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UNDERSTANDING WOMEN WHO USE DRUGS IN MALAYSIA



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Introduction - Women Who Use Drugs

Malaysian AIDS Council (MAC) is an umbrella organisation of 47 Partner Organisations across Malaysia working to improve the quality of life of people living with HIV (PLHIV), advocating for access to medicines, and undertaking advocacy activities to reduce the harms of injection drug use. Under the project of Asia Action, funded by the European Union, one of the objectives is to incorporate the gender-specific needs of women who use drugs into drug treatment, HIV prevention, and welfare services. As there is a dearth of research on women who use drugs in Malaysia, MAC is undertaking qualitative research with this population to document demographics and understand the needs and barriers facing women who use drugs.

Women who use drugs require specialised services and treatment that protects their dignity and preserve their rights to health and family life. They are at higher risk of contracting HIV due to biological, behavioural and structural reasons. Women who use drugs are also at greater risk of psychological disorders and exhibit riskier injecting behaviors.¹ Family physicians treating family drug users report having to deal with evident experiences of trauma and violence.² One study proved that female drug users face 2.42 times greater risk of intimate partner violence.³ Studies also show that women use drugs have different patterns of behaviour than men who use drugs and have different needs.⁴

Ethical Consideration for Reporting⁵

HIV reporting has always been something of a taboo in our country. Knowledge of HIV and AIDS itself is important as it touches around sensitive issues such as sex and sexuality, drug use, and social vulnerabilities. You must always remember that women drug users are more vulnerable and must avoid stigma and respect their confidentiality. People who are living with HIV or drug users are unlikely to speak to you unless you assure them of confidentiality. They, like any other person, have feelings and shame. So, treat them with the respect and dignity you would accord any other interview subject.

It would be best to discuss what confidentiality means with your interview subject (in the case of a female drug user). Below is a list of questions to pose at the start of the interview.

1. Selamat pagi kak, kami dari [name of media organisation]... nak borak-borak sikit boleh tak?
2. Ada ambil barang tadi? (barang = drugs)

¹ Gail Gilchrist, Alicia Blazquez and Marta Torrens, 'Psychiatric, Behavioral and Social Risk Factors for HIV Infection Among Female Drug Users' (2011) 15(8) AIDS and Behavior 1834-1834

² Susan Woolhouse, Judith Belle Brown and Amardeep Thind, 'Meeting People Where They're At: Experiences of Family Physicians Engaging Women Who Use Illicit Drugs' (2011) 9(3) Annals of Family Medicines 244-249

³ Gail Gilchrist, Alicia Blazquez and Marta Torrens, 'Exploring the Relationship between intimate partner violence, childhood abuse and psychiatric disorders among female drug users in Barcelona' (2012) 5(2) Advances in Dual Diagnosis 46-58

⁴ Bhagati Ghimire, S. Pilar Suguimoto, Saman Zamani, Masako Ono Kihara and Masahiro Kihara. Vulnerability to HIV infection among female drug users in Kathmandu Valley, Nepal: A Cross Sectional Study (2013). *13 BMC Public Health* 1238

⁵ Henry J Kaiser Foundation, 'HIV/AIDS Reporting Manual' July 2012.

3. Kalau ada, rehatlah dulu, kami interview lain kali.
4. Kalau tidak, boleh interview sekejap?
5. Jangan risau, interview ni rahsia. Kami tak akan gunakan nama sebenar akak. Kalau sudi, tolong tandatangan di sini sebagai tanda persetujuan.
6. Boleh kami ambil gambar?
7. Tak boleh? Tapi kalau ambil dari belakang, boleh?

Be aware that women who use drugs may be under the influence when you approach them. Discuss this with your subject. If they do not wish for their pictures to be taken, do not force them. If they agree, ensure that written informed consent is given. Informed consent cannot be given when they are heavily intoxicated, or when they are undergoing withdrawal pains.

Probe further if the answer you are looking for is still not answered but do not force the subject to answer.

Women who use drugs are particularly vulnerable because many have histories of childhood poverty and abuse, and continue to face increased risks of violence and mental illness. Some do not wish to relive their pasts so questions must be phrased respectfully and with empathy towards their circumstances.

Terms are also important to eliminate stigma. Avoid using terms such as “penagih dadah”, “pelacur”, and “pondan” as these terms perpetuate stigma and are downright offensive.

INSTEAD OF “penagih” USE “pengguna” (Even if they refer to themselves as “penagih”. There is a lot of self-stigma among people who use drugs).

INSTEAD OF “drug addicts” or “junkies”, USE “drug users”, “people who use drugs (PWUD)” or “women who use drugs”.

Remember, they are people overcoming difficult situations, with biological dependence on substances. They need comprehensive health services.

For a glossary of terms to use and avoid in HIV reporting, please refer to Annexes 1 & 2.

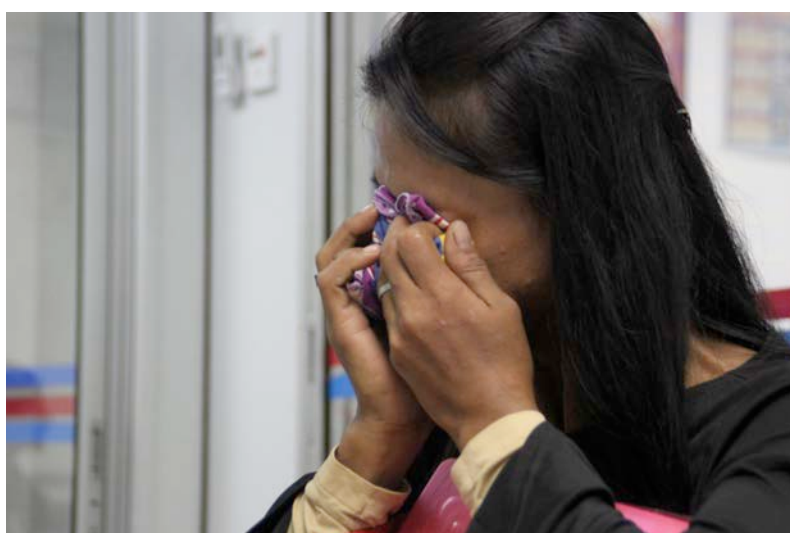
PRELIMINARY FINDINGS

PROFILING WOMEN WHO USE DRUGS IN MALAYSIA

A Qualitative Research by Malaysian AIDS Council – European Union Asia Action project in collaboration with Universiti Sains Malaysia

Methodology: Interviews are ongoing with 45 women who use drugs at urban settings in Kuala Lumpur, Penang, Kelantan and Johor using a semi-structured interview guide.

Preliminary Results: A majority of respondents were poly-drug users with the mean age of initiation into heroin use in their early 20s. Only one had not had any contact with police as a consequence of drug use. Those who had been held in police custody had been in police custody more times than prison. Poverty was a key theme. The respondents also felt that they did not have adequate access to reproductive health and welfare services. Health literacy was low and early marriage was prevalent.



"Sekarang ni makcik perlu apa tau... mak cik fikir, kalau makcik nak berhenti [ambil dadah] betul-betul lah, ada bagi sokongan kat belakang... support dari belakang. '*Kau mari sini duduk sini, aku jaga kau*'. Saya nak dengar perkataan tu je. Kaunseling, perubatan saya. Take care kat kita lah kan."

~Homeless woman who uses drugs, 55, Chow Kit, Kuala Lumpur

Excerpt from an interview about reproductive health checkup:

Respondent: Saya tahu diri saya elok.

Interviewer: ada uji untuk sakit kelamin tak?

Respondent: Pasal dia boleh tahu saya ada kelamin. Automatic dia boleh tahu.

Interviewer: Okay, tetapi tahu tak pasal sifilis atau gonorrhea.

Respondent: Tak tahu.

~Homeless woman who uses drugs living with HIV & TB, 46, Kuala Lumpur



YOUNG PEOPLE WHO USE DRUGS



Speaking about juvenile detention:

“Kadang-kadang saya rasa, masuk sana bukan lagi elok. Kalau dalam 300 orang tu, boleh katakan cuma 10 orang je yang boleh berubah.”

~Woman who uses drug, 21, Penang
Began sniffing glue at age nine
Was in juvenile detention between 15-17 years

Definitions of terms

Children: Below the age of 18 years, unless, under the law applicable to the child, majority is attained earlier.⁶

Adolescents: People aged 10-19 years⁷

Young People: People aged 10-24 years⁸

CRC: The United Nations Convention of the Rights of the Child (CRC, 1989), which a global treaty guiding the protection of human rights for people under 18 years of age.

Malaysia has ratified the CRC.

⁶ United Nations, United Nations Convention of the Rights of the Child (Article 1). U.N. Doc. A/Res/44/25, 1989 (<http://ochcr.org/EN/ProfessionalInterest/Pages/CRC.aspx>, accessed 1st August 2014) quoted in HIV and Young People Who Inject Drugs: A Technical Brief UNAIDS/JC2666 WHO/HIV/2014.17

⁷ Interagency Youth Working Group, Young people most at risk of HIV: a meeting report and discussion paper from the Interagency Youth Working Groups, U.S Agency for International Development, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Inter Agency Task Team on HIV and Young People, and FHI. Research Triangle Park (NC): FHI;2010 (<http://www.unfpa.org/public/home/publications/pid/6565>, accessed 16 June 2014) quoted in HIV and People Who Inject Drugs: A Technical Brief UNAIDS/JC2666 WHO/HIV/2014.17

⁸ World Health Organization. HIV and adolescents: Guidance for HIV testing and counseling and care for adolescents living with HIV. Geneva: World Health Organization; 2013 (<http://www.who.int/hiv/pub/guidelines/adolescents/en> accessed 16 June 2014) quoted in HIV and People Who Inject Drugs: A Technical Brief UNAIDS/JC2666 WHO/HIV/2014.17

Introduction

HIV and Young People who Inject Drugs; A Technical Brief Developed by the Inter-Agency Working Group on Key Populations was launched recently at the 20th International AIDS Conference in Melbourne, Australia. It examines the vulnerabilities and risks of young people, the legal and policy constraints that the government should start addressing and as well as service coverage and barriers to health care access.

Young People who Use Drugs

Young people now are more adventurous, curious and their new form of experimentation is through socialisation and pleasure seeking.⁹ Due to 'particular vulnerabilities of youth, power imbalances in relationships and sometimes, alienation from family and friends', the risk of them engaging in risky behaviours, whether willingly or not, is increased.¹⁰ The lack of stable and supportive family environments and vulnerability to peer pressure therefore increases the risk of HIV infection.¹¹

Young People who Use Drugs face:

- Longer detention periods than adults who use drugs.
- Barriers to access HIV prevention and testing as they need parental consent

Criminalisation is not the best way to move forward in the cases of young people because it will deter young people from getting help as they fear arrest and prosecution. Criminalisation reduces future employment prospects, resulting in the continuation of the entire cycle of poverty and unsupportive family environments.

What We Need To Do

- Change the law: Juvenile detention does not improve sexual and reproductive health or socioeconomic outcomes.
- Examine current consent policies to consider removing age-related barriers and parental consent requirements that impede access to HIV and STI testing, treatment and care.¹²
- Introduce additional services for young people – Basic medical and psychological services, housing, food, social protection, access to education/employment
- Improvement of drug education for adolescents in schools to address social norms, delivered by health professionals and peer educators.
- Increase funding for research on young people who use drugs.

⁹ HIV and Young People Who Inject Drugs: A Technical Brief (Draft), (July 2014) UNAIDS / JC2666 WHO/HIV/2014.17.

¹⁰ Id at 5

¹¹ HIV and Young People Who Inject Drugs: A Technical Brief (Draft), (July 2014) UNAIDS / JC2666 WHO/HIV/2014.17.

¹² Id at 26



Glossary of HIV and AIDS Associated Terminology

Language shapes beliefs and may influence behaviours. Considered use of correct and sensitive terms has the power to eradicate stigma often associated with HIV and AIDS, as well as people living with or are affected by HIV.

Terms to Avoid	Correct and Sensitive Terms	Rationale
HIV / AIDS (confusion between HIV and AIDS)	HIV should not be equated with AIDS (and vice versa).	HIV (Human immunodeficiency virus) is the virus that attacks the human immune system. AIDS (Acquired Immune Deficiency Syndrome), on the other hand, is the most progressive stage of HIV infection when the body's immune system has been completely weakened and the person is afflicted with opportunistic infections. Consider using the most specific and appropriate term based on the context of discussion to avoid confusion between HIV and AIDS (choose only one). For example, 'people living with HIV', 'HIV infection', 'HIV prevention programme', 'AIDS diagnosis' and 'children orphaned by AIDS'. Both 'HIV epidemic' and 'AIDS epidemic' are widely accepted, but 'HIV epidemic' is the more inclusive term.
AIDS carrier / HIV carrier	People living with HIV / HIV-positive persons	'AIDS carrier' / 'HIV carrier' is highly stigmatising and very offensive to people living with HIV. It implies that people living with HIV carry contagious diseases or misfortune. They are also highly inaccurate. One cannot be infected with AIDS. <u>HIV is the infectious agent</u>, not AIDS.

AIDS-infected / HIV-infected	People living with HIV	Use the internationally recognised term, people living with HIV, as it adds a human dimension to the issue discussed.
AIDS victims / AIDS sufferers	People living with HIV	'Victims' and 'sufferers' connote negatively that people living with HIV are powerless and have no control over their lives. Use the internationally recognised term, 'people living with HIV'.
AIDS virus	HIV	There is no AIDS virus. The virus that causes AIDS is the human immunodeficiency virus (HIV). Please note that 'virus' in the phrase 'HIV virus' is redundant. Use HIV.
AIDS infection	HIV infection	<u>AIDS is not infectious.</u> Use HIV infection.
AIDS test	HIV test	There is no test for AIDS. Use HIV test or HIV antibody test. 'HIV antibody test' is the more accurate term as the testing modality detects the presence of HIV antibodies in the blood, not the virus.
AIDS patient / HIV patient	People living with HIV	Use the term 'patient' only when referring to a clinical setting. For example, 'patient with HIV-related illness (or disease)'.
Risk of AIDS	Risk of HIV	More accurately, you may say 'risk of HIV infection' or 'risk of exposure to HIV'.
High risk groups	High risk behaviour / high risk practices (for example, 'sharing of contaminated injecting equipment, 'unsafe sexual practices')	'High risk groups' implies that membership to a certain group, rather than behaviour is the important factor in HIV transmission. This term may lull people who do not identify with this 'high risk group' into a false sense of security. It creates stereotypes also of the 'kinds' of people who are at risk of infection. It is high risk behaviour that spreads HIV.

Innocent victims	People living with HIV	It is commonly used to describe HIV-positive children or people with medically acquired HIV infection (for example, HIV infection from transfusion of contaminated blood products). It wrongly implies that people who get infected in other ways are guilty or immoral. Use clear non-judgmental descriptions instead, for example children living with HIV, people with medically acquired HIV, people living with HIV.
Aids	AIDS	AIDS is an acronym for 'acquired immune deficiency syndrome'. As such, it needs to be written in all uppercase letters; writing it as 'Aids' might cause confusion with 'aids' as in 'helps'.
Free sex / promiscuous sex / sex out of wedlock	Unprotected sex / Unsafe sex practices	Avoid using those terms when describing the risk of sexual transmission of HIV. One cannot get HIV just from having sex out of wedlock or having multiple partners. HIV can only be transmitted through HIV unprotected sex, i.e. sex without using a condom.
Drug addict	Drug user	The more sensitive and non-derogatory term is 'drug user'. When describing risk of HIV transmission, consider using injecting drug user to place emphasis on high risk behaviour.
Prostitute	Sex worker	The sensitive and non-derogatory term is sex worker. Likewise, when describing the profession, use sex work (as opposed to 'prostitution').

The above content is partially adapted from *UNAIDS Terminology Guidelines (January 2011)*. Updated September 2013.



Glosari Penggunaan Istilah-Istilah Berkaitan dengan HIV dan AIDS

Bahasa berupaya membentuk kepercayaan dan mempengaruhi peri laku. Penggunaan istilah-istilah yang tepat dan sensitif mempunyai kuasa untuk mengikis stigma yang sering dikaitkan dengan HIV dan AIDS, serta orang yang hidup dengan atau terjejas oleh HIV.

Istilah Yang Perlu Dielakkan	Istilah Yang Tepat Dan Sensitif	Rasional
HIV / AIDS (kekeliruan antara HIV dan AIDS)	HIV tidak seharusnya disamaertikan dengan AIDS (dan sebaliknya).	HIV (<i>Human immunodeficiency virus</i>) ialah virus yang menyerang sistem imun (sistem ketahanan badan melawan penyakit) manusia. AIDS (Sindrom Kurang Daya Ketahanan Melawan Penyakit) pula merupakan peringkat jangkitan HIV yang paling progresif yang berlaku apabila sistem imun tubuh telah benar-benar lemah dan orang tersebut mengalami jangkitan oportunistik (jangkitan yang mengambil kesempatan terhadap sistem imun yang lemah). Gunakan istilah yang paling spesifik dan bertepatan mengikut kesesuaian konteks bagi mengelakkan kekeliruan antara 'HIV' dan 'AIDS' (pilih satu sahaja). Contohnya, 'orang yang hidup dengan HIV', 'jangkitan HIV', 'program pencegahan HIV', 'diagnosa AIDS', dan 'kanak-kanak yang kematian ibu bapa disebabkan oleh AIDS'. Kedua-dua istilah 'epidemik (wabak) HIV' atau 'epidemik AIDS' adalah diterima pakai, tetapi 'epidemik HIV' adalah lebih menyeluruh.

Pembawa AIDS / Pembawa HIV	Orang yang hidup dengan HIV / mereka yang hidup dengan HIV / orang yang positif HIV	Perkataan ‘pembawa’ menunjukkan seolah-olah orang yang hidup dengan HIV ‘membawa’ penyakit atau nasib malang, dan ini hanya memperkukuh stigma terhadap mereka. Istilah ‘pembawa AIDS’ juga tidak tepat kerana AIDS tidak berjangkit; yang berjangkit hanyalah HIV.
Penghidap AIDS / Penghidap HIV	Orang yang hidup dengan HIV, atau singkatannya OHDA	Gunakan istilah orang yang hidup dengan HIV kerana lebih sensitif dan memberikan dimensi kemanusiaan kepada isu yang dibincangkan.
Mangsa AIDS / Penderita AIDS	Orang yang hidup dengan HIV (OHDA)	‘Mangsa’ atau ‘penderita’ melambangkan bahawa mereka yang hidup dengan HIV tiada kawalan atas kehidupan masing-masing, dan memberikan gambaran bahawa mereka golongan yang ‘lemah’.
Virus AIDS	HIV	Virus AIDS tidak wujud. Virus yang menyebabkan AIDS ialah <i>human immunodeficiency virus</i> atau HIV. Perhatikan juga bahawa ‘virus’ dalam ‘virus HIV’ adalah berulang. Oleh sebab itu, HIV sahaja sudah memadai.
Jangkitan AIDS	Jangkitan HIV	AIDS <u>tidak berjangkit</u> ; yang berjangkit hanyalah HIV.
Ujian AIDS	Ujian HIV	Tidak terdapat ujian untuk mengesahkan diagnosa AIDS. Gunakan istilah ujian HIV atau ujian antibodi HIV. ‘Ujian antibodi HIV’ adalah lebih tepat kerana ujian itu sebenarnya mengesan kehadiran antibodi HIV dalam darah, bukan virus itu sendiri.
Pesakit AIDS / Pesakit HIV	Orang yang hidup dengan HIV (OHDA).	Gunakan istilah ‘pesakit’ hanya dalam konteks perubatan atau keadaan klinikal; sebagai contoh, ‘pesakit yang menghidap penyakit berkaitan dengan HIV’.

Risiko AIDS	Risiko jangkitan HIV	<u>AIDS tidak berjangkit</u> ; yang berjangkit hanyalah HIV.
Golongan berisiko tinggi	Tingkah laku berisiko tinggi / amalan berisiko tinggi (contoh: perkongsian alat suntikan yang tercemar', 'amalan seks yang tidak selamat')	Istilah ini melambangkan bahawa keahlian dalam sesuatu 'kumpulan' atau 'kelompok' menjadikan seseorang itu berisiko untuk dijangkiti HIV. Ini tidak benar kerana kelakuan dan bukannya kumpulan sosial mendedahkan seseorang kepada risiko jangkitan HIV.
Mangsa tidak berdosa	Orang yang hidup dengan HIV	Istilah ini sering digunakan untuk merujuk kepada kanak-kanak yang positif HIV atau mereka yang dijangkiti HIV melalui faktor perubatan (contoh, pemindahan darah yang tercemar). Dengan ini, kita seolah-olahnya menyatakan bahawa mereka yang dijangkiti HIV melalui faktor-faktor lain adalah berdosa, bersalah atau tidak bermoral. Gunakan 'kanak-kanak yang hidup dengan HIV', 'orang yang dijangkiti HIV melalui pemindahan darah yang tercemar', atau 'orang yang hidup dengan HIV'.
Aids	AIDS	AIDS merupakan akronim bagi <i>Acquired Immune Deficiency Syndrome</i> . Oleh sebab itu, AIDS mesti <u>ditulis dengan huruf besar sepenuhnya</u> kerana jika ditulis dengan huruf kecil pembaca mungkin terkeliru dengan perkataan Inggeris 'aids' yang bermaksud 'membantu'.
Seks bebas / seks rambang / seks luar nikah	Amalan seks yang tidak selamat	Seseorang tidak dijangkiti HIV kerana bertukar-tukar pasangan seks atau seks sebelum bernikah, tetapi disebabkan oleh amalan seks yang tidak selamat (tanpa menggunakan kondom).

Penagih dadah	Pengguna dadah	'Pengguna dadah' merupakan istilah yang lebih sensitif dan tidak merendahkan martabat seseorang. Dalam menerangkan risiko jangkitan HIV, gunakan istilah 'pengguna dadah secara suntikan' untuk memberikan penekanan terhadap peri laku berisiko.
Pelacur	Pekerja seks	'Pekerja seks' istilah yang lebih sensitif dan tidak merendahkan martabat seseorang. Untuk menjelaskan bidang pekerjaan yang berkaitan, gunakan istilah 'pekerjaan seks' (bukan 'pelacuran').

Sebahagian kandungan di atas disuaipadankan daripada *UNAIDS Terminology Guidelines (January 2011)*. Dikemaskinkan September 2013.

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