

MALAYSIAN AIDS COUNCIL



HIV-RELATED STIGMA, DISCRIMINATION & HUMAN RIGHTS VIOLATIONS



REPORT 2019

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FOREWORD



FOREWORD BY DATUK DR. CHRISTOPHER LEE PRESIDENT OF THE MALAYSIAN AIDS COUNCIL

I am honoured to congratulate and acknowledge the Malaysian AIDS Council (MAC) team for their never-ending efforts and work on the national HIV and AIDS response being implemented across the country; with the support of our partners such as Yayasan Sime Darby, The Global Fund, Coalition Plus and the Ministry of Health Malaysia. Having unparalleled endorsement by the key partners in the HIV and AIDS response in Malaysia is crucial.

Public-private partnership for the HIV response is few and far between. Hence, we are particularly grateful to Yayasan Sime Darby (YSD) for its support to MAC since 2017, with the initiation of the Positive Audacious Living (PAL) Scheme; a financial scheme that has been pivotal in saving the lives of underprivileged People Living with HIV (PLHIV). It is a great pleasure to once again work in partnership with YSD on this important piece of work i.e. the documentation of **HIV – Related Stigma, Discrimination and Human Rights Violations**.

MAC's Human Rights Initiative aims to facilitate effective linkages to care and support for HIV-infected and affected individuals; and to protect them from the harmful impact of stigma and discrimination. Despite the effectiveness of HIV treatment and HIV being a manageable chronic illness, individuals living with HIV continue experiencing human rights violations in many circumstances, including in the education sector and workplace. MAC aims to end this vicious cycle by vigorously engaging with the relevant stakeholders in order to heighten the awareness about the issue.

MAC knows that we are not alone on this challenging journey. Therefore, I wish to extend my heartfelt gratitude to our Red Ribbon Celebrity Supporters, the Executive Committee of MAC, the Board of Trustees of the Malaysian AIDS Foundation, our Partner Organisations, volunteers and last but not least, the entire secretariat of MAC. Thank you for your endless support and tireless efforts, as well as your commitment to achieving a society free from stigma and discrimination.

ACRONYMS

| | |
|----------------|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Anti-Retroviral Therapy |
| FSW | Female Sex Worker |
| HIV | Human Immunodeficiency Virus |
| KP | Key Populations |
| MAC | Malaysian AIDS Council |
| MBCH | Malaysian Business Consortium on HIV/AIDS |
| MAF | Malaysian AIDS Foundation |
| MoH | Ministry of Health |
| MoHE | Ministry of Higher Education |
| MSM | Men Having Sex with Men |
| NGO | Non-Governmental Organisation |
| PLHIV | People Living with HIV |
| PO | Partner Organizations |
| PWID | Person/People who inject drugs |
| S&D | Stigma and Discrimination |
| STI | Sexual Transmitted Infection |
| TGW | Transgender Woman |

BACKGROUND



Since 1986 when the first case of HIV infection in Malaysia was diagnosed, HIV has been recognised as a serious public health issue. The epidemic is approaching its fourth decade and remains a major health threat in Malaysia.

Like many parts of the world, the rates of HIV infection are increasing rapidly among young people in Malaysia. Statistics from the Ministry of Health for 2018 demonstrated that 77% of people infected with HIV are in the 13 to 39 age group. Among young people aged <40 years, about 2,410 HIV cases were reported in 2015. The incidence of HIV among the same age group increased to 2,642 in 2018.

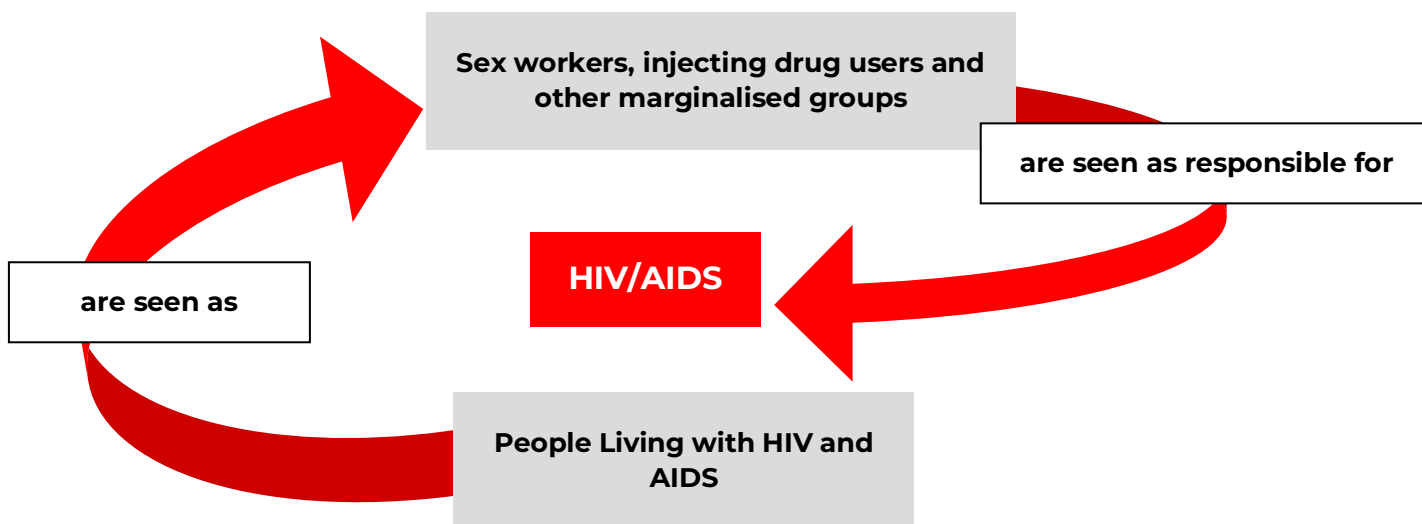
It is anticipated that these numbers will increase as the national programme steps up its efforts on HIV testing. Young people make up a significant proportion of the country's population and vital in the growth of the country. Those who have already been diagnosed with HIV are vulnerable to HIV-related stigma and discrimination in their daily life.

The epidemic in Malaysia is concentrated among KP, including men who have sex with men (MSM), female sex workers (FSW), transgender women (TGW), and people who inject drugs (PWID). The epidemic has transitioned from injecting behaviours as the primary mode of transmission to sexual transmission.

It is without a doubt, members of the Key Population face amplified stigma – from being associated with high risk behaviours, non-heteronormative gender and sexuality identifications – in addition to a HIV positive status. Human rights violations are experienced in every aspect of their daily lives. These violations, which stemmed from behaviours associated with stigma and discrimination, can be seen within the society, workplace, education, healthcare and even within the family unit (Williamson, Fiscian, Olson, Poku, & Whittal, 2017).

Stigma is linked to power and domination throughout the society whereby some groups are made to feel devalued by creating and reinforcing inequality. When it is associated with HIV/AIDS, the inequalities such as gender, race, ethnicity and sexuality come in place. The figure below illustrates the Circle of Stigmatisation and Marginalisation experienced by the members of KPs (Parker & Aggleton, 2002).

Figure 1: The circle of stigmatisation and marginalisation



In 2015, Malaysia’s high-level commitment and leadership to address stigma and discrimination (S&D) were reflected while drafting the National Strategic Plan for Ending AIDS 2016-2030. The strategy on S&D was included as Strategic 3: Reduction of Stigma and Discrimination.

Figure 2: National Strategic Plan for Ending AIDS 2016 -2030 (Ministry of Health, 2015)

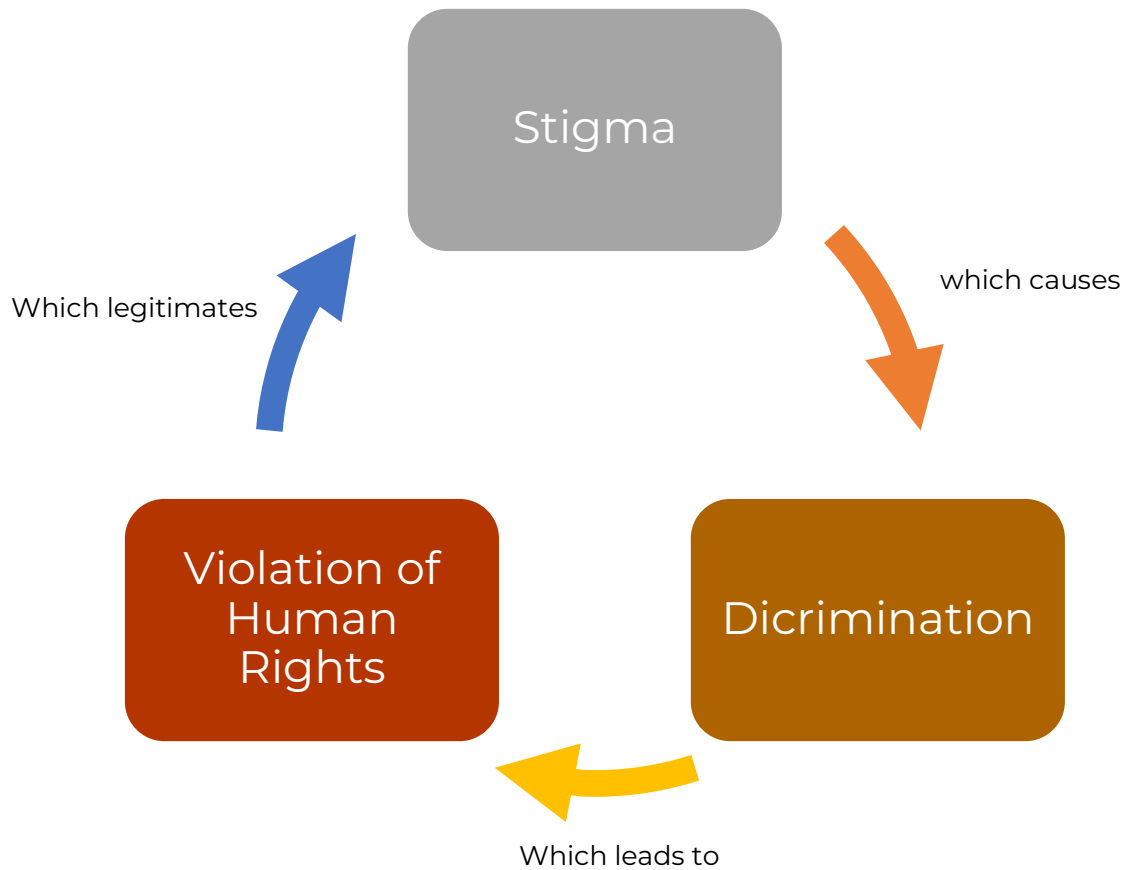
| | | |
|---|--------------------|---|
| NATIONAL STRATEGIC PLAN OF ENDING AIDS 2016-2030 | Strategy 1: | Testing & Treatment |
| | Strategy 2: | Improving the Quality and Coverage of Prevention Programs among Key Populations |
| | Strategy 3: | Reduction of Stigma and Discrimination |
| | Strategy 4: | Ensuring Quality Strategic Information and its Use by Policy Makers and Planners through Monitoring, Evaluation and Research |

The Ministry of Health recognised the fundamental role of civil society in complementing the Government's effort to effectively respond to the epidemic. MAC, comprising the Secretariat and its Partner Organisations, provides nationwide coverage of community-based HIV services and serves as the common voice for the communities served. The Secretariat helps to facilitate the activities of its Partner Organisations in:

- **Coordinating HIV/AIDS programmes** through structured annual programme planning to reduce HIV vulnerability in key affected populations via the prevention, care and support interventions.
- **Capacity-building** through training, programme management, financial, advocacy and technical (Secretariat Capacity Building process).
- **Advocacy** with other stakeholders (other NGOs, networks, government agencies and private sector bodies) to instil a sense of urgency of HIV/AIDS and create an enabling environment for effective responses.

The Connection between HIV, Stigma, Discrimination and Human Rights Violations

Figure 3: The cycle of stigma, discrimination and human rights violations



The diagram above, developed by Aggleton, Wood, Malcolm, Parker & Maluwa (2005), shows that stigma is the root of discriminatory actions, causing people to engage in actions such as denying services or having a sense of entitlement towards others. Discrimination then leads to the violation of human rights.

There are many direct and indirect links between the HIV epidemic and lack of protection of human rights. Violations of the rights may worsen the impact of HIV, increase vulnerability and hinder positive responses to the epidemic (Joint United Nations Programme On HIV/AIDS UNAIDS Staff, 1999).

This report is developed in the spirit of improving the national response towards the HIV/AIDS epidemic and at the same time, giving the PLHIV a voice in regards to their basic rights. S&D cases MAC received in 2019 will be highlighted in detail as well as MAC's response to them.

METHODOLOGY AND DATA COLLECTION

More than half of the clients who approached MAC to report incidents that occurred to them chose methods that can guarantee their anonymity. Methods such as emails, phone calls and Facebook messaging using anonymous profiles were the preferred ways.

Figure 4: Channels of incidents being reported



Given the importance of addressing the violation of human rights for the KPs, MAC has prepared an *'Incident Report Mechanism'* (**Appendix A**).

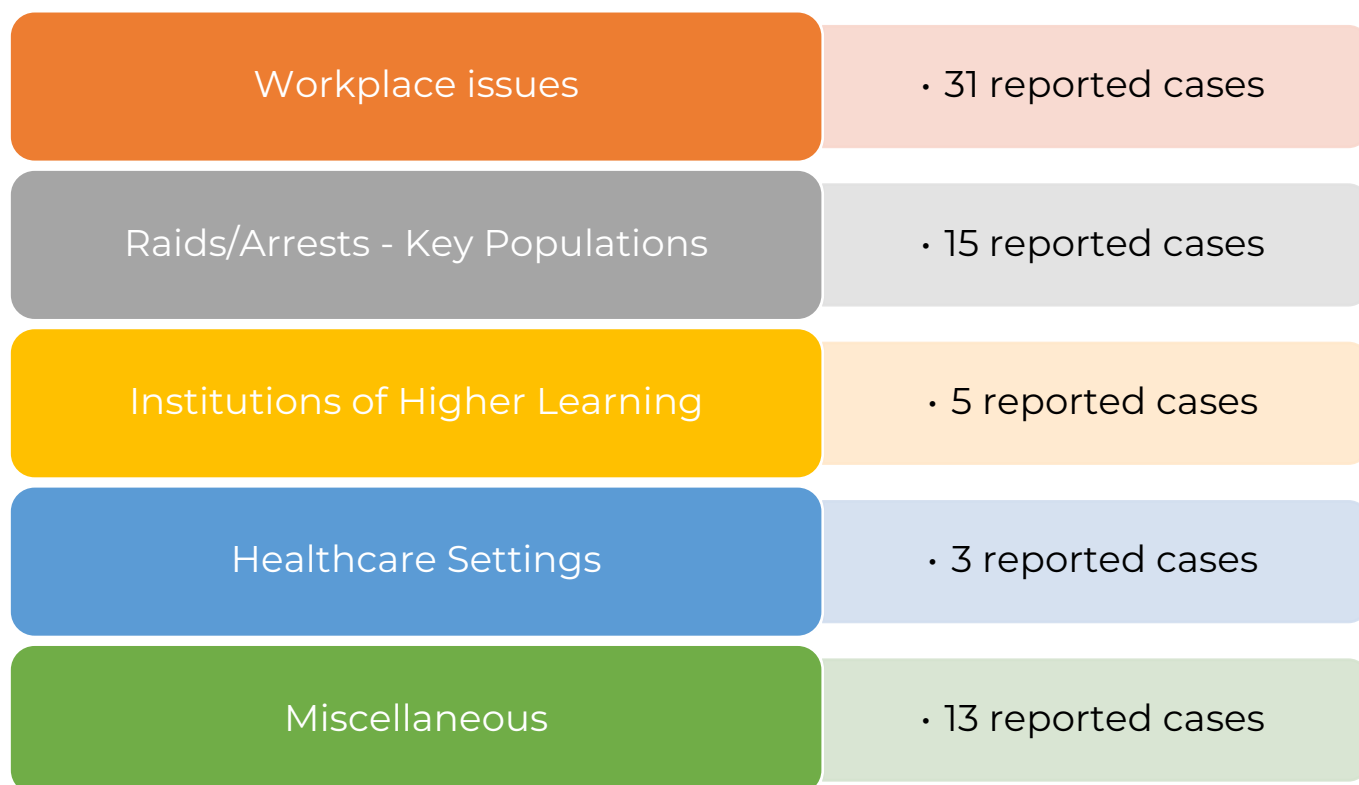
This mechanism can help those affected to channel their grievances and, in the process, assist in building cases for higher-level advocacy involving multiple stakeholders.

This report will highlight four main areas where violation of human rights occurred to the PLHIV in 2019. Several cases are included to illustrate how the violation of their rights occurred and how MAC mitigated the issue.

REPORTED CASES IN 2019

From January to December of 2019, a total of 67 cases were reported to MAC. The types of incidents and number of cases are illustrated in the figure below:

Figure 5: Types of incidents reported



Approximately 46% of the reported cases were related to workplace issues. This is followed by *raids/arrests of the key populations* at 22% and 7% on *discrimination in institutions of higher learning*. It is also important to note that the cases related to *stigma and discrimination in the healthcare settings* were also reported.

Some of the incidents are categorised as miscellaneous. These include:

1. A television show which provided incorrect information about sero-discordant (mixed -status) couples.
2. Misleading advertisement on Facebook, Instagram and other media channels on products which claim to cure HIV/AIDS by unqualified medical professionals.

A. Workplace Issues

Figure 6: Monthly workplace issues reported



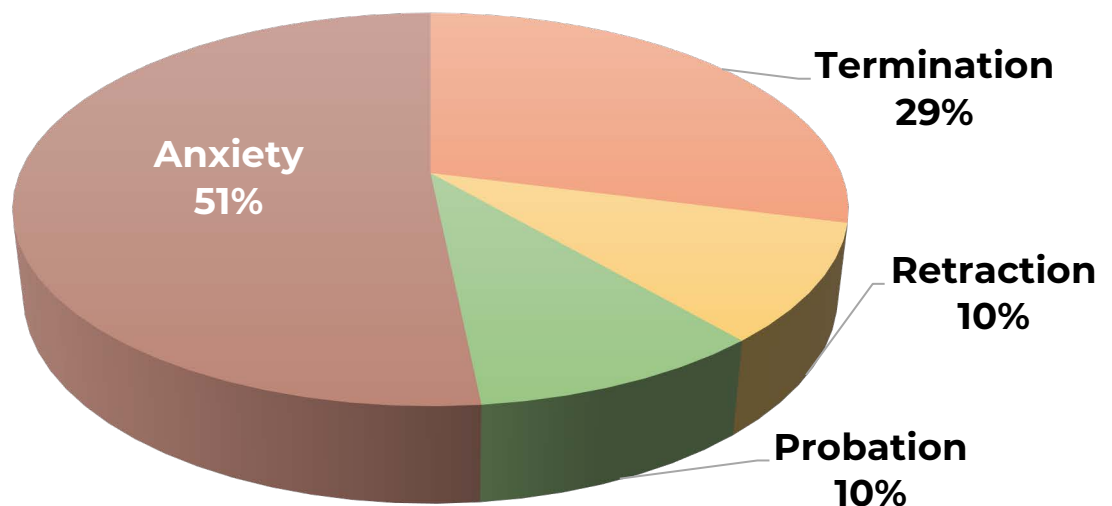
In 2019, MAC received a total of 31 workplace-related complaints, which is an average of 2.6 cases per month.

In December, there was a dramatic increase in workplace incidents. This is due to the awareness provided to key populations on the incident reporting platform. The community is more empowered to come forward and report the issue they were facing using this platform. Out of 31 individuals who submitted complaints, 28 are Malaysian citizens and three cases are immigrants.

Types of Workplace Incidents

The pie chart below illustrates the types of workplace issues MAC received in 2019.

Figure 7: Types of workplace issues reported



Reports of Anxiety-Related Issues

Issues related to anxiety account for half of the total cases. Lack of regulation that protects PLHIV from being discriminated in the workplace and poor adherence due to their rights to confidentiality were cited as among the reasons that caused PLHIV to develop chronic anxiety. As a result of poor confidence in the safety of their identity and overall well-being, many resorted to extreme measures such as quitting their job, letting go of job opportunities elsewhere or being jobless.

Termination

Two PLHIV clients were dismissed from their employment due to their status. Both managed to secure settlements, one with legal intervention, while the other received the settlement without legal intervention. Both cases were settled without MAC's intervention.

Retracted offer

A job offer was revoked after clients went through employment health screening. Such incidents took place regardless of whether the clients were certified as 'fit' or 'unfit' for work.

Probation

Client is neither dismissed nor revoked from the job. He/she had to go through a series of appeals. This situation is common among newly recruited government servants.

Stigma Reduction Approaches

MAC advocates the rights of PLHIV in the workplace by engaging with the relevant stakeholders. Our advocacy approach comprises three steps as depicted in the figure below:





Negotiation/Mediation

MAC represents the PLHIVs who reported the incidents of discrimination that occurred to them in the workplace. The mediation process strived to find the best resolution for both parties (the client and the organisation/company). This is important to secure an ideal and safe environment for the PLHIVs.

HIV Sensitisation

The mediation process provides an opportunity for MAC to promote evidence-based information about HIV/AIDS, not only to the top management but also the other members of the company/organisation. This is done while maintaining the confidentiality of the clients.

Psychosocial support

Continuous mental health support was provided to the clients throughout the advocacy process. Support also was given in the form of linking clients to their social networks such as family members, friends and peer support groups.

To the Human Resource Department of any company, if you ever encountered a PLHIV, I would like to plead, please be informed about the fact concerning HIV/AIDS before making any decision. It will greatly impact a person's life.

Case Study 1: HIV Workplace

29-year-old Credit Control Analyst

(November 2019): Client's job offer was verbally revoked after pre-employment health screening detected him as a person living with HIV. The client approached MAC for assistance.

Actions taken:

MAC's advocacy manager contacted the company and investigated the matter. Appeals and mediation were done with the Human Resource Manager of the company. Discussion with the company was based on the basic facts about HIV/AIDS, the need to secure the client's confidentiality and highlighting the need for safe environment for the client

Outcome:

Client's job was re-offered within 2 months.





B. Raids & Arrests of Members of Key Populations

Malaysia has a concentrated HIV epidemic with the prevalence rate remaining above 5% among key populations (KP) including people who inject drugs (PWID), female sex workers (FSW), transgender people (TG) and men having sex with men (MSM). The key populations size estimates were conducted in 2018 by the Ministry of Health.

Table 1: Size of Key Populations in Malaysia 2018

| Key Population | Size Estimation |
|---------------------------|-----------------|
| People who inject drugs | 75,000 |
| Men who have sex with men | 220,000 |
| Transgender sex workers | 15,000 |
| Female sex workers | 22,000 |

Members of KPs are constantly being targeted for raids and arrests due to the criminalization of drug use, sex work and transgender (Wickersham et al., 2017, p. 667). The fear of being prosecuted prevent them from accessing health care services (Dingake, 2018). In 2019, MAC received 15 complaints involving MSM, TG and PWID. There were no formal complaints from the FSW population. In the interest of public health, MAC is cognisant of protecting the well-being of KPs.

One of the most serious concerns about raids and arrests among the KPs is the fact that condoms and lubricants were confiscated and used as evidence to arrest them. This would lead to negative impact on the *Harm Reduction* initiatives (spearheaded by MAC and MOH) as the KPs would avoid carrying contraception (for their protection against HIV and STIs) for fear of getting arrested. It has and could endanger the public health programme and eventually, the health of the general population.

I just want this nightmare to be over.

~ All 12 Men

Case Study 2:

12 MSM (including PLHIVs) were apprehended in a raid in the Klang Valley area.

The raid and arrest triggered a series of events which concluded with the loss of employment, ostracisation by family members and individuals becoming victims of domestic violence and homelessness. The effects of these events caused depression, severe anxiety and suicidal tendencies. For the men with HIV status, adherence to treatment was severely impacted. During the raid, condoms and lubricants were confiscated and used as evidence. It is also important to note that several men, including those diagnosed with HIV, were imprisoned. During incarceration, those with HIV status were not given their ART medications. This shows that incarcerating key populations will severely affect treatment adherence and, in the process, endanger their lives.

Actions taken:

The MAC Advocacy member and other NGOs assisted in ensuring their safety, securing accommodation, employment, legal counsel, financial assistance and consistent mental health support.

Outcome:

This case is still ongoing. MAC will continue to provide continuous support, especially in terms of long-term engagement with relevant stakeholders and psychosocial support.



C. Discrimination in Institutions of Higher Learning

In Malaysia, there is a change in the demographic of people newly-diagnosed with HIV. It is reported that there is a steady increase in HIV prevalence among young population since 2009 (Ministry of Health, 2019). One of the most prominent issues faced by young PLHIV in Malaysia and reported to MAC is S&D occurring in institutions of higher learning, both in public and private institutions.

The cases reported were similar to workplace-related complaints, where offers of admission into higher learning institutions were retracted and the young PLHIV were dismissed from their studies. Besides that, HIV screening was enforced before getting into a programme, even for non-medical related courses. This had caused severe anxiety on the affected individuals.

To be honest, I really wish to continue my studies in this program and in this campus. However, after going through the traumatic events of coercions, harassments and stigmatization, I believe staying is no longer an option for me. The damage is done.

Case Study 3:

19-year-old Semester 3 engineering student, PLHIV since 2017

The student's confidentiality was breached by a healthcare worker stationed at the campus. It started with a request from the student to get his ART medications, then morphed into an incident that involved harassment, coercion and humiliation by individuals in the position of power in the campus. The client was coerced into admitting to sexual intercourse within the campus ground, which was then used to legitimise the dismissal. The client's main concern was having to pay back RM60,000 in study loan, which was supposed to be converted into a scholarship if he completed his studies.

Actions taken:

MAC assisted in drafting a show cause letter detailing the incidents, his condition (especially in terms of safety) and his rights to education, regardless of HIV status. The school and study loan provider agreed to allow him to withdraw from the studies without having to repay the loan as long as the client agreed to keep the incident confidential. The client was satisfied with the solution and is looking forward to moving on with the next chapter of his life.

Clients' wish:

Many potential high-level advocacies can be carried out from this incident, considering it involves several individuals in the position of power. However, the client was adamant not to pursue the case. Given this, MAC respected the client's wish.



D. Healthcare Discrimination

Healthcare discrimination is not a unique complaint among the PLHIV communities, even with the advancement of HIV treatment. It has a profound impact on PLHIV, particularly in regards to the motivation for them to access healthcare services (Feyissa, Abebe, Girma, & Woldie, 2012).

Some of the issues reported to MAC are:

Poor knowledge among healthcare providers

- Doctors (especially in the private health settings) certifying PLHIV as unfit for duty during pre-employment health screening even though the clients complied well with the treatments. This leads to retraction of job offers, discontinuation of work contract and difficulties in the mediation process.
- Healthcare workers, advised against serodiscordant (mixed-status) marriage.

Poor regard to confidentiality

- Case discussed openly while there was another patient in close proximity.

Unsolicited advice

- Clients, particularly young MSM, were given unwanted advice in a condescending manner.

Case Study 4:

The doctor asked me how I was diagnosed with HIV and she continued discussing my status. All done in the presence of another patient.

I was conflicted to continue talking about my status. I was embarrassed. In the end, I just kept quiet.

30-year-old architect living in east coast Malaysia, PLHIV since 2016.

The client's HIV status had advanced to AIDS stage, resulting in poor vision. He was referred to an ophthalmologist. The doctor discussed his condition in the presence of other patients in the consultation room.

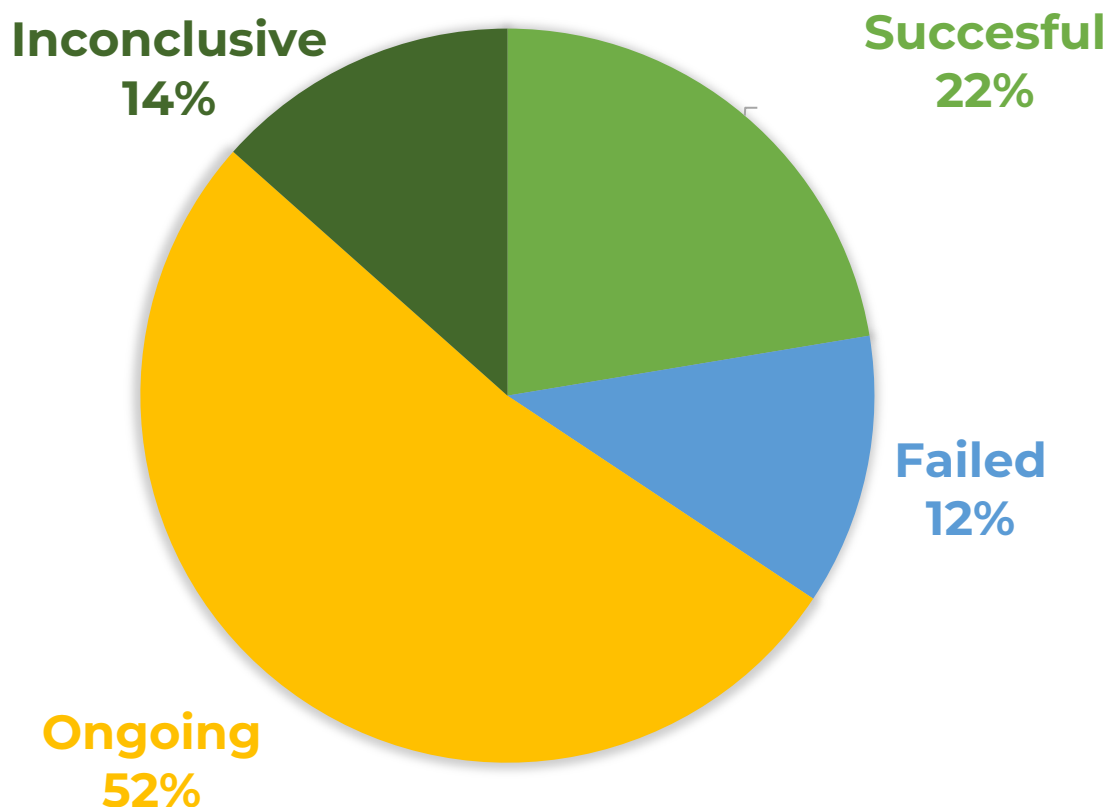
Actions taken:

The issue was handled by MAC's PO in the state. A reminder was given to the hospital and the doctor to be more mindful about PLHIV's need for confidentiality.



SUMMARY OF INTERVENTIONS

Figure 8: Summary of intervention



The interventions by MAC produced a varying degree of outcomes.

Successful - Interventions reached a satisfying conclusion, where both the client and MAC were satisfied with the outcome.

Failed - A couple of reasons:

- Organisations where S&D occurred refused to talk to MAC.
- Mediation failed after clients withheld information.

Ongoing - Situations that require long-term advocacy work. For example:

- Continuous dialogues with the enforcers about the rights of the KPs
- Continuous mental health support for the PLHIVs

Inconclusive - Cases where interventions by MAC produced none of the above-mentioned outcomes. This usually happens when clients stop contacting MAC after the initial contact.

MOVING FORWARD



HIV issues related to stigma, discrimination and human rights violations are critical and will continue to be a major concern for the KPs. A lot still needs to be done to address the sources of the issue, which are stigma and discrimination.

Some of MAC's long- and short-term advocacy plans to address the S&D issue are:

Short-Term Plan

- Continuous alliance-building with POs and stakeholders to heighten the awareness about S&D faced by the KPs.
- Mobilisation of religious leaders and law enforcement to discuss laws, policies and practices that hinder access to HIV services for MSM, TG and FSW
- To approach the MoHE to highlight the plight of young PLHIV, especially in the institutions of higher learning
- Raising awareness through media
- Legal Aid Clinic on workplace discrimination
- Implementation of the HOPE module that focuses on reducing S&D faced by the KPs in the healthcare settings

Long-Term Plan

- Provide support to the Malaysian Business Consortium on HIV/AIDS (MBCH) run by Malaysian AIDS Foundation in drafting the workplace policy
- Roundtable discussions with religious leaders and law enforcement to discuss laws, policies and practices that hinder access to HIV services for MSM, TG and FSW
- Establishment of a National PLHIV Peer Support Network which will be tasked to recruit/mobilise PLHIV willing to volunteer as peer supporters
- To review the PLHIV Stigma Index which was done in 2012 (Positive Malaysian Treatment Access & Advocacy Group, 2012)

CHALLENGES IN ADVOCACY



Underreported cases

MAC is aware that many are still hesitant to come forward and seek help. Again, the concern with their confidentiality demotivates them to report their concern. Some cases were successfully settled by the POs and not reported back to MAC..

Move People to Take Action

Example Case Study 3, although there were opportunities for higher level advocacy, however, the client was satisfied with the initial intervention and not keen to pursue the matter further. Advocacy MAC adhered to the client's request.

Fear of Seeking for Help

Many PLHIVs, especially young people, are reluctant to seek help. One of the reasons cited is the fear that their identity will be made public.

KEY MESSAGES

STRICT CONFIDENTIALITY AGREEMENT

It is the rights of the PLHIV not to disclose their status to anybody. Consent must be obtained for any matter related to their well-being.

THE NEED FOR EMPATHY

Empathy provides an opportunity for a dialogue that can help in ensuring a satisfying and sustainable solution.

WHAT THE STAKEHOLDER CAN DO

MENTAL HEALTHS UPPORT

Due to the extensive effect that S&D have on PLHIV, a sustainable mental health support should be provided. It allows PLHIV to regulate their emotions and improve their quality of life. This is in line with the NSPEA 2030.

ADHERENCE TO PROFESSIONAL WORK ETHICS

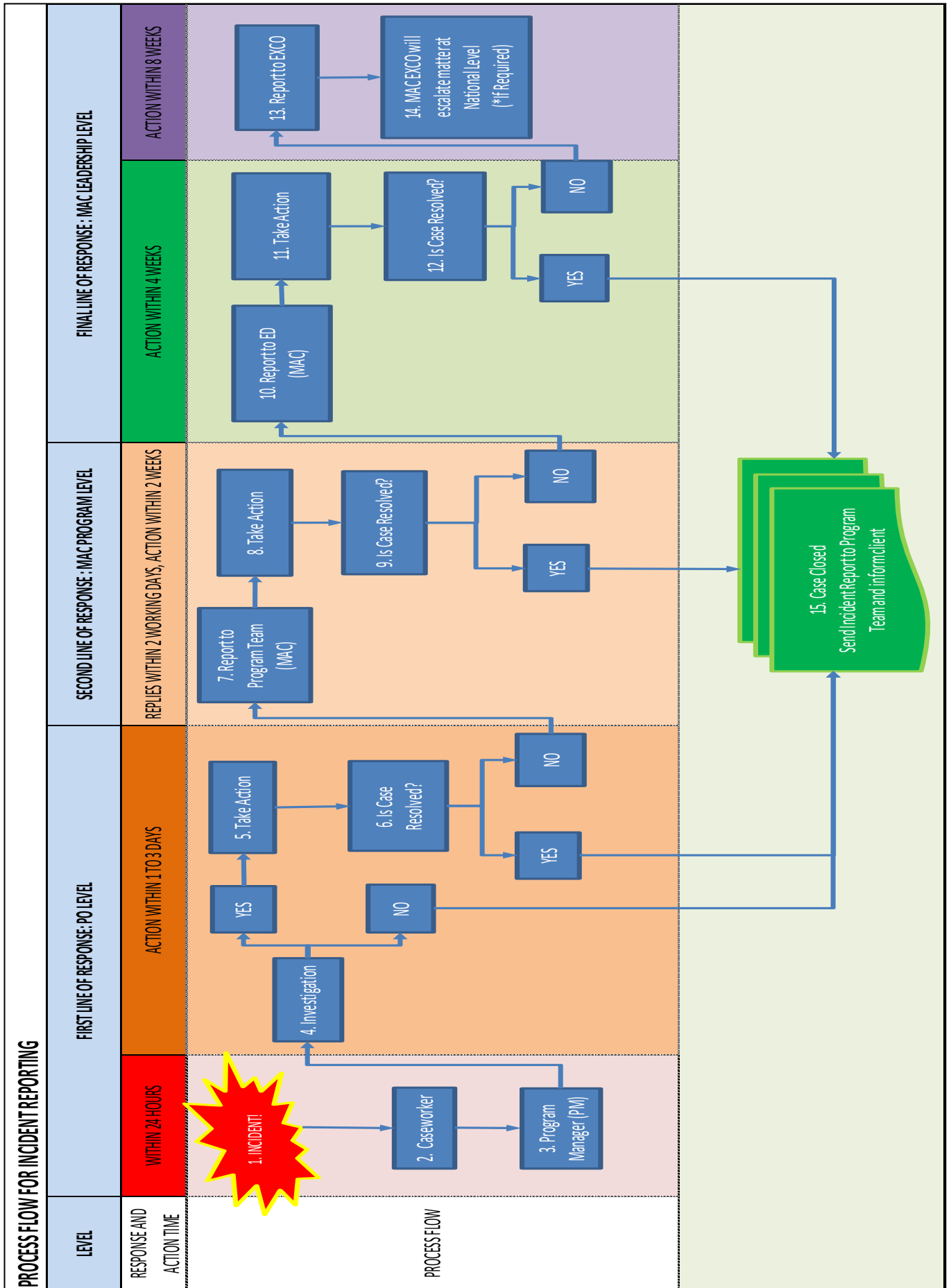
Unconditional positive regard should be practised at all times, regardless of the types of clients involved.



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APPENDIX A



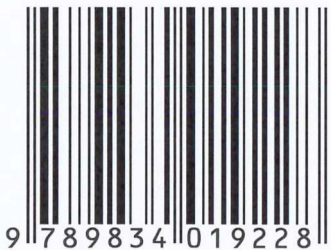
GUIDELINES

- 1/ Incident occurs - incidents are events which affect service delivery of PO. Examples are: Stigma and discrimination or human rights violations experienced by clients, police raids and arrests, etc.
- 2/ Caseworker documents with relevant information and evidence i.e. client statement, photos, etc.
- 3/ Caseworker reports incident to Programme Manager (PM).
- 4/ PM investigates and verifies validity of the report. If the case is valid, the PM will take the necessary actions to resolve the issues. If the report is not valid, the case will be closed and a copy of the incident report is submitted to the Programme Team at MAC.
- 5/ Programme Manager will attempt to resolve the case at the District or State Level. PM must keep the MAC Programme team informed at all times.
- 6/ If the case is resolved, an incident report for the case is closed and submitted to MAC. If the case is not resolved, move to Step 7.
- 7/ PM escalates by sending an Incident Report to MAC Programme Team and requests for action.
- 8/ Programme Team to take relevant steps to resolve a case.
- 9/ If the case is resolved PM, an incident report is closed and documented. If the case is unresolved, move to Step 10 and 11.
- 10/ MAC Programme Team escalates case to MAC Executive Director for further action.
- 11/ MAC ED takes relevant steps to resolve the case. If the case is resolved, an incident report is closed and documented. Otherwise, move to Step 12.
- 12/ MAC ED escalates matter to EXCO.
- 13/ MAC EXCO works to resolve incident at the national level with the relevant government agencies and other institutions.
- 14/ Note: At all times, regular updates and feedback must be provided to the complainant, i.e. reporting client.



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