an issue; 27.3% were told they could only receive ART if using contraception, and 22.7% were advised not to get pregnant.
9. Women showed high rates of community advocacy, with 50.8% actively providing emotional or financial support to other PLHIV facing discrimination.
10. Workplace and financial discrimination still affect women, with isolated cases of employment rejection and insurance denial explicitly tied to their HIV status

## **COMPARISONS: MYSES 2021 AND MYSES 2025 (SPECIAL SECTION FOR WOMEN)**

This section evaluates the shifting experiences of Women Living with HIV (WLHIV) in Malaysia over the four-year period between the 2021 and 2025 MySES reports. The comparative data highlights significant clinical and psychosocial shifts, as well as persistent structural barriers affecting female respondents.

### **1. Demographics and Socioeconomic Status**

- **Sample Size and Age:** The total number of female respondents decreased from 138 in 2021 to 61 in 2025. The demographic profile has trended older; in 2021, the median age was 37 with the majority (20%) in the 36-40 age group, whereas in 2025, a significant majority (55.7%) belonged to the 41-60 age group.
- **Key Populations:** The vast majority of women in both surveys continue to belong to the Non-Key Population group, shifting slightly from 97% in 2021 to 90.2% in 2025.
- **Education:** Educational attainment among WLHIV saw a notable improvement. Women holding tertiary education degrees increased from 14% in 2021 to 26.2% in 2025.
- **The Gendered Economic Gap:** Despite improvements in education, systemic economic barriers remain completely stagnant. The unemployment rate for WLHIV was 41% in 2021 and remained at a troubling 41.0% in 2025.

## 2. Disclosure and Privacy

- **Voluntary Disclosure:** There is a positive upward trend in WLHIV feeling safe enough to disclose their status. In 2021, only 25% of women shared their status. By 2025, this figure improved to 37.7%.
- **Non-Consensual Disclosure:** Unfortunately, breaches of privacy remain a persistent issue for women, rising slightly from 13% in 2021 to 14.8% in 2025.

## 3. Internal Stigma

- **Decreasing Psychological Burden:** While the general 2025 MySES report noted an *increase* in internal stigma across the broader PLHIV population, the data for *women specifically* shows an encouraging decline in internalized negative feelings:
  - Feelings of being **ashamed** dropped from 64% in 2021 to 52.5% in 2025.
  - Feelings of **guilt** dropped from 61% in 2021 to 44.3% in 2025.
  - Feelings of **worthlessness** dropped from 54% in 2021 to 41.0% in 2025.
- Despite these improvements, the overarching urge to hide their HIV status remains extremely high (88% in 2021 vs. 86.9% in 2025 ).

## 4. Maternal Healthcare and Elimination of Mother-to-Child Transmission (EMTCT) Implications

The experiences of WLHIV receiving antenatal and postnatal care reveal alarming shifts in maternal healthcare practices. The sample sizes for this specific metric were 30 women in 2021 and 22 women in 2025.

- **General Care:** In 2021, 57% of women reported being treated normally like other patients during maternal care. In 2025, this fell to just 31.8% (7 out of 22 women).
- **Reproductive Pressure:** The percentage of women advised not to get pregnant saw a minor decrease from 27% in 2021 to 22.7% in 2025. However, the practice of coercing contraception spiked dramatically. In 2021, only 7% of women were told they could only receive Antiretroviral Therapy (ART) if they used contraception. In 2025, this condition was imposed on 27.2% of the respondents.
- **Infant Feeding:** The mandate to use formula milk as a prerequisite for receiving ART tripled, rising from 3% in 2021 to 9.1% in 2025.
- **Severe Violations:** In both 2021 and 2025, 0% of women reported being forced to have an abortion or sterilized without their knowledge.

## 5. Workplace and Insurance Discrimination

- **Workplace:** In 2021, 0% of female respondents reported experiencing workplace discrimination. In 2025, the needle moved slightly, with 3.3% of women reporting that their employment applications were rejected specifically because their HIV status was known.
- **Insurance:** Exclusion from financial protection via insurance denials remains a hurdle, though it slightly improved. In 2021, 12% of women were denied coverage. In 2025, women accounted for 3.6% of the total national denials, representing roughly 4.9% of the female respondent pool.

### Conclusion

The four-year comparative data for Women Living with HIV (WLHIV) reveals a complex landscape. On a positive note, women are achieving higher levels of education and are experiencing a notable decrease in internalized feelings of shame, guilt, and worthlessness. Disclosure rates have also improved. However, these psychosocial gains are heavily offset by persistent structural barriers. The female unemployment rate remains frozen at a disproportionately high 41%. Most critically, maternal healthcare settings have seen a sharp rise in coercive practices—specifically tying life-saving ART access to mandatory contraception and formula feeding—which pose a severe threat to human rights and Malaysia's ongoing Elimination of Mother-to-Child Transmission (EMTCT) validation

## COMPENDIUM II: COMPARISONS MYSES 2021 AND MYSES 2025

### Section A: Background of Respondents

This section establishes the demographic baseline, revealing shifts in who is participating in the survey and their socioeconomic standing.

- i. **Sample Size and Reach:** The total number of valid respondents decreased from 1,107 in 2021 to 719 in 2025. Both studies successfully surpassed their statistical target of 398 respondents.
- ii. **Key Populations:** The representation of Men who Have Sex with Men (MSM) increased significantly from 60% in 2021 to 72.9% in 2025. Conversely, respondents identifying as Persons Who Inject Drugs (PWID) dropped from 9% to 4.3% and the Non-Key Population dropped from 28% (98% women) to 19.9% (90% women).
- iii. **Education and Employment:** Educational attainment improved over the four years, with tertiary education rates rising from 54% to 66.3%. Full-time employment also saw a positive bump, from 57% to 67.3%.
- iv. **The Gendered Economic Gap:** A stagnant and troubling trend is the high unemployment rate among female respondents. In 2021, 41% of women were unemployed, and this barely shifted in 2025, sitting at 40.9%. This indicates a persistent structural barrier to economic empowerment for Women Living with HIV (WLHIV).

### Section B: Disclosure

Disclosure is a primary indicator of psychological safety and social support.

- i. **Overall Disclosure Rates:** There is a highly encouraging upward trend in general disclosure. In 2021, only 30% of respondents shared their status. By 2025, this jumped to 53.3%.
- ii. **Shifts in Disclosure Targets:** While disclosure to close friends remained consistently high (77% in 2021 vs. 74.9% in 2025), workplace disclosure saw an alarming drop. In 2021, 28% disclosed to co-workers while in 2025, this plummeted to just 15.9%. This suggests the workplace is increasingly perceived as an unsafe environment.
- iii. **Non-Consensual Disclosure:** Breaches of privacy remain a systemic issue, rising from 13% in 2021 to 17.6% in 2025.

### Section C: Personal Experiences (including Harassment)

This section measures the overt, external hostility faced by the community.

- i. **External Harassment (Decreasing):** Reports of direct external hostility show a downward trend. In 2021, 11% reported verbal harassment and 3% reported physical harassment. By 2025, verbal harassment dropped to 5.8% and physical abuse to 1.8%. Interestingly, 2025 data specifically capture online abuse (3.6%), highlighting the modernization of harassment.
- ii. **Discriminatory Remarks:** Overt discrimination appears to be decreasing. In 2021, 32% of those who disclosed their status faced discriminatory remarks or gossip. By 2025, this fell to 14.7%.

#### **Section D: Internal Stigma**

A critical paradox emerges here: while external harassment is decreasing, the internal psychological trauma is worsening.

**Intensifying Negative Feelings (Increasing):** Despite fewer overt external attacks, the psychological burden on PLHIV has intensified

- i. Feelings of **guilt** rose from 72% in 2021 to 73.7% in 2025.
- ii. Feelings of **shame** increased from 70% to 75.1%.
- iii. Feelings of **worthlessness** surged from 55% to 62.2%.

**Social Isolation:** The urge to hide one's status remains overwhelmingly high (88% in 2021 and 88.9% in 2025). The loss of confidence in having close relationships also climbed from 59% to 64.2%. As a researcher, this indicates that current anti-stigma campaigns are failing to reach the internal psyche of PLHIV.

#### **Section E: Experiences with Services (Healthcare, Workplace and Insurance)**

The healthcare sector remains a strong pillar of support and clinical success.

- i. **ART Uptake and Viral Suppression:** In 2021, 95% of respondents were on Antiretroviral Therapy (ART). By 2025, this reached near-universal levels at 98.3% (with only 1.7% not receiving ART). Consequently, those reporting an undetectable viral load improved significantly, jumping from 58% to 71.2%.
- ii. **Healthcare Satisfaction:** Trust in public health systems remains exceptionally high. In 2021, 99% used government facilities. In 2025, 96.9% continued this trend, with over 95% affirming that staff protected their privacy and treated them with respect.
- iii. **Maternal Healthcare:** Experiences for WLHIV regarding maternal care showed slight improvement. Advice against getting pregnant dropped from 27% in 2021 to 22.7% in 2025. Importantly, both reports confirm zero instances of forced abortions or sterilizations.

- iv. **Workplace Discrimination:** While the overall reported incidence is low relative to the sample size, the severity is concerning. In 2021, 3% of full-time employees reported discrimination. In 2025, this rose to 5.1%. Crucially, of those facing discrimination in 2025, 32.4% reported being fired, and 56.8% reported their status was outed without consent. This directly correlates with the massive drop in workplace disclosure noted earlier.
- v. **Insurance Denials:** Financial and structural exclusion via insurance companies is a persistent barrier. In 2021, 11% were denied coverage. In 2025, this figure remained virtually unchanged at 11.4%, with Health and Life insurance being the primary categories denied.

## **Section F: Human Rights**

Systemic literacy and empowerment remain stubborn hurdles.

- i. **Violations:** Reports of being forced to test for HIV remained relatively stable and low, shifting from 4% in 2021 to 3.4% in 2025.
- ii. **Legal Literacy:** Awareness of human rights protections remains stagnant. In 2021, 62% were unaware of any protective laws, and only 35% knew they existed. In 2025, these figures barely moved: 61.8% remained unaware, and 33.7% were aware.

## **Section G: Experiences on Stigma Due to Appearance or Behaviour**

This section evaluates stereotyping based on societal biases.

- i. **Appearance-Based Bias:** The experience of facing discriminatory remarks made at them or gossiped about due to appearance or behavior slightly increased from 12% in 2021 to 14.8% in 2025.
- ii. **Harmful Stereotyping:** Being incorrectly perceived as a habitual drug user (PWID) rose slightly from 5% to 5.8%. Similarly, being perceived as exchanging sex for money increased from 2% to 4.5%. This reflects entrenched societal prejudices that continue to unfairly profile the community.

## **The Big Picture (2021 vs 2025)**

While Malaysia has made remarkable strides in the clinical and systemic management of HIV, the internalized, psychosocial trauma experienced by PLHIV is calcifying and, in many ways, getting worse.

## **The Central Paradox: Medical Thriving vs. Psychological Surviving**

From a clinical standpoint, the 2021 to 2025 MySES data represents a massive public health victory. In 2021, 95% of respondents were on Antiretroviral Therapy (ART). By 2025, that number reached near-universal coverage, with only 1.7% of respondents not receiving ART. Consequently,

reports of an undetectable viral load surged from 58% in 2021 to 71.2% in 2025. Furthermore, trust in government healthcare facilities remains exceptionally high across both reports. Over 95% of respondents in both years reported that their privacy was protected and they were treated with respect. However, despite these biomedical successes, significant psychological barriers persist that profoundly compromise the psychological well-being of PLHIV in Asia (Magantor et al., 2026). The clinical interventions are successfully keeping the community alive, but the lack of targeted, effective psychosocial interventions means the community is struggling to achieve a high quality of life free from stigma (Magantor et al., 2026).

### **The Deepening Crisis of Internalized Stigma**

The most alarming conclusion drawn from the data is the intensification of internalized stigma. As societal awareness campaigns have pushed overt discrimination slightly out of the public eye, the stigma has turned inward, becoming a deeply personal psychological burden. Every major metric for negative self-perception increased over the four-year period.

- i. Feelings of guilt rose from 72% in 2021 to 73.7% in 2025.
- ii. Feelings of shame climbed from 70% in 2021 to 75.1% in 2025.
- iii. Most concerning from a mental health perspective is the feeling of worthlessness, which surged from 55% in 2021 to 62.2% in 2025.
- iv. Recent academic consensus defines internalized stigma as a primary stressor that acts as a formidable barrier to well-being, manifesting directly as shame, guilt, and worthlessness (Magantor et al., 2026).
- v. This internal turmoil manifests directly in behavior, as the desire to completely hide their HIV status remains immovably high, moving from 88% in 2021 to 88.9% in 2025.
- vi. The MySES data shows that PLHIV are increasingly cutting themselves off from fundamental human experiences.
- vii. The loss of confidence in forming close relationships jumped from 59% in 2021 to 64.2% in 2025.
- viii. This self-deprecating process and fear of judgment has been robustly linked to social withdrawal and impaired psychological health (Magantor et al., 2026).

### **The Evolution of External Stigma: From Overt to Covert**

The way society discriminates against PLHIV has shifted from overt aggression to covert, structural, and appearance-based bias.

- i. Direct, face-to-face harassment is dropping, as verbal harassment decreased from 11% in 2021 to 5.8% in 2025.
- ii. Physical abuse dropped from 3% in 2021 to 1.8% in 2025.
- iii. Conversely, discrimination based purely on societal stereotyping of appearance and behavior increased from 12% in 2021 to 14.8% in 2025.
- iv. Harmful profiling—such as incorrectly assuming a PLHIV is an intravenous drug user—rose slightly from 5% in 2021 to 5.8% in 2025.

### **The Workplace as a Hostile Microcosm**

The workplace remains a major structural barrier, highlighting severe vulnerabilities in corporate policy and employment law.

- i. General workplace discrimination reports rose from roughly 3% of the full-time employed in 2021 to 5.1% in 2025. Devastatingly, of those who faced workplace discrimination in 2025, 56.8% had their status outed without their consent.
- ii. Furthermore, 32.4% of those facing discrimination in 2025 reported being fired from their employment.
- iii. In Malaysia, there has been a sharp rise in cases of bias against individuals with health conditions, particularly those living with HIV, leading to job offer revocations, forced resignations, or dismissals based purely on health status (LH-AG, 2024).
- iv. The absence of comprehensive legal frameworks in Malaysia leaves many workers vulnerable to discrimination, highlighting the urgent need for reforms in employment law to protect their rights and well-being (LH-AG, 2024).
- v. This hostile environment perfectly explains why workplace disclosure (to colleagues) plummeted from 28% in 2021 to just 15.9% in 2025—the workplace is rightfully perceived as an active threat to their livelihood.

The 2021 to 2025 MySES data, demands a paradigm shift in how we approach HIV in Malaysia. The era of focusing strictly on clinical adherence is effectively maturing into a success. The new frontier is entirely psychosocial and structural. The fact that 62.2% of the community feels "worthless" despite being medically healthy is a profound failure of social support systems. To bridge this gap, future policies and funding must pivot aggressively toward mental health infrastructure, peer-led trauma counseling, and strict, legally enforced anti-discrimination protections in the corporate sector. Social support and spiritual coping are crucial protective resources that partially mediate the pernicious relationship between

internalized stigma and the psychological well-being of PLHIV in Asia (Magantor et al., 2026). We have succeeded in ensuring PLHIV can survive the virus; the next decade's work must ensure they can survive the society.