



People Living with HIV Stigma Index 2.0 in Indonesia

Jaringan Indonesia Positif

2024





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ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-Retroviral Treatment
ARV	Anti-Retroviral
FGD	Focus Group Discussions
GNP+	Global Network of People living with HIV
HIV	Human Immunodeficiency Virus
JIP	Jaringan Indonesia Positif (Indonesia Positive Network)
KP	Key Populations
MSM	Men who have Sex with Men
PLHIV	People Living with HIV
PWID	People Who Inject Drugs
PWUD	People Who Use Drugs
S&D	Stigma and Discrimination
SW	Sex Workers
SIHA	Sistem Informasi HIV/AIDS (Information System of HIV/AIDS)
TG	Transgender
TWG	Technical Working Group
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	The United Nations Population Fund
WLHIV	Women Living with HIV



FOREWORD

Many people living with HIV face stigma and discrimination, and many more are not aware of their rights and ways to change their current situation. HIV-related stigma has an impact on their access to HIV testing, their status disclosure, and their treatment adherence, including the potential loss of jobs, housing, and educational opportunities. It will have an impact on the mental health and well-being of people living with HIV, as well as their interpersonal relationships with family and friends.

The Indonesia Positive Network (JIP) is a network of people living with HIV who aim to achieve equality in health rights through advocacy and collaborative work with a peer support system within a human rights framework so that every person has the same honour, dignity, and position before the law. Everyone also has the right to live and not experience discrimination. The state has guaranteed every citizen through Law Number 39 of 1999 concerning Human Rights. This foundation then became the legal umbrella for human rights and freedom from discriminatory behaviour, especially for key populations, including people living with HIV in Indonesia.

We are very proud of our role in providing evidence-based data on stigma and discrimination. We hope that the results of the Stigma Index 2.0 study in Indonesia will influence national policies and programs and improve the lives of people living with HIV. Building a stigma-free environment is critical to Indonesia's efforts to achieve its "95-95-95" targets and end AIDS by 2030. Recognizing the role of stigma and discrimination as barriers to engagement in HIV testing and treatment services, in 2021, the UN launched "Zero Stigma" campaign with the new global 10-10-10 framework: Less than 10% of countries have punitive legal and policy environments that deny access to justice, less than 10% of people living with HIV and key populations experience stigma and discrimination; less than 10% of women, girls, people living with HIV and key populations experience gender inequality and violence. We hope the 2023 Stigma Index study results will support Indonesia in reaching this goal.



The success of the Stigma Index study in Indonesia is a collective achievement. Special appreciation must be given to all the people living with HIV who have contributed to sharing their experiences in this study, all data collectors, data staff, and the Chair of the JIP Regional Secretariat in the 16 provinces where the research was conducted. We also thank the Indonesian Ministry of Health, Global Fund, GNP+, UNAIDS Indonesia, Indonesia AIDS Coalition, UN WOMEN Indonesia, and the International Community of Women Living with HIV who have supported the implementation of the Stigma Index 2.0 research. We also thank the steering committee members, local organizations, peer support groups, and community-based organizations who provided input and support in this study's design, implementation, and analysis.

Finally, we express our sincere thanks to the JIP team, who have worked tirelessly for the success of this study. We hope to utilise the data and learnings from the 2023 Stigma Index to guarantee the human rights of all people living with HIV in Indonesia to fair, high-quality treatment, dignity, and respect.

Meirinda Sebayang, S.H., MSc.PH.

Chair of the National Secretariat

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GLOSARIUM

Stigma is a discrediting attitude by someone toward another person caused by differences, deviations, or damaged identities held or carried out by other people. The mechanism of stigma experienced by people living with HIV can take the form of enacted stigma, anticipated stigma, and internalized stigma.

Enacted stigma stigma is a stigma that refers to acts of discrimination experienced by people living with HIV, such as violence and marginalisation. Stigma in the form of discrimination is a consequence of the stigma itself, which results in unfair actions towards someone in a non-objective manner.

Anticipatory stigma is awareness of negative social perceptions of HIV and the idea that people living with HIV will experience discriminatory actions by other people in the future.

Internalized stigma is stigma resulting from negative beliefs, views, and feelings of people living with HIV regarding their own HIV status. For example, internalized stigma can lead to thoughts such as: "I am ashamed of my HIV status", "I sometimes feel guilty / worthless because I am HIV-positive"

Intersectional Stigma and discrimination are the stigma and discrimination experienced by people living with HIV because of other aspects of their lives or identity for example, people who are marginalized because of their gender, gender identity, age, sexual orientation or involvement in sex work or drug use, social-economy status, or even cultures/norms.

Discrimination is when someone treats you unfairly based on their negative views and beliefs.

Key Populations in Indonesia, there are four groups categorized as key population, namely transgender, men who have sex with men (MSM), sex workers (SW), and people who used drugs (PWUD).

HIV/AIDS is Human immunodeficiency virus (HIV) is an infection that attacks the body's immune system. Acquired immunodeficiency syndrome (AIDS) is the most advanced stage of the disease.

EXECUTIVE SUMMARY

Until 2023, the number of people living with HIV in Indonesia was found to be 377,650 people from 515,455 estimated numbers, of which 62% were men and 38% were women. Over the years (2005-2023), the highest number of new HIV cases occurred in 2022, namely 52,955 cases. From January to March 2023, HIV case reports revealed the highest prevalence of key populations on men who have sex with men (27.7%), pregnant women (16.1%), people with tuberculosis (12.4%), sex worker (3.3%), female transgender populations (1.1%), person with sexually transmitted disease (0.9%), former prison inmate (0.8%), and people who inject drugs (0.5%)¹. Stigma still exists at various levels in Indonesia. People living with HIV are vulnerable to stigma and discrimination, which can affect their care and quality of life in both social and healthcare settings.

In 2023, the PLHIV Stigma Index 2.0 instrument was used to measure the intersection of stigma and the resilience that the people living with HIV face in Indonesia. The main aim of the 2023 Stigma Index research in Indonesia was to expand the understanding of the stigma and discrimination faced by PLHIV in Indonesia. The specific objectives were 1) to identify the various experiences of PLHIV regarding HIV-related stigma and discrimination of intersectionality, 2) to identify challenges and obstacles to reduce stigma and discrimination in each region by referring to the local cultural context of each region- representing each stratum, 3) to compare the situation of people living with HIV in one region with other regions in Indonesia, as well as with other countries that have similar issues, 4) to measure changes that occur over a certain period (years), so that we can answer questions about changes in conditions of stigma and discrimination in the community from this research, and 5) to



¹ SIHA Ministry of Health. 2023. HIV/AIDS & Sexually Transmitted Infectious Diseases (PIMS) Development Report for the First Quarter of 2023.

collect evidences for advocating the policy changes and for improving targeted intervention programs to protect people living with HIV from stigma and discrimination.

The Indonesia Positive Network carried out the PLHIV Stigma Index 2.0 study from November 2022 to December 2023 in 16 provinces in Indonesia, namely Aceh, North Sumatra, Riau, Lampung, DKI Jakarta, West Java, East Java, Bali, NTT, NTB, West Kalimantan, South Sulawesi, North Sulawesi, Maluku, Papua and West Papua. Formative efforts were made in each province to select research locations by dividing six strata: Sumatera Strata, Java Strata, Bali-Nusa Tenggara Strata, Kalimantan Strata, Sulawesi Strata, and Papua Strata. After the selection of study sites, a non-probability sample consisted of adults aged 18 years or older who were living with HIV, had known their HIV status for at least one year, and gave informed consent to be part of the study.

In the result, there were 1513 samples collected in the study, but after cleaning process, it was found that there were duplications due to technical difficulties in the field (mobile signal interruptions and other difficulties). After data cleaning, there were a total of 1400 people living with HIV from 16 provinces that could be analyzed in this study. The majority (n=1181, 84.4%) of participants were in the age range of 25 - 49 years and the median age was 36 years. Based on sex at birth, male respondents were higher (n=844, 60.3%) than female (n=556, 39.7%). A number of 167 (11.9%) respondents reported themselves as members of an indigenous community group, and 153 (10.9%) respondents claimed to be members of a racial, ethnic, or religious minority. Another finding was that most respondents (n=847, 60.5%) were not part of a network or support group of PLHIV.



564 (40.3%) respondents reported that they had sometimes been unable to meet their daily needs in the past 12 months. Most respondents reported disclosing their status to those closest to them (59.2% to husband/wife/partner, 51.7% to children, and 42.1% to other family members); however, less than 5.0% of

respondents disclosed their status to people outside their immediate circle (e.g., teachers, classmates, community leaders, and authority figures).

Overall, 187 (13.4%) people living with HIV reported having experienced stigma and discrimination from other people, for example, from family and friends because of their HIV status in the last 12 months. The forms of stigma and discrimination that often appeared were being given discriminatory comments or being gossiped about by other people who were not family members (7.2%) and family members (4.8%), as well as being verbally harassed (4.2%).

Results showed 502 (35.9%) of respondents agreed with one or more of six statements indicating internalized stigma. Among people living with HIV chose not to seek social support (n=201, 14.4%), not to have sex (n=179, 12.8%), and not to attend social gatherings (n=179, 11.6%). More importantly, 131 (9.4%) reported choosing to avoid going to a clinic or hospital because of their HIV status. Differentiation based on gender, 14 (20.0%) transgender respondents more often chose not to apply for jobs, not attend meetings 14 (17.1%), and isolate themselves 10 (11.8%) compared to respondents who were cis-women and cis-men. Internalized stigma also influences the choice of people living with HIV to hide their HIV status from others (n=1224, 87.6%) and the difficulty of disclosing their status (n=1165, 83.2%).

During the last 12 months, respondents reported receiving a diagnosis for non-communicable diseases (n=294, 21.2%) and mental health (n=251, 18.0%). A total of 1197 (85.5%) of respondents reported being on ARV treatment, and 755 (62.0%) had an undetectable viral load in the last 12 months. When asked about the timing of ART initiation, 472 (38.8%) of respondents started ART treatment immediately or on the same day as diagnosis, and 401 (33.0%) started within a maximum of one month after diagnosis. However, 820 (58.9%) of respondents reported that the reason that made them hesitate to start/avoid or delay ARV treatment was concern that other people who were not family members or friends would know their HIV status.

Overall, respondents reported experiencing stigma and discrimination when accessing HIV services (n=252, 19.5%) and non-HIV services (n=117, 15.9%) in the last 12 months. The most frequent reported forms of stigma discrimination were healthcare workers recommended not to have sex, 145 (11.2%) in HIV services and

50 (6.8%) in non-HIV services, and avoided physical contact or took extra precautions, 56 (4.3%) in HIV services and 41 (5.6%) in non-HIV services.

During the last 12 months, 74 (5.3%) of respondents reported having experienced rights violations, out of which 13 (17.6%) sought justice, and 8 (61.5%) of those resulted in a settlement. The most frequent forms of violations were being forced to have sex when one did not want to (n=46, 3.3%) and being forced to do HIV tests to obtain healthcare services (n=15, 1.1%). More than half of respondents (n=742, 53.2%) were not aware of the existence of any legal regulations that protect people living with HIV from stigma and discrimination.

Transgender people reported having experienced verbal harassment (n=18, 20.9%) and having felt that family members discriminated against them (n=9, 10.5%). Gay and other MSM respondents also felt that family members discriminated against or gossiped about them (16, 8.6%) and were excluded from family activities (n=11, 5.9%). In the sex worker group, 11 (13.8%) of respondents experienced verbal harassment from someone, with the most significant percentages being male sex workers (n=6, 20.0%) and transgender sex workers (n=7, 15.9%). In addition, 14 (10.7%) of people who used drugs had felt that family members discriminated against or gossiped about them because they used drugs.

In general, the sex worker group experienced more stigma and discrimination from others (n=31, 19.5%), while the transgender group (n=36, 41.9%) and people who use drugs (n=54, 41.2%) reported more internalized stigma than other key population groups. Furthermore, regarding the right to access healthcare services, PWUD (n=22, 16.8%) and transgender people (n=12, 15.4%) had avoided seeking healthcare services and PWUD (n=22, 16.8%) and transgender people (n=13, 16.7%) were afraid when accessing treatment in healthcare services, due to concern about being stigmatised and discriminated because of their intersectionality.

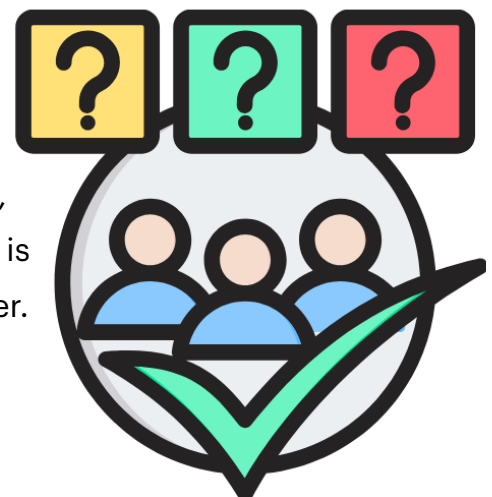
Overall, the study results showed that stigma and discrimination still often occurred among people living with HIV in Indonesia, both externally and internally. Stigma and discrimination can come from healthcare providers that unfortunately hold the key to services that PLHIV need, such as HIV-related health services. Stigma and discrimination could also come from PLHIV's family, which are often the place that they count on getting support from, which in this context hits hard on women living with HIV as they primarily count on their family as a safe space that

they disclosed their status to, which often then turned to a space where they got most discrimination from. Key population respondents showed higher levels of stigma and discrimination than those not belonging to any KP. These stigma and discrimination were influenced by values related to norms, customs, and beliefs that were closely related to heteronormative values.

A total of 1343 (95.9%) of respondents were recruited through the venue-based sampling method; and 57 (4.1%) were recruited through the limited chain referral method. Participants completed interviews lasting 40 to 90 minutes. The questionnaire was programmed using SurveyMonkey and collected via smartphone using side-by-side interview techniques. Participants were given IDR 150,000.00 (approximately USD 10.0) for their time and transportation.

This study has several limitations, and the results must be interpreted in the context of these limitations. Although the translation of the questionnaire was reviewed by the steering committee and tested for readability, certain terminologies were difficult to find equivalent words that suit the Indonesian context when conducting interviews or gathering information from respondents. The nature of the Stigma Index is self-reported and lived experience sharing and does not ask for specific verification. The recall bias may occur since some incidents may happen way earlier than the study took place. Data generalisation is limited to be carried out only at the national level. Focus is needed in interpreting data in each region.

The number of respondents were unequal in each variable because not all questions were answered by respondents due to errors during the interviews, or the participants felt uncomfortable to provide the answers to certain questions. Hence, data interpretation did not depict a sequence and must be interpreted carefully and justified by this situation. In the context of gender representation, the transgender man is very limited, so this report is still limited to a specific population and gender. There was also an error when



developing the questionnaire on SurveyMonkey, which failed to recognize respondents who are sex workers or having sold sex, so the following next questions prior to this population could only be filled by those who identified themselves as sex workers and not eligible for those who had sold sex.

The Stigma Index Study in Indonesia 2023 demonstrated a higher number of stigma and discrimination than the targets of UNAIDS 10-10-10, especially in HIV-related services, young key population (under 25 years) and sex workers. These findings underscore the importance of multi-sector collaboration to reduce stigma and discrimination. Integration of legal aid service and psychosocial support is crucial for handling cases of people living with HIV and key populations. The efforts should focus on reactivating family support programs, increasing the availability and socialization of psychosocial support, and strengthening the capacity of health workers to address mental health issues among HIV-affected populations. Also,

there is a need for increased education and public awareness campaigns to combat stigma and discrimination surrounding HIV. Engaging religious, traditional, and community leaders can be a recommended strategy to create a handling mechanism in the local area. Certification and recognition of community workers by the government for healthcare support is recommended to increase the participation of the



community. Lastly, further research is needed to understand the challenges of accessing healthcare services for people living with HIV in Indonesia.

1. INTRODUCTION

1.1. ABOUT THE STIGMA INDEX

The Stigma Index has been used globally to document different experiences among people living with HIV regarding stigma and discrimination, to encourage policy changes in certain areas, and to change program interventions because of the stigma or discrimination experienced by people living with HIV. The 2023 Stigma Index 2.0 study in Indonesia collected diverse information regarding the experiences of PLHIV in Indonesia who face stigma and discrimination.

Stigma Index is led by and for people living with HIV and is the most widely used study to measure stigma and discrimination experienced by people living with HIV. In 2018, the questionnaire was updated (Stigma Index 2.0), and in 2020 a standardised methodology was launched to increase comparability between different contexts and across time. In 2019, Indonesia conducted a study related to stigma and discrimination that used the Stigma Index instrument, but it should not be compared because it has a different methodology. In 2022, Stigma Index study was conducted firstly, led by Jaringan Indonesia Positif (JIP)/The Positif Indonesia Network.



1.2. HIV IN INDONESIA

Until 2023, the number of people living with HIV in Indonesia was found to be 377,650 people from 515,455 estimated numbers, of which 62% were men and 38% were women. Over the years (2005-2023), the highest number of new HIV cases occurred in 2022, namely 52,955 cases. From January to March 2023, HIV case reports revealed the highest prevalence of key populations on men who have sex with men (27.7%), pregnant women (16.1%), people with tuberculosis (12.4%), sex worker (3.3%), female transgender populations (1.1%), person with sexually transmitted disease (0.9%), former prison inmate (0.8%), and people who inject drugs (0.5%)².

² Ministry of Health of Indonesia. Annual Report HIV AIDS 2022. Indonesia: Ministry of Health of Indonesia

Difficulties in the promotion of HIV healthcare among key populations contributed to the spread of HIV in Indonesia. The difficulties could be due to the different accessibility of HIV knowledge in each region and the educational level of the key populations of Indonesia³.

The HIV epidemiological cascade showed that in 2022, the number of people living with HIV who received ARV treatment reached 41.8% (179,659) of the total number of people living with HIV who knew their status. This figure remains low compared to the 2030 target of 95% of people living with HIV receiving treatment; the percentage of PLHIV who are on ART have achieved viral suppression which only reached 18.7% of the number of people living with HIV who received treatment. When we look at the perception of key populations who are still worried about getting access to HIV-related services, we can see that this is due to high levels of stigmatisation and discrimination in healthcare facilities and society in general. This low number means that the Indonesian government still must do extensive work to achieve the target of accelerating HIV elimination by 2030.

1.3. HIV STIGMA AND DISCRIMINATION

Stigma still exists at various levels in Indonesia. People living with HIV are vulnerable to stigma and discrimination, which can affect their care and quality of life in both social and healthcare settings. Stigma and discrimination in healthcare services include the refusal of healthcare workers to provide care or treatment; negative attitudes and insulting practices by healthcare workers; people forced to take HIV tests without consent; and lack of privacy about the identity of PLHIV; forced sterilization, among others⁴. People living with HIV face significant stigma and discrimination. These behaviours can result in poor mental health in people living with HIV, including emotional stress, depression, low self-esteem, anxiety, and even a lower quality of life. The Ministry of Health, through its representatives, acknowledges that efforts to control HIV/AIDS are hampered not only by limitations

³ Arifin, B., Rokhman, M. R., Zulkarnain, Z., Perwitasari, D. A., Mangau, M., Rauf, S., ... & Postma, M. J. (2023). The knowledge mapping of HIV/AIDS in Indonesians living on six major islands using the Indonesian version of the HIV-KQ-18 instrument. *PloS One*, 18(11), e0293876.

⁴ Fauk, N. K., Ward, P. R., Hawke, K., & Mwanri, L. (2021). HIV stigma and discrimination: perspectives and personal experiences of healthcare providers in Yogyakarta and Belu, Indonesia. *Frontiers in medicine*, 8, 625787.

and disparities in the screening capabilities of healthcare facilities but also by stigma against people living with HIV from families, healthcare workers, and the wider community. In this regard, the lack of support from other parties has an impact on the poor adherence of ARV treatment. Commonly reported factors that led to poor adherence were lack of status disclosure within the family, school pressure, and inadequate support from guardians and parents⁵.

1.4. STUDY OBJECTIVE

The main objective of the People Living with HIV Stigma Index 2.0 in Indonesia in 2023 is to expand the understanding of the stigma and discrimination faced by people living with HIV in Indonesia. The results of this study are presented and used as an advocacy tool at the local, national, regional and global levels to fight for the rights of people living with HIV.

Specific Objectives

1. Identify the diverse experiences of people living with HIV in a particular community regarding HIV-related intersectional stigma and discrimination in Indonesia.
2. Identify challenges and obstacles to reduce stigma and discrimination in Indonesia by referring to the local cultural context of each region representing each stratum.
3. Compare the situation of people living with HIV in one region with other regions in Indonesia, as well as comparisons with other countries that have similar issues.



⁵ Villiera JB, Katsabola H, Bvumbwe M, Mhango J, Khosa J, Silverstein A, et al. (2022) Factors associated with antiretroviral therapy adherence among adolescents living with HIV in the era of isoniazid preventive therapy as part of HIV care. PLOS GLOB Public Health 2(6): e0000418.

4. Measure changes that occurred over a certain period (years) so that we can answer questions about increasing/decreasing conditions of stigma and discrimination in the community from this research.
5. Serves as a tool and evidence base for advocating for policy change and for scaling up targeted intervention programs to protect people living with HIV from stigma and discrimination.

2. METHODOLOGY

2.1. STUDY DESIGN

The Indonesia Positive Network carried out the Stigma Index 2.0 research from November 2022 to December 2023 in 16 provinces in Indonesia. This research used quantitative and qualitative methods. The quantitative method used a cross-sectional approach, and the qualitative method used a phenomenological approach. The criteria for respondents in this study were adults living with HIV who had known their status for at least one year. Respondents were recruited in two strategies: 1) venue-based sampling, 2) limited chain referral. Each respondent completed an interview lasting 45-90 minutes. The questionnaire was prepared using SurveyMonkey and documented via smartphone using side-by-side interview techniques.



2.2. SELECTION OF STUDY PROVINCES

The study population area was divided into six regions: Sumatera Region, Java Region, Bali-Nusa Tenggara Region, Kalimantan Region, Sulawesi Region, and Papua Region. This study chose two to three provinces to represent each existing region. Each province was selected based on the following:

1. The calculation of the highest number of people living with HIV per group was based on the Technical Report on Estimating the Number of Populations at Risk of HIV Infection in Indonesia 2020 and ranking each province based on strata and number of people living with HIV. We selected 1-3 provinces with the highest number of people living with HIV from each strata as priority research areas.
2. Review journals or articles that describe each province's culture or indigenous communities to consider and identify factors that support or hinder implementation of stigma and discrimination reduction programs.
3. Considering the high amount of stigma identified through the attitudes of healthcare workers in 7 districts/cities in Aceh, this research also added the Aceh Province as one of the research target populations.
4. Consider the availability of partners at the provincial level as resources to recruit enumerators and data field research coordinators, recruit respondents, collect data, and monitor the quality of the data produced.

In the development of the study, identification of locus would be carried out in 17 provinces in Indonesia. However, there were no research implementers available in East Borneo provinces, so a recalculation was carried out for each research locus only in 16 provinces after excluding East Borneo.

Sample Size

Quantitative

Based on the Stigma Index 2.0 sample size calculation and the estimated prevalence of people living with HIV who avoided seeking treatment because of anticipated stigma (10.7%) from stigma and discrimination study in Indonesia in 2020 using the Stigma Index instrument, the minimum target sample size of respondents is 1,616. This figure was obtained from the Stigma Index calculator, there seemed like an under-representation of avoidance of seeking healthcare due to anticipated stigma, which was potentially related to the sampling/recruitment methods applied in the 2020 study, so the estimated prevalence of avoidance of seeking healthcare services due to anticipated stigma was doubled from 10.7% to

21.4%. The target precision is 4%, and the confidence level is 95%. After determining the number of samples, samples for each stratum are calculated using the following formula:

$$n = \frac{\text{Key Population (stratum)}}{\text{Total Population Size}} \times \text{specified population size}$$

Table 1. Distribution of respondents by province (n=1400)

Provinces	Number of PLHIV	Target Sample	Actual	% Results
Aceh	6282	26	26	100.0%
North Sumatera	30328	124	67	54.0%
Riau	11596	47	47	100.0%
Lampung	10093	41	29	70.7%
DKI Jakarta	65916	269	208	77.3%
West Jawa	64635	264	242	91.7%
East Jawa	59317	242	240	99.2%
Bali	25996	106	88	83.0%
NTB	5972	24	24	100.0%
NTT	10115	41	39	95.1%
West Kalimantan	9986	41	41	100.0%
South Sulawesi	23759	97	80	82.5%
North Sulawesi	11008	45	28	62.2%
Maluku	3996	16	16	100.0%
Papua	44024	179	172	96.1%
Southwest Papua	13293	54	53	98.1%
Grand Total	396316	1616	1400	86.6%

Sample Distribution Based on Key Populations

Stigma Index data was presented by comparing each variable with community groups to see what proportion of the population was affected by stigma or discrimination. As a result, the sample group consisted of:

1. Group 1: The four identified key populations in Indonesia, namely transgender people (TG), men who have sex with men (MSM), sex workers (SW), and people who use drugs (PWUD), were found to constitute 525 (37.5%) respondents of the specified target group, representing at least 25% of the total sampled population.
2. Group 2: The non-key population group refers to groups not classified as key populations. These include youth living with HIV, women living with HIV, clients of female sex workers, housewives, and other people living with HIV. It was identified that 875 (62.5%) respondents belonged to non-key population groups within the anticipated target, slightly below the expected target 75% of the total research respondents.

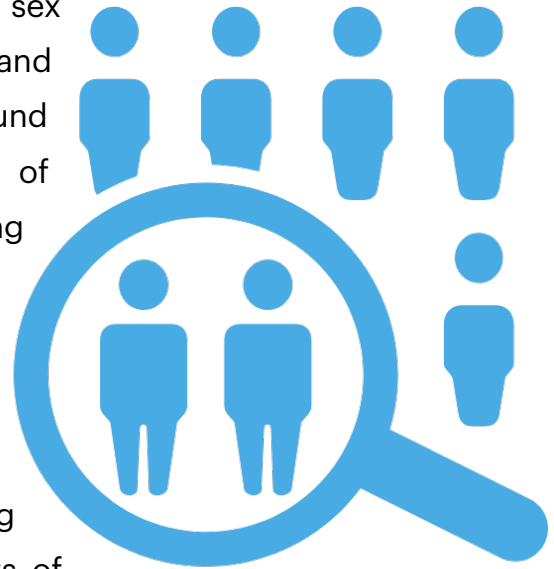


Table 2. Target and actualization of respondents based on key populations

	Target	Actual
Non- Key Populations	1212	875
Key Populations	404	525
Total (N)	1616	1400

Table 3. Identification of respondents per population and ARV treatment status

Characteristics	n (%)
Identification of Respondents per Population and ARV Treatment Status	
Non-Key Population	875 (62.5)
ARV	767 (87.7)
Non-ARV	108 (12.3)
Key Population	525 (37.5)
ARV	459 (87.4)
Non-ARV	66 (12.6)
Identification of Respondents by Sex at birth and ARV Treatment Status	
Female	433 (30.9)
ARV	385 (88.9)
Non-ARV	48 (11.1)
Male	442 (31.6)
ARV	382 (86.4)
Non-ARV	60 (13.6)
Identification of Respondents based on key population and ARV Treatment Status*	
MSM	185 (13.2)
ARV	168 (90.8)
Non-ARV	17 (9.2)
Transgender	86 (6.1)
ARV	76 (88.4)
Non-ARV	10 (11.6)
Sex Worker	283 (20.2)
ARV	248 (87.6)
Non-ARV	35 (12.4)

PWUD	131 (9.4)
ARV	106 (80.9)
Non-ARV	25 (19.1)
MSM	185 (13.2)
ARV	168 (90.8)

*) Respondents may represent more than one key population identity

Sampling Strategy and Recruitment

The respondent recruitment process was completed in 60 days with a predetermined strategy sequence. Venue-based sampling targeted areas and hotspots where people living with HIV can be found. Through this strategy, 1343 (95.9%) respondents were successfully recruited. Limited chain referral sampling was used to increase respondent variance, especially with several criteria explained in the inclusion criteria section. A total of 57 (4.1%) were recruited through this strategy.

Qualitative

Qualitative data collection was carried out through focus group discussions. The recruitment of respondents used a purposive sampling method. Overall, there were 127 respondents involved, namely 59 female respondents (46.4%), 57 male respondents (44.9%), and 11 transgender respondents (8.7%). The respondents in each group ranged from 5 - 10 people, with a median of 7 respondents per group. Furthermore, the distribution of respondents per province and based on sex and gender was explained in the table below.

Table 4. Characteristics of qualitative respondents by location

No	District/City	n (%)	No	District/City	n
1	Aceh	10 (7.9)	10	Kupang	8 (6.3)
2	Ambon	7 (5.5)	11	Makassar	8 (6.3)
3	Bandar Lampung	7 (5.5)	12	Manado	8 (6.3)
4	Bandung	6 (4.7)	13	Mataram	6 (4.7)
5	Denpasar	6 (4.7)	14	Medan	8 (6.3)
6	DKI Jakarta	8 (6.3)	15	Mimika	7 (5.5)
7	Jember	5 (3.9)	16	Nabire	5 (3.9)
8	Jayapura	8 (6.3)	17	Pekanbaru	7 (5.5)
9	Sorong	6 (4.7)	18	Pontianak	7 (5.5)

Table 5. Characteristics of qualitative respondents based on sex and gender identity

No	Respondents Characteristics	n (%)
Sex		
1	Male	68 (53.5)
2	Female	59 (46.4)
Gender Identity		
1	Male	57 (44.9)
2	Female	59 (46.4)
3	Transgender woman	11 (8.7)

Eligibility Criteria

The following are the inclusion criteria for respondents:

Quantitative:

1. Individuals aged 18 years or older and are living with HIV
2. Individuals who have known their HIV status for at least 12 months.
3. Able to provide informed consent, demonstrating a comprehensive understanding of all research elements.
4. Proficiency in at least one of the languages used in the questionnaire which is Bahasa Indonesia is necessary.

Qualitative:

1. Have experienced stigma and discrimination (optional)
2. Respondents who completed the questionnaire and were nominated by the enumerator.

The following are the exclusion criteria for respondents:

1. Individuals who identify as key populations but are not living with HIV.
2. Those who have previously participated in the ongoing Stigma Index study.

2.3. DATA COLLECTOR

Data collection team consisted of field research coordinators, data officers, and enumerators. Each province had one field research coordinator who helped organise the data collection. The field research coordinator was the head of the regional secretariat of the Indonesia Positive Network in 16 Indonesian provinces. The data officers were responsible for data cleaning, verification, and validation. Meanwhile, enumerators were selected through a selection process based on the criteria, 1) people living with HIV aged > 18 years; preferably part of key populations including: MSM, transgender, sex workers, and people who use drugs, 2) Have at least secondary level education and can speak regional languages to assist with the instrument fulfilment process.



Field research coordinators and enumerators collaborated with the initiating groups at each research locus during the data collection process, especially in respondent's recruitment and referring assistance if the respondent was not yet part of a group of people living with HIV. The entire data collection team was given training to understand the research questionnaire. The material provided included interview techniques, data confidentiality, knowledge of healthcare service referral pathways, legal support, and psychosocial support for respondents who need it.

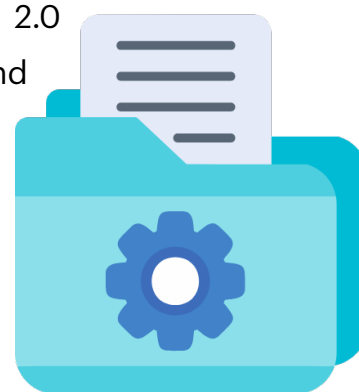
2.4. INTERVIEW PROCEDURES

Respondents were invited to complete one face-to-face interview after reviewing the recruitment process and selection criteria. Enumerators would ask for a convenient place and time as per request the respondents to take to interview. Respondents who provided information letters and signed for informed consent were recruited. Respondents completed the Stigma Index questionnaire via electronic devices operated by enumerator, besides all participants can choose to withdraw from the study at any time. The average time of the interview process was 60-105 minutes. After the interview, respondents were given IDR 150,000 (approximately USD 10.0) for their time and transportation.



2.5. DATA COLLECTION AND MANAGEMENT

The research questionnaire used the Stigma Index 2.0 instrument after translation into Bahasa Indonesia and tested for readability during training with the field research coordinator and enumerator. The steering committee and ethical committee also joined to review the translation. After the enumerator training, the instruments and FGD guidelines were tested on people living with HIV who had the same criteria as the respondents needed in the research process. The trial phase was conducted in two weeks via online in 17 provinces. There was a simulation process for filling in the questionnaire and FGD, as well as observations made by the observer (researcher) regarding the instrument readability, and other assessments related to: time,



language and how enumerator will deliver the question to the respondent, and also feedback between respondents and enumerators towards the instruments. After the trial phase, an evaluation meeting was held, and validity and reliability tests related to quantitative instruments were conducted.

The questionnaire contains eight dimensions: (i) Demographics, (ii) Disclosure of status, (iii) Experiences of stigma and discrimination in the last 12 months, (iv) Internalized stigma, (v) Interaction with healthcare services, (vi) Human rights and affecting change, (vii) Stigma and discrimination for reasons other than HIV status, and (viii) Personal experiences of stigma and discrimination.

The research team took steps to guarantee the confidentiality of research data. First, all study staff received training in human subjects' safeguards, informed consent, good clinical practice, quality management, confidentiality, and adverse event reporting. All study staff also signed a confidentiality agreement. Second, all research subjects were given a unique identification code (UIC).

UIC was used for all research data and all research forms. The study questionnaire used no participant names or other identifying information. A Microsoft Excel file was used to associate names with assigned UICs. No data other than the name and UIC was stored on the file, and the file link was password-protected and stored on a secure device. Lastly, no identifying information has ever been or will be presented in any publication, presentation, or other format.

2.6. ETHICAL CONSIDERATIONS

The research protocol was reviewed by the International Partnership of the PLHIV Stigma Index (GNP+, ICW, and UNAIDS) with support from Johns Hopkins University to provide initial comments, including input regarding research protection procedures, but the International Partnership did not interact with research respondents. The research ethics commission of Atma Jaya Catholic University reviewed and approved this research with number 0004F/III/PPPE.PM.10.05/04/2023 on April 28, 2023. Verbal consent was obtained from each research participant before starting any data collection activities.

2.7. DATA ANALYSIS

Quantitative Data Analysis

Descriptive analysis was summarised in tables and graphs depicting sub-sections/scales in each thematic area. Results were stratified by key population groups, sex (male, female), and gender (cisgender male, cisgender female, and transgender). All data entry was performed in STATA 16 by StataCorp LP, Texas, USA.

Qualitative Data Analysis

Thematic analysis (TA) methodology was employed for qualitative data analysis to explore and interpret patterned meaning across the Stigma Index datasets.

3. RESULTS

The total number of respondents involved in this research was 1513 from 1616 targeted-sample, but after data cleaning, only 1400 respondents' data from 16 provinces in Indonesia could be analyzed. A total of 1343 (95.9%) respondents were recruited through the venue-based sampling method, and 57 (4.1%) were recruited via the limited chain referral method.

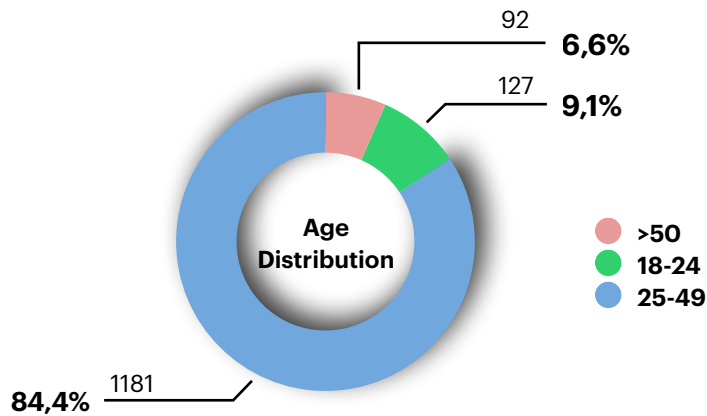
Fig 1. Distribution of respondents based on data collection area



3.1 DEMOGRAPHICS

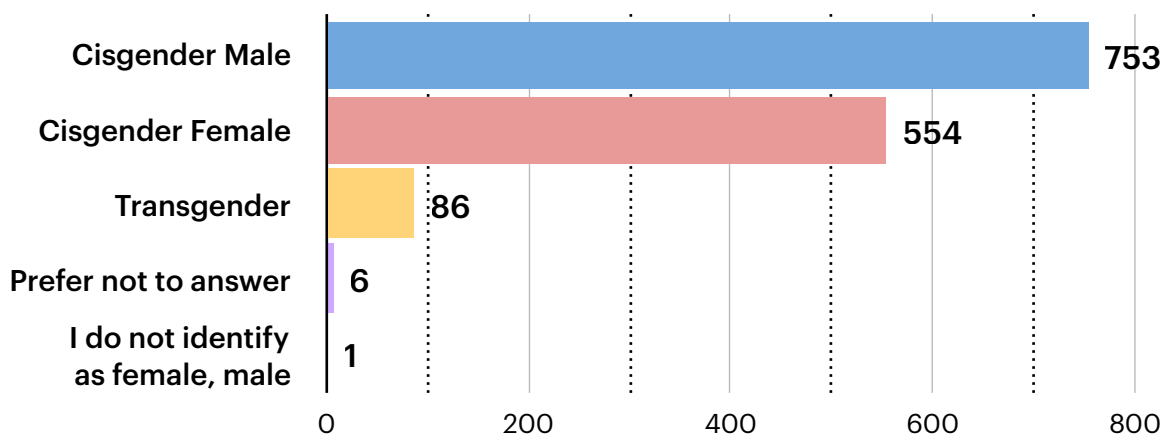
Of the 1400 respondents, the majority came from the 25-49 year age group, 1181 (84.4%), with a median age of 36.

Fig 2. Age distribution



Based on sex at birth, 60.3% of respondents whose sex at birth was male, and 39.7% of respondents were assigned female at birth. Meanwhile, looking at gender identity, 753 (53.8%) respondents identified as cisgender male, 554 (39.6%) as cisgender female, and 86 (6.1%) respondents as transgender.

Fig 3. Gender identity (n=1400)



Among 525 (37.5%) respondents identified as the key population, as many as 283 (20.2%) as sex workers, 185 (13.2%) respondents identified as gay and other MSM, 131 (9.4%) respondents identified as PWUD, and 86 (6.1%) respondents

identified as transgender. Respondents exhibited intersectionality in their key population identities, ie. individuals representing multiple identities (Table 6).

Table 6. Characteristics of respondents based on key populations

Key Population	n (%)
Men who have Sex with Men (MSM)	185 (13.2)
MSM	108 (58.4)
MSM + SW	60 (32.4)
MSM + TG	1 (0.5)
MSM + PWUD	1 (0.5)
MSM + SW + TG	11 (6.0)
MSM +SW +PWUD	4 (2.2)
Sex Worker (SW)	283 (20.2)
SW	144 (50.9)
SW + MSM	60 (21.2)
SW + TG	51 (18.0)
SW + PWUD	9 (3.2)
SW + MSM + TG	11 (3.9)
SW + TG + PWUD	4 (1.4)
SW + MSM + PWUD	4 (1.4)
Transgender (TG)	86 (6.1)
TG	19 (22.1)
TG + MSM	1 (1.2)
TG + SW	51 (59.3)
TG+MSM+SW	11 (12.8)
TG + SW + PWUD	4 (4.6)
People Who Use Drugs (PWUD)	131 (9.4)
PWUD	113 (86.3)
PWUD + MSM	1 (0.8)
PWUD + SW	13 (9.9)
PWUD + SW+ TG	4 (3.0)

A total of 1,365 (97.5%) respondents were able to remember how long they had known their HIV status, with the median respondent knowing their HIV status for six years and two respondents having known their HIV status for 25 years.

Table 7. Length of time knowing HIV status disaggregated by sex (n=1365)

Status Knowing Period	Female (n[%])	Male (n[%])
Median 6 years (1-25 years)		
1-5 years	239 (44.0%)	449 (54.6%)
6-10 years	176 (32.4%)	214 (26.0%)
11-15 years	93 (17.1%)	110 (13.4%)
>16 years	35 (6.4%)	49 (6.0%)
Total	543 (100%)	822 (100%)

Most respondents were at that time in an intimate/sexual relationship, namely 965 (68.9%) respondents. Of this number, 335 respondents (34.7%) stated that their partner also had HIV-positive status. As many as 633 (45.2%) respondents stated that they were not currently cared for a single child, 373 (26.6%) respondents stated that they were currently cared for two to three children, and 322 (23.0%) respondents stated that they were caring for one child. As many as 72 (5.1%) respondents said they cared for more than three children.

As many as 1,232 (88.0%) respondents had secondary education or higher, and 168 (12.0%) of respondents had less primary education. Even though there were 412 (29.4%) respondents who worked part-time as entrepreneurs and 326 (23.3%) respondents who worked full-time formally as employees, the number of respondents who were not working/unemployed was found in 307 (21.9%) respondents. 564 (40.3%) respondents reported that they had sometimes been unable to meet their daily needs in the past 12 months.



Table 8. Distribution of respondents based on education and employment status

Variable	n (%)
Level of education (n=1400)	
No formal education	21 (1.5)
Elementary School Equivalent	147 (10.5)
Middle School Equivalent	225 (16.1)
High School Equivalent	804 (57.4)
College	203 (14.5)
Job Status (n=1398)	
Full time (as an employee)	326 (23.3)
Part time (as an employee)	176 (12.6)
Full time (as self-employed)	176 (12.6)
Part time (as self-employed)	412 (29.4)
Pensionary	1 (0.1)
Unemployment	307 (21.9)

As many as 167 (11.9%) respondents stated they were members of an indigenous group, and 153 (10.9%) respondents stated that they were a member of a racial, ethnic, or religious minority. While 38 (2.7%) respondents were living with a disability of any kind, 16 (1.1%) respondents were internally displaced persons, 12 (0.9%) respondents stated they were incarcerated/in prison, 8 (0.6%) respondents stated they were refugees and 3 (0.2%) respondents stated that they were migrant workers. 847 (60.5%) respondents were not part of a network or support group of people living with HIV.



Fig 4. Membership in other vulnerable groups

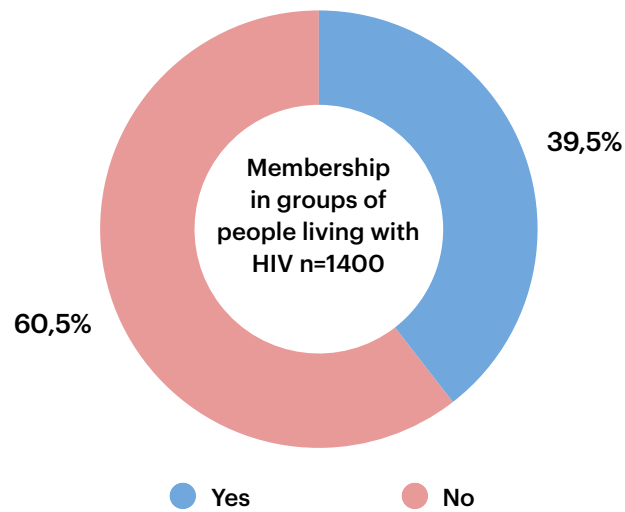
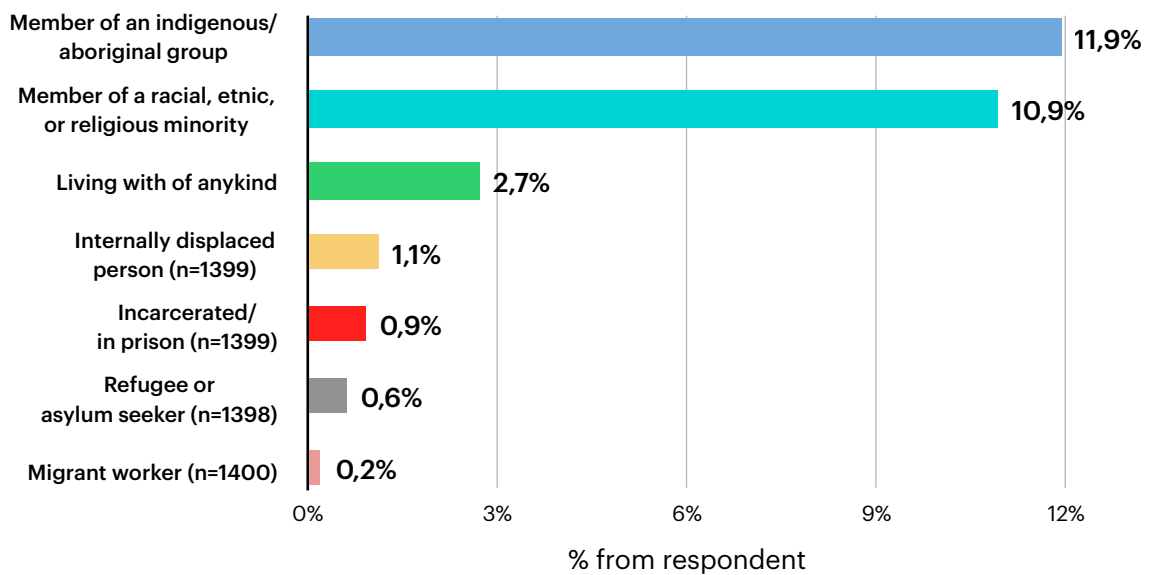


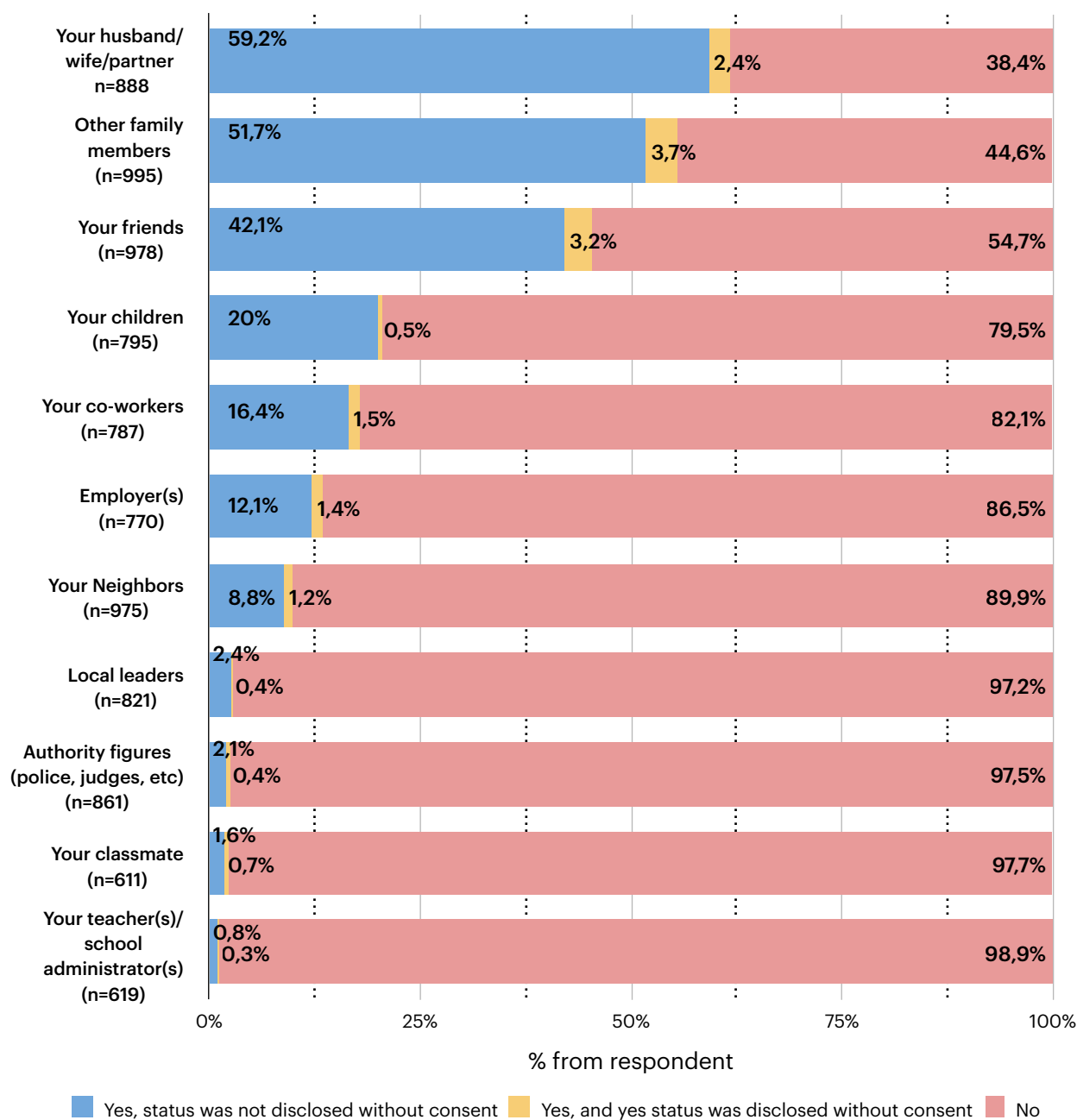
Fig 5. Membership in groups of people living with HIV n=1400



3.2. DISCLOSURE OF HIV STATUS

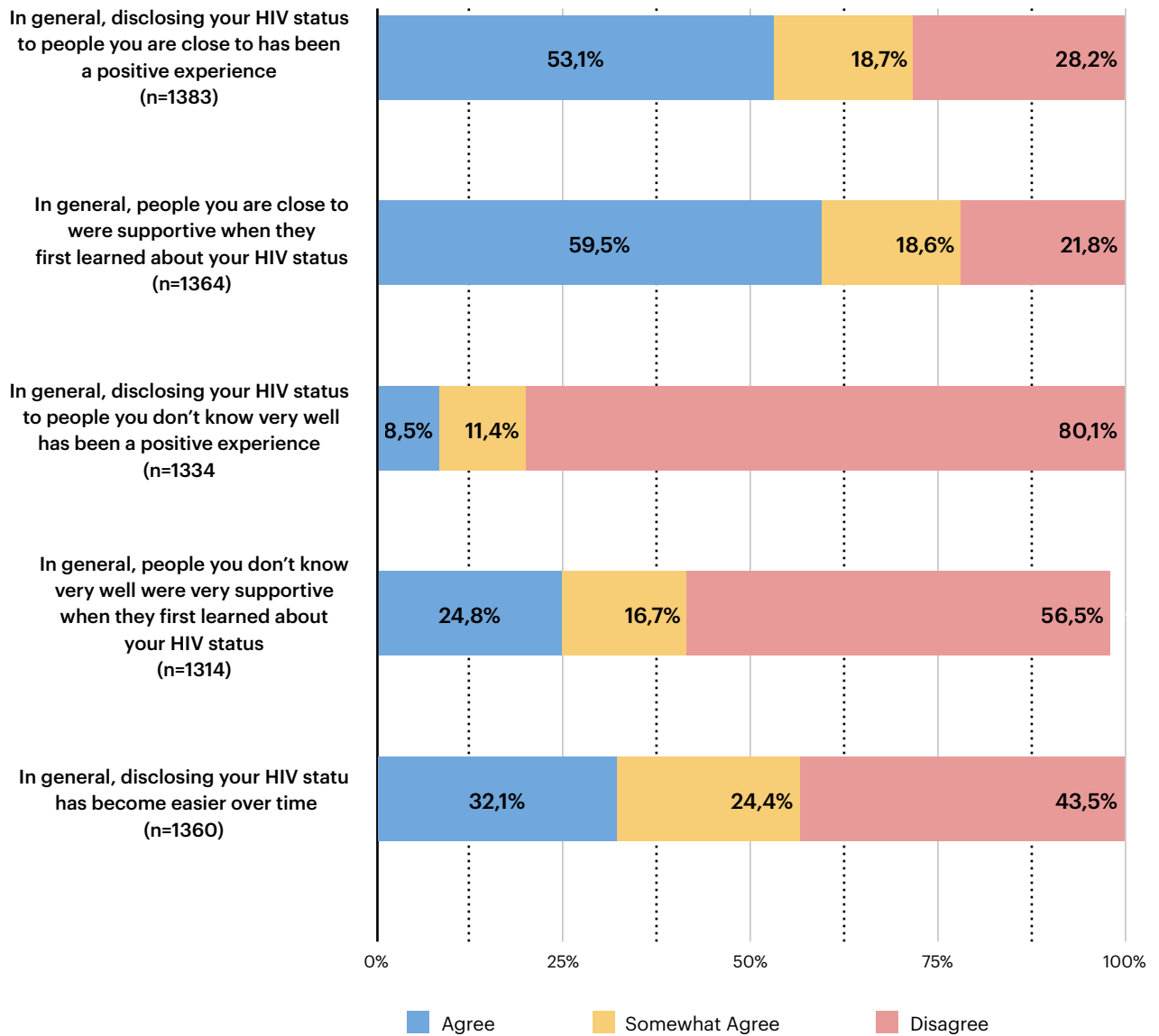
A total of 526 (59.2%) respondents stated that their HIV status was not disclosed without consent to husband/wife/partner, other family members (n=514, 51.7%), and their friend (n=412, 42.1%). Disclosure of respondents' HIV status was made the least to their teachers(s)/school administrator (n=7, 0.8%).

Fig 6. Disclosure of HIV status



Even though 812 of respondents (59.5%) stated that they received support from people closest to them when they first learned about their HIV status, however 1068 (80.1%) respondents reported disagreeing that in general, disclosing their HIV status to people they don't know very well has been a positive experience, 769 (58.5%) respondents disagreed that in general, people they don't know very well were supportive when they first learned about their HIV status and 592 (43.5%) respondents disagreed that in general, disclosing their HIV status has become easier overtime.

Fig 7. Experience of disclosing HIV status



According to disaggregation based on sex at birth: the disclosure of HIV status tended to be done by women compared to men. Women had the highest level of openness to husband/wife/partner (n=339, 66.9%), family members (n=310, 56.2%), and children (n=162, 31.5%). However, men tended to be more open to friends (n=405, 49.5%) than women (n=191, 35.3%). Based on gender-disaggregation, cis-female tended to disclose their HIV status to husband/partner (n=337, 66.6%), children (n=161, 31.4%), and family members (n=308, 56.0%) than cis-male and transgender. While transgender respondents tended to be more open to their friends (n=56, 66.7%), employees (n=14, 21.9%), and co-worker (n=24, 34.8%) than cis-female and cis-male.

Fig 8. Disaggregation of HIV status disclosure based on sex

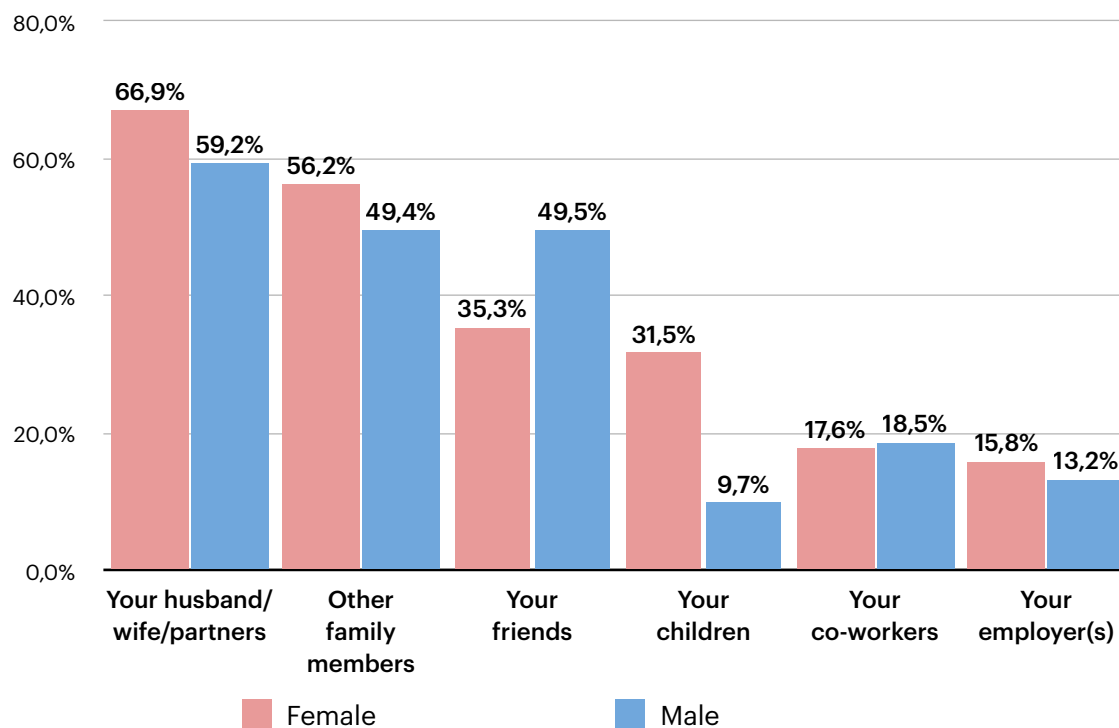
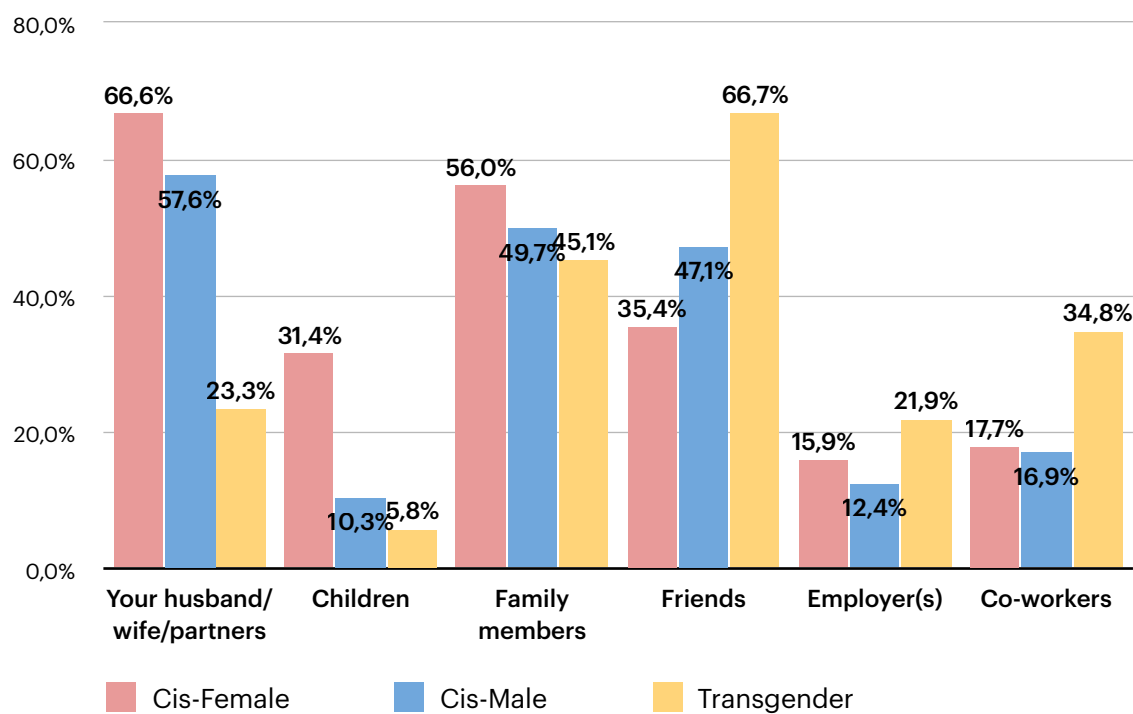


Fig 9. Disaggregation of HIV status disclosure by gender



Most people living with HIV stated that they felt uncomfortable disclosing their HIV status—concerns about stigma and discriminatory treatment, such as exclusion and rejection, triggered this.

“

In my opinion, I am not comfortable (revealing my status) because, in society, HIV is still considered a despicable disease that is disgusting and easily transmitted.

—E, Bandar Lampung.

”

Even though disclosing status was an effort to provide education and prevent transmission to other people, this effort resulted in respondents experiencing stigma and discrimination. Thus, experience was one of the impacts of respondents' reluctance to disclose their status to other people, which was also found on FGD.

“

When I am at a community gathering, tell the community that I am PLHIV so that they do not become like me. The goal is to educate. Few understand it, but it backfires. If (I), I always have an open status with my partner, but after that, my partner disappears. Since then, I no longer want to open the status.—R, Medan.

My experience (disclose my HIV status) from my household. My husband went with another woman

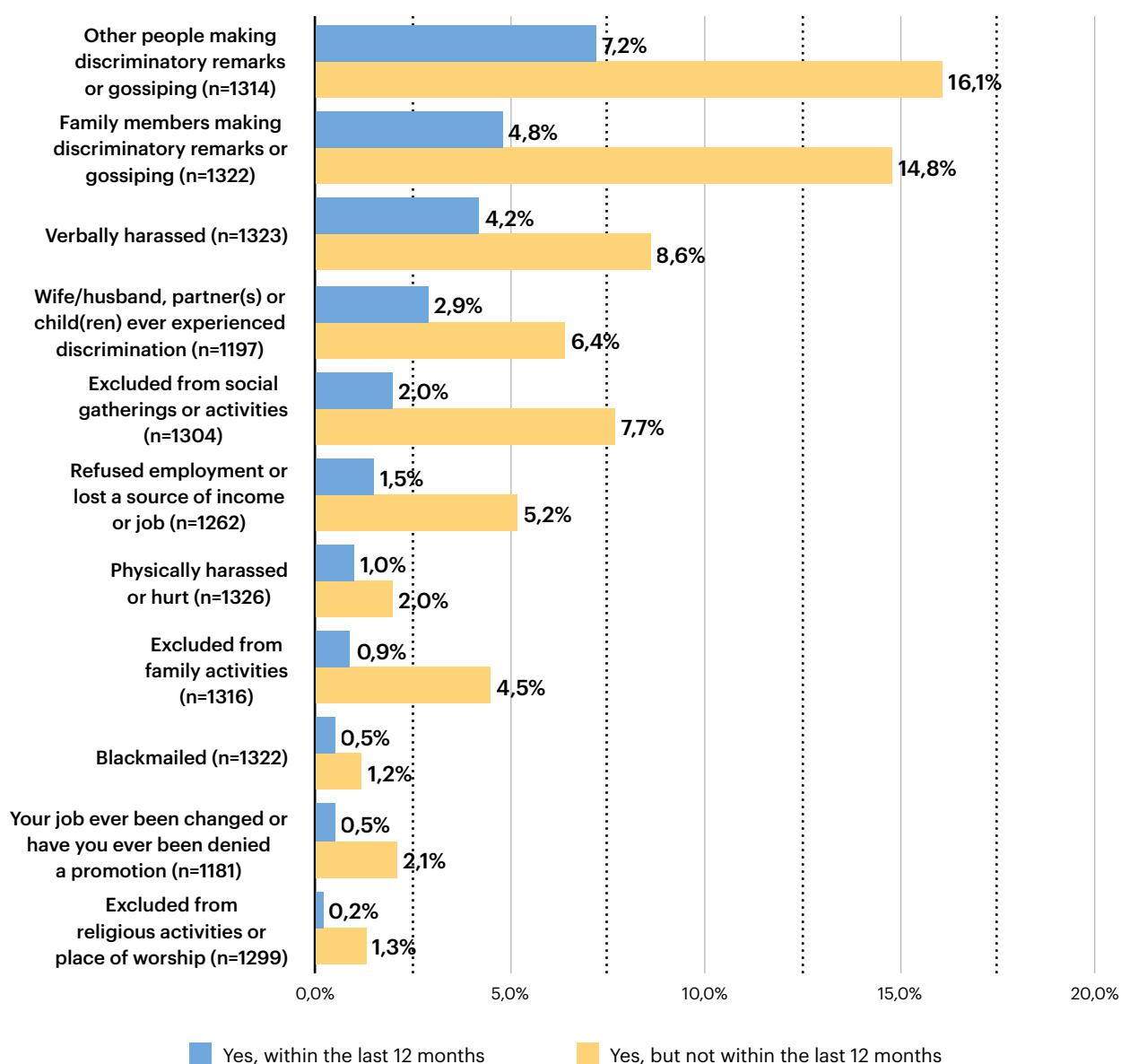
—A, Pontianak.

”

3.2. HIV- RELATED STIGMA AND DISCRIMINATION

From the total number, 13.4% of respondents experienced at least one type of stigma and discrimination from other people in the last 12 months, while 23.9% experienced at least one type of stigma and discrimination from other people beyond the last 12 months. From those experiences within last 12 months, the external stigma most commonly reported by respondents was being gossiped about or talked about by other people (7.2%) and family members (4.8%), as well as verbal violence (4.2%), for example, being shouted at or scolded with harsh words, 19 (1.5%) respondents were refused work or lost their source of income because of their HIV status.

Fig 10. Stigma experiences in the last 12 months and beyond



HIV-related stigma in the family and community was generally encountered by people living with HIV. Forms of stigma found in society included 'diseases or dirty' people, 'naughty' people, and 'lowly' people. Not only that, people living with HIV were also often associated with certain behaviours which were marginalized by society, such as the identity of key populations.

“

[...] Society in general thinks that people who live with HIV have a behaviour that likes to snack carelessly (change partners) and think that HIV is a disease of MSM (gay) people.—BP, Jember.

”

People living with HIV often experienced various forms of discriminatory treatment, such as expulsion, not being allowed to interact with children, and not being allowed to leave the room by the family and community. This treatment was detrimental to people living with HIV including those from the key populations, even causing death—even people living with HIV being shackled or physically bound or restrained by their families.

“

We know of cases that ended up in shackles (because of HIV status),—Y, Kupang.

If I am from my mother [getting stigma and discrimination], I have children, and if I want to feed the children [...] do not leave a mark on my mouth, especially since I have mouth ulcers, do not use one cutlery. It is sad, (how) my mother looked (stigmatised) because only she knew my (HIV) status. My mother was still looked down upon; I did not dare to tell my sister.. —A, Pontianak.

”

Qualitative findings from Pekanbaru City, Bandung City, and Jember City showed that family support can reduce worries and be a strength for people living with HIV, especially in treatment retention.

“

...previously, I was cared for at my parents' house, so they already knew, which gave me much motivation.—SS, Bandung.

feeling safe and comfortable, because the family is more attentive, such as reminding them to take medicine.—AR, Jember.

”

In the context of HIV-related stigma and discrimination within indigenous communities, customary regulations and laws influenced the perspectives of surrounding indigenous communities. Negative views from indigenous communities impacted the discriminatory treatment received by people living with HIV. A form of discrimination against people living with HIV in indigenous communities was the imposition of customary fines for people living with HIV. The form of rejection most often expressed in discussions was the funeral procession, which was identical to customary law.

“

From one of the clans whose status is known (HIV Positive) and the partner is negative, then there will be a fine, it could be a monetary fine or even death.—I, Sorong.

If you are in X (customary tribe), people living with HIV cannot be buried...—N, Nabire.

”

As a sign of gratitude, distributing clothes to funeral directors and residents is a habit of the Makassar traditional community. However, there was rejection when residents found out that the body was of a person living with HIV.

“

The custom in Makassar is that when someone dies, the undertaker is given clothes from the corpse during his lifetime as a form of gratitude for helping to take care of the body, but when it is discovered that he has HIV, the resident is afraid to accept the gift.— KK, Makassar.

”

This study also dug deeper into stigma and discrimination against women living with HIV by focus group discussion. Another discriminatory treatment that often happened to women living with HIV was discrimination against giving birth. Women living with HIV said they had received poor treatment and rejection when they wanted to give birth because of their HIV status.

“

When I was about to give birth, then when I was being taken to the OP's room, all the clothes and bed sheets were usually washed, but instead, they were thrown in the trash box. The doctor carried out sterilisation without an assessment and without asking for approval because, at that time, I was in a panic, signing the letter given by the doctor without explaining the details.—E, Pekanbaru.

”

The children of women living with HIV were also impacted. Even though the child was not living with HIV, children of women living with HIV often still received stigma and discriminatory treatment from society (i.e., secondary stigma and discrimination), such as rejection and examination. This situation also gave women living with HIV rise to feelings of guilt and a tendency to blame themselves.

“ *I have heard that because of the status of the mother being an HIV-positive person, in the end, either children who are an HIV-positive person or not an HIV-positive person will be taken along, they will be labelled as bad, in the end, society will think that if the parents are ugly, the child will be ugly too.—E, Bandar Lampung.*

My son has HIV; he is very skinny and small. In the past, they (other people) did not want to be near my son, 'do not play with him,' I said to the Pastor, 'Father, ask God to pray for him to take his life' because I feel sorry for him. My son never plays with other children, but he still goes to school; I told him not to go to school because he has an unhealthy body (infected with HIV).

—N, Nabire.

”

Through focus group discussion, this study also found the stigma and discrimination experienced by children living with HIV in the educational environment. The educational institution refused children living with HIV who wished to enter a school until children living with HIV were expelled from school.

“ *I once accompanied a child with HIV where the child was not accepted at school (because of HIV status).—RI, Kupang.*

Children have experienced stigma from local residents, whether if their child goes to school will it spread to other children.—L, Banda Aceh.

”

The school environment, especially teachers, were the ones who interacted with students the most but did not have a good understanding of HIV, causing mistakes and potentially encouraging students to commit acts of discrimination.

“

When I was at school, eee... so there was like, not a lesson like a teacher was explaining about HIV. According to the information (from the teacher), do not approach it (PLHIV) like that. From my side, sometimes it is like keeping quiet.... How does it spread? How do I think HIV is dangerous, that is at school.—KN, Bandung.

”

In the context of beliefs, it influences public perceptions regarding HIV. Especially when religious leaders or figures did not have an understanding of HIV and stigmatised people living with HIV, the beliefs also influenced the perceptions of the surrounding community, who tended to follow the perceptions and actions of these religious leaders.

“

In the church, the pastor preaches about promiscuity, which will lead to them getting AIDS—people who attend the service gossip and gossip about the fear that today's children will get HIV. Pastors do not understand a bit, especially regarding transmission to children. Pastors who do not understand still discriminate slightly.—RI, Kupang.

”

Stigma and discrimination in the workplace were also found in this study. People living with HIV were denied employment because of their HIV status.

“

There was someone who wanted to work as a household assistant, and she was rejected as a household member because she was afraid of being infected (HIV).—E, Pekanbaru.

[...] I was fired from work due to HIV status.—MS, Medan.

”

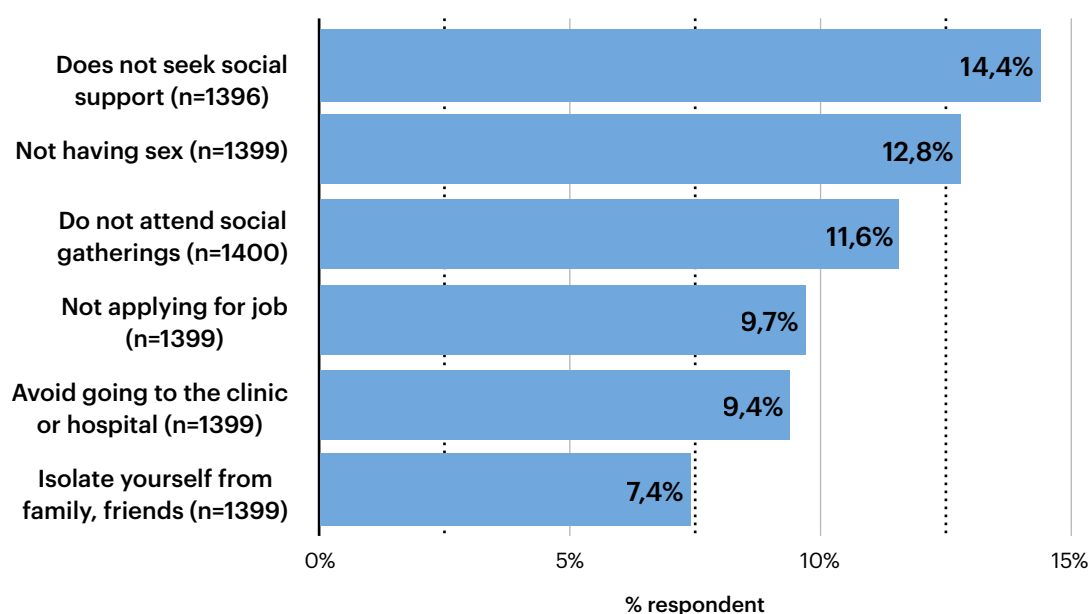
Apart from that, stigma that encouraged discriminatory treatment of people living with HIV also occurred within the government agency. The findings were found in the government's social agency, namely the Social Service. The shelter provided by the Social Service should be a source of hope for people who need help. However, people living with HIV still experienced discrimination because of their HIV status in places that should be safe houses..

“..then my husband had already left, I was afraid that I would drop out even more, what would it be like, (then) a support person advised me, finally I entered the social service (Social Service), I was in the social service, and it turned out that I continued to be stigmatised and discriminated against by security, 'this is the person HIV positive.—FA, Bandung.”

3.4. INTERNALIZED STIGMA AND RESILIENCE

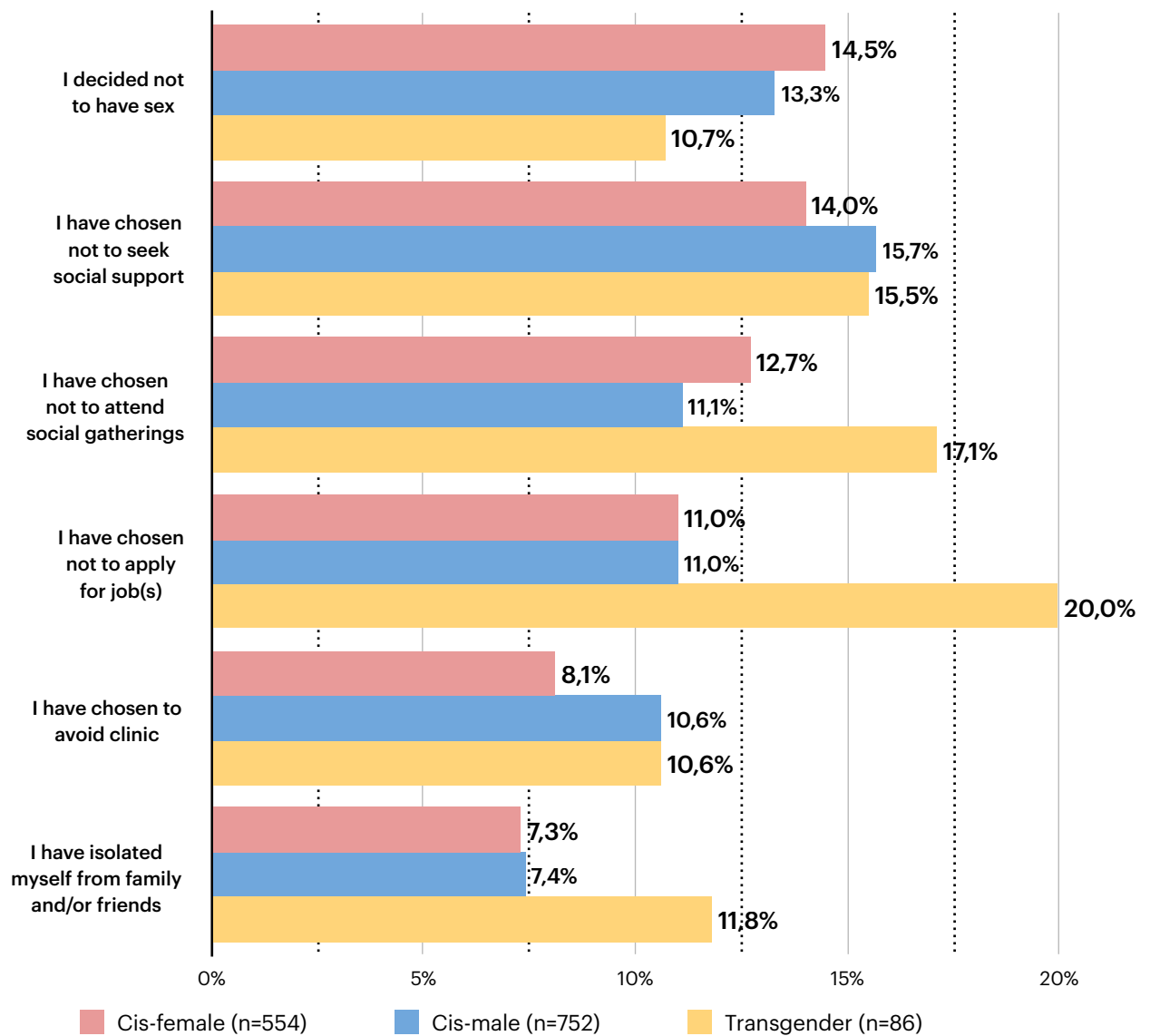
A total of 502 (35.9%) of respondents experienced at least one type of internalized stigma during the last 12 months; 201 (14.4%) of respondents did not seek social support because of their HIV status, and 179 (12.8%) of respondents decided to not have sex because of their HIV status.

Fig 11. Internalized Stigma over the last 12 months



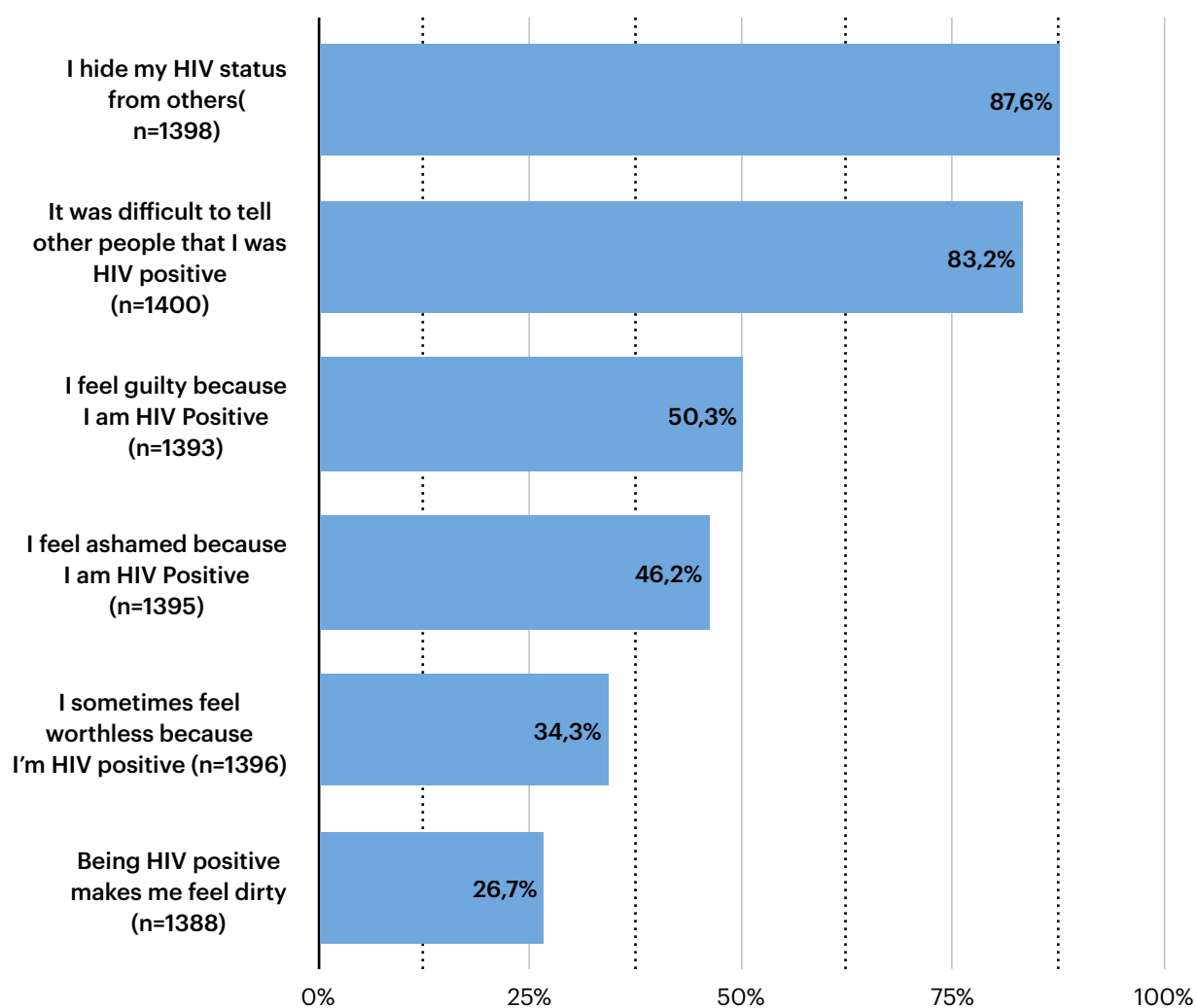
Analysis of differentiation based on gender: Transgender respondents tended to choose not to apply for jobs (20.0%), not to attend social gatherings (17.1%), and isolate themselves (11.8%). The impact of internalized stigma on cisgender women choosing not to have sex (14.5%) showed to be slightly higher than for cisgender men (13.3%) and transgender people (10.7%).

Fig 12. Impact of internalized stigma based on gender



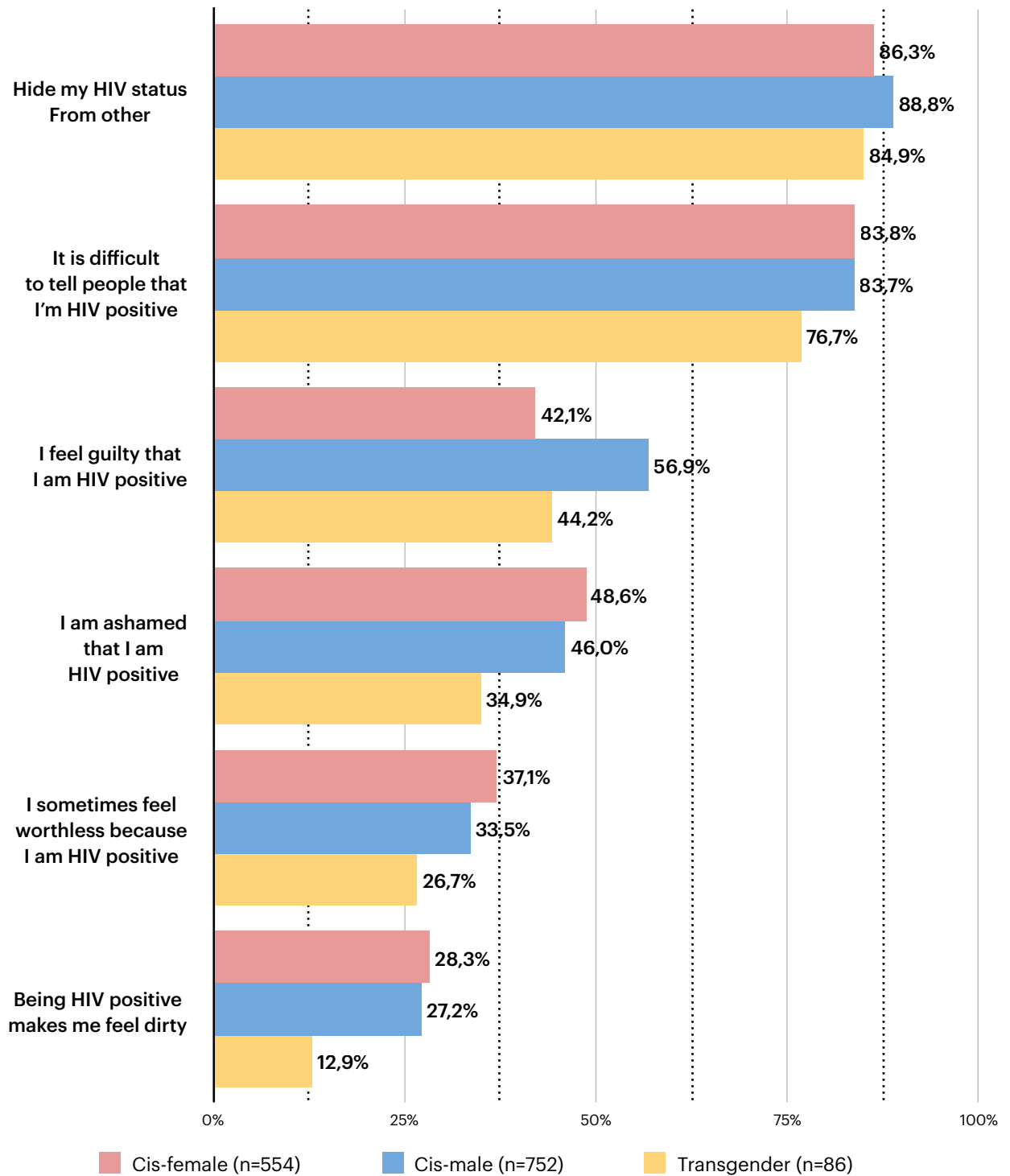
Respondents' agreement to certain statements showed the levels of internalized stigma such as that they hide their HIV status from others (n=1224, 87.6%); felt difficult to tell other people about their HIV status (n=1165, 83.2%), felt guilty (n=700, 50.3%) and felt ashamed because they were HIV positive (n=644, 46.2%).

Fig 13. Statements related to internalized stigma due to HIV status



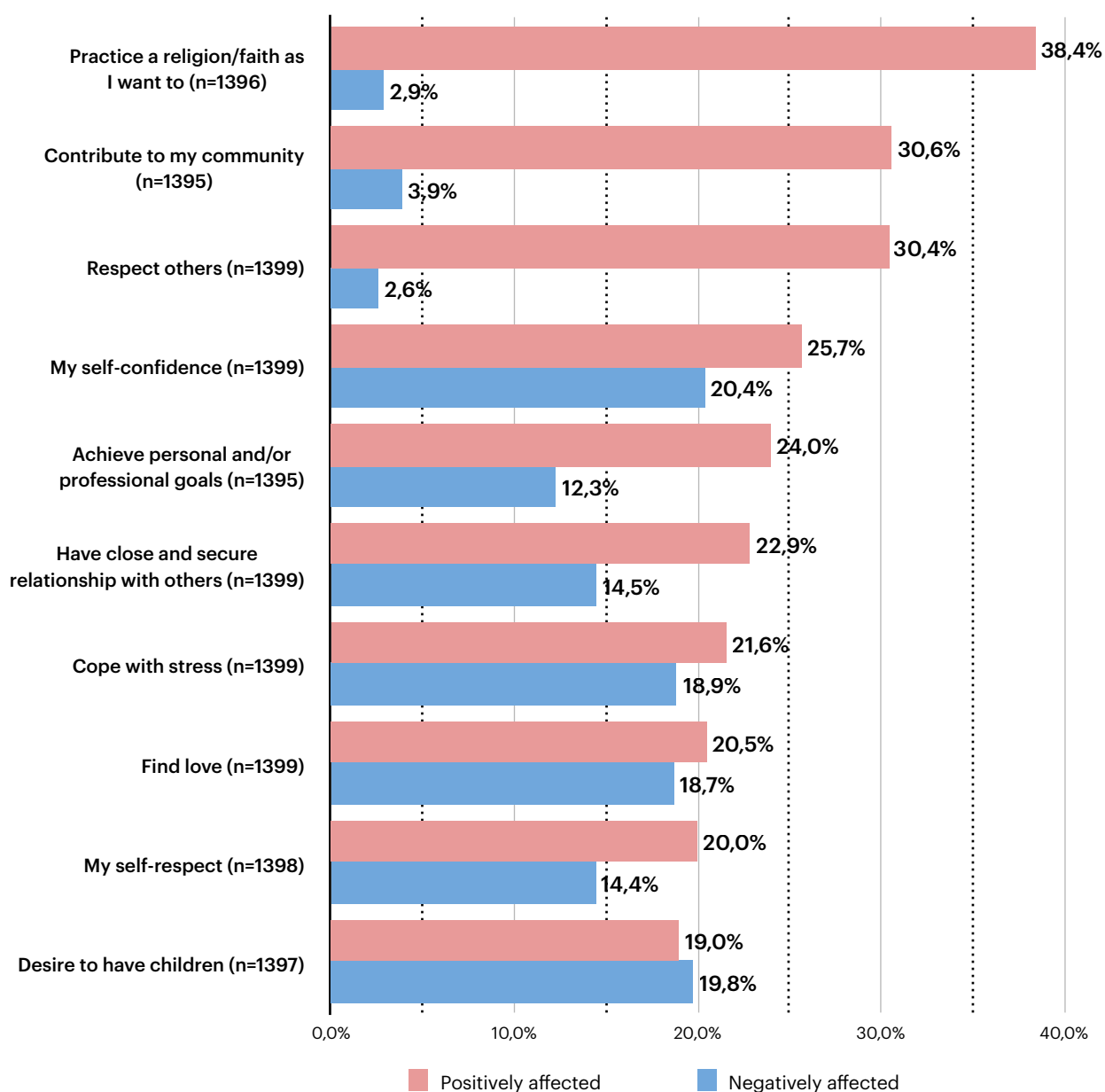
Based on gender, respondents who answered the influence of internalized stigma due to HIV status, cis-female (83.8%) and cis-male (83.7%) admitted that it was difficult for them to tell people about their HIV status, compared to transgender people (76.7%) (Figure 15). Cis-male respondents reported a higher percentage that they felt guilty of being HIV positive (56.9%), compared to transgender (44.2%) and cis-female (42.1%).

Fig 14. Statement related to internalized stigma based on gender



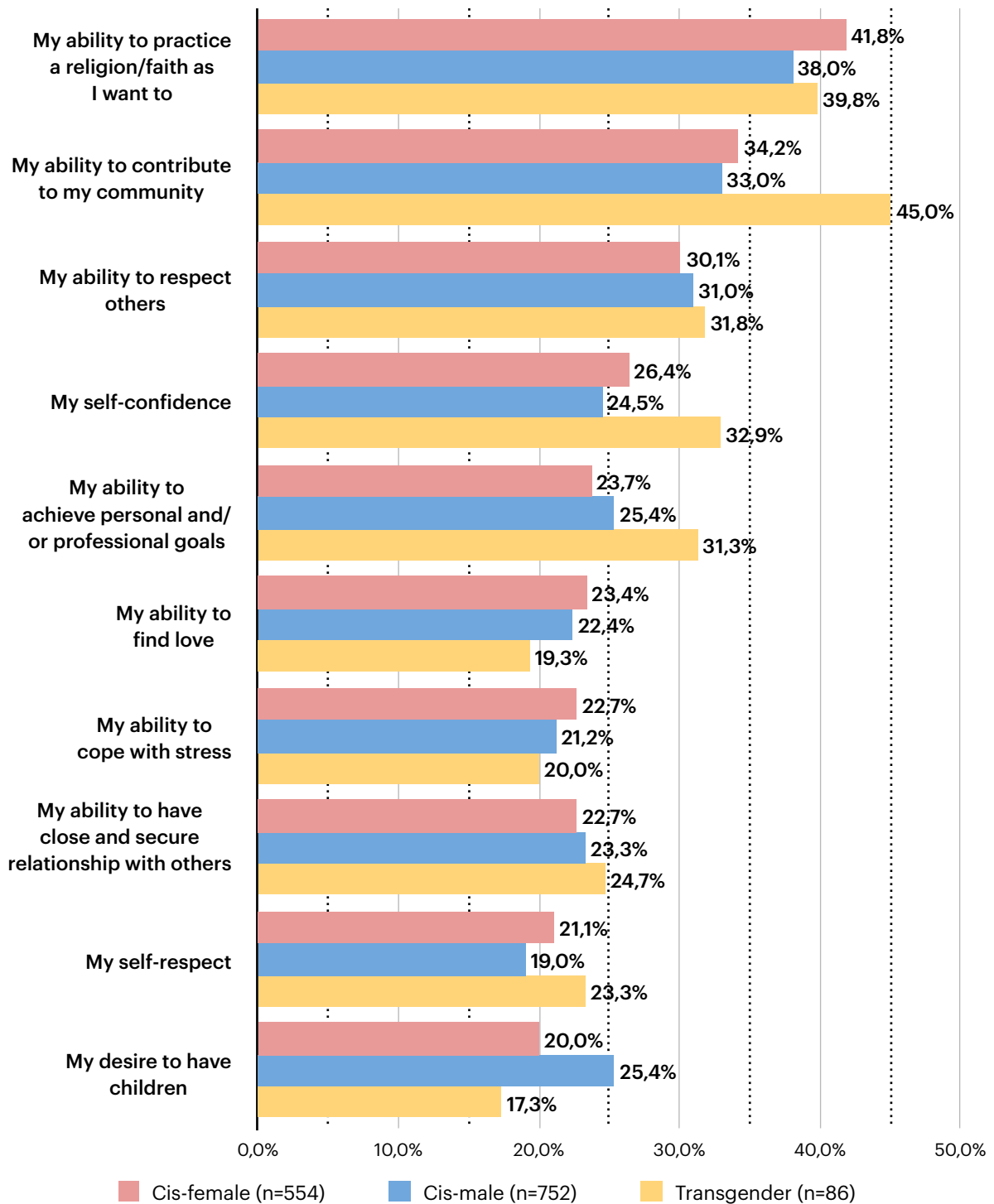
This study also looked at the impact of HIV status on the abilities of people living with HIV. Based on Figure 16, responses indicated that HIV status had a positive impact on aspects of implementing religion/beliefs (38.4%), contributing to the community (30.6%), and respecting others (30.4%) in the last 12 months.

Fig 15. Impact of HIV status on self during the last 12 months



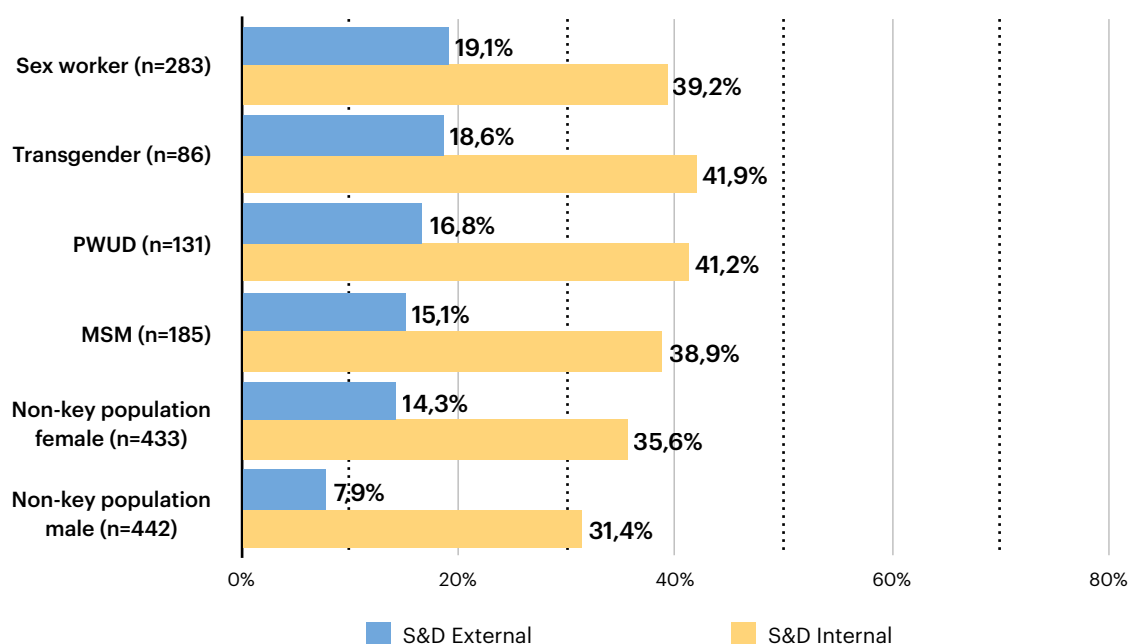
Based on differentiation of gender, transgender respondents more often stated that their HIV status had positively affected their ability to contribute to the community (45.0%) compared to cis-female respondents (34.2%) and cis-male respondents (33.0%). Among cis-female respondents 41.8% reported that HIV status had a positive impact on their ability to practise their religion/faith as they wanted to compared to transgender (39.8%) and cis-male (38.0%). Among cis-male respondents, 25.4% reported that HIV status had a positive impact on their desire to have children, compared to cis-female (20.0%) and transgender (17.3%).

Fig 16. Impact of HIV status on ability to meet needs based on gender



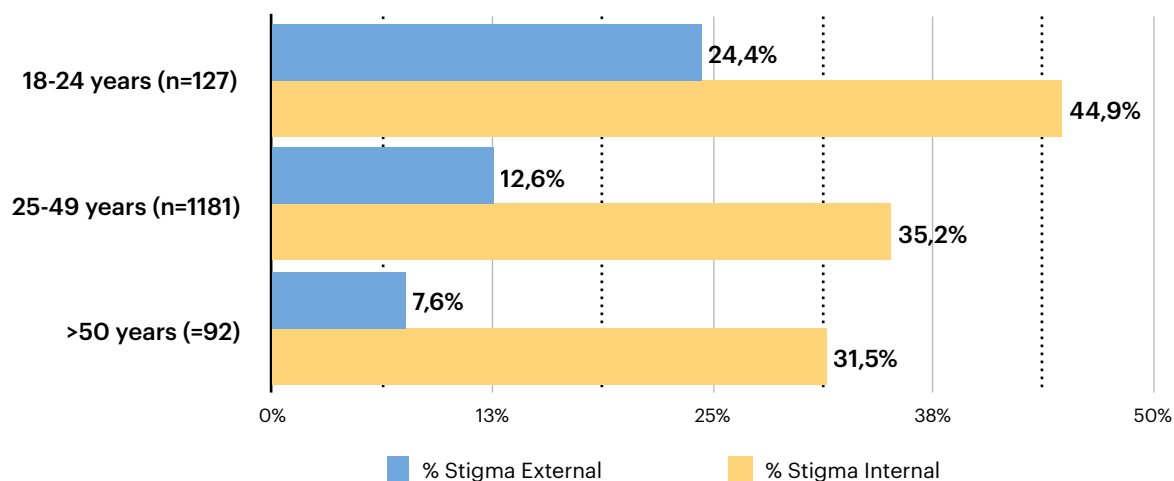
Compared to the condition of respondents in the last 12 months, most respondents were in almost the same condition (n=673, 49.1%) and 578 (42.2%) of respondents were better before the last 12 months, while 120 (8.8%) of respondents experienced worse conditions before the last 12 months.

Fig 17. Differentiation of stigma and discrimination based on key population groups in the last 12 months



Among those who said Yes to at least one of the statements in the last 12 months (Figure 11) and those who agreed at least one statement related to internalized stigma in the last 12 months (Figure 12), disaggregated by key population groups, Figure 18 shows that the key population groups reported a higher percentage on both internalized and external stigma compared to non-KP group. Based on age group, respondents who were younger (18-24 years) experienced more stigma and discrimination both externally and internally than older age groups.

Fig 18. Differentiation of stigma and discrimination based on age groups in the last 12 months



The qualitative study also wanted to find out more about how people living with HIV understand the difference between stigma and discrimination (Figure 20 – Figure 22). It was found that people living with HIV had sufficient understanding of stigma and discrimination, although some respondents were not able to explain the difference between these two terms. In general, people living with HIV tended to interpret stigma and discrimination as detrimental perceptions and actions, where there were psychological impacts resulting from these actions. These perceptions and actions came from partners, families, the surrounding community, and public servants such as healthcare workers and community officials. Respondents also stated that this perception came from their own internalized stigma.

Fig 19. Treatment associated with defining stigma and discrimination



Fig 20. Perceptions associated with defining stigma and discrimination



Fig 21. The psychological impact of stigma and discrimination



“

Stigma is what people think about us, while discrimination is an action—more negative.—SW, Banda Aceh.

Stigma and discrimination for people living with HIV include bullying, boxing, injustice from several aspects, for example when accessing medicines at services, skewed responses from officers at the Community Healthcare Center.—A, Pekanbaru.

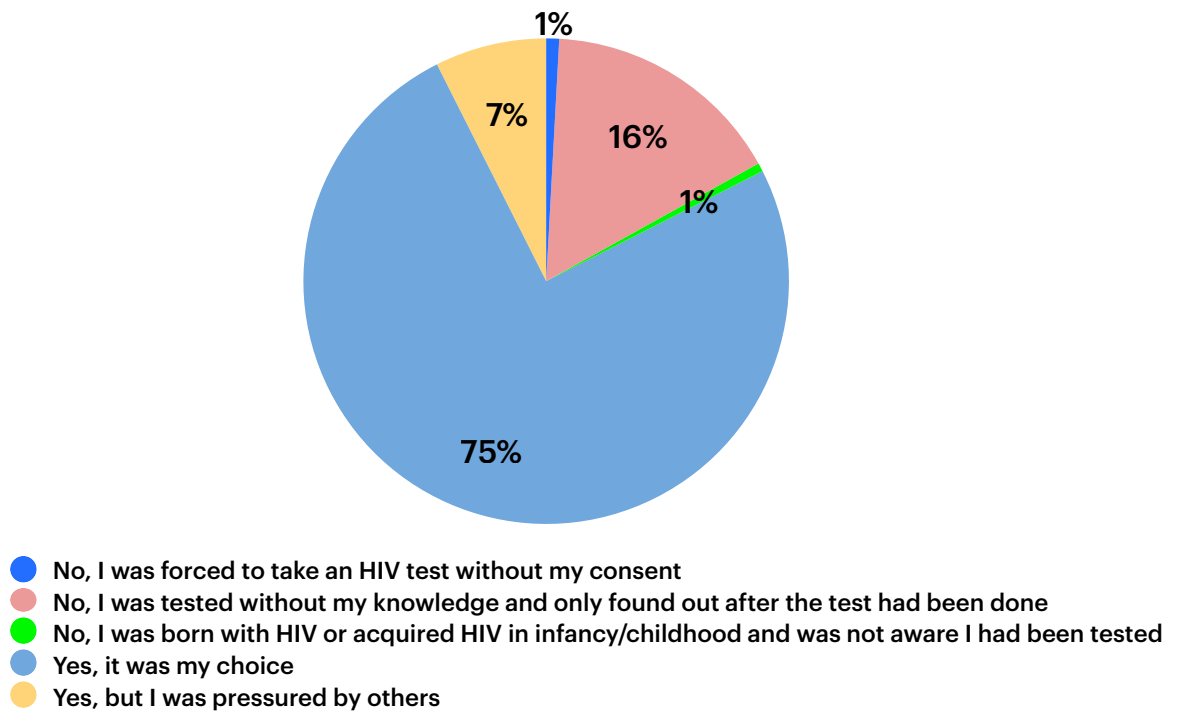
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3.5. INTERACTION WITH HEALTHCARE FACILITY

HIV Testing

Regarding interactions at healthcare facilities, 1050 respondents decided to test for HIV of their own choice (75.1%). However, 225 (16.1%) of respondents were tested without the respondent's knowledge and were only notified after the test was completed, and 104 (7.4%) of respondents were pressured by others, 12 (0.9%) respondents were forced to take an HIV test without their consent, and 8 (0.6%) of respondents was born with HIV or acquired HIV in infancy/childhood and was not aware they had been tested.

Fig 22. Decision to test for HIV (n=1399)

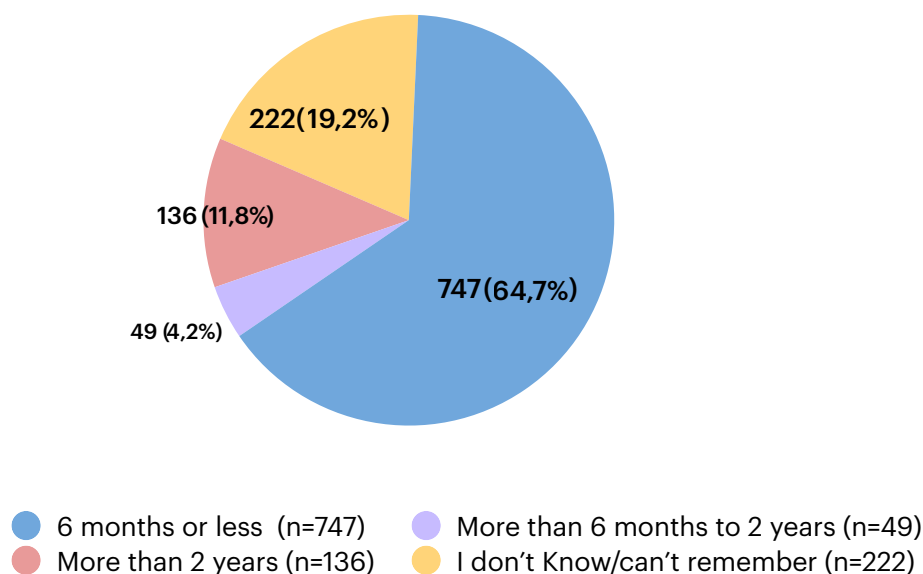


The experienced respondents had tests without their knowledge and found out after the test had been done also found on FGD.

“
*Once, when I dropped off, I had diarrhoea for more than one month, then suddenly the doctor immediately had my blood taken, and not long after that, I was called for counselling and told that I was HIV positive; I was shocked because there was no consent (HIV test), it felt like the world was going to collapse.—
 I, Banda Aceh.*
 ”

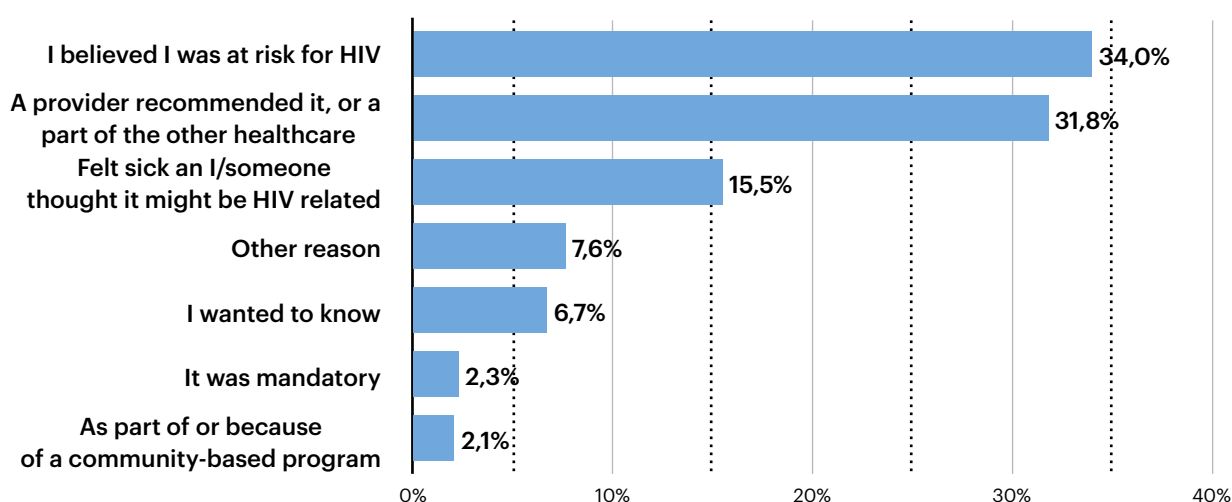
When asked about how long it took for them to get tested for HIV, most respondents reported that decisions to undergo HIV testing were made within six months or less from the moment they first thought about testing (n=747, 64.7%).

Fig 23. Time duration between test plan and actualization (n=1154)



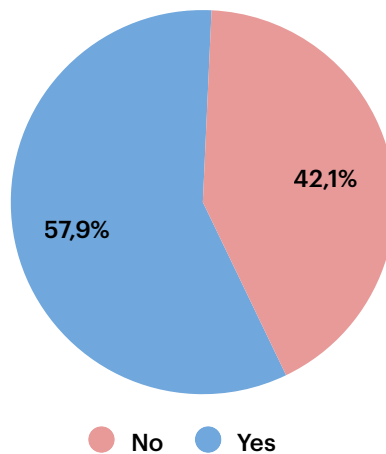
Respondents stated that the main reason they took an HIV test was because they believed they were at risk of HIV infection (n=383, 34.0%), it was recommended by a healthcare provider or as part of other health care (n= 358, 31.8%), or the respondent felt sick and other people suspected it was related to HIV (n=174, 15.5%).

Fig 24. Main reason to get tested for HIV (n=1126)



However, the findings above were inversely proportional to the findings that many respondents felt hesitant to carry out an HIV test because they were afraid of other people's reactions (n=666, 57.9%).

Fig 25. Hesitancy to test for HIV because of fear of other people's reactions (n=1151)



HIV Care and Treatment

1226 (87.6%) of respondents were currently or had ever been on ARV treatment. There were 875 (71.4%) of non-key population respondents who had ever been on ARV treatment, while in the respondents of the key population there was 351 (28.6%). Among the key populations, MSM had the highest percentage of respondents who ever been on ARV treatment (n=168, 90.8%), followed by sex worker (n=248, 87.6%), transgender (n=76, 88.4%), and PWUD (n=106, 80.9%). There were doubts about hesitancy, delay, or prevention from ARV treatment because of concerns that other people who were not family members or friends will know the HIV status (n=820, 58.9%) and worry that partners, family, or friends will know the respondent's HIV status (n=643, 46.0%).

Fig 26. ARV Treatment Experience (n=1400)

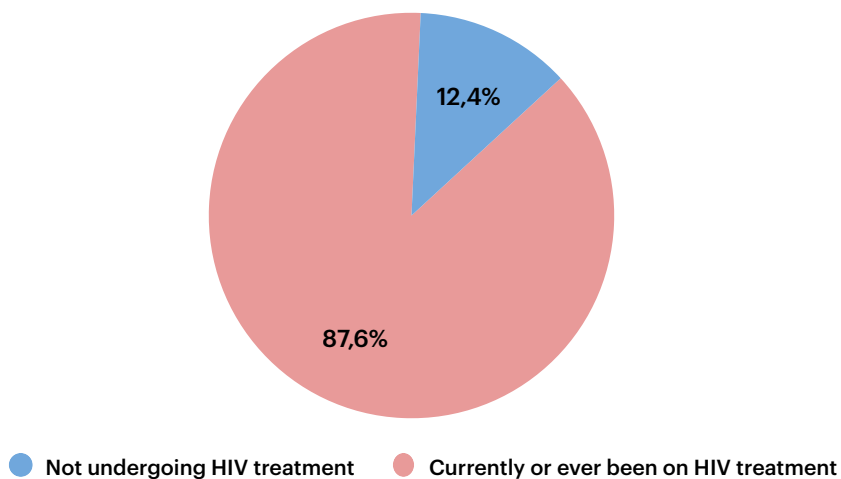
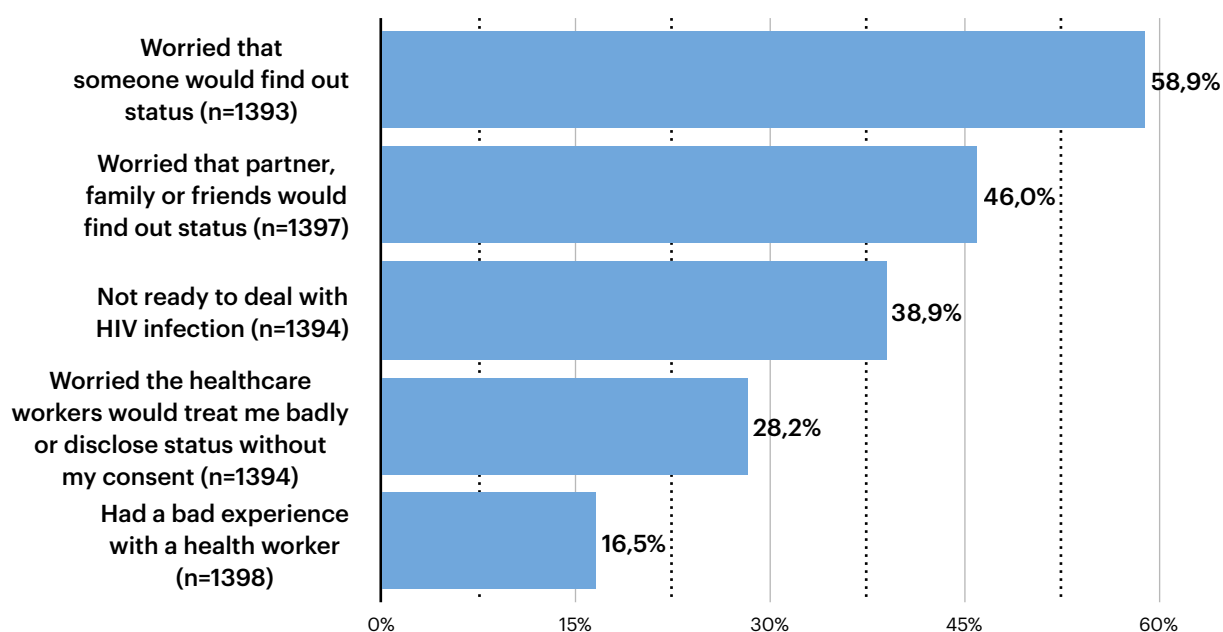
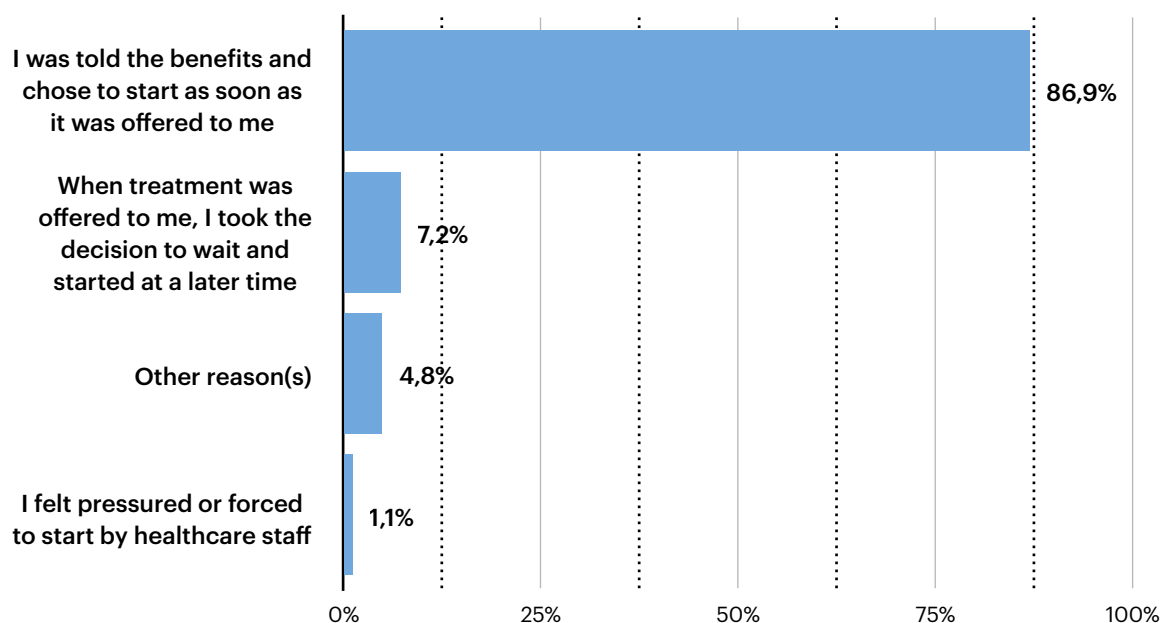


Fig 27. Hesitancy to start/avoid/delay treatment



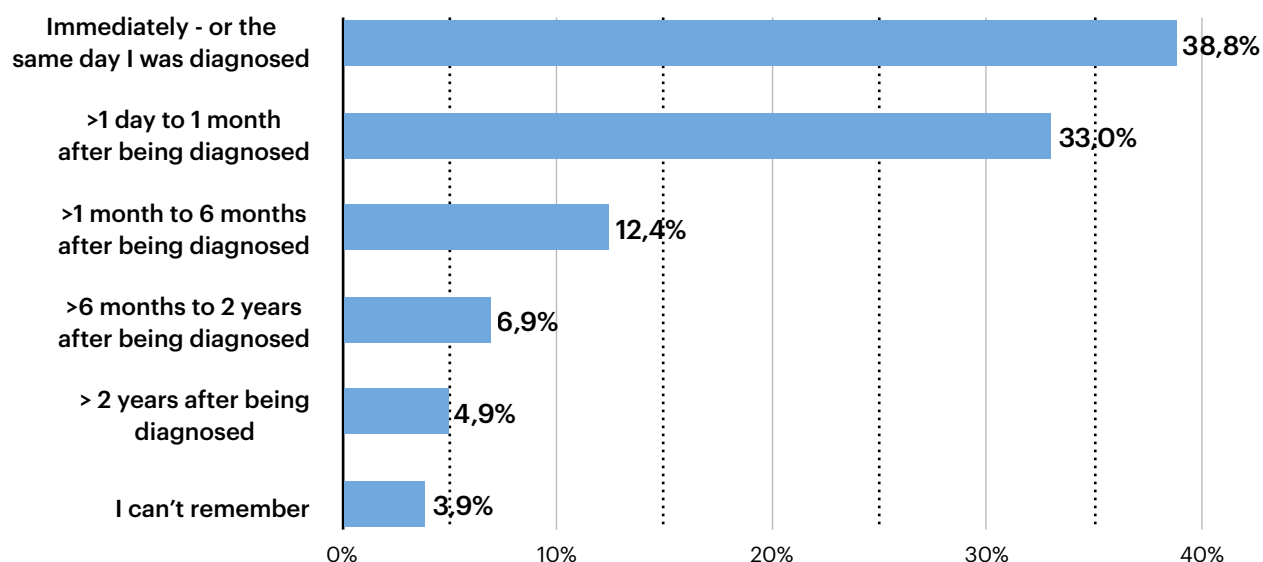
1065 (86.9%) respondents were told the benefits and chose to start ARV treatment as soon as it was offered to them. There were 88 (7.2%) of respondents who decided to postpone treatment even though it had been offered, and other 14 (1.1%) respondents reported feeling pressured or forced by healthcare workers to start treatment.

Fig 28. Reasons for starting ARV treatment (n=1226)



However, most respondents started HIV treatment no later than six months after being diagnosed as HIV positive. Most respondents started treatment immediately or on the same day after diagnosis (n=472, 38.8%) or >1 to 30 days after diagnosis (n= 401, 33.0%).

Fig 29. Duration of ART initiation since HIV diagnosis (n=1216)



Respondents' concerns about other people knowing their HIV status had an impact on 275 (22.4%) of respondents, which led them to having missed an ARV dose. When asked about the experience of treatment interruptions, 236 (19.4%) respondents reported that they had ever stopped their ARV treatment.

Fig 30. Missing a dose of ARV because I was afraid people knowing my HIV status (n=1226)

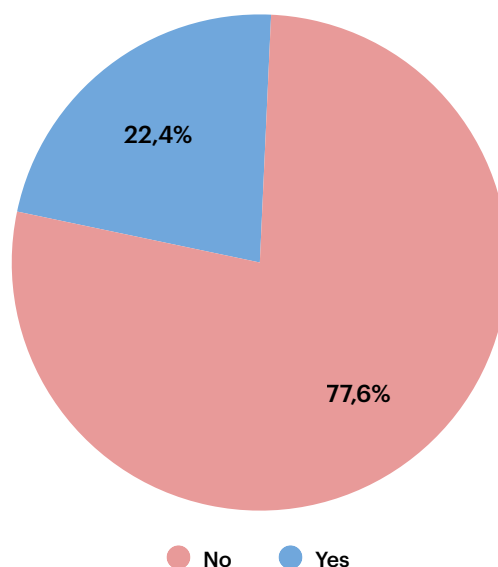
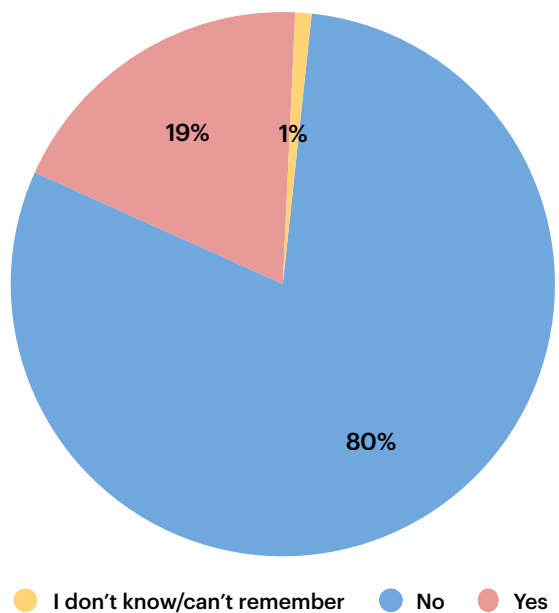


Fig 31. Ever stopped ARV treatment (n=1218)



For those who ever interrupted or stopped ART in the last 12 months, the stigma-related reasons were worrying that someone will find out their HIV status (n=27, 11.4%), not being ready to deal with their HIV infection (n=26, 11%) and other reasons (n=138, 58.5%), while 45 (19.1%) respondents have not been taking ART in the last 12 months or not stop ART in the last 12 months. Meanwhile, non-stigma related reasons were other reasons (n=189, 47.0%) and do not feel treatment is needed (n=117, 29.1%).

Fig 32. Stigma related reasons to stop ARV in the last 12 months

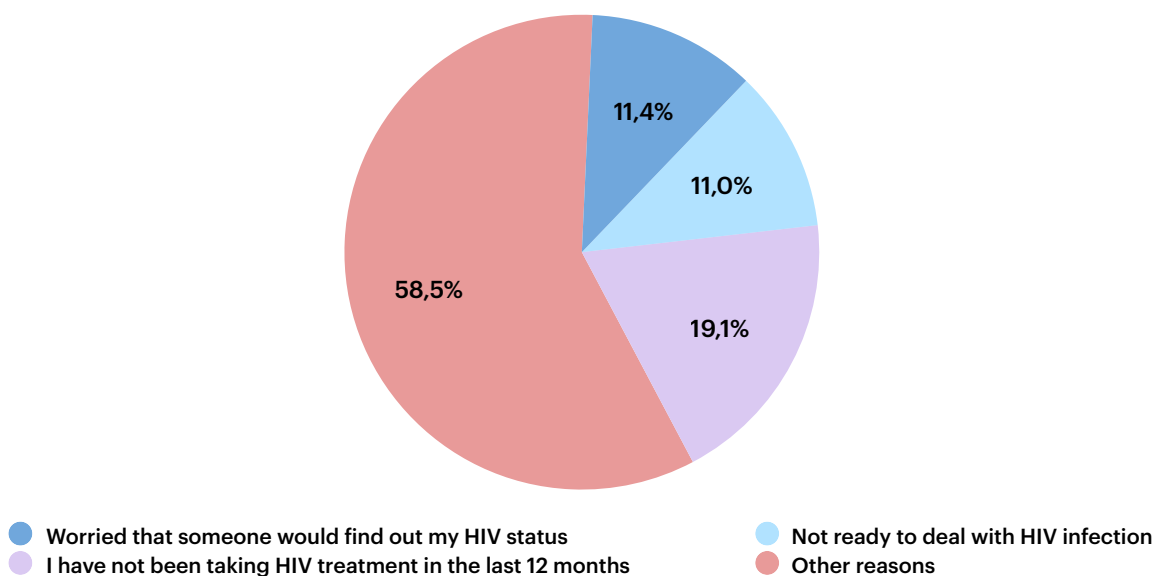
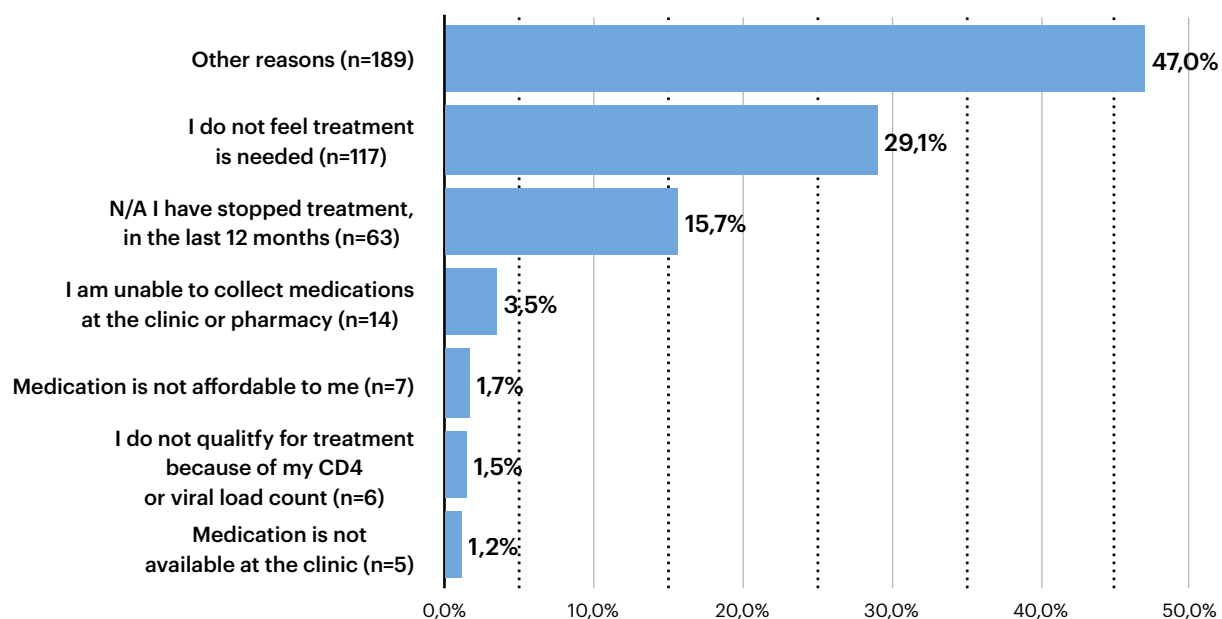
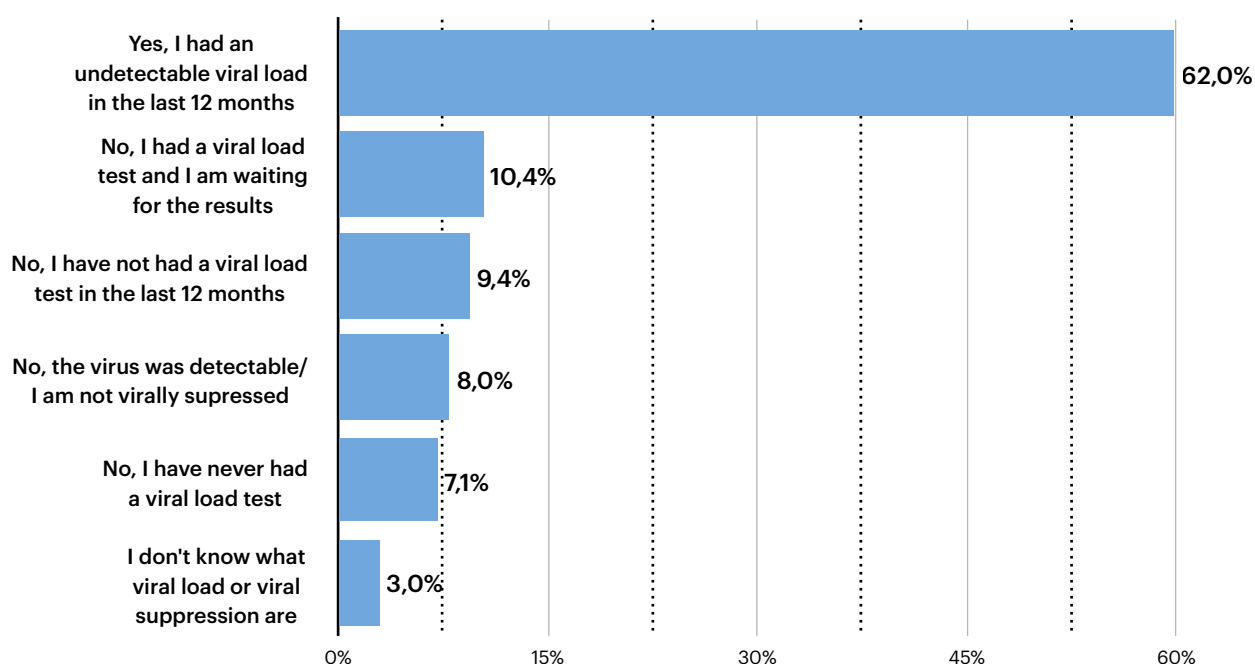


Fig 33. Non-stigma related reasons to stop ART in the last 12 months (n= 236)



Most respondents (n=755, 62.0%) said they had performed a viral load test in the last 12 months and obtained undetectable viral load results. However, it was found that few respondents had never undergone a viral load test (n=87, 7.1%), and even some respondents didn't know what viral load or viral suppression are (n= 36, 3.0%).

Fig 34. Viral Load testing (n=1218)



Almost all respondents generally stated that currently their health condition was good (n=1145, 82.4%). The most frequently reported diagnoses during the past 12 months were non-communicable diseases (n=294, 21.2%) and mental health conditions (n=251, 18.0%).

Fig 35. Current health condition (n=1389)

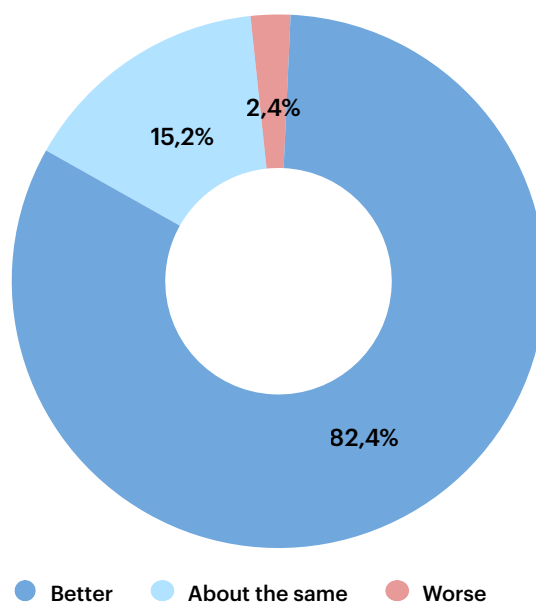
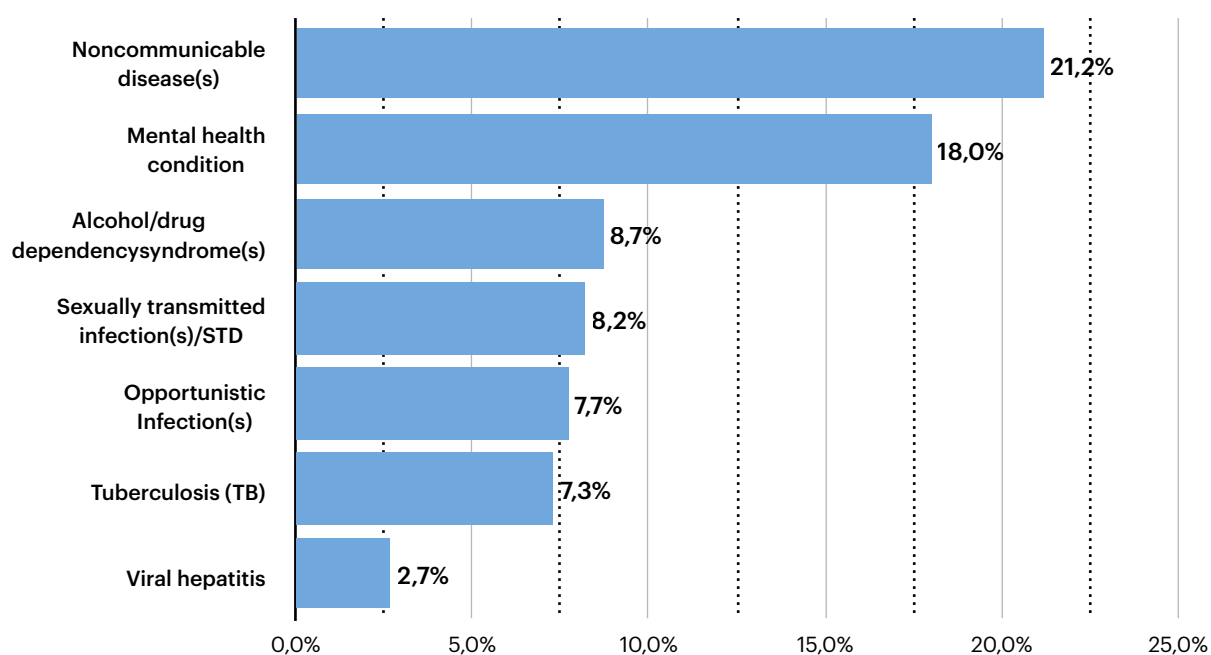


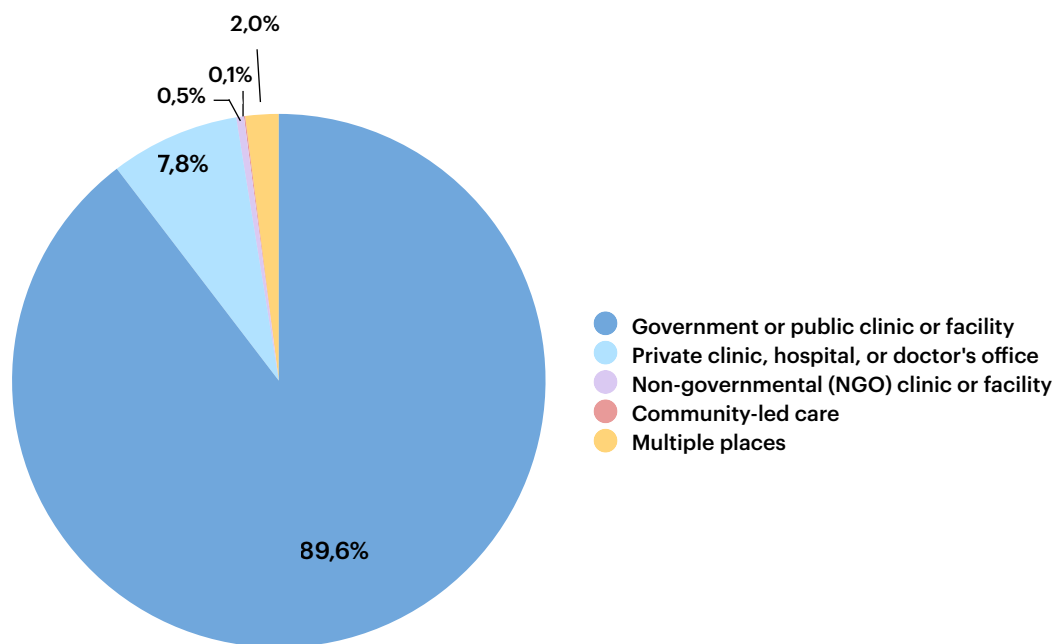
Fig 36. Disease diagnoses during the last 12 months



3.6. STIGMA AND DISCRIMINATION IN HEALTHCARE SERVICES

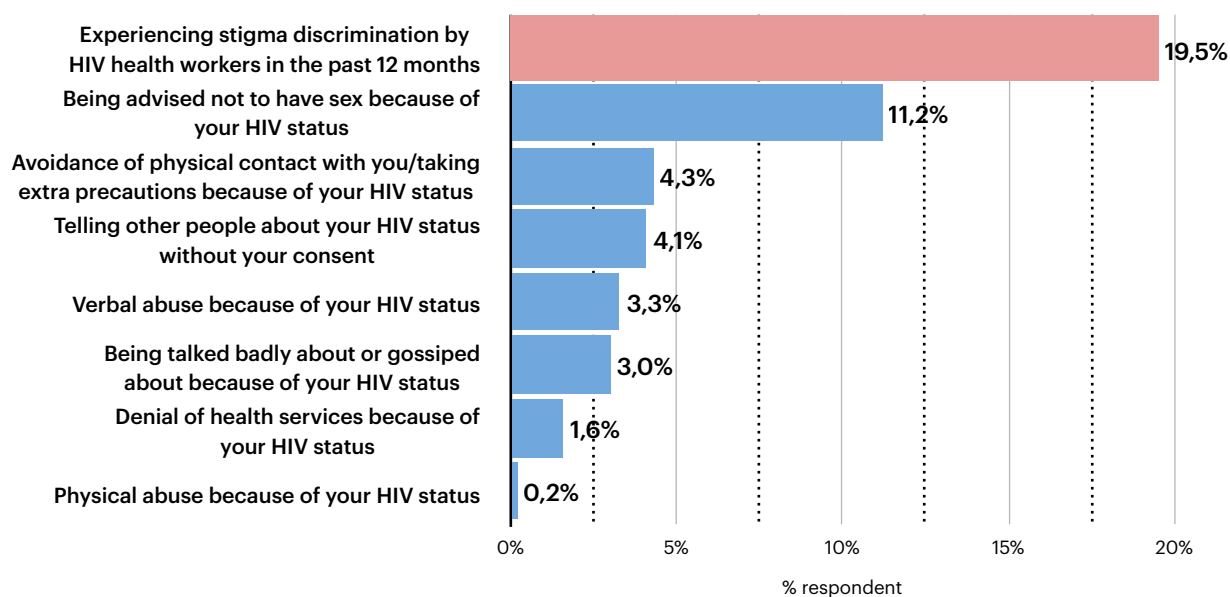
Of the total 1290 respondents who routinely accessed HIV services, 1156 (89.6%) respondents received routine HIV care and treatment at government or public clinics or facilities, 101 (7.8%) at private clinic, hospital or doctor’s office, 26 (2.0%) at multiple places, 6 (0.5%) at non-governmental (NGO) clinic or facility, and 1 (0.1%) at community-led care.

Fig 37. Distribution of HIV care and treatment service facilities (n=129)



During the last 12 months, 252 (19.5%) respondents indicated having experienced at least one form of stigma and discrimination by healthcare workers when seeking HIV-specific healthcare. Stigma and discrimination experienced by people living with HIV included healthcare workers advising respondents not to have sex because of their HIV status (n=145, 11.2%) and avoiding physical contact or taking extra measures (for example, wearing double gloves) because of HIV status (n=56, 4.3%).

Fig 38. Experiences of stigma and discrimination when accessing HIV services during the last 12 months (n=1290)

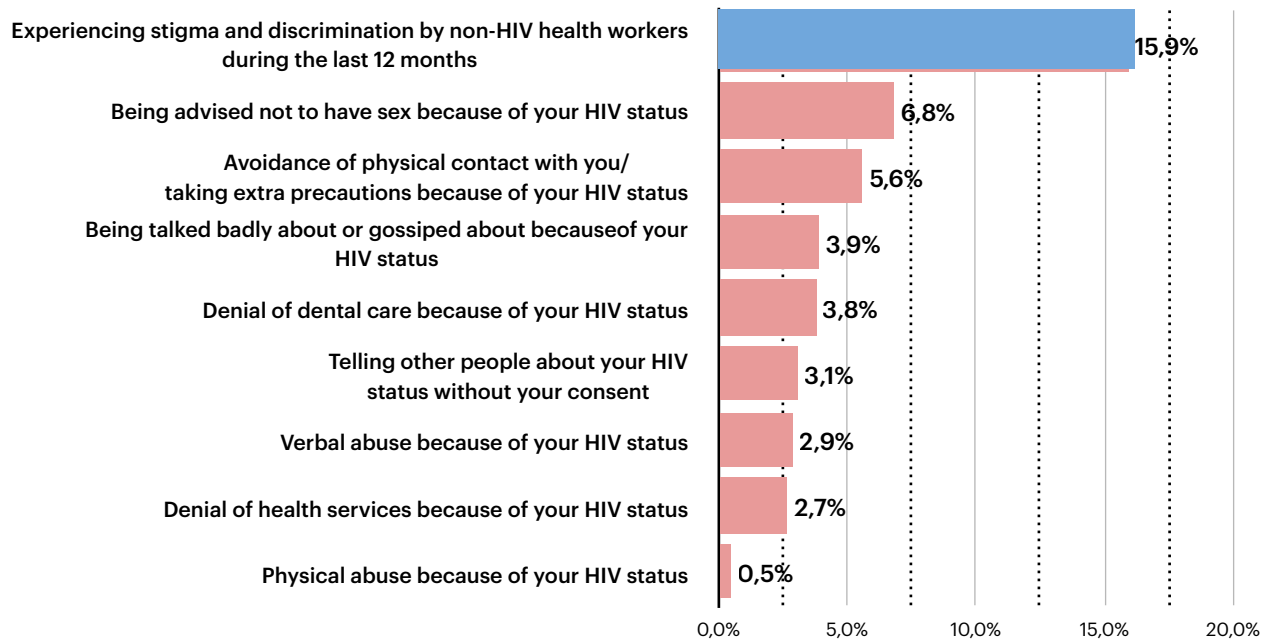


The results of the group discussion also strengthened the findings above. There was reluctance on the part of health workers to provide health services when they knew a patient's HIV status.

“ ... once (experiencing S&D), when I went to the midwife it was received well at first, then I received information that my wife was positive, my wife and I were gently sent away, and referred to RSAM (Dr. Abdoel Moeloek Hospital), after being admitted to RSAM accepted, when I was in the room my wife was ignored, other patients were paid attention to, but my wife was not paid attention to.—EN, Bandar Lampung. ”

Meanwhile, regarding non-HIV healthcare services, as many as 735 respondents accessed non-HIV services during the last 12 months. Regarding stigma and discrimination in other healthcare services (excluding HIV services), 114 (15.9%) respondents stated that they had experienced at least one form of stigma and discrimination during the last 12 months. 50 (6.8%) of respondents were advised not to have sex because of their HIV status, and 41 (5.6%) of respondents experienced avoidance of physical contact from health care workers or health workers took extra precautions.

Fig 39. Experiences of stigma and discrimination when accessing non-HIV services during the last 12 months (n=735)



Differentiation of stigma and discrimination in the last 12 months by key population groups shows that the key population respondent group experienced stigma and discrimination in both HIV healthcare services and non-HIV healthcare services at a higher rate than the non-key population respondent group. Stigma and discrimination in non-HIV healthcare services experienced by all key population respondents in percentage >20% than non-key population respondents (18.2%). When looking at differences in age, 33 (29.5%) respondents from the younger age group (18-24 years) reported more experiences of stigma and discrimination in HIV healthcare services and non-HIV healthcare services than other age groups.

Fig 40. Differentiation of stigma and discrimination in healthcare services in the last 12 months by key population groups

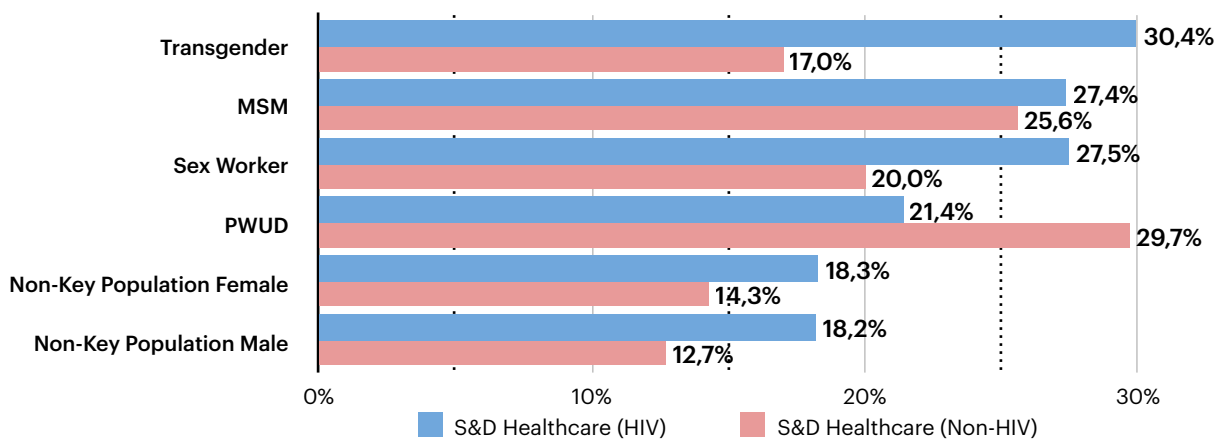
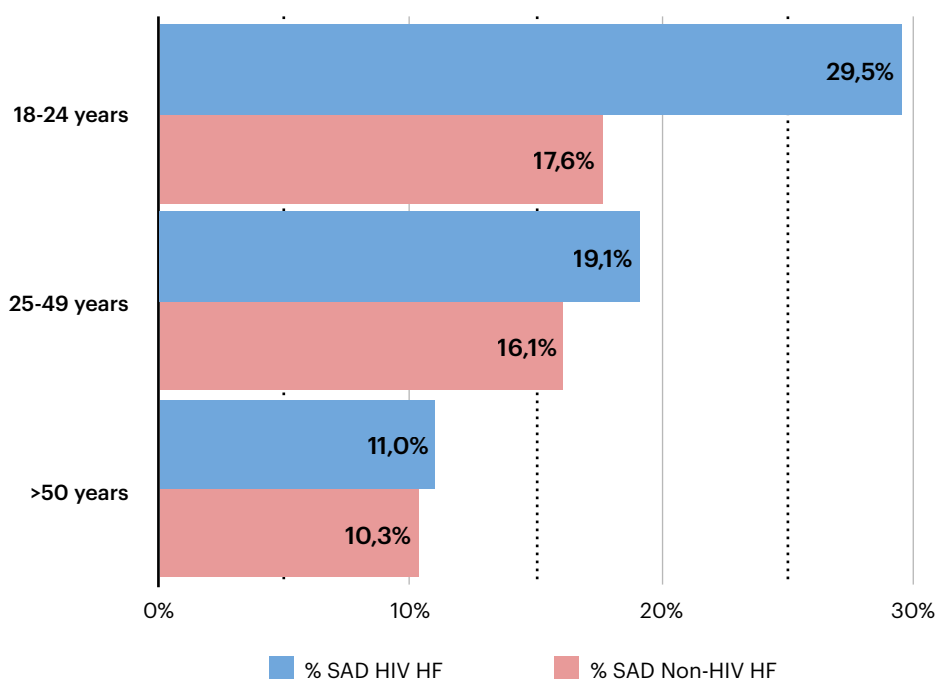


Fig 41. Differentiation of stigma and discrimination in healthcare services in the last 12 months by age groups



266 (19.1%) of respondents usually disclosed their HIV status when accessing healthcare services other than HIV. 1070 (76.8%) respondents were confident that their medical records were kept confidential and will not be shared without their consent, 277 (19.9%) were unsure if their medical records were kept confidential and the rest (n=47, 3.4%) were certain it was clear that their medical records were not being kept confidential.

Fig 42. Open status when accessing services other than HIV (n=1394)

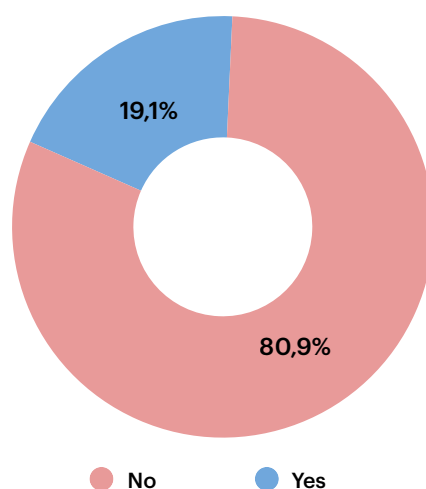
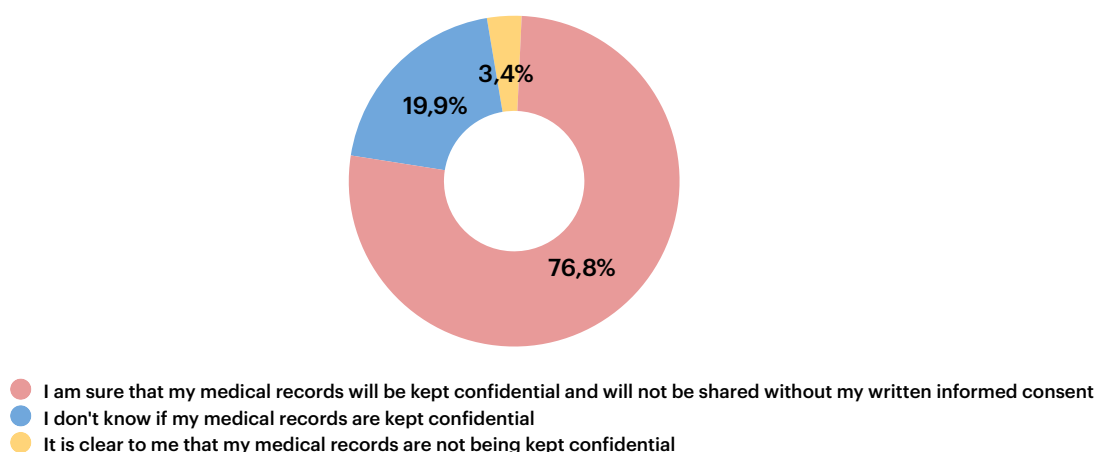


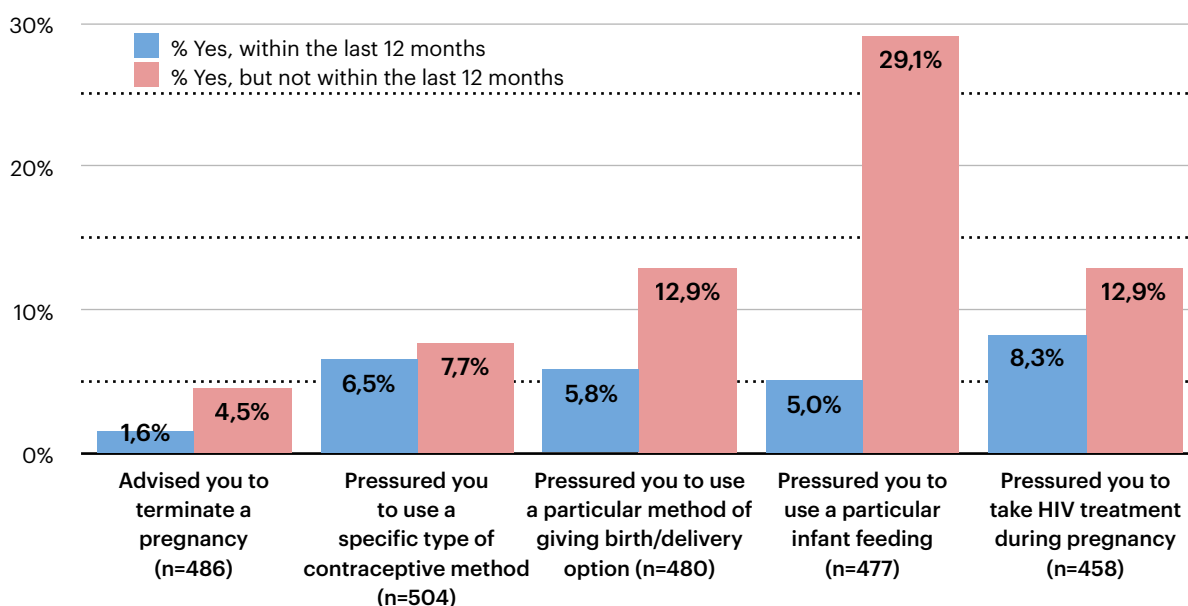
Fig 43. Confidentiality of medical records (n=1394)



3.7. SEXUAL AND REPRODUCTIVE HEALTH

One question was asked exclusively of respondents assigned female at birth about discrimination against them by healthcare professional solely because of their HIV status. A number of 33 (6.5%) of respondents were told by health professionals to use a specific method of contraception to get their HIV treatment in the last 12 months, 38 (8.3%) were pressured to take ARV treatment during pregnancy in the last 12 months and 28 (5.8%) were pressured to use a particular method of giving birth/delivery option in the last 12 months. Beyond the last 12 months, 139 (29.1%) respondents were pressured to use a particular infant feeding practice.

Fig 44. Discrimination done by healthcare professionals because of HIV status (only for female on sex at birth respondents)

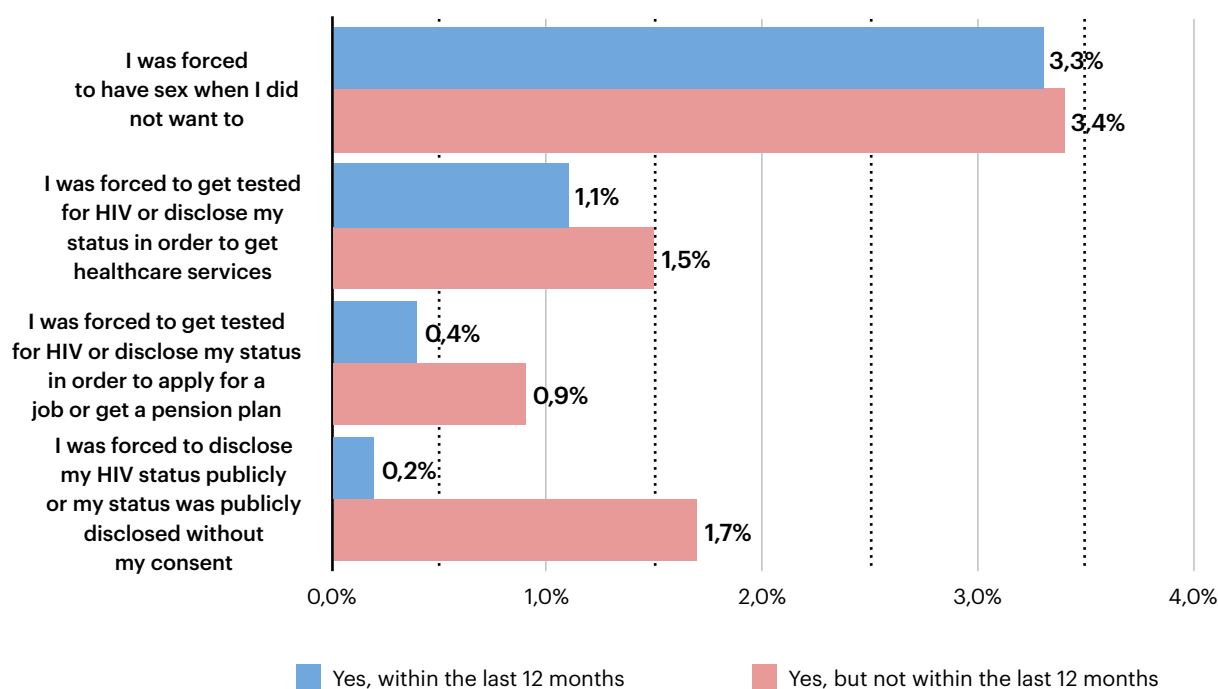


3.8. HUMAN RIGHTS AND AFFECTING CHANGE

A total of 74 (5.3%) respondents experienced at least one type of rights violation during the last 12 months, of which 13 (17.6%) respondents had sought justice, and among those who had sought justice, 8 (61.5%) respondents stated that the problem had been resolved.

The most common rights violation experienced was when respondents in the last 12 months were forced to have sex when they did not want to do so (n=46, 3.3%). This percentage was almost same with experience before the last 12 months (n=47, 3.4%). The second highest percentage was that some respondents were forced to undergo an HIV test or reveal their HIV status to receive healthcare services, where 15 (1.1%) said this had happened in the last 12 months, and 21 (1.5%) of respondents said this had happened before the last 12 months

Fig 45. Right violations related to HIV status (n=1396)



Even though the finding of forced HIV testing during the last 12 months or before the last 12 months was less than 2%, the findings from focus group discussions indicated that the forced HIV testing affected the level of self-confidence of people living with HIV.



*Some jobs require an HIV check, so my self-confidence drops.—
RA, Bandar Lampung.*

There is a case in Ketapang. There was a Medical Check Up (MCU) inspection at a palm oil company issued by the company, and it was leaked (HIV status).—A, Pontianak.



Justice efforts undertaken by those who had experienced a rights violation within the last 12 months and had chosen to seek redress included other efforts (n=7, 53.8%), contacting organisations/networks of people living with HIV (n=3, 23.1%), and filing a complaint (n=3, 23.1%). Among respondents who had experienced a human rights violation within the last 12 months, 47 (63.5%) did not seek redress, the most reported reasons were that they did not know what to do (n=14, 29.8%), other reasons (n=11, 23.4%), or were afraid of their HIV status would be known by others (n=7, 14.9%).

Fig 46. Justice efforts for rights violations (n=13)

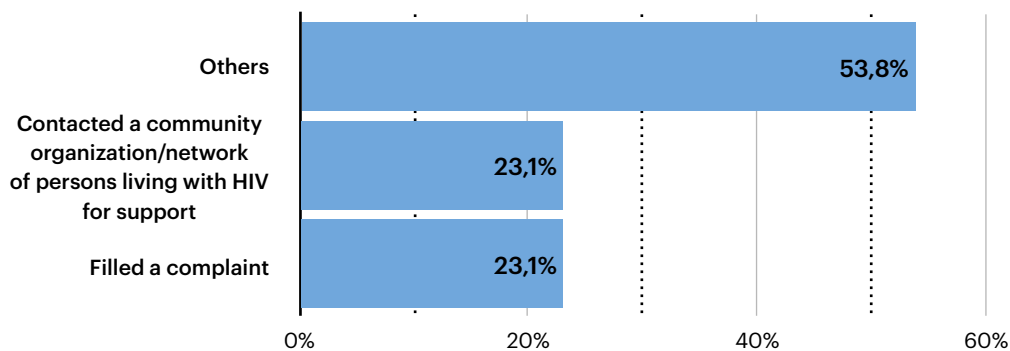
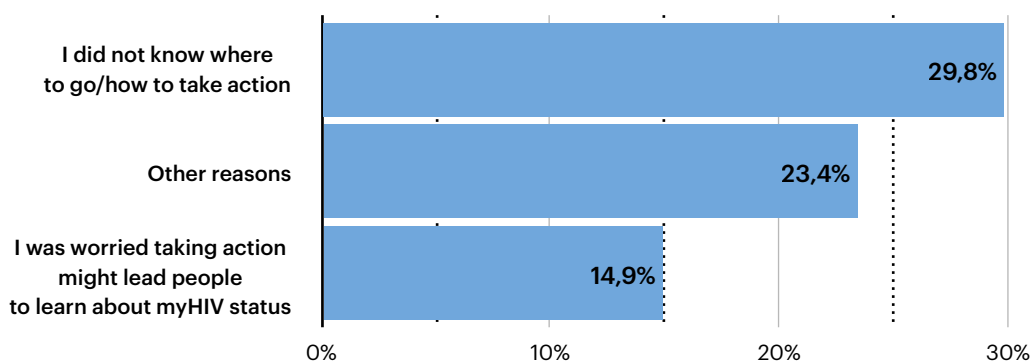
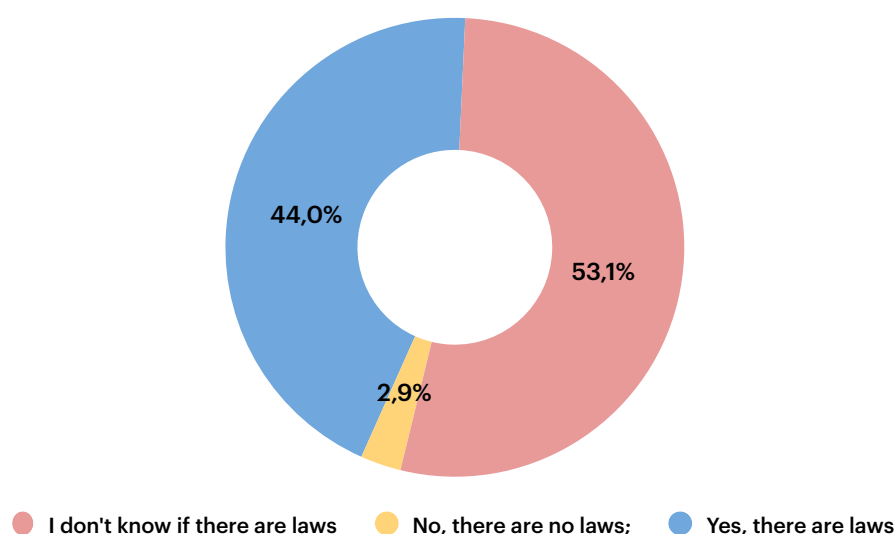


Fig 47. Reasons for not seeking justice for violations in the last 12 months (n=47)



Most respondents (n=742, 53.1%) stated that they did not know about the availability of legal regulations that protected people living with HIV from stigma and discrimination, but 614 (44.0%) of respondents indicated that they knew that there were legal regulations that protected people living with HIV from stigma and discrimination, and 40 (2.9%) of respondents indicated that there were no laws that protected people living with HIV from stigma and discrimination.

Fig 48. Awareness of legal regulations that protect people living with HIV from stigma and discrimination (n=1396)



Another reason to not seek justice found through focus group discussions was that people living with HIV were disappointed by passive action after reporting and there was also fear that the legal assistance from paralegals would cost money or the process of seeking legal redress could reveal their HIV status. As a result, respondents tended to look for ways not to take part in these activities.

“
I reported it, but there was no action.—D, Kupang
”

“
No, so just swallow it yourself. After all, if we want to go to a paralegal, we are afraid we will incur costs.—FA,
”

On focus group discussion, respondents indicated that they knew that there were legal regulations that protected people living with HIV from stigma and discrimination. However, they cannot explain the regulations or policies in detail. In addition, even people living with HIV were aware of the existence of regulations and policies that can protect them from stigma and discrimination, but they still felt that the implementation of these policies had not been optimal.

“

From the Department of Manpower (Indonesian Ministry of Manpower), there is, but the policies are not in line with those in the field. There are still human rights violations by companies being expelled [because of HIV status].—A, Pontianak.

”

Discriminatory policies by the Ministry of Home Affairs or regional governments discriminate against state civil servants who are living with HIV by banning them from promotions due to their HIV status.

“

There is a policy in the region that if a civil servant is found to be HIV positive, they cannot get a promotion.—R, Pekanbaru.

”

Likewise, the government's localization closure policy hindered the elimination of AIDS by 2030. This policy also triggered stigma and discrimination against the sex worker population.

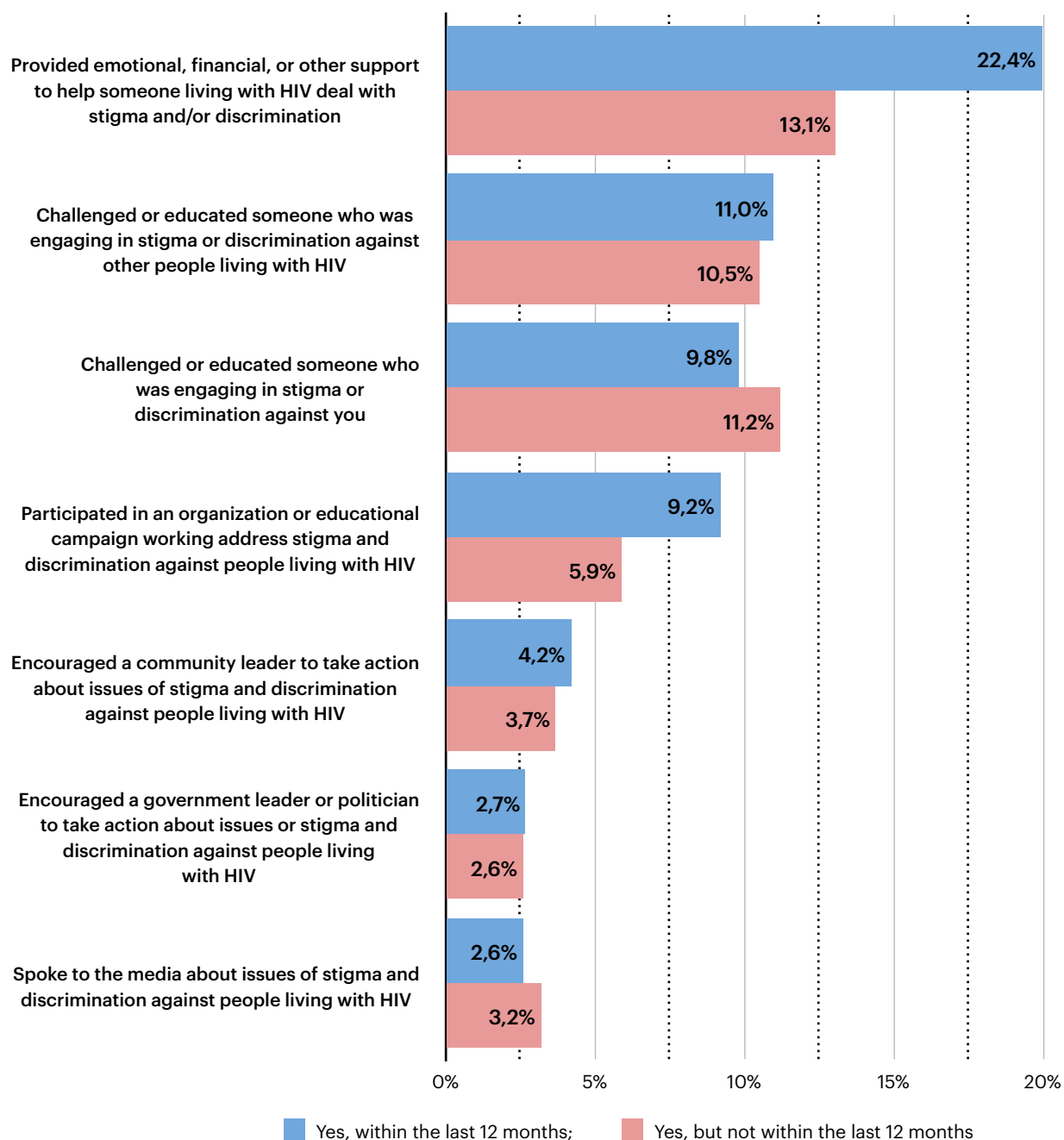
“

The closure of local areas has resulted in more widespread growth in HIV cases. Sex workers were thrown stones until they died.—YO, Kupang.

”

Respondents who had experienced stigma and discrimination undertook advocacy efforts and impacted change, both during the last 12 months and beyond the last 12 months. The action most often taken by respondents to impact change was to provide emotional, financial, or other support to help someone living with HIV deal with stigma, and/or discrimination within the last 12 months (n=313, 22.4%).

Fig 49. Advocacy and affecting change



3.9. INTERSECTIONAL STIGMA

People living with HIV who belong to key population groups had the potential to experience intersectional stigma due to their HIV status and key population identity. From qualitative study, it was found that female sex workers and transgender people were seen as the groups most vulnerable to stigma and discrimination. Gay men and other MSM tended to receive discriminatory treatment because of their non-conforming gender expressions.

“*Sex workers [are most vulnerable to stigma and discrimination], for them it is a despicable job, and HIV is considered a cursed disease.”—N, Pekanbaru*

“Transwomen (transwomen) can access (healthcare services), but there is much gossip, MSM is seen based on their sexual orientation, even the doctors themselves [are carrying out stigma and discrimination]. [...] The officers often say, 'That is an HIV patient who wants to take medicine,' they take medicine, and then they are called 'patient B20'. TG (transgender) friends are not comfortable taking it there. Feeling uncomfortable being stared at by many people, he continues to be called his real name (according to his KTP) with the three letters (HIV).”

—L, Banda Aceh.

Transgender Population

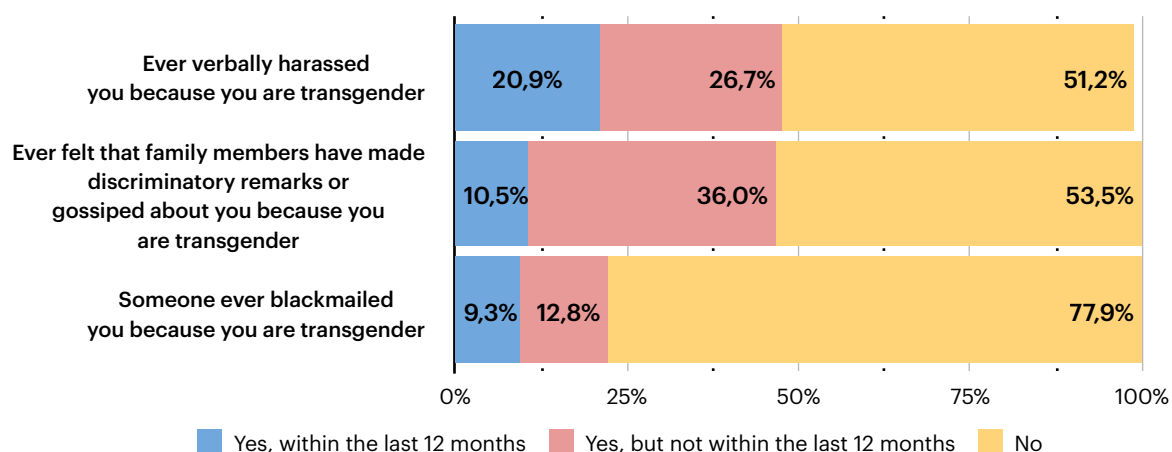
Among 86 transgender respondents, 18 (20.9%) had experienced verbal harassment from someone, 9 (10.5%) had felt that family members discriminated against or gossiped about them and 8 (9.3%) reported someone ever blackmailed them because they are transgender. Transgenders who received discrimination because of their gender expression were also found in FGD.

“

At immigration, if you are applying for a TG (transgender) passport, you are not allowed to look or dress up; it prevents you from expressing yourself.”—R, Makassar.

”

Fig 50. Experiences of stigma and discrimination due to transgender identity (n=86)



The transgender population, in the context of qualitative study, trans women; they lived side by side with communities, like they ran salons and organized weddings for a living. However, this did not necessarily mean that trans women were accepted by society. There was a view that transgender people are not by the values prevailing in society, where men express themselves like women and are considered striking, contrary to the rules, and against nature. The stigma attached to this group placed them at risk of discriminatory treatment and even exclusion.

“

TG (transgender) [is most vulnerable to stigma and discrimination] because it is also strange in society because its treatment is not by its gender and is prohibited by religion, so it is seen as strange by society.”—RA, Bandar Lampung.

”

“

*Once, when (community organisations) forcibly evicted trans women's friends from their boarding houses, they did not accept our presence; there were brochures distributed in several places by stakeholders that excluded the community and made friends not come to services.”—
A, Pekanbaru.*

”

Heteronormative values that indigenous people also understand made it difficult for trans women to be accepted by indigenous people. It related to how gender and gender expression of trans women did not conform to the heteronormative concept understood by indigenous people.

“

The family that carries the surname becomes problematic. At the same time, she (the trans woman) wants to be a woman, even though she is the bearer of the surname. So, when she goes home, she has to cut her hair to be a man when home..... she has to "live with 2 life scenarios. That is how it is in tribe" T—Medan.

”

In the focus group discussion, trans women also stated that they did not have equal opportunities with cis-identifying people

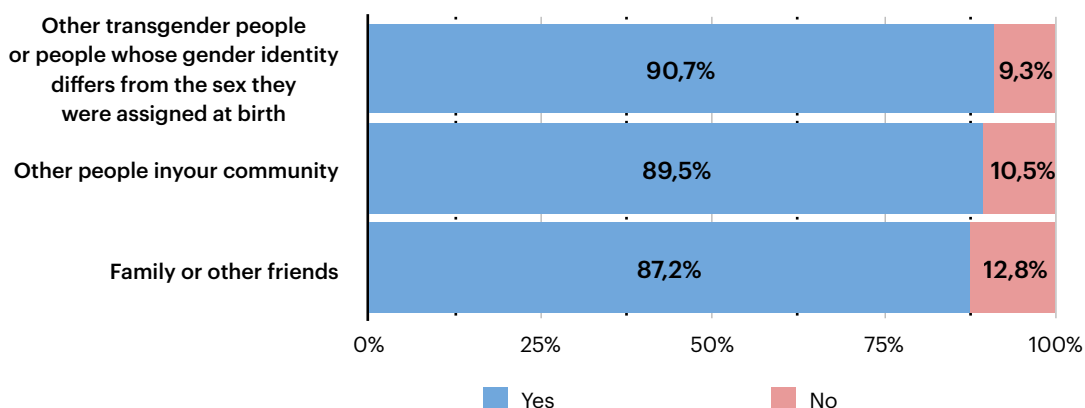
“

There is inequality or injustice for TG (transgender), namely that when companies open lockers (job vacancies), it is always a requirement that they must be either male or female. If a TG had a different appearance, they would have been rejected”—A, Makassar.

”

Most transgender respondents had joined transgender organizations/networks/groups (52.3%). Those who knew the respondent's transgender identity were other transgender people or people whose gender identity differs from the sex they were assigned at birth (90.7%).

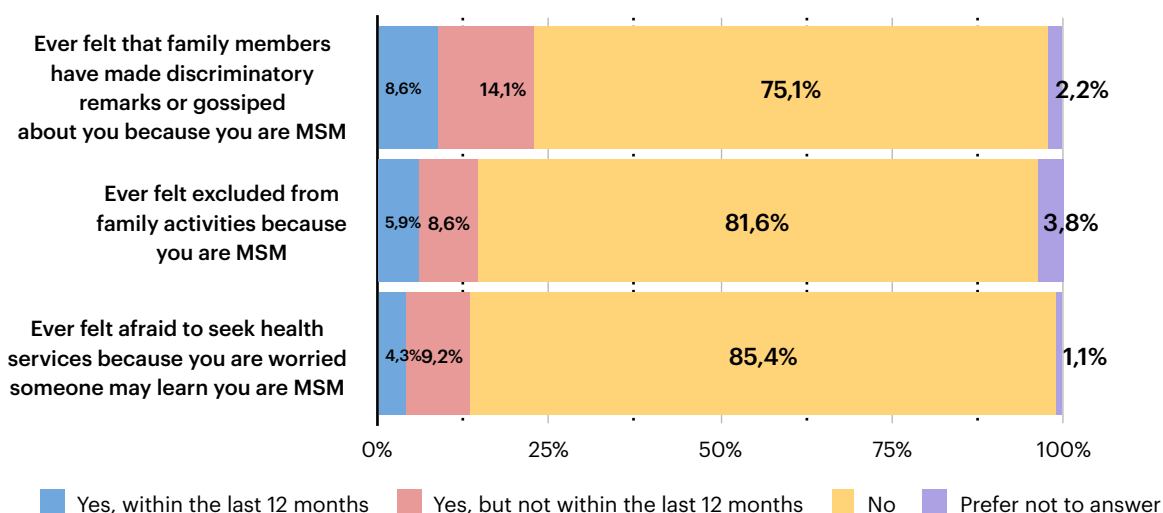
Fig 51. Identity disclosure by transgender (n=86)



Gay and other MSM Populations

Among 525 (37.5%) key population respondents, there were 185 (48.1%) respondents who stated that they identify as gay or men who has sex with men (MSM). Respondents had felt that family members discriminated against or gossiped about respondents because of their MSM identity during the last 12 months (n=16, 8.6%) or before the last 12 months (n=26, 14.1%).

Fig 52. Experiences of stigma and discrimination due to MSM identity (n=185)



MSM who had joined MSM organizations/networks/groups was 55 (29.7%). Most of those who knew the identity of MSM respondents were other people who are also gay/homosexual/MSM/have sex with men (n=157, 84.9%).

Fig 53. Joining in MSM organization/network/group (n=185)

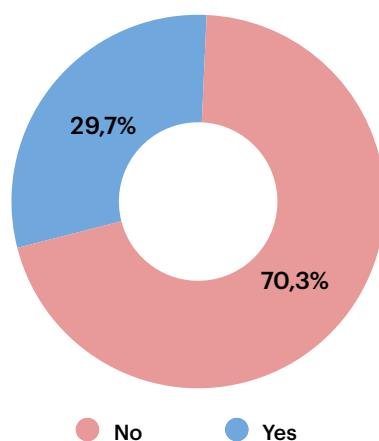
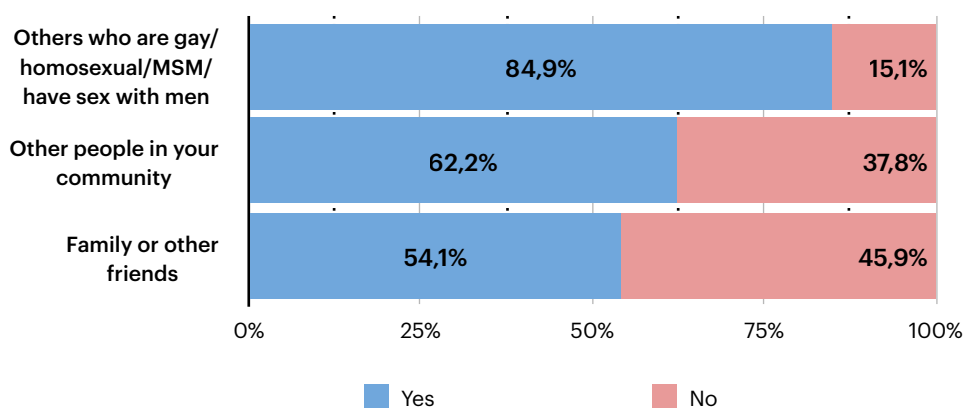


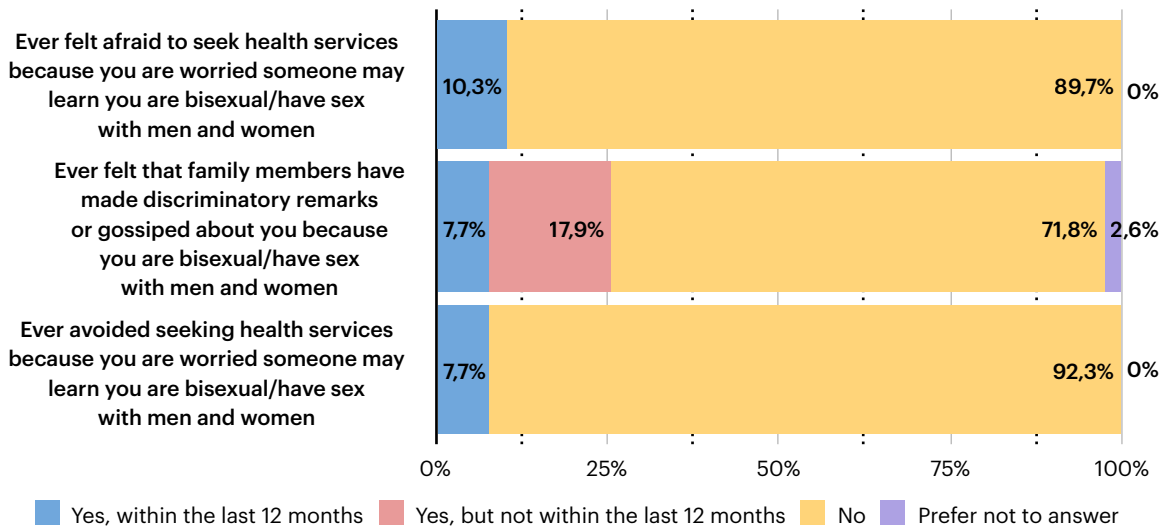
Fig 54. Identity disclosure by MSM (n=185)



Bisexual Populations

There were 40 (10.0%) respondents who stated that they had a bisexual sexual orientation. In the last 12 months, 4 (10.3%) respondents who had a bisexual orientation had felt afraid of seeking treatment at a healthcare facility, and 3 (7.7%) of respondents had avoided seeking healthcare services because they were worried someone may learn they are bisexual and 3 (7.7%) respondents felt discriminated against/rumoured about by family members because of their bisexual orientation.

Fig 55. Experiences of stigma and discrimination due to bisexual identity (n=39)



Most respondents who have a bisexual orientation had not joined a bisexual organization/network/group (n=33, 84.6%). The majority of parties who knew that the respondent has a bisexual orientation were people who are also bisexual (n=27, 69.2%).

Fig 56. Joining a bisexual organization/network/group (n=39)

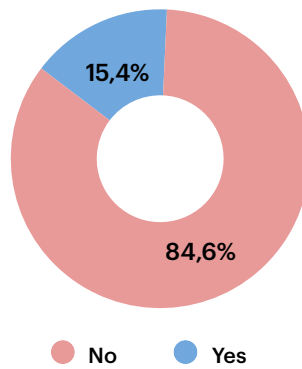
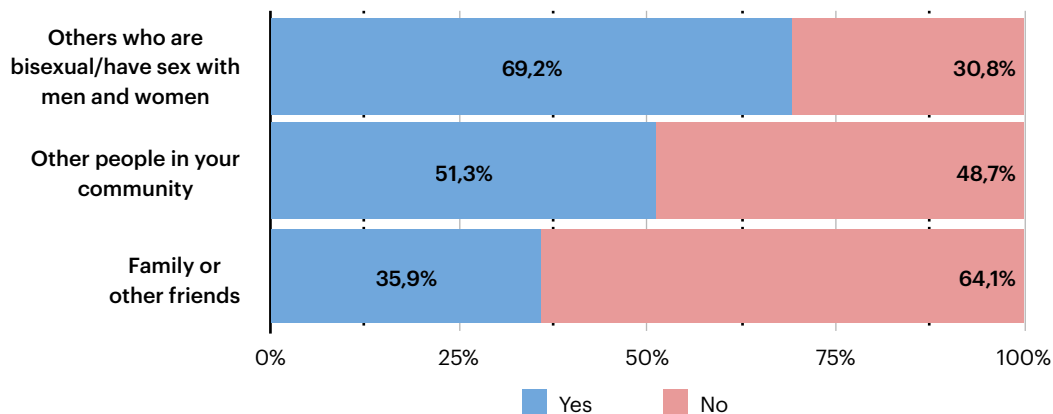


Fig 57. Identity disclosure by bisexuals (n=39)



Sex Worker Populations

There were 283 (53.9%) respondents who identified themselves as sex workers or had ever sold sex, but due to error when programming the questionnaire on SurveyMonkey, the following questions were only filled by those who identified themselves as sex workers (n=159, 63.1%). There were 11 (13.8%) of these respondents who had experienced verbal harassment from someone in the last 12 months. Sex workers had also experienced blackmail (n=10, 6.9%) and physical harassment because the respondent was a sex worker in the last 12 months (n=10, 6.9%).

The stigma against sex workers in society was also found in the focus group discussion that their work was seen as bad work and they faced intersectional stigma of being sex workers living with HIV.

“Sex workers [are most vulnerable to stigma and discrimination]. For them, it is a despicable job, and HIV is considered a cursed disease.”—N, Pekanbaru

Fig 58. Experiences of stigma and discrimination due to sex worker identity (n=159)

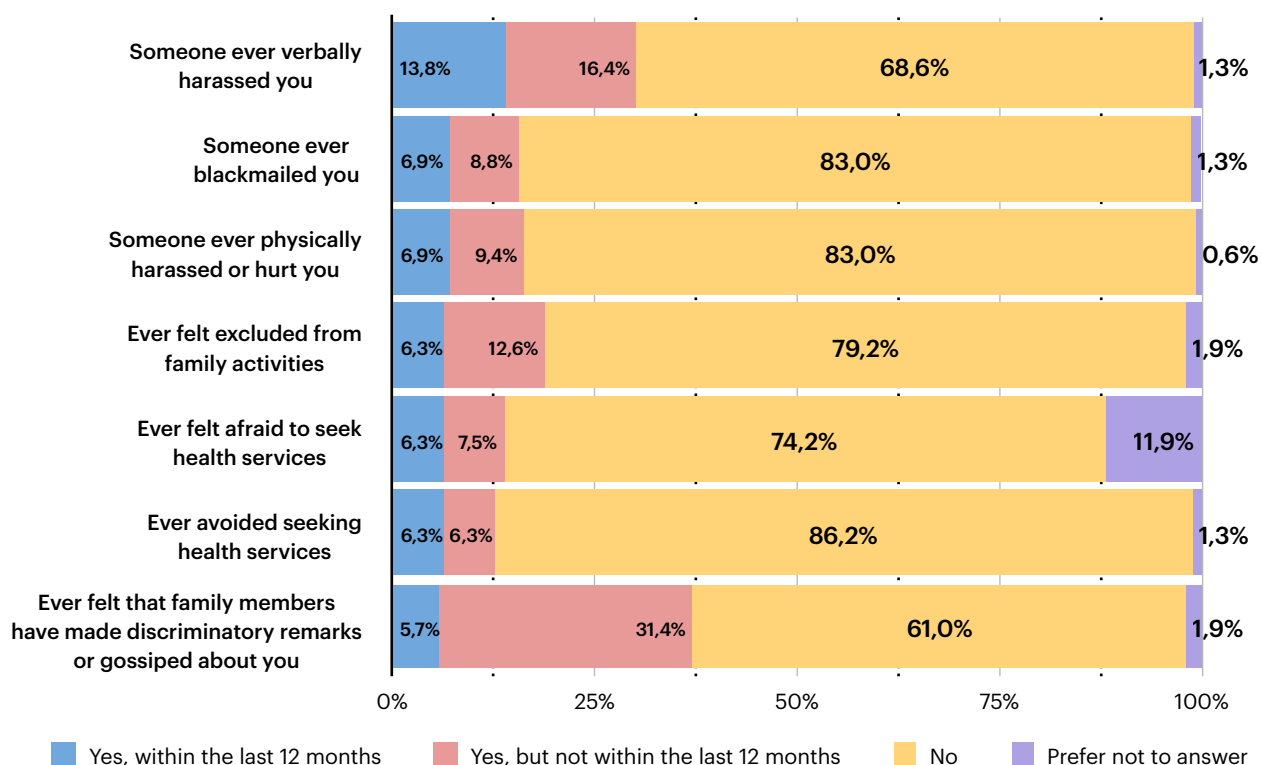
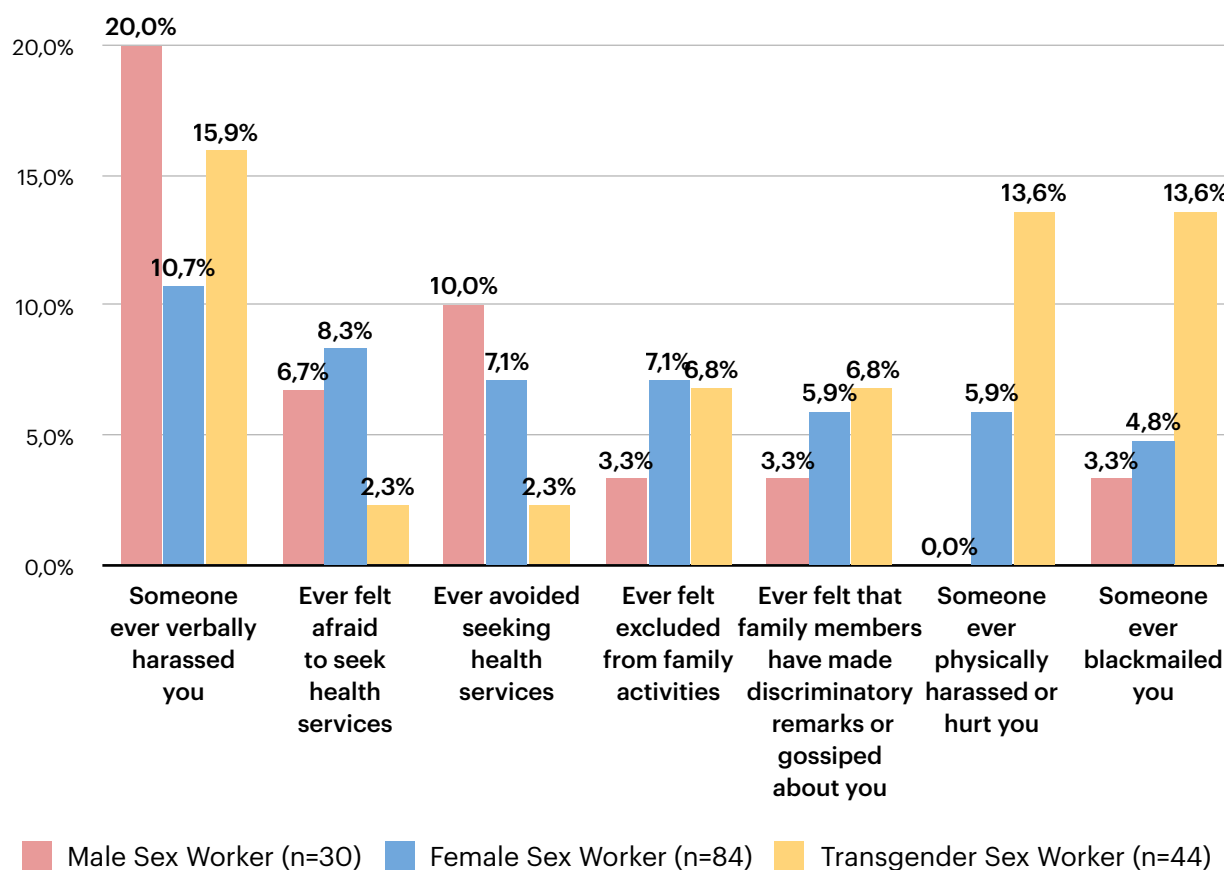


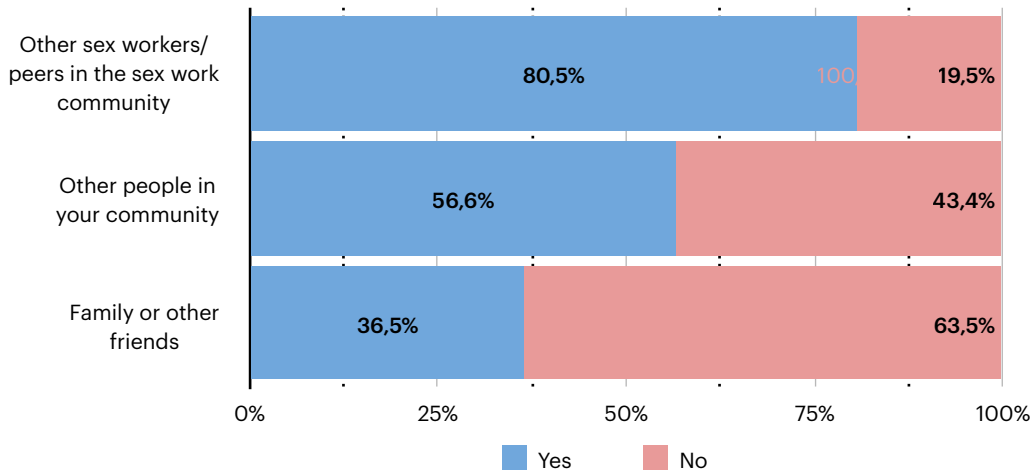
Figure 59 shows the experiences of discrimination experienced by sex workers because of their identity as a sex worker, disaggregated by gender. Male sex workers experienced verbal harassment more often (n=6, 20.0%) than transgender sex workers (n=7, 15.9%) or female sex workers (n=9, 10.7%). For health seeking behavior, sex worker respondents who had avoided seeking healthcare services because they were worried about their sex worker identity being known were mostly stated by male respondents (n=3, 10.0%), followed by women (n=6, 7.1%) and transgender (n=1, 2.3%). As many as 4 (13.6%) of respondents who were sex workers from the transgender group had been physically harassed and blackmailed in the last 12 months.

Fig 59. Sex workers' experiences of discrimination based on gender in last 12 months



From the total number of sex workers, 115 (72.3%) respondents who were sex workers had joined sex worker organizations/networks/groups. Meanwhile, disclosure of the respondent's identity as a sex worker was mainly done to other sex workers/peers in the sex worker community (n=128, 80.5%).

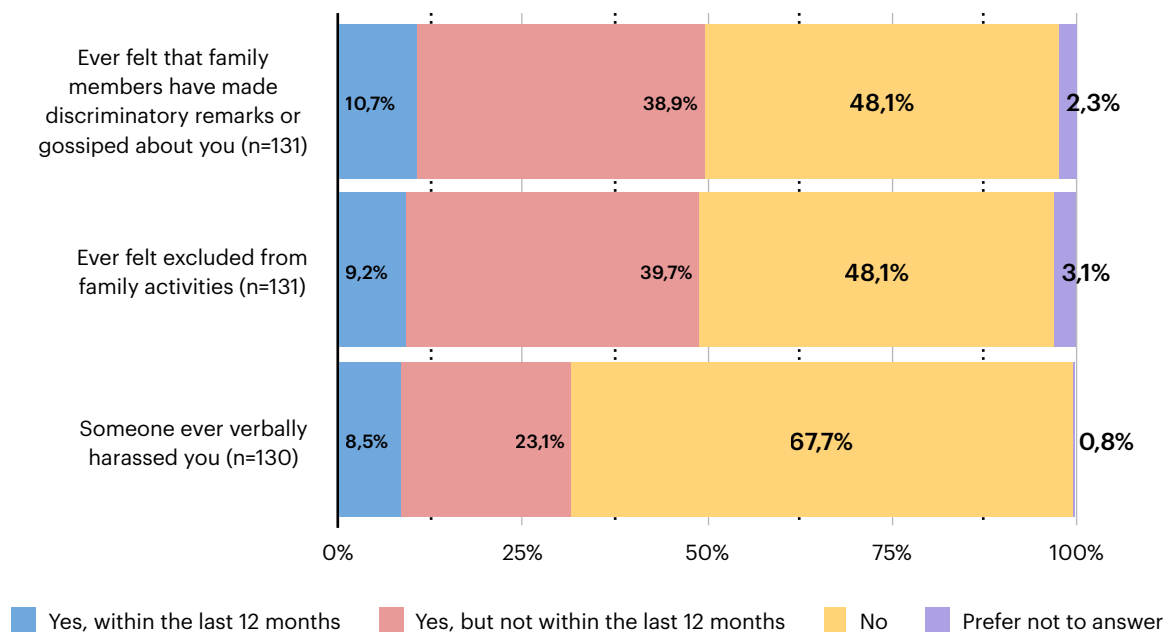
Fig 60. Identity disclosure by sex workers (n=159)



People Who Using Drugs (PWUD)

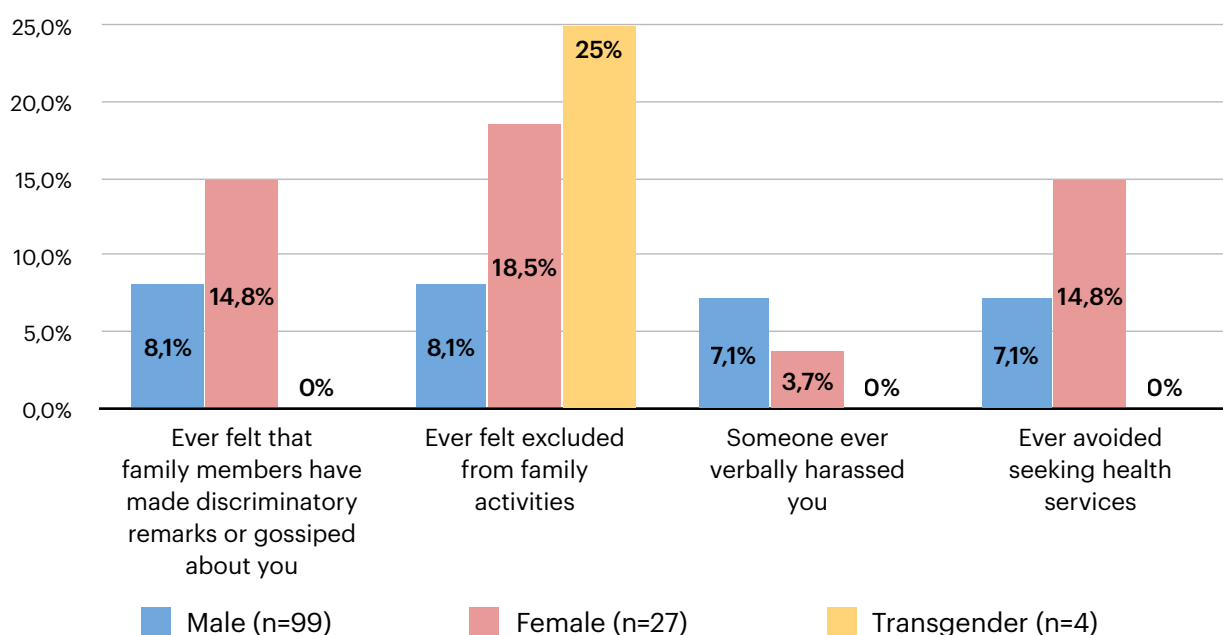
From key population respondents, 131 (32.4%) of respondents identified as PWUD. In the last 12 months, as many as 14 (10.7%) of respondents had felt that family members discriminated against or gossiped about respondents because they were PWUD. As many as 12 (9.2%) of respondents had felt excluded from family activities and 11 (8.5%) had experienced verbal violence from someone because of their identity as PWUD.

Fig 61. Experiences of stigma and discriminations due to PWUD identity



Based on gender, PWUD who were transgender experienced the highest stigma and discrimination (n=1, 25.0%) in terms of ever feeling excluded from family activities. PWUD who were cisgender female experienced the highest stigma (n=4, 14.8%) in terms of ever felt that family members discriminate and gossip about them. PWUD who were cisgender male also experienced the highest stigma (n=7, 7.1%) that someone ever verbally harassed them.

Fig 62. PWUD's experiences of discrimination based on gender in the last 12 months



As many as 98 (74.8%) of respondents who were PWUD were not members of PWUD organisations/networks/groups. Disclosure of the respondent's identity as a PWUD was most often done to other PWUD /peers in their community (n=110, 71.0%) and family or other friends (n=106, 68.7%).

Fig 63. Joining in an organization/network/ PWUD group (n=131)

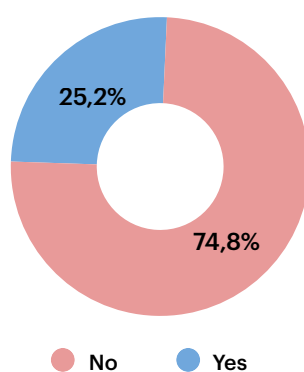
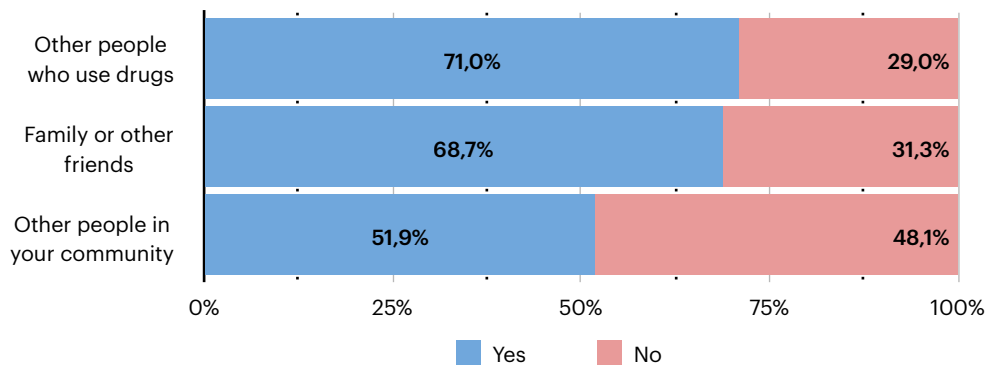


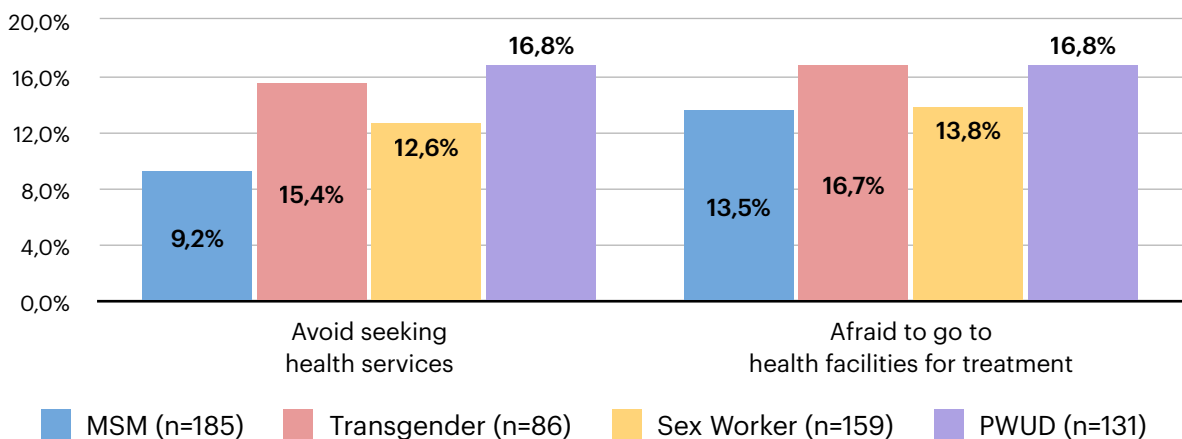
Fig 64. Identity disclosure by PWUD (n=131)



Throughout time, key population groups had avoided seeking healthcare services due to concerns regarding the stigma and discrimination they may receive due to their intersectionality. The experiences were mostly reported by many respondents who are PWUD (n=22, 16.8%), transgender (n=12, 15.4%), and sex workers (n=20, 12.6%). Respondents from these four key populations also felt afraid to go to health facilities for treatment, mostly experienced by PWUD (n=22, 16.8%), and Transgender (n=13, 16.7%). Based on qualitative methods, these key populations had also experienced fear when accessing treatment in healthcare services, worried about being stigmatised and discriminated against because of their identity.

“TG (transgender) friends do not want to open a salon; they are afraid to access services to take ARVs if they find out their HIV status, the salon will be empty.”—T, Medan.

Fig 65. Key populations groups avoiding healthcare services



4. DISCUSSION

Overall, the study results revealed that PLHIV in Indonesia commonly face stigma and discrimination due to their HIV status as well as other aspects of their key population identity (e.g., sexual behavior, sex work or drug use). Anticipated or experienced discrimination has led to social isolation, avoidance of healthcare, fear of disclosure and other negative consequences.

In 2020, the Ministry of Health organised a partner and child notification program to achieve zero new HIV infections⁶. Disclosure of HIV status is essential to prevent transmission to partners and children, as well as to obtain support for treatment. However, as presented through this study, disclosing status is still a significant challenge for PLHIV as they prefer to conceal their HIV status to themselves due to the potential discrimination, and therefore, find it difficult to disclose their serostatus. In this study, it was found that cisgender male tended to conceal their HIV status and feel guilty about it more often than cisgender female and transgender people. This was potentially worsened also by the heavy local culture that enforced patriarchy and put additional gender-based pressure into an already complex health/moral/social situation⁷.

As for people living with HIV who revealed their status to partners, children, family and friends, female respondents more often revealed their status to partners and children compared to male respondents, while male respondents more often revealed their status to friends and co-workers compared to females. This is an interesting finding as this may emphasize the importance of understanding where someone receives their support from, their role in a family and how it can influence

⁶ Indonesian Ministry of Health. Technical Instructions for Notifying Spouses and Children in Indonesia. (2020). Indonesia: Ministry of Health.

⁷ Ross, R., Stidham, A. W., & Drew, B. L. (2012). HIV disclosure by perinatal women in Thailand. *Archives of Psychiatric Nursing*, 26(3), 232–239. <https://doi.org/10.1016/j.apnu.2011.09.005>

their identity as someone who is living with HIV. It is very likely that the difference between male and female HIV status disclosure is caused by the way they set up their support network and their role in their family⁸. Other study conducted by JIP also revealed that among women living with HIV, the highest prevalence of HIV status disclosure was observed with partners⁹.

For male respondents, they may have perceived their family as a space where they are demanded and responsible for and therefore, they have to perform according to cultural standards (which is as a head of a family). Therefore, male respondents disclosed their status to friends and co-workers because that's where they have been getting support as individuals and there are less demands and burden of responsibility. Meanwhile, female respondents tend to see family as their safe space and as their source of support and therefore, it is a space where they immediately disclose their status.



PLHIV reported significant reluctance and concern over disclosure of their HIV status. A high number of respondents disagreed on the statements that other people who they didn't know very well were more supportive than the close ones. They also disagreed that HIV-status disclosure had become easier over time.



Disclosure is also a major concern for PLHIV when they access healthcare services to get ARV treatment and seek justice for rights violations. Healthcare-related stigma and discrimination appears to be particularly common among KPs and younger age (18-24 years) compared to non-KPs and adults. Nearly a half of PLHIV reported experiencing discrimination when seeking healthcare during the prior year, both in HIV-

⁸ Harjana, N. P. A., Nita, S., Sebayang, M., Mukuan, O. S., Widiastuti, A. S., & Januraga, P. P. (2023). Intimate partner violence and factors influencing HIV status disclosure among women living with HIV in Indonesia: a cross-sectional study. *AIDS care*, 1-12.

⁹ Laure, H. S., Talahatu, A. H., & Riwu, R. R. (2022). Response of People Living with HIV-AIDS to HIV-AIDS Stigma in Kupang City. *Media Kesehatan Masyarakat*, 4(2), 170-178

related and non-HIV-related health services. However, it is highly concerning that most discrimination experienced by the respondents happened within the HIV-related health services, which were places where they accessed more frequently than any other healthcare services, and these are also services that they particularly need to increase the quality of their lives.

The situations are usually worsened by the fact that PLHIV were not usually taking actions to respond to acts of discrimination or human rights abuses. Very few respondents attempted to take any action after suffering a violation of their rights. Participants cited concern about they did not know what to do, lack of evidence, and afraid to disclose their HIV status. These findings reflected anticipated stigma as well as a potential barrier to receiving good quality of care, both in health services and legal services. These findings also indicated the need for more of an active approach by community organizations and legal aid organizations, in comparison to passively waiting for reports or complaints.



For external stigma, the high levels of stigma and discrimination came from family members and other people making discriminatory remarks or gossiping due to HIV status. Stigma and discrimination also came from health workers who



suggested PLHIV to have no sex and avoided physical contact/taking extra precaution to PLWIH, especially on certain key population identities such as PWUD and SW. KPs experienced higher rates of HIV-related stigma than non-KPs and our data indicate

that stigma and discrimination may be more common for MSM and SW, although the data could be confounded by the membership of a network or support group of people living with HIV and younger age in these groups.

This form of stigma and discrimination where healthcare providers; a group that is supposed to be trusted with accurate health information, ended up misinforming those who accessed their services and the public. This is even more concerning, in comparison to receiving no information at all. Misinformation will

not only further perpetuate external stigma and discrimination, but unfortunately will also further put pressure on PLHIV through internalized stigma and potentially counter the intended effect of social support.

The stigma and discrimination experienced by people living with HIV is carried out by various parties, from the closest circle, such as family and partners, to the broader community, such as the general public and various agencies. The response of the closest circle of people living with HIV after finding out their HIV status can be very influential on them. This result also shows in the study by Laure et al that PLWHA continue to interact and carry out the same activities as society in general because of the support from those closest to them such as husbands, wives, children and friends as well as NGOs who always accompany and protect PLWHA even though they are often shunned or receive bad treatment from family, neighbours and health workers¹⁰.



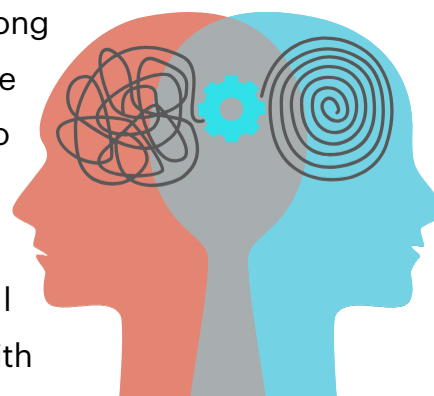
Even though some people living with HIV have received support and acceptance from those closest to them, quite a few still receive rejection, ostracism, and even abandonment from those closest to them. This situation is in the interpersonal, community, structural, and social spheres. Stigma and discrimination related to HIV are also influenced by the values believed by society. Through this study, it was found that norms, traditional values, and society's perception of religion, which are robust with heteronormative values, make stigma and discrimination related to HIV continue to be 'permanent' and occur in society. This condition then becomes more complicated because of the lack of public understanding about HIV, especially regarding the mechanisms of HIV transmission. Through this study, it was also found that families and children of people living with HIV also experienced the effects of stigma and discrimination.

However, in focus group discussion we found that their understanding of the differences between stigma and discrimination were still mixed up, so they tend to

¹⁰ Nuwa, M. S., Kiik, S. M., & Vanchapo, A. R. (2019). Penanganan Terhadap Stigma Masyarakat tentang Orang Dengan HIV/AIDS (ODHA) di Komunitas. *Jurnal Penelitian Kesehatan "SUARA FORIKES"(Journal of Health Research "Forikes Voice")*, 10(1), 49-54.

describe these two terms with the influence of stigma and discrimination felt by that group. This situation has the potential to influence how respondents identify stigma and discrimination, especially when they were not a member of a network or support group of PLHIV.

HIV-related stigma in society also influences how people living with HIV view themselves. Our findings highlighted the high levels of internalized stigma, far beyond external stigma, along with the findings that mental health conditions were often diagnosed among PLHIV. The labelling given to people living with HIV has given rise to internalized stigma, which also affects psychological conditions, openness regarding HIV status, interpersonal relationships, and the resilience of people living with HIV⁷. This condition has other impacts, such as a reluctance to seek support and a decision not to have sex. Respondents also stated that internalized stigma made them tend to hide their status from others and felt difficult to tell other people about their HIV status.



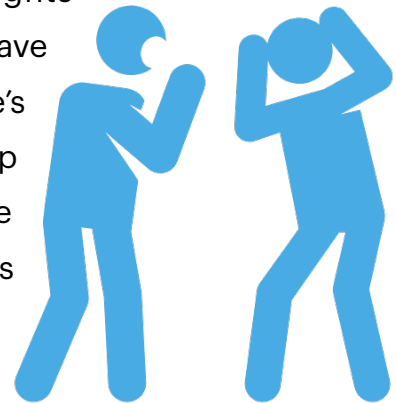
From qualitative findings, another influence of internalized stigma is the creation of negative attitudes toward living with HIV such as feeling dirty, having low self-esteem, and even thinking about ending their life. On the other hand, women who are seen as subordinate in heteronormative values tend to be more vulnerable to HIV-related stigma and discrimination from partners and families. In addition, children of women living with HIV are also affected by stigma and discrimination.

People living with HIV need to access healthcare services regularly throughout their lives. At the same time, they often experience stigma and discrimination in the healthcare environment, both when seeking HIV-specific healthcare services and non-HIV specific services. Different experiences of stigma and discrimination were widely reported by respondents, amongst others stating that they were advised by healthcare workers not to have sex because of their HIV status. In addition, through discussions with women living with HIV, they still

receive poor treatment and rejection regarding giving birth in certain healthcare services because of their HIV status.

Apart from healthcare institutions, stigma and discrimination are also found in other public service institutions such as educational, work environment, and social and legal aid institutions. Stigma and discrimination in educational and employment institutions are the discovery of unequal opportunities in obtaining education and employment, up to the threat of being expelled. It contradicts the Decree of the Minister of Manpower and Transmigration of the Republic of Indonesia No. KEP.68/MEN/IV/2004 concerning Prevention and Management of HIV/AIDS in the Workplace, which states that protection for people living with HIV in the work environment, as well as Article 28C paragraph (1) of the 1945 Constitution, regulates the right of citizens to obtain education.

Stigma and discrimination place people living with HIV at risk of violence and rights violations. Through this study, several rights violations were identified, such as being forced to have sex and being forced to test for HIV or revealing one's HIV status. Apart from that, through focus group discussions, several respondents also mentioned the experiences of psychological violence such as exclusion, rejection, and neglect; physical abuse; verbal violence; and sexual violence. For example, in educational institutions, UGM Faculty of Engineering Dean's Circular No. 2480112/UN1/FTK/I/KM/2023 UGM concerning Prohibition of LGBT within the UGM Faculty of Engineering hinders gender expression and is stigmatized by this law. At the same time, as a group that is vulnerable to being affected by stigma and discrimination, most people living with HIV are not aware of the existence of legal regulations that can protect them from stigma and discrimination, such as Omnibus Law no. 17 of 2023 concerning health, Law number 1 of 2023 concerning the Criminal Code, etc.



Although other respondents are aware of laws that can protect people living with HIV from stigma and discrimination, the respondents involved in focus group discussion have not been able to identify the specific regulations in question. Some also believe that resolving cases of stigma and discrimination through legal

approaches is not yet effective, and there are concerns that it will cost money. In addition, as the data shows people are still having human rights violations experiences, while the legal system in Indonesia doesn't criminalize PLHIV and LGBTIQ.

At the same time Indonesia has decentralisation system in its governance which provides provincial government to develop their own law and regulation for their respective province. Such legal environment has implication to conflicting laws and regulation between national and provincial level. Indonesia implements a regional autonomy government system, which gives each region the authority to regulate regional regulations and policies that apply in that region. While these regional regulations only have the character of guidance, they can include social sanctions, fines and imprisonment for a maximum of 6 months, in terms of implementation. Therefore, at regional level, human rights violations still exist, despite the absence of any legal rules at national level that criminalize communities of PLHIV and LGBTIQ.

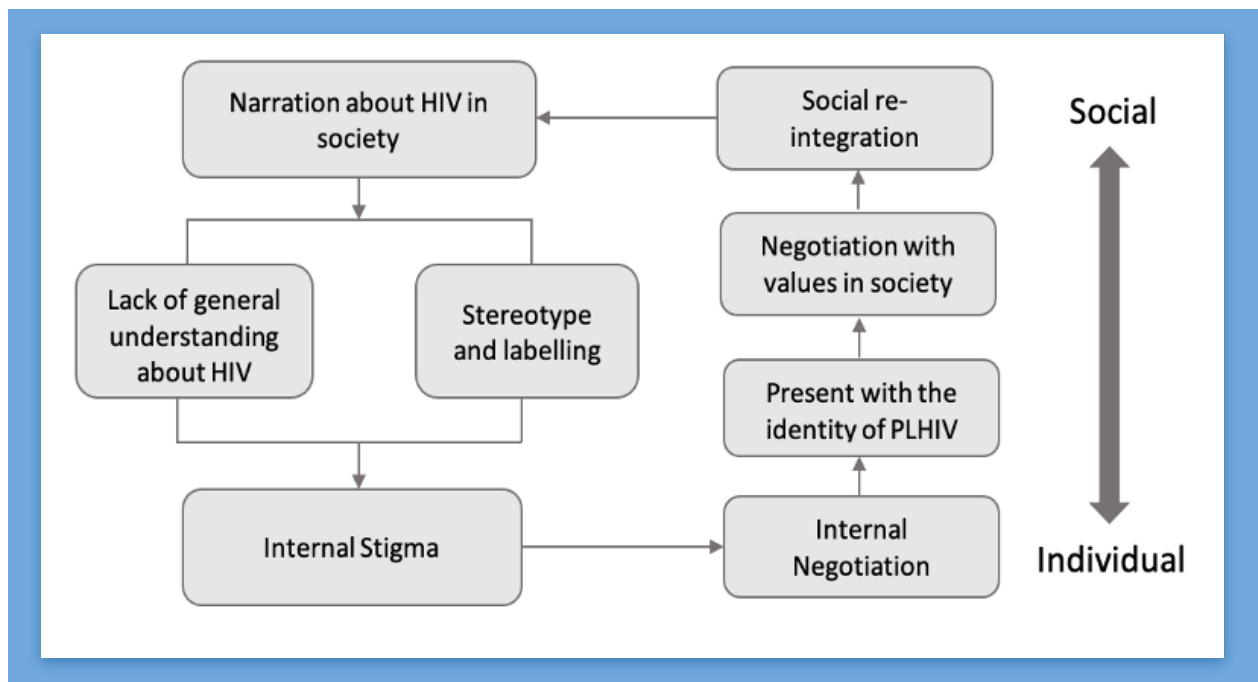


Groups of people living with HIV who are vulnerable to intersectionality often experience double stigma because of their identity. Although some respondents chose not to reveal their HIV status, those living as key HIV populations might be stigmatised because of their identity.

This situation means that groups of people living with HIV who identify as MSM, sex workers, PWUD, and transgender often receive discriminatory treatment. For example, in sex worker society, society gives negative labels to sex workers, especially female sex workers, such as 'cheap women' and 'naughty women.' This perception also causes sex workers to experience rejection and verbal violence in society. Not only that, PLHIV with intersectional vulnerabilities tend to avoid coming to healthcare services and taking ARV treatment because of their background.

Based on findings regarding stigma that occurs in people living with HIV from various ecological layers, as well as the perceptions and responses of people living with HIV regarding stigma, this study adapted the framework developed by Sayles et al.¹¹ to describe HIV-related stigma that occurs at the individual level to society at large. In general, four domains influence stigma towards people living with HIV, namely narratives related to HIV in society, internal perceptions of people living with HIV regarding HIV, internal negotiations of people living with HIV, and reintegration of people living with HIV into social life.

Fig 66. Framework of HIV-related stigma domains in Indonesia



Through this study, it was found that narratives related to HIV in Indonesian society are influenced by heteronormative values, which are also closely related to norms, customs, and perceptions of religion. Furthermore, these values are linked to the identity of key populations, which have intersectionality such as sex workers, MSM, PWUD, and transgender. The internalized stigma of people living with HIV takes the form of feelings of inferiority due to living with an identity that reaps stigma, where there is a muscular tension between the stigma that exists in society at large and the internalized stigma of people living with HIV, namely a lack of

¹¹ Sayles, Jennifer & Ryan, Gery & Silver, Junell & Sarkisian, Catherine & Cunningham, William. (2007). Experiences of Social Stigma and Implications For Healthcare Among a Diverse Population of HIV Positive Adults. *Journal of urban health: bulletin of the New York Academy of Medicine*. 84. 814-28. 10.1007/s11524-007-9220-4.

understanding by people living with HIV regarding HIV and HIV-related stereotypes and labelling.

Furthermore, at the individual level, people living with HIV respond to the stigma that exists in society by negotiating internally in the form of self-closure or self-acceptance. In focus group discussion, several respondents explained that they were in the denial phase, but they chose to accept themselves as time passed. After negotiating internally, people living with HIV need to negotiate with their social environment, interpersonally and in wider circles, with their identity as people living with HIV. It makes people living with HIV also negotiate with the values that apply in society to be able to represent themselves as part of that society.

The new global strategy formulates the 10 - 10 – 10 strategies as a target indicator for 2025 for elimination social barriers and law to access services i.e.,

- **Less than 10% of countries have punitive legal and policy environments that deny access to justice.**
- **Less than 10% of people are living with HIV and key populations experience stigma and discrimination.**
- **Less than 10% of women, girls, HIV-positive people, and key populations experience gender inequality and violence.**



The indicators above will encourage the achievement of indicators 95-95-95 if the medical approach (95-95-95) succeeds and the social approach (10-10-10) is carried out simultaneously and continuously.

The 2023 Stigma Index study in Indonesia found that the stigma and discrimination experienced by people living with HIV exceeds 10%, whether it is stigma from external (13.4%) and internalized (35.9%) stigma, and S&D in different settings. For example, stigma in health services/settings is part of external stigma and discrimination/stigma from other people. This study could be an evaluation of achieving the second 10% indicator target and there is a need for efforts to reduce

stigma and discrimination. The Indonesian government should have encouraged this indicator to reduce stigma and discrimination among PLHIV to mitigate social barriers to the existing targeted 95-95-95.

4.1. VALIDATION AND FEEDBACK

In December 2023, a validation workshop was held to bring together community members (gay men and other MSM, transgender people, people who use drugs, and sex workers) and key stakeholders including Indonesian AIDS Coalition, National Commission on Human Rights Indonesia, UNAIDS and so on to review, reflect on and validate the findings, explain to them possible reasons for the stigma and discrimination experiences documented by the research, and propose interventions to improve the situation.

Sex Worker Community

They agree with the results of this research that sex workers tend not to disclose their employment status as sex workers to healthcare workers. The situation is being affected by the uptake of ARV. Another situation states that sex workers tend to hide their HIV status at work and in the family. They do it because sex workers think they will face stigma and discrimination if they reveal their HIV status. There are several other statements regarding S&D (Stigma and discrimination) in other sex workers. Firstly, transgender sex workers are more open about their HIV status than female sex workers. In their perception, they become infected with HIV because of their behaviour in selling services.

PWUD

There are still many people who use drugs who experience S&D, especially women who use drugs. Based on cases that occur in the field, women who use drugs have difficulty coming to healthcare facilities. One of the causes of this situation is that healthcare workers are reluctant to serve people who use drugs. There are even pregnant women who use drugs whose HIV status is positive and are referred (multiple times) to other services. However, this situation cannot be seen in the results of this study

4.2. LIMITATION

Recruitment methodology and proportion of respondents based on gender, ARV status, and key population background have been determined. However, there are several challenges in meeting this target, namely reducing the target study area from 17 to 16 provinces due to the unavailability of enumerators and data entry staff as implementers at the regional level. In addition, people living with HIV who are not currently undergoing ARV treatment (non-ARV) are challenging to find, even though limited-chain referral and venue-based sampling approaches have been carried out.

Even though our respondents have maximized the use of the limited-chain referral method, respondents previously tended to be reluctant to provide referrals because they respected the confidentiality of the status of people living with HIV. Although the translation of the questionnaire was reviewed by the steering committee and tested for readability, certain terminologies were difficult to find equivalent words that suit the Indonesian context when conducting interviews or gathering information from respondents.

In the context of gender representation, the transgender man is very limited. For example, in quantitative, there was only one among 86 transgender respondents identified as transgender men. But in qualitative, only trans women were recruited. So, this report is still limited to a specific population and gender. There was also an error when programming the questionnaire on SurveyMonkey, which failed to recognize respondents who identified themselves as sex workers or had ever sold sex, so the following next questions to this population were only filled by those who identified themselves as sex workers and not eligible for those who had ever sold sex.

Because all variables are self-reporting, the recall bias may occur since some incidents may happen way earlier than the study took place. The number of respondents were unequal in each variable because not all questions were answered by respondents due to errors during the interviews, or the participants felt uncomfortable to provide the answers to certain questions. This causes the number of respondents to be unequal in each variable, so data interpretation must be interpreted carefully and justified by this situation. Data generalisation is limited to be carried out only at the national level.

5. RECOMMENDATION

Based on the results of the Stigma Index 2.0 study in Indonesia, there are various opportunities to reduce stigma and discrimination for people living with HIV including those who belong to one or more key populations. Furthermore, these recommendations are arranged based on the research sub-theme structure.

No	Themes	Findings	Recommendations	Aim of Advocate
1	Status Disclosure	The differences between gender in the openness of their HIV status. PLHIV tended to disclose their HIV status more likely to people closest to them, along with their experience getting support when disclosing their status.	<ul style="list-style-type: none"> Strengthen strategies about HIV status disclosure cases that can provide benefits for people living with HIV in every aspect of their lives, including supporting the Partner Notification program. 	<ul style="list-style-type: none"> Working Team of HIV and STD Directorate General of Diseases Prevention & Control (P2P) Ministry of Health Implementers of the National HIV program (PR).
2		PLHIV were being gossiped about or talked about by other people and family members, also being verbally harassed	<ul style="list-style-type: none"> Strengthen education and support mechanisms for people living with HIV at community and public service levels. 	<ul style="list-style-type: none"> Directorate General of Diseases Prevention and Control (P2P) Ministry of Health NGO (Non-Governmental Organization) Directorate of Mental Health, Ministry of Health Integrated Service Center for the Empowerment of Women and Children (P2TP2A) PPA Unit (Police)

No	Themes	Findings	Recommendations	Aim of Advocate
	Experiences of Stigma and Discrimination	PLHIV were associated with certain behaviours which were marginalized by society., such as the identity of key populations.	Increase educational efforts and public campaigns related to HIV and key populations, including efforts on anti-stigma and anti-discrimination, to increase public awareness.	<ul style="list-style-type: none"> • PR program implementer • Regional Community Organizations/ Institutions
		Negative views from indigenous communities impacted the discriminatory treatment received by people living with HIV.	<ul style="list-style-type: none"> • Approach and educate religious leaders, traditional leaders and community leaders. 	<ul style="list-style-type: none"> • Ministry of Religion • Ministry of Home Affairs
		Children living with HIV experienced stigma and discrimination in the educational environment.	<ul style="list-style-type: none"> • Incorporate sensitization of HIV issues, stigma and discrimination as well as anti-bullying into the educational curriculum in schools by using the trust determination risk communication theory approach. 	<ul style="list-style-type: none"> • Ministry of Education and Culture • School boards and committees • Educational Accreditation Institutions • Ministry of Health
		Even though the child was not living with HIV, children of women living with HIV often still received stigma and discriminatory treatment from society.	<ul style="list-style-type: none"> • Strengthen multi-sector collaboration (government, society, non-governmental organizations, community, media and private sector) to reduce stigma and discrimination. 	<ul style="list-style-type: none"> • Coordinating Ministry for Human Development and Culture • Ministry of Communications and Informatics • Public Broadcasting Commission • KPI • PWI • AJI • Influencers

No	Themes	Findings	Recommendations	Aim of Advocate
		Family support can reduce worries and be a strength for people living with HIV, especially in treatment retention.	<ul style="list-style-type: none"> Reactivate family support engagement programs for people living with HIV. 	Directorate of Family Health, Ministry of Health
3	Internalized Stigma	Higher number of internalized than external stigma, PLHIV chose to not seek social support because of their HIV status, and to not have sex because of their HIV status.	<ul style="list-style-type: none"> Strengthen efforts to increase the resilience of people living with HIV who experience internalized stigma through psychosocial support 	PRs (IAC, SPIRITIA and Directorate General of Diseases Prevention and Control (P2P) Ministry of Health)
		People living with HIV tended to interpret stigma and discrimination as detrimental perceptions and actions, where there were psychological impacts resulting from these actions.	Increase the capacity of health workers to provide counselling support related to mental health issues and violence experienced by people living with HIV and at-risk population groups in accordance with the family health screening scheme carried out by health service workers.	Working Team of HIV and STD Directorate General of Diseases Prevention and Control (P2P) Ministry of Health
4	Interaction with Health Services	<ul style="list-style-type: none"> Stigma and discrimination more were frequent in HIV-related healthcare settings than non-HIV related healthcare. 	<ul style="list-style-type: none"> Increase understanding of health workers regarding the risk communication & the confidentiality to people living with HIV. 	<ul style="list-style-type: none"> Presidential Staff Office (Div. II) Directorate General of Diseases Prevention & Control (P2P) Ministry of Health Health Service BKN, BKD
		Healthcare workers advised respondents not to have sex because of their HIV status & avoiding physical contact or taking extra measures.	<ul style="list-style-type: none"> Promote (on-site) community workers to support people living with HIV when accessing healthcare services. 	<ul style="list-style-type: none"> PR Provincial KPA Health services Provincial Health Service

No	Themes	Findings	Recommendations	Aim of Advocate
5	Human Rights and Affecting Change	<p>PLHIV experienced human right abuse due to their HIV status, but they did not know about the availability of legal regulations that protected people living with HIV from stigma and discrimination. Some of them did not seek redress, with reasons that they did not know what to do.</p>	<ul style="list-style-type: none"> • Increase education regarding rights, policies, types of regulations and violations as well as reporting cases of rights violations, both to people living with HIV, key populations, community workers, public services and the private sectors, including skills in documenting evidence of rights violations. 	<ul style="list-style-type: none"> • Ministry of Law & Human Rights of the Republic of Indonesia • Ministry of Home Affairs of the Republic of Indonesia • Ministry of Social Affairs of the Republic of Indonesia • Ministry of Health of the Republic of Indonesia • Ministry of Education & Culture of the Republic of Indonesia • Ministry of Manpower of the Republic of Indonesia. • Labor Unions • Indonesian Police • KSP • National Police Commissioner
<p>There are regulations and policies that can protect PLHIV from stigma and discrimination, but they still felt that the implementation of these policies had not been optimal.</p>		<ul style="list-style-type: none"> • Incorporate the 10-10-10 target indicators in the national framework and cross-ministerial government financing plans on HIV control issues 	<ul style="list-style-type: none"> • Ministry of Law & Human Rights of the Republic of Indonesia • Ministry of Home Affairs of the Republic of Indonesia • Ministry of Social Affairs of the Republic of Indonesia • Ministry of Health of the Republic of Indonesia • Ministry of Education & Culture of the Republic of Indonesia • Ministry of Manpower of the Republic of Indonesia. • Labor Unions • Indonesian Police. • KS • Kemendes • Ministry of PMK • KemenPPA/Bapennas 	

No	Themes	Findings	Recommendations	Aim of Advocate
		<p>There are regulations that discriminate against people living with HIV by banning them from work promotions due to their HIV status.</p>	<ul style="list-style-type: none"> • Elimination of regulations that are discriminatory and detrimental to people living with HIV and key populations 	<ul style="list-style-type: none"> • Ministry of Law and Human Rights of the Republic of Indonesia • Ministry of Home Affairs of the Republic of Indonesia • Ministry of Social Affairs of the Republic of Indonesia • Ministry of Health of the Republic of Indonesia • Ministry of Education and Culture of the Republic of Indonesia • Ministry of Manpower of the Republic of Indonesia. • Labor Unions • Indonesian Police • KSP • Kemendes • kemenPPA/Bapennas
		<p>The government's localization closure policy triggered stigma and discrimination against the sex worker population</p>	<ul style="list-style-type: none"> • Enforcement of regulations and policies related to legal protection for people living with HIV and key populations from discriminatory treatment refers to the target indicator 10-10-10. 	<ul style="list-style-type: none"> • Ministry of Law and Human Rights of the Republic of Indonesia • Ministry of Home Affairs of the Republic of Indonesia • Ministry of Social Affairs of the Republic of Indonesia • Ministry of Health of the Republic of Indonesia • Ministry of Education and Culture of the Republic of Indonesia • Ministry of Manpower of the Republic of Indonesia. • Labor Unions • Indonesian Police. • KSP • kemenPPA

No	Themes	Findings	Recommendations	Aim of Advocate
		PLHIV were afraid that the process of seeking legal redress could reveal their HIV status	<ul style="list-style-type: none"> Strengthen legal aid service mechanisms and psychosocial support for handling cases of people living with HIV and key populations which conflict with the law 	<ul style="list-style-type: none"> Ministry of Law and Human Rights of the Republic of Indonesia Ministry of Social Affairs of the Republic of Indonesia Ministry of Health of the Republic of Indonesia Ministry of Manpower of the Republic of Indonesia. Indonesian Police KSP Ministry of PPA Labor Union
6	Intersectional Stigma and discrimination	People living with HIV who belong to key population groups had the potential to experience intersectional stigma due to their HIV status and key population identity	<ul style="list-style-type: none"> Strengthen educational content related to intersectional vulnerabilities beyond HIV status (transgender, MSM, bisexual, sex workers and drug users) in HIV education programs at the individual, community and multi-sectoral levels. 	<ul style="list-style-type: none"> PMK Coordinating Ministry Republic of Indonesia Communications and Information Technology Public Broadcasting Commission KPI Ministry of Health Ministry of Education
			<ul style="list-style-type: none"> Strengthen an inclusive public service system. 	<ul style="list-style-type: none"> Regional Government Ombudsman
			<ul style="list-style-type: none"> Strengthen a sustainable multi sectoral response to eliminate stigma and discrimination against people with intersectional vulnerability backgrounds beyond HIV status (transgender, MSM, bisexual, sex workers and drug users). 	<ul style="list-style-type: none"> Local government Health services

No	Themes	Findings	Recommendations	Aim of Advocate
7	Needs for Further Research	<ul style="list-style-type: none"> Stigma and discrimination were also found in other public service institutions such as educational, work environment, and social and legal aid institutions. 	<ul style="list-style-type: none"> Conduct further research to determine the needs and challenges of people living with HIV in accessing health services as an effort to ensure friendly services for people living with HIV and intersectionality. 	<ul style="list-style-type: none"> Local government Health services
			<ul style="list-style-type: none"> Identification of the need for inclusive public services. 	<ul style="list-style-type: none"> Regional Government Ombudsman
			<ul style="list-style-type: none"> Conduct studies regarding effective strategies in efforts to reduce stigma and discrimination among people living with HIV and key populations 	<ul style="list-style-type: none"> Ministry of Health Ministry of Social Affairs Bappenas
			<ul style="list-style-type: none"> Conduct studies regarding regulations and policies that have the potential to impact stigma and discrimination against people living with HIV and key populations 	<ul style="list-style-type: none"> Ministry of Law and Human Rights Local government

6. CONCLUSION

The situation in Indonesia related to stigma and discrimination towards people living with HIV is critical. Stigma and discrimination can come from healthcare providers that unfortunately hold the key to services that PLHIV need, such as HIV-related health services especially to achieving the 95-95-95 target. Stigma and discrimination could also come from PLHIV's family, which are often the place that they count on getting support from, which in this context hits hard on women living with HIV as they primarily count on their family as a safe space that they disclosed their status to, which often then turned to a space where they got most discrimination from.



The situation is worsened by the fact that discrimination often takes form and happens indirectly (through gossip and social isolations), rather than a direct form (verbalized insults or accusations) which makes it difficult to document (for legal purposes) or to confront or clarify. This is particularly harmful when it happens in HIV-related health services as it can discourage people living with HIV from disclosing their status, but also may prevent them from accessing the services at all, while they critically need these services to further improve their quality of lives. While this study does not investigate the linkages between stigma and discrimination and the capacity of PLHIV in protecting themselves and others from infection, further study should be done in looking at the link between the two and how discrimination can further increase HIV incidence rate, by preventing PLHIV from accessing the ARV treatment that we know for sure can prevent further infection.

It is also clear that heteronormative culture that perpetuates the patriarchal social complexities makes the stigma and discrimination situation particularly difficult for non-cisgender male who are living with HIV and those coming from key population backgrounds. There needs to be further investigation on the level of burden due to stigma and discrimination, particularly in relation to the intersectional stigma and discrimination that women and other key population members experienced. All indications point to significantly worse experience for

these sub populations. However, more importantly, there should be more discussions and investigations on how to effectively reduce and in the end, eliminate various forms of stigma and discrimination.

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An abstract line drawing in blue ink, showing the profile of a person's face and neck. The lines are fluid and expressive, capturing the essence of the human form without fine detail. The drawing starts at the top left and flows down towards the bottom right, with some lines looping back to suggest hair or a neck.

**People Living
with HIV
Stigma Index 2.0
in Indonesia**

Jaringan Indonesia Positif

2024