

Qualitative Assessment of Sexual and Reproductive Health and Rights and Access to Health Care Services Among Women Living with HIV Within the Context of Prevention of Mother-To-Child Transmission of HIV in Malaysia

Research Report

25 January 2022



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Foreword



Along with the successful validation of the elimination of mother-to-child transmission of HIV and syphilis in Malaysia in 2018, the Global Validation Advisory Committee made several recommendations, including that Malaysia undertake an independent assessment of current practices in sexual and reproductive health and rights and service delivery and access for women living with HIV.

In preparation for a qualitative research study on sexual and reproductive health and rights for women living with HIV in Malaysia, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Regional Office

for Asia and the Pacific and the International Community of Women Living with HIV Asia Pacific (ICWAP) conceptualized a regional multistakeholder advisory committee to oversee and provide strategic direction for the key steps of the research process. Terms of reference were developed in consultation with ICWAP, and a regional advisory committee was formed, including representatives from ICWAP, the Ministry of Health Malaysia, the Network of Women Living with HIV in Malaysia (WAPOMA), Persatuan Wahidayah Malaysia (PEWAHIM), the Malaysia AIDS Council, the UNAIDS Regional Office for Asia and the Pacific, an academician with expertise in maternal, child and reproductive health research, and the Asia Pacific Alliance for Sexual and Reproductive Health and Rights.

The advisory committee adhered rigorously to meaningful involvement of people living with HIV/AIDS (MIPA) and greater involvement of people living with HIV/AIDS (GIPA) principles. The community networks chose their own representatives and were allocated additional seats for people from their networks. In addition, eight women living with HIV were nominated by the community and civil society networks to form a team of community researchers to lead, guide and participate in the research study implemented by Universiti Sains Malaysia. The advisory committee, with participation by ICWAP, the Malaysia AIDS Council, PEWAHIM and WAPOMA, voted, reached consensus and selected to endorse Universiti Sains Malaysia to undertake the community research.

The advisory committee considered and approved the terms of reference for the technical research; membership of the team to conduct the research, including community members to facilitate and conduct interviews; and development of the research protocol, implementation and data analysis methodologies. At each step, the advisory committee ensured women living with HIV in Malaysia were in the lead, and that any concerns or issues were addressed by the implementor of the research. The advisory committee operated with full transparency and impartiality, and all issues were tabled and collectively resolved.

After the research team had developed the research protocol and qualitative research questions, several rounds of reviews and feedback allowed concerns raised by advisory committee members, including ICWAP, PEWAHIM and WAPOMA, to be addressed. At each step, the Universiti Sains Malaysia team made the changes requested by the three organizations and gave every indication of valuing and learning from the input and community perspectives. An additional offer was provided to ICWAP, PEWAHIM and WAPOMA for UNAIDS to convene an online working session to resolve any outstanding issues and to further strengthen the research protocol. This offer was not taken up, and the representatives did not give any indication that there were unresolvable issues. The representatives reported to the advisory committee that they were resolving the issues but feeling time-pressured given the tight timeline for the revalidation and research process. ICWAP, PEWAHIM and WAPOMA then withdrew their participation from the advisory committee and their community researchers from the research, despite offers to remain part of the advisory committee even if they chose not to take part in the research itself.

The remaining advisory committee members, including the remaining representatives from the communities of women living with HIV in Malaysia, continued to work in partnership with Universiti Sains Malaysia to conduct interviews in all regions of the country; process the data; hold virtual discussions with users of sexual and reproductive health and rights services; analyse the findings; and verify the results.

The community representatives who participated expressed appreciation at the level and quality of their engagement and ownership throughout the process, and the Universiti Sains Malaysia team noted how much it had learned from the community representatives.

UNAIDS, on behalf of the advisory committee, extends sincere appreciation to all committee members, including representatives of ICWAP, PEWAHIM and WAPOMA, who contributed to making this a valid research study.

The advisory committee also thanks to the technical research team and community researchers for their valuable contributions and dedicated efforts to accomplish the research project.



Stuart David Watson
Chair
On behalf of the Regional Multistakeholder Advisory Committee

Foreword



Mother to child transmission (MTCT) of sexually transmitted infections including HIV and syphilis is currently a public health concern around the world. MTCT of HIV and syphilis are preventable. Thus, Malaysia started implementing prevention program (PMTCT) that entails antenatal screening for HIV and syphilis, treatment and prophylaxis more than 2-3 decades ago.

Although Ministry of Health is the custodian of the PMTCT program but, achieving elimination is indeed a collective effort with involvement of various sectors and stakeholders.

In 2017, Malaysia achieved elimination target set by the WHO when the vertical transmission rate fell below 2% for the first time and the prevention coverage remained above 95% for at least two consecutive years. This achievement led to the certification of elimination by WHO in 2018, ranking Malaysia as the first country in the Western Pacific Region to eliminate vertical transmission of HIV and congenital syphilis.

Between 2019 and 2020, many changes have been accomplished – all towards improving the quality of our maternal and child health services. Thousands of doctors and paramedics were trained using the latest guideline focusing on early and adequate treatment, infant feeding and delivery options and sexual reproductive health rights of every woman living with HIV (WLHIV). Reduction of stigma and discrimination against people living with HIV at selected health facilities using quality improvement approach became one of the many highlights' of 2021 despitely being hit hard by the COVID-19 pandemic.

This report narrates an important finding of the current practices in sexual and reproductive health and rights and service delivery and access for WLHIV in Malaysia that will assist the country to further improve its services. Malaysia is grateful to the Joint United Nations Programme on HIV/AIDS (UNAIDS) Regional Office for Asia and the Pacific and the International Community of Women Living with HIV Asia Pacific (ICWAP) for moderating and overseeing the research process. Our sincere appreciation also goes to the advisory committee, technical research team and the community members involved directly or indirectly in accomplishing this study.

A handwritten signature in black ink, appearing to read "Norhayati Rusli".

Datuk Dr. Norhayati Rusli
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This qualitative assessment was conducted between July and October 2021 with the support of many people, organizations and communities, without whom it would not have been possible.

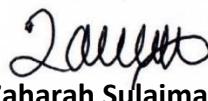
Our gratitude goes to all the people who gave their time to participate in the discussions and interviews and provided unique insights into their lived experiences. Despite the challenges of using an unfamiliar virtual platform, the participants overcame barriers and shared their experiences generously.

The research team was supported by community research supporters, whose contributions deserve special mention. Special thanks go to Puan Lina Muhammad from Komuniti Cakna Terengganu, Puan Revathi a/p Harikrishnan from Community AIDS Service Penang, and Puan Siti Fazariah Abdul Hamid from Persatuan Perkhidmatan Sokongan AIDS Sabah for their collaborations and dedication.

We would like to acknowledge the AIDS officers from the Ministry of Health Malaysia, whose engagement and assistance from the very start helped push the project to the end.

Our sincere appreciation goes to the Joint United Nations Programme on HIV/AIDS Regional Office for Asia and the Pacific for guidance, support and trust in us to produce this research project on time. We are deeply indebted to the Regional Multistakeholder Advisory Committee members for their coordination, support and guidance through all stages of the project.

We wish to extend our thanks to all others who have in one way, or another given us encouragement towards the successful completion of this project.


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Abbreviations

AIDS	acquired immunodeficiency syndrome
EMTCT	elimination of mother-to-child transmission
GVAC	Global Validation Advisory Committee
HIV	human immunodeficiency virus
ICWAP	International Community of Women Living with HIV Asia Pacific
MySES	Malaysia Stigma Evaluation Survey
PCR	polymerase chain reaction
PEWAHIM	Persatuan Wahidayah Malaysia
PMTCT	prevention of mother-to-child transmission
SDGs	Sustainable Development Goals
UNAIDS	Joint United Nations Programme on HIV/AIDS
TB	tuberculosis
WAPOMA	Network of Women Living with HIV in Malaysia
WHO	World Health Organization

Executive summary

In October 2018, Malaysia was awarded the validation certificate for elimination of mother-to-child transmission (EMTCT) of HIV and syphilis, making it the first country in the World Health Organization (WHO) Western Pacific Region to achieve such status. The validation strongly recommended that Malaysia make sexual and reproductive health and rights of women living with HIV a crucial component in the HIV response. Women living with HIV are central to an effective HIV response. Although achieving the validation of EMTCT is a laudable accomplishment, maintaining this status is even more important for Malaysia.

The Global Validation Advisory Committee (GVAC) for EMTCT has made several recommendations, including for Malaysia to undertake an independent assessment of current practices concerning sexual and reproductive health and rights of women living with HIV in the context of prevention of mother-to-child transmission (PMTCT). GVAC has proposed to the Ministry of Health that GVAC will make a visit to learn the progress made on human rights and community engagement issues before the maintenance review of EMTCT validation.

Between July and October 2021, a nationwide assessment exploring the development of EMTCT programmes, with particular focus on sexual and reproductive health and rights and access to healthcare services among women living with HIV since 2018, was carried out by a research team from the School of Medical Sciences, Universiti Sains Malaysia. Implementation of the project was facilitated by community research supporters working with local community and civil society organizations. Using qualitative enquiries, the project assessed the lived experiences and views of women living with HIV and perspectives of healthcare providers on access to healthcare services, sexual and reproductive health and rights, and stigma and discrimination in healthcare settings.

Qualitative approaches were used to explore research objectives. The study used focus group discussions and in-depth interviews to reveal patterns of lived experiences and views of women living with HIV in the context of the PMTCT programme. Due to restrictions imposed by the COVID-19 pandemic, the Zoom application was used to bring together researchers and participants. This allowed the research project to be carried out nationally within a limited timeframe, capturing as many diverse voices as possible.

To portray a more recent and ongoing practice that has taken place since the validation of EMTCT, three categories of women living with HIV were included in the study: general, antenatal and postnatal women who are using healthcare services or who have done so since January 2018. Experiences and views were also sought from key stakeholders, including doctors, nurses and counsellors involved in providing services to women living with HIV from January 2018. A total of 11 in-depth interviews and 16 focus group discussions were conducted over 5 weeks, with 73 women living with HIV and 18 healthcare providers.

The main findings of the study are summarized below.

Access to healthcare services

Parallel to infrastructure investment and growth, access of women living with HIV to healthcare services has improved considerably since the implementation of EMTCT. Women from Peninsular Malaysia had the fewest difficulties, and generally access was available, accessible, acceptable and of good quality. In rural areas, especially in Sabah, accessibility is still a challenge. Geographical inequalities in healthcare access are not specific to women living with HIV but apply to the delivery of health care in general.

The challenge of delivering healthcare services is related to infrastructural limitations, which is an ongoing agenda for improvement by the Malaysian Government. Healthcare services have responded with various initiatives, such as the Flying Doctors Service, setting up more primary care centres, and innovative service provision (e.g., postal delivery of medicines). Most HIV-related tests and treatments and sexual and reproductive health and rights services for PMTCT clients were available to women free of charge at clinics and hospital-based settings.

Second- and third-line antiretroviral medicines were available free of charge during pregnancy. Financial aids were provided to eligible women living with HIV to continue their medicines beyond pregnancy. In this situation, rights-based assessment of welfare needs for all women living with HIV should be performed at first contact with the healthcare services. Adapting to restrictions imposed by the COVID-19 pandemic, options to procure medicines through alternative routes such as drive-through pharmacies and courier services were also offered. Personalization of care by healthcare providers often extended beyond their scope of duty, and this triumphed over minor limitations of the healthcare system.

Many women were especially happy with the treatment they received from specialist-led infectious diseases clinics in tertiary hospitals. Nonetheless, some women raised issues around the quality of provision of healthcare services, in particular regarding the provision of infant formula and have the choice to receive care at healthcare facilities further away from home.

Sexual and reproductive health and rights

Women living with HIV are largely able to exercise their rights to receive information, give informed consent and participate in decision-making. Women living with HIV typically received counselling for tests or procedures being performed, but sometimes this was overlooked when women were admitted for non-HIV-related illnesses.

Women living with HIV were able to access a wide range of contraceptive methods. No women reported being coerced, threatened or forced to undergo tubal ligation. Some women reported difficulty in accessing their preferred methods of contraception. Women were familiar with their right to choose a safe delivery method guided by clinical parameters such as CD4 count and viral load test results and obstetric history. Although many women had aspirations for breastfeeding, they were aware of the risk of vertical transmission and hence abstained from doing so. None of the women were aware that they could be supported with breastfeeding if they fulfil certain eligibility criteria.

There were many complaints regarding the right to respectful care, privacy and confidentiality in healthcare settings. Structural limitations in healthcare facilities in hospital or primary care settings

hindered women living with HIV from having private discussions with healthcare providers. There were some isolated reports from women living with HIV about services that are perceived to be judgemental or not evidence-informed. There were mixed responses regarding the management of the placenta, and some women were allowed to take their placenta home for burial according to customary practice.

Overall, the overarching principle of providing woman-centred care was observed by healthcare providers. The nonconfrontational culture pervasive in Malaysian society, however, often translates into women living with HIV enduring experiences in silence. Creating an enabling environment and promoting meaningful participation of women living with HIV and civil society organizations working with people living with HIV, is very much needed to enhance the experiences of women living with HIV in relation to healthcare services.

Stigma and discrimination

HIV does not have to be synonymous with stigma, but women are still experiencing stigma and discrimination across the healthcare continuum. Some women reported being ignored or treated harshly, with condemnatory language, breaching of confidentiality through gossiping, or use of unnecessary precautions such as double-gloving. Several women voiced dissatisfaction over being served food and drinks in disposable containers and not having their bedlinen changed during their stay on the postnatal ward.

Despite good intentions, some practices, such as having a dedicated clinic day for people living with HIV, could lead to women being identified and resultant stigma and discrimination.

Women living with HIV often have internalized stigma and low self-esteem. They prefer to keep their HIV-positive status private but are prepared to declare their status to their healthcare providers. To protect their privacy, many choose to travel longer distances and receive care in facilities away from their homes to avoid being recognized by local residents.

Negative portrayal of people living with HIV by the media was considered unhelpful.

More than half of the married women living with HIV in the study were in serodiscordant relationships, which may suggest social acceptance of women living with HIV and diminishing community-level resistance to HIV-related stigma.

Recommendations

Improve access to healthcare services

- a) Adapt the values and preferences of women living with HIV in the provision of choice of healthcare facilities.
- b) Ensure decentralized settings, especially in rural areas and community-level sites in decentralization of care, are sufficiently equipped to manage care of women living with HIV.
- c) Offer a wider range of contraception options to increase use among women living with HIV.
- d) Provide vouchers in lieu of infant formula to improve access, particularly for children who are not tolerant of the prescribed formula or who require special formulations due to allergies.

- e) Enhance the quality and scope of counselling services by increasing training opportunities for healthcare providers.
- f) Facilitate rights-based assessment of welfare needs for all women living with HIV at first contact with healthcare services.
- g) Encourage telehealth and multi-month dispensing of antiretroviral medicines, especially for people who are stable on routine treatment.

Ensure sexual and reproductive health and rights of women living with HIV

- a) Ensure informed consent with proper documentation from women living with HIV before any test or procedure is carried out, particularly during hospital admission.
- b) Distribute booklets and checklists to women living with HIV as part of overall health and rights literacy and to communicate about the PMTCT programme and what to expect during pregnancy and beyond.
- c) Ensure effective communication between women living with HIV and healthcare providers, and among healthcare providers, through regular women-centered multidisciplinary team meetings.
- d) Update clinical practices in accordance with the Model of Good Care, as in the national guideline:
 - Assist eligible women living with HIV who wish to breastfeed their babies.
 - Educate women living with HIV about hospital management of the placenta in accordance with standard universal precautions, while respecting cultural norms.
 - Provide lactation suppressors to postnatal women living with HIV if they choose not to breastfeed their babies.
- e) Collate feedback from women living with HIV on the performance of healthcare services and address any issues transparently.
- f) Offer quiet, private consultation areas to respect the rights of women living with HIV and keep their information confidential.
- g) Hold regular awareness programmes for healthcare providers and partners and spouses of women living with HIV on prevention and protection from gender-based and intimate partner violence.
- h) Encourage gender empowerment initiatives and elimination of gender-based discrimination, such as through communications campaigns.

Eliminate stigma and discrimination

- a) Prohibit any form of labeling of documents that may result in women being identified as living with HIV and their babies, especially on the front cover of the antenatal record book (Buku Record Kesihatan Ibu Hamil, “Pink Book”) and appointment cards. While acknowledging the risk to healthcare providers, any form of HIV status identifier should be discreet and only on the inside of the documents.
- b) Address internalized stigma and foster resilience among women living with HIV through:
 - Peer-conducted skills-building workshops specifically for women living with HIV.
 - Increasing the capacity of organizations of women living with HIV to advocate for their rights and meaningfully engage in decision-making.
- c) Address provider stigma in healthcare settings through:

- Sensitization training for clinical and non-clinical healthcare providers.
 - Regular nationwide assessment and monitoring of HIV-related stigma and discrimination in healthcare settings using a standardized stigma measurement tool and with the engagement of women living with HIV.
- d) Reinvigorate HIV awareness and education campaigns through mass and social media.
- e) Encourage a more positive narrative around people living with HIV by the media.

External quality assurance audit

Engage an independent and objective external auditor to review the PMTCT programme to overcome compliance challenges and promote efficiency.

Conclusion

The findings of this qualitative assessment reflect the views and experiences of many of the women living with HIV in Malaysia. The study found that since the implementation of the EMTCT programme, there have been encouraging improvements across all areas related to provision of healthcare services. Women living with HIV were satisfied with their care in general, although there were some isolated experiences that threaten the rights of women. No women reported being coerced, threatened or forced to undergo tubal ligation. Some women reported difficulty in accessing their preferred methods of contraception. Women were familiar with their right to choose a safe delivery method guided by clinical parameters such as CD4 count and viral load test results and obstetric history. Healthcare services have been responsive towards these events when they were highlighted. An enabling environment with women-centred policies should be developed further.

Background

Global HIV targets

Globally, about 1.5 million new HIV infections among adults occurred in 2020, a decline of only 31% since 2010. In Asia and the Pacific, there were 240 000 new HIV infections in 2020, a 21% decline since 2010 (1). The Sustainable Development Goals (SDGs) aim to end AIDS as a public health threat by 2030 (Target 3.3) and to achieve universal health coverage, access to good-quality healthcare services, and access to safe, effective, good-quality and affordable essential medicines and vaccines for all (Target 3.8) (2, 3). Since the deadline for achieving the targets called for by the Start Free, Stay Free, AIDS Free framework passed in December 2020, the 2025 targets have been set to demonstrate revitalized global interest (3, 4).

The Global Health Sector Strategy on HIV sets out a sector-wide strategy for ending AIDS as a public health threat by 2030 (5). It promotes a people-centred approach grounded in principles of human rights and health equity (5, 6).

Using the SDGs as an overarching goal, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has provided a Global AIDS Strategy 2021-2026 - End Inequalities, End AIDS that uses an inequalities framework to close the gaps that are preventing progress towards ending AIDS and that sets the 2025 AIDS targets (7). The Strategy focuses on three interlinked areas: the enabling environment (“the 10s”), service access (“the 95s”), and service integration with communities at increased risk and people living with HIV at the centre.

“The 10s” call for the removal of societal and legal barriers to HIV services: by 2025, less than 10% of countries have punitive laws and policies that affect people living with HIV and marginalized populations; less than 10% of people living with HIV and key populations experience stigma and discrimination; and less than 10% of people living with HIV, women and girls and key populations experience gender-based inequalities and gender-based violence.

“The 95s” call for 95% testing, treatment and viral suppression targets: 95% access to combination prevention services; 95% access to sexual and reproductive health services; and 95% coverage of services for eliminating vertical transmission.

The integration target calls for 90% of people living with HIV to receive preventive treatment for tuberculosis and 90% of people living with HIV or at increased risk of HIV to be linked to integrated services for their overall health, including for mental health, gender-based violence, sexual reproductive health and rights, and communicable and non-communicable diseases.

Implementation of PMTCT programme in Malaysia

Malaysia implemented the prevention of mother-to-child transmission (PMTCT) programme for HIV in 1997 by introducing antenatal screening for HIV and syphilis. The programme focuses on early detection and treatment of HIV for mothers and babies, safer delivery modes, and safer infant feeding practices. It also includes timely commencement of antiretroviral therapy for women living

with HIV and early neonatal follow-up for HIV (8). The free antenatal HIV screening programme caters to all women. This has reduced the number of babies born with HIV. The programme has been extended to private clinics and hospitals. To further strengthen PMTCT, monitoring of infants living with HIV includes information on their general well-being, such as immunization status (8, 9).

In 2000, HIV antibody testing for infants was introduced. The HIV-DNA polymerase chain reaction (PCR) test was established in 2004 to diagnose HIV in babies delivered by women living with HIV. PCR testing should be carried out on all babies exposed to HIV at birth and then six weeks later. When a baby exposed to HIV has two concordant early infant diagnosis positive results, it is considered a new paediatric HIV infection (8).

Since 2013, according to HIV programme statistics, vertical transmission of HIV in Malaysia has fallen to below 2% that is one of the elimination targets set by the World Health Organization (WHO). When using Spectrum v5.754, a similar trend of transmission was observed, with the rate falling from 2.38% in 2015 to 1.99% in 2018.

Achievement of EMTCT in Malaysia

The mother-to-child transmission rate is one of the impact indicators of the elimination of mother-to-child transmission of HIV (EMTCT). Malaysia received the EMTCT validation certificate for HIV in October 2018, making it the first country in the WHO Western Pacific Region to do so. This achievement highlights Malaysia's strengths in the response to HIV, the process that led to EMTCT validation, and the difficulties and opportunities recognized to maintain and strengthen the country's efforts (10).

Several aspects have been credited for this success: strong political commitment; universal health coverage of the public healthcare system and primary health care; integration of PMTCT in maternal and child health services; HIV prevention and control programmes; an effective monitoring process for infants exposed to HIV; diagnostic service procurement and quality assurance; HIV partner notification and contact tracing; surveillance, monitoring and evaluation systems; and community engagement in local government (10).

The success of EMTCT was influenced by the wide-ranging implementation of the PMTCT programme, including a comprehensive antenatal package starting with the screening of antenatal women for HIV. PMTCT strategies include early detection and treatment of HIV for mothers and babies, safer modes of delivery, safer infant feeding practices, timely commencement of antiretroviral therapy for women living with HIV, and early neonatal follow-up (8).

Rights, stigma and discrimination in healthcare settings

The right to sexual and reproductive health is an integral part of the right of everyone to the highest attainable standard of physical and mental health. It includes the interrelated and essential elements of the availability of facilities, goods and services to realize the right to sexual and reproductive health. It also includes physical accessibility, affordability and provision of information for all people and all groups, without discrimination and free from barriers; acceptability and respect of the culture of individuals, minorities, peoples and communities; and sensitivity to gender, age,

disability, sexual diversity and lifecycle requirements. Services must be of good quality, evidence-based, scientifically and medically appropriate, and up to date (11).

All women, including women living with HIV, deserve equal human rights. Forcing a person to have an HIV test without their consent is a violation of their human rights. According to the Malaysia Stigma Evaluation Survey (MySES) report, only 3% of women were aware of this, and only one woman had exercised her right to refuse an HIV test. Almost half of women know there are laws to protect them. Among the actions people living with HIV have taken for their rights are supporting each other, participating in campaigns, educating about HIV-based stigma and discrimination, and encouraging community and political leaders to take similar actions (12).

In many countries, although the law is against any form of discrimination in the delivery of health care for people seeking healthcare services, healthcare settings are still a source of stigma and discrimination for many people living with HIV. Clients may experience avoidance of physical contact, delays in or lack of treatment, inadequate care, neglect and harassment, all of which infringe on the human rights of people living with HIV. HIV-related stigma and discrimination in healthcare settings are often exhibited through healthcare providers taking unnecessary precautions (e.g., double-gloving, wearing masks), use of judgemental or insensitive language, and lack of informed consent and confidentiality. This may be attributed to misconceptions and fears about HIV transmission (13).

Eliminating HIV-related stigma and discrimination is pivotal in promoting health-seeking behaviours and improving the lives of people living with HIV and their children. Achieving the validation of EMTCT is a laudable accomplishment for Malaysia. Despite having better access to healthcare services, women living with HIV are still marginalized and experience stigma and discrimination within healthcare settings. This can precipitate the provision of poor-quality care and delivery of services to women living with HIV.

Stigma is a barrier to HIV prevention, treatment and care. It can result in women presenting late for antenatal check-ups, poor adherence to antiretroviral therapy, and loss to follow-up (10). In East Peninsular Malaysia, 50% of participants said they experienced internal stigmas, such as loss of self-assurance, or discriminatory remarks from non-family members, and chose to hide their HIV-positive status. Most participants were satisfied with their healthcare services, but most were unaware of existing policies that protect women living with HIV (14).

Rationale of the research

GVAC recommendations related to sexual and reproductive health and rights and service access among women living with HIV include the following:

- a) Ensure informed consent and confidentiality in laws, policies, standards of care, and HIV prevention, testing, counseling and treatment.
- b) Review and revise policies, standards of care and practices around infant feeding options and delivery methods for women living with HIV according to WHO guidelines.
- c) Align Malaysian policies and standards of care for voluntary HIV testing with the WHO Consolidated Guidelines on HIV Testing Services (15). Develop legislation, policies and standards of care that prohibit mandatory HIV testing in all settings, including as a prerequisite for marriage. Develop and implement training for healthcare providers. Inform

GVAC of existing training modules, training coverage, standards of practice, and protocols regarding voluntary testing and informed consent.

- d) Ensure Malaysian policies and standards include voluntary partner notification and maintain the anonymity of clients and their partners.
- e) Ensure availability of guidelines on counseling for violence prevention and services for survivors of intimate partner violence.
- f) Ensure the sexual and reproductive rights of women living with HIV, including the right to contraception and other reproductive health services, align with those of all other women. Carry out an independent assessment of current practices (including forced sterilization) in collaboration with and guided by key community organizations. Ensure services are based on appropriate clinical standards and provided in a way that respects and fulfils human rights.

Malaysia is scheduled to have a GVAC country visit to take stock of the progress made on human rights and review the validation of EMTCT of HIV in the fourth quarter of 2021. The assessment is focused on past GVAC recommendations made at the time of validation and mid-term review in 2019.

Engagement with community supporters

Participation of communities in developing and implementing HIV programmes is critical to provide health care to people from key populations and people living with HIV. A country's AIDS response should involve people living with HIV, key population communities, national stakeholders and civil society organizations. The Global AIDS Strategy 2021–2026 recommends people living with HIV and key population communities are at the centre of the AIDS response (7). Community-based organizations provide peer counselling in the community, organize fundraising programmes, and act as links between healthcare providers and people living with HIV to provide and promote information about interventions and treatment programmes. Effective community engagement can be measured by the increase of awareness and involvement in HIV-related activities, processes and decision-making.

The engagement of community supporters in research should follow the principles recommended by the HIV/AIDS Network Coordination (16):

- a) Set clear goals to meet the needs of the population and strengthen the community's role and capacity.
- b) Learn about the community, especially its social and cultural contexts, and predominant attitudes, perceptions and practices.
- c) Foster transparency by encouraging people from the community to express themselves independently during the community engagement process.
- d) Build partnerships and trust with community stakeholders to create change, build mutual trust and improve health.
- e) Provide and promote capacity-building to sustain community engagement.
- f) Maintain a long-term commitment.

Research objectives

General objective

To explore the views and experiences of women living with HIV in Malaysia regarding access to healthcare services, sexual and reproductive health and rights, and stigma and discrimination, and to provide practical recommendations to stakeholders.

Specific objectives

- a) To explore the experiences and barriers faced by women living with HIV in Malaysia in relation to access to healthcare services in PMTCT settings, particularly the availability, accessibility, acceptability and quality of healthcare services.
- b) To explore the experiences of women living with HIV in Malaysia in relation to sexual and reproductive health and rights, particularly informed consent and confidentiality, gender-based violence, infant feeding options, delivery methods and contraception.
- c) To explore the experiences of women living with HIV in Malaysia in relation to stigma and discrimination, particularly in healthcare settings.
- d) To explore the views of healthcare providers and to propose practical recommendations to stakeholders to address access to healthcare services, sexual and reproductive health and rights, and stigma and discrimination among women living with HIV in Malaysia.

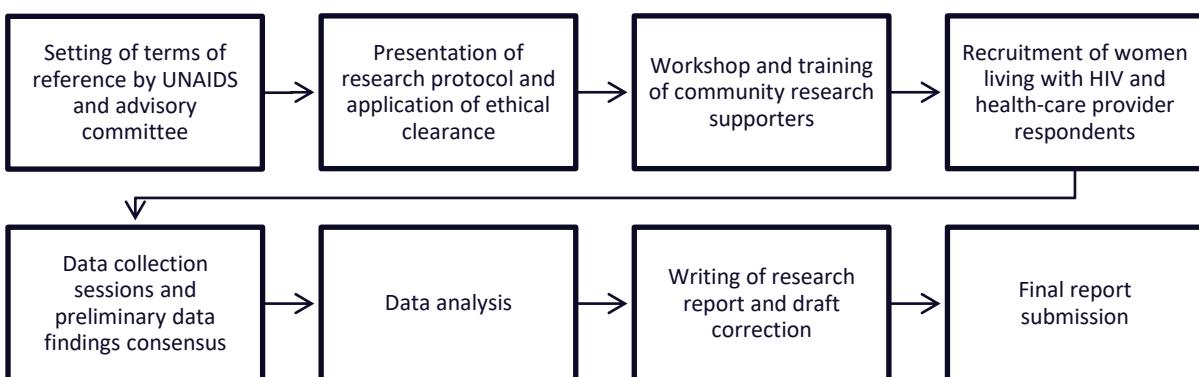
Methodology

Introduction

The UNAIDS Regional Office for Asia and the Pacific funded and coordinated to support the research. A regional multistakeholder advisory committee was formed from key stakeholders of the HIV response at the national and regional levels, civil society, women living with HIV, academia, and the Ministry of Health Malaysia to provide strategic guidance and support to the research team.

The Universiti Sains Malaysia research team was selected and invited to present the research protocol to the advisory committee on 29 July 2021. The Network of Women Living with HIV in Malaysia (WAPOMA), Persatuan Wahidayah Malaysia (PEWAHIM), and the International Community of Women Living with HIV Asia Pacific (ICWAP) along with other advisory committee members contributed to the development of the research protocol. The concerns and suggestions of the advisory committee, especially by civil society and women living with HIV community members, were helpful and constructive and guided the appropriate amendments made by the research team before the protocol was approved. The question guide to be used in the actual research was finalized by early August 2021. This assessment research was completed within three months of approval of the research protocol (Figure 1).

Figure 1. Research plan flowchart



Research timeline

The study lasted 12 weeks, from 24 July to 16 October 2021 (Annex 1). After the protocol was submitted and presented to the regional multistakeholder advisory committee, a grant application to the ethics committee was submitted for ethical clearance. Following a training workshop and review of research tools, 27 focus group discussions and in-depth interviews were conducted over 5 weeks. Inductive data analysis was carried out simultaneously with data collection. By the first week of October 2021, the first draft report for the study was ready. By the middle of October 2021, the final report was submitted to the regional multistakeholder advisory committee for review and verification.

The daily and weekly team plan is detailed in Annex 2.

Ethics, confidentiality and data security

Ethical approval for the study was granted by two ethics committees. The Human Research Ethics Committee of Universiti Sains Malaysia granted clearance on 11 August 2021 (USM/JEPeM/21070517; see Annex 3) before the pilot study was conducted. The Medical Research and Ethics Committee, Ministry of Health Malaysia granted clearance on 2 September 2021 (NMRR-21-1583-60936 IIR; see Annex 4). The research team is independent, has no conflicts of interest regarding the study, and is not involved with any HIV-related projects with the Ministry of Health Malaysia.

The researchers kept the information confidential. The research transcriber, research officer and community research supporters provided written declarations to maintain confidentiality and nondisclosure (see Annexes 5–7). Data from the study did not identify individuals and were published only to share knowledge. The original records could be reviewed by the researchers, the ethical review board for the study, and regulatory authorities to verify the study procedures or data.

Field notes and recordings of all sessions were kept on a hard drive offline. Only soft copies of raw data were stored. The information was held and processed on a computer in the principal investigator's office at the Women's Health Development Unit, Universiti Sains Malaysia. All shared online data related to the study have been deleted. Only research team members and UNAIDS were authorized to access the data through the principal investigator.

Vulnerability of participants

The researchers understood the sensitive nature of people living with HIV and stigmatization, which is heavily attached to the condition. A more concerning issue is the vulnerability of the participants living with HIV. The researchers protected the identity of all participants. Participants were invited to join the study by peer community research supporters. If a woman declined to be contacted by a community research supporter, her healthcare provider contacted her. The introductory scripts used to recruit women living with HIV are shown in Annexes 8 and 9.

Healthcare providers were contacted by the Universiti Sains Malaysia research team to act as participants. The small number of senior doctors means they may be identifiable; to protect the identity of all participants, they were asked to select pseudo-names, which the research team used throughout their engagement, including in focus group discussions. If context-specific information was needed (e.g., type of employment), the information was replaced with an alternative of equal value or status. Participation in the study was voluntary and based on informed consent, and the right to withdraw from the study at any time was guaranteed. The researchers emphasized that they are independent and have no association with or conflict of interest to healthcare providers.

Verbal consent was taken before the in-depth interviews and focus group discussions. Participants were assured of confidentiality in the recorded Zoom sessions. Names and identities were not exposed, and only pseudo-names were used. In quotes, participants were identified only by their participant number and the session they participated in. If a participant developed any stress due to an interview, they were referred for appropriate medical management if needed.

Annexes 10 and 11 show the participant information sheets.

Training of community research supporters

The research team comprised researchers from Universiti Sains Malaysia and community research supporters from community and civil society organization networks. The researchers worked together, from the first workshop on 10 August 2021 until completion of the final report in October 2021. A series of workshops and training sessions on data collection and analysis were held to ensure community research supporters understood the research process (Table 1).

Table 1. Workshops and training sessions for community research supporters

Session	Topic	Date	Duration
Workshop 1	Introduction to qualitative research and detailed research work plan	10 August 2021	Full day
Pilot session for focus group discussion	Pilot session with participants from the group of postnatal women living with HIV	14 August 2021	Half day
Workshop 2	Data management: how to make sense of data and basics of data analysis	29 August 2021	Half day
Workshop 3	Data collection: training for moderator	3 September 2021	Half day
Hands-on training session on data collection	Data-collection sessions with a Universiti Sains Malaysia researcher as observer	5 September 2021	Full day

Weekly work plan

The timeline for the research was agreed with the advisory committee. Data collection and submission of the draft report were a week later than agreed. The research team planned details of research activities weekly (Table 2). A team meeting was held every Sunday morning before the scheduled data-collection session to discuss the plan for the week and any updates. The team identified the members to be moderators and observers in each session. Meetings after every data-collection session allowed the moderators and observers to share their findings with the rest of the team and reach consensus on the main factors. Annex 12 shows the attendance log of the research team.

Table 2. Research team weekly schedule

Work plan	Activity	Duration
Weekly Sunday meeting	Plan for weekly sessions and confirm participant lists	2 hours
For each data-collection session	Confirm moderator, co-moderator and observers	1.5–2.5 hours

After every data-collection session	Validate preliminary findings	1 hour
Weekly commitment	10–12 online interactions session a week	6 half-days a week

A pilot data-collection session was held on 14 August 2021 using Zoom to check the questions were appropriate, to estimate the time required, and to serve as a test for technical issues. The session was delayed for about 15 minutes to allow participants to join and adjust their audio. Participants were asked to mute their audio unless they were speaking, and for only one person to speak at any time.

Overall, the session went smoothly, with only minor audio interruptions. The moderator was able to ask questions and elicit responses from multiple participants. All participants contributed to the questions asked. Some minor changes to the questions made them easier to understand. The session lasted about two hours.

Study design

A qualitative study was conducted as the epistemological foundation to address the research objectives. Qualitative approaches stem from constructivism philosophy, which proposes that not all knowledge can be measured but can be understood. An important aspect of this is the subjectivity of the social world, where there is no single reality but multiple realities for any phenomenon. Qualitative approaches focus on participants' real-world experiences (17, 18). The researchers sought to engage women living with HIV and understand their experiences. They engaged with participants using in-depth interviews and focus group discussions. The use of open-ended questions in both data-collection methods allowed participants to express themselves in their own words, which would be difficult to attain using the closed-ended questions of quantitative methods.

Study area

Malaysia is divided into five regions—Central, North, South and East Peninsular Malaysia, and East Malaysia (Table 3). Participants were recruited from all states and territories from all regions to capture as many voices as possible.

Table 3. Regions of Malaysia

Region	States and territories
Central Peninsular	Kuala Lumpur, Negeri Sembilan, Putrajaya, Selangor
North Peninsular	Kedah, Penang, Perak, Perlis
South Peninsular	Johor, Melaka
East Peninsular	Kelantan, Pahang, Terengganu
East Malaysia	Sabah, Sarawak

Study population

The study recruited participant from two categories: women living with HIV and healthcare providers.

One of the key aspects of PMTCT programmes and services are the identification of HIV in antenatal women to prevent vertical transmission (19). To foster a women-centred approach to EMTCT, sexual and reproductive health rights and services within the context of PMTCT must be strengthened. The study aimed to illustrate the experiences and health needs of women living with HIV at various stages of their lives. Participants included antenatal women living with HIV, postnatal women living with HIV, and other women living with HIV. Participants were selected to acknowledge the diversity of experiences that may be linked to social and societal determinants of health, such as race, ethnicity and location of health facilities.

The study recruited healthcare providers directly involved in care for women living with HIV, including medical doctors, allied health workers and counsellors. Focus group sessions for healthcare providers were conducted after completion of all data-gathering activities for women living with HIV to allow triangulation of data.

Only 30% of women living with HIV in Malaysia engage with a support group or community and civil society organization network in the community (12). The study used two sources to recruit women living with HIV as participants: those engaging with community networks and receiving healthcare services, and those who are not engaging with community networks but receiving healthcare services. The source population for healthcare providers was the Malaysian health service.

Inclusion criteria

Women living with HIV and healthcare providers fulfilling the following inclusion criteria were invited to participate in the study:

All participants

- a) Aged 18 years or over.
- b) Malaysian citizen.
- c) Able to communicate well in Bahasa Malaysia or English.
- d) Has a smartphone and internet access. (The community support researchers or AIDS officers at study locations provided technical assistance for participants who needed it)

Women living with HIV

- a) Women living with HIV who used any healthcare services between January 2018 and July 2021.
- b) Antenatal women living with HIV currently using any healthcare services.
- c) Postnatal women living with HIV who gave birth between January 2018 and July 2021.

Healthcare providers

- a) Doctors, nurses and counsellors providing services to women living with HIV between January 2018 and July 2021.
- b) Minimum of five years' experience in providing services to women living with HIV.

- c) Involved at state or district level.

Sampling method and recruitment

All participants who fulfilled the selection criteria were purposively sampled. The maximum-variation technique was used to ensure a wide spread of socioeconomic groups, marital status, age, ethnicity, and geographical location. The sample included women engaging with networks of women living with HIV and those who were not part of such networks. Potential participants with networks were invited via their networks while those without were invited by community research supporters or the service providers and formally recruited by the study team. We ensured participants voluntariness by reiterating their freedom to participate and withdraw, confidentiality of the data and independence of the study team from the health service providers.

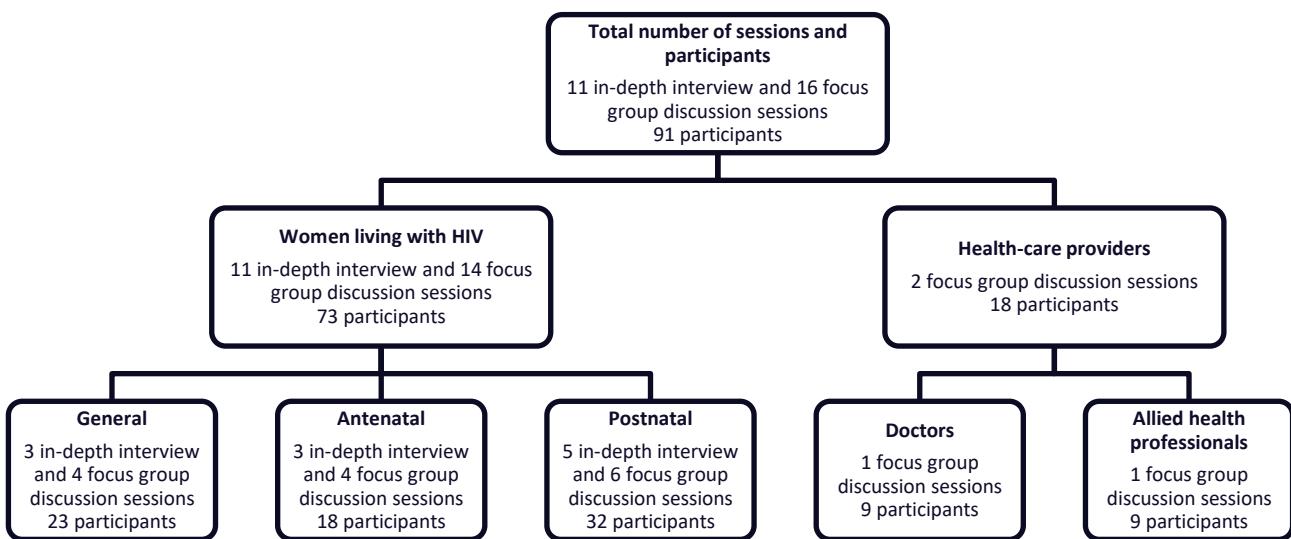
Sessions and participants

In qualitative research, the number of samples is influenced by saturation. Saturation is achieved when there is no new information emerging from the data-collection sessions. Usually, a few data-collection sessions from the same participant category are required to achieve saturation. A total of 27 sessions (11 in-depth interviews, 16 focus group discussions) were held with 91 participants, and there is a good possibility that saturation was achieved (Figure 2).

A total of 73 women living with HIV participated in 14 focus group discussions and 11 in-depth interviews. There were four or five participants in each focus group discussion.

Sessions with healthcare providers were conducted after completion of all sessions with women living with HIV to allow triangulation of data and to clarify any contradicting information. Two focus group discussions were held with healthcare providers, with nine participants in each group.

Figure 2. Distribution of sessions and participants



Recruitment process for women living with HIV

Three community research supporters from the community and civil society organization network were part of the research team and fully involved in the recruitment of participants. Women living with HIV who agreed to be participants were briefed, invited to be part of the research, and given an appointment to join an in-depth interview or focus group discussion. If a woman living with HIV refused to be contacted by a community research supporter, the research team from Universiti Sains Malaysia contacted the woman and formally invited her. Annexes 13 and 14 show the forms used to collect the background details of women living with HIV.

Recruitment process for healthcare providers

Healthcare providers from each of the five regions were invited to participate in focus group discussions. There was at least one doctor, one nurse and one counsellor from each region. Participants were briefed, invited to be part of the research, and given an appointment to join an in-depth interview or focus group discussion.

Data-collection sessions

Data-collection sessions ran from 14 August 2021 to 17 September 2021. On average, five sessions were scheduled for each week, usually with only one session a day. All sessions were conducted using Zoom. After each session, all research team members had a discussion to reach consensus on the findings. Sessions with healthcare providers were conducted after all sessions for women living with HIV were completed. Annex 15 shows the details of the data-collection sessions.

Each category of participants was asked questions from each domain to elicit detailed responses (Table 4). All except one session (with doctors) were conducted in Malay. All participants consented for the sessions to be recorded and transcribed verbatim. In-depth interviews took about an hour, and focus group discussions about two hours. Before each session, the researchers explained the research objectives and obtained verbal consent from each participant. Within a day of completing the session, participants received an honorarium and customized e-card for their participation. Feedback from participants was translated (Annex 16).

Table 4. Domains and question guide for women living with HIV

Domain	Number of questions		
	General	Antenatal	Postnatal
A Experiences regarding access to healthcare services (focusing on PMTCT services)	4	4	4
B Experiences regarding sexual and reproductive health and rights	3	4	6
C Experiences regarding stigma and discrimination	3	3	4
Total number of questions	10	11	14

A set of guide questions were constructed and discussed by the researchers based on the three domains of interest: access to healthcare services, sexual and reproductive health and rights, and stigma and discrimination (Table 5). General questions were posed to all the women living with HIV, and more specific questions were posed to the antenatal and postnatal women living with HIV (Annexes 17–24). These questions were agreed by the Research Advisory Committee and approved by the Human Research Ethics Committee of Universiti Sains Malaysia and the Medical Research and Ethics Committee Ministry of Health Malaysia.

Table 5. Question guide

Category			Domains and questions
Experiences regarding access to healthcare services (focusing on PMTCT services)			
General	Antenatal	Postnatal	Would you like to tell me about your experiences in accessing healthcare services?
			Can you tell us about any barriers you have faced in accessing healthcare services?
			What are your experiences in relation to your HIV treatment and medicines?
			How satisfied are you with your health care?
Experiences regarding sexual and reproductive health and rights			
General	Antenatal	Postnatal	Can you tell me about your experiences as a woman living with HIV in relation to your sexual and reproductive health and rights?
			What were your experiences in relation to your initial HIV testing?
			What are your experiences in relation to accessing contraception?
			What were your experiences in relation to antenatal booking and services to prevent your baby from being infected with HIV?
			What was your experience during childbirth?
			What was your experience in relation to feeding your newborn baby?

Experiences regarding stigma and discrimination in accessing healthcare services		
General	Antenatal	Postnatal
		What are your day-to-day experiences as a woman living with HIV?
		What is the attitude of society towards people living with HIV and key populations, including people who use drugs, sex workers, transgender people, and gay men and other men who have sex with men?
		How can society help women living with HIV to address stigma and discrimination?
		What is your experience of being in a situation where you were asked why you do not breastfeed your baby?

Data analysis

Data analysis was done in parallel with transcribing the interviews. All recordings from the sessions were transcribed verbatim. The research team reviewed the transcripts to develop a coding frame. The key topics and issues emerging from the data were identified. Thematic charts were devised, and data from each in-depth interview and focus group discussion were summarized under each topic area. A six-step process was followed in the thematic analysis (20):

- a) Familiarization with the data: the researchers read each transcript several times to become familiar with the information.
- b) Coding: codes were generated to identify important features of the data in relation to the research questions. Initial codes were compared with those that emerged from subsequent transcripts to facilitate the development of conceptual categories.
- c) Searching for themes: relevant data were collated to each theme, and the researchers reviewed the viability of each theme.
- d) Reviewing themes: the themes were refined by splitting, combining or discarding data.
- e) Defining and naming themes: the researchers determined the scope and focus of each theme and agreed on a name for each.
- f) Writing up: the narrative and data extracts were combined, and the analysis was put in the context of the existing literature.

Field notes were written after each session to summarize the researchers' and community research supporters' impressions and document significant findings. The community research supporters' experiences in dealing with relevant situations were studied. The transcripts were reviewed with field notes and relevant literature during the data analysis to gain insights into potential patterns. The field notes were used as supporting information to explain discussions when needed.

Rigour and trustworthiness

To measure research quality, rigour is essential to ensure the results are as relevant and trustworthy as possible (21). This study exercised rigour through triangulation and audit trails. Triangulation entails using multiple strategies including use of the experiences of the community research supporters to increase understanding and reliability of the research. Data were triangulated using in-depth interviews and focus group discussions. The researchers read all the transcripts, agreed on the main findings, and documented field notes for each session.

Prolonged engagement of the researchers in the field ensured the findings reflected what was happening in reality. The researchers kept records of all stages of the research, including their

decisions and the thinking behind them. Writing occurred throughout the study to ensure ideas and their context were captured in a timely fashion.

During the data-collection sessions, if a participant did not understand a question, the question was rephrased. No comments or gestures were made by the researchers since this could create bias in the participants' responses. The maximum-variation sampling strategy was used to ensure a wide range of participant characteristics were represented, including from people in hard-to-reach communities.

Results and discussion

Participants' characteristics

Participants' details are shown in Annexes 25 and 26.

Sociodemographic characteristics of women living with HIV

A total of 73 women living with HIV were recruited (31% general, 25% antenatal, 44% postnatal; Table 6). The majority were diagnosed with HIV before 2018 (80%), but 15 had been diagnosed in the past 3 years (1 general, 7 antenatal, 7 postnatal). The East Peninsular region made up the highest proportion of participants (33%), and the South Peninsular region the lowest (8%). The mean age was 33.8 years (range 18–58 years, standard deviation 8.7). Most of the participants were of Malay race (77%).

Table 6. Sociodemographic characteristics of women living with HIV (*n* = 73)

Category	<i>n</i> (%)
General	23 (31.5)
Antenatal	18 (24.7)
Postnatal	32 (43.8)
Region	<i>n</i> (%)
Central Peninsular	16 (21.9)
North Peninsular	18 (24.7)
South Peninsular	6 (8.2)
East Peninsular	24 (32.9)
East Malaysia	9 (12.3)
Year of diagnosis	<i>n</i> (%)
Before 2018	58 (79.5)
2018–2021	15 (20.5)
Race	<i>n</i> (%)
Malay	56 (76.7)
Chinese	5 (6.9)
Indian	6 (8.2)
Other	6 (8.2)
Age group (years)	<i>n</i> (%)
< 20	3 (4.1)
20–29	24 (32.9)
30–39	30 (41.1)
40–49	12 (16.4)
≥ 50	4 (5.5)

Using the maximum-variation technique, the study recruited women from key populations (female sex workers, women who use drugs), women from marginalized groups (adolescent girls, single mothers, women living in shelters), and women who contracted HIV through vertical transmission or blood transfusion.

Education and employment status of women living with HIV

A large proportion of the women had secondary or higher education (74%). Many were unemployed or homemakers (67%). About 29% were in active employment, with 10% in white-collar professions (Table 7).

Table 7. Education and employment status of women living with HIV ($n = 73$)

Highest level of formal education	<i>n</i> (%)
Primary	3 (4.1)
Secondary	44 (60.3)
Tertiary	10 (13.7)
Unavailable	16 (21.9)
Type of employment	<i>n</i> (%)
Unemployed or homemaker	49 (67.1)
Self-employed	7 (9.6)
Blue-collar	7 (9.6)
White-collar	7 (9.6)
Retired	1 (1.4)
Unavailable	2 (2.7)

Marital status and children of women living with HIV

About 84% of the participants were married, 14% did not have any children, and 23% had at least 3 children (Table 8).

Table 8. Marital status and children of women living with HIV ($n = 73$)

Marital status	<i>n</i> (%)
Single	4 (5.5)
Married	61 (83.6)
Divorced	2 (2.7)
Widowed	6 (8.2)
Number of children	<i>n</i> (%)
0	10 (13.7)
1	23 (31.5)
2	23 (31.5)
≥ 3	17 (23.3)

Spouses of women living with HIV

A total of 61 participants reported being in a marriage (84%). Of these, a majority were in serodiscordant relationships (71%). The average age of the participants' spouses was 34.5 years (range 22–67 years, standard deviation 8.3). A large proportion of the spouses had secondary or higher education (62%) and were in employment (74%; Table 9).

Table 9. Spouses of women living with HIV (*n* = 61)

Age (years)	n (%)
20–29	9 (14.8)
30–39	25 (40.9)
40–49	9 (14.8)
≥ 50	1 (1.6)
Unavailable	17 (27.9)
Highest level of formal education	n (%)
Secondary	30 (49.2)
Tertiary	8 (13.1)
Unavailable	23 (37.7)
Type of employment	n (%)
Unemployed	3 (4.9)
Self-employed	11 (18.1)
Blue-collar	24 (39.3)
White-collar	10 (16.4)
Unavailable	13 (21.3)
HIV status	n (%)
Positive	16 (26.2)
Negative	43 (70.5)
Unavailable	2 (3.3)

Healthcare providers

Of the 18 healthcare providers who participated in the study, 9 were doctors and 9 were nurses or counsellors. Most were working in the Central Peninsular region (28%). Most were women (89%). The average age was 41.3 years (range 32–60 years, standard deviation 6.7). About 61% had more than 10 years' professional experience (Table 10).

Table 10. Sociodemographic characteristics of healthcare providers (*n* = 18)

Category	n (%)
Doctor	9 (50.0)
Nurse or counsellor	9 (50.0)
Region	n (%)
Central Peninsular	5 (27.8)
North Peninsular	3 (16.7)
South Peninsular	4 (22.2)
East Peninsular	4 (22.2)
East Malaysia	2 (11.1)
Sex	n (%)
Female	16 (88.9)
Male	2 (11.1)
Age (years)	n (%)
30–39	9 (50.0)
40–49	7 (38.9)
≥ 50	2 (11.1)
Race	n (%)
Malay	15 (83.3)
Chinese	1 (5.6)
Indian	2 (11.1)
Professional experience (years)	n (%)
5–10	7 (38.9)
> 10	11 (61.1)

Context and availability of HIV-related healthcare services

The Committee on Economic, Social and Cultural Rights and the Committee on the Elimination of Discrimination against Women state that women's right to health includes their sexual and reproductive health, and countries must respect, protect and fulfil this (22). The Special Rapporteur on the right to health maintains that women are entitled to reproductive healthcare services, goods and facilities that are available in adequate numbers, are accessible physically and economically, are accessible without discrimination, and are of good quality.

Healthcare services for the women in this study were available in hospital and primary care settings (Table 11). With the exception of obstetrics and gynaecology wards, all clinics operated during office hours. All treatments, medicines and contraception services at these facilities were provided free of charge. Each clinic served a distinct purpose, but shared care between healthcare providers was common—for example, some women attending infectious diseases clinics also attended primary care clinics.

Access to healthcare services was inconvenient. Women had to seek care from multiple clinics due to the structure of the healthcare system. There are no one-stop centres in Malaysia providing integrated and comprehensive services for women living with HIV.

The settings mentioned most frequently by the women were infectious diseases clinics, outpatient clinics, maternal and child health clinics, and obstetrics and gynaecology clinics and wards.

Table 11. Hospital and primary care settings for HIV-related care

Hospital	Primary care
Infectious diseases clinics	Outpatient clinics
Medical outpatient clinics	Maternal and child health clinics
Obstetrics and gynaecology clinics and wards	Community clinics
Paediatric clinics	

Infectious diseases clinics are located in tertiary hospitals and offer outpatient care for communicable diseases, including HIV. They are managed by infectious diseases specialists, medical doctors and nurse counsellors. They offer treatment, follow-up, medicines and counselling for all people living with HIV. Similar services are provided at outpatient departments, but prescriptions for second- and third-line antiretroviral therapy are available only at infectious disease clinics.

Second- and third-line antiretroviral medicines cost RM 700–3000 (US\$ 160–700) per month and are not subsidized by the Malaysian Government, except for antenatal women living with HIV. To ensure access to medicines, infectious diseases clinics advise non-pregnant women living with HIV who cannot afford to buy medicines to seek funding from the Department of *Zakat* (a government institution that distributes donations under Islamic law) and community and civil society organizations such as the Buddhist Tzu-Chi Merits Society or the Malaysia AIDS Council.

Appointments for infectious diseases clinics are scheduled two to four times a year, depending on health status. Some clinics have a dedicated day or specific rooms for people living with HIV.

Outpatient clinics and maternal and child health clinics are primary care facilities in rural and urban areas. They are usually situated in the same compound and led by a family medicine specialist. Outpatient clinics provide similar services to infectious diseases clinics and also offer premarital HIV screening for couples. Women living with HIV visit maternal and child health clinics for antenatal and postnatal care.

The healthcare system follows a shared-care model. People living with HIV may attend a number of sessions with an infectious diseases specialist and other sessions with a family medicine specialist.

For antenatal services, shared-care criteria are defined by the woman's risk. All high-risk antenatal women are followed up by obstetrics and gynecology specialists in a hospital. Medium-risk antenatal women (including those living with HIV, unless they have other risks) have shared care with obstetrics and gynaecology specialists and family medicine specialists. Low-risk antenatal women are cared for by family medicine specialists. Referral to an obstetrics and gynecology department can be made at any time if a woman's risk changes. Following delivery, women visit maternal and child health clinics for family planning services and childhood vaccinations.

During antenatal clinic visits, all women underwent routine rapid blood test screening for HIV and were given their Pink Books containing their health records. These books were tagged to show the risk of the pregnancy. A yellow sticker in the upper right-hand corner of the Pink Book indicates medium risk (which includes HIV and other diseases such as hypertension and diabetes mellitus). Sometimes "HIV" or "RVD" was written on the cover. This system was put in place to ensure appropriate management of obstetric risks and appointment categories.

Medical officers or obstetrics and gynaecology specialists advise on delivery. Obstetrics and gynaecology clinics do not run routine blood investigations for women living with HIV and rely on results from infectious diseases clinics.

After delivery, women living with HIV are admitted to a private room on a maternity ward. Lactation suppressors are prescribed before discharge for women who choose formula feeding, according to the national policy (14). Babies are screened for HIV, observed by paediatricians and prescribed prophylaxis; they remain under follow-up care at a paediatric clinic until age 18 months.

Women living with HIV take their babies for regular HIV screening at clinics and collect monthly supplies of infant formula if they choose not to breastfeed. Hospital dietitians usually manage the procurement and provision of infant formula, but there may be exemptions for women who prefer to collect their formula from an outpatient clinic or maternal and child health clinic or have it delivered to their home.

Comprehensive healthcare services are available, but access is often inconvenient. The Ministry of Health Malaysia is committed to ensuring access to healthcare services for all women living with HIV, as evidenced in the newly released Guideline to Strengthen Prevention of Mother-to-child Transmission of HIV and Syphilis (14). Decentralization of HIV treatment is slowly underway, demonstrated by the placement of family medicine specialists in most outpatient clinics and maternal and child health clinics.

With combined care and clinics under the Model of Good Care, women living with HIV now have more feasible care options and do not need to rely on infectious diseases clinics in tertiary centres. Infant formula and first-line antiretroviral medicines are available from outpatient department

clinics, maternal and child health clinics and community clinics. Availability of first-line antiretroviral medicines and lactation suppressors has been improved by allowing prescription by trained medical officers and family medicine specialists at outpatient department clinics and maternal and child health clinics.

Access to healthcare services and quality of care

Availability, accessibility, acceptability and quality of healthcare services are interconnected. HIV screening, counselling, family planning, mode of delivery, infant feeding and overall delivery were all investigated as part of access to healthcare services and quality of care.

Given the extensive history of PMTCT programmes in Malaysia, the availability of healthcare services is the domain where participants reported fewest difficulties. Availability of healthcare services is worthless, however, if the services are not accessible. Geographical accessibility and distance are major determinants of access to care. Women living with HIV have to attend regular follow-ups at multiple clinics, which poses financial, time and logistic barriers and can affect retention on treatment. Women living with HIV consider many factors when deciding which health facilities to use. Attending the nearest facility may seem the obvious decision, but most women choose facilities further away to protect their privacy. For some women, this creates further issues, such as financial constraints.

For the majority of women in Peninsular Malaysia, geographical barriers to care were minimal. As a result of the Ministry of Health Malaysia policy that a health facility should be made available within every 15-mile radius, most of the health facilities that the participants frequented were less than an hour's trip away. It may be possible, however, that selection of participants with internet access inadvertently excluded many participants with geographical barriers to care.

For some women, lack of access persists, especially for those who usually obtain care in other districts or states, which has become challenging during the COVID-19 pandemic. One participant defaulted on her treatment for five years because she had no transport to attend the clinic. After she conceived her third child, she transferred to another state and resumed her treatment at a clinic closer to her home. Buying her own car enabled her to maintain regular follow-up at the infectious disease clinic, and she is now fully adherent with her treatment.

A doctor in a rural area of Sabah described her clients' difficulties in reaching the clinic. Many missed treatments because they had no transport or travel costs were too high:

"[They are from a] very poor social background ... [The] majority are defaulters ... [They] don't even have money to buy rice ... We give them money out of our own pockets to enable them to come to the clinic" (H7S23).

Women living with HIV have to make complex, difficult decisions when juggling between comfort, personalization of care, privacy, confidentiality and distance. Some participants chose to use clinics away from their homes to avoid being recognized and stigmatized:

"If I were to get treatment near where I live, I am worried that people living in the same area would find out [my HIV status]" (R27S6).

“I received treatment from a clinic five to six kilometres from my home, but then I did not feel at ease. So, I made a decision in 2003 to transfer my care to Hospital Kuala Terengganu, even though it is 60 kilometres away” (R7S2).

Rescheduling appointments were generally easy, and telephone emotional support was available, demonstrating the availability of person-centred, coordinated care, support and treatment:

“I call the infectious diseases clinic and pour my feelings out” (R20S5).

Many participants spoke of being treated “like a family”, illustrating partnerships between them and their healthcare providers. Offering person-centred care was beneficial for healthcare professionals and clients. As engagement increases, there is a corresponding increase in staff performance and morale. One nurse counsellor said:

“At the infectious diseases clinic, we are not only counsellors, we are their friends, almost like their family” (H13S24).

The COVID-19 pandemic has led to access to care becoming more organized and systematic. Booking for antenatal care can now be done online to control the daily numbers of clients. Wearing facemasks during COVID-19 has made it less awkward for many WLHIV who wear masks to avoid infections or to protect their identity and avoid stigmatization.

There were acceptability issues with some healthcare services. Acceptability is the degree to which a service satisfies a person’s expectations and preferences—in this case, the responsiveness of the healthcare system. Some participants experienced violation of the “5 Cs” (consent, confidentiality, counselling, correct results, connection):

HIV screening was carried out without consent:

“When I was admitted for TB, they took my blood and then just told me that I have HIV” (R12S3).

Insensitive or inappropriate advice was given by untrained healthcare providers:

“I was a bit offended ... [The doctor said] once you have this disease, your chances of employment are limited” (R61S19).

Questionable HIV screening test results were not followed up by confirmatory tests. One WLHIV was presumed to be HIV-negative during booking and was left undetected and untreated during her first pregnancy:

“After 15 minutes, she retested me ... [The result] was negative ... so the nurse considered my previous test to be invalid and she did not refer me to the doctor. She booked me for antenatal follow-up and gave me the Pink Book” (R61S19).

The woman breastfed her baby and unknowingly transmitted HIV. The baby became ill at age three months and spent two months in intensive care and then died on the eve of Eid. Doctors were unable to diagnose the baby’s illness, which could have been avoided if the nurse in charge had followed the correct HIV testing protocol.

An integral part of PMTCT is the provision of post-test and follow-up counselling. Post-test counselling aims to help people deal with the results of their positive test and understand the services available. Follow-up counselling supports the prevention of transmission among serodiscordant couples and introduces women of reproductive age to PMTCT programmes. All the participants in the study were offered counselling after HIV diagnosis. The extent of follow-up counselling is not known as it was rarely mentioned during the interviews. Most of the women

thought counselling must be conducted by trained counsellors. All healthcare providers, however, regardless of whether they are trained as counsellors, have a role as informal counsellors, and participants may not realize they received follow-up counselling. Some participants made it clear they did not want follow-up counselling because they found their own ways to cope.

The women reported ease of access to PMTCT and healthcare services, including counselling and medicines, but thought the acceptability and quality could be improved. Most were warned of the side effects of antiretroviral medicines by doctors and pharmacists. Most experienced uncomfortable but not serious side-effects.

“When I first started taking the medicines, I always skipped some doses ... because initially, I experienced very bad hallucinations” (R9S2).

One participant experienced side-effects that drew attention from her colleagues:

“I needed to use the toilet frequently ... my colleagues asked me why I often frequented the toilet ... I have to take two pills at 11 am and two more pills at night ... but I did not take the morning dose—I took all four pills at night” (R60S18).

Many participants did not know they could ask to change medicines at walk-in sessions if their side-effects were severe.

One woman experienced side effects for three months until her body finally adapted to the medicines:

“I see the doctor every six months ... but after three months my problems have resolved on their own” (R29S8).

It is uncertain whether access and availability of preconception counselling were adequate since this was mostly offered by infectious diseases clinics. All the women demonstrated a general understanding of the role of CD4 count and viral load in safe pregnancy and mode of delivery. Younger women expressed the intention to have more children when the timing is right. This suggests they had appropriate access to information on reproductive health.

Some women became pregnant when their CD4 counts, and viral loads were dissatisfactory. By disregarding healthcare providers' advice on the appropriateness of conceiving with a poor CD4 count, some women put themselves and their children at risk.

“I asked the doctor if I could conceive. The doctor said I should avoid pregnancy as my condition was not optimum ... but after a few months, I was pregnant ... so the doctor was angry” (R28S7).

Access to first-line antiretroviral medicines and prophylaxis for newborn babies was perceived to be good and well-received. Participants seeking care at infectious diseases clinics received their antiretroviral medicines during their clinic sessions. Appointment dates for prescription refills were sent via text message. Medicines were obtained at drive-through pharmacies, by courier delivery (for a small fee), or at prearranged times from a dispensing pharmacist. There were no shortages of first-line medicines.

“We give them two months’ supply of medicines; three months’ supply is also possible; at times we even supply six months’ worth of medicines to clients working offshore” (H15S24).

Access to and affordability of second- and third-line antiretroviral medicines were problematic. The long-term costs of second- and third-line antiretroviral treatment can become an economic burden, even for people who can afford it initially.

“Even though I was a single mother, I could still afford to pay for my medicines ... but in the end, I could not afford the bills, so I decided to stop taking the medicines” (R67S21).

One woman was told to buy second-line antiretroviral medicines when her viral load was unresponsive to first-line treatment. She was from a low economic background, uneducated and overwhelmed by other issues, and finding extra resources to afford her treatment seemed futile. She stopped going to the clinic. Although the clinic reminded her to attend for treatment, she was not given any options to fund her treatment.

One participant said she had to pay for a pregnancy test and laboratory tests, but we were unable to corroborate this. These are usually provided free of charge by the health service. Most women had access to safe, effective and acceptable methods of family planning. Infectious diseases clinics provide condoms. Other reversible methods of contraception are available from maternal and child health clinics. Despite accessibility, participants expressed feeling embarrassed when requesting condoms at clinics.

“At times, I felt embarrassed asking for them, so I pretended that I was not ... I felt embarrassed because [the nurse] was older than me” (R28S7).

There was little negotiation of condom use between the participants and their spouses. Most of the participants used condoms inconsistently or not at all. Some women explained their HIV-negative partners’ refusal to use condoms as denial of risk, acceptance of fate, or a “way to express their love”.

Most women in the general group used natural contraception. Among postnatal women, there was an emphasis on low-maintenance methods such as implants and injection.

“I was afraid that my adherence to the [contraceptive] pill would be poor, so [the doctor] suggested that I took the injections as they were more convenient for me” (R29S8).

Some women received explanations and options that enabled them full autonomy to make informed choices, but some reported a level of paternalism.

“I wanted to use the pill, but the doctor said I must not ... that every three months I must get the injection” (R60S18).

“I think the doctors know what is best for us” (R50S16).

Access to free infant formula for women who chose not to breastfeed was almost always guaranteed, except for some isolated cases that occurred due to poor coordination of supplies. Women who depended on free formula were more likely to be from poor socioeconomic backgrounds. Access to services was hampered due to distance and costs. A limited number of brands were available because formula was contracted from a single supplier, and a number of women said the formula was not suitable for their babies. Healthcare providers said this was beyond their control. The health service made a limited choice as to comply with the Baby-Friendly Hospital Initiative of the organization.

Inconsistent advice on the mode of delivery from infectious diseases specialists, family medicine specialists and obstetricians created confusion for many women. CD4 monitoring was not available at primary care diagnostic laboratories, and some family medicine specialists were not able to ascertain viral load to inform the mode of delivery. The mode of delivery depends on the trajectory of the viral load up to the time of delivery, length of time on antiretroviral therapy, adherence issues and obstetric factors, and therefore should not be finalized until the expected date of labour.

"The obstetrics and gynaecology doctor asked me to decide between caesarean section and natural birth ... I asked her, don't we have to know about our viral load first? Even though the viral load has been suppressed, [the doctors] cannot guarantee that the risk of transmission will be zero ... whether it is natural birth or caesarean section, there will be a 2% chance [of HIV transmission]" (R41S12).

Women and healthcare providers agreed there were inconsistent standard operating procedures and conflicting advice regarding disposal of the placenta after birth. Some hospitals allowed mothers to take their placenta home, following strict protocols.

Testing for early infant diagnosis is run by the Institute of Medical Research virology laboratory. The turnaround time is supposed to be one to five days but may take up to six weeks. One woman said:

"[They] have taken the blood of my baby and said the results would be available in about a week's time ... after 10 days [my husband and I] phoned them up every day to find out about the test results ... they said the baby is OK and the results were not out yet. After the baby was discharged, they did not phone us—we were not told anything" (R42S13).

Most women complimented healthcare providers on the treatment they gave and described good relationships with their doctors and nurses. These relationships were established and maintained due to the continuity of care.

"Whoever cared for [the woman] when she was pregnant will also care for her after birth" (H14S24).

Quality of care varied by the type of clinic and healthcare provider. Infectious diseases clinics tended to be rated more highly than other clinics due to their specialized care, but one woman expressed her sadness over the treatment she experienced from an infectious diseases specialist who humiliated her in front of other doctors, nurses and patients:

"The door was open when he scolded me ... everybody can see ... he called the other doctors as well ... he said, 'Because of you I have wasted my time, just you alone are causing me headaches' ... and then he slammed the medicines hard on the table until the nurse came in to see what was happening ... He said, 'I am going to give you this last chance to comply with these medicines'" (R42S13).

The woman understood her non-compliance and poor insight were unhelpful, but nobody should be treated in such a degrading way.

Most women were pleased with the treatment they received from family medicine specialists and staff at maternal and child health clinics, although a minority of healthcare providers acted unprofessionally and were unkind or insensitive. Some healthcare providers attributed this to a lack of training, motivation and awareness. Such behaviours were isolated events or from individual

providers rather than organization-wide. The COVID-19 pandemic has also stretched resources more thinly.

Some women expressed dissatisfaction over sharing rooms with HIV-negative people. They felt they could not discuss their health problems fully without exposing their HIV-positive status.

“I think we should speak up about this, but [wards] may have problems with high number of clients and lack of available consultation rooms. They have to treat many clients ... we just have to accept it ... Even if I complain about it, they must have their own reasons for doing it” (R12S3).

Sexual and reproductive health and rights

Women’s sexual and reproductive health and rights are related to multiple human rights, including the right to life, the right to be free from torture, the right to health, the right to privacy, the right to education, the prohibition of discrimination (23), and the right to reproductive healthcare services, goods and facilities that are available in adequate numbers, are accessible, are acceptable, and are of good quality (24).

Some of the women felt they had to “accept things” in order to access healthcare services. Many WLHIV are in a difficult position due to their vulnerability and lack of power. Two overarching principles of sexual and reproductive health and rights—a woman-centred approach and an enabling environment (including women’s participation)—are essential for the health service to become great rather than good.

“I kept silent because I need [the nurse] to help save me and my baby” (R4SP).

Some women felt their rights were threatened, intentionally or unintentionally, which gave rise to stigma and discrimination. Many of the participants live their everyday lives defending such rights, especially the rights to privacy and confidentiality. Almost all the participants preferred to keep their HIV-positive status private, even from family members, and to disclose their status only to those who may be at risk in the course of looking after them.

“Our society is not yet that open-minded ... there is still stigma ... I feel that if you can hide [your status], that is better ... I think if there is no necessity to reveal the status, it should be kept a secret” (R5SP).

The participants described the constraints of family relationships as a result of accidental disclosure. Most of the women living with HIV contracted HIV from previous husbands or partners; a minority of cases were the result of vertical transmission. Most women found it easier to keep their status hidden by taking their medicines and retaining good health.

“I heed the advice of the nurses and doctors ... to take the medicines properly ... so that I am healthy and others can see me healthy ... [They] told me not to miss my doses. If I look weak, too weak to go to work ... people will think that I am ill” (R11S2).

Many of the women said healthcare providers asked in conversation how they contracted HIV, without understanding the sensitivity of the issue. This placed the women in a difficult situation, who had to choose between not answering or running the risk of being judged. In many cases, they felt this information was not essential to the provision of good-quality services, as some of the staff

were not involved directly in their care. Some women said their HIV-positive status was revealed to them in an insensitive way. Some described breaches of confidentiality, reception staff who gossiped about them, and staff using practices such as double-gloving.

“The doctor had already put on a pair of gloves, but the nurse told the doctor to put on three pairs of gloves” (R4SP).

Primary care centres are typically situated near to clients’ homes and staffed by local people. Many women expressed discomfort with this. One participant shared her experience about her late husband who was living with HIV and worked in the health service:

“My late husband was a healthcare staff member. When [his] friend [a member of staff at a primary care centre] heard that I was going to remarry, he phoned my future husband and told him that I am ill ... I don’t know how [he] knew, but I think all the healthcare staff knew the cause of death of my husband” (R6S1).

In this situation, the staff at the health centre supported the woman and advised her on actions she could take if she wanted to. It should be noted that this event occurred before 2018. We have highlighted the case to illustrate how the privacy of WLHIV can be breached and demonstrate the fears they have to live with every day.

The participants placed emphasis on the right to information and choice of contraception. The revised WHO guideline on contraceptive use states that WLHIV can use any form of reversible contraceptive method, and all options should be offered. A number of women chose not to use any form of contraception. The use of barrier methods such as condoms is widely advocated by healthcare providers, but they are not routinely used by the partners of WLHIV, who “leave it to the will of God”.

Many women denied any form of gender-based violence as a result of asking their partners to use condoms. Gender-based violence was also reported to be rare by the healthcare providers and community research supporters. This sensitive topic may be taboo, however. The fact these women were able to participate in this research suggests they were supported by their partners.

Decisions regarding contraception are usually negotiated between the client and the healthcare provider based on the context and the woman’s lifestyle. Most participants were informed and given a choice of methods, including condoms, the contraceptive pill, implants, injections, intrauterine devices and bilateral tubal ligation. If a particular method was not suitable, most women were told why it was not the best choice and given other options. At times, however, the personal views of healthcare providers clouded their decisions rather than respecting their clients’ wishes.

“I told the doctor that I don’t want any more children, one child is enough because I’m already 40 years old ... but the doctor did not agree ... she said I’m in good health, and then she also said that according to our religious beliefs, it’s best if we do as we should” (R50S16).

Some participants were confused about the management of their health, including whether they would have a normal or caesarean delivery. Decisions differed between infectious diseases clinics, obstetrics clinics and primary care clinics. Some participants were told normal delivery was possible if certain criteria are met, and others were told caesarean delivery was the only delivery method available. There should be a clear communication strategy among healthcare providers regarding

management of delivery for WLHIV, and complex decisions should be communicated effectively with the women, moving a step closer to empowering WLHIV and shared decision-making.

Another source of confusion is the management of the placenta after delivery. The Ministry of Health Malaysia guideline states that after delivery by a woman living with HIV, the placenta should be disposed of by the hospital according to standard universal precautions (14). In local cultural practice, however, many women in Malaysia prefer to take the placenta home and bury it. Most of the women understood the risk but wanted to be informed about how their placenta would be managed. Some women were given their placenta with specific instructions on how to manage it, but others were not given an explanation. One participant asked for her placenta but was told she could not have it because it had to be discarded. One participant said she was asked to sign a form regarding her placenta, but she was not sure what the form was for and she was not told what would happen to her placenta.

“They will manage the placenta on our behalf, we cannot take it home ... at the beginning of the antenatal booking, the nurse had explained it ... she asked my husband if it will be OK ... we have been informed earlier ... my husband said we are OK with it”
(R59S17).

A senior healthcare provider stated that his hospital protocol, which does not follow the Ministry of Health Malaysia guideline, is very clear: the placenta is cleaned by the hospital, packed securely, and handed to the family, with instructions not to open the package, to wear gloves, and to manage the placenta according to their cultural requirements. Another healthcare provider stated that in her hospital, the placenta is not given to the woman, but the woman is informed that the hospital will manage the placenta due to the high risk, in line with the guideline.

None of the women in the study breastfed their babies. All expressed fear of transmitting HIV to their babies. Some expressed disappointment at not breastfeeding, especially those who had breastfed other babies before they were diagnosed with HIV. One mother secretly used her sister-in-law as a wet nurse. Women who had used infant formula previously were more accepting of formula feeding. There appears to be a consensus that breastfeeding is not encouraged among WLHIV due to the risk of vertical transmission. Women with full understanding of the consequences and who chose infant milk formula were prescribed lactation suppressors.

Recent developments in breastfeeding by WLHIV elsewhere are not reflected in the national policy. A senior clinician reported that it is possible for a woman living with HIV to breastfeed her baby if certain criteria and procedures are followed. The discussion on alternatives to breastfeeding, such as wet nursing, with the involvement of religious experts, is ongoing. The national policy should be revised to ensure the rights of women to breastfeed their babies when circumstances allow (25).

Women must be asked for consent before undergoing any procedure. In all situations, consent was sought, and an explanation of the procedures was given. Decisions were usually negotiated between the woman and the healthcare provider. Two participants related instances where variations on consent took place, related to bilateral tubal ligation and caesarean section. Some women mentioned the need for spousal consent for bilateral tubal ligation and caesarean section. On further questioning, these women discussed the procedures and were supported by their spouses. Consenting procedures in Malaysia should be reviewed because all women have the right to decide what happens to their bodies. Limitations on hospital visits during the COVID-19 pandemic have meant only the women themselves have consented to these procedures.

An interesting finding was the informal role of healthcare providers in ensuring women's social rights. For WLHIV, aspirations for marriage and children may be difficult. Some healthcare providers supported their clients by counselling on their options and possible outcomes. In one centre, healthcare providers acted as "matchmakers" at the request and consent of the women. Although such a situation may not be encouraged by the health authority, the healthcare providers should be complimented for their informal role in meeting the social needs of their clients. The human rights agenda ensures the rights of the person are protected while allowing free choice for self-determination—in this case, an opportunity to be in a meaningful relationship while living with HIV.

Stigma and discrimination

HIV-related stigma and discrimination are well-known and documented. Stigmatization occurs in healthcare settings, as demonstrated in the MySES report (12) and by the findings of this study. Participants felt most comfortable at infectious diseases clinics. When stigma and discrimination occurred and were reported, actions were taken to overcome the situation.

Labelling during antenatal visits can lead to stigma and discrimination. Until recently, "HIV" was written on the cover of the antenatal Pink Book, but "RVD" is now used instead. Participants prefer this, as most other clients at the clinic do not know what RVD is.

"On my book, it was written RVD ... I think that is much safer than having [HIV] written" (R32S9).

Health services use colour-coded labels on the Pink Book to denote different levels of pregnancy risk. A yellow label denotes HIV. Although the same colour is used for hypertension and diabetes, the participants felt uncomfortable when other clients asked them about the label. Any form of labelling will eventually, directly or indirectly, break client confidentiality, and most participants thought it was unnecessary. If essential, labels should be placed inside rather than on the cover of the Pink Book.

Several healthcare providers unintentionally labelled their clients by using a particular room or nurse for WLHIV. Some WLHIV were placed in private rooms after delivery. Some participants felt this was discriminatory, but others considered being given a more comfortable room a blessing. Other WLHIV shared wards with HIV-negative women, but discrimination and stigmatization became obvious at mealtimes, when the women were served different food, with disposable containers and utensils.

"They served me food on polystyrene plates, and drinks were also served in polystyrene cups. So other people on the ward looked at me differently" (R68S21).

Some women were asked to change their own bedlinen while the staff changed other clients' beds. One participant revealed how she felt humiliated after disposing of a sanitary pad in the bin like the other women on the ward:

"[The nurse] asked me where did I put my sanitary pads ... Of course, I threw them in the bin. And then she said, OK, I will tell the cleaner to put the bin by your bed ... so that my pads could be disposed of separately" (R4SP).

One participant said she took action over her discriminatory treatment. With the assistance of a community and civil society organization, she reported the incident to hospital management. The management team investigated the incident and made necessary changes, including training staff on how to treat WLHIV.

One woman described how she was given a box of gloves to use when she wanted to touch her own baby:

"She asked me to put on gloves if I wanted to hold my baby. Why do I need the gloves? She had already prepared a box of gloves by the baby cot for me when I come, I have to put on the gloves there" (R4SP).

She complained to the ward sister, who told the staff to remove the box of gloves. The ward sister later arranged a briefing session to educate the staff on managing mothers living with HIV.

Discriminatory practices can have a huge impact: one woman has decided not to have any more children because of how she was treated. One healthcare provider said segregation and isolation of people living with HIV does not happen now, and to her knowledge the last time such an incident occurred was in 2016. The incidences of segregation and isolation reported by the women in this study, however, all occurred between 2018 and 2021.

The healthcare providers in the study emphasized the importance of treatment compliance, as non-compliance may result in the need to use second- or third-line medications. Some participants reported intolerance to their treatment at first. Most got used to taking the medicines, but not all women can tolerate the side-effects.

Some healthcare providers' actions regarding compliance were perceived as aggressive. One participant said she was shouted at and threatened during her consultation regarding treatment compliance. The healthcare providers in the study were experienced and showed passion, respect and dedication in caring for WLHIV. Most doctors aim to persuade their clients to adhere to treatment but resorting to the use of threats is well-documented, despite being shown to be ineffective. The healthcare providers in the study were asked about using threats, but they did not respond.

There are other ways that healthcare providers can try to ensure treatment compliance, including pill counts and social support groups.

Some participants felt they were treated unprofessionally and judged according to the worldview of their healthcare providers. One participant was told to "repent and seek forgiveness from God" by the treating doctor during her consultation session. She was relieved when she moved to another state and engaged with new healthcare providers:

"The doctor said to me that I deserved it ... that I must repent to God ... I must pray often and stop doing those [bad] things" (R10S2).

Health professionals should be aware of the differences between virtue ethics and professional standard practice. One participant was told she should not get married or have children. Other women felt healthcare providers imposed religious morality by denying access to recommended services such as bilateral tubal ligation. This made them feel uncomfortable, and some avoided using health services in the future. Using religion as a source of empowerment needs a subtle, sensitive,

non-judgemental approach. One woman related how she lost faith and accepted her fate, and ultimately was hospitalized due to her deteriorating health. She said the kindness of the nurses and doctors, who asked her to have faith in God in a non-judgemental manner, became her source of encouragement, and their holistic care gave her a second chance.

Discriminatory behaviors by healthcare providers threaten the right to health of WLHIV. The participants felt they had seen improvements in many aspects of their interaction with health services. Many healthcare providers talked with passion and dedication about their roles. Having adequate experience and formal training were important elements for them. Many without formal training took the initiative to consult with other professionals or joined infectious diseases clinics to observe how to interact with WLHIV.

Healthcare providers should be sensitized to their own actions when interacting with WLHIV. Some of the women who participated in the study previously remained silent but now have a voice. Women who have avoided using health services are still hard to reach, however, and their voices remain silent—and they may be the women with the worst outcomes and quality of life.

Recommendations

The PMTCT programme provides a strong foundation for elimination of mother-to-child transmission of HIV and serves as a road map to end the HIV epidemic as a public health threat. This would not have been possible without the leadership of the Ministry of Health Malaysia and commitment of policy-makers and programmers at the national and subnational levels. Efforts to ensure children in Malaysia are born without and remain free of HIV, and their mothers are supported to remain healthy and lead productive lives, are commendable.

In general, the participants in the study were able to access healthcare services with few issues in Peninsular Malaysia but not in East Malaysia. Most healthcare facilities were only open during normal working hours, but most participants were able to attend appointments. First-line antiretroviral medicines were provided free of charge to all WLHIV in the study. Second- and third-line antiretroviral medicines were available for antenatal WLHIV, but there were economic barriers to accessing these medicines. There were opportunities to access medicines through alternative routes such as drive-through pharmacies and courier services. All WLHIV had access to institutional deliveries and were attended by skilled birth attendants (26).

We found no reports of WLHIV who were coerced, threatened or forced to undergo tubal ligation. The women had low negotiating power, however, due to gender-based power imbalances. Most antenatal WLHIV were given options on the mode of delivery after accounting for several factors, including obstetric history, CD4 count and viral load. Participants mentioned issues related to confidentiality and HIV-related stigma and discrimination in healthcare settings. Unsympathetic staff and lack of privacy were cited as aspects that need to change in order to tackle stigma and discrimination in healthcare settings.

Substantial progress has been made since the PMTCT initiatives were put in place, but challenges remain. This study identified several potential strategies to address issues regarding access to health care, sexual and reproductive health and rights, stigma and discrimination.

The recommendations below are based on evidence from the data, existing literature, and the WHO *Consolidated guideline on sexual and reproductive health and rights of WLHIV* (24).

Improve access to healthcare services

Primary recommendations:

- a) Adapt the values and preferences of WLHIV in the provision of choice of healthcare facilities. Adequate choices are vital in the provision of good-quality and patient-centred care. Some WLHIV, such as those from key populations, choose to travel and receive HIV services at facilities further from their homes because of concerns over stigma or privacy. Healthcare providers should incorporate the values and preferences of such groups in adapting the delivery of care and facilitate them in accessing the most appropriate and convenient facilities.
- b) Ensure decentralized settings are sufficiently equipped to manage in rural areas, with the integration of related comprehensive services in the same settings. This can bring HIV

services closer to home and optimize accessibility, acceptability, affordability and retention in care. Peripheral facilities or community-level sites must be able to initiate and maintain antiretroviral therapy through strengthened linkages to adequate laboratory and medicine supply systems. This is especially true in East Malaysia for WLHIV.

- c) Offer a wider range of contraception options to increase use among WLHIV.
- d) Provide vouchers in lieu of infant formula to improve access to different brands, particularly for children who are not tolerant of the prescribed formula or who require special formulations due to allergies.
- e) Enhance the quality and scope of counselling services by increasing training opportunities for healthcare providers.

Secondary recommendations:

- a) Facilitate the rights-based assessment of welfare needs for all WLHIV at first contact with health services, and access to more holistic care that takes a woman-centred approach and considers priorities beyond HIV-related care. This includes increased access to support for mental health, family dynamics, logistics, financial adequacy and employment opportunities and requires interagency collaboration.
- b) Encourage telehealth and multi-month dispensing of antiretroviral medicines, especially for people who are stable on routine treatment.

Ensure sexual and reproductive health and rights of women living with HIV

Primary recommendations:

- a) Ensure informed consent with proper documentation from WLHIV before any test or procedure is carried out, particularly during hospital admission.
- b) Ensure the right of access to comprehensive information to enable WLHIV to make well-informed decisions on treatment plans and general health, including sexual and reproductive health and rights. Booklets containing answers to frequently asked questions and checklists of what to expect should be distributed to women at antenatal clinics to inform them about PMTCT initiatives and promote proactive health-seeking behaviours.
- c) Ensure effective communication between WLHIV and healthcare providers, and among healthcare providers, through regular women-centred multidisciplinary team meetings. A woman-centred approach and shared decision-making must be encouraged. Within the limits of healthcare providers' duty to practice medicine responsibly, WLHIV must be enabled to voluntarily express preferences for certain treatments or interventions, such as modern methods of contraception, delivery mode, or infant feeding options. This research is a demonstration of such a collaboration, producing meaningful evidence grounded in the voices of those who matter the most—WLHIV.
- d) Update clinical practices in accordance with the Model of Good Care (14):
 - Assist eligible WLHIV who wish to breastfeed their babies.
 - Educate WLHIV about hospital management of the placenta in accordance with standard universal precautions, while respecting cultural norms
 - Provide lactation suppressors to postnatal WLHIV if they choose not to breastfeed their babies.

- e) Empower WLHIV to have an active voice in their rights by collating feedback on the performance of the health services through a secure and anonymous mechanism. This promotes transparency and allows women to give a complete picture of their experiences and concerns. In turn, health authorities should be open about such evaluations by sharing results and demonstrating willingness to address feedback at all levels with quality improvement exercises.
- f) Offer quiet, private consultation areas to respect the rights of WLHIV and keep their information confidential.

Secondary recommendations:

- a) Hold regular awareness programmes for healthcare providers and partners and spouses of WLHIV on prevention and protection from gender-based and intimate partner violence.
- b) Encourage gender empowerment initiatives and elimination of gender-based discrimination, such as through communications campaigns.

Eliminate stigma and discrimination

Primary recommendations:

- a) Prohibit any form of labelling of documents that may result in women being identified as living with HIV without their permission, such as on the front pages of appointment cards, patient records or antenatal follow-up books. Having a designated system of patient numbering or a clinic day catering only for WLHIV may lead to stigmatization of WLHIV and must be avoided.
- b) Address internalized stigma and foster resilience among WLHIV through:
 - Increasing the capacity of organizations of WLHIV to advocate for their rights and meaningfully engage in decision-making.
 - Introduce a range of peer-conducted and peer-led skills-building workshops specifically for WLHIV to boost their self-esteem, confidence and mental health. Peer support groups are a starting point for developing social support interventions for WLHIV. The capacity of women's organizations to advocate for their rights and meaningfully engage in decision-making on HIV-related issues should be enhanced at local and national levels.
- c) Address provider stigma in healthcare settings through:
 - Sensitization training for clinical and non-clinical healthcare providers.
 - Regular nationwide assessment and monitoring of HIV-related stigma and discrimination in healthcare settings using a standardized stigma index.

Secondary recommendations:

- a) Reinvigorate HIV awareness and education campaigns through mass and social media.
- b) Encourage a more positive narrative around people living with HIV by the media.

Table 12 summarizes the recommendations based on the three domains of access to healthcare services, sexual and reproductive health and rights, and stigma and discrimination.

Table 12. Summary of practical recommendations based on research findings

Domain	Primary recommendations	Secondary recommendations
Improve access to healthcare services	<p>Adapt the values and preferences of WLHIV in the provision of choice of healthcare facilities</p> <p>Offer a wider range of contraception options to increase use among WLHIV</p> <p>Ensure decentralized settings, especially in rural areas and community-level sites in decentralization of care, are sufficiently equipped to manage care of WLHIV</p> <p>Provide vouchers in lieu of infant formula vouchers to improve access to different brands, particularly for children who are not tolerant of the prescribed formula or who require special formulations due to allergies</p> <p>Enhance the quality and scope of counselling services by increasing training opportunities for healthcare providers</p>	<p>Facilitate rights-based assessment of welfare needs for all WLHIV at first contact with health services</p> <p>Encourage telehealth and multi-month dispensing of antiretroviral medicines, especially for people who are stable on routine treatment</p>
Ensure sexual and reproductive health and rights of WLHIV	<p>Ensure proper documentation of informed consent from WLHIV before any test or procedure, particularly during hospital admission</p> <p>Distribute booklets and checklists to WLHIV as part of overall health literacy and to communicate about the PMTCT programme and what to expect during pregnancy and beyond</p> <p>Ensure effective communication between WLHIV and healthcare providers, and among healthcare providers, through regular women-centred multidisciplinary team meetings</p> <p>Update clinical practices in accordance with the Model of Good Care:</p> <ul style="list-style-type: none"> • Assist eligible WLHIV who wish to breastfeed their babies • Educate WLHIV about hospital management of the placenta in accordance with standard universal precautions, while respecting cultural norms • Provide lactation suppressors to postnatal WLHIV if they choose not to breastfeed their babies <p>Collate feedback from WLHIV on the performance of healthcare services, and address issues transparently</p> <p>Offer quiet, private consultation areas to respect the rights of WLHIV and keep their information confidential</p>	<p>Hold regular awareness programmes for healthcare providers and partners and spouses of WLHIV on prevention and protection from gender-based and intimate partner violence</p> <p>Encourage gender empowerment initiatives and elimination of gender-based discrimination, such as through communications campaigns</p>
Eliminate stigma and discrimination	<p>Prohibit any form of labelling of documents that may result in women being identified as living with HIV without their permission</p> <p>Address internalized stigma and foster resilience among living with HIV through:</p> <ul style="list-style-type: none"> • Peer-conducted skills-building workshops specifically for women living with HIV 	<p>Reinvigorate HIV awareness and education campaigns through mass and social media</p> <p>Encourage a more positive narrative around people living with HIV by the media</p>

Domain	Primary recommendations	Secondary recommendations
	<ul style="list-style-type: none"> Increasing the capacity of organizations of WLHIV to advocate for women's rights and meaningfully engage in decision-making <p>Address provider stigma in healthcare settings through:</p> <ul style="list-style-type: none"> Sensitization training for clinical and non-clinical healthcare providers Regular nationwide assessment and monitoring of HIV-related stigma and discrimination in healthcare services using a standardized stigma measurement tool 	
External quality assurance audit	Engage an independent and objective external auditor to review the PMTCT programme to overcome compliance challenges and promote efficiency	

External quality assurance audit

Engage an independent and objective external auditor to review the PMTCT programme to overcome compliance challenges and promote efficiency.

The Ministry of Health Malaysia should take pride in having a well-trained and competent internal auditing team. To ensure integrity, however, an independent and objective external auditor should be engaged to review the PMTCT programme to overcome compliance challenges and promote efficiency.

Research reflections

The COVID-19 pandemic has forced many people to change how they do things, including conducting research. The online approach to conducting in-depth interviews and focus group discussions provided an alternative perspective and access to research participants, with advantages and limitations. The research team must evaluate these trade-offs to determine whether their use is appropriate for the area under investigation.

Using an online approach made it possible to gather a reasonable sample size of an accessible population within a relatively short time. Participants had the choice to be visible or to remain anonymous by turning off their cameras during the sessions. This way of working eliminated the need for research team members to travel to recruit and collect data from participants. With a virtual conference platform, researchers and participants were able to come together from their own homes or safe spaces to exchange views and experiences.

There were some challenges with internet access, unfamiliarity with Zoom, and minor audio interruptions. The research team overcame these setbacks, and overall, the experience was smooth. This new norm of gathering data saved the team a significant amount of energy, time and costs, while allowing simultaneous engagement with participants from diverse regions and backgrounds.

The nature of the study ensured participants could retain their anonymity and protect their privacy. Based on the participants' feedback, the research team was able to accommodate the limitations of the COVID-19 pandemic without compromising the quality of research and the credibility of research findings.

For some team members, virtual interaction removed personal attention and other body language cues that may be important in strengthening interpretation of data and reacting to participants' emotions. The team found, however, that most participants were happy to talk in private. Perhaps life has taught them to distance themselves. While we as qualitative researchers were not able to practise the art of the methods, the community research supporters were there to provide such role which shall be described below.

It quickly became apparent that finding and connecting with the study population would be difficult. The involvement of community research supporters from various community and civil society organizations and networks was essential. The community research supporters played a large role in finding and recruiting eligible participants into the study. During the data-collection sessions, the community research supporters engaged with the participants and built rapport between the researchers and the participants.

The presence of community research supporters as peers and advocates to champion the causes of WLHIV helped to minimize barriers between researchers and participants. Where participants had issues with internet access or electronic devices, community research supporters went beyond expectations and helped with the provision of materials, ensuring a smooth data-collection process. Subsequently, the community research supporters provided the researchers with additional insight and validation in post-interview session discussions.

The team hopes the community research supporters have benefited from the study by enhancing their exposure to and understanding of scientific research methodologies and gained hands-on practice at conducting research. Collaboration through this qualitative research study has connected academic experts in the research area with community representatives proficient in community related fields and perspectives.

A number of community research supporters who were due to engage with the study team eventually withdrew their commitment for various reasons. Initially there were eight community research supporters, but only three remained with the study team to the end—Kak Lily (Lina), Ri (Revathi) and Siti (Siti Fazariah) are the giants whose shoulders we stood on.

Partnerships with multistakeholder groups have proved advantageous. By leveraging know-how and technical knowledge from academia, the Ministry of Health Malaysia, community and civil society organizations, UNAIDS and international organizations and the voices of WLHIV, the team considered various aspects crucial to the assignment. Each stakeholder brought unique capacities to the table, and this collective effort empowered the researchers to address issues that surfaced during the research process. Although it was challenging to accommodate conflicting interests and numerous stakeholder demands, multisectoral engagement throughout the research process encouraged transparency and accountability and promoted value-for-money delivery of projects.

In contrast to the traditional top-down approach, the team believes this has been a good model to drive forward revisions to healthcare practice and policy changes and development. A multistakeholder strategy will serve in the revalidation of achievement of EMTCT in Malaysia.

Conclusions

Bold recommendations and interim recommendations made by GVAC in 2018 and 2019 have been earmarked to measure the progress made by Malaysia on human rights-related issues and to review the validation of achievement of EMTCT. Keeping EMTCT programmes in context, the researchers heeded the requirements from the terms of reference to provide a much-needed update to the understanding and knowledge of the state of healthcare services, sexual and reproductive health and rights, and stigma and discrimination experienced by WLHIV across the country. Through nuanced but focused questions, this assessment generated evidence to illustrate the recent experiences of WLHIV in Malaysia as part of the aim to end the AIDS epidemic as a public health threat by 2030.

Access to healthcare services and critical information on HIV has improved, in parallel with advancement in standards of education and infrastructural and technological development in Malaysia. One of the study findings, however, is that internalized stigma among WLHIV remains high. Although reports of external stigma among healthcare providers were not high, discrimination continues to occur in healthcare settings. Awareness of sexual and reproductive health and rights among WLHIV, and respect of healthcare providers for these rights, have improved, but the non-confrontational culture pervasive in Malaysian society may hinder women from asking questions and standing up for their rights. The empowerment of women in decision-making is at the heart of changing the landscape to ensure inclusive and equitable access to good-quality healthcare services.

The findings and recommendations highlighted in this report are an impetus to promote dialogue among policy-makers and communities of people living with HIV, leading to improvement of standards of healthcare services and development of programmes and policies to support the rights of WLHIV and their families to live healthy, happy and productive lives.

The qualitative research in this study was done using the online platform as a research tool and a field site, and it is the research team's hope that this strategy, and the collaborative multistakeholder approach, can initiate other projects to foster a collective-impact research culture while practically adapting to the new norms brought on by the COVID-19 pandemic.

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Annex 1

Research Timeline

Activity												
	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7	Week 8	Week 9	Week 10	Week 11	Week 12
Ethics and advisory meeting												
Revision of protocol and questions												
Training, pilot and recruitment												
Data collection S1–S5												
Data collection S6–S9												
Data collection S10–S15												
Data collection S16–S20 + ST1–2												
Data collection S21–S24												
Data analysis												
Draft report												
Final report												
1–7 August 2021	24–31 July 2021											

Annex 2

Daily and Weekly Team Plan

Date	Week	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Weekly summary
18–24 July 2021	0								Apply for ethical clearance from Universiti Sains Malaysia and National Medical Research Register
25–31 July 2021	1				Ethics	Meeting with Advisory Committee			Create questionnaire and plan for workshop Search and write literature review Ethics presentation and advisory meeting
1–7 August 2021	2	Revision of questions and protocol							Organize and plan training workshop Recruit potential participants Schedule in-depth interview and focus group discussion sessions Plan for 1 pilot focus group discussion—schedule next week
8–14 August 2021	3	Sunday research team meeting			Workshop 1	Setting appointment	Setting appointment	Pilot session	Conduct workshop—Wednesday Conduct 1 pilot focus group discussion—Saturday Discussion meeting after pilot session Make appointment for next week—5 sessions
15–21 August 2021	4	Sunday research team meeting	S1	S2	S3	S4		S5	5 sessions (2 in-depth interviews, 3 focus group discussions) for general WLHIV Discussion meeting after each session Make appointment for next week—4 sessions
22–28 August 2021	5	Sunday research team meeting	S6	S7	S8	S9			1 session (focus group discussion) for general WLHIV 3 sessions (2 in-depth interviews, 1 focus group discussion) for antenatal WLHIV Discussion meeting after each session Make appointment for next week—6 sessions
29 August–4 September 2021	6	Sunday research team meeting and workshop 2	S10		S11	S12	S13 and workshop 3	S14 and S15	3 sessions (1 in-depth interview, 2 focus group discussions) for antenatal WLHIV 3 sessions (2 in-depth interviews, 1 focus group discussion) for postnatal WLHIV Discussion meeting after each session Conduct workshops—Sunday and Friday

Date	Week	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Weekly summary
5–11 September 2021	7	Sunday research team meeting and 2 additional training sessions (ST)	S16	S17	S18	S19		S20	4 sessions (2 in-depth interviews, 2 focus group discussions) for postnatal WLHIV 1 session (focus group discussion) for antenatal WLHIV 2 additional sessions (in-depth interviews) moderated by community research supporters Discussion meeting after each session
12–18 September 2021	8	Sunday research team meeting	S21	S22	S23 and mid-review meeting		S24		2 sessions (focus group discussions) for postnatal WLHIV 2 sessions (focus group discussions) for healthcare providers Meeting with advisory committee
19–26 September 2021	9	Sunday research team meeting	Report outline and framework	Analysis and research finding writing					Consolidate findings and write up
27 September–2 October 2021	10	Sunday research team meeting	Continue writing recommendation and conclusion			Compile and structure recommendation			Merge all findings for first draft report
3–9 October 2021	11	Sunday research team meeting	Submission of first draft to Advisory Committee			Present to Advisory Committee			Submit first draft to advisory committee Presentation of findings to committee Revision
10–16 October 2021	12		Revision			Submission of final report			Final report

S: session; ST: additional training session.

Annex 3

Letter of ethical approval from Human Research Ethics Committee of Universiti Sains Malaysia



11th August 2021

Assoc. Prof. Dr. Zaharah Sulaiman
Women's Health Development Unit
School of Medical Sciences
Universiti Sains Malaysia
16150 Kubang Kerian, Kelantan.

Jawatankuasa Etika
Penyelidikan Manusia USM (JEPeM)
Human Research Ethics Committee USM (HREC)

Universiti Sains Malaysia
Kampus Kesihatan
16150 Kubang Kerian, Kelantan, Malaysia.
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Laman Web : www.jepem.kk.usm.my
www.usm.my

JEPeM Code : USM/JEPeM/21070517

Protocol Title : Qualitative Assessment on Sexual and Reproductive Health and Rights, and Health Service Access among Women Living with HIV in Malaysia.

Dear Dr.,

We wish to inform you that your study protocol has been reviewed and is hereby granted approval for implementation by the Jawatankuasa Etika Penyelidikan Manusia Universiti Sains Malaysia (JEPeM-USM). Your study has been assigned study protocol code **USM/JEPeM/21070517**, which should be used for all communications to JEPeM-USM in relation to this study. This ethical approval is valid from 11th August 2021 until 10th August 2022.

Study Site: Peninsular Malaysia.

The following researchers are also involved in this study:

1. Assoc. Prof. Dr. Norhayati Mohd Noor
2. Dr. Noor Aman A. Hamid
3. Dr. Surianti Sukeri

The following documents have been approved for use in the study.

1. Research Proposal

In addition to the abovementioned documents, the following technical documents were included in the review on which this approval was based:

1. Participant Information Sheet and Consent Form (English version)
2. Participant Information Sheet and Consent Form (Malay version)
3. Interview / FGD Guide for Antenatal Women Living with HIV
4. Interview / FGD Guide for Postnatal Women Living with HIV
5. FGD Guide for Healthcare Providers
6. Interview / FGD Guide for Antenatal Women Living with HIV (in Bahasa Malaysia)
7. Interview / FGD Guide for Postnatal Women Living with HIV (in Bahasa Malaysia)
8. FGD Guide for Healthcare Providers (in Bahasa Malaysia)

The list of JEPeM-USM members present during the full board meeting reviewing your protocol is attached.

While the study is in progress, we request you to submit to us the following documents:

1. Application for renewal of ethical approval 60 days before the expiration date of this approval through submission of **JEPeM-USM FORM 3(B) 2019: Continuing Review Application Form**.
2. Any changes in the protocol, especially those that may adversely affect the safety of the participants during the conduct of the trial including changes in personnel, must be submitted or reported using **JEPeM-USM FORM 3(A) 2019: Study Protocol Amendment Submission Form**.



3. Revisions in the informed consent form using the **JEPeM-USM FORM 3(A) 2019: Study Protocol Amendment Submission Form**.
4. Reports of adverse events including from other study sites (national, international) using the **JEPeM-USM FORM 3(G) 2019: Adverse Events Report**.
5. Notice of early termination of the study and reasons for such using **JEPeM-USM FORM 3(E) 2019**.
6. Any event which may have ethical significance.
7. Any information which is needed by the JEPeM-USM to do ongoing review.
8. Notice of time of completion of the study using **JEPeM-USM FORM 3(C) 2019: Final Report Form**.

Please note that forms may be downloaded from the JEPeM-USM website:
www.jepem.kk.usm.my

JEPeM-USM is in compliance with the Declaration of Helsinki, International Conference on Harmonization (ICH) Guidelines, Good Clinical Practice (GCP) Standards, Council for International Organizations of Medical Sciences (CIOMS) Guidelines, World Health Organization (WHO) Standards and Operational Guidance for Ethics Review of Health-Related Research and Surveying and Evaluating Ethical Review Practices, EC/IRB Standard Operating Procedures (SOPs), and Local Regulations and Standards in Ethical Review.

Thank you.

"PRIHATIN RAKYAT: DARURAT MEMERANGI COVID-19"

"WAWASAN KEMAKMURAN BERSAMA 2030"

"BERKHIDMAT UNTUK NEGARA"

Sincerely,



ASSOC. PROF. DR. AZLAN HUSIN

Chairperson

Jawatankuasa Etika Penyelidikan (Manusia) JEPeM
Universiti Sains Malaysia

Annex 4

Letter of ethical approval from Medical Research and Ethics Committee, Ministry of Health Malaysia



JAWATANKUASA ETIKA & PENYELIDIKAN PERUBATAN
(MEDICAL RESEARCH & ETHICS COMMITTEE)
KEMENTERIAN KESIHATAN MALAYSIA
MINISTRY OF HEALTH MALAYSIA
Kompleks Institut Kesihatan Negara (NIH)
No.1, Jalan Setia Murni U13/52,
Seksyen U13 Bandar Setia Alam,
40170 Shah Alam, Selangor.



Tel.: +(6)03-33628888/ 33628205

Ref. : KKM/NIIHSEC/P21-1483(11)
Date : 2-September-2021

ASSOCIATE PROFESSOR ZAHARAH SULAIMAN
UNIVERSITI SAINS MALAYSIA (USM), HEALTH CAMPUS

Dear Dato'/ Dr/ Sir/ Madam,

LETTER OF ETHICAL APPROVAL:

NMRR-21-1583-60936 (IIR)

**QUALITATIVE ASSESSMENT ON SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS AND
HEALTHCARE SERVICE ACCESS AMONG WOMEN LIVING WITH HIV IN MALAYSIA**

This letter is made in reference to the matter above.

2. The Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia (MOH) has provided ethical approval for this study. Please take note that all records and data are to be kept strictly **CONFIDENTIAL** and can only be used for the purpose of this study. All precautions are to be taken to maintain data confidentiality. Permission from the District Health Officer / Hospital Administrator/ Hospital Director and all relevant heads of departments /units where the study will be carried out must be obtained prior to the study. You are required to follow and comply with their decision and all other relevant regulations including the Access to the Biological and Benefit Sharing Act 2017.

3. The investigators and sites involved in this study are:

Disease Control Division, Section of Aids

Associate Professor Zaharah Sulaiman (Principal / Coordinating Investigator)
Dr. Anita Suleiman
Dr. Noor Aman Bin A Hamid
Dr. Norhayati Binti Mohd Noor
Dr. Surianti Sukeri

Malaysian Aids Council

Associate Professor Zaharah Sulaiman (Principal / Coordinating Investigator)
Dr. Anita Suleiman
Dr. Noor Aman Bin A Hamid
Dr. Norhayati Binti Mohd Noor
Dr. Surianti Sukeri

4. The following study documents have been received and reviewed with reference to the above study:

Documents received and reviewed with reference to the above study:

1. Cover letter to MREC (Version 2, dated 01-09-2021)
2. Declaration of Conflict of Interest (COI) (Version 1, dated 03-08-2021)
3. Protocol (Version 2, dated 03-08-2021)

- 4. English: Patient Information Sheet/ Informed Consent Form (Version 2, dated 03-08-2021)
- 5. Malay: Patient Information Sheet/ Informed Consent Form (Version 2, dated 03-08-2021)
- 6. Questionnaire (Version 2, dated 03-08-2021)
- 7. Follow-up Review Report (Version 1, dated 01-09-2021)
- 8. IA-HOD-IA and CV of:
 - Associate Professor Zaharah Sulaiman
 - Dr. Anita Suleiman
- 9. CV and GCP Certification of:
 - Dr. Norhayati Binti Mohd Noor
- 10. CV of:
 - Dr. Noor Aman Bin A Hamid
 - Dr. Surianti Sukeri

5. Please note that the approval is valid until **1-September-2022**. The following are to be reported upon receiving ethical approval. Required forms can be obtained from the National Medical Research Registry (NMRR) website.

- i. **Continuing Review Form** has to be submitted to MREC within 2 months (60 days) prior to the expiry of ethical approval.
 - ii. **Study Final Report** upon study completion to the MREC.
 - iii. Ethical approval is required in the case of **amendments/ changes to the study documents/ study sites/ study team**. MREC reserves the right to withdraw ethical approval if changes to study documents are not completely declared.
 - iv. **Applicable for Clinical interventional Studies only:** Report occurrences of all **Serious Adverse Events (SAEs)**, **Suspected Unexpected Serious Adverse Reaction (SUSARs)** and **Protocol Deviation/Violation** at all MREC approved sites to MREC. SAEs are to be reported within 15 calendar days from awareness of event by investigator. Initial report of SUSARs are to be reported as soon as possible but not later than 7 calendar days from awareness of event by investigator, followed by a complete report within 8 additional calendar days.
6. There will be **88 subjects/ patients/ respondents** targeted to be enrolled in this study within Malaysia.
7. Please take note that the reference number of this letter must be stated in all future correspondence related to this study to facilitate the administrative processes.

Project Sites:

**DISEASE CONTROL DIVISION, SECTION OF AIDS
MALAYSIAN AIDS COUNCIL**

Decision by Medical Research & Ethics Committee:

- () Approved
() Disapproved

Date of Approval : **02-September-2021**



.....
DR. HJH SALINA BINTI ABDUL AZIZ
Chairperson
Medical Research & Ethics Committee
Ministry of Health Malaysia
(MMC No: 27117)

Annex 5

Confidentiality agreement for research transcriber



CONFIDENTIALITY AGREEMENT FOR TRANSCRIPTION SERVICE

Research Study Title Qualitative Assessment on Sexual and Reproductive Health and Rights and Healthcare Service Access Among Women Living with HIV within the Context and Setting of PMTCT of HIV in Malaysia Following the 2018 EMTCT Validation

Period of Service 14 August 2021 – 22 September 2021

As a transcriptionist of this research study, I understand that I will be listening to audio/video recordings of private and confidential interviews. The information relayed in these recordings have been voluntarily revealed by research participants who requested strict confidentiality. I understand that I have a responsibility of honouring this non-disclosure agreement.

I, _____ the transcriptionist, agree to maintain full confidentiality of all research data received from the research team related to the research study.

I agree not to discuss or share any information found in the recordings with any third parties except the research team providing the recordings. Violation of this agreement or any of the terms set below will be considered a breach of contract and can lead to legal action being taken against me.

1. I will hold in strictest confidence the contents of the recordings and any associated documents.
2. I will hold in strictest confidence the identity of any individuals that may be revealed during the transcription of recordings or in any associated documents.
3. I will not make copies of any audio-recordings, video-recordings or other research data.
4. I will not provide the research data to any third parties without the consent of the research team.
5. I will transcribe the audio/video recordings in private and store all study-related data in a safe, secure location as long as they are in my possession.
6. All data provided or created for the purpose of the agreement, including any back-up records, will be returned to the research team and/or permanently deleted.
7. When I have received confirmation that the transcription service I performed has been satisfactorily completed, any of the research data that remains with me will be destroyed, pursuant to the instructions of the research team.

.....
Transcriptionist
Name (print):
IC Number:
Date: 22 September 2021

.....
Witness/Principal Investigator
Name (print): DR ZAHARAH BINTI SULAIMAN
IC Number:
Date: 22 September 2021

Annex 6

Nondisclosure agreement for research officer



NON-DISCLOSURE AGREEMENT

Research Study Title Qualitative Assessment on Sexual and Reproductive Health and Rights and Healthcare Service Access Among Women Living with HIV within the Context and Setting of PMTCT of HIV in Malaysia Following the 2018 EMTCT Validation

Period of Service 26 July 2021 – 17 October 2021

As a research officer of this research study, I understand that I will have access to research data relayed by research participants during private and confidential interviews. The information has been voluntarily revealed by research participant(s) who requested strict confidentiality. I understand that I have a responsibility of honoring this non-disclosure agreement.

I, _____ the research officer, agree to maintain full confidentiality of all research data received from the research participants related to the research study.

Violation of this agreement or any of the terms set below will be considered a breach of contract and can lead to legal action being taken against me.

1. I will hold in strictest confidence the identity of any individuals that may be revealed during the data collection session and/or in any associated documents.
2. I will not discuss or share any information with any third parties except the research team.
3. I will store all study-related data in a safe, secure location as long as they are in my possession.
4. All data provided or created for the purpose of the research study, including any back-up records, will be returned to the research team and/or permanently deleted.
5. When I have received confirmation that the service I performed has been satisfactorily completed, any of the research data that remains with me will be destroyed, pursuant to the instructions of the research team.
6. Any interaction with research participant(s) beyond the scope of this research study is not a responsibility of the research team.

.....
Research Officer
Name (print): SITI AISHAH BINTI
IBRAHIM
IC Number:
Date: 10 October 2021

.....
Witness/Principal Investigator
Name (print): DR ZAHARAH BINTI SULAIMAN
IC Number:
Date: 10 October 2021

Annex 7

Nondisclosure agreement for community research supporters



NON-DISCLOSURE AGREEMENT

Research Study Title Qualitative Assessment on Sexual and Reproductive Health and Rights and Healthcare Service Access Among Women Living with HIV within the Context and Setting of PMTCT of HIV in Malaysia Following the 2018 EMTCT Validation

Period of Service 10 August 2021 – 10 October 2021

As a community research supporter of this research study, I understand that I will have access to research data relayed by research participants during private and confidential interviews. The information has been voluntarily revealed by research participant(s) who requested strict confidentiality. I understand that I have a responsibility of honouring this non-disclosure agreement.

I, _____ the community research supporter, agree to maintain full confidentiality of all research data received from the research participants related to the research study.

Violation of this agreement or any of the terms set below will be considered a breach of contract and can lead to legal action being taken against me.

1. I will hold in strictest confidence the identity of any individuals that may be revealed during the data collection session and/or in any associated documents.
2. I will not discuss or share any information with any third parties except the research team.
3. I will store all study-related data in a safe, secure location as long as they are in my possession.
4. All data provided or created for the purpose of the research study, including any back-up records, will be returned to the research team and/or permanently deleted.
5. When I have received confirmation that the service I performed has been satisfactorily completed, any of the research data that remains with me will be destroyed, pursuant to the instructions of the research team.
6. Any interaction with research participant(s) beyond the scope of this research study is not a responsibility of the research team.

.....
Community Research Supporter
Name (print):
IC Number:
Date:

.....
Witness/Principal Investigator
Name (print): DR ZAHARAH BINTI SULAIMAN
IC Number:
Date:

Annex 8

Introductory script for recruitment of women living with HIV (English version)

Assalamualaikum / Good morning, Madam,

My name is _____, I am one of the (staff from _____ / representative from the NGO _____).

The purpose of contacting you today is to inform you about a study that we are conducting with Universiti Sains Malaysia. This study is conducted to get to know women living with HIV more closely and to understand their experiences. We would like to get your views and perceptions as a woman living with HIV on women's rights in (i) making choices in using health services in Malaysia (ii) gaining access to services and (iii) dealing with stigma and discrimination, if any.

If you do not mind, I would like to invite you to participate in (a) a single interview or (b) a group interview in this study.

(a) For the interview session, there will be only you with two more people from our research team. To participate, you need to spend about an hour in an online session.

(b) For the group interview, there will be about 4-5 other women living with HIV as well as 2-3 people from our research team. To participate, you need to spend a little over an hour in an online session.

All you need is a smartphone and an internet line. We would like to suggest that this session be held on _____ at ____ am, if this date and time are suitable for you.

I would like to inform you that this interview will be recorded for our storage and reference only. It is also important for me to inform you that your identity will not be disclosed and all information shared will be kept confidential. You can use a nickname and even switch off the video if doing so are more comfortable for you. The researcher will ask some questions about your experience and you can choose not to answer if you prefer it that way. You will also receive a small token after the interview as a sign of our appreciation for your time spent in this study.

You are welcome to take some time to think about participating in this study. If you have any questions about this study, I will try to answer them as best as I can.

[For health staff only] Since you are interested in participating in this study, may I know if you would like to be contacted by a representative from an NGO to get more information from you? If you are reluctant to be contacted by an NGO representative, I can also get the research team to contact you directly.

Annex 9

Introductory script for recruitment of women living with HIV (Bahasa Malaysia version)

Assalamualaikum / Selamat pagi Puan,

Nama saya (_____), saya adalah salah seorang (staf dari _____ / wakil dari NGO _____).

Tujuan saya menghubungi puan hari ini adalah untuk memaklumkan mengenai sebuah kajian yang sedang kami jalankan bersama Universiti Sains Malaysia. Kajian ini dibuat untuk kami mengenali wanita yang hidup dengan HIV secara lebih dekat dan memahami pengalaman mereka. Kami ingin mendapatkan pandangan puan sebagai wanita yang hidup dengan HIV mengenai hak puan dalam (i) membuat pilihan dalam menggunakan perkhidmatan kesihatan di Malaysia (ii) mendapat akses kepada perkhidmatan dan (iii) pengalaman berhadapan dengan stigma dan diskriminasi, jika ada.

Jika puan tidak keberatan, saya ingin menjemput puan untuk menyertai (a) temubual / interview atau (b) temubual berkumpulan dalam kajian ini.

- (a) *Untuk sesi temubual cuma ada puan seorang dengan dua orang dari tim kami. Untuk mengambil bahagian, puan perlu meluangkan masa lebih kurang sejam secara maya / online.*
- (b) *Untuk temubual berkumpulan ada lebih kurang 4-5 orang wanita lain yang hidup dengan HIV serta 2-3 orang lagi dari tim kami. Untuk mengambil bahagian, puan cuma perlu meluangkan masa lebih kurang sejam lebih dalam sesi secara maya / online.*

Apa yang puan perlukan hanyalah telefon pintar/smartphone dan talian internet. Saya ingin mencadangkan sesi ini diadakan pada _____ pukul __ pagi jika tarikh dan masa ini sesuai untuk puan.

Saya juga ingin memaklumkan bahawa temubual ini akan direkod untuk simpanan dan rujukan kami sahaja. Penting untuk saya maklumkan, identiti puan tidak akan didedahkan dan segala maklumat yang dikongsi akan dirahsiakan. Puan boleh gunakan nama samaran dan juga tutup video jika lebih selesa begitu. Penyelidik akan bertanya beberapa soalan mengenai pengalaman puan dan puan boleh memilih untuk tidak menjawab. Puan juga akan menerima sedikit sumbangan setelah temubual tamat sebagai tanda penghargaan untuk masa yang puan luangkan dalam kajian ini.

Puan boleh mengambil sedikit masa untuk berfikir mengenai penglibatan ini. Sekiranya puan mempunyai sebarang soalan mengenai kajian ini, saya akan cuba menjawab sebaik mungkin.

[Untuk staf kesihatan sahaja] Memandangkan puan berminat untuk mengambil bahagian dalam kajian ini, boleh saya tahu jika puan boleh dihubungi oleh wakil dari NGO untuk mendapatkan maklumat lanjut daripada puan? Jika puan keberatan untuk dihubungi NGO, saya juga boleh dapatkan pasukan penyelidik untuk menghubungi puan secara terus.

Annex 10

Participant information sheet (English version)

Research information

Research title: Qualitative assessment on sexual and reproductive health and rights, and health service access among women living with HIV in Malaysia

Main researcher: Associate Prof. Dr Zaharah Sulaiman (MMC no: 36457)

Co-researchers: Associate Prof. Dr Norhayati Mohd Noor (MMC no: 35994)
Dr Noor Aman A Hamid (MMC no: 63187)
Dr Surianti Sukeri

Introduction

You are invited to participate in a qualitative research study on a voluntary basis. This study is related to the qualitative assessment of sexual and reproductive health and rights, and access to health services for women living with HIV in Malaysia.

It is important that you read and understand this research information before agreeing to participate in this study. You will receive a copy of this form to keep for your records if you agree to participate.

Your participation in this study is expected to take one and a half to two hours in online focus group discussions. A total of 88 people is expected to participate in this study.

Purpose of this study

The purposes of this study are to:

- a) Explore sexual and reproductive health and rights, and health service access among women living with HIV in Malaysia.
- b) Explore experiences and barriers faced by women living with HIV in accessing healthcare services in Malaysia.
- c) Propose practical recommendations to the stakeholders in addressing stigma and discrimination towards women living with HIV.

Participant criteria

The research team members will discuss your eligibility to participate in this study. It is important that you are completely truthful with the staff, including about your health history.

General criteria

- a) Aged 18 years or over.
- b) Malaysian.
- c) Can communicate well.
- d) Has smartphone and internet accessories.

Criteria for women living with HIV

- a) Women living with HIV who used health services of the Ministry of Health Malaysia from January 2018 to July 2021:
 - Antenatal women living with HIV.
 - Postnatal women living with HIV.
- b) Geographical area: representatives from regions in Peninsular Malaysia (Central, North, South, East) and East Malaysia.

Criteria for healthcare providers

- a) Healthcare providers involved in providing services to women living with HIV from January 2018 to July 2021.
- b) Geographical area: representatives from regions in Peninsular Malaysia (Central, North, South, East) and East Malaysia.
- c) Level of involvement: national, state and district.

Study procedures

You have been identified by the research team as an eligible participant in this study according to the category of women living with HIV. If you agree to participate in this study, you must give written consent by signing the attached participant consent form.

The study will be conducted through two methods: online focus group discussions and in-depth interviews on some important aspects related to health services for women living with HIV. If you are selected as a study participant, you will be given an appointment date to attend online on the appropriate date. The discussion will revolve around some questions related to health service programmes for women living with HIV and facilitated by the research team.

The survey is expected to last for one and a half to two hours. Participants will be given an honorarium for the time they spend for the interview or focus discussion session.

If you have any doubts or do not understand any aspect of the survey, you can ask the researcher, who will always be there to help you.

Risks

You will not face any physical risk by participating in this research because it does not involve taking blood or other procedures to the body. If you experience any emotional stress or emotional disturbance during the interview or discussion sessions, you will be referred to the support group, counsellors or appropriate physician as you prefer.

We will also always ensure that your identity is kept confidential by all involved in this research.

Please inform the study staff if you encounter any problems or have any important information that may change your agreement to continue participating in this study.

Reporting health experiences

Please contact, at any time, the following researcher if you experience any health problem either directly or indirectly related to this study:

Dr Zaharah Sulaiman (MMC registration no. 36457): 09-767 6886

Participation in the study

Taking part in this study is entirely voluntary. You may refuse to take part in the study, or you may stop your participation in the study at any time, without any penalty or loss of benefits to which you are otherwise entitled.

Your participation may be stopped by the research team without your consent if, in any way, you violate the study eligibility criteria. The research team members will discuss with you if this happens.

Possible benefits

This study may benefit the community in the following ways:

- a) The information obtained will help the Ministry of Health Malaysia and other relevant parties to improve the quality of services and management in the prevention of HIV among women, pregnant women and children born in our country.
- b) Through online focus group discussions, the survey can provide an opportunity for relevant people, clients or users to voice their views, suggestions and needs in more detail in all relevant aspects of the programme.
- c) The survey can help the management of the hospital or clinic, including the medical officer who treats you, in assessing the impact of treatment, procedures and interventions on the quality of life of women and children living with HIV.

Questions

If you have any questions about this study or your rights, please contact:

Prof Madya Dr Zaharah Sulaiman (MMC no: 36457), Women's Health Development Unit,
School of Medical Sciences

If you have any questions about the ethical approval of this study or any issues related to the study, please contact:

Mr Mohd Bazlan Hafidz Mukri, Secretary of Human Research Ethics Committee USM, Division of Research and Innovation, USM Health Campus; 09-767 2354 or 09-767 2362

or:

Ms Nor Amira Khurshid Ahmed, Secretariat of Human Research Ethics Committee USM, Research Creativity and Management Office, USM Main Campus, Penang; 04-653 6537noramira@usm.my

Confidentiality

Your information will be kept confidential by the researchers and will not be made publicly available unless disclosure is required by law.

Data obtained from this study that do not identify you individually may be published for research purposes.

Your original records may be reviewed by the researcher, the ethical review board for this study, and regulatory authorities for the purpose of verifying the study procedures or data. Your information may be held and processed on a computer. Only research team members will be authorized to access your information.

By signing this consent form, you authorize the record review, information storage and data process described above.

Signatures

To be entered into this study, you or a legal representative must sign and date the signature page.

ATTACHMENT S

Subject Information and Consent Form (Signature Page)

Research Title: QUALITATIVE ASSESSMENT ON SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, AND HEALTH SERVICE ACCESS AMONG WOMEN LIVING WITH HIV IN MALAYSIA

Name of main researcher: Prof Madya Dr Zaharah Sulaiman (MMC No: 36457)
Name of co-researchers: Prof Madya Dr. Norhayati Mohd Noor (MMC No: 35994)
Dr Noor Aman A Hamid (MMC No: 63187)
Dr Surianti Sukeri

To become a part this study, you or your legal representative must sign this page. By signing this page, I am confirming the following:

- I have read all of the information in this Participant Information and Consent Form **including any information regarding the risk in this study** and I have had time to think about it.
- All of my questions have been answered to my satisfaction.
- I voluntarily agree to be part of this research study, to follow the study procedures, and to provide necessary information to the doctor, nurses, or other staff members, as requested.
- I may freely choose to stop being a part of this study at any time.
- I have received a copy of this Participant Information and Consent Form to keep for myself.

Participant Name

Participant I.C No

Signature of Participant or Legal Representative

Date (dd/MM/yy)

Name of Individual

Conducting Consent Discussion

Signature of Individual

Conducting Consent Discussion

Date (dd/MM/yy)

Name & Signature of Witness

Date (dd/MM/yy)

Note: i) All participants who are involved in this study will not be covered by insurance.

ATTACHMENT P

Participant's Material Publication Consent Form Signature Page

Research Title: QUALITATIVE ASSESSMENT ON SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, AND HEALTH SERVICE ACCESS AMONG WOMEN LIVING WITH HIV IN MALAYSIA

Name of main researcher: Prof Madya Dr Zaharah Sulaiman (MMC No: 36457)
Name of co-researchers: Prof Madya Dr. Norhayati Mohd Noor (MMC No: 35994)
Dr Noor Aman A Hamid (MMC No: 63187)
Dr Surianti Sukeri

To become a part this study, you or your legal representative must sign this page.

By signing this page, I am confirming the following:

- I understood that my name will not appear on the materials published and there have been efforts to make sure that the privacy of my name is kept confidential although the confidentiality is not completely guaranteed due to unexpected circumstances.
- I have read the materials or general description of what the material contains and reviewed all photographs and figures in which I am included that could be published.
- I have been offered the opportunity to read the manuscript and to see all materials in which I am included, but have waived my right to do so.
- All the published materials will be shared among the medical practitioners, scientists and journalist worldwide.
- The materials will also be used in local publications, book publications and accessed by many local and international doctors worldwide.
- I hereby agree and allow the materials to be used in other publications required by other publishers with these conditions:
- The materials will not be used as advertisement purposes nor as packaging materials.
- The materials will not be used out of context – i.e.: Sample pictures will not be used in an article which is unrelated subject to the picture.

Participant Name

Participant I.C No.

Participant's Signature

Date (dd/MM/yy)

**Name and Signature of Individual
Conducting Consent Discussion**

Date (dd/MM/yy)

Note: i) All participants who are involved in this study will not be covered by insurance.

Annex 11

Participant information sheet (Bahasa Malaysia version)

Maklumat kajian

Tajuk Kajian: Penilaian Kualitatif Mengenai Kesihatan Dan Hak Seksual Dan Reproduktif, Dan Akses Perkhidmatan Kesihatan Terhadap Wanita yang hidup dengan HIV di Malaysia

Nama penyelidik utama: Prof Madya Dr Zaharah Sulaiman (MMC no: 36457)

Nama penyelidik bersama: Prof Madya Dr Norhayati Mohd Noor (MMC no: 35994)

Dr Noor Aman A Hamid (MMC no: 63187)

Dr Surianti Sukeri

Pengenalan

Anda adalah dipelawa untuk menyertai satu kajian penyelidikan kualitatif secara sukarela. Kajian ini adalah berkaitan Penilaian Kualitatif Mengenai Kesihatan dan Hak Seksual dan Reproduktif, dan Akses Perkhidmatan Kesihatan Terhadap Wanita yang hidup dengan HIV di Malaysia.

Adalah penting bagi anda membaca dan memahami maklumat kajian sebelum anda bersetuju untuk menyertai kajian penyelidikan ini. Sekiranya anda menyertai kajian ini, anda akan menerima satu salinan borang ini untuk simpanan anda.

Penyertaan anda di dalam kajian ini dijangka mengambil masa selama satu setengah hingga dua jam di dalam perbincangan kumpulan fokus secara dalam talian. Seramai 88 orang dijangka akan menyertai kajian ini.

Tujuan kajian

Kajian ini bertujuan:

- a) Untuk meneroka kesihatan dan hak seksual dan pembiakan, dan akses perkhidmatan kesihatan di kalangan wanita yang hidup dengan HIV di Malaysia
- b) Untuk memahami bagaimana penghapusan penularan ibu ke anak (EMTCT) dapat dikekalkan
- c) Untuk mengemukakan cadangan praktikal kepada pihak berkepentingan dalam menangani stigma dan diskriminasi terhadap wanita yang hidup dengan HIV.

Kelayakan penyertaan

Salah seorang kakitangan kajian akan membincangkan kelayakan untuk menyertai kajian ini. Adalah penting anda berterus terang dengan kakitangan tersebut.

Kelayakan umum adalah

- a) Dewasa (18 tahun ke atas).
- b) Warganegara Malaysia.
- c) Mampu berkomunikasi dengan baik.
- d) Mempunyai aksesori telefon pintar dan internet.

Kelayakan untuk wanita yang hidup dengan HIV adalah

- a) Wanita yang hidup dengan HIV yang menggunakan khidmat kesihatan Kementerian Kesihatan Malaysia dari Januari 2018 hingga Julai 2021:

- Wanita antenatal yang hidup dengan HIV.
 - Wanita selepas bersalin yang hidup dengan HIV.
- b) Kawasan geografi: Mewakili semua wilayah di Semenanjung Malaysia (Utara, Tengah, Timur dan Selatan).

Kelayakan bagi kakitangan kesihatan adalah

- a) Kakitangan kesihatan yang berkhidmat di bahagian HIV/ AIDS dengan Kementerian Kesihatan Malaysia dari Januari 2018 hingga Julai 2021.
- b) Bekerja di dalam bahagian perkhidmatan HIV/ AIDS di peringkat: Pusat, Negeri atau Daerah.
- c) Kawasan geografi: Mewakili semua wilayah di Semenanjung Malaysia [Utara, Tengah, Timur, Selatan dan Sabah dan Sarawak].

Prosedur-prosedur kajian

Anda telah dikenalpasti oleh pasukan penyelidik sebagai peserta yang layak dalam kajian ini mengikut kategori wanita yang hidup dengan HIV. Sekiranya anda bersetuju untuk turut serta di dalam kajian ini, anda perlulah memberi persetujuan bertulis dengan cara menandatangani borang keizinan responden yang dilampirkan.

Kajian ini akan dijalankan melalui kaedah: perbincangan kumpulan fokus secara dalam talian mengenai beberapa aspek penting berkaitan perkhidmatan kesihatan kepada wanita yang hidup dengan HIV. Sekiranya ada terpilih sebagai peserta kajian, anda akan diberi tarikh temujanji untuk hadir secara dalam talian pada tarikh yang sesuai. Perbincangan itu nanti akan berkisar tentang beberapa soalan berkaitan program perkhidmatan kesihatan kepada wanita yang hidup dengan HIV dan dipermudahkan oleh tim penyelidik.

Tempoh bagi kaji selidik melalui kaedah tersebut dijangka berlangsung selama satu setengah hingga dua jam. Para peserta akan diberi honorarium atas masa yang diberikan untuk sesi temubual.

Jika anda mempunyai sebarang kemosyikilan atau tidak memahami apa-apa aspek dalam kaji-selidik tersebut, anda bolehlah merujuk masalah tersebut kepada penyelidik yang akan sentiasa berada di situ bagi membantu anda.

Risiko

Tiada sebarang risiko fizikal yang bakal anda hadapi sekiranya menyertai penyelidikan ini kerana ianya tidak melibatkan aktiviti mengambil darah atau lain-lain prosedur kepada badan. Walau bagaimanapun, sekiranya anda mengalami apa-apa tekanan perasaan atau gangguan emosi semasa sesi perbincangan kumpulan fokus secara dalam talian, anda boleh dirujuk kepada kumpulan sokongan pilihan anda, kaunselor atau doktor yang sesuai mengikut kehendak anda.

Kami juga akan sentiasa memastikan pengenalan diri anda dirahsiakan oleh semua yang terlibat dalam penyelidikan ini.

Sila maklumkan kepada kakitangan kajian sekiranya anda menghadapi sebarang masalah atau mempunyai sebarang maklumat penting yang mungkin mengubah persetujuan anda untuk terus menyertai kajian ini.

Melaporkan pengalaman kesihatan (Jika Kajian Melibatkan Kesihatan Sahaja)

Sila hubungi kakitangan berikut pada bila-bila masa sekiranya anda mengalami sebarang masalah kesihatan, samada berkaitan atau tidak berkaitan dengan kajian ini.

Dr Zaharah Sulaiman (no. Pendaftaran Penuh Majlis Perubatan Malaysia: 36457) di talian 09-767 6886 secepat mungkin.

Penyertaan dalam kajian

Penyertaan anda dalam kajian ini adalah secara sukarela. Anda berhak menolak untuk menyertai kajian ini atau menamatkan penyertaan anda pada bila-bila masa, tanpa sebarang kehilangan manfaat yang sepatutnya anda perolehi.

Penyertaan anda juga mungkin boleh diberhentikan oleh kakitangan kajian ini tanpa persetujuan anda sekiranya anda didapati tidak sesuai untuk meneruskan kajian ini berdasarkan protokol kajian. Kakitangan kajian akan memaklumkan anda sekiranya anda perlu diberhentikan dari menyertai kajian ini.

Manfaat yang mungkin

Kajian ini adalah penting kerana:

- a) Maklumat-maklumat yang bakal diperolehi nanti dapat membantu Kementerian Kesihatan Malaysia dan pihak-pihak berkenaan meningkatkan lagi mutu perkhidmatan dan pengurusan dalam pencegahan jangkitan HIV serta penyakit AIDS dalam kalangan wanita, ibu mengandung dan anak yang lahir di negara kita ini.
- b) Melalui perbincangan kumpulan fokus secara dalam talian, kaji selidik ini juga dapat memberi peluang kepada individu, pesakit atau pengguna yang berkaitan dalam menyuarakan pandangan, cadangan dan keperluan mereka secara lebih terperinci dalam semua aspek yang berkaitan dalam program ini.
- c) Kaji selidik ini juga dapat membantu pihak pengurusan hospital atau klinik termasuklah pegawai pegawai perubatan yang merawat anda dalam menilai impak rawatan, prosedur dan intervensi ke atas kualiti kehidupan wanita dan kanak-kanak yang hidup dengan HIV.
- d) Anda tidak akan menerima sebarang pampasan kerana menyertai kajian ini.

Persoalan

Sekiranya anda mempunyai sebarang soalan mengenai prosedur kajian ini atau hak-hak anda, sila hubungi:

Prof. Madya Dr Zaharah Sulaiman (MMC no: 36457), Unit Perkembangan Kesihatan Wanita, Pusat Pengajian Sains Perubatan, USM Kampus Kesihatan

Sekiranya anda mempunyai sebarang soalan berkaitan kelulusan Etika atau sebarang pertanyaan dan masalah berkaitan kajian ini, sila hubungi:

En. Mohd Bazlan Hafidz Mukrim, Setiausaha Jawatankuasa Etika Penyelidikan (Manusia) USM, Bahagian Penyelidikan dan Inovasi, USM Kampus Kesihatan; 09-767 2354/09-767 2362

Atau:

Cik Nor Amira Khurshid Ahmed, Sekretariat Jawatankuasa Etika Penyelidikan (Manusia) USM, Pejabat Pengurusan dan Kreativiti Penyelidikan, USM Kampus Induk, Pulau Pinang; 04-653 6537

Kerahsiaan

Maklumat yang anda berikan akan dirahsiakan oleh kakitangan kajian. Ianya tidak akan dedahkan secara umum melainkan jika ia dikehendaki oleh undang-undang.

Data yang diperolehi dari kajian ini tidak akan mengenalpasti anda secara perseorangan. Hasil kajian mungkin akan diterbitkan untuk tujuan perkongsian ilmu.

Semua borang kajian dan data yang anda berikan yang asal mungkin akan disemak oleh pihak penyelidik, Lembaga Etika kajian ini dan pihak berkuasa regulatori bagi tujuan mengesahkan prosedur dan/atau data kajian klinikal. Maklumat anda akan disimpan dalam komputer dan hanya kakitangan kajian yang dibolehkan sahaja dibenarkan untuk mendapatkan dan memproses data tersebut.

Dengan menandatangani borang persetujuan ini, anda membenarkan penelitian rekod, penyimpanan maklumat dan pemrosesan data seperti yang diuraikan di atas.

Tandatangan

Untuk dimasukkan ke dalam kajian ini, anda atau wakil sah anda mesti menandatangani serta mencatatkan tarikh halaman tandatangan (Lihat contoh Borang Keizinan Peserta di LAMPIRAN S atau LAMPIRAN G (untuk sampel genetik) atau LAMPIRAN P).

LAMPIRAN S

Borang Keizinan Peserta (Halaman Tandatangan)

Tajuk Kajian: Penilaian Kualitatif Mengenai Kesihatan Dan Hak Seksual Dan Reproduktif, Dan Akses Perkhidmatan Kesihatan Terhadap Wanita yang hidup dengan HIV di Malaysia

Nama penyelidik utama: Prof Madya Dr Zaharah Sulaiman (MMC No: 36457)
Nama penyelidik bersama: Prof Madya Dr. Norhayati Mohd Noor (MMC No: 35994)
Dr Noor Aman A Hamid (MMC No: 63187)
Dr Surianti Sukeri

Untuk menyertai kajian ini, anda atau wakil sah anda mesti menandatangani mukasurat ini. Dengan menandatangani mukasurat ini, saya mengesahkan yang berikut:

- Saya telah membaca semua maklumat dalam Borang Maklumat dan Keizinan Pesakit ini **termasuk apa-apa maklumat berkaitan risiko yang ada dalam kajian** dan saya telah pun diberi masa yang mencukupi untuk mempertimbangkan maklumat tersebut.
- Semua soalan-soalan saya telah dijawab dengan memuaskan.
- Saya, secara sukarela, bersetuju menyertai kajian penyelidikan ini, mematuhi segala prosedur kajian dan memberi maklumat yang diperlukan kepada doktor, para jururawat dan juga kakitangan lain yang berkaitan apabila diminta.
- Saya boleh menamatkan penyertaan saya dalam kajian ini pada bila-bila masa.
- Saya telah pun menerima satu salinan Borang Maklumat dan Keizinan Peserta untuk simpanan peribadi saya.

Nama Peserta

No. Kad Pengenalan Peserta

Tandatangan Peserta atau Wakil Sah

Tarikh (dd/MM/yy)
(Masa jika perlu)

Nama & Tandatangan Individu yang Mengendalikan Perbincangan Keizinan

Tarikh (dd/MM/yy)

Nama Saksi dan Tandatangan

Tarikh (dd/MM/yy)

Nota: i) Semua peserta yang mengambil bahagian dalam projek penyelidikan ini tidak dilindungi insuran.

LAMPIRAN P

Borang Keizinan bagi Penerbitan Bahan yang berkaitan dengan Peserta Kajian (Halaman Tandatangan)

Tajuk Kajian: Penilaian Kualitatif Mengenai Kesihatan Dan Hak Seksual Dan Reproduktif, Dan Akses Perkhidmatan Kesihatan Terhadap Wanita yang hidup dengan HIV di Malaysia

Nama penyelidik utama: Prof Madya Dr Zaharah Sulaiman (MMC No: 36457)
Nama penyelidik bersama: Prof Madya Dr. Norhayati Mohd Noor (MMC No: 35994)
Dr Noor Aman A Hamid (MMC No: 63187)
Dr Surianti Sukeri

Untuk menyertai kajian ini, anda atau wakil sah anda mesti menandatangani mukasurat ini.

Dengan menandatangani mukasurat ini, saya memahami yang berikut:

- Bahan yang akan diterbitkan tanpa dilampirkan dengan nama saya dan setiap percubaan yang akan dibuat untuk memastikan ketanpanamaan saya. Saya memahami, walaubagaimanapun, ketanpanamaan yang sempurna tidak dapat dijamin. Kemungkinan sesiapa yang menjaga saya di hospital atau saudara dapat mengenali saya.
- Bahan yang akan diterbitkan dalam penerbitan mingguan/bulanan/dwibulanan/suku tahunan/dwi tahunan merupakan satu penyebaran yang luas dan tersebar ke seluruh dunia. Kebanyakan penerbitan ini akan tersebar kepada doktor-doktor dan juga bukan doktor termasuk ahli sains dan ahli jurnal.
- Bahan tersebut juga akan dilampirkan pada laman web jurnal di seluruh dunia. Sesetengah laman web ini bebas dikunjungi oleh semua orang.
- Bahan tersebut juga akan digunakan sebagai penerbitan tempatan dan disampaikan oleh ramai doktor dan ahli sains di seluruh dunia.
- Bahan tersebut juga akan digunakan sebagai penerbitan buku oleh penerbit jurnal.
- Bahan tersebut tidak akan digunakan untuk pengiklanan ataupun bahan untuk membungkus.

Saya juga memberi keizinan bahawa bahan tersebut boleh digunakan sebagai penerbitan lain yang diminta oleh penerbit dengan kriteria berikut:

- Bahan tersebut tidak akan digunakan untuk pengiklanan atau bahan untuk membungkus.
- Bahan tersebut tidak akan digunakan di luar konteks – contohnya: Gambar tidak akan digunakan untuk menggambarkan sesuatu artikel yang tidak berkaitan dengan subjek dalam foto tersebut.

Nama Peserta

No. Kad Pengenalan Peserta

T/tangan Peserta

Tarikh (dd/MM/yy)

Nama & Tandatangan Individu yang Mengendalikan
Perbincangan Keizinan

Tarikh (dd/MM/yy)

Nota: i) Semua peserta yang mengambil bahagian dalam projek penyelidikan ini tidak dilindungi insuran.

Annex 12

Research team attendance log

Meeting no.	Date	Time	Session	Hours	LM	SAH	RH	ZS	AI	SS	NAH	NMN
1	10 August 2021	9.00am	Workshop 1	7	/	/	/	/	/	/	/	
2	14 August 2021	11.00am	Pilot session: focus group discussion, postnatal	2	/		/	/	/			
3	14 August 2021	12.30pm	Post-pilot session meeting	1	/	X	/	/	/	X	/	
4	15 August 2021	9.00am	Sunday morning meeting	2	/	/	/	/	/	/	/	
5	16 August 2021	9.00am	Session 1: in-depth interview, general	1.5		/				/		
6	16 August 2021	11.30am	Post-session 1 meeting	1	/	/	X	/	/	/	/	
7	17 August 2021	9.00am	Session 2: focus group discussion, general	2	/	/		/	/			
8	17 August 2021	12.15pm	Post-session 2 meeting	1	/	/	X	/	/	X	/	
9	18 August 2021	9.00am	Session 3: in-depth interview, general	1			/			/		
10	18 August 2021	11.15am	Post-session 3 meeting	1	/	X	/	/	/	/	X	
11	19 August 2021	9.00am	Session 4: focus group discussion, general	2	/	/		/	/			
12	19 August 2021	12.00pm	Post-session 4 meeting	1	/	/	/	/	/	/	X	
13	21 August 2021	11.00am	Session 5: focus group discussion, general	2	/	/		/	/			
14	21 August 2021	1.00pm	Post-session 5 meeting	1	/	/	X	/	/	X	X	
15	22 August 2021	9.00am	Sunday morning meeting	2	/	X	X	/	/	/	/	
16	23 August 2021	9.00am	Session 6: focus group discussion, general	2.5	/	/		/	/			
17	23 August 2021	12.15pm	Post-session 6 meeting	1	/	/	/	/	/	/	/	

Meeting no.	Date	Time	Session	Hours	LM	SAH	RH	ZS	AI	SS	NAH	NMN
18	24 August 2021	9.00am	Session 7: in-depth interview, antenatal	1.5	/					/		
19	24 August 2021	1.00pm	Post-session 7 meeting	1	/	X	X	/	/	/	X	
20	25 August 2021	9.00am	Session 8: in-depth interview, antenatal	1.5	/		/			/		
21	25 August 2021	1.00pm	Post-session 8 meeting	1	/	X	/	/	/	/		/
22	26 August 2021	9.00am	Session 9: focus group discussion, antenatal	2.5	/		/	/	/			
23	26 August 2021	1.00pm	Post-session 9 meeting	1	/	X	/	/	/	X	X	
24	29 August 2021	9.00am	Sunday morning meeting and workshop 2	4	/	/	/	/	/	/		
25	30 August 2021	9.00am	Session 10: focus group discussion, antenatal	2.5	/		/	/	/			
26	30 August 2021	1.00pm	Post-session 10 meeting	1	/	/	/	/	/	X		/
27	1 September 2021	9.00am	Session 11: focus group discussion, antenatal	1.5	/		/	/	/			
28	1 September 2021	12.30pm	Post-session 11 meeting	1	/	/	/	/	/	X	X	
29	2 September 2021	9.00am	Session 12: in-depth interview, antenatal	1.5		/					/	
30	2 September 2021	12.00pm	Post-session 12 meeting	1	/	/	/	/	/	/		/
31	3 September 2021	9.00am	Session 13: in-depth interview, postnatal	1.5hr		/					/	
32	3 September 2021	11.30am	Post-session 13 meeting	1	/	/	/	/	/	/		/
33	3 September 2021	3.00pm	Workshop 3	2	/	/	/	/	/	/		/
34	4 September 2021	11.00am	Session 14: focus group discussion, postnatal	2		/	/	/	/			
35	4 September 2021	3.00pm	Session 15: in-depth interview, postnatal	1		/	/					

Meeting no.	Date	Time	Session	Hours	LM	SAH	RH	ZS	AI	SS	NAH	NMN
36	4 September 2021	5.00pm	Post-sessions 14 and 15 meeting	2	/	/	/	/	/	/	/	
37	5 September 2021	9.00am	Additional session 1: in-depth interview, general	1		/	/	/				
38	5 September 2021	11.00am	Additional session 2: in-depth interview, postnatal	1	/			/				
39	5 September 2021	1.00pm	Post-additional session 1 and 2 meeting and Sunday afternoon meeting	2	/	/	/	/	/	/	/	
40	6 September 2021	9.00am	Session 16: focus group discussion, postnatal	2	/		/	/	/			
41	6 September 2021	12.30pm	Post-session 16 meeting	1	/	X	/	/	/	/	x	
42	7 September 2021	9.00am	Session 17: focus group discussion, postnatal	2		/	/	/	/			
43	7 September 2021	12.30pm	Post-session 17 meeting	1	/	/	/	/	/	x	x	
44	8 September 2021	9.00am	Session 18: in-depth interview, postnatal	1			/			/		
45	8 September 2021	12.15pm	Post-session 18 meeting	1	/	X	/	/	/	/	/	
46	9 September 2021	2.00pm	Session 19: in-depth interview, postnatal	2		/						
47	9 September 2021	4.00pm	Post-session 19 meeting	1	/	/	X	/	/	/	/	
48	11 September 2021	10.00am	Session 20: focus group discussion, antenatal	2	/		/	/	/			
49	11 September 2021	12.30pm	Post-session 20 meeting	1	/	/	/	/	/	x	/	
50	12 September 2021	10.00am	Sunday morning meeting	3	/	/	/	/	/	/	/	
51	13 September 2021	9.00am	Session 21: focus group discussion, postnatal	2	/		/	/	/			
52	13 September 2021	12.00pm	Post-session 21 meeting	1	/	/	/	/	/	/	/	
53	14 September 2021	9.00am	Session 22: focus group discussion, postnatal	2	/	/		/	/			

Meeting no.	Date	Time	Session	Hours	LM	SAH	RH	ZS	AI	SS	NAH	NMN
54	14 September 2021	12.30pm	Post-session 22 meeting	1	/	/	/	/	/	/	/	
55	15 September 2021	9.00am	Session 23: focus group discussion, healthcare providers	1.5				/	/	/	/	
56	15 September 2021	12.00pm	Post-session 23 meeting	1	/	/	/	/	/	/	/	
57	17 September 2021	9.00am	Session 24: focus group discussion, healthcare providers	1.5				/	/	/	/	
58	17 September 2021	12.15pm	Post-session 24 meeting	1	/	/	/	/	/	/	/	
59	19 September 2021	9.00am	Sunday morning meeting	3				/	/	/	/	/
60	19 September 2021	12.00pm	Sunday afternoon meeting	1	/	X	/	/	/	/	X	
61	26 September 2021	9.00am	Sunday morning meeting	3				/	/	/	/	/
62	26 September 2021	12.00pm	Sunday afternoon meeting	2	/	/	/	/	/	/	/	
63	3 October 2021	4.30pm	Sunday morning meeting	1	/	/	/	/	/	X	X	

Not required to attend

/ Present

X Absent

AI: Siti Aishah Ibrahim; LM: Lina Muhammad; NAH: Noor Aman A Hamid; NMN: Norhayati Mohd Noor; RH: Revathi a/p Harikrishnan; SAH: Siti Fazariah Abdul Hamid; SS: Surianti Sukeri; ZS: Zaharah Sulaiman.

Annex 13

Form to collect background information of women living with HIV (English version)

Form filled by:

General information about data collection session

Day/time:

Date:

Session type:

Category:

State:

Region:

Information about respondent

Name:

Participant ID:

Age:

Race:

Religion:

Year of HIV diagnosis:

Education level:

Occupation:

Monthly income:

Health status:

Marital status:

Number of children:

Information about spouse

Age:

Race:

Religion:

Education level:

Occupation:

Health status:

HIV status:

Annex 14

Form to collect background information of women living with HIV (Bahasa Malaysia version)

Borang diisi oleh:

Maklumat umum mengenai sesi pengumpulan data

Hari/masa:

Tarikh:

Jenis sesi:

Kategori:

Negeri:

Wilayah:

Maklumat responden

Nama:

ID peserta:

Umur:

Bangsa:

Agama:

Diagnosis tahun:

Tahap pendidikan:

Pekerjaan:

Pendapatan bulanan:

Status kesihatan:

Status perkahwinan:

Bil anak:

Maklumat pasangan/suami

Umur:

Bangsa:

Agama:

Tahap pendidikan:

Pekerjaan:

Status kesihatan:

Status HIV:Annex 15

Data-collection sessions

Session	Date	Day, time	Session type	Category	Moderator	Co-moderator	Observer
SP	14 August 2021	Saturday, 11am	Focus group discussion	Postnatal	ZS	LM	RH, AI
S1	16 August 2021	Monday, 9am	In-depth interview	General	SS	SAH	—
S2	17 August 2021	Tuesday, 9am	Focus group discussion	General	ZS	SAH	LM, AI
S3	18 August 2021	Wednesday, 9am	In-depth interview	General	SS	RH	—
S4	19 August 2021	Thursday, 9am	Focus group discussion	General	ZS	LM	SAH, AI
S5	21 August 2021	Saturday, 11am	Focus group discussion	General	ZS	SAH	LM, AI
S6	23 August 2021	Monday, 9am	Focus group discussion	General	ZS	LM	SAH, AI
S7	24 August 2021	Tuesday, 9am	In-depth interview	Antenatal	SS	LM	—
S8	25 August 2021	Wednesday, 9am	In-depth interview	Antenatal	SS	RH	LM
S9	26 August 2021	Thursday, 9am	Focus group discussion	Antenatal	ZS	LM	RH, AI
S10	30 August 2021	Monday, 9am	Focus group discussion	Antenatal	ZS	LM	RH, AI
S11	1 September 2021	Wednesday, 9am	Focus group discussion	Antenatal	ZS	RH	LM, AI
S12	2 September 2021	Thursday, 9am	In-depth interview	Antenatal	SS	SAH	—
S13	3 September 2021	Friday, 9am	In-depth interview	Postnatal	SS	SAH	—
S14	4 September 2021	Saturday, 11am	Focus group discussion	Postnatal	ZS	RH	SAH, AI
S15	4 September 2021	Saturday, 3pm	In-depth interview	Postnatal	ZS	SAH	—
ST1	5 September 2021	Sunday, 9am	In-depth interview	General	RH	ZS	—
ST2	5 September 2021	Sunday, 11am	In-depth interview	Postnatal	LM	ZS	—
S16	6 September 2021	Monday, 9am	Focus group discussion	Postnatal	ZS	LM	RH, AI
S17	7 September 2021	Tuesday, 9am	Focus group discussion	Postnatal	ZS	SAH	RH, AI
S18	8 September 2021	Wednesday, 9am	In-depth interview	Postnatal	SS	RH	—
S19	9 September 2021	Thursday, 9am	In-depth interview	Postnatal	SS	SAH	—
S20	11 September 2021	Saturday, 10am	Focus group discussion	Antenatal	ZS	RH	LM, AI
S21	13 September 2021	Monday, 9am	Focus group discussion	Postnatal	ZS	LM	RH, AI
S22	14 September 2021	Tuesday, 9am	Focus group discussion	Postnatal	ZS	SAH	LM, AI
S23	15 September 2021	Wednesday, 9am	Focus group discussion	Healthcare providers	NAH	ZS	SS, AI
S24	17 September 2021	Friday, 9am	Focus group discussion	Healthcare providers	NAH	ZS	SS, AI

AI: Siti Aishah Ibrahim; LM: Lina Muhammad; NAH: Noor Aman A Hamid; RH: Revathi a/p Harikrishnan; SAH: Siti Fazariah Abdul Hamid; SS: Surianti Sukeri; ZS: Zaharah Sulaiman.

Annex 16

Participants' feedback

Participant	Feedback (Bahasa Malaysia)	English translation
R4SP	Dr Z ok je, baik orangnya, terima kasih cakap dekat Dr Z sanggup dengar luahan dan masalah hati kecil macam kita. Soalan bagus ok je, selesa sangat-sangat, dapat pengalaman dari sahabat-sahabat lain, dan tak lupa juga ribuan terima kasih bagi saguhati dekat kita semua.	Dr Z was OK; she was nice. Thank you to Dr Z for listening to our feelings and problems. The questions were fine, I felt comfortable, and I got to listen to the experiences of my peers. Thank you too for giving us the honorarium.
R10S2	Syok pula bila orang share pengalaman masing-masing, bagi semangat. Suka sangat dengan Dr Z, selesa sangat cakap dengan Dr Z.	It was interesting to hear each person sharing her experiences; it was motivating. I like Dr Z; it was comfortable talking to her.
R11S2	Terima kasih bagi peluang menjayakan program ni, boleh lah sikit untuk motivasi.	Thank you for giving me an opportunity to participate in this programme; it motivated me a little.
R13S4	Semua, alhamdulillah. Dr Z pun tanya ok saja, cara dia cakap pun tak ada ayat yang terasa, lembut saja cara dia, jelas dan faham. Tak lama pun sesi, rasa macam nak cakap lagi ada lah. Suka dapat dengar pengalaman yang lain, dapat kongsi kisah hidup cerita masing-masing. Selesa saja cuma saya rasa malu pula menangis hari tu, balik tu fikir lagi sebab ape ternangis.	Praise be to God for everything. Dr Z's questions were OK. I was not offended by her words or manners; she was gentle, clear and understandable. The session was not that long; I actually felt that I wanted to keep on talking. I was happy to be able to listen to the experiences of others, and to share our stories. It was comfortable, but now I feel embarrassed that I cried during the session. I could not remember why I did so.
R14S4	Semuanya ok, selesa, macam sekejap saja masa hari tu.	Everything was OK, comfortable. The time went by quickly during the session.
R17S4	Saya kongsi apa yang terjadi dekat saya, ikhlas saya berkongsi sebab saya nak yang lain kuat macam saya, saya seronok berkongsi sama-sama.	I shared what happened to me. I sincerely shared because I want others to be strong like me. I felt good sharing with others.
R20S5	Dr Z ok, dia tanya soalan semua ada makna, soalan jelas, dia faham dengan jawapan saya. Saya sangat selesa, boleh luahkan apa yang terbuku dalam hati selama ini.	Dr Z was OK. She asked meaningful questions and they were clear; she understood what I was trying to say. I was very comfortable; I could express what I have been bottling in my heart all this while.
R21S5	Ok, puas hati, jelas dan mudah difahami. Selesa sangat.	It was OK. I was satisfied with the session and the questions were clear and easy to understand. I was very comfortable.
R26S6	Dr Z ok and sangat open-minded, soalan pun jelas dan saya mudah faham. Masa tu tak lama sangat, saya selesa saja sharing sebab ramai kenalan yang ada pengalaman macam saya juga, jadi pemikiran lebih terbuka.	Dr Z was OK. She was open-minded. The questions were clear and easy to understand. The session did not take too long. I was comfortable with sharing because there were other women with similar experiences, so they were not judgemental.
R27S6	Seronok dapat sembang dengan doktor.	It was enjoyable to speak with the doctor.
R28S7	Ok saja Dr S tanya, semua soalan yang diajukan saya faham, tak ambil masa lama pun, saya selesa saja.	Dr S was fine. I understood all the questions she asked. It didn't take too long and I was comfortable in the session.

Participant	Feedback (Bahasa Malaysia)	English translation
R31S9	Seronok dapat dengar kawan-kawan yang lain kongsi pengalaman. Saya suka dengan sesi, seronok sangat dapat kongsi pengalaman masing-masing dan semua peserta yang ada semalam wanita yang hebat dan sentiasa positif vibes.	It was rather enjoyable to listen to my peers sharing their experiences. I liked the session. Each one of us got to share our experiences. All those women in the session are strong, great women with positive vibes.
R34S10	Alhamdulillah. Terima kasih tak terhingga sebab sudi mendengar luahan, rasa lega sebab dapat luah.	Praise be to God. Thank you very much for listening to my experiences. I felt relieved because I was able to share my feelings.
R35S10	Soalan jelas dan ok, bagi saya tidak sensitif nak jawab sebab kawan-kawan yang bercakap pun semua HIV macam saya. Masa tak panjang sangat dan saya selesa dalam sesi.	The questions were clear and OK to me—not too sensitive for me to answer because other participants in the session were also women living with HIV like me. The session did not take too long and I felt comfortable.
R36S10	Interview ok, boleh share experience.	The interview was OK. I could share my experiences.
R37S10	Saya rasa bila saya join ini, saya rasa sedikit lega sebab sepanjang saya menghidap penyakit ini, saya rasa kenapa kerajaan tak pernah buat benda macam ini kan. Rasanya benda ini sepatutnya dari dulu lagi patut dibuat untuk golongan yang macam kamilah. Tapi bersyukur sebab ada juga yang dapat dengar keluhan orang-orang macam kamilah. Saya rasa ini patut diteruskan sampai bila-bila.	I felt relieved when I joined the session because as long as I have been living with HIV, I was wondering why the government never did something like this. I think this programme should have been done a long time ago for people like us. I felt grateful that somebody is willing to listen to our complaint. I think this programme should be continued.
R38S11	I hope my participation can benefit other mothers.	
R39S11	Terima kasih sebab tak pandang sebelah mata pada orang macam saya ini. Alhamdulillah, saya rasa bersyukur ada yang sudi amik berat dan mendengar luahan kami, saya happy sangat.	Thank you for not looking down upon people like me. Praise be to God, I feel happy and grateful that there are others out there who are concerned about us and are willing to listen to what we have to say.
R40S11	Ok, sporting semuanya. Terima kasih, semoga dimurahkan rezeki semuanya.	OK—everything was so laidback. Thank you—may everyone be blessed.
R42S13	Banyak puas hati, dapat meluahkan perasaan, kongsi pengalaman, banyak dapat information.	I felt really satisfied to be able to express how I feel, share my experiences and also obtain a lot of information.
R44S14	Saya ok saja, seronok juga dengar pengalaman dari orang lain.	I felt OK. It was enjoyable to listen to others' experiences.
R45S14	Semua soalan jelas dan faham, tak ada soalan yang sensitif dan tak ada soalan yang tak patut ditanya. Masa dekat 2 jam tapi bila berbual tak terasa masa tu macam panjang, rasa macam sekejap saja, selesa sangat-sangat masa sharing tadi.	All the questions were clear and easily understood; none was too sensitive or irrelevant. The session was almost two hours long but time flew by really quickly when we were chit-chatting. I felt very comfortable sharing with others.
R46S14	Sungguh bermanfaat ilmu tadi dan dapat berkongsi masalah walaupun tak kenal doktor dan kawan-kawan yang lain.	The session was beneficial, and I got to share my problems, even though I did not personally know the doctor and other people there.
R47S15	Semua ok, soalan jelas dan selesa bercerita. Terima kasih.	Everything was OK. The questions were clear, I felt comfortable sharing my story with others. Thank you.
R48A1	Nervous sikit nak cakap sebab first time sharing secara online. Semasa sesi rasa ok, selesa.	I was nervous to share my experiences because it was the first time for me doing it virtually, but during the session I felt OK and comfortable.
R49A2	Ok semua, saya senang bercerita dengan mereka, seronok.	Everything was OK. I felt at ease sharing my story with them. Enjoyable.
R50S16	So far okay saja, soalan pun okay tak ada masalah. Terima kasih bagi saya peluang untuk bercerita serba sedikit dalam kajian ini.	So far, it was OK. Questions were OK too, no problem. Thank you for giving me an opportunity to share a little in this research.

Participant	Feedback (Bahasa Malaysia)	English translation
R51S16	Rasa sangat lega sebab boleh kenal dengan wanita yang senasib dengan saya dan boleh kongsi pengalaman. Rasa sangat positif dan kuat lagi untuk teruskan hidup dan menghadapi masalah seperti saya ini di kalangan masyarakat.	It was such a relief because I got to know other women like me, and we could share our experiences. It made me feel positive and motivated me to keep going and deal with the problems I face in society.
R53S16	Selesa sangat...ok tak ada masalah dari segi soalan, saya faham and jelas, Dr pun ok, sporting, saya suka.	It was comfortable—no problem with regard to the questions—they were clear and I could understand well. The doctor was also OK, laidback; I liked it.
R54S16	Saya rasa selesa juga, cuma agak kekok sikitlah. Tak tahu nak bercerita dari mana, tak banyak benda yang saya kongsikan tadi. Apa yg Prof ingin tahu, itulah yang saya sampaikan. Tapi syukur, lega jugalah, sekurang-kurangnya ada juga yang sama macam saya, senasib dengan saya. Seronok dengan perkongsian rakan-rakan yang lain. Walaupun ada yang saya tak faham bahasa mereka, tapi dapat juga tangkap maksud mereka.	I felt at ease, just a little awkward—I didn't know where to begin. I probably didn't share much just now. I just answered what the professor asked. But it was a relief to hear about other women like me—at least we are in the same boat. I enjoyed listening to the experiences of others, even though I did not really understand their dialect, but I could fathom what they meant.
R55S17	Seronok dapat join tadi tapi masa mula-mula nak start ada juga berasa sebak dengar cerita-cerita kawan-kawan yang lain.	It was enjoyable, but in the beginning, I was choked with tears when I listened to the stories of my friends here.
R56S17	Actually, macam short kan, but I hope Dr dapat all the info she needs for the research. Saya rasa quite shocked dengar experience yang lain, zaman ni ada lagi diskriminasi macam ini. Rasa macam sesi hari ini sangat-sangat membuka minda, tak pernah dengar experience orang lain living with HIV. Nanti kalau sudah siap research boleh lah share-share, teringin nak baca.	The session actually felt quite short, but I hope the doctor got all the information she needed for the research. I felt quite shocked when I heard of others' experiences; I can't believe discrimination still exists these days. I felt that today's session really opened up my mind. I have never listened to the experiences of other people living with HIV before. When the research is done, please share it with me—I would like to read about it.
R57S17	Soalan jelas, cuma saya yang segan, tak biasa ditemuramah. Rasa lega lepas cerita sebab ada yang sudi mendengar apa yang saya rasakan selama ini. Semoga dengan perkongsian tadi, pihak kesihatan dapat menambah baik perkhidmatan terhadap pesakit seperti kami.	The questions were clear, but I was shy—I am not used to being interviewed. I felt relieved after sharing my story because there are others who are willing to listen to how I feel all this while. Hopefully, with this sharing, the health authority can improve their services for people like us.
R60S18	I'm very happy to share my experiences. I get knowledge from the doctor about RVD.	
R61S19	Soalan semua tadi pun okay sahaja dengan Dr S yang friendly dan memahami. Alhamdulillah, semoga memberi manfaat untuk masa hadapan. Overall, sesi semalam ok dan berbincang secara santai dan tiada pun soalan-soalan yang mengguris hati. Moderator pendengar yang bagus.	The questions were all OK. Dr S was friendly and understanding. Praise be to God, hopefully, this session will benefit others in the future. Overall, the session was OK; the discussion was relaxed and the questions did not hurt my feelings. The moderator was a good listener.
R62S20	Terima kasih juga luangkan masa dan mendengar luahan hati saya dengan penyakit saya ini.	Thank you for spending the time to listen to how I feel about my condition.
R63S20	Dr Z tak ada tanya benda-benda yang personal, selesa lah.	Dr Z never asked about personal matters. I was at ease.
R65S20	Soalan jelas, mudah difahami dan skill komunikasi pihak yang menjalankan kajian buat saya selesa untuk berkongsi.	The questions were clear and understandable, and the communication skills of the research team made me comfortable in sharing my experiences.
R67S21	Suka lah benda macam ini, boleh dengar cerita orang-orang kan, pengalaman mereka. Rupanya pengalaman mereka tak sama pun macam saya punya. Mereka punya macam sedih saja cerita, sedih juga dengar. Kalau ada lagi benda macam ini, nak saja join, sebab boleh kongsi cerita masing-masing kan.	I like this sort of thing because I can listen to the stories from other people and their experiences. Now I know their experiences were not similar to mine; their stories were heart-breaking. I felt upset when I heard them. If there is a programme like this in the future, I would like to join, because we can share our stories together.

Participant	Feedback (Bahasa Malaysia)	English translation
R68S21	<p>Terima kasih menjemput saya untuk menyertai program berkongsi cerita suka duka serta stigma para petugas klinik dan hospital dengan pesakit RVD waktu mengandung sehingga kami bersalin. Seronok dapat bercerita dengan Prof yang baik masa mendengar cerita kami. Agar program seperti ini selalu dilakukan untuk pesakit-pesakit baru supaya tak merasa stigma yang kami rasa selama ini.</p>	<p>Thank you for inviting me to participate in this programme, sharing bittersweet stories and stigma from the healthcare staff that we experience during pregnancy and childbirth. I enjoyed talking to the professor—she was nice when listening to our stories. I hope programmes like this can be done often for new people, so they do not experience stigma like we have before.</p>
R69S21	<p>Selesa sangat sebab dapat meluahkan sedikit di hati, walaupun line keadaan tak ok.</p>	<p>Even though my internet connection was not optimum, I felt good as I got to share a little of how I feel.</p>
R70S22	<p>Terima kasih kepada pihak pengajur kerana menyediakan platform ini. Ini dapat memberi peluang hak bersuara kepada individu yang hidup dengan HIV yang sering dipinggirkan oleh masyarakat. Dalam program ini, kami diberi peluang untuk berkongsi pengalaman masing-masing yang pernah didiskriminasi oleh pihak petugas hospital mahupun klinik kesihatan. Sepanjang sesi di dalam group ini, pelbagai kisah hidup wanita HIV yang diperlakukan dan diberi layanan tidak setimpal seperti pesakit-pesakit lain.</p> <p>Diskriminasi bukan hanya cerita, ianya kenyataan yang dilalui oleh kami wanita-wanita HIV. Saya sendiri pernah melalui (diskriminasi) pelbagai kisah peristiwa yang sukar untuk dilupakan. Patah hati, patah semangat untuk terus berjuang hidup. Diskriminasi berlaku dari klinik kesihatan sehingga ke hospital, dari seorang jururawat hingga kepada doktor pelatih.</p> <p>Siapa yang harus kami cari apabila kami sakit? Ke mana harus kami pergi jika bukan hospital? Kami perlukan bantuan, mengapa harus melayan kami sebegini?</p> <p>Tolong jangan layan bayi kecil saya seperti saya. Dia dilahirkan sihat! Jika masyarakat melakukan diskriminasi terhadap kami, kami masih faham. Akan tetapi, apabila seorang jururawat atau doktor yang bertauliah memperlakukan kami sebegini, agak menyedihkan.</p> <p>Walaubagaimanapun bukan semua doktor atau jururawat begitu, hanya segelintir kecil. Bukan semua klinik kesihatan yang tidak dapat menerima kami. Ada klinik kesihatan yang melayan kami dengan baik sepanjang tempoh kandungan awal sehingga kami bersalin.</p> <p>Jangan pandang sinis terhadap pesakit seperti kami. Kami perlukan bantuan doktor sepanjang hidup kami. Tolong bantu kami.</p> <p>Terima kasih kepada hospital saya kerana tidak pernah jemu memberi rawatan terbaik buat saya. Terima kasih kepada pihak ID hospital yang merawat anak-anak saya dengan baik. Terima kasih kepada pihak USM kerana memberi perhatian terhadap kes-kes diskriminasi terhadap wanita HIV seperti kami. Jasa anda kami hargai.</p> <p>Kepada Prof, jutaan terima kasih kerana sama-sama mendengar pengalaman dan cerita pahit kami. Serta sokongan dan kata-kata semangat untuk kami</p>	<p>Thank you to the organizer for providing this platform. This gave us—people living with HIV who have been marginalized by society—an opportunity to voice out. This session gave us an opportunity to share our experiences of being discriminated against by healthcare staff, either in hospitals or in clinics. Throughout the session, I heard the life stories of women living with HIV who have been treated unfairly.</p> <p>Discrimination is not a fiction: it is a reality endured by us, women living with HIV. I have experienced discrimination and it was difficult to forget. I was heartbroken, too devastated to live. Discrimination occurred at many levels, from the clinic to the hospital, from the nurse to the trainee doctor.</p> <p>Who should we look for when we are ill? Where should we go to the hospital? We need help—why do we have to be treated this way?</p> <p>Please don't treat my baby like me—he was born healthy!</p> <p>If society discriminated against us, we could still understand. But when a qualified nurse or doctor treated us that way, it is depressing.</p> <p>Nevertheless, only a minority of doctors or nurses behaved this way. Not all clinics rejected us—there are those who treated us well throughout our pregnancy.</p> <p>Please don't be cynical towards us. We need doctors to help us throughout our lives. So please help us.</p> <p>Thank you to my hospital who never stops giving the best for me. Thank you also to the infectious diseases department for treating my children well.</p> <p>Thank you to the university for paying attention to women living with HIV who have been discriminated against like us. We really value your effort. Many thanks to the professor for listening to our sad stories and experiences. We appreciate your support and encouraging words for us to keep going.</p> <p>HIV will not be the death of me, but the scorn of society will kill me.</p>

Participant	Feedback (Bahasa Malaysia)	English translation
	terus berjuang melalui hari-hari akan datang. Saya tak akan mati sebab HIV, tapi saya akan mati dengan cemuhan masyarakat terhadap saya.	
R72S22	Sepanjang sesi semalam, semuanya jelas dari Dr Z bermula dari perkenalan sampai akhir. Semuanya jelas dan senang faham semua yang diterangkan. Semasa sesi tersebut saya berasa selesa sahaja kerana dapat berkongsi pengalaman sesama yang lain, saya berasa seperti meluahkan perasaan saya semalam, saya berasa lega, saya berasa tenang sangat, lagi-lagi ini pertama saya join sesi Zoom meeting. Dr Z pun sangat baik dari segi percakapan, semuanya saya suka, lembut saja. Perasaan saya dari mula sampai akhir saya sangat gembira dapat berkongsi pengalaman semasa bersalin, semasa menjalani rawatan bersama rakan yang senasib dengan saya, saya dapat mendengar banyak pengalaman dari rakan yang lain juga. Alhamdullilah semuanya berjalan dengan baik, saya pun selesa, inshaAllah kalau ada Zoom meeting sebegini saya ingin turut menyertai supaya saya lebih dapat banyak pengalaman. Terima kasih telah memberikan saya semangat dan penghargaan yang cukup bernilai bagi saya.	Everything was clear in the session, from the beginning until the end, I could easily understand what was explained. I felt comfortable during the session because I could share my experiences with others; I felt relieved and even calm as I could pour my feelings out, particularly because this was my first time joining a Zoom meeting. I like Dr Z; she was very gentle and polite. From the beginning until the end, I felt happy that I could share my experiences during birth and also my treatment journey with other women like me. I also got to hear their experiences. Praise be to God, everything went well, I was at ease during the session. God willing, if there is another Zoom meeting like this, I would like to join again so that I could get more experience. Thank you for giving me encouragement—your appreciation of me is invaluable.
H3S23	Thanks for having me in this session. Really learnt a few positive points on improving our management from the input of other participants.	
H7S23	Thank you to the research team for having me. Through this discussion, I have also obtained some new information from the perspective of a gynaecologist.	
H10S24	So far ok...cuma boleh divide slot untuk hospital setting and klinik kesihatan setting. Sebab flow tak sama, sesi mungkin akan jadi lebih pendek jika divide, sekadar pandangan. Apa pun I'm okay with that.	So far it was OK, but perhaps the slot could have been divided into two—hospital setting and clinic setting. Because the flow is not the same, and the session may have been shorter if it was separated. This is just my opinion, but anyway I'm OK with it.
H11S24	Sebenarnya ini pertama kali saya terlibat dalam isu perbincangan ini, sesi tadi amat menarik dan saya sangat bertuah dapat meluangkan masa dan bercerita tentang pengalaman yang kami hadapi semasa sesi klinik. Masa 2 jam rasanya sekejap apabila isu yang kita bincangkan sangat-sangat berguna dan boleh diperbaiki di tempat masing-masing. Inshallah saya juga minat jika ada next sesi lagi.	Actually, this is my first time being involved in a discussion like this. The session was very interesting and I felt fortunate to have been able to spend some time and talk about what we experienced in the clinic. These two hours of discussion felt really quick when the issue at hand was very important and can be used to improve the service at our facility. God willing, I would like to join the next session if there is any.
H12S24	Thank you sebab masukkan saya dalam program ini; soalan-soalan ok saja, tak ada masalah.	Thank you for letting me participate in this programme; the questions were fine, no problem.
H13S24	Alhamdulillah, melalui zoom tadi kami boleh kongsi pengalaman macam mana nak handle orang yang hidup dengan HIV. Lain tempat lain cara dia, jadi kami boleh cuba praktik.	Praise be to God, through the Zoom session just now, we could share our experiences on how to handle people living with HIV. Each place has its own way of management, so we could try to practise some.
H14S24	Terbaik dah.	It was already the best.
H15S24	Sebenarnya tak cukup masa tu, kalau nak bercerita panjang, sehari paling bagus.	Actually, the time was not enough. If we wanted to share more, a whole-day session would be better.

Participant	Feedback (Bahasa Malaysia)	English translation
H16S24	Pengalaman dan perkongsian yang bermakna pada kami, semoga projek mendapat outcome yang dapat membantu membuka minda masyarakat kita dalam menangani masalah stigma dan diskriminasi terhadap klien HIV. Client saya yang terlibat dalam kajian pun beri feedback yang positif, mereka suka sangat, ada tempat mereka bersuara dengan lebih terbuka.	It was a meaningful experience for us. Hopefully this project will produce an outcome that can help our society overcome the stigma and discrimination towards people living with HIV. My clients who were involved in this research also gave positive feedback; they were happy that they have a channel to openly voice out their opinion.
H17S24	Sesi ok saja, faham soalan dan dapat sharing and dengar pengalaman dari tempat lain.	The session was OK, questions were clear and I could share and learn about the experiences from other places.
H18S24	Saya ok saja sepanjang sesi tu, dapat dengar pengalaman dari staf-staf lain dari negeri lain.	I felt OK during the session. I could listen to the experiences from staff in other states.

Annex 17

Guide questions for women living with HIV (English version)

Opening

- Greet participant(s).
- Explain the purpose and process of the face-to-face interview or focus group discussion.
- Explain that all questions asked will be in the context of a woman living with HIV.
- Explain the audiovisual recording of the session.
- Emphasize that participants' identities will not be disclosed in any report or presentation.
- Emphasize that participants can refuse to answer any question without any consequences of any kind.
- Emphasize that there is no right or wrong answer, and all opinions are accepted.
- Emphasize that the information provided by participants will be treated confidentially.
- Explain that participants are free to contact any of the people involved in the research for further clarification and information.
- The participants will give verbal informed consent if they voluntarily agree to participate in the interview or discussion. Say, "I am going to start recording now," but emphasize that participants can withdraw or make a request to stop the recording at any time.

	Warming up
	Before we go into the details, would you like to tell me about yourself? (For focus group discussions, ask each participant if they would like to introduce themselves to the whole group.)
	How do you prefer to be addressed? You can choose any name you would like to be called.
A	Experiences regarding access to healthcare services (focusing on PMTCT services)
1	Would you like to tell me about your experiences in accessing health services?
2	Can you tell us about any barriers you have faced in accessing healthcare services? <i>Probing:</i> For example, in relation to counselling services, can you tell us about any difficulties you have faced in using this service?
3	What are your experiences in relation to your HIV treatment and medicines? <i>Probing:</i> Has a healthcare provider ever explained to you about how your medicines work and their side-effects? Can you tell me how you feel about taking your medicines, and why? Have you ever not received the antiretroviral medicines you usually take? What options were you given with regard to your treatment, and are you satisfied with them?
4	How satisfied are you with your health care?

	Warming up
	<p>Probing:</p> <p>On a scale of 1 to 5, with 1 being poor quality and 5 being excellent quality, how would you rate the health services? Why?</p> <p>How can health services be improved for you?</p>
B	Experiences regarding sexual and reproductive health and rights
5	Can you tell me about your experiences as a woman living with HIV in relation to your sexual and reproductive health and rights? (<i>Use non-technical terminology.</i>)
6	<p>What were your experiences in relation to your initial HIV testing?</p> <p><i>Probing:</i></p> <p>What was your experience of being given sufficient information about the purpose and nature of the procedure before the test was done?</p> <p>Were you given space and time to think further about the test?</p> <p>What was your experience of giving your consent to the healthcare provider before the test was done?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner before the test was done? What was your experience?</p> <p>How do you feel about the confidentiality of your test results?</p> <p>How do you feel about the clinic or hospital informing your husband, spouse or partner about your test results?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
7	<p>What are your experiences in relation to accessing contraception?</p> <p><i>Probing:</i></p> <p>What was your experience in relation to being given sufficient information about the choices and nature of the contraceptive methods available to you?</p> <p>What choices were you given on methods of contraception (oral contraceptive pill, injections, sterilization, others)?</p> <p>Were you given information, space and time to think further about the contraceptive methods of your choice? What was your experience about?</p> <p>Has a healthcare provider ever suggested you should use a particular contraceptive method, such as sterilization?</p> <p>Did the healthcare provider ask for your consent before providing contraception?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner with regard to the contraceptive method of your choice?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>

	Warming up
C	Experiences regarding stigma and discrimination in accessing healthcare services
8	<p>What are your day-to-day experiences as a woman living with HIV?</p> <p>Probing:</p> <p>Have you ever had any experiences of being stigmatized or prejudiced against because of your HIV status or any other status?</p> <p>What about stigma and discrimination in clinics? Any experiences you would like to share?</p> <p>How does this make you feel? Did you seek any support?</p> <p>How does this impact your decision to access health services?</p> <p>How does this impact your sexual and reproductive health and rights?</p>
9	<p>What is the attitude of society towards people living with HIV and key populations, including people who use drugs, sex workers, transgender people, and gay men and other men who have sex with men?</p> <p>Probing:</p> <p>How about your neighbourhood, workplace and clinics you go to?</p> <p>How does this make you feel? What are your experiences?</p>
10	How can society help women living with HIV to address stigma and discrimination?
	Closing
	<p>Is there anything else you would like to tell or ask me?</p> <p>Thank you very much for your time and your willingness to share your experiences with us.</p> <p>If you wish to have a copy of the interview transcript, I can share it with you.</p> <p>We greatly value your time and contribution in this session. There will be a small token of appreciation for you.</p>

Annex 18

Guide questions for antenatal women living with HIV (English version)

Opening

- Greet participant(s).
- Explain the purpose and process of the face-to-face interview or focus group discussion.
- Explain that all questions asked will be in the context of a woman living with HIV.
- Explain the audiovisual recording of the session.
- Emphasize that participants' identities will not be disclosed in any report or presentation.
- Emphasize that participants can refuse to answer any question without any consequences of any kind.
- Emphasize that there is no right or wrong answer, and all opinions are accepted.
- Emphasize that the information provided by participants will be treated confidentially.
- Explain that participants are free to contact any of the people involved in the research for further clarification and information.
- The participants will give verbal informed consent if they voluntarily agree to participate in the interview or discussion. Say, "I am going to start recording now," but emphasize that participants can withdraw or make a request to stop the recording at any time.

	Warming up
	Before we go into the details, would you like to tell me about yourself? (<i>For focus group discussions, ask each participant if they would like to introduce themselves to the whole group.</i>)
	How do you prefer to be addressed? You can choose any name you would like to be called.
A	Experiences regarding access to health services (focusing on PMTCT services)
1	Would you like to tell me about your experiences in accessing health services? <i>Probing:</i> Where is the facility nearest your house? How do you find the opening hours of the facility? How do you usually travel to the clinic or hospital for your treatment? What is the cost involved? How much do you have to pay to get treatment at the health facility?
2	Can you tell us about any barriers you have faced in accessing healthcare services? <i>Probing:</i> For example, in relation to counselling services, can you tell us about any difficulties you have faced in using this service?
3	What are your experiences in relation to your HIV treatment and medicines? <i>Probing:</i>

	Warming up
	<p>Has a healthcare provider ever explained to you about how your medicines work and their side-effects?</p> <p>Can you tell me how you feel about taking your medicines, and why?</p> <p>Have you ever not received the antiretroviral medicines you usually take?</p> <p>What options were you given with regard to your treatment, and are you satisfied with them?</p>
4	<p>How satisfied are you with your health care?</p> <p><i>Probing:</i></p> <p>On a scale of 1 to 5, with 1 being poor quality and 5 being excellent quality, how would you rate the health services? Why?</p> <p>How can health services be improved for you?</p>
B	Experiences regarding sexual and reproductive health and rights
5	<p>Can you tell me about your experiences as a woman living with HIV in relation to your sexual and reproductive health and rights? (<i>Use nontechnical terminology.</i>)</p>
6	<p>What were your experiences in relation to your initial HIV testing?</p> <p><i>Probing:</i></p> <p>What was your experience of being given sufficient information about the purpose and nature of the procedure before the test was done?</p> <p>Were you given space and time to think further about the test?</p> <p>What was your experience of giving your consent to the healthcare provider before the test was done?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner before the test was done? What was your experience?</p> <p>How do you feel about the confidentiality of your test results?</p> <p>How do you feel about the clinic or hospital informing your husband, spouse or partner about your test results?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
7	<p>What were your experiences in relation to accessing contraceptive methods?</p> <p><i>Probing:</i></p> <p>What was your experience in relation to being given sufficient information about the choices and nature of the contraceptive methods available to you?</p> <p>What choices were you given on methods of contraception (oral contraceptive pill, injections, sterilization, others)?</p>

	Warming up
	<p>Were you given information, space and time to think further about the contraceptive methods of your choice? What was your experience about?</p> <p>Has a healthcare provider ever suggested you should use a particular contraceptive method, such as sterilization?</p> <p>Did the healthcare provider ask for your consent before providing contraception?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner in relation to the contraceptive method of your choice?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
8	<p>What were your experiences in relation to antenatal booking and services to prevent your baby from getting infected with HIV? (<i>Note: use nontechnical terminology.</i>)</p> <p><i>Probing:</i></p> <p>What was your experience during antenatal booking in relation to being given sufficient information about the purpose and nature of the test or screening and taking preventive medicines for your unborn baby? (<i>Note: use nontechnical terminology.</i>)</p> <p>Were you given space and time to think further about the test or screening and taking preventive medicine for your unborn baby? (<i>Note: use nontechnical terminology.</i>)</p> <p>What are your experiences of receiving tests or screening and taking preventive medicine for your unborn baby?</p> <p>What are your experiences of getting support services during antenatal booking, such as psychosocial support or counselling?</p> <p>How do you feel about your voluntary consent and confidentiality of the test and screening results?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
C	Experiences regarding stigma and discrimination in accessing healthcare services
9	<p>What are your day-to-day experiences as a woman living with HIV?</p> <p><i>Probing:</i></p> <p>Have you ever had any experiences of being stigmatized or prejudiced against because of your HIV status or any other status?</p> <p>What about stigma and discrimination in clinics? Any experiences you would like to share?</p> <p>How does this make you feel? Did you seek any support?</p> <p>How does this impact on your decision to access health services?</p> <p>How does this impact on your sexual and reproductive health and rights?</p>

	Warming up
10	<p>What is the attitude of society towards people living with HIV and key populations, including people who use drugs, sex workers, transgender people, and gay men and other men who have sex with men?</p> <p><i>Probing:</i></p> <p>How about your neighbourhood, workplace and clinics you go to?</p> <p>How does this make you feel? What are your experiences?</p>
11	How can society help women living with HIV to address stigma and discrimination?
	Closing
	<p>Is there anything else you would like to tell or ask me?</p> <p>Thank you very much for your time and your willingness to share your experiences with us.</p> <p>If you wish to have a copy of the interview transcript, I can share it with you.</p> <p>We greatly value your time and contribution in this session. There will be a small token of appreciation for you.</p>

Annex 19

Guide questions for postnatal women living with HIV (English version)

Opening

- Greet participant(s).
- Explain the purpose and process of the face-to-face interview or focus group discussion.
- Explain that all questions asked will be in the context of a woman living with HIV.
- Explain the audiovisual recording of the session.
- Emphasize that participants' identities will not be disclosed in any report or presentation.
- Emphasize that participants can refuse to answer any question without any consequences of any kind.
- Emphasize that there is no right or wrong answer, and all opinions are accepted.
- Emphasize that the information provided by participants will be treated confidentially.
- Explain that participants are free to contact any of the people involved in the research for further clarification and information.
- The participants will give verbal informed consent if they voluntarily agree to participate in the interview or discussion. Say, "I am going to start recording now," but emphasize that participants can withdraw or make a request to stop the recording at any time.

	Warming up
	Before we go into the details, would you like to tell me about yourself? (For focus group discussions, ask each participant if they would like to introduce themselves to the whole group.)
	How do you prefer to be addressed? You can choose any name you would like to be called.
A	Experiences regarding access to health services (focusing on PMTCT services)
1	Would you like to tell me about your experiences in accessing health services? <i>Probing:</i> Where is the facility nearest your house? How do you find the opening hours of the facility? How do you usually travel to the clinic or hospital for your treatment? What is the cost involved? How much do you have to pay to get treatment at the health facility?
2	Can you tell us about any barriers you have faced in accessing healthcare services? <i>Probing:</i>

	Warming up
	For example, in relation to counselling services, can you tell us about any difficulties you have faced in using this service?
3	<p>What are your experiences in relation to your HIV treatment and medicines?</p> <p><i>Probing:</i></p> <p>Has a healthcare provider ever explained to you about how your medicines work and their side-effects?</p> <p>Can you tell me how you feel about taking your medicines, and why?</p> <p>Have you ever not received the antiretroviral medicines you usually take?</p> <p>What options were you given in relation to your treatment, and are you satisfied with them?</p>
4	<p>How satisfied are you with your health care?</p> <p><i>Probing:</i></p> <p>On a scale of 1 to 5, with 1 being poor quality and 5 being excellent quality, how would you rate the health services? Why?</p> <p>How can health services be improved for you?</p>
B	Experiences regarding sexual and reproductive health and rights
5	Can you tell me about your experiences as a woman living with HIV in relation to your sexual and reproductive health and rights? (<i>Use nontechnical terminology.</i>)
6	<p>What were your experiences in relation to your initial HIV testing?</p> <p><i>Probing:</i></p> <p>What was your experience of being given sufficient information about the purpose and nature of the procedure before the test was done?</p> <p>Were you given space and time to think further about the test?</p> <p>What was your experience of giving your consent to the healthcare provider before the test was done?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner before the test was done? What was your experience?</p> <p>How do you feel about the confidentiality of your test results?</p> <p>How do you feel about the clinic or hospital informing your husband, spouse or partner about your test results?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
7	What were your experiences in relation to accessing contraceptive methods?

	Warming up
	<p><i>Probing:</i></p> <p>What was your experience in relation to being given sufficient information about the choices and nature of the contraceptive methods available to you?</p> <p>What choices were you given on methods of contraception (oral contraceptive pill, injections, sterilization, others)?</p> <p>Were you given information, space and time to think further about the contraceptive methods of your choice? What was your experience about?</p> <p>Has a healthcare provider ever suggested you should use a particular contraceptive method, such as sterilization?</p> <p>Did the healthcare provider ask for your consent before providing contraception?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner in relation to the contraceptive method of your choice?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
8	<p>What were your experiences in relation to antenatal booking and services to prevent your baby from getting infected with HIV? (<i>Note: use nontechnical terminology.</i>)</p> <p><i>Probing:</i></p> <p>What was your experience during antenatal booking in relation to being given sufficient information about the purpose and nature of the test or screening and taking preventive medicines for your unborn baby? (<i>Note: use nontechnical terminology.</i>)</p> <p>Were you given space and time to think further about the test or screening and taking preventive medicine for your unborn baby? (<i>Note: use nontechnical terminology.</i>)</p> <p>What are your experiences of receiving tests or screening and taking preventive medicine for your unborn baby?</p> <p>What are your experiences of getting support services during antenatal booking, such as psychosocial support or counselling?</p> <p>How do you feel about your voluntary consent and confidentiality of the test and screening results?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p>
9	<p>What was your experience during childbirth?</p> <p><i>Probing:</i></p> <p>What was your experience in relation to being given sufficient information about the purpose and nature of the methods of delivering your baby?</p> <p>What choices were you given on methods of delivery (vaginal or surgery)?</p>

	Warming up
	<p>Were you given information, space and time to think further about the delivery method of your choice?</p> <p>What was your experience about providing your consent to the healthcare provider before any procedure was conducted?</p> <p>Did the healthcare provider ask for consent from your husband, spouse or partner before any procedure was conducted?</p> <p>What kind of reaction did you receive from your husband, spouse or partner in relation to this issue?</p> <p>Was your support person, husband, spouse or partner present with you during childbirth? How do you feel about this?</p>
10	<p>What was your experience in relation to feeding your newborn baby?</p> <p><i>Probing:</i></p> <p>What was your experience in relation to being given sufficient information about the ways of feeding your newborn baby?</p> <p>What choices were you given on ways of feeding your newborn baby?</p> <p>Were you given information, space and time to think further about the feeding method of your choice?</p> <p>How do you feel about the support given to you in relation to feeding your newborn baby?</p>
C	Experiences regarding stigma and discrimination in accessing healthcare services
11	<p>What are your day-to-day experiences as a woman living with HIV?</p> <p><i>Probing:</i></p> <p>Have you ever had any experiences of being stigmatized or prejudiced against because of your HIV status or any other status?</p> <p>What about stigma and discrimination in clinics? Any experiences you would like to share?</p> <p>How does this make you feel? Did you seek any support?</p> <p>How does this impact on your decision to access health services?</p> <p>How does this impact on your sexual and reproductive health and rights?</p>
12	<p>What is the attitude of society towards people living with HIV and key populations, including people who use drugs, sex workers, transgender people, and gay men and other men who have sex with men?</p> <p><i>Probing:</i></p> <p>How about your neighbourhood, workplace and clinics you go to?</p> <p>How does this make you feel? What are your experiences?</p>
13	How can society help women living with HIV to address stigma and discrimination?

	Warming up
14	<p>(Only applicable to mothers who are not breastfeeding.)</p> <p>What is your experience of being in a situation where you were asked why you do not breastfeed your baby?</p> <p><i>Probing:</i></p> <p>How did you react in the situation? Did you seek any support?</p>
	Closing
	<p>Is there anything else you would like to tell or ask me?</p> <p>Thank you very much for your time and your willingness to share your experiences with us.</p> <p>If you wish to have a copy of the interview transcript, I can share it with you.</p> <p>We greatly value your time and contribution in this session. There will be a small token of appreciation for you.</p>

Annex 20

Guide questions for women living with HIV (Bahasa Malaysia version)

Permulaan

- Menyapa responden.
- Menerangkan mengenai tujuan dan proses perbincangan berkumpulan.
- Menerangkan bahawa semua soalan yang diajukan adalah di dalam konteks sebagai seorang wanita yang hidup dengan HIV.
- Menerangkan mengenai rakaman audio-visual bila sesi akan dimulakan.
- Menekankan bahawa identiti responden tidak akan didedahkan di dalam laporan/pembentangan.
- Menekankan bahawa responden boleh menolak untuk menjawab sebarang soalan tanpa sebarang akibat.
- Menekankan bahawa tiada jawapan yang betul atau salah, semua pendapat adalah diterima.
- Menekankan bahawa maklumat yang diberikan oleh responden dalam sesi ini akan dirahsiakan.
- Menerangkan bahawa responden bebas menghubungi kumpulan penyelidik untuk mendapatkan maklumat lanjut jika perlu.
- Responden akan memberikan keizinan lisan sekiranya mereka bersetuju untuk turut serta dalam temubual/perbincangan [untuk tujuan rakaman sahaja].
- Sebut “saya akan mulakan rakaman sekarang” tetapi terangkan bahawa responden boleh menarik diri atau meminta supaya rakaman ditamatkan pada bila-bila masa.

	Suai-kenal
	<p>Sebelum kita mulakan sesi, bolehkan puan ceritakan sedikit tentang diri masing-masing? (Untuk perbincangan berkumpulan, setiap responden diminta memperkenalkan diri kepada seluruh kumpulan jika mahu)</p> <p>Bagaimana patut kami panggil puan? Puan boleh menggunakan sebarang nama jika mahu.</p>
A	Pengalaman berhubung akses perkhidmatan kesihatan
1	<p>Bolehkah puan kongsikan tentang pengalaman puan dalam mendapatkan perkhidmatan kesihatan?</p> <p>Perincian:</p> <p>Di manakah fasiliti kesihatan yang terdekat dari rumah puan?</p> <p>Apa pandangan puan terhadap waktu operasi fasiliti tersebut?</p> <p>Bagaimana selalunya puan pergi ke klinik/hospital untuk rawatan HIV? Berapa kos untuk sampai ke sana?</p> <p>Berapa yang puan perlu bayar untuk mendapatkan perkhidmatan di fasiliti kesihatan?</p>
2	<p>Bolehkan puan ceritakan tentang sebarang cabaran yang puan hadapi dalam mendapatkan perkhidmatan kesihatan?</p> <p>Perincian:</p>

	Suai-kenal
	Contohnya, berhubung dengan perkhidmatan kaunseling, boleh puan kongsikan sekiranya puan menghadapi sebarang kesulitan dalam menggunakan khidmat ini?
3	<p>Apa pengalaman puan berkaitan dengan rawatan/ubat-ubatan HIV?</p> <p>Perincian:</p> <p>Pernahkan kakitangan kesihatan menerangkan kepada puan tentang fungsi rawatan/ubat-ubatan dan kesan sampingan jika ada?</p> <p>Apa perasaan puan tentang pengambilan ubat-ubatan ini dan mengapa?</p> <p>Pernahkah puan berpengalaman tidak menerima ubat-ubatan yang selalu puan ambil (rawatan antiretroviral)?</p> <p>Apa pilihan yang diberikan kepada puan dalam hal rawatan puan dan adakah puan berpuas hati dengannya?</p>
4	<p>Sejauh manakah puan berpuas hati dengan mutu perkhidmatan kesihatan?</p> <p>Perincian:</p> <p>Bolehkah puan menilai perkhidmatan kesihatan dalam skala 1 hingga 5; 1 bermaksud kualiti paling rendah dan 5 bermaksud kualiti paling memuaskan?</p> <p>Bagaimanakah mutu perkhidmatan kesihatan dapat ditingkatkan untuk puan?</p>
B	Pengalaman berhubung hak dan kesihatan seksual dan reproduktif
5	Bolehkan puan kongsikan tentang pengalaman puan sebagai seorang wanita hidup dengan HIV berhubung dengan hak dan kesihatan seksual dan reproduktif?
6	<p>Apa pengalaman puan berkaitan dengan keputusan ujian HIV?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang tujuan dan cara-cara prosedur sebelum ujian dilakukan?</p> <p>Adakah puan diberikan ruang dan masa untuk berfikir lebih lanjut tentang ujian tersebut?</p> <p>Apa pengalaman puan dalam memberikan keizinan/persetujuan kepada kakitangan kesihatan sebelum ujian dilakukan?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada suami/pasangan puan sebelum ujian dilakukan? Apa pengalaman puan dalam hal ini?</p> <p>Apa perasaan puan mengenai kerahsian keputusan ujian tersebut?</p> <p>Apa perasaan puan mengenai klinik/hospital menghubungi suami/pasangan puan berkenaan keputusan ujian?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan isu keputusan ujian ini?</p>
7	<p>Apa pengalaman puan berkaitan dengan kaedah perancangan keluarga?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang pilihan dan cara-cara perancangan keluarga yang ada untuk puan?</p>

	Suai-kenal
	<p>Apa pilihan yang telah diberikan kepada puan dalam kaedah-kaedah perancangan keluarga (pil, suntikan, kaedah kekal (ikatan tiub peranakan) atau lain-lain)?</p> <p>Adakah puan diberikan masa dan ruang untuk berfikir dengan lebih lanjut mengenai kaedah perancangan keluarga pilihan puan? / atau yang dicadangkan? Apa pengalaman puan dalam hal ini?</p> <p>Pernahkan puan berpengalaman yang kakitangan kesihatan menyarankan supaya puan menggunakan kaedah perancangan keluarga tertentu seperti kaedah kekal (ikatan tiub peranakan)?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada puan sebelum memberikan perancangan keluarga?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada suami/pasangan puan sebelum memberikan perancangan keluarga?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan perancangan keluarga ini?</p>
C	Pengalaman berhubung stigma dan diskriminasi
8	<p>Apa pengalaman puan sebagai seorang wanita hidup dengan HIV?</p> <p>Perincian:</p> <p>Adakah puan berpengalaman disisihkan atau dilayan dengan prejedis disebabkan status HIV atau latar belakang puan?</p> <p>Bagaimana dengan stigma dan diskriminasi di klinik (sebarang perkhidmatan kesihatan)? Ada pengalaman yang puan mahu kongsikan?</p> <p>Bagaimana perasaan atau reaksi puan dalam hal ini? Pernahkan puan mendapatkan sokongan?</p> <p>Bagaimanakah ini mempengaruhi pilihan puan untuk mendapatkan perkhidmatan kesihatan?</p> <p>Bagaimanakah ini mempengaruhi hak dan kesihatan seksual dan reproduktif puan?</p>
9	<p>Pada pendapat puan, apakah sikap masyarakat terhadap orang yang hidup dengan HIV termasuklah orang-orang yang menggunakan dadah, pekerja perkhidmatan seks, orang transgender dan lelaki yang melakukan hubungan seks dengan lelaki?</p> <p>Perincian:</p> <p>Bagaimana dengan jiran-jiran, tempat kerja, klinik (perkhidmatan kesihatan yang dikunjungi)?</p> <p>Bagaimana perasaan puan dalam hal ini?</p>
10	Pada pendapat puan, bagaimanakah masyarakat dapat membantu wanita yang hidup dengan HIV untuk menangani stigma dan diskriminasi?
	Penutup
	<p>Puan ada sebarang soalan lain untuk saya?</p> <p>Terima kasih atas masa dan kesudian puan berkongsi pengalaman dengan kami.</p>

	Suai-kenal
	Jika puau mahukan salinan transkrip temubual ini, saya boleh berikan kemudian. Atas penghargaan kami untuk masa dan sumbangan puau dalam sesi ini, kami ada menyediakan sedikit sumbangan.

Annex 21

Guide questions for antenatal women living with HIV (Bahasa Malaysia version)

Permulaan

- Menyapa responden.
- Menerangkan mengenai tujuan dan proses perbincangan berkumpulan.
- Menerangkan bahawa semua soalan yang diajukan adalah di dalam konteks sebagai seorang wanita yang hidup dengan HIV.
- Menerangkan mengenai rakaman audio-visual bila sesi akan dimulakan.
- Menekankan bahawa identiti responden tidak akan didedahkan di dalam laporan/pembentangan.
- Menekankan bahawa responden boleh menolak untuk menjawab sebarang soalan tanpa sebarang akibat.
- Menekankan bahawa tiada jawapan yang betul atau salah, semua pendapat adalah diterima.
- Menekankan bahawa maklumat yang diberikan oleh responden dalam sesi ini akan dirahsiakan.
- Menerangkan bahawa responden bebas menghubungi kumpulan penyelidik untuk mendapatkan maklumat lanjut jika perlu.
- Responden akan memberikan keizinan lisan sekiranya mereka bersetuju untuk turut serta dalam temubual/perbincangan [untuk tujuan rakaman sahaja].
- Sebut "saya akan mulakan rakaman sekarang" tetapi terangkan bahawa responden boleh menarik diri atau meminta supaya rakaman ditamatkan pada bila-bila masa.

	Suai-kenal
	Sebelum kita mulakan sesi, bolehkan puan ceritakan sedikit tentang diri masing-masing? (Untuk perbincangan berkumpulan, setiap responden diminta memperkenalkan diri kepada seluruh kumpulan jika mahu) Bagaimana patut kami panggil puan? Puan boleh menggunakan sebarang nama jika mahu.
A	Pengalaman berhubung akses perkhidmatan kesihatan
1	Bolehkah puan kongsikan tentang pengalaman puan dalam mendapatkan perkhidmatan kesihatan? Perincian: Di manakah fasiliti kesihatan yang terdekat dari rumah puan? Apa pandangan puan terhadap waktu operasi fasiliti tersebut? Bagaimana selalunya puan pergi ke klinik/hospital untuk rawatan HIV? Berapa kos untuk sampai ke sana? Berapa yang puan perlu bayar untuk mendapatkan perkhidmatan di fasiliti kesihatan?
2	Bolehkan puan ceritakan tentang sebarang cabaran yang puan hadapi dalam mendapatkan perkhidmatan kesihatan?

	<p>Perincian:</p> <p>Contohnya, berhubung dengan perkhidmatan kaunseling, boleh puan kongsikan sekiranya puan menghadapi sebarang kesulitan dalam menggunakan khidmat ini?</p>
3	<p>Apa pengalaman puan berkaitan dengan rawatan/ubat-ubatan HIV?</p> <p>Perincian:</p> <p>Pernahkan kakitangan kesihatan menerangkan kepada puan tentang fungsi rawatan/ubat-ubatan dan kesan sampingan jika ada?</p> <p>Apa perasaan puan tentang pengambilan ubat-ubatan ini dan mengapa?</p> <p>Pernahkah puan berpengalaman tidak menerima ubat-ubatan yang selalu puan ambil (rawatan antiretroviral)?</p> <p>Apa pilihan yang diberikan kepada puan dalam hal rawatan puan dan adakah puan berpuas hati dengannya?</p>
4	<p>Sejauh manakah puan berpuas hati dengan mutu perkhidmatan kesihatan?</p> <p>Perincian:</p> <p>Bolehkah puan menilai perkhidmatan kesihatan dalam skala 1 hingga 5; 1 bermaksud kualiti paling rendah dan 5 bermaksud kualiti paling memuaskan?</p> <p>Bagaimanakah mutu perkhidmatan kesihatan dapat ditingkatkan untuk puan?</p>
B	Pengalaman berhubung hak dan kesihatan seksual dan reproduktif
5	Bolehkan puan kongsikan tentang pengalaman puan sebagai seorang wanita hidup dengan HIV berhubung dengan hak dan kesihatan seksual dan reproduktif?
6	<p>Apa pengalaman puan berkaitan dengan keputusan ujian HIV?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang tujuan dan cara-cara prosedur sebelum ujian dilakukan?</p> <p>Adakah puan diberikan ruang dan masa untuk berfikir lebih lanjut tentang ujian tersebut?</p> <p>Apa pengalaman puan dalam memberikan keizinan/persetujuan kepada kakitangan kesihatan sebelum ujian dilakukan?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada suami/pasangan puan sebelum ujian dilakukan? Apa pengalaman puan dalam hal ini?</p> <p>Apa perasaan puan mengenai kerahsian keputusan ujian tersebut?</p> <p>Apa perasaan puan mengenai klinik/hospital menghubungi suami/pasangan puan berkenaan keputusan ujian?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan hal ini?</p>
7	<p>Apa pengalaman puan berkaitan dengan kaedah perancangan keluarga?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang pilihan dan cara-cara perancangan keluarga yang ada untuk puan?</p>

	<p>Apa pilihan yang telah diberikan kepada puan dalam kaedah-kaedah perancangan keluarga (pil, suntikan, kaedah kekal (ikatan tiub peranakan) atau lain-lain)?</p> <p>Adakah puan diberikan masa dan ruang untuk berfikir dengan lebih lanjut mengenai kaedah perancangan keluarga pilihan puan? / atau yang dicadangkan? Apa pengalaman puan dalam hal ini?</p> <p>Pernahkan puan berpengalaman yang kakitangan kesihatan menyarankan supaya puan menggunakan kaedah perancangan keluarga tertentu seperti kaedah kekal (ikatan tiub peranakan)?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada puan sebelum memberikan perancangan keluarga?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada suami/pasangan puan sebelum memberikan perancangan keluarga?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan hal ini?</p>
8	<p>(Ujian/saringan di ‘Booking’ Antenatal.)</p> <p>Apa pengalaman puan berkaitan dengan ujian/saringan yang dilakukan di ‘booking’ antenatal dan perkhidmatan untuk mencegah bayi puan daripada dijangkiti HIV? (Nota: gunakan istilah bukan teknikal)</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang tujuan dan cara-cara ujian/saringan dan pengambilan rawatan pencegahan bagi bayi yang belum dilahirkan? (Nota: gunakan istilah bukan teknikal)</p> <p>Adakah puan diberikan ruang dan masa untuk berfikir lebih lanjut tentang ujian/saringan dan rawatan pencegahan bagi bayi yang belum dilahirkan? (Nota: gunakan istilah bukan teknikal)</p> <p>Apa pengalaman puan dalam menjalankan ujian/saringan dan mengambil rawatan pencegahan bagi bayi yang belum dilahirkan?</p> <p>Apa pengalaman puan dalam mendapatkan khidmat sokongan semasa ‘booking’ antenatal seperti sokongan psikososial/kaunseling?</p> <p>Apa perasaan puan mengenai keizinan dan kerahsian keputusan ujian/saringan tersebut?</p> <p>Apa reaksi suami/pasangan puan berhubung hal ini?</p>
C	<p>Pengalaman berhubung stigma dan diskriminasi</p> <p>9</p> <p>Apa pengalaman puan sebagai seorang wanita hidup dengan HIV?</p> <p>Perincian:</p> <p>Adakah puan berpengalaman disisihkan atau dilayan dengan prejedis disebabkan status HIV atau latar belakang puan?</p> <p>Bagaimana dengan stigma dan diskriminasi di klinik (sebarang perkhidmatan kesihatan)? Ada pengalaman yang puan mahu kongsikan?</p> <p>Bagaimana perasaan atau reaksi puan dalam hal ini? Pernahkan puan mendapatkan sokongan?</p>

	<p>Bagaimakah ini mempengaruhi pilihan puan untuk mendapatkan perkhidmatan kesihatan?</p> <p>Bagaimakah ini mempengaruhi hak dan kesihatan seksual dan reproduktif puan?</p>
10	<p>Pada pendapat puan, apakah sikap masyarakat terhadap orang yang hidup dengan HIV termasuklah orang-orang yang menggunakan dadah, pekerja perkhidmatan seks, orang transgender dan lelaki yang melakukan hubungan seks dengan lelaki?</p> <p>Perincian:</p> <p>Bagaimana dengan jiran-jiran, tempat kerja, klinik (perkhidmatan kesihatan yang dikunjungi)?</p> <p>Bagaimana perasaan puan dalam hal ini?</p>
11	<p>Pada pendapat puan, bagaimakah masyarakat dapat membantu wanita yang hidup dengan HIV untuk menangani stigma dan diskriminasi?</p>
	<p>Penutup</p> <p>Puan ada sebarang soalan lain untuk saya?</p> <p>Terima kasih atas masa dan kesudian puan berkongsi pengalaman dengan kami.</p> <p>Jika puan mahukan salinan transkrip temubual ini, saya boleh berikan kemudian.</p> <p>Atas penghargaan kami untuk masa dan sumbangan puan dalam sesi ini, kami ada menyediakan sedikit sumbangan.</p>

Annex 22

Guide questions for postnatal women living with HIV (Bahasa Malaysia version)

Permulaan

- Menyapa responden.
- Menerangkan mengenai tujuan dan proses perbincangan berkumpulan.
- Menerangkan bahawa semua soalan yang diajukan adalah di dalam konteks sebagai seorang wanita yang hidup dengan HIV.
- Menerangkan mengenai rakaman audio-visual bila sesi akan dimulakan.
- Menekankan bahawa identiti responden tidak akan didedahkan di dalam laporan/pembentangan.
- Menekankan bahawa responden boleh menolak untuk menjawab sebarang soalan tanpa sebarang akibat.
- Menekankan bahawa tiada jawapan yang betul atau salah, semua pendapat adalah diterima.
- Menekankan bahawa maklumat yang diberikan oleh responden dalam sesi ini akan dirahsiakan.
- Menerangkan bahawa responden bebas menghubungi kumpulan penyelidik untuk mendapatkan maklumat lanjut jika perlu.
- Responden akan memberikan keizinan lisan sekiranya mereka bersetuju untuk turut serta dalam temubual/perbincangan [untuk tujuan rakaman sahaja].
- Sebut "saya akan mulakan rakaman sekarang" tetapi terangkan bahawa responden boleh menarik diri atau meminta supaya rakaman ditamatkan pada bila-bila masa.

	Suai-kenal
	Sebelum kita mulakan sesi, bolehkan puan ceritakan sedikit tentang diri masing-masing? (Untuk perbincangan berkumpulan, setiap responden diminta memperkenalkan diri kepada seluruh kumpulan jika mahu) Bagaimana patut kami panggil puan? Puan boleh menggunakan sebarang nama jika mahu.
A	Pengalaman berhubung akses perkhidmatan kesihatan
1	Bolehkah puan kongsikan tentang pengalaman puan dalam mendapatkan perkhidmatan kesihatan? Perincian: Di manakah fasiliti kesihatan yang terdekat dari rumah puan? Apa pandangan puan terhadap waktu operasi fasiliti tersebut? Bagaimana selalunya puan pergi ke klinik/hospital untuk rawatan HIV? Berapa kos untuk sampai ke sana? Berapa yang puan perlu bayar untuk mendapatkan perkhidmatan di fasiliti kesihatan?
2	Bolehkan puan ceritakan tentang sebarang cabaran yang puan hadapi dalam mendapatkan perkhidmatan kesihatan?

	Suai-kenal
	<p>Perincian:</p> <p>Contohnya, berhubung dengan perkhidmatan kaunseling, boleh puan kongsikan sekiranya puan menghadapi sebarang kesulitan dalam menggunakan khidmat ini?</p>
3	<p>Apa pengalaman puan berkaitan dengan rawatan/ubat-ubatan HIV?</p> <p>Perincian:</p> <p>Pernahkan kakitangan kesihatan menerangkan kepada puan tentang fungsi rawatan/ubat-ubatan dan kesan sampingan jika ada?</p> <p>Apa perasaan puan tentang pengambilan ubat-ubatan ini dan mengapa?</p> <p>Pernahkah puan berpengalaman tidak menerima ubat-ubatan yang selalu puan ambil (rawatan antiretroviral)?</p> <p>Apa pilihan yang diberikan kepada puan dalam hal rawatan puan dan adakah puan berpuas hati dengannya?</p>
4	<p>Sejauh manakah puan berpuas hati dengan mutu perkhidmatan kesihatan?</p> <p>Perincian:</p> <p>Bolehkah puan menilai perkhidmatan kesihatan dalam skala 1 hingga 5; 1 bermaksud kualiti paling rendah dan 5 bermaksud kualiti paling memuaskan?</p> <p>Bagaimanakah mutu perkhidmatan kesihatan dapat ditingkatkan untuk puan?</p>
B	Pengalaman berhubung hak dan kesihatan seksual dan reproduktif
5	Bolehkan puan kongsikan tentang pengalaman puan sebagai seorang wanita hidup dengan HIV berhubung dengan hak dan kesihatan seksual dan reproduktif?
6	<p>Apa pengalaman puan berkaitan dengan keputusan ujian HIV?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang tujuan dan cara-cara prosedur sebelum ujian dilakukan?</p> <p>Adakah puan diberikan ruang dan masa untuk berfikir lebih lanjut tentang ujian tersebut?</p> <p>Apa pengalaman puan dalam memberikan keizinan/persetujuan kepada kakitangan kesihatan sebelum ujian dilakukan?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada suami/pasangan puan sebelum ujian dilakukan? Apa pengalaman puan dalam hal ini?</p> <p>Apa perasaan puan mengenai kerahsian keputusan ujian tersebut?</p> <p>Apa perasaan puan mengenai klinik/hospital menghubungi suami/pasangan puan berkenaan keputusan ujian?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan isu keputusan ujian ini?</p>
7	<p>Apa pengalaman puan berkaitan dengan kaedah perancangan keluarga?</p> <p>Perincian:</p>

	Suai-kenal
	<p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang pilihan dan cara-cara perancangan keluarga yang ada untuk puan?</p> <p>Apa pilihan yang telah diberikan kepada puan dalam kaedah-kaedah perancangan keluarga (pil, suntikan, kaedah kekal (ikatan tiub peranakan) atau lain-lain)?</p> <p>Adakah puan diberikan masa dan ruang untuk berfikir dengan lebih lanjut mengenai kaedah perancangan keluarga pilihan puan? / atau yang dicadangkan? Apa pengalaman puan dalam hal ini?</p> <p>Pernahkan puan berpengalaman yang kakitangan kesihatan menyarankan supaya puan menggunakan kaedah perancangan keluarga tertentu seperti kaedah kekal (ikatan tiub peranakan)?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada puan sebelum memberikan perancangan keluarga?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan daripada suami/pasangan puan sebelum memberikan perancangan keluarga?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan perancangan keluarga ini?</p>
8	<p>Apa pengalaman puan berkaitan dengan ujian/saringan yang dilakukan di ‘booking’ antenatal dan perkhidmatan untuk mencegah bayi puan daripada dijangkiti HIV? (Nota: gunakan istilah bukan teknikal)</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang tujuan dan cara-cara ujian/saringan dan pengambilan rawatan pencegahan bagi bayi yang belum dilahirkan? (Nota: gunakan istilah bukan teknikal)</p> <p>Adakah puan diberikan ruang dan masa untuk berfikir lebih lanjut tentang ujian/saringan dan rawatan pencegahan bagi bayi yang belum dilahirkan? (Nota: gunakan istilah bukan teknikal)</p> <p>Apa pengalaman puan dalam menjalankan ujian/saringan dan mengambil rawatan pencegahan bagi bayi yang belum dilahirkan?</p> <p>Apa pengalaman puan dalam mendapatkan khidmat sokongan semasa ‘booking’ antenatal seperti sokongan psikososial/kaunseling?</p> <p>Apa perasaan puan mengenai keizinan dan kerahsian keputusan ujian/saringan tersebut?</p> <p>Apa reaksi suami/pasangan puan berhubung hal ini?</p>
9	<p>Apa pengalaman puan semasa bersalin?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang tujuan dan kaedah kelahiran bayi?</p> <p>Apa pilihan yang telah diberikan puan dalam kaedah-kaedah kelahiran bayi (secara biasa atau pembedahan)?</p>

	Suai-kenal
	<p>Adakah puan diberikan maklumat, ruang dan masa untuk berfikir lebih lanjut tentang kaedah kelahiran bayi pilihan puan? / atau yang dicadangkan?</p> <p>Apa pengalaman puan dalam memberikan keizinan/persetujuan puan kepada kakitangan kesihatan sebelum sebarang prosedur semasa bersalin dijalankan?</p> <p>Adakah kakitangan kesihatan meminta keizinan/persetujuan suami/pasangan puan sebelum sebarang prosedur semasa bersalin dijalankan?</p> <p>Apa reaksi suami/pasangan puan berhubung dengan isu ini?</p> <p>Adakah peneman/suami/pasangan puan hadir semasa proses kelahiran? Apa perasaan puan tentang hal ini?</p>
10	<p>Apa pengalaman puan berkaitan dengan penyusuan bayi?</p> <p>Perincian:</p> <p>Apa pengalaman puan berkenaan dengan pemberian maklumat yang cukup tentang cara-cara menyusukan bayi yang sesuai?</p> <p>Apa pilihan yang diberikan kepada puan tentang cara-cara menyusukan bayi yang sesuai?</p> <p>Adakah puan diberikan maklumat, ruang dan masa untuk berfikir lebih lanjut tentang cara-cara penyusuan bayi pilihan puan? / atau yang dicadangkan?</p> <p>Apa perasaan puan terhadap sokongan yang diberikan kepada puan berhubung dengan penyusuan bayi?</p>
C	Pengalaman berhubung stigma dan diskriminasi
11	<p>Apa pengalaman puan sebagai seorang wanita hidup dengan HIV?</p> <p>Perincian:</p> <p>Adakah puan berpengalaman disisihkan atau dilayan dengan prejedis disebabkan status HIV atau latar belakang puan?</p> <p>Bagaimana dengan stigma dan diskriminasi di klinik (sebarang perkhidmatan kesihatan)? Ada pengalaman yang puan mahu kongsikan?</p> <p>Bagaimana perasaan atau reaksi puan dalam hal ini? Adakah puan mendapatkan sokongan?</p> <p>Bagaimanakah ini mempengaruhi pilihan puan untuk mendapatkan perkhidmatan kesihatan?</p> <p>Bagaimanakah ini mempengaruhi hak dan kesihatan seksual dan reproduktif puan?</p>
12	<p>Pada pendapat puan, apakah sikap masyarakat terhadap orang yang hidup dengan HIV termasuklah orang-orang yang menggunakan dadah, pekerja perkhidmatan seks, orang transgender dan lelaki yang melakukan hubungan seks dengan lelaki?</p> <p>Perincian:</p> <p>Bagaimana dengan jiran-jiran, tempat kerja, klinik (perkhidmatan kesihatan yang dikunjungi)?</p> <p>Bagaimana perasaan puan dalam hal ini?</p>

	Suai-kenal
13	Pada pendapat puan, bagaimanakah masyarakat dapat membantu wanita yang hidup dengan HIV untuk menangani stigma dan diskriminasi?
14	[Hanya untuk ibu-ibu yang tidak menyusukan bayi] Pernahkah puan berada dalam situasi di mana seseorang bertanya mengapa puan tidak menyusukan bayi puan? Perincian: Jika ya, bagaimanakah reaksi puan dalam situasi sedemikian? Adakah puan mendapatkan sokongan?
	Penutup Puan ada sebarang soalan lain untuk saya? Terima kasih atas masa dan kesudian puan berkongsi pengalaman dengan kami. Jika puan mahukan salinan transkrip temubual ini, saya boleh berikan kemudian. Atas penghargaan kami untuk masa dan sumbangan puan dalam sesi ini, kami ada menyediakan sedikit sumbangan.

Annex 23

Guide questions for healthcare providers (English version)

Opening

- Greet participant(s).
- Explain the purpose and process of the focus group discussion.
- Explain that all questions asked will be in the context of women living with HIV.
- Explain the audiovisual recording of the session.
- Emphasize that participants' identities will not be disclosed in any report or presentation.
- Emphasize that participants can refuse to answer any question without any consequences of any kind.
- Emphasize that there is no right or wrong answer, and all opinions are accepted.
- Emphasize that the information provided by participants will be treated confidentially.
- Explain that participants are free to contact any of the people involved in the research for further clarification and information.
- The participants will give verbal informed consent if they voluntarily agree to participate in the interview or discussion. Say, "I am going to start recording now," but emphasize that participants can withdraw or make a request to stop the recording at any time.

	Warming up
	Before we go into the details, would you like to tell me about yourself? (<i>For focus group discussions, ask each participant if they would like to introduce themselves to the whole group.</i>)
	How do you prefer to be addressed? You can choose any name you would like to be called.
A	Perception regarding access to health services
1	In terms of the provision of healthcare facilities, is there any difference between rural and urban settings?
2	Are there any options for after-hours services or home visits?
3	How do you support women living with HIV who are facing financial constraints?
4	How do you provide or distribute supplies of formula milk in rural or urban settings?
5	How do you provide counselling services to women living with HIV? <i>Probing:</i> How do you ensure the emotional and mental well-being of women living with HIV?
6	How do you measure the service satisfaction at a healthcare facility? <i>Probing:</i> Do you provide opportunities for women living with HIV to give feedback about the health service?
B	Perception regarding sexual and reproductive health and rights

	Warming up
7	What are the challenges healthcare providers face in getting/explaining informed consent and confidentiality from/to women living with HIV?
8	How does the healthcare provider deal with cases of refusal of informed consent?
9	How does the healthcare provider handle cases of treatment preferences? <i>Probing:</i> How do you feel about women living with HIV making decisions about their own health and treatment?
10	To what extent are people living with HIV given the choice to choose and determine the tests and screening done, ways of giving birth, family planning methods and feeding their baby? <i>Probing:</i> Do you take time and space to explain and inform women about the purpose and nature of each procedure or treatment? If not, why?
11	How do you ensure the safety of survivors of gender-based violence in matters of consent?
C	Perception regarding stigma and discrimination
12	How do you feel about treating women living with HIV?
13	How do you ensure women living with HIV feel welcomed and unbiased at the healthcare facility? <i>Probing:</i> How often do you explore this issue with women living with HIV you are treating?
14	How can the healthcare system help women living with HIV to address stigma and discrimination?
D	Clarification from the participants' findings
15	Are there circumstances where women living with HIV have to pay for any clinical tests or procedures?
16	What is the procedure regarding disposal of the placenta of women living with HIV after birth? <i>Probing:</i> After birth, are women living with HIV allowed to bring their placenta home? If so, are they given an explanation about the safest way of disposal?
17	How do you manage requests for bilateral tubal ligation from women living with HIV? <i>Probing:</i> What factors are given consideration in relation to bilateral tubal ligation requests (e.g. patient's age, number of children, religion)?
18	What is the recommended feeding option for an infant born to a woman living with HIV other than infant formula?

	Warming up
	<p><i>Probing:</i></p> <p>Are wet-nursing (from HIV-negative women) or breastmilk banks recommended?</p>
19	What is the current policy in relation to giving birth in a private hospital for women living with HIV?
	Closing
	<p>Is there anything else you would like to tell or ask me?</p> <p>Thank you very much for your time and your willingness to share your experiences with us.</p> <p>If you wish to have a copy of the interview transcript, I can share it with you.</p> <p>We greatly value your time and contribution in this session. There will be a small token of appreciation for you.</p>

Annex 24

Guide questions for healthcare providers (Bahasa Malaysia version)

Permulaan

- Menyapa responden.
- Menerangkan mengenai tujuan dan proses perbincangan berkumpulan.
- Menerangkan bahawa semua soalan yang diajukan adalah di dalam konteks sebagai seorang wanita yang hidup dengan HIV.
- Menerangkan mengenai rakaman audio-visual bila sesi akan dimulakan.
- Menekankan bahawa identiti responden tidak akan didedahkan di dalam laporan/pembentangan.
- Menekankan bahawa responden boleh menolak untuk menjawab sebarang soalan tanpa sebarang akibat.
- Menekankan bahawa tiada jawapan yang betul atau salah, semua pendapat adalah diterima.
- Menekankan bahawa maklumat yang diberikan oleh responden dalam sesi ini akan dirahsiakan.
- Menerangkan bahawa responden bebas menghubungi kumpulan penyelidik untuk mendapatkan maklumat lanjut jika perlu.
- Responden akan memberikan keizinan lisan sekiranya mereka bersetuju untuk turut serta dalam temubual/perbincangan [untuk tujuan rakaman sahaja].
- Sebut “saya akan mulakan rakaman sekarang” tetapi terangkan bahawa responden boleh menarik diri atau meminta supaya rakaman ditamatkan pada bila-bila masa.

	Suai-kenal
	<p>Sebelum kita mulakan sesi, bolehkan tuan/puan ceritakan sedikit tentang diri masing-masing kepada semua dalam kumpulan ini?</p> <p>Bagaimana patut kami panggil tuan/puan? Tuan/puan boleh menggunakan sebarang nama jika mahu.</p>
A	Persepsi terhadap akses servis kesihatan
1	Adakah terdapat sebarang perbezaan dalam peruntukan fasiliti kesihatan antara kawasan bandar dan luar bandar?
2	Adakah terdapat pilihan untuk mendapatkan servis di luar waktu operasi atau rawatan di rumah?
3	Bagaimanakah kakitangan kesihatan memberikan sokongan terhadap wanita hidup dengan HIV yang mempunyai masalah kewangan?
4	Bagaimanakah anda menyediakan atau mengedarkan bekalan susu formula di kawasan bandar atau luar bandar?
5	Bagaimanakah anda menyediakan perkhidmatan kaunseling untuk wanita yang hidup dengan HIV? Perincian:

	Suai-kenal
	Bagaimanakah anda memastikan kesejahteraan emosi dan mental wanita yang hidup dengan HIV?
6	Bagaimanakah anda menilai tahap kepuasan pesakit terhadap mutu perkhidmatan di fasiliti kesihatan? Perincian: Adakah anda memberikan peluang kepada wanita hidup dengan HIV untuk memberikan maklum balas terhadap mutu perkhidmatan?
B	Persepsi terhadap hak dan kesihatan seksual dan reproduktif
7	Apakah cabaran yang dihadapi oleh kakitangan kesihatan dalam mendapatkan persetujuan/keizinan wanita atau dalam menjaga kerahsiaan wanita?
8	Bagaimanakah kakitangan kesihatan berhadapan dengan wanita yang tidak memberi keizinan atau tidak bersetuju dengan rawatan/prosedur yang diberikan?
9	Bagaimanakah kakitangan kesihatan mengendalikan kes untuk permintaan rawatan tertentu? Perincian: Apa pandangan anda terhadap wanita yang hidup dengan HIV yang menentukan sendiri rawatan mereka?
10	Sejauh manakah wanita yang hidup dengan HIV diberi peluang untuk memilih dan menentukan ujian/saringan yang dilakukan, kaedah kelahiran bayi, perancangan keluarga dan penyusuan bayi mereka? Perincian: Adakah anda mengambil masa dan ruang untuk menjelaskan kepada wanita hidup dengan HIV tentang tujuan dan cara setiap prosedur/rawatan? Jika tidak, mengapa?
11	Bagaimanakah anda dapat memastikan keselamatan wanita yang menjadi mangsa keganasan berasaskan gender dalam hal mendapatkan keizinan/persetujuan?
C	Persepsi terhadap stigma dan diskriminasi
12	Apakah perasaan anda dalam memberikan rawatan kepada wanita yang hidup dengan HIV?
13	Bagaimanakah anda memastikan mereka rasa selesa dan diterima serta tidak disisihkan di fasiliti kesihatan? Perincian: Sekerap manakah anda memastikan hal ini terjaga/diambil perhatian?
14	Pada pendapat anda, bagaimanakah perkhidmatan kesihatan dapat membantu wanita yang hidup dengan HIV untuk menangani stigma dan diskriminasi?

	Suai-kenal
D	Penjelasan berhubung maklumat daripada responden
15	Adakah terdapat situasi di mana wanita yang hidup dengan HIV perlu membayar untuk sesetengah ujian klinikal atau prosedur?
16	Apakah polisi berkenaan cara pelupusan uri setelah bersalin bagi wanita yang hidup dengan HIV? Perincian: Setelah bersalin, adakah wanita yang hidup dengan HIV dibenarkan untuk membawa pulang uri untuk diuruskan sendiri? Jika ya, adakah mereka diberi penerangan mengenai cara selamat untuk mananam atau melupuskan uri?
17	Bagaimanakah anda menguruskan permintaan untuk kaedah perancangan keluarga secara kekal bagi wanita yang hidup dengan HIV? Perincian: Apakah faktor-faktor yang dipertimbangkan dalam permintaan untuk kaedah perancangan keluarga secara kekal, contohnya umur pesakit, bilangan anak, agama?
18	Apakah cara penyusuan yang disarankan untuk bayi yang dilahirkan oleh ibu positif-HIV selain daripada susu formula? Perincian: Adakah ibu susuan atau bank susu juga disarankan?
19	Apakah polisi semasa berkaitan dengan proses kelahiran di hospital swasta bagi wanita yang hidup dengan HIV?
	Penutup Tuan/puan ada sebarang soalan lain untuk saya? Terima kasih atas masa dan kesudian tuan/puan berkongsi pengalaman dengan kami. Jika tuan/puan mahukan salinan transkrip temubual ini, saya boleh berikan kemudian. Atas penghargaan kami untuk masa dan sumbangan tuan/puan dalam sesi ini, kami ada menyediakan sedikit sumbangan.

Annex 25

Details of women living with HIV

ID	Day, time	Date	Session type	Category	State	Region	Age (years)	Race	Year of HIV diagnosis	Education level	Occupation	Marital status	HIV status of spouse or partner	No. of children
R1SP	Saturday, 11am	14 August 2021	Focus group discussion	Postnatal	Johor	South	32	Chinese	2013	Secondary school	N/A	Married	Negative	3
R2SP	Saturday, 11am	14 August 2021	Focus group discussion	Postnatal	Sabah	Borneo	24	Malay	2008	Secondary school	Unemployed	Married	Negative	1
R3SP	Saturday, 11am	14 August 2021	Focus group discussion	Postnatal	Kelantan	East	38	Malay	2011	Secondary school	Unemployed	Married	Positive	3
R4SP	Saturday, 11am	14 August 2021	Focus group discussion	Postnatal	Terengganu	East	28	Malay	2012	Secondary school	Unemployed	Married	Negative	2
R5SP	Saturday, 11am	14 August 2021	Focus group discussion	Postnatal	Johor	South	37	Malay	2010	Higher education	White-collar	Married	Negative	2
R6S1	Monday, 9am	16 August 2021	In-depth discussion	General	Perlis	North	50	Malay	2005	Higher education	Pensioner	Married	Negative	1
R7S2	Tuesday, 9am	17 August 2021	Focus group discussion	General	Terengganu	East	49	Malay	2003	Secondary school	Unemployed	Widowed	N/A	4
R8S2	Tuesday, 9am	17 August 2021	Focus group discussion	General	Sarawak	Borneo	32	Malay	2012	N/A	Unemployed	Married	Negative	2
R9S2	Tuesday, 9am	17 August 2021	Focus group discussion	General	Pahang	East	39	Malay	2016	Secondary school	Self-employed	Married	Negative	1
R10S2	Tuesday, 9am	17 August 2021	Focus group discussion	General	Kedah	North	38	Malay	2011	Secondary school	Unemployed	Married	Negative	1

R11S2	Tuesday, 9am	17 August 2021	Focus group discussion	General	Negeri Sembilan	Central	46	Malay	2009	Secondary school	Blue-collar	Widowed	N/A	2
R12S3	Wednesday, 9am	18 August 2021	In-depth discussion	General	Kedah	North	49	Malay	2015	Secondary school	Blue-collar	Divorced	N/A	1
R13S4	Thursday, 9am	19 August 2021	Focus group discussion	General	Terengganu	East	40	Malay	2006	Secondary school	Unemployed	Married	Positive	2
R14S4	Thursday, 9am	19 August 2021	Focus group discussion	General	Selangor	Central	48	Malay	2012	Secondary school	Unemployed	Widowed	N/A	1
R15S4	Thursday, 9am	19 August 2021	Focus group discussion	General	Pulau Pinang	North	43	Malay	2017	Secondary school	Blue-collar	Married	Positive	3
R16S4	Thursday, 9am	19 August 2021	Focus group discussion	General	Selangor	Central	39	Malay	2008	Secondary school	Unemployed	Married	Positive	1
R17S4	Thursday, 9am	19 August 2021	Focus group discussion	General	Selangor	Central	31	Malay	2001	Secondary school	Unemployed	Married	Positive	1
R18S5	Saturday, 11am	21 August 2021	Focus group discussion	General	Kedah	North	58	Indian	2012	Secondary school	Unemployed	Widowed	N/A	3
R19S5	Saturday, 11am	21 August 2021	Focus group discussion	General	Pahang	East	45	Malay	2005	Secondary school	Unemployed	Married	Negative	4
R20S5	Saturday, 11am	21 August 2021	Focus group discussion	General	Terengganu	East	38	Malay	2004	Secondary school	Unemployed	Married	Negative	3
R21S5	Saturday, 11am	21 August 2021	Focus group discussion	General	Pahang	East	47	Malay	2002	Secondary school	Blue-collar	Married	Positive	5
R22S5	Saturday, 11am	21 August 2021	Focus group discussion	General	Kuala Lumpur	Central	35	Malay	2016	Higher education	White-collar	Married	Positive	1
R23S6	Monday, 9am	23 August 2021	Focus group discussion	General	Kedah	North	52	Indian	2001	Secondary school	Unemployed	Widowed	N/A	2

R24S6	Monday, 9am	23 August 2021	Focus group discussion	General	Sabah	Borneo	19	Bajau	2011	Secondary school	Unemployed	Single	N/A	0
R25S6	Monday, 9am	23 August 2021	Focus group discussion	General	Sabah	Borneo	18	Bajau	2012	Primary school	Unemployed	Single	N/A	0
R26S6	Monday, 9am	23 August 2021	Focus group discussion	General	Pahang	East	30	Malay	2019	N/A	N/A	Married	N/A	0
R27S6	Monday, 9am	23 August 2021	Focus group discussion	General	Terengganu	East	50	Malay	2008	N/A	Self-employed	Widowed	N/A	2
R28S7	Tuesday, 9am	24 August 2021	In-depth discussion	Antenatal	Terengganu	East	36	Malay	2009	N/A	Blue-collar	Married	N/A	2
R29S8	Wednesday, 9am	25 August 2021	In-depth discussion	Antenatal	Pahang	East	39	Malay	2010	N/A	White-collar	Married	Negative	1
R30S9	Thursday, 9am	26 August 2021	Focus group discussion	Antenatal	Perlis	North	29	Malay	2009	Secondary school	Unemployed	Married	Negative	2
R31S9	Thursday, 9am	26 August 2021	Focus group discussion	Antenatal	Johor	South	28	Malay	2019	Secondary school	Unemployed	Married	Negative	0
R32S9	Thursday, 9am	26 August 2021	Focus group discussion	Antenatal	Kedah	North	24	Malay	2018	Secondary school	White-collar	Married	Negative	0
R33S9	Thursday, 9am	26 August 2021	Focus group discussion	Antenatal	Pulau Pinang	North	38	Chinese	2017	Secondary school	Unemployed	Married	Negative	4
R34S10	Monday, 9am	30 August 2021	Focus group discussion	Antenatal	Sarawak	Borneo	32	Malay	2021	Primary school	Unemployed	Married	Negative	4
R35S10	Monday, 9am	30 August 2021	Focus group discussion	Antenatal	Pahang	East	32	Malay	2012	N/A	Unemployed	Married	Negative	2
R36S10	Monday, 9am	30 August 2021	Focus group discussion	Antenatal	Perak	North	42	Chinese	2021	Secondary school	Unemployed	Married	Negative	0

R37S10	Monday, 9am	30 August 2021	Focus group discussion	Antenatal	Sarawak	Borneo	27	Malay	2015	Secondary school	Self-employed	Married	Negative	1
R38S11	Wednesday, 9am	1 September 2021	Focus group discussion	Antenatal	Kuala Lumpur	Central	33	Chinese	2015	Secondary school	Unemployed	Married	Positive	2
R39S11	Wednesday, 9am	1 September 2021	Focus group discussion	Antenatal	Selangor	Central	25	Malay	2019	Higher education	Unemployed	Married	Negative	0
R40S11	Monday, 9am	1 September 2021	Focus group discussion	Antenatal	Negeri Sembilan	Central	35	Malay	2010	N/A	Blue-collar	Married	Negative	1
R41S12	Thursday, 9am	2 September 2021	In-depth discussion	Antenatal	Perak	North	29	Indian	2019	Higher education	White-collar	Married	Positive	0
R42S13	Fri/ 9am	3 September 2021	In-depth discussion	Postnatal	Kedah	North	28	Indian	2016	Secondary school	Unemployed	Married	Negative	1
R43S14	Saturday, 11am	4 September 2021	Focus group discussion	Postnatal	Melaka	South	38	Malay	2014	Secondary school	Unemployed	Married	Positive	1
R44S14	Saturday, 11am	4 September 2021	Focus group discussion	Postnatal	Penang	North	31	Malay	2018	Higher education	Unemployed	Married	Positive	2
R45S14	Saturday, 11am	4 September 2021	Focus group discussion	Postnatal	Terengganu	East	23	Malay	2015	Secondary school	Unemployed	Married	Negative	2
R46S14	Saturday, 11am	4 September 2021	Focus group discussion	Postnatal	Pahang	East	43	Malay	2019	N/A	Unemployed	Married	Negative	5
R47S15	Saturday/ 3pm	4 September 2021	In-depth discussion	Postnatal	Pahang	East	36	Malay	2020	N/A	Unemployed	Single	Inapplicable	8
R48ST1	Sunday, 9am	5 September 2021	In-depth discussion	General	Sabah	Borneo	21	Bajau	2000	Secondary school	Unemployed	Single	Inapplicable	0

R49ST2	Sunday, 11am	5 September 2021	In-depth discussion	Postnatal	Melaka	South	30	Malay	2010	Secondary school	Unemployed	Married	Negative	1
R50S16	Monday, 9am	6 September 2021	Focus group discussion	Postnatal	Terengganu	East	40	Malay	2005	Secondary school	Unemployed	Married	Positive	2
R51S16	Monday, 9am	6 September 2021	Focus group discussion	Postnatal	Kelantan	East	29	Malay	2015	Secondary school	Unemployed	Married	Negative	2
R52S16	Monday, 9am	6 September 2021	Focus group discussion	Postnatal	Kuala Lumpur	Central	34	Indian	2011	Secondary school	Unemployed	Married	Negative	2
R53S16	Monday, 9am	6 September 2021	Focus group discussion	Postnatal	Pahang	East	27	Malay	2014	N/A	Blue-collar	Divorced	Inapplicab le	3
R54S16	Monday, 9am	6 September 2021	Focus group discussion	Postnatal	Sarawak	Borneo	29	Iban	2016	Secondary school	Unemployed	Married	Negative	1
R55S17	Tuesday, 9am	7 September 2021	Focus group discussion	Postnatal	Melaka	South	27	Malay	2016	Secondary school	Unemployed	Married	Negative	3
R56S17	Tuesday, 9am	7 September 2021	Focus group discussion	Postnatal	Kuala Lumpur	Central	35	Malay	1997	Higher education	White-collar	Married	Negative	1
R57S17	Tuesday, 9am	7 September 2021	Focus group discussion	Postnatal	Terengganu	East	38	Malay	2007	N/A	Unemployed	Married	Negative	2
R58S17	Tuesday, 9am	7 September 2021	Focus group discussion	Postnatal	Kedah	North	37	Malay	2014	Secondary school	Self- employed	Married	Negative	4
R59S17	Tuesday, 9am	7 September 2021	Focus group discussion	Postnatal	Perak	North	31	Malay	2017	Secondary school	Unemployed	Married	Negative	1
R60S18	Wednesday, 9am	8 September 2021	In-depth discussion	Postnatal	Pulau Pinang	North	23	Indian	2019	Higher education	Self- employed	Married	Positive	1

R61S19	Thursday, 9am	9 September 2021	In-depth discussion	Postnatal	Negeri Sembilan	Central	23	Malay	2020	Higher education	Unemployed	Married	Positive	2
R62S20	Saturday, 10am	11 September 2021	Focus group discussion	Antenatal	Kelantan	East	32	Malay	2017	Secondary school	Unemployed	Married	Negative	2
R63S20	Saturday, 10am	11 September 2021	Focus group discussion	Antenatal	Selangor	Central	28	Malay	2009	Secondary school	Unemployed	Married	Negative	2
R64S20	Saturday, 10am	11 September 2021	Focus group discussion	Antenatal	Selangor	Central	24	Chinese	2007	N/A	Unemployed	Married	Negative	1
R65S20	Saturday, 10am	11 September 2021	Focus group discussion	Antenatal	Selangor	Central	28	Malay	2021	N/A	Self- employed	Married	Positive	0
R66S21	Monday, 9am	13 September 2021	Focus group discussion	Postnatal	Pulau Pinang	North	36	Malay	2013	Higher education	White-collar	Married	Negative	2
R67S21	Monday, 9am	13 September 2021	Focus group discussion	Postnatal	Selangor	Central	29	Bidayuh	2011	Secondary school	Unemployed	Married	Negative	2
R68S21	Monday, 9am	13 September 2021	Focus group discussion	Postnatal	Pahang	East	43	Malay	2004	N/A	Unemployed	Married	Negative	3
R69S21	Monday, 9am	13 September 2021	Focus group discussion	Postnatal	Pahang	East	26	Malay	2016	N/A	Self- employed	Married	Positive	2
R70S22	Tuesday, 9am	14 September 2021	Focus group discussion	Postnatal	Pulau Pinang	North	30	Malay	2018	Secondary school	Unemployed	Married	Negative	3
R71S22	Tuesday, 9am	14 September 2021	Focus group discussion	Postnatal	Selangor	Central	28	Malay	2014	Secondary school	Unemployed	Married	Negative	1
R72S22	Tuesday, 9am	14 September 2021	Focus group discussion	Postnatal	Terengganu	East	21	Malay	2020	N/A	Unemployed	Married	Negative	1

R73S22	Tuesday, 9am	14 September 2021	Focus group discussion	Postnatal	Sabah	Borneo	18	Sino	2006	Primary school	Unemployed	Married	Negative	1
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Annex 26

Details of healthcare providers

ID	Day, Time	Date	Session type	Category	Position	State	Region	Age	Sex	Race	Years of experience
H1S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Medical officer	Melaka	South	37	Female	Malay	5–10
H2S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Medical officer	Pahang	East	36	Female	Malay	5–10
H3S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Medical officer	Putrajaya	Central	35	Female	Indian	5–10
H4S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Medical officer	Selangor	Central	34	Male	Malay	5–10
H5S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Medical officer	Pulau Pinang	North	32	Female	Malay	5–10
H6S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Medical officer	Perak	North	38	Female	Malay	5–10
H7S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Specialist	Sabah	Borneo	38	Female	Chinese	5–10
H8S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Specialist	Selangor	Central	53	Female	Malay	>10
H9S23	Wednesday, 9am	15 September 2021	Focus group discussion	Healthcare provider	Specialist	Johor	South	60	Male	Indian	>10
H10S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Nurse	Negeri Sembilan	Central	38	Female	Malay	>10
H11S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Nurse	Johor	South	43	Female	Malay	>10
H12S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Counsellor	Perlis	North	47	Female	Malay	>10
H13S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Counsellor	Terengganu	East	41	Female	Malay	>10
H14S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Nurse	Kelantan	East	45	Female	Malay	>10

H15S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Counsellor	Sarawak	Borneo	45	Female	Malay	>10
H16S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Nurse	Melaka	South	42	Female	Malay	>10
H17S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Counsellor	Pahang	East	41	Female	Malay	>10
H18S24	Friday, 9am	17 September 2021	Focus group discussion	Healthcare provider	Nurse	Kuala Lumpur	Central	39	Female	Malay	>10

