

► **A study on medical insurance coverage for people living with HIV in selected multinational insurance companies in Malaysia**



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Undertaken by: The Malaysian AIDS Foundation

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*A study on medical insurance coverage for people living with HIV in selected multinational insurance companies in Malaysia*

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## ► Preface

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Antiretroviral treatment has changed HIV from a fatal disease into a manageable, chronic condition. Not only does it improve the health outcomes for people living with HIV, it improves their longevity, quality of life and keeps them productive.

Why should then HIV not be included in insurance policies and schemes? This study, undertaken by the Malaysian AIDS Foundation (MAF) with the support of the ILO, explores answers to this question.

Data from Malaysia and interviews with medical practitioners/people living with HIV show improvement in the health status of people living with HIV thanks to antiretroviral treatment. Antiretroviral treatment for HIV is provided by the Ministry of Health. Yet, HIV is not covered by health insurance in Malaysia, even though multi-national insurance companies operating in Malaysia cover HIV in other countries.

The study reviews examples of insurance coverage of HIV in other countries, analyses the social and economic benefits of providing health insurance for HIV and makes important policy recommendations for including HIV in health insurance in Malaysia.

People living with HIV should not be left behind by insurance companies. It is their right, and it also makes economic sense for insurance companies. We hope the study will contribute to initiating a dialogue between relevant stakeholders in Malaysia on enhancing access to insurance for people living with HIV. The study provides a wealth of evidence from other settings and therefore can be applied in other countries as well to enhance the access to public and private insurance for people living with HIV.

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From the ILO Geneva, Afsar Syed Mohammad, Senior Technical Specialist led the study in collaboration with Diddie Schaaf, Technical Officer. Ms Rakawin Leechanavanichpan provided useful support in this work from the ILO Regional Office for Asia and the Pacific in Bangkok.

The process of preparing this report involved engaging with a diverse array of stakeholders whose input enriched this report, including members of government agencies, parliamentarians and most importantly people living with HIV. Professionals from infectious disease physicians to individuals in different capacities in the insurance industry as well as from the corporate sector also made important contributions to this study. Due to the nature of the study and the request for anonymity from many of the participants, we are unable to acknowledge the contributions of many individuals who engaged in the research process by name.

We take this opportunity to thank all those who were involved in the process of the study in one way or another.

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## ► Abbreviations

<b>3TC</b>	Lamivudine	<b>OIC</b>	Office of Insurance Commission, Thailand
<b>Ab</b>	Antibody	<b>OOPs</b>	Out-of-pocket payments
<b>Ag</b>	Antigen	<b>PCR</b>	Polymerase chain reaction
<b>AIDS</b>	Acquired Immunodeficiency Syndrome	<b>PEPFAR</b>	President's Emergency Plan for AIDS Relief
<b>ART</b>	Antiretroviral therapy	<b>PhilHealth</b>	Philippine Health Insurance
<b>ARV</b>	Antiretroviral	<b>PJP</b>	Pneumocystis Jirovecii Pneumonia
<b>ASEAN</b>	Association of South-East Asian Nations	<b>PrEP</b>	Pre-exposure prophylaxis
<b>AZT</b>	Zidovudine	<b>RM</b>	Ringgit Malaysia
<b>cART</b>	Combination antiretroviral therapy	<b>RNA</b>	Ribonucleic acid
<b>DALY</b>	Disability-Adjusted Life Year	<b>SHI</b>	Social Health Insurance
<b>DTG</b>	Dolutegravir	<b>SJS</b>	Stevens-Johnson Syndrome
<b>EFV</b>	Efavirenz	<b>STIs</b>	Sexually transmitted infections
<b>FBC</b>	Full blood count	<b>TDF</b>	Tenofovir
<b>FGD</b>	Focus group discussion	<b>THE</b>	Total health expenditure
<b>FLP</b>	Fasting lipid profile	<b>TB</b>	Tuberculosis
<b>FTC</b>	Emtricitabine	<b>UFEME</b>	Urine full examination and microscopic examination
<b>GDP</b>	Gross domestic product	<b>UHC</b>	Universal Health Coverage
<b>HBV</b>	Hepatitis B virus	<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>HCV</b>	Hepatitis C virus	<b>US\$</b>	United States dollar
<b>HIV</b>	Human immunodeficiency virus	<b>WHO</b>	World Health Organization
<b>HMO(s)</b>	Health maintenance organization(s)		
<b>ILO</b>	International Labour Organization		
<b>IPT</b>	Isoniazid preventive therapy		
<b>LFT</b>	Liver function test		
<b>LIAM</b>	Life Insurance Association of Malaysia		
<b>MASHM</b>	Malaysian Society of HIV Medicine		
<b>MeSH</b>	Medical Subject Headings		
<b>MRTA</b>	Mortgage reducing term assurance		
<b>MSF</b>	Médecins Sans Frontières		
<b>NGOs</b>	Non-governmental organizations		
<b>NVP</b>	Nevirapine		



# Executive summary



## Background

HIV and HIV-related illnesses are excluded from private medical and health insurances in Malaysia. People living with HIV are denied insurance coverage because of their pre-existing condition and there are no insurance policies that specifically cover HIV and AIDS in Malaysia. This is despite the fact that the parent companies of some insurance companies in Malaysia provide coverage for people living with HIV in other countries.

This predicament impacts people living with HIV in different ways. Not only can they not purchase private insurance, but those who may have purchased private medical and health insurance prior to their diagnosis experience challenges in attempting to make claims even when they have been contributing toward the premiums.

## Methodology

This exploratory study used qualitative methods to achieve the following research objectives:

1. To determine factors related to the provision of private health insurance coverage (or lack of it) by private insurance companies in Malaysia.
2. To identify good practices with regard to private health insurance coverage for people living with HIV in developing countries, particularly in South-East Asia.
3. To examine the barriers to private health insurance and the healthcare financing consequences thereof for people living with HIV in Malaysia.
4. To generate policy recommendations related to the coverage of private health insurance for people living with HIV in Malaysia.

A scoping review of literature was accompanied by a document analysis, in-depth interviews with people living with HIV, insurers and corporate sector members in Malaysia and overseas, focus group discussions with people living with HIV, a qualitative survey with 11 life insurance companies in Malaysia and email interviews with selected insurance companies. Triangulation was achieved by using multiple sources of data and research methods in the study.

Taking an interdisciplinary approach, this study examined data from several domains related to the issues and includes: (i) the epidemiology of HIV – globally and in Malaysia; (ii) current treatment approaches to HIV and evidence regarding current treatment outcomes for people living with HIV globally and in Malaysia; (iii) economic benefits to societies and countries as a result of expansion of HIV treatment; (iv) medical and health insurance coverage of people living with HIV in Malaysia; and (v) country case examples of coverage of people living with HIV by private medical and health insurance within the context of the health systems and financing arrangements for HIV in these countries.

## Results

The review of literature and primary research revealed the following findings:

### Epidemiology of HIV

Outside of Sub-Saharan Africa, key populations comprising gay men and other men who have sex with men, sex workers, transgender people, people who inject drugs and people in prisons and other closed settings who are particularly vulnerable to HIV and frequently lack adequate access to services, accounted for the majority of new infections. This trend was mirrored in Malaysia too, with the epidemic in Malaysia recently showing shifting trends away from injecting drug users to sexual transmission, tending more towards men who have sex with men.

Nearly 90 per cent of those living with HIV are among the working-age group of 20 to 49 years of age and most people diagnosed with HIV are men. One of the global goals set for 2020, 90 per cent of people who know their status access treatment, was 55 per cent in Malaysia for 2018.

### Current HIV treatment approaches and effectiveness of treatment

Current treatment regimens, unlike treatment regimens in the early days, have demonstrated proven effectiveness controlling HIV replication with life expectancy close to the expected life expectancy of the general population, improving immunologic outcomes, improving the management of comorbidity and opportunistic infections and reducing all-cause mortality among people living with HIV. The emerging body of evidence in Malaysia with regard to treatment outcomes resonates with similar global evidence whenever study participants had access to Antiretroviral Therapy (ART). This evidence shows that people living with HIV on ART had an increase in mean survival time, a lower all-cause mortality rate and lower AIDS-defining events. These findings also cohere with treatment outcomes experienced by the people living with HIV

participants who were interviewed in the study. In Focus Group Discussion, 13 of the 14 people living with HIV had undetectable viral loads, the 14th person was recently diagnosed and awaiting the viral load test result. Additionally, many of them stated that they were in much better health than before, with some admitting that the routine follow-up and testing which were part of the HIV treatment and care they were receiving, were significant factors in enabling them to maintain good health.

The advent of combination ART has brought about a shift in the HIV epidemic, changing HIV from a fatal disease to a chronic condition that can be managed with appropriate medication.

In Malaysia, treatment costs for HIV are by and large free or subsidised by the government in the Ministry of Health and Ministry of Education facilities with some exceptions. Charges at private hospitals and clinics are fully borne by the individual at the respective private rates.

### **Economic benefits of expanding HIV treatment**

Evidence from several countries indicates economic gains flowing from the expansion of HIV treatment at the individual, household, business and country levels. At the individual level, initiation of and adherence to ART led to increased and sustained employment levels for people living with HIV and avoidance of catastrophic health expenditures. At the household level, gains included prevented end-of-life health and funeral expenditures, more time for schooling and less

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The Antiretroviral Therapy Cohort Collaboration estimated that the life expectancy of a 20-year old person starting ART was close to the expected life expectancy of the general population (Antiretroviral Therapy Cohort Collaboration, 2017).

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time for work for children of people living with HIV and preventing children in the household from becoming orphans. Benefits to businesses included gains in terms of retaining institutional memory, averting disruptions to production processes and cost savings through prevention of hiring and retraining new employees. The sum of these benefits accruing to people living with HIV, their household and companies they are employed at have been found to translate into country-level increases in employment and labour productivity, as well as prevented orphan care, medical treatment for opportunistic infections and end-of-life care.

### **Medical and health insurance coverage of people living with HIV in Malaysia**

Private insurance comprises a significant and growing percentage of the total private health expenditure in the country. However, HIV is generally considered as an exclusion criterion with a few exceptions. Interviews with people living with HIV revolved around the negative impact of the exclusion criteria with regard to HIV on their lives. Combined with the generally



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good treatment outcomes they maintained, they unequivocally affirmed that the exclusion clause that prohibited them from purchasing health insurance and MRTA (Mortgage reducing term assurance) was not justified under the circumstances.

Although most insurers were not aware of advances in HIV treatment and treatment outcomes, some insurance companies expressed openness to consider providing coverage for HIV subject to having more information required for risk assessment and price quantification and other services such as reinsurance.

### Country case examples of coverage of people living with HIV by private medical and health insurance

The review of literature and key informant interviews examining the factors that facilitated the expanded coverage of private health insurance for people living with HIV in many countries reveal the following factors:

1. The recognition of HIV as a chronic condition by insurers.
2. The salience of legislation and policies (either through constitutional provisions, legislation related to HIV management, general anti-discrimination legislation or specifically discrimination against people living with HIV, or national policies or legislation related to private health insurance) in nudging insurers in developing countries especially to initiate new private insurance products for people

It seems that there might be untapped win-win opportunities for people living with HIV, the insurance sector, and the government in dynamically and vigorously moving forward the discussion on removing the exclusion related to HIV in the insurance sector.

living with HIV, including for medical and health insurance.

3. Advances in treatment and improved health outcomes for people living with HIV as a result of newer treatment regimes, which through improved life expectancy and better ability to manage opportunistic infections, helped in mitigating the perception of risk for private insurers.
4. Free and/or subsidized ART through state intervention, which also modified the perception of risk associated with HIV once treatment became widely available and at no/low cost.
5. Opening up of payroll based social health insurance to private insurance.
6. Assistance from international organizations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and PEPFAR which expanded the accessibility to free of cost ART.
7. Increasing capacity of insurers to assess risks because of the above factors, notably, the objective measurement of patient progress with regard to HIV.



## The case for extending insurance coverage for people living with HIV in Malaysia

Although an actuarial analysis assessing the viability of extending private insurance cover to people living with HIV is a different exercise requiring other data, the review has identified several factors which make a case for exploring such an analysis in Malaysia based on the following factors:

1. The strong role played by the Government in undertaking a range of initiatives in making available free and subsidized ART for people living with HIV in line with international standards. Integrating this service into primary care increases the accessibility to HIV treatment services.
2. A normal CD4<sup>1</sup> count and viral load<sup>2</sup> suppression of people living with HIV who had initiated treatment early and were adherent to treatment with studies showing a significant increase in life expectancy and a decrease in all-cause mortality rate and AIDS-defining events.
3. The openness of some insurers to consider offering private insurance for people living with HIV provided they received support from the government and reinsurers in distributing and mitigating risk.
4. Relatedly, a key point that emerged from the review is that insurers seemed to be missing a business opportunity. This included the knowledge gap regarding the state of treatment and treatment outcomes enjoyed by people living with HIV and the transmission shift in the people living with HIV population with sexual transmission overtaking injecting drug use as the leading route of transmission.
5. People living with HIV are currently using out-of-pocket payments to meet their healthcare needs in the private sector. With out-of-pocket payments for healthcare constituting a substantial 77 per cent share of the private sector health expenditure, private medical and health insurance offers a substitute to move these out-of-pocket payments into a prepaid system of financing healthcare through private medical and health insurance.

In short, there is a human, as well as a business case for insurance companies to include HIV. Inclusion of people living with HIV in existing health insurance will be beneficial for the following reasons:

- a) ART is provided free by the government. Hence, no cost to insurance companies for a life-long treatment which has shown to keep people healthy and productive.
- b) The current focus of the HIV response is helping people living with HIV to know their status early and start ART early, reducing the incidence of opportunistic infections and hospitalizations.
- c) Advances in HIV testing and introduction of HIV self-testing is yet another way that is helping people to do an initial screening in their own private settings; companies should, therefore, cover HIV testing and self-testing as well.
- d) Coverage of HIV will demonstrate that insurance companies do not discriminate and are making their contribution to the 2030 Agenda for Sustainable Development, following the principle of leaving no one behind.

1 Viral load refers to the number of viral particles of HIV found in each millilitre of blood. With successful treatment, the virus cannot be detected in the blood and this is known as viral load suppression. When the viral load is suppressed, HIV infection is unlikely to progress to AIDS and the likelihood of transmitting the virus to partners is very low.

2 CD4 cells are white blood cells, also known as T cells that play an important role in the immune system. CD4 cell count is the number of CD4 cells in a cubic millilitre of blood. The human immunodeficiency virus reduces the CD4 cell count. With successful treatment, the CD4 levels recover to normal levels.

## Key Recommendations

- The Ministry of Health, in consultation with people living with HIV and other relevant stakeholders, should lead the development of legislation/policy prohibiting discrimination against people living with HIV in all sectors on grounds of real or perceived HIV status.
- The Ministry of Health should also take up the mantle of facilitating a discussion between stakeholders in line with the Government's commitment to the 2030 Agenda for Sustainable Development, Goal 3: Ensure healthy lives and promote well-being for all at all ages, and the pledge of leaving no one behind (United Nations, 2015).
- Include the voices and participation of people living with HIV in all discussions. Paying attention to the voices and perspectives of the people living with HIV would deepen the understanding of the needs of the community and sharpen the focus and direction of discussions on the inclusion of HIV in private health insurance coverage.
- The government, insurance, health, research communities and the Malaysian AIDS Foundation should engage in a dialogue, and exchange information to foster greater cooperation in development and implementation of non-discriminatory policy/legislative framework.
- The world of work can play a key role in expanding the coverage of insurance for HIV. The ILO Recommendation Concerning HIV and AIDS and the World of Work, 2010 (No. 200) calls on Member States 'to ensure that workers living with HIV and their dependants benefit from full access to health care, whether this is provided under public health, social security systems or private insurance or other schemes. Members should also ensure the education and awareness raising of workers to facilitate their access to health care' (ILO, 2010).
- Enterprises, both public and private as well as multinational companies should review their health insurance policies and negotiate with the providers for inclusion of HIV.

- Given the positive impact of ART on health and longevity of people living with HIV, HIV should be included in the coverage of insurance. This requires continued dialogue with insurance companies.

While it is important to advocate for coverage of HIV in private insurance, it is critical to work with the government to **ensure that HIV sensitive social protection is expanded**. A combination of public and private sector approaches is desirable.

Since the factors in the assessment of risk seem to be common to medical and health insurance and other types of insurance, including life insurance and mortgage insurance, related to people living with HIV, **this review recommends that the insurance sector considers the removal of the exclusion related to HIV for all insurance products in future deliberations**.

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ILO's Recommendation 202 - Recommendation concerning national floors of social protection - urges Member States to ensure at a minimum that, over the life cycle, all in need have access to essential health care and to basic income security which together secure effective access to goods and services defined as necessary at the national level (ILO, 2012).

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# 1.

## Introduction



### Objectives

In the broader context of Universal Health Coverage and reaching Sustainable Development Goal 3, ensure healthy lives and promote well-being for all, the aim of this qualitative study was to undertake a review of private health insurance coverage of HIV and AIDS by multinational insurance companies in Malaysia including the consequent effects.

The specific objectives of the study included:

1. To determine factors related to the provision of private health insurance coverage (or lack of it) by private insurance companies in Malaysia.
2. To identify good practices with regard to private health insurance coverage for people living with HIV in developing countries, particularly in South-East Asia.
3. To examine the barriers to private health insurance and the healthcare financing consequences thereof for people living with HIV in Malaysia.
4. To generate policy recommendations related to the coverage of private health insurance for people living with HIV in Malaysia.

Adopting an inter-disciplinary approach, this study analyses these objectives, reviewing evidence from a range of domains that have a bearing on the coverage of medical and health insurance for people living with HIV. Particular emphasis is placed on the context of HIV and private health insurance in select countries in Asia, Africa and the developed world. These countries were chosen for their proximity to Malaysia (South-East Asia), the availability of private health insurance for people living with HIV (Sri Lanka and key countries from the African continent) and where private insurance coverage has been already established for a longer period of time (select countries from North America, Europe and Latin America).

Within this context, the Malaysian government has been actively engaging in the response to HIV, albeit with a greater focus on treatment and mostly with public financing of such efforts (Tanguay, 2017). Toward this end, the Government has initiated a complement of strategies which aims at reducing new infections and expanding treatment and care for those living with HIV.

## Overview of the document

Inclusive of this section, the report is divided into **nine sections**. The **second section** introduces the methodology of the study and the range of methods and data sources used in this exploratory qualitative study.

The **third section** focuses on the epidemiology, treatment and management of HIV globally and assesses the Malaysian context against global epidemiological trends and clinical approaches related to HIV. The understanding of the magnitude and distribution of the disease within the broader population while assessing the implications for control of the disease is important for the assessment of risk from a private health insurance perspective.

The **fourth section** expands on current treatment approaches to HIV globally and examines the related treatment outcomes before scrutinizing the treatment outcomes related to people living with HIV in Malaysia. This information too is critical for risk rating in private insurance.

The **fifth section** reviews economic gains arising as a result of the expansion of HIV treatment and current HIV treatment outcomes globally while the **sixth section** looks at private medical and health insurance coverage for HIV in Malaysia and the lived experiences of people living with HIV in Malaysia with private insurance.

The **seventh section** reviews country case examples of private medical and health insurance and evaluates the factors in these countries that facilitated the initiation and sustainability of private medical and health insurance.

Based on the above evidence, **section eight** makes the case for exploring the introduction of private insurance for people living with HIV in Malaysia before concluding with recommendations in **section nine**.

Most of the sections mentioned have annexes with the complete research that was conducted.



2.

# Methodology



## Methodology

The methodology of the study included:

1. A scoping review of literature on topics that have been identified below.
2. Document analysis of relevant legislation, policies and reports.
3. Focus group discussions.
4. Key informant interviews using semi-structured in-depth interviews with people living with HIV, representatives from the insurance sector and representatives from the corporate sector.
5. A qualitative survey with 11 life insurance companies.
6. E-mail interviews with selected insurance companies regarding their coverage with respect to HIV.

## Research questions

In this regard, the review focused on answering the following research questions:

- i. How effective is the current HIV treatment for people living with HIV and what are the treatment outcomes?
- ii. What are the economic benefits of being on ART for people living with HIV and the societies they belong to?
- iii. Which countries provide good case examples of the availability of private health insurance for people living with HIV and why?
- iv. What are the factors associated with the availability of private health insurance for people living with HIV?

## Review of literature

The review of literature aimed at summarizing key issues related to current treatment regimens for people living with HIV, the effectiveness of current treatment and their consequent clinical and economic benefits. Specifically, the study sought to examine the factors associated with the availability of private health insurance for people living with HIV in countries where such insurance is available.

## Search strategy

In order to capture relevant information contributing to the broad scope of this review, eligible records retrieved and analysed included studies or reviews that examined, described, or discussed the following:

1. HIV treatment effectiveness and treatment outcomes related to current treatments:
  - 1.1. HIV treatment and treatment outcomes related to ART for people living with HIV and
  - 1.2. Access to antiretroviral therapy (ART) or treatment adherence to ART related to treatment outcomes for people living with HIV.
2. Economic benefits of people living with HIV on ART.

3. The association between having private health insurance and treatment outcomes for people living with HIV.
4. Factors associated with the availability of private health insurance for and access of people living with HIV to private health insurance in the Association of South-East Asian Nation (ASEAN) countries, Sri Lanka, Africa and North America.
5. The predominant healthcare financing options for people living with HIV, in particular for countries in the ASEAN, Africa, North America and Sri Lanka.

The search methodology of the literature sources can be found in **annex 1**.

A Google search and search of websites of relevant organizations was also conducted for reports pertinent to the purpose of the review from the following organizations' websites:

1. Malaysian AIDS Council.
2. Malaysian Ministry of Health.
3. Joint United Nations Programme on HIV/AIDS (UNAIDS).
4. International Labour Organization (ILO).
5. World Health Organization (WHO).

Importantly, data related to the epidemiology of HIV, globally and from Malaysia, were extracted from reports published by UNAIDS, WHO and the Malaysian Ministry of Health. Clinical guidelines for the management of HIV published by the WHO and the Malaysian Ministry of Health were also analysed.

In addition, further literature was hand searched based on identified citations in the published and grey literature.

## Focus group discussions (FGD)

Two focus group discussions were undertaken. The first included partner organisations of the Malaysian AIDS Council as well as other Non-Governmental Organizations (NGOs) and individuals that work with people living with HIV. The majority of the participants included members of NGOs working with people living with HIV and one individual supporting people living with HIV particularly on issues related to insurances. The second included people living with HIV and their family members who had experience with trying to claim private medical insurance, life insurance and mortgage reducing term assurance (MRTA) in relation to home loan insurance. Both discussions were conducted at the premises of one of the NGOs, in an enclosed setting to accommodate comfort and confidentiality. The participants were introduced to the study as well as the purpose of the FGD. Both FGDs included men and women who were working in different occupational sectors.

During the discussion, questions were asked exploring the experiences with regards to insurance coverage that had either been purchased directly by people living with HIV or by spouses living with HIV who had passed on.

## In-depth interviews

The in-depth interviews provided an opportunity for those respondents who preferred a private and one-on-one interview format to participate in the study. Structured in-depth interviews were conducted with people living with HIV, representatives of the life insurance sector and the corporate sector. All

participants were purposively sampled; people living with HIV for their experience with regard to purchasing/claiming health/life insurance and participants from the corporate sector because they or their companies had experience with insurance coverage for people living with HIV either in Malaysia or overseas.

With regard to people living with HIV, 14 individuals were purposively sampled. Age, gender, employment and duration of infection were considered in order to achieve diversity in the sample. Study participants were invited through NGOs, support groups and peers. Twelve of the individuals were male while two were female. Male participants were between 25 and 59 years old while female participants were 30 and 49 years old. Four were married and one was divorced. Eight were single while the remaining one was in a long-term relationship. Three participants had secondary level education while 11 had tertiary education. All participants were working, with 12 in the private sector and two in the government sector. Of the 12 in the private sector, three were working in multinational companies, one in a family business, two in non-governmental organizations and three participants were self-employed. The remaining three did not further specify their employment. Topics explored in the in-depth interviews with people living with HIV included their experiences with purchasing and/or claiming medical and health insurance, experiences of employment offers related to people living with HIV status and availability of group health insurance coverage for people living with HIV and detailed discussions on treatment, treatment outcomes and treatment costs. Clinical data related to treatment outcomes were also collected.

In-depth interviews were also conducted with eight participants based in Malaysia and overseas and belonging to the insurance sector. The interviews were conducted via Skype and face to face. Topics discussed during these interviews included rationale for inclusion of HIV in health insurance coverage offered by their companies or lack of it, key evidence that had been used in the analysis to cover people living with HIV, contextual factors that bolstered the decision to cover people living with HIV and the manner in which risks of providing insurance coverage to people living with HIV were managed.

Additionally, in-depth interviews were conducted with two participants from the corporate sector who represented views of employers in employing and providing health insurance coverage for people living with HIV.

The in-depth interviews with participants from the insurance and corporate sectors were conducted in a place suggested by the participants.

## Qualitative survey with life insurance companies

An anonymous qualitative survey was conducted with insurance companies by email. The dissemination of the surveys was facilitated by the Life Insurance Association of Malaysia (LIAM). Eleven companies responded to the invitation to participate in the survey. The survey focused on clarifying if people living with HIV were covered by their companies and under what circumstances and conditions, types of insurance they were eligible for, approach of the company if the person acquired HIV after purchase of an insurance policy, factors an insurance company would look into in order to consider covering a person living with HIV and finally if there were any studies that had been conducted in the last three years by the company regarding the current epidemiology of HIV, treatment approaches and by regimens and treatment outcomes for people living with HIV.

## Email interviews with members of insurance companies

Email interviews were also conducted with members of insurance companies regarding their company's insurance coverage with respect to HIV, exclusionary clauses and their rationale and under what conditions the insurance sector might cover people living with HIV for life and health insurance.

3.

# Findings



## ► 3a. Global goals, epidemiology in Malaysia, treatment and costs

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In order to assess the arguments related to the merits of inclusion or exclusion of people living with HIV from health insurance coverage it is important to examine key issues related to the epidemiology of HIV and evaluate the implications of treatments available for HIV currently and how the treatment and management of HIV in Malaysia compare with global standards.

### Global goals

In 2016, world leaders embarked on an initiative under the United Nations General Assembly Political Declaration on Ending AIDS by 2030 (UNAIDS, 2016). The initiative was intended to end AIDS as a public health threat by 2030, by achieving dramatic reductions in new HIV infections, deaths and illness, through the following targets set to be reached by 2020:

- 90 per cent of all people living with HIV to know their status.
- 90 per cent of all people diagnosed with HIV to receive antiretroviral therapy.
- 90 per cent of all people receiving treatment to achieve viral suppression.

By 2019, 81 per cent of people living with HIV globally knew their status. Among people who knew their status, 82 per cent were accessing treatment and among people accessing treatment, 88 per cent were virally suppressed (UNAIDS, 2020b).

### Malaysia

Malaysia is committed to the United Nations Political Declaration of Ending AIDS by 2030. In 2018, 86 per cent of people living with HIV knew their status. Of these, 55 per cent were on ART and 97 per cent of people on ART had suppressed viral loads<sup>3</sup> (Ministry of Health, 2019a), this last percentage indicates that there is a high adherence to treatment. The percentage of people on ART in Malaysia is very low and private health insurances can play an important role in reaching the 90 per cent goal.

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3 Viral load refers to the number of viral particles of HIV found in each millilitre of blood. With successful treatment, the virus cannot be detected in the blood and this is known as viral load suppression. When the viral load is suppressed, HIV infection is unlikely to progress to AIDS and the likelihood of transmitting the virus to partners is very low.

It is estimated that there were 87,041 people living with HIV at the end of 2018 (Ministry of Health, 2019a) while the rate of people who have died from AIDS related causes halved from 2016 to 2018, i.e. from 16.86 per 100,000 population in 2016 to 8.3 per 100,000 population in 2018 (Ministry of Health, 2019a). New cases declined by more than 50 per cent from 2002 to 2018, i.e. from 6,978 new notified HIV cases in 2002 to 3,293 cases in 2018 (Ministry of Health, 2019a). Of the 3,293 new infections in 2018, more than 94 per cent was by sexual transmission (57 per cent homo/bisexual and 37 per cent heterosexual). Injecting drug users, mother to child transmission and other modes comprised 6 per cent. In relation to age and gender, 90 per cent of new HIV infections in 2018 were reported among people 20 to 49 years old and 88 per cent were male. (Information provided by the HIV/AIDS Unit, Ministry of Health).

The early phase of the country's epidemic was driven by people who inject drugs, however, the trend has shifted toward sexual transmission since 2000. The group of men having sex with men is expected to become the main driver of the epidemic in the years to come beginning 2018, as projected by the Asian Epidemic Modelling (AEM) (Ministry of Health, 2019a).

More details on the epidemiology of HIV and AIDS can be found in [annex 2](#).

## Treatment guidelines for Antiretroviral Therapy (ART)

Combination treatment with at least three different antiretroviral medicines is now standard treatment for all people newly diagnosed with HIV. Combination ART stops HIV from multiplying and can suppress HIV to undetectable levels in the blood. This allows a person's immune system to recover, overcome infections and prevent the development of AIDS and other long-term effects of HIV infection. ART also has an important benefit in the prevention of HIV transmission, people with an undetectable viral load cannot transmit HIV sexually.

A comparison of the WHO Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infections 2016 (WHO, 2016a) with the Malaysian Consensus Guidelines (2017) (Ministry of Health & MASHM, 2017) shows that they are aligned for HIV treatment. Both guidelines recommend initiation of ART for all adults (above 18 years of age) living with HIV, regardless of CD4 count, to reduce the mortality and morbidity associated with HIV infection.

The details on treatment and management of HIV can be found in [annex 3](#).

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The clinical guidelines used in Malaysia for treatment of HIV and prophylactic treatment related to HIV align with global standards.

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## Availability and cost of treatment

The cost of management of HIV in Malaysia varies depending on the facility.

### Government hospitals and clinics

According to a representative of the Ministry of Health interviewed, the cost of HIV related laboratory tests is free in hospitals and clinics under the Ministry of Health. First line treatment is also provided free of cost. With

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In Malaysia, treatment costs for HIV are by and large free or subsidised by the Government in the Ministry of Health and Ministry of Education facilities with some exceptions. Charges at private hospitals and clinics are fully borne by the individual at the respective private rates.

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regard to second line treatment, the Government provides part of the treatment free while the individual has to pay for the other part of the medication.

However, there are also agencies and organizations which subsidize treatment for people living with HIV on second line or third line treatment. These include bodies such as the Malaysian AIDS Foundation and Baitulmal related to Jabatan Agama Islam (Islamic Religious Departments) among others.

All other HIV related or non-related costs, including admissions are provided for free for people living with HIV.

## University hospital

For hospitals under the Ministry of Education, a physician from one of the hospitals explained that in that hospital the costs of laboratory tests are to be borne by the individual. First line regime treatment is free while for second line regimes, there is a cost-sharing between the hospital and the individual. One third is borne by the individual and two thirds by the hospital.

## Private facilities

In private facilities, the full cost of treatment is borne by the individual according to the rates in the respective private facilities. A comparison of the costs of HIV medication and tests is given in [Table 1](#).

► **Table 1. HIV care costs: Diagnosis, treatment and prophylaxis**  
(Cost in RM, Ringgit Malaysia<sup>1</sup> and, between brackets, in US\$)

HIV Care aspects	Healthcare centre		
	Private (Red clinic)	Hospital (Pusat Perubatan Universiti Malaya, PPUM)	NGO (Community Healthcare Clinic, CHCC)
<b>Diagnosis</b>			
HIV screening blood test	65 (16)	13 (3)	50 (12)
Confirmation test	300 (74) (Western Blot)	280 (69)	250 (62) (PCR)
CD4	240 (59)	120 (30)	140 (35)
Viral Load	350 (86)	280 (69)	200 (49)
FBC, LFT, RP, UFEME, FLP	50 (12)	90 (22)	60 (15)
Chest X ray	50 (12)	15 (4)	Not available
<b>Treatment for people living with HIV (per month)</b>			
First line (Tenofovir EM+Efavirenz)	300 (74)	95 (23)	280 (69)
First line (Dolutegravir +Tenofovir EM)*	990 (244)	680 (167)	960 (236)
Second line – Kaletra	Not available	410 (101)	Not available
Follow up tests (6 monthly) FBC, LFT, RP, UFEME, FLP	50 (12)	90 (22)	60 (15)
Viral load/CD4 (6-12 monthly)	590 (145)	400 (99)	340 (84)

PCR = Polymerase Chain Reaction, FBC = full blood count, LFT = liver function test, RP = renal profile, UFEME = urine full examination and microscopic examination, FLP = fasting lipid profile, Ag = antigen, AB = antibody.

Information obtained from: Rosvinder Singh, 2019

<sup>1</sup> 100 RM = 24,63 US\$ (Bank Negara rates: 1 February 2020)

\* Recommended by WHO.



## ▶ 3b. Treatment outcomes related to HIV: Current evidence at global level and in Malaysia<sup>4</sup>

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### Price reductions

Before 2006, treatment was expensive, at 10,000–15,000 US\$ per person per year. Due to a combination of price negotiations with drug manufacturers, manufacturing of generics and trade agreements, the costs of ART drugs (especially for the older first line treatments) have decreased tremendously throughout the years (Forsythe et al., 2019).

According to MSF (Médecins Sans Frontières), if countries are able to import and use generics, the price for the WHO-recommended first line treatment can be as low as 100 US\$ per year. The lowest-priced generic second line regimen is now priced at 286 US\$ per year (MSF, 2016).

### Increase in life expectancy

#### Causes of death for people living with HIV

A population-based retrospective cohort study in Canada estimating rates of and risk factors for all-cause and cause-specific mortality from 1995 to 2014 among people living with HIV in Ontario found that the cause of death was increasingly due to common chronic conditions rather than to HIV infection itself (Burchell et al., 2019).

A systematic review and meta-analysis by Farahani et al reveals that a significant number of people living with HIV receiving antiretroviral therapy across the world die from cardiovascular disease (CVD), non-AIDS malignancies and liver disease (Farahani et al., 2017). While not statistically significant, there was a consistent trend in both the high/upper-middle income countries and lower-middle income countries from the Asian Pacific countries, in that the proportion of AIDS-related mortality decreased from 2007 to 2017 and the proportion of non-AIDS-related mortality increased from 2007 to 2017.

Nevertheless, life expectancies of people living with HIV increased over time in all studies and regions due to advances in HIV treatment albeit with some variations in the clinical characteristics and socio-demographic profile of the study participants.

#### Factors contributing to increased life expectancy

Emerging evidence shows that, in part, increased life expectancy has been due to advances in combination ART which is better able to control HIV replication, proffer higher genetic barriers to resistance, is less toxic, has fewer side effects and has reduced pill burden (Antiretroviral Therapy Cohort Collaboration, 2017).

4 The complete details of this section can be found in annex 4.

Treatment and prophylaxis for opportunistic infections and management of comorbidity, improvements in intensive care management, disease screening and health promotion have also reduced all-cause mortality among people living with HIV. In spite of an elevated risk to HIV-associated cancers, the extensive availability of ART which restores patient immunity have also decreased the rates of these cancers among people living with HIV (Coghill et al., 2019).

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Current treatment regimens have demonstrated proven effectiveness in increasing life expectancy, controlling HIV replication, improving immunologic outcomes, improving the management of comorbidity and opportunistic infections and reducing all-cause mortality among people living with HIV. In addition HIV treatment is highly effective in reducing the transmission of HIV.

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### **Life expectancy of people living with HIV compared to the general population**

The Antiretroviral Therapy Cohort Collaboration estimated that the life expectancy of a 20-year old person starting ART between 2008 and 2010, with a CD4 count of more than 350 cells per micro litre one year after starting ART, to be 78 years, close to the expected life expectancy of the general population (Antiretroviral Therapy Cohort Collaboration, 2017).

### **Life expectancy of people living with HIV in low- and high-income countries**

According to a meta-analysis comparing life expectancy of people living with HIV after starting combination antiretroviral therapy in low/middle- and high-income countries, life expectancy improved over time although the gain in high-income countries was more than in low- and middle-income countries (Teeraananchai et al., 2017c). Nonetheless, studies in Thailand (Teeraananchai et al., 2017a) and Uganda (Mills et al., 2011) cohere with global evidence of increasing life expectancy related to being on ART. The study in Uganda showed that persons receiving combination ART were able to expect an almost normal life expectancy (Mills et al., 2011), with women having higher life expectancy compared to men. The Thai study also showed that HIV positive Thai women had a higher life expectancy compared with HIV positive men (Teeraananchai et al., 2017b). The life expectancy of HIV positive women was around 84 per cent of the general Thai female population (67.0 vs 80.0 years) and the life expectancy of HIV positive men was around 73 per cent of the general male population (53.6 vs 73.2 years) (Teeraananchai et al., 2017a). The Thai study attributed increased life expectancy to the effectiveness of combined ART as well as early initiation of treatment (Teeraananchai et al., 2017a).

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The Antiretroviral Therapy Cohort Collaboration estimated that the life expectancy of a 20-year old person starting ART was close to the expected life expectancy of the general population (Antiretroviral Therapy Cohort Collaboration, 2017).

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## Benefits of early initiation of treatment: Increase in CD4 cell count and viral suppression

In addition to the benefits of increased life expectancy related to being on ART, evidence from a landmark study reinforced the benefits of early initiation of ART in adults living with HIV. Early initiation of ART was significantly associated with lower serious AIDS-related and serious non-AIDS-related events (INSIGHT START Study Group, 2015).

The TEMPRANO clinical trial in Ivory Coast found that people living with HIV on the early-ART arm had nearly 50 per cent lower risk of death or severe HIV related illness (Danel et al., 2015). Importantly, a meta-analysis on the implications of rapid ART initiation (including same day initiation and initiation within two weeks) and comprising both clinical trials and observational studies also revealed that accelerated ART initiation could lead to improved clinical outcomes (Ford et al., 2018).

These findings complement the 2019 Cochrane review among people living with HIV in low- and middle-income countries which revealed a significant association between rapid initiation of ART (within a week of HIV diagnosis) and greater viral suppression, better ART uptake and improved retention in care at 12 months (Mateo-Urdiales et al., 2019).

Viral suppression refers to the reduction in a person's viral load to an undetectable level and is also highly effective in reducing the risk of transmission of HIV. A 2016 study revealed that among sero-discordant heterosexual and homosexual couples in which the HIV-positive partner was using ART and who reported condomless sex there were no documented cases of HIV transmission (Rodger et al., 2016). Similarly, the 2019 study also indicates that the risk of HIV transmission in gay couples is effectively zero through condomless sex when HIV viral load is suppressed (Rodger et al., 2019). These findings are significant since the global epidemic and that of Malaysia are driven by sexual transmission.

The undeniable evidence on the benefits of early initiation of ART is reflected in the WHO guidelines; ART is recommended to be initiated in everyone living with HIV at any CD4 cell count (World Health Organization, 2015).

## Consequence of increased life expectancy

As early diagnosis and early initiation of treatment leads to improved CD4 count and suppression of viral replication is maintained, people living with HIV tend to manifest clinical conditions commonly associated with ageing such as cardiovascular disease, lung disease, certain cancers, HIV-Associated Neurocognitive Disorders (HAND) and liver disease (including hepatitis B and hepatitis C). HAND is used to describe neurocognitive disorders (the most severe form being severe dementia) among people living with HIV treated with ART.

Together with the increased life expectancy of people living with HIV, other co-morbidities that would typically appear in older aged people have been observed in people living with HIV, at younger ages (Brown and Qaqish, 2006, Chan et al., 2018, Guaraldi et al., 2011, Guaraldi et al., 2014, Hidalgo et al., 2018, Pelchen-Matthews et al., 2018, Ruzicka et al., 2018, Thrift and Chiao, 2018).

The 'greying' of the HIV epidemic including increased life expectancy and new cases of older people living with HIV calls for a new understanding of the effect of HIV on the ageing process and the significance of ageing on people living with HIV (Harris et al., 2018).

## Benefits of ART treatment: lowered risk of comorbidities and non-AIDS related complications

At the same time, it has also been found that the benefit of ART treatment extends to lowering the risk of comorbidities and non-AIDS-related complications, such as HIV associated neurocognitive disorders (HAND) (Heaton et al., 2011, McArthur et al., 2004).

The benefits of ART for people living with HIV extend beyond the management of HIV symptoms and progression. While ART controls the disease progression effectively, the HIV infection in itself carries long term consequences (accelerated ageing and increased risk of comorbidities) that are showing up in people living with HIV who survived well with treatment. The evidence so far showed that people living with HIV on ART may also lower the risk of these consequences, compared to not being on ART.

## Pre-exposure Prophylaxis (PrEP) for HIV-uninfected persons at substantial risk of HIV infection

A significant advance in relation to preventing HIV transmission has been the role of pre-exposure prophylaxis (PrEP). PrEP refers to the use of antiretroviral medications by HIV-uninfected individuals to prevent the acquisition of HIV. PrEP does not prevent the transmission of other sexually transmitted infections.

In 2015, the WHO recommended the use of daily oral PrEP as a prevention choice for people at substantial risk of HIV infection as part of combination prevention approaches (World Health Organization, 2015).

## Role of adherence to treatment in maintaining improved health outcomes for people living with HIV

The above evidence indicates that subject to adherence to treatment, ART can significantly improve the overall health status, life expectancy and survival, economic status and quality of life of people living with HIV. In order to maintain good health and optimise medical costs in people living with HIV, access and adherence to ART are crucial factors, including to scale up prevention efforts.

Overall, the key to longer survival time is access and adherence to ART. The Cochrane review cited earlier (Mateo-Urdiales et al., 2019) reports that early initiation of treatment also had positive benefits on treatment adherence. However, factors affecting the access and adherence to HIV treatment are complex.

Barriers to access include (but are not limited to) stigma, poor disease knowledge, logistic issues, high treatment costs and lack of medical insurance (Ankomah et al., 2016, Dombrowski et al., 2015, Koirala et al., 2017, Yehia et al., 2015).

In a peer reviewed study, based on 15 programmes across Asia, Africa and South America with over 5,000 patients pooled for the analysis, higher probability of treatment drop-outs were found in fee-for-service programmes compared to free treatment programmes in developing countries (Brinkhof et al., 2008), although ARV is free in many countries. Financial cost is one of the main barriers to accessing HIV treatment and care.

Thus, healthcare financing is an important component of access to healthcare, adherence to treatment and consequent accrual of the medical and health and economic benefits in relation to people living with HIV.

## Evidence from Malaysia

Lubis et al's study (Lubis et al., 2013) was based on records of 845 patients living with HIV from a large teaching hospital in Malaysia from 1989 to 2009, among whom 74.1 per cent had been on ART with triple drugs or more. This study reported that 72.7 per cent of the patients survived and the mean survival time was 130.9 months (10.9 years).

More significant was Mat Shah et al's retrospective cohort study to evaluate the effectiveness of ART in Malaysia. Records from the Infectious Diseases Clinic, Hospital Sungai Buloh from 1997 to 2008, were matched with the National Registration Department Death Records and Selangor State HIV/AIDS/Death Surveillance database taking the same period of time. Patients not on ART had a median survival duration of 19 months (Mat Shah et al., 2012). In direct comparison, 75 per cent of patients on ART were estimated to live for up to 11 years in comparison to 75 per cent of patients who were not on ART and were estimated to have a survival time of eight months. The ART group had a lower all-cause mortality rate and AIDS-defining events (Mat Shah et al., 2012).

More recently, Lee et al's retrospective cohort study (Lee et al., 2019) based on 339 people living with HIV who were attended in Hospital Sungai Buloh and had initiated ART between 2007 and 2016, reported overall survival rates of 95.9 per cent, 93.8 per cent, 90.4 per cent, 84.9 per cent and 72.8 per cent at six months, one year, three years, five years and ten years, respectively.

The emerging body of knowledge in Malaysia indicates that people living with HIV are able to achieve positive outcomes when they are on ART. Adopting WHO guidance and policy, the Ministry of Health in Malaysia also recommends ART for all people living with HIV, regardless of CD4 cell count, to reduce the morbidity and mortality associated with HIV infection and also to prevent HIV transmission (Ministry of Health & MASHM, 2017).

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Combination ART has brought about a shift in the HIV epidemic, changing HIV from a fatal disease to a chronic condition that can be managed with appropriate medication and adherence.

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In addition to the recommendations related to management of the clinical symptoms, the Malaysian Consensus Guidelines on ART 2017 also provides guidance to assess and provide support related to the psycho-social dimensions of illness and treatment and to support patient autonomy and participation in the treatment process. Acknowledging that more research on treatment outcomes for people living with HIV in Malaysia would bring about a more nuanced understanding of the issue, it can also be inferred that with robust access to treatment, early initiation of ART and the required support services, the prognosis for people living with HIV in Malaysia could be good, allowing them to live productive lives.

In one of the main teaching hospitals in Malaysia, a study comparing people living with HIV (n=336) and controls who were non-HIV infected members from the community (n=172) (Rajasuriar et al., 2017) mirrored findings from around the world (Althoff et al., 2015, Guaraldi et al., 2011, Islam et al., 2012, Petoumenos et al., 2017) where premature ageing and increase in non-AIDS related comorbidities were found in people living with HIV. In the Malaysian study, people living with HIV were found to have a higher burden of geriatric related conditions (Rajasuriar et al., 2017).

Thus, the advent of combination ART has brought about a shift in the HIV epidemic, changing HIV from a fatal disease to a chronic condition that can be managed with appropriate medication and adherence.

## Treatment outcomes with regard to people living with HIV participants in the study

This similar trend was evidenced in the narratives and records of the people living with HIV who had been interviewed in this study. As mentioned earlier, 14 people living with HIV participated in in-depth interviews. The earliest diagnosis was in 1994 while the most recent was a few months before the interview.

**Table 2** provides details of the study participants' year of diagnosis, CD4 count, viral load and treatment payment details.

► **Table 2. Treatment outcomes of people living with HIV interviewed in the study**

PLHIV	Year of diagnosis	CD4 at diagnosis	Viral load at diagnosis	Present treatment	Latest CD4	Latest viral load	Payment for treatment
R5	2009	>1000	NA	1st line	600+	Undetectable	Free
R6	1995	NA	NA	2nd line	NA	Undetectable	Self
R7	2018	200+	NA	1st line	400+	Undetectable	Free
R8	2014	175	High	1st line	NA	Undetectable	Free
R9	2014	200+	NA	2nd line	NA	Undetectable	Free
R10	2019	300+	NA	1st line	NA	NA	Free
R11	2017	356	1038	1st line	NA	Undetectable	Free
R12	2017	100+	NA	1st line	NA	Undetectable	Free
R13	2012	400+	NA	2nd line	NA	Undetectable	Shared
R14	1994	149	NA	2nd line	839	Undetectable	Shared
R15	2016	222	Millions	2nd line	NA	Undetectable	Free
R16	2008	7	284,000	1st line	886	Undetectable	Free
R17	2008	230	NA	1st line	660	Undetectable	Free
R18	2011	Normal	Normal	1st line	800+	Undetectable	Free

Note: NA = Not Available

All the interviewees were on treatment, with nine on first line ART and five on second line ART. The medication was taken either as a once daily or twice daily dosage.

Eight had CD4 levels below 300 per cubic mm on diagnosis, while three had symptoms of AIDS when starting treatment, like oral thrush or pneumonia.

Currently, 13 of the 14 people living with HIV interviewed had undetectable viral loads. Six had normal CD4 levels while seven more had not taken a CD4 test recently as the viral load was stable over a period of time, following the guidelines stated previously. The interview participant who was diagnosed recently had an initial CD4 of more than 300 cells per cubic millimetre and was awaiting the viral load test result.

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13 of the 14 people living with HIV interviewed had undetectable viral loads. The 14th person was recently diagnosed and was awaiting the viral load test result.

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As **Table 2** shows, except for one person living with HIV who had only recently known his HIV status and was awaiting his viral load results, all the other people living with HIV study participants were adherent to treatment and had achieved viral load suppression.

Additionally, many of them stated that they were in much better health than before, with some admitting that the routine follow-up and testing which were part of the HIV treatment and care they were receiving, were significant factors in enabling them to maintain good health.

One study participant who stated that he remains healthy with no current side effects explained that he felt healthier as he had regular check-ups and had not gone on medical leave since his diagnosis two years prior to the interview.

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▀▀ I feel like I can live just like a normal person and in fact I think I am healthier because my health condition is monitored every 6 months - whether my sugar level is increased, or if my cholesterol is increased. So, the doctor is having all that data and is keeping us in check every step of the way. Every 6 months we have blood tests and meeting with the doctor. The good news is that was my last hospitalization (at diagnosis) and until today, I don't remember taking any medical certificate. (R11)

Another study participant who had switched to second line treatment also stressed that he felt healthier as he has regular check-ups and takes care of his health.

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▀▀ I exercise. I think people living with HIV are a lot healthier than people who are not positive. Because you have a medical check-up every half a year. You know what I mean right, because we know our condition, we have to take care of ourselves. We have to eat well, sleep well, exercise regularly. We know how to take care of ourselves. (R5)



### ► 3c. Economic gains as a result of expansion of HIV treatment and current HIV treatment outcomes globally

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#### Economic benefits of ART to people living with HIV and their societies

Prior to the expansion of ART in low- and middle-income countries, quite a few quantitative studies demonstrated the major costs and loss of economic benefits for people living with HIV who had progressed to AIDS because of decline in labour productivity, added burden of household members to provide for care and offset lost income, poor nutrition and schooling outcomes for children of people living with HIV and negative effects on employer production costs and efficiencies of government services delivery. Conversely, the benefits of the treatment have been shown to extend beyond improved health outcomes in people living with HIV with wider social and economic gains to their families (Kakinami et al., 2011) and the economies they belong to (Ventelou et al., 2008).

Thus, it can be observed that the benefits of ART therapy reach beyond the well-established clinical benefits in prevention, morbidity and mortality reduction discussed earlier. A review of the economic impact of ART therapy programmes supported by the President's Emergency Plan for AIDS Relief (PEPFAR) showed that between the years of 1995 to 2015, ART averted 9.5 million deaths worldwide which translated to global benefits of US\$1.05 trillion. For every US\$1 spent on ART, US\$3.50 in benefits accrued globally (Forsythe et al., 2019). These economic benefits accrued mainly

through the improvement of health status (through better disease control) leading to better functional ability to do productive work. This then spilt over to the other members of the household as there was less time spent on caregiving activities and averting catastrophic expenditures related to worsening disease states and end of life spending (funerals). Employers too benefited through the maintenance of skilled workers living with HIV in the workforce. This review estimated that in 2030, economic gains could reach US\$4.02 trillion by averting 40.2 million new HIV infections (Forsythe et al., 2019).

In a prior study, synthesizing the findings of key studies of the economic impact of antiretroviral therapy programmes that have been supported by PEPFAR and others, Thirumurthy et al (2012) found that at the individual level, initiation and maintenance of ART led to increased and sustained employment levels for people living with HIV. At the household level, economic benefits, especially for poorer households included prevented end-of-life health and funeral expenditures, more time for schooling and less time for work for children of people living with HIV and preventing children in the household from becoming orphans which in itself requires significant economic resources to avert its negative outcomes. Significantly, the benefits to employers include gains in terms of retaining institutional memory, averting disruptions to production processes and cost savings as hiring and retraining new employees is not needed, which is especially pertinent to companies with high value output like utility companies (Thirumurthy et al., 2012).

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Economic gains flowing from expansion of HIV treatment have been evidenced at the individual, household, business and country levels. At the individual level, initiation and maintenance on ART led to increased and sustained employment levels for people living with HIV and avoidance of catastrophic health expenditures.

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Several studies have thus suggested that the significant health gains generated from ART are worth the cost of treatment to argue for greater investment in ART programmes to meet growing treatment needs.

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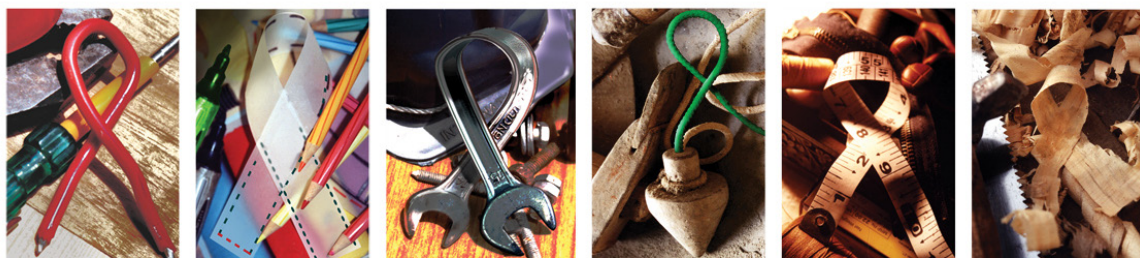
Several studies have suggested that the significant health gains generated from ART are worth the cost of treatment.

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A significant part of the economic gains relates to harnessing the productivity of people living with HIV who are on ART. In South Africa, a study on people living with HIV who were followed up for a maximum of 5.5 years after ART initiation showed an increase in employment (32 per cent to 44 per cent), decrease in the proportion of people living with HIV who were not able to perform normal activities (47 per cent to 5 per cent), decrease in experiencing difficulties in job performance (56 per cent to 6 per cent) and decrease in relying on caretaker (81 per cent to 1 per cent) (Rosen et al., 2014). People living with HIV on ART were also associated with having fewer mental health issues (such as depression) (Martin et al., 2014) which may also contribute to overall health status. Economic gains to people living with HIV and their families when given access to sustained treatment are also witnessed in other studies in South Africa (Kakinami et al., 2011) and Uganda (Thirumurthy et al., 2013).

In Malaysia, the AIDS Epidemic Model (AEM) version 4.05 was used to project the best options that would yield the highest impact in saving lives, averting costs and advancing productivity and economic growth. The model that guided the development of the Malaysia Third National Strategic Plan for HIV and AIDS 2016-2030 projected that by scaling up harm reduction for people who inject drugs and accelerating prevention and treatment for key populations for seven years starting 2015 Malaysia could save up to 644,000 Disability-Adjusted Life Years (DALYs)<sup>5</sup>, or healthy, productive life years equivalent to US\$6 billion (Ministry of Health, 2019c).

Thus, evidence from the literature points to the importance of ART in retaining or maintaining the wellness of people living with HIV, thereby enabling employment and work productivity.

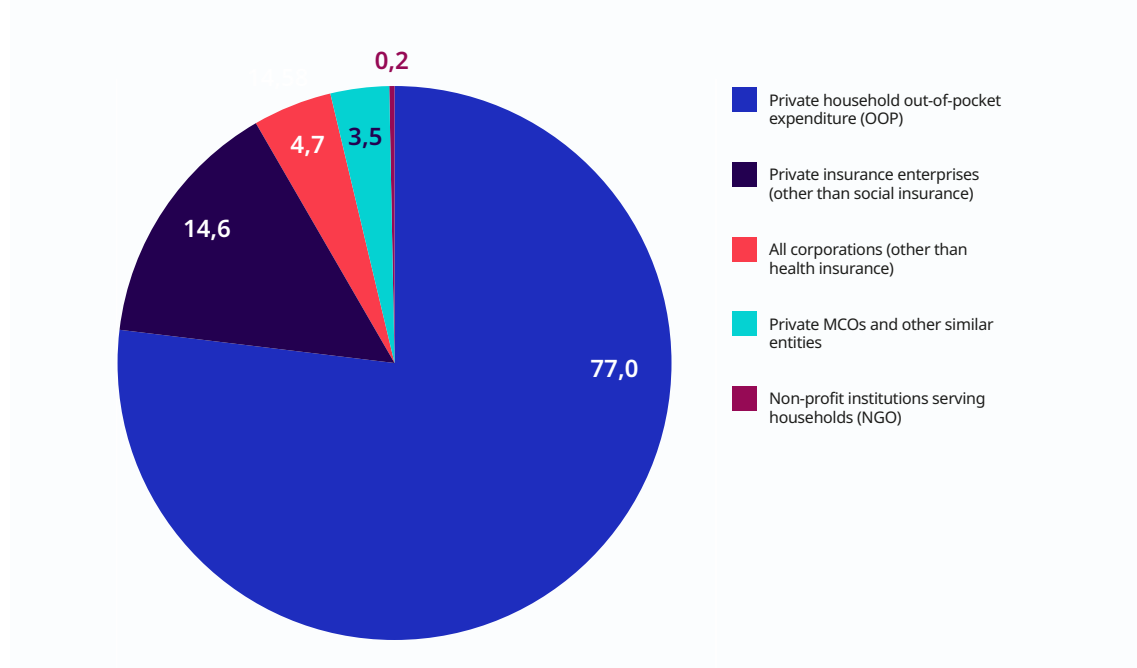


5 DALY is the summary measure used to give an indication of overall burden of disease. One DALY represents the loss of the equivalent of one year of full health. WHO, *Disability-adjusted life years (DALYs)* [Online]. World Health Organization. Available: [https://www.who.int/gho/mortality\\_burden\\_disease/daly\\_rates/text/en/](https://www.who.int/gho/mortality_burden_disease/daly_rates/text/en/) [Accessed 10 Feb 2020].

### ► 3d. Private medical and health insurance coverage for people living with HIV in Malaysia

As shown in **Figure 1** below, private insurance comprises almost 15 per cent of the total private health expenditure in Malaysia constituting the second highest spending in this category (Ministry of Health, 2019b). The spending by private insurance enterprises (other than social insurance) is inclusive of personal, family and company insurance policies. All corporations contributed to five per cent of private sector health expenditure and this is exclusive of group or company purchases of employee insurances, which are reported under private insurance enterprises expenditure (Ministry of Health, 2019b). Note that out-of-pocket expenditures on healthcare formed the major part of private sources of healthcare financing in Malaysia with 77 per cent.

► **Figure 1. Health expenditure by private sector sources of financing, 2017 in per cent (MOH, 2019)**



The sales of medical and health policies increased following the introduction of personal income tax relief for the purchase of medical and health policies in 1996 and following policy relaxation to allow life insurers to sell standalone medical and health policies in 1997 (Bank Negara Malaysia, 2006).

Private medical and health insurance products in Malaysia typically fall under four categories:

- Medical, hospitalization and surgical benefits
- Critical illness cover which involves a lump sum payment for an illness that would typically be listed in the critical illness list of different insurance companies
- Disability income insurance which provides an income to replace pre-disability income when one is unable to work because of sickness or injury
- Hospital income insurance which includes a predetermined monetary compensation paid out on a daily, weekly or monthly basis, subject to an annual limit

A few companies may even offer additional screening and health promotion benefits to some of its customers.

Medical and health insurance products can be stand-alone products or can also be written by life and composite insurers, through extensions to life insurance policies or investment linked insurance plans. Yet, in spite of being the second highest contributor toward private health expenditures, market penetration is still far from optimal (Bank Negara Malaysia, 2018) and is skewed toward urban middle- to high-income classes (The Star Online, 2018).

Compared to the 1990s, the sales of group medical and health insurance policies have been increasing as employers include healthcare benefits as part of compensation packages offered to employees (Bank Negara Malaysia, 2006). Although the growth of group insurance has outpaced that of individual insurance policies individual policies are said to drive the market (Chassat, 2013). In general, individual policies in South-East Asia are said to be subject to limited regulations with regard to underwriting and claims processing (Chassat, 2013).

## Medical and health insurance coverage of people living with HIV

In general, private medical and health insurance coverage in Malaysia excludes people living with HIV. This is currently a standard exclusion for medical insurance in the industry, wherein HIV and its related diseases fall within the policy exclusion. Some companies cover HIV when it is due to blood transfusion, occupationally acquired HIV and full-blown AIDS under their critical illness plans. An internet search revealed that these include companies such as AIA Malaysia, Am MetLife, Great Eastern Malaysia, Hong Leong Assurance Berhad, Zurich Malaysia, Pacific Insurance Berhad and Prudential Malaysia.

With advances in the treatment and management of HIV, the phenomenon of full-blown AIDS is not common. Moreover, the pay-out for occupationally acquired HIV in Malaysia is reckoned to include only a few single digit cases over the past several years. So, while HIV is covered under critical illness coverage, it is not likely that it is of substantive support to people living with HIV.

The Malaysian AIDS Foundation was aware that parent firms of some insurance companies in Malaysia provide coverage for people living with HIV in other countries. Below is a list of insurance companies (with presence in Malaysia) that extend coverage to people living with HIV in different countries:

▶ **Table 3. Multinational insurance companies with presence in Malaysia covering people living with HIV in other parts of the world**

Company	Parent company	Countries where HIV/AIDS is covered
AIG	New York, United States	US, UK
AIA	Hong Kong	Hong Kong
ALLIANZ	Munich, Germany	Sri Lanka
AXA	Paris, France	US
LIBERTY INSURANCE	Massachusetts, United States	South Africa
TOKIO MARINE HOLDINGS	Tokyo, Japan	UK
PRUDENTIAL	New Jersey, United States	US
MANULIFE	Toronto, Canada	Canada

Source: Malaysian AIDS Foundation, 2019

In the survey conducted in this study with the 11 insurance companies affiliated with LIAM, three companies stated that they provided limited coverage for HIV. While two companies had critical illness plans that cover for full-blown AIDS, HIV infection due to blood transfusion and occupationally acquired HIV infection, one company stated that it would provide coverage if the person was diagnosed with HIV after purchasing the policy, subject to the policy definitions and exclusions. Positively, another company stated that coverage for persons with pre-existing HIV was available under its Group Life and Group Medical policies for employees and dependents, subject to medical underwriting requirements and policy definitions and exclusions related to the coverage. Since an anonymous survey had been requested, it was not possible to identify the companies in the survey that offered critical illness cover or group life and group medical coverage for people living with HIV.

Nevertheless, most of the companies that were surveyed acknowledged that the policy would remain in force if people living with HIV had purchased insurance cover prior to being diagnosed with HIV. They added that claims may be made if they were not related to HIV directly or indirectly, subject to policy criteria.

Any claim related to HIV directly or indirectly would be declined in view of the exclusion policy. However, in cases where there is limited coverage for HIV, the relevant exceptions would be taken into account.

The survey also revealed that the participating insurance companies in Malaysia had not engaged in research that would have expanded the knowledge base of the industry with regard to current treatment approaches and outcomes of people living with HIV in Malaysia. Neither were they aware of the shift in the transmission profile that had occurred in the people living with HIV population in recent years in the country.

Some of the companies were, however, open to considering the inclusion of people living with HIV in medical insurance coverage depending on the health status of the individual (e.g. no comorbidities such as Hepatitis B and C, no significant comorbidities, no psychiatric history or other sexually transmitted diseases evidenced in medical tests), the route of transmission of HIV, optimal clinical management of HIV and potential support from reinsurers. Only one company stated that no consideration would be shown for the inclusion of people living with HIV in medical insurance cover; no explanation was offered for such a position.

Overall, some of the key concerns expressed by insurance companies regarding insurance coverage for people living with HIV included the gaps in data which made price quantification challenging. These included data related to the size of the risk pool, clinical characteristics of the population (such as CD4 count and viral load, comorbidities, route of transmission and life-style factors and socio-demographic characteristics such as age, gender and occupation). The other factors that were of concern to insurance companies included the possibility of reinsurance, the problem of adverse selection and medical inflation. With regard to medical inflation, insurance companies noted with concern that medical costs had increased close to 1.5 times between 2017 and 2019 with the 2019 rate of 13 per cent being the second highest in the Asia Pacific after Vietnam (16 per cent) (Willis Towers Watson, 2019). While the availability and adoption of new medical technologies were acknowledged as one of the contributing factors to spiralling costs, unnecessary procedures and treatments being recommended by service providers and the absence of preventive measures in corporate wellness programmes were also cited as problematic (Willis Towers Watson, 2019).

Local insurers also talked about the distribution of risk as an incentive to initiate insurance products for people living with HIV. Two types of suggestions were made in this regard, keeping in mind that it would be risky for any one company alone to embark on an initiative to extend insurance medical and health coverage for people living with HIV. The first had to do with the role of the government. Some insurers opined that a directive from the government to extend insurance coverage to people living with HIV would help distribute the risk because there would be more players in the market and risk would be spread. One individual stated that companies have gone on to 'add new diseases to appease the regulator or at the urge of Government'. As such, they posited that direction from the government would help address one of the key concerns related to risk. The second suggestion had to do with the

range of products, wherein it was stated that being able to offer other products besides medical and health coverage would also help to mitigate risk. The latter augurs well with experiences of people living with HIV who were interviewed in this study and who raised several issues related to insurance products other than medical and health.

## Medical and health insurance coverage: People living with HIV voices

Although the focus of this study was on private health/medical insurance, the in-depth interviews and focus group discussions with people living with HIV revealed that their experience with insurance spanned a range of insurance products (see [Table 4](#)) including life, endowment, investment linked, critical illness, medical and hospitalization, workplace group insurance as well as mortgage reducing term assurance (MRTA).

► **Table 4. Types of insurance policies purchased by people living with HIV study participants**

PLHIV	Type of insurance
R5	Medical, Critical Illness, Company Group Insurance
R6	Medical (International), Company Group Insurance
R7	No
R8	Medical, Company Group Insurance
R9	No
R10	Life, Medical, Investment Linked
R11	Life, Endowment, Critical Illness, Investment Linked, Medical Card and Hospitalization
R12	Life, Investment Linked, Medical, Company Group
R13	Company Group
R14	No
R15	No
R16	NGO sponsored
R17	No
R18	No

The emerging themes from the in-depth interviews and focus group discussions were both directly and indirectly linked to insurance and included:

1. Leading productive lives
2. Group insurance being a barrier to employment opportunities
3. Questions regarding life insurance purchased prior to diagnosis
4. Out-of-pocket payments and catastrophic health expenditures
5. Insurance promotions like telemarketing and credit/debit card related promotions
6. Successful claims

### Leading productive lives

All the participants living with HIV in the study were employed and were financially independent. [Table 5](#) provides details of the educational attainment and employment status of the people living with HIV study participants. Most of the participants interviewed cited this factor in questioning the logic of being excluded from purchasing private health insurance.

This fact was reaffirmed by a study participant who had been living with HIV for almost 26 years. He had an insurance policy before diagnosis but he had stopped paying the premiums shortly after. This was because he felt that he would not be able to claim benefits under the insurance in view of the general exclusion policy that existed for insurance coverage for people living with HIV at the time of diagnosis in 1994. Additionally, he was depending on his savings initially, as at that time he had to pay for the treatment on his own. With enabling policies initiated by the government to expand HIV treatment to people living with HIV, he is currently receiving treatment in a university hospital, mostly free of charge, sometimes subsidised by the hospital.

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►► If somebody was smart enough to sell me an insurance policy when I was diagnosed HIV positive, I would be paying my premiums for 26 years you know and they would have got 26 years of premiums without paying out anything, so there was a huge loss of income for insurance companies because people are surviving longer now and if you multiply that by 3,334 people getting diagnosed per year that's a lot of money potential. (R14)

► **Table 5. Education and employment status of people living with HIV study participants**

Study participant	Age group (years)	Sex	Education	Work	Relationship Status
R5	40-49	Male	Degree	Multinational company	Single
R6	50-59	Male	Masters	Multinational company	Single
R7	30-39	Male	Diploma	Government employment	Married
R8	50-59	Male	Diploma	Non-Governmental Organization	Single
R9	20-29	Male	Degree	Government employment	Single
R10	30-39	Male	Degree	Multinational company	Single
R11	50-59	Male	Diploma	Private company	Single
R12	40-49	Male	Degree	Private company	Single
R13	40-49	Male	Degree	Private company	Single
R14	50-59	Male	Degree	Family business	Partnered
R15	40-49	Male	Degree	Non-Governmental Organization	Divorced
R16	40-49	Male	Sijil Pelajaran Malaysia*	Self employed	Married
R17	40-49	Female	Sijil Pelajaran Malaysia*	Self employed	Married
R18	30-39	Female	Sijil Pelajaran Malaysia*	Self Employed, part time	Married

\*Sijil Pelajaran Malaysia – Malaysia fifth form secondary school certification

Another female study participant who took part in one of the focus group discussions was the spouse of a person living with HIV who had passed on. She shared her experience of problems she had with the MRTA contributions her husband had made toward the mortgage of their house. She reported that although he had diligently been paying his monthly mortgage instalments including his mortgage reducing term assurance (MRTA) payment, because the cause of death was stated to be HIV on his death certificate, the bank insisted that she repays the balance of the loan. This respondent stated that in spite of being a single mother, she had repaid the rest of the housing loan from her earnings. She went on to emphasize the great hardship she had to endure because of the exclusion clauses applied to people living with HIV. However, she also emphasized the financial independence of the people living with HIV in her community and questioned the justice and wisdom of such a policy.

In this connection, the study team also found out about another individual who in spite of being covered for HIV treatment by his company, opted to pay for his treatment at a private health facility to avoid revealing his HIV status to his employer and because he could afford it.

Similar views were shared for MRTA related to housing loans where medical examinations are required for applicants who need to undergo a blood test. If they are found to be HIV positive, the MRTA may be rejected due to the exclusion policy.

One person who was interviewed found out that he was living with HIV when applying for the MRTA and a bank loan to purchase his house. The MRTA facility was denied. Fortunately, he managed to secure the loan without the MRTA and paid up the loan within 10 years.

► The insurance company called me, they said that well this is the scenario, and we could not cover for you. Look I have lived more than 10 years and the house has been paid off already. (R5).

This led study participants to question why people living with HIV could not purchase insurance at a higher premium like people living with diabetes and with heart diseases.

Further, a number of people living with HIV who were interviewed were still keen to purchase insurance policies, having in mind the welfare of their family in the event of their demise, such as life policies or MRTA for housing loans.

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► Of course, I even would buy my MRTA because you never know what is going to happen tomorrow. And this is just to protect my family right. Anything happen to me, they do not need to worry about the remaining package on the mortgage, right? It's the right thing to do. Insurance is a good thing. We should really invest in it. (R5)

## Group insurance being a barrier to employment opportunities

The issues of employment and group medical insurance are closely related. Many employers impose a medical examination for prospective employees, which have been reported to include an HIV test although it is not warranted in many cases. The medical examination is done prior to employment or in conjunction with promotions. This medical examination is also done for group medical insurance as part of the employee benefits that a company provides for its employees. The study interviews showed that mandatory medical tests that were necessary to qualify for the group medical insurance that was part of the employment benefits offered to the prospective employee were inadvertently a barrier to employment for people living with HIV.

During the FGD it was noted that many people living with HIV refuse to go for employment related medical examinations because they do not wish to declare their status; they just give up the job opportunity. During the course of employment too, people living with HIV are reluctant to use the employer's group medical insurance, as they are worried that the company will find out their HIV status if it is disclosed that they have HIV in the process of using their group medical insurance.

Some participants reported that the job offer was rescinded when the medical examination revealed that they were HIV positive. A case in point was a study participant who went to interview for the job of a hotel receptionist, obtained a verbal agreement for employment and was sent for a medical check-up. During the check-up, the study participant was found to be HIV positive. The human resource manager then retracted the offer citing difficulties in obtaining group insurance coverage, which was part of the employee compensation package as per company policy.

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The FGD pointed out that many people living with HIV refuse to go for employment related medical examinations because they do not wish to declare their status; they just give up the job opportunity. During the course of employment too, people living with HIV are reluctant to use the employer's group medical insurance, as they are worried that the company will find out their HIV status, they prefer not to take a job promotion if that means undergoing a medical exam. Also, job offers were rescinded when the medical examination revealed an HIV positive status.

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Participants were also worried about being terminated from employment if in the process of using the company medical insurance their HIV status would be detected and reported to the company. A case example was a study participant who was gainfully employed at the same company before getting HIV. He was scheduled for a promotion and was asked to go for a medical check-up pertaining to better medical benefits. However, to avail these benefits he needed to undergo a medical examination. This study participant declined the promotion instead because he was afraid to go for the medical check-up.

Another interview participant went through a number of interviews for a job application and was successful. However, upon taking the required medical examination, which included an HIV test, he tested positive for HIV. He discussed the diagnosis with the doctor who then clarified with the company's human resource department whether the HIV test was required. The company informed the doctor that the HIV test was not necessary and this had caused unwarranted anxiety.

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▶ You know, sometimes the company sends people for medical screening; they just do a standard one without looking at it. And then, they said that they do not require it. So, the doctor did not disclose it. So, that's why I got the job you see. You should not be screening any people or qualified technical person for technical job because he is having a chronic illness. It doesn't affect the job at all. (R 5)

However, it was noted that for group insurance, there are instances when the company is large, as in the case of large multinational companies, the HIV status is of no consequence and people living with HIV will still be covered.

## Out-of-pocket payments and catastrophic health expenditures

In the absence of their ability to claim insurance policies they might have purchased prior to their diagnosis or their inability to purchase private insurance, most of the people living with HIV who were interviewed stated that they coped with non-HIV related emergency medical expenditures via out-of-pocket payments (OOPs).

This put hardship on the household and had catastrophic consequences as in the case of a person living with HIV with neurosyphilis and newly diagnosed HIV who was admitted to a private hospital. Owing to an oversight of the admitting doctor, the insurance company did not initially get the information about the HIV status of the patient. The hospital later sent the information to the insurance company in the interest of being transparent. The patient, in the meantime, had developed a catheter related bloodstream infection and other problems which had increased the cost of his inpatient stay. By the end of two weeks, the bill had increased to RM 30,000 or US\$7,390<sup>6</sup> and

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There should be no discrimination against or stigmatization of workers, in particular jobseekers and job applicants, on the grounds of real or perceived HIV status or the fact that they belong to regions of the world or segments of the population perceived to be at greater risk of or more vulnerable to HIV infection.

Recommendation concerning HIV and AIDS and the world of work, 2010 (No. 200) (ILO, 2010).

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6 Bank Negara rates, 27 January 2020

the insurance company refused to pay the bill. He did not have resources to pay the bill and approached his employer for help. Not only did the employer not provide support, but he also lost his job, putting him in tremendous hardship and catastrophe.

## Questions regarding life insurance purchased prior to diagnosis

During the focus group discussions, it was reported that people living with HIV who had purchased life insurance prior to their HIV diagnosis, were not clear about how to proceed as they were aware that HIV is an exclusion in most insurance policies. They were not sure if they should continue paying premiums but at the same time, they were worried about protection if other non-AIDS-related conditions develop as life insurance policies often have attached medical/hospitalization cover and critical illness riders. They stated that having clear or standardized guidelines and policies, which are easily accessible, would be useful to help them make decisions with regard to insurance policies.

One of the FGD participant who assists people living with HIV in insurance matters, brought up experiences of people living with HIV with regards to insurance policies, if discovered to have HIV. The persons will be asked by insurance companies to go to panel doctors to verify and then either allow premiums to continue, or to be declared null and void. Some companies will refund the policy, some will return cash value though there were no clear guidelines on what will happen. Usually, it was decided on a case by case basis, depending on the insurance company and the particular insurance policy. Some people living with HIV interviewed allowed their policies to lapse because of this.

## Telemarketing and credit/debit card related promotions with regard to insurance

One interview participant, R5, claimed to have experience with telemarketers from banks that offer insurance coverage without requiring medical examinations. The premiums are paid via debit from credit cards and the policy would be sent by post later. However, he noted that when the policy arrived, it stated that people living with HIV are not covered. He mentioned that if the policies were then cancelled, the insurance companies would give a refund but only within the stipulated period when refund was possible.

Some of the participants noted that there were instances when they were approached by agents, telemarketers or banks to purchase insurance products which were on promotion. Medical examinations were not required for these policies. After purchasing the insurance and reviewing the policy, it was noted that HIV was not covered. A refund is made available but only within a specified period.

## Successful claims

However, not all study participants had the same experience. Two participants reported that they had been successful in claiming their medical insurance for dengue fever, surgery related to a fracture, an angiogram and a cataract surgery. Both did not declare their HIV status when making these claims.

► **Example of insurance coverage for HIV in the corporate sector**

This particular company provides medical benefit coverage for its staff, including those living with HIV, through a fund set up by the company. The company’s interest in sustainability and human rights drove the establishment of an inclusive human resource policy including HIV. The company considered examples from related multinational companies overseas, as well as guidelines from the ILO and the Malaysian Department of Safety and Health.

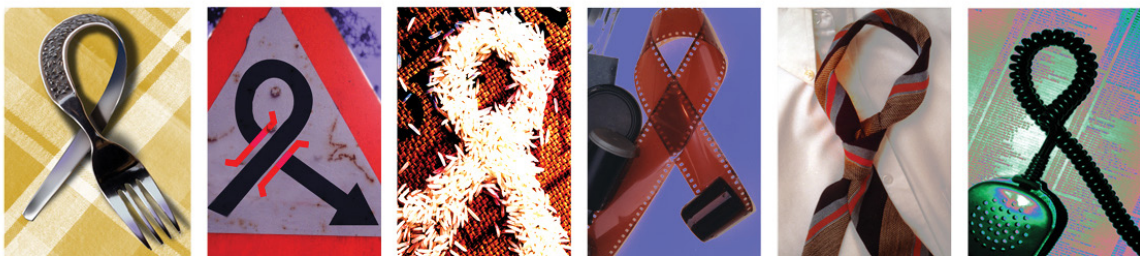
The company has set up its own fund for medical insurance coverage, which is managed by a third-party service provider. All medical bills are sent to the third-party provider. The third-party provider is paid an administrative fee based on the number of employees. No co-payment is collected from the employees when making claims.

In terms of medical benefits, all illnesses are treated the same, without discrimination. Under the company’s policy, treatment and management of HIV are completely covered. There are no exclusions with regard to medical insurance coverage for people living with HIV and the company itself does not deal with any information regarding HIV as the third-party provider handles this. However, owing to fear of stigma and discrimination, some employees still prefer to manage HIV from government facilities.

According to the company, the cost of covering HIV is low because of the low cost of treatment and the low number of employees with HIV.

To avoid stigmatization in relation to HIV the company adopts an integrated approach to wellness programmes for employees living with HIV, integrating such activities into the wider wellness programme of the company rather than initiating specific programmes for HIV. Under the company’s wellness programme, employees are encouraged to take care of themselves by managing unhealthy habits. The company also has an employee assistance programme, which is a professional counselling service that they can access anonymously, via a hotline. This counselling covers any illness, including HIV.

With regard to pre-employment medical examination, there are no restrictions on the type of illness, the company adopts the concept of ‘fitness to work’, which is the employee’s ability to work. Since the tasks to be performed in the company do not involve any risk of transmission of HIV, HIV status is not used as an exclusion criterion. Owing to this, HIV tests are not required. These criteria apply throughout the company, including its contractors.



## ► 3e. Private medical and health insurance coverage for people living with HIV: Country case examples

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One of the key elements of this review was to assess good practices in other countries with regard to private health insurance for people living with HIV, particularly in South-East Asia. In this section private health insurances and coverage of people living with HIV will be discussed within the context of healthcare financing in the countries selected for review. The understanding of healthcare financing in a country is important to contextualize the significance and role of private health insurance in HIV financing.

### Country case examples: Rationale for countries selected

This review included countries from three categories and regions. The first group of countries was selected because of their close proximity to Malaysia - the South-East Asian countries of Cambodia, Indonesia, Philippines, Thailand and Vietnam. The second group of countries was selected because of the availability of private medical and health insurance coverage for people living with HIV - Sri Lanka and key countries from the African continent (Kenya, Malawi, Namibia, Nigeria, South Africa, Tanzania and Uganda). The third group are countries from North America, Europe and Latin America where private insurance coverage has been already established for a longer period of time. The case studies were developed by supplementing primary research with a review of literature and assessments that had been done on this topic, to pull together key emerging themes.

### National health expenditures and financing for HIV

#### Health care financing

Healthcare financing occurs through a mix of public and private financing arrangements. Public health expenditures include government spending on health and private health expenditures include private spending on health such as voluntary health insurance and out-of-pocket payments on health. Often times, the government might also mandate a compulsory health insurance to be paid, including, but not limited to payroll deductions. External aid plays a significant role in healthcare financing in many low-income countries, especially in the HIV sector. This section examines the sources (public/private or external) of healthcare expenditures before assessing the financing of HIV and the role of private health insurance in the countries under review.

Full details on the review of health expenditure for HIV can be found in [annex 5](#).

#### Patterns of health expenditure

With regard to health expenditure as a share of gross domestic product (GDP), in general, lower-middle-income countries (Cambodia, Laos, Philippines, Vietnam) and upper-middle-income countries (China, Malaysia) tend to spend between three to seven per cent of their GDP with some exceptions like Brazil and South Africa (see [Table 6](#)). High-income countries (Australia, Canada, Japan, New Zealand and Singapore) spend around 10 per cent of their GDP on healthcare. At close to four per cent, Malaysia's

total expenditure on health as a proportion of GDP may be considered to be close to the middle in the range as a proportion of the GDP in the countries listed in [Table 6](#).

► **Table 6. Total, public and private expenditure on health**

Country	Total expenditure on health as % of GDP (2016) **	Public Spending on Health (% of current health expenditure) (2016) **	Private Spending on Health (% of current health expenditure) (2016) **	External Spending on Health (% of current health expenditure) (2016) **
Cambodia	6.1	21.8	59.2	18.9
Indonesia	3.1	44.7	54.8	0.4
Laos	2.4	32.4	49.5	18.1
Malaysia	3.8	50.5	49.5	0.02
Philippines	4.4	31.5	66.3	2.2
Singapore	4.5	54.5	45.5	0.0
Thailand	3.7	78.1	21.6	0.2
Vietnam	5.7	47.4	48.5	4.1
Brazil	11.8	33.2	66.7	0.1
Kenya	4.5	36.2	44.4	19.5
Sri Lanka	3.9	43.1	55.8	1.1
Uganda (2014)	6.2	16.6	43.1	40.4
Nigeria	3.6	13.0	76.7	10.3
South Africa	8.1	53.7	44.3	2.0
Australia	9.3	68.3	31.7	0.0
Canada	10.5	73.4	26.6	0.0
Japan	10.9	83.6	16.4	0.0
New Zealand	9.2	78.7	21.3	0.0
United States of America	17.1	81.8	18.2	0.0

Source: \*\*WHO Global Health Expenditure Database (<http://apps.who.int/nha/database>)

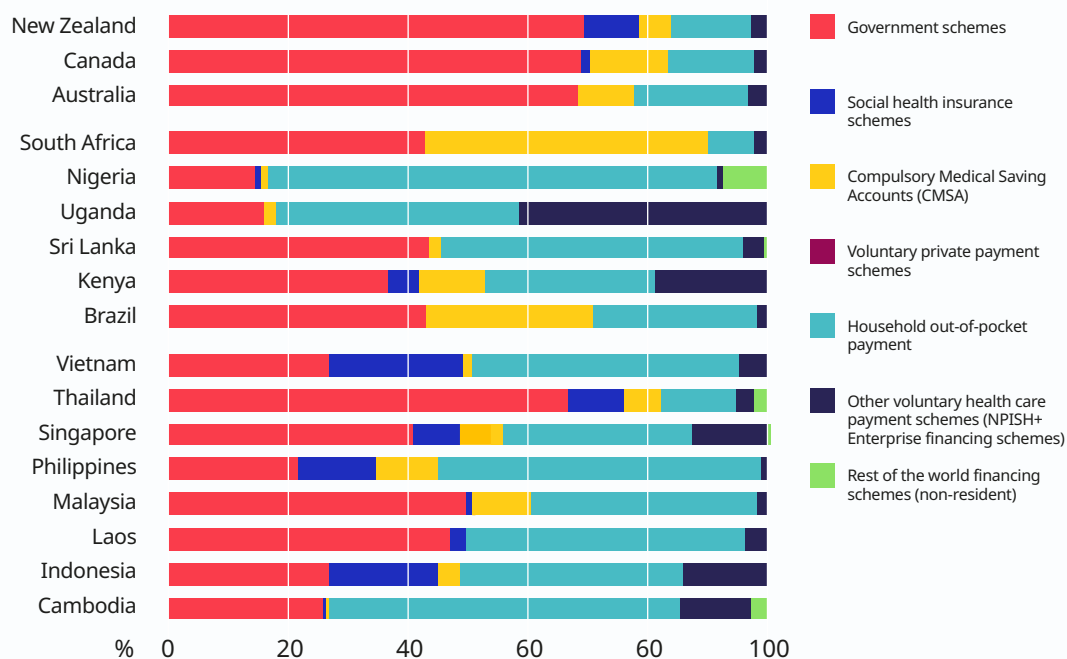
**Table 6** also provides the proportion of public-private health expenditures in the selected countries. On the whole, in high-income countries, the proportion of domestic public health expenditure exceeds that of domestic private health expenditure. However, higher public spending on health does not necessarily translate into health equity and equity in access to healthcare, as seen in the case example of the United States of America which has one of the largest income-based health and healthcare disparities in the world (Khullar and Chokshi, 2018). On the other hand, Thailand with a total health expenditure on health of less than four per cent of the GDP has been lauded as a successful case example of reducing catastrophic health expenditures and medical impoverishment and increasing coverage through its Universal Health Coverage (UHC) programme (Tangcharoensathien et al., 2019, Sumriddetchkajorn et al., 2019). Conversely, while total health expenditure as a proportion of GDP in Vietnam is an impressive 5.7 per cent, regressive out-of-pocket (OOP) expenditure on healthcare appropriates an alarming 44.57 per cent of current health expenditure (World Bank, 2016).

In Malaysia, although there is a rapidly growing private healthcare sector with private health expenditure capturing a 49.5 per cent share (Ministry of Health, 2019b), by and large, the Malaysian system is a tax-funded system where the government is also a major provider of health services which are heavily subsidised. After the government’s contribution of 50.5 per cent of healthcare spending, it is household out-of-pocket expenditure which contributes to 38 per cent of the spending on healthcare (Ministry of Health, 2019b).

### Role of private health insurance

Within this scenario, there are also countries where private sources of funding, including private health insurance, play a significant role. **Figure 2** highlights the proportion of private health insurance within the healthcare financing sources of the countries selected in this review and indicates that countries such as Brazil, Kenya, Malaysia, Philippines and South Africa, have an active private health insurance sector.

► **Figure 2. Current health expenditure (CHE) in select countries by sources of financing (%), 2016**



Notes:

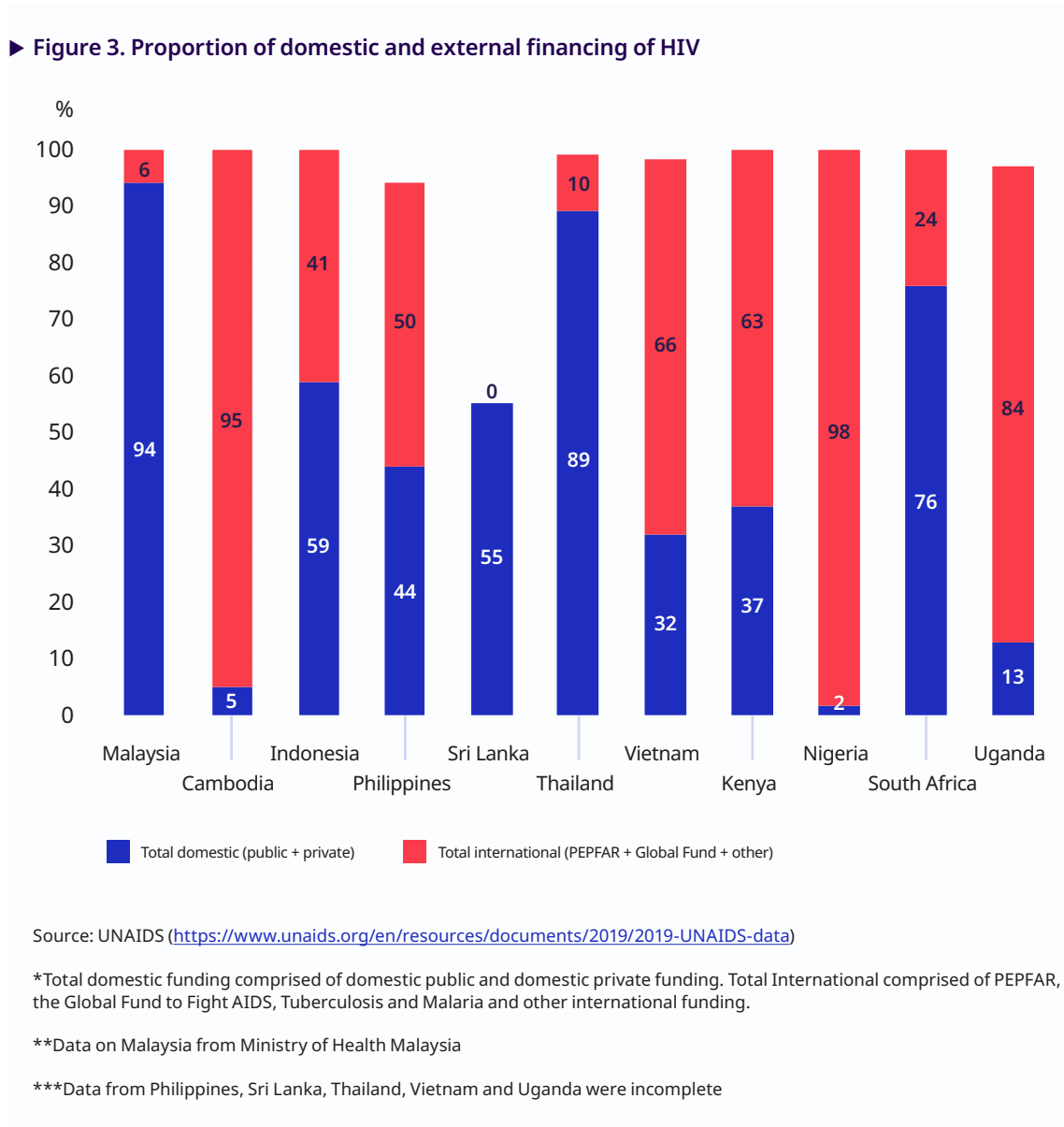
1. NPISH = Non-profit institutions serving households, refers to the funds allocated from government domestic revenues to financing schemes operated by institutional units other than government units.
2. Enterprise financing schemes primarily include arrangements where enterprises provide or directly finance health services for their employees (such as occupational health services), without the involvement of an insurance-type scheme.

Source: WHO Global Health Expenditure Database (<http://apps.who.int/nha/database/Home/Index/en> - (accessed 6 Dec. 2019)

**Figure 3** shows that both low-and-middle-income countries rely to different degrees on external aid for HIV financing. Malaysia, Thailand and South Africa are fully or nearly fully domestically self-financed compared to Cambodia, Nigeria, Kenya, Uganda and Vietnam. In countries that are fairly self-reliant for HIV financing, the government is considerably engaged in the financing and provision of healthcare services and private health insurance plays a relatively minor role in healthcare financing.

**Figure 3** indicates that in Malaysia, domestic spending on HIV constituted approximately 94 per cent of spending on HIV. Of this, domestic public spending comprised 90 per cent and domestic private spending comprised 4 per cent (Ministry of Health). External aid accounted for only 6 per cent of spending on HIV.

Both Malaysia and Thailand spend a major portion of the HIV budget on care and treatment (65.1 per cent and 66.8 per cent respectively) (Tanguay, 2017). However, overall coverage for essential HIV prevention and treatment services is considered to be prominently lower in South-East Asia than in some other regions (WHO, 2016b).



Pendse et al (2016) report that while domestic funding for HIV has been on the rise in Indonesia, Sri Lanka and Thailand, there is greater need to commit more funds in these countries for an effective HIV response (Pendse et al., 2016). As external aid to lower- and upper-middle-income countries generally declines globally (WHO, 2018), there are ongoing concerted efforts in countries including Indonesia, Malaysia, the Philippines and Thailand to build capacity to transition towards domestic funding (Tanguay, 2017).

This is evidenced in other parts of the world too where flows of financial and material aid are beginning to plateau as countries grapple with transitions in demography, health and health systems requiring greater resources. Consequently, it becomes important to explore new ways of building partnerships to finance the HIV response. In this context, drawing on the synthesis of findings across countries on this issue by Thirumurthy et al (2012), may be useful. Citing examples of assistance provided by employers to employees for the purchase of ARV medication, they highlight a range of employer-based programmes as good practice. These programmes include supporting and subsidising treatment for people living with HIV, making referrals to public health facilities that offer free or subsidised treatment and providing private health insurance for employees and their families to increase access to ART (Thirumurthy et al., 2012).

Overall, within such a scenario where both low- and middle-income countries rely to some extent on external aid for HIV financing, private health insurance may have a role to play in bridging the existing resource gap domestically.

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As external aid to lower- and upper-middle-income countries generally declines globally, ongoing efforts are needed to build capacity to transition towards domestic funding.

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## Private health insurance and people living with HIV

People living with HIV, however, are excluded from most private insurance plans across many countries world-wide. If they are not totally excluded, they are charged exclusionary premiums. Oftentimes, critical illness pay-outs only cover claims when HIV is acquired through occupational injury or when full-blown AIDS is diagnosed.

The major body of evidence, however, on the association between private health insurance and access to ART as well as treatment for opportunistic infections and other health problems for people living with HIV is understandably from the United States of America where private health insurance is the predominant form of healthcare financing. The general approach in the United States of America was that most private health insurance was associated with employment, with job loss implying loss of insurance coverage. Further, private insurers refused new coverage for people with HIV infection (Westmoreland, 2016). Studies published in the last couple of years in the United States of America put forward evidence showing that people living with HIV with cancer were more likely found to be uninsured (Coghill et al., 2019), detrimental effects on viral load after a treatment gap were greater in those without private health insurance (Gardner et al., 2018), insured people living with HIV had better health outcomes (well controlled HIV with viral suppression) and better treatment adherence (Furl et al., 2018), people living with HIV who have private medical insurance have higher utilization rates of health services compared to people living with HIV who were not insured (Brennan et al., 2015) and people living with HIV with private health insurance had a higher likelihood of initiating ART than people living with HIV on Medicare, private health insurance has penetrated quite a few countries in Africa, its Medicaid or those incurring out-of-pocket health expenditures (Marcus et al., 2016).



Although private health insurance has penetrated quite a few countries in Africa, its contribution to total health expenditures for HIV and AIDS was 0.9 per cent in Tanzania, 6.1 per cent in Kenya, 3 per cent in Malawi, 0.7 per cent in Namibia and 2 per cent in Zambia (Talib and Hatt, 2013). In general, the review reveals that private health insurance in sub-Saharan Africa, by its very nature, excludes large segments of the population and only covers a minority (2 per cent), in addition to creating the problem of moral hazard (ILO, 2016). There is also a knowledge gap in terms of the association between private health insurance and people living with HIV, health and healthcare access in countries in Africa.

Nonetheless, the developing countries where private health insurance is offered to people living with HIV and which were included in this review are South Africa, Kenya, Uganda, Nigeria, Tanzania, Namibia and Malawi in Africa and Sri Lanka and the Philippines in Asia.

In examining the factors that facilitated the expanded coverage of private health insurance for people living with HIV in many of the above-mentioned countries, the review of literature and key informant interviews reveal the following themes:

## 1. The recognition of HIV as a chronic condition

In research conducted on the role of private health insurance in relation to HIV, insurance firms that were surveyed stated that they covered HIV as a chronic condition, subject to a monetary limit based on the insurance package which was founded on actuarial analysis (Talib and Hatt, 2013).

This aligned with an interview that the researchers did with a major life insurer in South Africa who also stated that:

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▶▶ That's one of the evolutions in the South African market. Couple of years ago, we used to have a separate insurer; if someone was HIV reactive, we would refer them to another insurer who then would provide cover as well as support the compliance to treatment. But since then our market and products have evolved to the extent that we now treat it as a chronic disease. (R22)

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▶▶ ... we recognise that HIV is a disease similar to any other kind of chronic disorder that has certain outcomes, more favourable outcomes, should the disease be well controlled. (R22)

Talking about why they began covering people living with HIV, another major multinational insurer in North America stated:

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▶▶ ... we didn't do it because there would be large numbers. Rather because we consider HIV to be a chronic disease, not life threatening. (R2)

On the strength of existing evidence and because they were a large multinational corporation, this company went on to begin covering people living with HIV even without a reinsurer.

In both countries, amplifying the decision to extend coverage to people living with HIV based on the recognition of HIV as a chronic disease, respondents cited robust evidence derived from population-based studies. These studies showed that life expectancy of people living with HIV had improved vastly and was close to that of the general population when they adhered to treatment; more so when diagnosis and initiation of treatment were early.

In Malaysia, interviews with key informants from the insurance sector and a survey with 11 insurance companies in this study revealed that none of the companies updated their evidence base related to current treatment for HIV, outcomes of treatment for HIV and the epidemiology of HIV. Thus, there is a need for more dialogue and information sharing between the health and insurance sectors to in relation to treatment outcomes in Malaysia.

## 2. Legislation and policies

Legislation and/or policy prohibiting discrimination in general and/or constitutional provisions for the protection of health rights have been found to play an important role in the expansion of private insurance in Africa. Examples include constitutional guarantees of the right to health as in South Africa, or constitutional prohibition of discrimination on the basis of health status in Kenya where the National AIDS Control Act prohibits insurance companies from requiring an HIV test before offering health insurance (Talib and Hatt, 2013). Citing the Medical Schemes Act No. 131 of 1998, a respondent representing a major South African insurance company affirmed that one could not decline insurance to a person on the basis of their health status and said:

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►► ... You can apply and there is a waiting period between application and when you can avail the basket of benefits. So, someone who has had kidney failure and you know has to have dialysis, you can assist the person and say, 'Well you can't access the dialysis services immediately as a member, there will be a six month waiting period of time before you can use it.' But the regulation says you can never decline or turn someone away because of that. (R22)

It was also found that having a clear national policy and having government initiatives focusing on strengthening access to treatment increases financial risk protection, including the expansion of private health insurance to people living with HIV on more fair terms (ILO, 2016, Talib and Hatt, 2013).

Conversely, Nigeria's National Health Insurance Plan guidelines suggesting that health maintenance organizations (HMOs) refer clients to public sector providers were found to undermine the possibility of them expanding benefits to people living with HIV (ILO, 2016).

The Kenyan experience shows that where companies are compliant with national policies or legislation prohibiting discrimination against people living with HIV, actuarial benefits arising from early diagnosis and initiation of treatment lead to savings in the form of not having to incur treatment costs for opportunistic infections requiring inpatient care that may arise later. These inadvertently become incentives for expanding health insurance coverage for people living with HIV (ILO, 2016).

However, it must be noted that the action of expanding private insurance is secondary to state intervention on the issue through anti-discrimination and/or AIDS control legislation and policy and the provision of free/subsidised ART by governments. The exception may be the Nigerian HMO, Expatcare Health International Ltd which provides coverage for HIV because of the low prevalence of HIV and the related low perceived risk and cost (Talib and Hatt, 2013).

Closer to home, the Philippines which has the fastest growing HIV epidemic in the Asia and the Pacific region (UNAIDS, 2018), recently adopted the Republic Act 11166 or the Philippine HIV and AIDS Policy Act which became effective on 25 January 2019 (Government of Philippines, 2018). Senator Risa Hontiveros who authored the bill described it as one that “incorporated a concerted response that makes use of the most recent developments in prevention and treatment in medical and health science” (Senate of the Philippines, 2018). Based on inputs from a range of stakeholders, especially the communities, the bill explicitly prohibits discrimination against people living with HIV, especially in accessing HIV prevention, testing and treatment services and makes provision for Philhealth, the social health insurance system of the Philippines, to develop a package of benefits related to HIV, including treatment. Section 42 of the Bill states that,

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► No person living with HIV shall be denied or deprived of private health insurance under a Health Maintenance Organization (HMO) and private life insurance coverage under a life insurance company on the basis of the person’s HIV status. Furthermore, no person shall be denied of his insurance claims if he dies of HIV or AIDS under a valid and subsisting life insurance policy (Section 42) (Senate of the Philippines, 2018).

In an interview with the researchers in this study, the legislative office of Senator Hontiveros stated that the Ministry of Health of the Philippines, played a lead role in the discussions and consultations related to the bill in the years leading to its adoption. According to the same office, although it is the Insurance Commission that regulates insurance companies, the Ministry of Health also plays a role in securing the participation of health insurance companies and coordinates with the Insurance Commission with regard to the regulation of health insurance companies, if required.

Such an emphasis on governance and regulation is also found in the literature on private health insurance. Examining the impact of private medical and health insurance in developed and developing countries, Wouters and McKee state that the impact of private health insurance depends on the type of private health insurance, the regulatory environment and the relationship between the private and statutory systems if there are co-existing dual systems of insurance (Wouters and McKee, 2017).

In regard to private health insurance, the case of Thailand also warrants attention where the role and functioning of the Office of Insurance Commission (OIC) may offer lessons for Malaysia considering that it aimed to achieve market penetration as well as make micro-insurance accessible to low income and rural populations.

The Federal Constitution, which is the supreme law of the Federation of Malaysia, provides in its Part II, a primary list of legally guaranteed rights to individuals. Articles 8 and 12 of the Malaysian Constitution contain the main provisions which protect the rights to equality and non-discrimination while accommodating the special status of the indigenous people and the Malays in Article 153. There is no other comprehensive anti-discrimination legislation in Malaysia. The Malaysian AIDS Foundation has worked in recent months to garner support for an amendment to the Employment Act to provide for non-discrimination for people living with HIV in terms of employment. The draft regulation (Tommy Thomas Advocates & Solicitors, 2019) also provides a mechanism for remedy for those who might be discriminated because of their HIV status. Several individuals from the corporate and government sectors who were interviewed in this study concurred that should such a regulation come to pass, corporates would need

to align workplace policies and practices which would include the removal of the exclusion of HIV status for employment-based healthcare protection.

In summary, from the case examples in other countries, it can be inferred that political will manifested in robust legislation and policy is a strong predictor of engagement of the insurance sector in the coverage of private medical and health insurance for people living with HIV. The case of the Philippines also demonstrates that the Ministry of Health has a niche role in bridging perspectives by educating the insurance sector about scientific advances in the treatment of HIV and playing a supportive role in the overall regulation of the sector and governance related to this issue.

### 3. Advances in treatment regimens for people living with HIV and consequences for treatment outcomes

Advances in treatment and improved health outcomes for people living with HIV as a result of newer treatment regimens were a significant factor in the expansion of private health insurance in many parts of sub-Saharan Africa (Talib and Hatt, 2013). Improved life expectancy and better ability to manage opportunistic infections, helped in mitigating the perception of risk for private insurers (Talib and Hatt, 2013).

This was also the case in Sri Lanka, where the support from the ILO led to the opening of doors by private insurance companies such as Janashakthi Insurance for people living with HIV. In commenting on the adoption of this policy providing health insurance cover, Chandra Schaffter, Deputy Chairman of Janashakthi Insurance said:

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►► The number of AIDS-related deaths is far lower than deaths due to other critical diseases, thanks to the treatment that enables people to live longer. So, it makes sense for insurance companies to cover HIV. I did it in my company. The fact that there were no claims in the past 20 years shows that I was right. I hope other insurance companies will do the same.

Similarly, Surekha Alles, Chief Executive Officer of Allianz Insurance Lanka Ltd, which also now provides health insurance cover for people living with HIV in Sri Lanka said:

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►► Thanks to the ILO, we realized that the exclusion of HIV from insurance makes no sense in this day and age with advances made in medical research. Now, we cover HIV and AIDS in our medical insurance policies. This gives people living with HIV more peace of mind and security.

#### 4. Availability of free and or subsidised ART

In many of the countries where the expansion of private health insurance took place, it was after free and/or subsidised ART became available through state intervention. Kenya and Uganda are typical examples where private insurers modified their perception of risk associated with HIV once treatment was subsidised or provided free by the government. In fact, private insurers opined that some other conditions were more expensive to under-write than HIV (Talib and Hatt, 2013).

Validating this significant role of the government in making available free/subsidized ART in the expansion of private health insurance in South Africa, the respondent from a major insurance company said:

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▶▶ I think one of the big factors was that the government-run programmes provided access to ARV, which helped to manage the disease. The other thing is that it became a chronic disease. And those two things are related. And they provided enough data for us to be able to make informed decisions. So, all of that came together at the same time. (R22)

This perspective was also echoed by another of the corporate sector interviewees from Malaysia in this study. This respondent opined that in the context of the breakthrough in HIV treatment and the easily accessible ART in the country, there were other conditions that were currently covered by health insurance companies, which were more expensive to treat than HIV.

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▶▶ I think with HIV, I am not saying it's benign. But it is quite treatable and straightforward. (R1)

Lower costs of early detection and low prevalence as in Nigeria and HIV prevention via male circumcision in Namibia were also found to increase the financial viability of providing health insurance for HIV. But packages differed across countries. In tandem with the high prevalence of HIV in many parts of sub-Saharan Africa, risk perception in relation to people living with HIV became more favourable toward them (Talib and Hatt, 2013).

As stated earlier, in Malaysia, first line drugs to treat HIV are provided free of cost and second line drugs are heavily subsidised by the Malaysian government.

## 5. Role of social health insurance

Private health insurance also thrives where payroll based social health insurance is opened up to them. In obtaining access to a large client base of government workers as is the case in many developing countries, such companies also benefit from a large risk pool that reduces the cost of treatment like ART (Talib and Hatt, 2013).

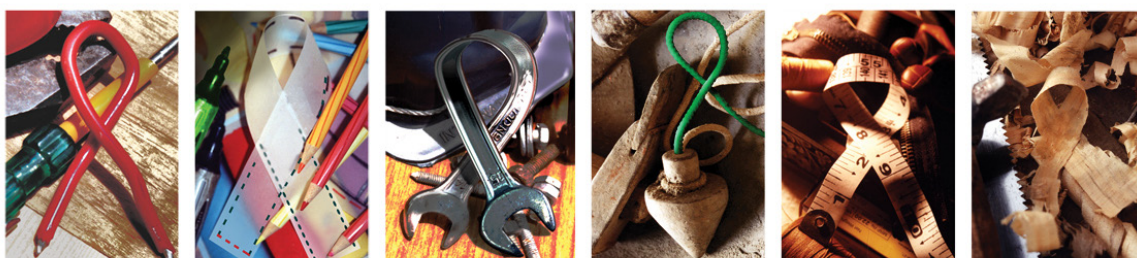
For example, it is reported that an estimated 70 to 80 per cent of corporate employers buy the optional HIV and AIDS coverage from Jubilee insurance in Kenya. Jubilee also organizes education sessions for clients by bringing medical specialists who provide advice to members on how they can optimise their insurance benefits to improve health outcomes. This strategy is based on the actuarial imperative of keeping costs down and insurance companies like Jubilee are able to recognise that engaging on HIV with their clients by supporting early testing and treatment initiation brings about long term actuarial gains. They note that, conversely, some other chronic conditions remain undetected and lead to higher treatment costs than HIV later (Talib and Hatt, 2013).

## 6. Role of international organisations

In addition to the positive measures by States, assistance from international organisations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and PEPFAR has also played a role in expanding private health insurance. By making ART available free of cost (as in Uganda) such bodies played a critical role in the expansion of private health insurance. The case of Leapfrog Labs in providing grant capital and actuarial analysis support for benefit packages and premiums to Apollo insurance company in Kenya, is another good example of the role of international organisations, philanthropies and investors in nudging private insurance companies toward providing health insurance for people living with HIV (Talib and Hatt, 2013).

## 7. Navigating risks

The development of strategies to navigate the associated risks of covering people living with HIV with insurance has been another factor enabling the expansion of private health insurance to this group. With scientific advances and objectively measurable data, most multinational insurance companies stated that risk rating was possible by focusing on the following factors: CD4 count, viral load, comorbidity, if it was an early diagnosis, how long the applicant has been on treatment, treatment adherence, age, gender, occupation and life-style factors such as use of tobacco, alcohol and drugs. They reiterated that this information allowed them to quantify the price of insurance including the loading that was required for covering people living with HIV.



# 4.

## Major findings of the review and the case for extending insurance coverage for people living with HIV in Malaysia and in general



## ► Major findings

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### Epidemiology, treatment and management

#### Epidemiology

In 2019, 81 per cent of people living with HIV globally knew their status, 82 per cent of people aware of their status were accessing treatment and among people accessing treatment 88 per cent were virally suppressed. For Malaysia in 2018, 86 per cent of people living with HIV knew their status, of these, 55 per cent were on ART and 97 per cent of people on ART had suppressed viral loads (UNAIDS, 2020a). The percentage of people on ART in Malaysia is low and private health insurances can play an important role in reaching the 90 per cent goal. The group of men having sex with men is expected to become the main driver of the epidemic, as projected by the Asian Epidemic Modelling.

#### Guidelines on antiretroviral treatment

The WHO Consolidated Guidelines (WHO, 2016a) and the Malaysian Consensus Guidelines (Ministry of Health & MASHM, 2017) are aligned in most aspects in relation to treatment of adults with HIV. Both guidelines recommend to start ART for all HIV-infected adults, regardless of CD4 count, to reduce the mortality and morbidity associated with HIV infection.

#### Availability and cost of medication in Malaysia

The cost of HIV related laboratory tests is free in hospitals and clinics under the Ministry of Health. First line treatment is also provided free of cost. With regard to second line treatment, the government provides part of the treatment free of charge while the individual has to pay for the other part of the medication.





## Treatment outcomes

The evidence analysed in this review indicates that subject to early initiation and adherence to treatment, ART can significantly improve the overall health status, life expectancy close to the expected life expectancy of the general population, economic status and quality of life of people living with HIV. The emerging body of knowledge in Malaysia also indicates that people living with HIV on ART are achieving positive outcomes in survival rates and life expectancy.

Overall, the key to longer survival time is access and adherence to ART, key elements are:

- ▶ The costs of ART drugs have decreased dramatically due to a combination of price negotiations, manufacturing of generics and trade agreements.
- ▶ ART has improved in effectiveness, has fewer side effects and has reduced pill burden. Management of opportunistic infections and comorbidity have also reduced all-cause mortality among people living with HIV.
- ▶ The cause of death among people living with HIV is increasingly due to common chronic conditions rather than to HIV infection itself. At the same time, the benefit of ART treatment extends to lowering the risk of comorbidities and non-AIDS-related complications.
- ▶ Co-morbidities that would typically appear in older aged people have been observed in people living with HIV, at younger ages. The evidence so far showed that being on ART might also lower the risk of these consequences, compared to not being on ART.
- ▶ People living with HIV who take HIV medication daily as prescribed and maintain an undetectable viral load have effectively no risk of sexually transmitting HIV to their HIV-negative partners.
- ▶ In the focus group discussion, 13 of the 14 people living with HIV interviewed had undetectable viral loads, meaning they were adherent to treatment and had achieved viral load suppression. The 14th person was recently diagnosed and was awaiting the viral load test result. Additionally, many of them stated that they were in much better health than before, saying that the routine follow-up and testing which are part of the HIV treatment and care, were significant factors in enabling them to maintain good health.
- ▶ Barriers to access ART include stigma, poor disease knowledge, logistic issues, high treatment costs and lack of medical insurance.

## Economic benefits of ART to people living with HIV and their societies

Evidence from the literature points to the importance of ART in retaining or maintaining the wellness of people living with HIV, thereby enabling employment and work productivity. Also, several studies have thus suggested that the significant health gains generated from ART are worth the cost of treatment.

From 1995 to 2015, ART averted 9.5 million deaths worldwide, which translated to global benefits of US\$1.05 trillion. For every US\$1 spent on ART, US\$3.50 in benefits accrued globally.

At the individual level, ART led to increased and sustained employment levels and productivity for people living with HIV. At the household level, economic benefits included prevented end-of-life health and funeral expenditures, more time for schooling, less time spent on caregiving tasks, and preventing children in the household from becoming orphans. The benefits to employers include gains in terms of retaining institutional memory, averting disruptions to production processes and cost savings as hiring and retraining new employees is not needed.

The model that guided the development of the Malaysian strategic plan for HIV and AIDS 2016-2030 projected that by scaling up harm reduction for people who inject drugs and accelerating prevention and treatment for key populations for seven years, Malaysia could save up to 644,000 Disability-Adjusted Life Years (DALYs)<sup>7</sup>, or healthy, productive life years, equivalent to US\$6 billion.

## Medical and health insurance coverage of people living with HIV in Malaysia

### Outcomes survey insurance companies

In general, private medical and health insurance coverage in Malaysia exclude people living with HIV, HIV and its related diseases fall within the policy exclusion. Some companies cover HIV when it is due to blood transfusion, occupationally acquired HIV and full-blown AIDS under their critical illness plans. While HIV in these cases is covered, it is not likely that it is of substantive support to people living with HIV as these circumstances are very rare.

A survey conducted with the 11 insurance companies affiliated with LIAM, revealed the following (subject to policy criteria):

- Most of the companies acknowledged that the policy would remain in force if people living with HIV had purchased insurance cover prior to being diagnosed with HIV. They added that claims might be made if they were not related to HIV directly or indirectly.
- One company would provide coverage if the person was diagnosed with HIV after purchasing the policy.
- Another company has coverage for persons with pre-existing HIV available under its Group Life and Group Medical policies.
- Some of the companies were open to considering the inclusion of people living with HIV in medical insurance coverage depending on the health status of the individual.
- The insurance companies had not researched the effect of treatment and the outcomes of people living with HIV.
- A key concern were the gaps in data which made price quantification challenging. These included data related to the size of the risk pool and clinical and socio-demographic characteristics.
- The distribution of risk would be an incentive to initiate insurance products for people living with HIV. A directive from the government to extend insurance coverage to people living with HIV would help distribute the risk to all insurance companies. Also amplifying the range of products, being able to offer other products, would also help to mitigate risk.

7 DALY is the summary measure used to give an indication of overall burden of disease. One DALY represents the loss of the equivalent of one year of full health. WHO, Disability-adjusted life years (DALYs) [Online]. World Health Organization. Available: [https://www.who.int/gho/mortality\\_burden\\_disease/daly\\_rates/text/en/](https://www.who.int/gho/mortality_burden_disease/daly_rates/text/en/) [Accessed 10 Feb 2020].

## In-depth interviews and focus group discussions of people living with HIV

### Leading productive lives

All the participants living with HIV in the study were employed and were financially independent. Most of the participants interviewed cited this factor in questioning the logic of being excluded from purchasing private health insurance (and life insurance and MRTA related to housing loans). Study participants also questioned why people living with HIV could not purchase insurance at a higher premium like people living with diabetes and with heart diseases.

### Group insurance being a barrier to employment opportunities

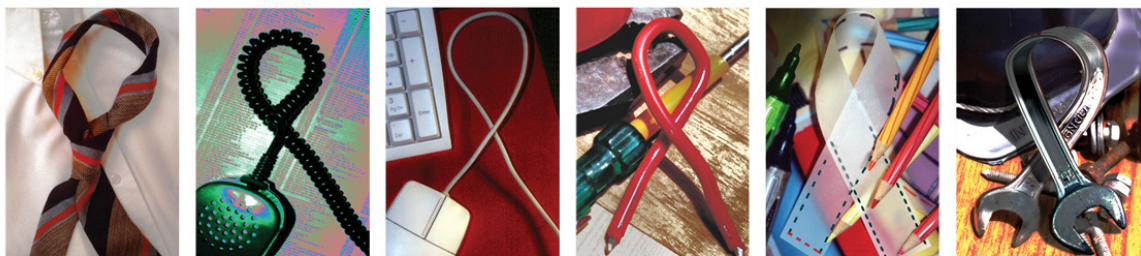
Many employers impose a medical examination for prospective employees, the medical examination is done prior to employment or in conjunction with promotions. This medical examination is also part of employee benefits such as group medical insurance. The study interviews showed that mandatory medical tests were inadvertently a barrier to employment for people living with HIV. On the other hand, in the case of some large multinational companies, the HIV status is of no consequence and people living with HIV will still be covered.

### Stigma and discrimination related to insurance coverage

The Focus Group Discussion pointed out that many people living with HIV refuse to go for employment related medical examinations because they do not wish to declare their status; they just give up the job opportunity. During the course of employment too, people living with HIV are reluctant to use the employer’s group medical insurance, as they are worried that the company will find out their HIV status, and they prefer not to take a job promotion if that means undergoing a medical exam. On the employers’ side, job offers were rescinded when the medical examination revealed an HIV positive status.

### Out-of-pocket payments and catastrophic health expenditures

In the absence of their ability to claim insurance policies they might have purchased prior to their diagnosis or their inability to purchase private insurance, most of the people living with HIV who were interviewed stated that they coped with non-HIV related emergency medical expenditures via out-of-pocket payments (OOPs). This put hardship on the household and had catastrophic consequences.



## Country case examples of health insurance coverage for people living with HIV

The review of literature and key informant interviews from the different countries reveal the following good practices for expanding coverage of medical insurance for people living with HIV:

### 1. The recognition of HIV as a chronic condition

Several insurance firms cover HIV as a chronic condition, subject to a monetary limit based on the insurance package which was founded on actuarial analysis.

### 2. Legislation and policies

National policies or legislation prohibiting discrimination against people living with HIV and/or constitutional provisions for the protection of health rights have been found to play an important role in the expansion of private insurance in Africa (South Africa and Kenya) and the Philippines. Political will manifested in robust legislation and policy is a strong predictor of engagement of the insurance sector in the coverage of private medical and health insurance for people living with HIV.

### 3. Advances in treatment regimens and treatment outcomes

Improved health outcomes for people living with HIV as a result of newer treatment regimens were a significant factor in the expansion of private health insurance in many parts of sub-Saharan Africa. Improved life expectancy and better ability to manage opportunistic infections, helped in mitigating the perception of risk for private insurers.

### 4. Availability of free and or subsidized ART

In many of the countries where the expansion of private health insurance took place, it was after free and/or subsidised ART became available through state intervention. As stated earlier, in Malaysia, first line drugs to treat HIV are provided free of cost and second line drugs are heavily subsidised by the Malaysian government.

### 5. Role of social health insurance

Private health insurance also thrives where payroll based social health insurance is opened up to them. In obtaining access to a large client base of government workers as is the case in many developing countries, such companies also benefit from a large risk pool that reduces the cost of treatment like ART.

### 6. Role of international organizations

In addition to the positive measures by States, assistance from international organisations such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and PEPFAR has also played a role in expanding private health insurance, by making ART available free of cost.

### 7. Navigating risks

The development of strategies to navigate the associated risks of covering people living with HIV with insurance has been another factor enabling the expansion of private health insurance to this group. With scientific advances and objectively measurable data, most multinational insurance companies stated that risk rating was possible and allowed them to quantify the price of insurance including the loading that was required for covering people living with HIV.

## ▶ The case for extending insurance coverage

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The discussions in the preceding sections bring one to the question: Is there a case to consider private medical and health insurance cover for people living with HIV?

Although an actuarial analysis assessing the viability of extending private insurance cover to people living with HIV is a different exercise requiring other data, the review has identified several factors which make a case for exploring such an analysis in Malaysia based on the following factors:

### 1. The availability of free and subsidized ART for people living with HIV in line with international guidelines

The Ministry of Health in Malaysia, has been actively engaged at the forefront of the fight against HIV and AIDS. The review also shows that Malaysia's treatment guidelines for HIV as well as prophylactic treatment related to HIV, align with global standards set by the World Health Organization.

First line treatment is provided free of cost. With regard to second line treatment, the government provides part of the treatment free while the individual has to pay for part of the medication.

The government has actively worked toward lowering of HIV drug prices through negotiations with highly active ART patent holders, encouraging local HIV drug production and giving due consideration to the application of 'Right of Government' under the Patent Act 1983 for the sustainable supply of HIV drugs. Through the initiative of the Ministry of Health, Malaysia became the first country to issue a compulsory license in 2003 (Ministry of Health, 2016).

To scale up access to HIV screening and treatment, HIV care has been integrated in health services provided at primary care, along with the desire to make health care accessible, acceptable and affordable to the whole community, especially key populations. Additionally, Family Medicine Specialists have been trained in HIV care country wide and mobile CD4 point of care tests have been placed in primary care clinics with a view of achieving positive treatment outcomes for people living with HIV (Ministry of Health, 2016).

As the review revealed, such a context was found to be favourable in other countries for the introduction of private medical and health insurance for people living with HIV.

### 2. Stable CD4 count and viral load suppression

The review also revealed that a stable CD4 count and viral load suppression were key indicators in making medical and health insurance for people living with HIV viable. These were also indicators that were used in other countries to quantify price, rate risk and be used as a basis for renewal of the annual policy. The few studies that have been done on this topic in Malaysia show that those who had initiated treatment earlier and had been adherent to treatment had achieved positive outcomes in relation to increased life expectancy. The study by Mat Shah et al also showed that those who were on treatment also had a lower all-cause mortality rate and AIDS-defining events (Mat Shah et al., 2012). The clinical data of the people living with HIV study participants in this research also showed that out of the 14 who were interviewed, except for the newly diagnosed individual (R10), all the others had an undetectable viral load.

The government has also invested in treatment adherence peer support services, psychosocial support and treatment literacy, to complement and support ART delivery, retention in care and adherence to treatment (Ministry of Health, 2018).

Existing data on treatment outcomes could be used to explore the viability of an actuarial assessment of extending insurance to people living with HIV in Malaysia.

### 3. Mitigating and distributing risk

Interviews with local insurers brought up strategies for mitigating risk. One related to the role of the government while the other related to diversifying the products that can be offered to people living with HIV.

As such, the Ministry of Health could work with partner ministries to explore the suggestion for the government to provide direction on this issue to expand the number of players and distribute risk.

The interviews with people living with HIV showed that medical and health insurance coverage was only one concern related to insurance. There were other concerns related to life insurance and mortgage reducing term assurance (MRTA) among others. Given the narratives of people living with HIV who lead productive lives and have gone on to complete the payment of property mortgage, insurance products such as MRTA could also be extended to people living with HIV.

Importantly, rules related to life insurance and other insurance products need to be clarified clearly and transparently, especially when these products were purchased before the individual was diagnosed with HIV. In this regard, many of the people living with HIV who were interviewed reported that they were willing to pay higher loading for insurance coverage. A fair solution could be explored within such parameters of improving access to insurance for people living with HIV and profitability for the industry.

A key point that emerged from the review is that insurers seemed to be missing a business opportunity. This included the knowledge gap regarding the state of treatment and treatment outcomes enjoyed by people living with HIV and the transmission shift with sexual transmission overtaking injecting drug use as the leading route of transmission. The preponderance of the men who have sex with men population in this cohort and their relatively higher educational attainment and employment in high wage sectors is an area of research that requires greater examination in this discussion.

### 4. Addressing Out-of-Pocket Payments (OOPs) for healthcare

As shown in **Figure 1**, out-of-pocket payments for healthcare in Malaysia amounts to RM 21,573 million (5,190 million US\$<sup>8</sup>), which is equivalent to 38% of the Total Expenditure on Health and 77 per cent share of the private sector health expenditure and at 1.59 per cent of GDP (Ministry of Health, 2019b). Private household OOPs constitutes the highest source of financing in the private sector. With regard to health expenditure by private sector sources of financing, although the share of private health insurance doubled from seven per cent in 1997 to 14.58 per cent in 2017, private household OOPs for healthcare have remained stubbornly unmovable from 75.55 per cent in 1997 to 76.98 per cent in 2017 (Ministry of Health, 2019b). While the largest share of OOPs, i.e. 46 per cent, was for public and private outpatient services, in-patient services in both public and private health facilities took about 24 per cent of OOPs (Ministry of Health, 2019b) increasing from 39 per cent and 17 per cent respectively in 1997 (Ministry of Health, 2015b).

A prepaid system of healthcare that provides financial protection for individuals who might otherwise experience catastrophic health expenditures for OOPs at the point of use of services is imperative for Universal Health Coverage. OOPs for healthcare undermine access to healthcare and drive people into medical impoverishment. Although one might posit that the relatively higher share of OOPs going

toward outpatient services may not be a cause for alarm, the increasing share of OOPs overall does call for attention in alignment with the government's vision of Universal Health Coverage (UHC). With regard to HIV, the study by Ghailan et al. conducted in the major referral hospitals in Kedah, Johor, Kelantan and Selangor reported that the median OOPs for healthcare for people living with HIV was RM 1,080 (259 US\$6) per annum (equal to 14.7 per cent of the median income of a person with HIV), which was incurred toward cost of transportation, hospital charges, health food supplements and traditional medicine (Ghailan et al., 2010). A lower CD4 count was also significantly associated with higher OOPs on healthcare. These results in tandem with the emerging body of knowledge revealing that coverage for catastrophically costly treatments is uneven and inequitable in Malaysia (Kaur et al., 2017) and are associated with certain diseases and socio-economic groups (Azzani et al., 2017, Bhoo-Pathy et al., 2017, Kaur et al., 2017, Loganathan et al., 2015, Sukeri et al., 2017), highlights the necessity to address OOPs for healthcare for greater effectiveness, efficiency and equity in the healthcare financing system of the country.

It also points to the need to review the interlinkages in the issue of healthcare financing and explore the role of private health insurance in mitigating these problems.

Although the share of private medical and health insurance has increased in the last two decades, it does not seem to have made a substantive dent on the OOPs share of total expenditure on health which has hovered around 37 to 38 per cent between 1997 and 2017 (Ministry of Health, 2019b). Moreover, market penetration of private medical and health insurance is far from optimal as admitted by policy makers and the industry (Bank Negara Malaysia, 2006, The Star Online, 2018). This scenario offers potential for the industry. In this regard, the removal of the exclusion criteria of HIV from medical and health insurance and employment would augur well to enhance coverage of people living with HIV under employment-based group insurance coverage as well as individual insurance. In fact, if the insurance sector does roll out products for people living with HIV, working with their communities to reach members, insurance companies may be able to broaden and deepen their reach within a generally hard to reach community. This would also depend on the attractiveness of the products to the community of people living with HIV.

In this review, many people living with HIV expressed their interest in purchasing different insurance products and being open to a higher loading for medical and health insurance. They paid OOPs to cope with non-HIV related treatment, even incurring medical expenditures that drove them into poverty as demonstrated in the case of the young man mentioned earlier who ratcheted a bill of RM 30,000 (7,390 US\$<sup>9</sup>). Facilitating a way to channel the OOPs for healthcare paid by this population group into a pre-paid system of health financing that averts financial ruin through catastrophic health expenditures aligns with the government's commitment to UHC within the context of an emerging dual burden of disease, an ageing population and increasing healthcare costs.







## ► Recommendations on the process of inclusion of HIV in private health insurance coverage

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- 1. The Ministry of Health to take up the mantle of facilitating a discussion** between stakeholders on next steps in line with the Government's commitment towards Goal 3: Ensure Healthy Lives and Promote Well-Being for All at All Ages of the Sustainable Development Goals (SDGs) 2016-2030 and the pledge of leaving no one behind.

Owing to the guidance that is being sought from the Ministry of Health and the cross-cutting nature of this issue, this study recommends that facilitation of future discussions be led by high level leadership in the Ministry of Health for a sustainable process. As in other countries where medical and health insurance was facilitated through the leadership of the Ministry of Health, the Ministry of Health is encouraged to play this facilitative role in mobilizing other ministries and stakeholders.

- 2. Include the voices and participation of people living with HIV communities in the discussions.** Paying attention to the voices and perspectives of the people living with HIV community would deepen the understanding of the needs of the community and sharpen the focus and direction of discussions on the inclusion of HIV in private health insurance coverage. Participation of the community would also enhance the sustainability of the endeavours that could be adopted in this regard. It is recommended that the Malaysian AIDS Foundation plays a strategic interlocutory role in ensuring the relevance of the potential insurance products to people living with HIV.
- 3. The government, insurance, health, research communities, and the Malaysian AIDS Foundation to dialogue, exchange information and foster greater cooperation in this process.** Greater dialogue is required between the stakeholders mentioned earlier to bridge the current knowledge gap and to explore cooperation for sustainable solutions. Toward this end, insurers are encouraged to work closely with the Ministry of Health, research communities, NGOs and people living with HIV to access relevant evidence that might be needed for actuarial risk assessment.
- 4. The world of work can play a key role in expanding the coverage of insurance for HIV.** The ILO Recommendation concerning HIV and AIDS and the World of Work, 2010 (No. 200)<sup>10</sup> calls on Member States 'to ensure that workers living with HIV and their dependants benefit from full access to health care, whether this is provided under public health, social security systems or private insurance or other schemes. Members should also ensure the education and awareness raising of workers to facilitate their access to health care.'

10 [https://www.ilo.org/global/topics/hiv-aids/WCMS\\_142706/lang--en/index.htm](https://www.ilo.org/global/topics/hiv-aids/WCMS_142706/lang--en/index.htm)

5. **Employers should work with their insurer providers** to review and expand workplace-based group medical and health insurance to include HIV.
6. **Advocacy with insurance companies must continue.** Given the positive impact of ART on health and longevity of people living with HIV, HIV should be included in the coverage of insurance.
7. **There is a human, as well as a business case for insurance companies to include HIV.** Inclusion of people living with HIV in existing health insurance will be beneficial for the following reasons:
  - a) ART is provided free by the government. Hence, no cost to insurance companies for a life-long treatment which has shown to keep people healthy and productive.
  - b) The current focus on the HIV response to promote HIV testing is helping people living with HIV to know their status early and start ART early. This is showing a huge impact on lowering the incidence of opportunistic infections and hospitalizations. This will lower the cost to companies, should they start covering HIV.
  - c) Advances in HIV testing and introduction of HIV self-testing is yet another way that is helping people to do an initial screening in their own private settings, without the fear of stigma and discrimination. Companies should, therefore, cover HIV testing as well, including HIV self-testing, as and when the products become available in Malaysia.
  - d) Coverage of HIV will demonstrate that insurance companies do not discriminate and are making their contribution to the SDGs, following the principle of leaving no one behind.
8. While it is important to advocate for coverage of HIV in private insurance, it is critical to **work with the government to ensure that HIV sensitive social protection is expanded.** A combination of public and private sector approaches is desirable, given the huge role of the public sector.

Since the factors in the assessment of risk seem to be common to medical and health insurance and other types of insurance, including life insurance and mortgage insurances, related to people living with HIV, **this review recommends that the insurance sector considers the removal of the exclusion related to HIV for all insurance products in future deliberations.**



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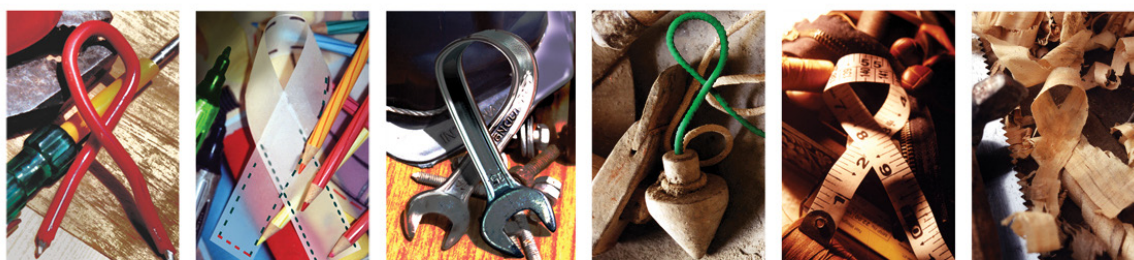


# Annex 1

## ► Methodology of literature search

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Given the breadth of topics that needed to be covered in this review, we conducted an initial search of electronic databases (PubMed and Scopus) using truncated keywords individually and in combination including "HIV", "AIDS", "treatment", "ART", "ARV", "access", "insurance", "adherence", "outcome", "private insurance", "medical insurance", "health insurance", "healthcare financing", "treatment regimen", "economic", "benefit", "impact" and "healthcare financing". For PubMed, Medical Subject Headings (MeSH) terms were used to streamline some definitions and terms. No restrictions on publication status or date were applied at the initial search. Detailed search terms and areas of search are listed in the table below:



► **Table 7. Search terms and areas of search**

Broad areas of concern	Search terms in PUBMED	Search term in SCOPUS	Number of articles from the search
<b>Treatment, treatment regimen and outcomes</b> a. Treatment regimen and treatment outcomes for people living with HIV b. Access to ART or treatment adherence and treatment outcomes for people living with HIV	1. (treatment OR regimen OR ART OR HAART OR ARV OR "Anti-retroviral Agents"[MeSH])) AND ((outcome* OR efficacy)) AND ((HIV OR AIDS))	TITLE-ABS-KEY ((treatment OR regimen OR art OR haart OR arv OR "Anti-retroviral Agents") AND (outcome* OR efficacy) AND (hiv OR aids))	9,224 sorted by best match, prioritising review studies first and then sorted by citations score
<b>Economic benefits of people living with HIV on ART</b>	((("economic"AND ("benefit*"OR "impact*") AND ("HIV" OR "AIDS") AND "treatment"))	TITLE-ABS-KEY (((("economic" AND ("benefit*"OR"impact*")) AND ("HIV"OR"AIDS") AND "treatment")) AND (LIMIT-TO (EXACTKEYWORD, "Economics" ) )	869 About 400 were sorted according to best match and screened
<b>Access to health insurance and treatment outcomes for people living with HIV</b>	("medical insurance" OR "health insurance" OR "private insurance") AND ("HIV" OR "AIDS") AND ("access") ((("barriers" OR "facilitators") AND ((("health insurance") AND ("HIV" OR "AIDS"))	TITLE-ABS-KEY (((("medical insurance" OR "health insurance") AND "access")) AND ("HIV" OR "AIDS")) AND (LIMIT-TO ( EXACTKEYWORD , "Health Insurance")) ("benefit*"OR"impact*")) AND	456 (all were screened)
<b>Barriers and facilitators to private health insurance for people living with HIV</b>		TITLE-ABS-KEY ((("barriers" OR "facilitators") AND ("health insurance") AND ("HIV" OR "AIDS"))	231 (all were screened)
<b>Predominant healthcare financing options for people living with HIV in geographical regions identified</b>	("healthcare financing") AND ("HIV" OR "AIDS"))	TITLE-ABS-KEY ("healthcare financing") AND ("HIV" OR "AIDS") AND (LIMIT-TO (EXACTKEYWORD , "HIV Infections"))	60 (all were screened)

# Annex 2

## ► Detailed HIV/AIDS: Epidemiology

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In order to assess the arguments related to the merits of inclusion or exclusion of people living with HIV from health insurance coverage it is important to examine key issues related to the epidemiology of HIV and evaluate the implications of treatments available for HIV currently and how the treatment and management of HIV in Malaysia compare with global standards.

### Global

In 2019, 38 million people globally were living with HIV and out of the total of 36.2 million adults living with HIV, 53% are women and 47% men (UNAIDS, 2020a). In 2019, 1.7 million people became newly infected with HIV. The annual number of new infections continued to decline gradually in 2019, with a 23 per cent reduction since 2010. In 2019 there were worldwide 690,000 AIDS related deaths (UNAIDS, 2020b).

Key populations including their sexual partners accounted for 62 per cent of new HIV infections globally. Key populations being sex workers, people who inject drugs, gay men and other men who have sex with men, transgender people and people in prisons or other closed settings (UNAIDS, 2020b).

In 2016, world leaders embarked on the Ending AIDS by 2030, an initiative under the United Nations General Assembly Political Declaration on Ending AIDS by 2030 (UNAIDS, 2016). The initiative was intended to end AIDS as a public health threat by 2030, by achieving dramatic reductions in new HIV infections, deaths and illness. It includes specific targets on HIV testing and treatment. The fast track targets by 2020 are for:

- 90 per cent of all people living with HIV to know their status.
- 90 per cent of all people diagnosed with HIV to receive antiretroviral therapy.
- 90 per cent of all people receiving treatment to achieve viral suppression.

In line with Ending AIDS by 2030, 81 per cent of people living with HIV globally knew their status by 2019. Among people who knew their status, 82 per cent were accessing treatment and among people accessing treatment, 88 per cent were virally suppressed (UNAIDS, 2020b).

Worldwide, tuberculosis (TB) is the most common opportunistic infection in people living with HIV and remains the leading cause of death among people living with HIV, accounting for one in three AIDS-related deaths (UNAIDS, 2019a). In 2017, it was estimated that 49 per cent of people living with HIV and tuberculosis are unaware of their co-infection and are therefore not receiving care (UNAIDS, 2019a).

### Regional

A comparison of HIV prevalence in the population aged 15 to 49 years as well in different key populations in countries selected for this report was also done and is shown in [Table 8](#). This age group was selected because it comprises the major proportion of people living with HIV in Malaysia.

In countries selected, those with a close proximity to Malaysia showed prevalence of between 0.1 per cent and 1.1 per cent in the population aged 15-49 years, in 2018. It was highest in Thailand at 1.1 per cent and lowest in the Philippines at 0.1 per cent (UNAIDS, 2019b).

For key populations, Cambodia, Indonesia, Malaysia, Philippines, Thailand and Vietnam showed a prevalence of between 11 per cent and 29 per cent among people who inject drugs. Among men who have sex with men, the prevalence was between 4.9 per cent and 25.8 per cent for Indonesia, Malaysia, Philippines, Thailand and Vietnam. For transgendered people, it was between 5.9 per cent and 24.8 per cent for Cambodia, Indonesia, Malaysia and Thailand (UNAIDS, 2019c). Singapore and Sri Lanka showed a lower prevalence in the population aged 15-49 years as well as in key populations.

In the sub-Saharan African countries selected, prevalence was between 4.7 per cent and 20.4 per cent in the population aged 15-49 years in 2018; the highest being in South Africa. South Africa and Uganda also showed high prevalence among the key populations of sex workers, people who inject drugs and people in prisons and other closed settings (UNAIDS, 2019c).

Data available in the other more developed countries selected showed a general low prevalence in the population aged 15-49 years, though prevalence in men who have sex with men was comparably high.

► **Table 8. HIV prevalence in selected countries disaggregated by key population, 2018**

Broad areas of concern	Population 15-49 years	Sex workers	Men who have sex with men	People who inject drugs	Trans-gender	Prisoners
Cambodia	0.5%	2.3%	2.3%	15.2%	5.9%	1.6%
Indonesia	0.4%	5.3%	25.8%	28.8%	24.8%	1.0%
Laos	0.3%	1.0%	2.8%	NA	NA	NA
Malaysia	0.4%	6.3%	21.6%	13.5%	10.9%	0.2%
Philippines	0.1%	0.6%	4.9%	29.0%	1.7%	NA
Singapore	0.2%	0.0%	2.2%	1.5%	NA	1.1%
Thailand	1.1%	1.7%	11.9%	20.5%	11.0%	1.2%
Vietnam	0.3%	3.6%	10.8%	11.0%	NA	NA
Brazil	0.5%	5.3%	18.3%	NA	30.0%	NA
Kenya	4.7%	NA	NA	NA	NA	NA
Sri Lanka	<0.1%	0.3%	0.2%	NA	0.5%	0.0%
Uganda	5.7%	85%	NA	26.7%	NA	15%
Nigeria	1.5%	14.4%	23%	3.4%	NA	NA
South Africa	20.4%	57.7%	18.1%	21.8%	NA	8.9%
Australia	0.1%	0.0%	18.3%	1.7%	NA	1.0%
Canada	NA	NA	NA	NA	NA	NA
Japan	<0.1%	0.0%	4.8%	0.0%	NA	NA
New Zealand	0.1%	NA	6.5%	0.2%	NA	NA
United States of America	NA	NA	14.5%	3.6%	13.7%	NA

Source: (UNAIDS, 2019c)



## Malaysia

Aligning with global aspirations, Malaysia too is committed to the United Nations Political Declaration of Ending AIDS by 2030, adopting the UNAIDS strategic guidance on Fast Tracking to reach 90-90-90 by the year 2020 in developing the implementation of the National Strategic Plan for Ending AIDS 2016-2030, giving the highest priority to achieve the fast-track target of 90-90-90 (Ministry of Health, 2019a).

It is estimated that there were 87,041 people living with HIV at the end of 2018 (Ministry of Health, 2019a) while the rate of people who have died from AIDS related causes halved from 2016 to 2018, i.e. from 16.86 per 100,000 population in 2016 to 8.3 per 100,000 population in 2018 (Ministry of Health, 2019a). New cases have declined by more than 50 per cent from 2002 to 2018, i.e. from 6,978 new notified HIV cases in 2002 to 3,293 cases in 2018 (Ministry of Health, 2019a).

In 2018, 86 per cent of people living with HIV knew their status. Of these, 55 per cent were on ART and 97 per cent of people on ART had suppressed viral loads<sup>11</sup> (Ministry of Health, 2019a), this last percentage indicates that there is a high adherence to treatment. The percentage of people on ART in Malaysia is very low and private health insurances can play an important role in reaching the 90 per cent goal.

About 90 per cent of those living with HIV are among the productive age group of 20 to 49 years and most people diagnosed with HIV are men (83%) (Ministry of Health, 2019a, UNAIDS, 2019c). The epidemic in Malaysia is concentrated in people who inject drugs, female sex workers, transgender populations and men who have sex with men. The early phase of the country's epidemic was driven by people who inject drugs, which made up the main key population at high risk (Ministry of Health, 2019a).

With regard to mode of transmission however, the trend has shifted toward sexual transmission since 2000. The group of men having sex with men is expected to become the main driver of the epidemic in the years to come beginning 2018, as projected by the Asian Epidemic Modelling (AEM) (Ministry of Health, 2019a).

Of the 3,293 new infections in 2018 in Malaysia, more than 94 per cent was by sexual transmission, with 57 per cent being homo/bisexual and 37 per cent being heterosexual. Injecting drug users, mother to child transmission and other modes comprised 6 per cent. In relation to age and gender, more than 77 per cent of new HIV infections in 2018 were reported among people aged 20 to 39 years old and 90 per cent among people 20 to 49 years old. In 2018, 88 per cent of newly diagnosed cases were male. (Information provided by the HIV/AIDS Unit, Ministry of Health).

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The percentage of people on ART in Malaysia is low and private health insurances can play an important role in reaching the 90 per cent goal.

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In 2018 in Malaysia, more than 94 per cent of HIV infection was by sexual transmission, with 57 per cent being homo/bisexual and 37 per cent being heterosexual. Injecting drug users, mother to child transmission and other modes comprised 6 per cent.

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<sup>11</sup> Viral load refers to the number of viral particles of HIV found in each millilitre of blood. With successful treatment, the virus cannot be detected in the blood and this is known as viral load suppression. When the viral load is suppressed, HIV infection is unlikely to progress to AIDS and the likelihood of transmitting the virus to partners is very low.

According to UNAIDS estimates, overall prevalence of HIV in the population of 15-49 years of age is 0,4%, whereas for sex workers, men who have sex with men, people who inject drugs and transgender people prevalence was estimated at 6,3%, 21,6%, 13,5% and 10,9% respectively.

In Malaysia, TB/HIV co-infection prevalence has hovered around 6 per cent since 2014 despite a steady increase in the number of cases of tuberculosis since 2002 (Ministry of Health, 2019a). Management of co-infection among people living with HIV has become routine in HIV management and care since 1997, incorporating TB screening among people living with HIV and HIV screening among TB patients. The number of active TB cases among newly enrolled people living with HIV had remained below 10 per cent from 2013 to 2017. In 2018 however, the proportion has increased to 19 per cent probably an indirect reflection of increased burden of tuberculosis in Malaysia (Ministry of Health, 2019a). In 2010, Isoniazid prophylaxis was started to reduce morbidity and mortality of TB/HIV co-infection. In 2018, 38 per cent of people living with HIV newly enrolled in HIV care were started on TB preventive therapy (Ministry of Health, 2019a).

# Annex

## 3

### ► Treatment and management of HIV

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#### Treatment and management of HIV/AIDS: WHO guidelines

##### Antiretroviral Therapy (ART)

Different classes of antiretroviral medicines work against HIV in different ways and when combined they are much more effective at controlling the virus and less likely to promote drug-resistance than when used singly.

Combination treatment with at least three different antiretroviral medicines is now standard treatment for all people newly diagnosed with HIV. Combination ART stops HIV from multiplying and can suppress HIV to undetectable levels in the blood. This allows a person's immune system to recover, overcome infections and prevent the development of AIDS and other long-term effects of HIV infection. ART also has an important benefit in the prevention of HIV transmission, people with an undetectable viral load cannot transmit HIV sexually.

##### When to start ART?

The WHO published guidelines on the use of ART (WHO, 2016a) after extensive review and consultations, updating the 2013 consolidated guidelines.

The recommendations (WHO, 2016a) were that:

- ART should be initiated in all adults living with HIV, regardless of WHO clinical stage and at any CD4<sup>12</sup> cell count.
- As a priority, ART should be initiated in all adults with severe or advanced clinical disease (WHO clinical stage 3 or 4) and adults with CD4 count  $\leq$ 350 cells per cubic millimetre.

First-line ART is the first choice three-drug combination of the many drugs available, for treating HIV. The WHO Consolidated Guidelines provide recommendations for preferred and alternative first-line ART regimes for adults.

The WHO Consolidated Guidelines provide recommendations for preferred and alternative first-line ART regimes for adults (See [Table 9](#)).

<sup>12</sup> CD4 cells are white blood cells, also known as T cells that play an important role in the immune system. CD4 cell count is the number of CD4 cells in a cubic millilitre of blood. The human immunodeficiency virus reduces the CD4 cell count. With successful treatment, the CD4 levels recover to normal levels.

► **Table 9. First-line ART regimens for adults, WHO recommendation**

Preferred first line regime	Alternative first line regimes
TDF + 3TC (or FTC) +EFV	AZT + 3TC + EFV (or NVP) TDF + 3TC (or FTC) + DTG TDF + 3TC (or FTC) + EFV TDF + 3TC (or FTC) + NVP

Note: TDF = Tenofovir, 3TC = Lamivudine, FTC = Emtricitabine, EFV = Efavirenz, AZT = Zidovudine, NVP = Nevirapine, DTG = Dolutegravir.

Source: (WHO, 2016a)

## Monitoring the response to ART and diagnosing treatment failure

The aim of treatment is to reduce the viral load and increase the CD4 levels, raising it to normal levels.

Viral load refers to the number of viral particles found in each millilitre of blood. To assess the effectiveness of treatment for HIV, the amount of HIV genetic material in blood or viral load is measured. With successful treatment, the virus cannot be detected in the blood and this is known as viral load suppression. When the viral load is suppressed, HIV infection is unlikely to progress to AIDS and the likelihood of transmitting the virus to partners is very low.

Routine viral load testing can be carried out at six months, at 12 months and then every 12 months thereafter if the patient is stable on ART in order to synchronise with routine monitoring and evaluation reporting (WHO, 2016a).

CD4 cells are white blood cells, also known as T cells that play an important role in the immune system. CD4 cell count is the number of CD4 cells in a cubic millilitre of blood. The human immunodeficiency virus reduces the CD4 cell count. With successful treatment, the CD4 levels recover to normal levels.

For patients receiving ART, CD4 cell count is recommended every 6 months until patients are stable on ART. In settings where routine viral load monitoring is available, CD4 cell count monitoring can be stopped in individuals who are stable on ART and virally suppressed (WHO, 2016a).

**Prophylaxis in the prevention of opportunistic infections** refers to providing medication to prevent a disease. In HIV management, two types of prophylaxis are commonly used. These are co-trimoxazole prophylaxis and Isoniazid preventive therapy.

**Co-trimoxazole prophylaxis** is used in the prevention of some AIDS-associated opportunistic diseases (Pneumocystis jirovecii pneumonia and toxoplasmosis) and reduces HIV associated mortality in people with low CD4 cell counts (WHO, 2016a).

Co-trimoxazole prophylaxis is recommended for adults with severe or advanced HIV clinical disease (WHO Stage 3 or 4) and/or with a CD4 count of  $\leq 350$  cells per cubic millimetre. Co-trimoxazole prophylaxis may be discontinued in adults with HIV who are clinically stable on ART, with evidence of immune recovery and viral suppression. Routine co-trimoxazole prophylaxis should be given to all HIV-infected patients with active TB disease regardless of CD4 cell count (WHO, 2016a).

**Isoniazid Preventive Therapy (IPT)** is the use of anti-tuberculosis medication for prevention of TB and/or management of latent TB in people living with HIV (WHO, 2016a).

WHO guidelines for IPT recommend that adults and adolescents living with HIV who have an unknown or positive Tuberculin Skin Test status and are unlikely to have active TB should receive at least six months of IPT as part of a comprehensive package of HIV care. IPT should be given to such individuals regardless of the degree of immunosuppression, or history of previous TB treatment (WHO, 2016a).

Isoniazid 300mg given daily prevents the progression of latent TB infection to active clinical disease. The use of combined IPT and ART has also been shown to have both TB prevention and mortality benefits, including in people with higher CD4 counts (WHO, 2016a).

## Pre-Exposure Prophylaxis (PrEP)

Oral PrEP is the use of antiretroviral drugs before HIV exposure by people who are not infected with HIV in order to block the acquisition of HIV (WHO, 2016a).

The WHO recommendation (WHO, 2016a) is that Oral PrEP containing TDF should be offered as an additional prevention choice for people at substantial risk of HIV infection as part of combination HIV prevention approaches.

This recommendation enables the offer of PrEP to be considered for people at substantial risk of acquiring HIV rather than limiting the recommendation to specific populations. It also allows the offer of PrEP to be based on local epidemiology and individual assessment, rather than risk group, and is intended to foster implementation that is informed by local information regarding the settings and circumstances of HIV transmission.

Substantial risk of HIV infection is provisionally defined as HIV incidence around 3 per 100 person-years or higher in the absence of PrEP. HIV incidence higher than 3 per 100 person-years has been identified among some groups of men who have sex with men, transgender women in many settings, and heterosexual men and women who have sexual partners with undiagnosed or untreated HIV infection (WHO, 2016a).

## Malaysian Consensus Guidelines

### Treatment and management of HIV/AIDS: Malaysia

Even before the first case of HIV in Malaysia was reported in 1986, the Malaysian Ministry of Health has been on the forefront, implementing strategies that strive to align with global standards. The Malaysian response to HIV started in 1985 with the establishment of the National AIDS Task Force and the National Surveillance System (Ministry of Health, 2019a).

The first National Plan for Action on AIDS was developed in 1988 with the subsequent launch of different programmes and campaigns for screening, prevention and treatment. In 2006, the First National Strategic Plan for HIV and AIDS was launched together with the provision of free first line ART to all Malaysians (Ministry of Health, 2019a).

### Antiretroviral Therapy (ART)

The Malaysian Consensus Guidelines (Ministry of Health & MASHM, 2017) recommend Antiretroviral Therapy (ART) for all HIV-infected adults (above 18 years of age), regardless of CD4 count, to reduce the mortality and morbidity associated with HIV infection.

► **Table 10. Preferred and alternative first-line regimens, Malaysian guidelines**

Preferred first line ART	Alternative regime
TDF + FTC + EFV	AZT + 3TC + EFV (or NVP) ABC + 3TC + EFV (or NVP) TDF + FTC + NVP

Note: TDF = Tenofovir, FTC = Emtricitabine, EFV = Efavirenz, AZT = Zidovudine, 3TC = Lamivudine, NVP = Nevirapine, ABC = Abacavir.

Source: (Ministry of Health & MASHM, 2017) p.21

### Monitoring while on ART

According to the guidelines adopted in Malaysia (Ministry of Health & MASHM, 2017), successful therapy is defined as an increment in CD4 cell counts that averages 50-150 cells per cubic millimetre per year. CD4 counts should be monitored 4-6 months after initiation of ART. Once viral load is suppressed and CD4 counts are more than 350 cells per cubic millimetre on two occasions six months apart, further repeat of CD4 count is not needed (Ministry of Health & MASHM, 2017).

Similarly, HIV viral load is more accurate and reliable than CD4 cell count to monitor treatment response and for early detection of treatment failure. HIV viral load is recommended for ART (Ministry of Health & MASHM, 2017):

- Just before initiation of ART.
- Every four to six months after initiation of ART to assess treatment response and for early detection of treatment failure.
- Every six to 12 months in patients who have achieved virological suppression for more than one year.
- Before changing treatment regimes.

### Prophylaxis in prevention of opportunistic infections

Aligning with global standards, co-trimoxazole preventive prophylaxis is recommended for *Pneumocystis jirovecii* Pneumonia (PJP) prophylaxis to all susceptible individuals as it has been shown to decrease the risk of PJP by nine-fold in this population. Individuals are considered susceptible in the following situations:

- CD4 count of less than 200 per micro litre or CD4 percentage of less than 14 per cent.
- Oropharyngeal candidiasis.
- Opportunistic infections or AIDS-defining illness.
- Patients who have completed successful treatment for PJP.

The total daily dose is 960mg either once daily or split into two doses per day. PJP prophylaxis may be stopped when CD4 is more than 200 per micro litre for two consecutive readings or when CD4 is 100 per micro litre to 200 per micro litre and viral load is undetectable more than once (Ministry of Health & MASHM, 2017).

With regard to Isoniazid Preventive Therapy (IPT), the Malaysian guidelines state that all patients with HIV need to be screened for active tuberculosis using standard screening tools. IPT should be offered to all HIV patients for six months, once active tuberculosis has been ruled out. IPT can reduce overall tuberculosis risk by 33 per cent. 5mg of Isoniazid per kilogram body weight is the recommended dose with a maximum dose of 300mg per day (Ministry of Health & MASHM, 2017).

### Pre-Exposure Prophylaxis

Pre-exposure prophylaxis (PrEP) is when an HIV negative person at substantial risk of HIV infection takes TDF and FTC or 3TC to prevent himself/herself from contracting the virus. It is a temporary method for reducing the chances of contracting HIV during phases of high-risk behaviour.

The Malaysian Consensus Guidelines on Antiretroviral Therapy, 2017 states that the decision to start PrEP should be made after a detailed assessment to ensure that the person is not infected with HIV and after the person fully understands the limitation of PrEP and the required adherence. More than one review may be required prior to starting PrEP and PrEP should always be used as part of a package of HIV prevention services which includes the provision of condoms and lubricants as contraception, regular HIV testing, sexually transmitted infection management and risk reduction counselling (Ministry of Health & MASHM, 2017).

PrEP is recommended for persons who are (Ministry of Health & MASHM, 2017):

- ▶ HIV sero-negative with no suspicion of acute HIV infection.
- ▶ At substantial risk of HIV infection (by history in the last six months).
- ▶ Without contraindications to TDF or FTC.
- ▶ Willing to use PrEP as prescribed and come for follow up.

## Comparison of the WHO and Malaysian guidelines for the management of HIV

Comparison of the WHO Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infections 2016 (WHO, 2016a) to the Malaysian Consensus Guidelines (2017) (Ministry of Health & MASHM, 2017) shows alignment in many/most aspects in relation to treatment of adults with HIV, especially with regard to first line regimes. Guidelines for prophylactic treatment for people living with HIV as well as for PrEP are also similar.

**Table 11** lists the comparison of the WHO global guidelines and Malaysian guidelines for treatment of HIV as well as prophylactic treatment related to HIV. It reveals that the Consensus Guidelines used in Malaysia for the treatment of HIV are essentially similar to those recommended by WHO. These include when to start treatment, details pertaining to the first line treatment regimes and monitoring of treatment.

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The clinical guidelines used in Malaysia for treatment of HIV and prophylactic treatment related to HIV align with global standards.

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► **Table 11. Comparison of guidelines between WHO and Malaysia**

Guidelines	WHO	Malaysia
<b>When to start ART</b>	All adults living with HIV (above 19 years of age), regardless of WHO clinical stage and at any CD4 cell count.	All HIV-infected adults (above 18 years of age), regardless of CD4 count.
<b>Preferred 1st line regime</b>	TDF + 3TC (or FTC) + EFV	TDF + FTC + EFV
<b>CD4 cell count</b>	Every 6 months until patients are stable on ART. Can be stopped in individuals who are stable on ART and virally suppressed.	Every 4-6 months after ART. Not needed once viral load is suppressed and CD4 counts > 350 cells per cubic millimetre on two occasions six months apart.
<b>Viral load</b>	At six months, at 12 months and then every 12 months thereafter if the patient is stable.	Every four to six months after initiation of ART. Every six to 12 months in patients who have achieved virological suppression for ≥ one year.
<b>Co-trimoxazole prophylaxis</b>	Adults with severe or advanced HIV clinical disease (WHO Stage 3 or 4) and/ or with a CD4 count of ≤350 cells per cubic millimetre.	All susceptible individuals in the following situations: - CD4 count of <200/μl or CD4 percentage of <14%. - Oropharyngeal candidiasis. - Opportunistic infections or AIDS-defining illness. - Patients who have completed successful treatment for PJP.
<b>Isoniazid Preventive Therapy</b>	Adults and adolescents living with HIV who have an unknown or positive Tuberculin Skin Test (TST) status and are unlikely to have active TB should receive at least 6 months.	All HIV patients for 6 months, once active tuberculosis has been ruled out.
<b>PrEP</b>	Oral PrEP containing TDF should be offered as an additional prevention choice for people of substantial risk of HIV infection as part of combination HIV prevention approaches.	Recommended for persons who are at substantial risk of HI infection by history in the last six months. TDF and FTC or 3TC are recommended.

Note: TDF = Tenofovir, 3TC = Lamivudine, FTC = Emtricitabine, EFV = Efavirenz, AZT = Zidovudine, NVP = Nevirapine, DTG = Dolutegravir.

Source: (WHO, 2016a and Ministry of Health & MASHM, 2017)



## Availability and cost of treatment

The cost of management of HIV in Malaysia varies depending on the facility.

### Government hospitals and clinics

According to a representative of the Ministry of Health interviewed, the cost of HIV related laboratory tests is free in hospitals and clinics under the Ministry of Health. First line treatment is also provided free of cost. With regard to second line treatment, the government provides part of the treatment free while the individual has to pay for the other part of the medication.

However, there are also agencies and organizations which subsidize treatment for people living with HIV on second line or third line treatment. These include bodies such as the Malaysian AIDS Foundation and Baitulmal related to Jabatan Agama Islam (Islamic Religious Departments) among others.

All other HIV related or non-related costs, including admissions are provided for free for people living with HIV.

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In Malaysia, treatment costs for HIV are by and large free or subsidised by the government in the Ministry of Health and Ministry of Education facilities with some exceptions. Charges at private hospitals and clinics are fully borne by the individual at the respective private rates.

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### University hospital

For hospitals under the Ministry of Education, a physician from one of the hospitals explained that in that hospital the costs of laboratory tests are to be borne by the individual. First line regime treatment is free while for second line regimes, there is a cost-sharing between the hospital and the individual. One third is borne by the individual and two thirds by the hospital.

### Private facilities

In private facilities, the full cost of treatment is borne by the individual according to the rates in the respective private facilities. A comparison of the costs of HIV medication and tests is given in [Table 12](#).

► **Table 12. Detailed HIV care costs: Diagnosis, treatment and prophylaxis**  
(Cost in RM, Ringgit Malaysia<sup>1</sup> and, between brackets, in US\$)

HIV Care aspects	Healthcare centre		
	Private (Red clinic)	Hospital (Pusat Perubatan University Malaya, PPUM)	NGO (Community Healthcare Clinic, CHCC)
<b>Diagnosis</b>			
HIV screening blood test	65 (16)	13 (3)	50 (12)
Confirmation test	300 (74) (Western Blot)	280 (69)	250 (62) (PCR)
CD4	240 (59)	120 (30)	140 (35)
Viral Load	350 (86)	280 (69)	200 (49)
FBC, LFT, RP, UFEME, FLP	50 (12)	90 (22)	60 (15)
Chest X ray	50 (12)	15 (4)	Not available
<b>Treatment for people living with HIV</b>			
First line (Tenofovir EM+Efavirenz)	300 (74)	95 (23)	280 (69)
First line (Dolutegravir +Tenofovir EM)*	990 (244)	680 (167)	960 (236)
Second line – Kaletra	Not available	410 (101)	Not available
Follow up tests (6 monthly) FBC, LFT, RP, UFEME, FLP	50 (12)	90 (22)	60 (15)
Viral load/CD4 (6-12 monthly)	590 (145)	400 (99)	340 (84)
<b>Prophylaxis</b>			
<b>Pre Exposure Prophylaxis (PrEP)</b>			
Base line tests + HIV test (Ag/ AB) * 3-6 monthly follow up with similar tests	79 (19)	100 (25)	110 (27)
Tenofovir EM	165 (41)	35 (9)	120 (39)
<b>Prophylaxis</b>			
<b>Post exposure Prophylaxis (PEP)</b>			
Base line tests + HIV test (Ag/ AB) * post 28 days follow up with similar tests	79 (19)	100	90 (22)
Tenofovir EM + Efavirenz	300 (74)	95 (23)	280 (69)
Tenofovir EM + Dolutegravir*	990 (244)	680 (167)	960 (236)

PCR = Polymerase Chain Reaction, FBC = full blood count, LFT = liver function test, RP = renal profile, UFEME = urine full examination and microscopic examination, FLP = fasting lipid profile, Ag = antigen, AB = antibody.

\* Recommended by WHO.

Information obtained from: Rosvinder Singh, 2019

<sup>1</sup> 100 RM = 24,63 US\$ (Bank Negara rates, 1 February 2020)

# Annex 4

## ► Treatment outcomes related to HIV: What is the current evidence? What do we know about people living with HIV in Malaysia?

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The first treatment for HIV/AIDS (azidothymidine or AZT) was approved by the US Food and Drug Administration in 1987 as a monotherapy. However, the benefits were only seen for a limited time and before long, HIV developed resistance to AZT (Richman, 1990). Since then, research has spurred on to focus on developing other alternative treatments with lasting results. Within ten years, other drugs were developed for HIV/AIDS. Dual antiretroviral (ARV) therapy was introduced and found to be better than monotherapy (Hammer et al., 1996, Katlama et al., 1996). However, treatment effects were still of limited duration. It was only in 1996 when the triple antiretroviral therapy (ART) was introduced that the treatment effects endured (Gulick et al., 1997). Currently, ART is also referred to as combination antiretroviral therapy (cART).

Due to a combination of price negotiations with drug manufacturers, manufacturing of generics and trade agreements, the costs of ART drugs (especially for the older first line treatments) have decreased tremendously throughout the years (Forsythe et al., 2019).

### Increase in life expectancy

#### Causes of death for people living with HIV

Generally, the probability of 12-month mortality in people living with HIV initiating ART in low- and middle-income countries has been found to be highest in sub-Saharan Africa, followed by Asia and the Americas, likely reflecting variations in the incidence of opportunistic infections, nutrition levels, socioeconomic levels, disease stage of study participants, economic levels and health infrastructure capacities in the regions (Gupta et al., 2011). Further, this systematic review and meta-analysis reported that most deaths occurred within the first three months of ART initiation, reflecting the advanced stage of HIV disease of many participants in whom ART was initiated (Gupta et al., 2011).

Overall, large and small scale empirical studies show that mortality is lower among people living with HIV who have initiated ART in more recent years (2008-2010) than in earlier years (1996-2007) (Antiretroviral Therapy Cohort Collaboration, 2017), have early initiation of treatment (Mangal et al., 2019, Tang et al., 2018, Collaboration, 2010, Chen et al., 2017) and early diagnosis (Tang et al., 2018, Chen et al., 2017).

Significantly, a population-based retrospective cohort study in Canada estimating rates of and risk factors for all-cause and cause-specific mortality from 1995 to 2014 among people living with HIV in Ontario found that the cause of death was increasingly due to common chronic conditions rather than to HIV infection itself (Burchell et al., 2019). Similar results were found in a collaborative analysis of 13 HIV cohort studies examining the causes of death in people living with HIV treated with ART between 1996 and 2006 where a little over half the deaths were non-AIDS-related (Collaboration, 2010). Another cohort study in China on patients diagnosed between 2006 to 2013 also demonstrated that early detection of HIV infection and increased uptake of ART resulted in decrease in all-cause mortality, AIDS-associated

mortality and non-AIDS-related mortality although 76.4 per cent of deaths among AIDS patients and 49.6 per cent of deaths of HIV-infected people were due to AIDS-associated diseases (Chen et al., 2017).

Examining the differences between regions, the systematic review and meta-analysis by Farahani et al (2016) on the prevalence and distribution of non-AIDS causes of death among HIV-infected individuals receiving antiretroviral therapy reveals that a significant number of people living with HIV across the world die from cardiovascular disease (CVD), non-AIDS malignancies and liver disease (Farahani et al., 2017). There are varied associated factors for these differences. For example, whereas in developing countries and sub-Saharan Africa where initiation of care is delayed and HIV associated inflammation might potentially mediate the risk of CVD (Farahani et al., 2017), the relative risk of CVD among those on ART was found to be twice that of HIV uninfected individuals and 1.5 times that of treatment naïve people living with HIV, reflecting the risks also associated with ART (Islam et al., 2012). Nevertheless, another systematic review and meta-analysis (Shah et al., 2018) on the global burden of atherosclerotic cardiovascular disease indicates that although people living with HIV are twice as likely to develop cardiovascular disease compared to individuals without HIV, the crude rate for incident cardiovascular disease is comparable to other high-risk cardiovascular groups such as diabetes mellitus. Underlining the significance of specific clinical characteristics, a systematic review and meta-analysis synthesizing the available evidence to establish the risk of myocardial infarction (MI) among people living with HIV compared with individuals without HIV found that HIV infection, low CD4, high plasma viral load, cumulative ART use in general were associated with increased risk of MI (Eyawo et al., 2019). Another study comparing a cohort of Australian people living with HIV with a cohort of people living with HIV from the Asian-Pacific countries (further divided into two groups: high/upper-middle income countries and lower-middle-income countries) showed that while AIDS and non-AIDS-related mortality rates have decreased over the past years, the risk of non-AIDS-associated deaths in the Australian cohort was higher (Jung et al., 2019). While not statistically significant, there was a consistent trend in both the high/upper-middle income countries and lower-middle income countries from the Asian Pacific countries, in that the proportion of AIDS-related mortality decreased from 2007 to 2017 and the proportion of non-AIDS-related mortality increased from 2007 to 2017.

Interestingly, a French study examining the causes of death among people living with HIV on ART and having a CD4 cell value above 500 per cells per cubic millimetre and a plasma HIV-1 RNA below 50 copies per cubic millilitre at their last periodic check-up before death between 2000 to 2010 found that non-AIDS/non-viral hepatitis-related malignancy (19 per cent), suicide (12.5 per cent), cardiovascular disease (11.5 per cent) and liver disease (11 per cent) were the main causes of death. Only three died of an AIDS-related event while socioeconomic difficulty had been reported by 41 per cent of them (Goehringer et al., 2017). This study again underscores the importance of socio-economic factors, psychosocial support and a multidisciplinary approach to achieving positive treatment outcomes, including a reduction in mortality of people living with HIV.

Nevertheless, life expectancies of people living with HIV increased over time in all studies and regions mentioned in this section due to advances in HIV treatment albeit with some variations in the clinical characteristics and socio-demographic profile of the study participants.

## Factors contributing to increased life expectancy

Emerging evidence shows that, in part, increased life expectancy has been due to advances in combination ART which is better able to control HIV replication, proffer higher genetic barriers to resistance, is less toxic, has fewer side effects and has reduced pill burden (Antiretroviral Therapy Cohort Collaboration, 2017).

Other factors such as treatment and prophylaxis for opportunistic infections and management of comorbidity, improvements in intensive care management, disease screening and health promotion have also been known to reduce all-cause mortality among people living with HIV. In terms of management of comorbidity, in spite of an elevated risk to infection associated cancer, the rates of many infection-associated cancers among people living with HIV reportedly decreased after the extensive availability of ART which restores patient immunity (Coghill et al., 2019).

## Role of ART in increased life expectancy

Overall, an increase in life expectancy was observed in many studies. Aligning with previous studies (Antiretroviral Therapy Cohort, 2008) a major study including data from 18 European and North American HIV-1 cohorts showed that life expectancy in 20-year-old patients starting ART increased by about 9 years in women and 10 years in men in the period 1996 to 2010 (Antiretroviral Therapy Cohort Collaboration, 2017).

Persons who started ART with a low CD4 cell count significantly improved their life expectancy if they had a good CD4 cell count response and undetectable viral load (May et al., 2014).

A more recent study from Switzerland showed that improvements in ART treatment increased life expectancy at age 20 years from 11.8 years in the monotherapy era to 54.9 years in the combination ART period (Gueler et al., 2017).

Furthermore, a meta-analysis which examined 57 studies involving 294,662 participants showed that 61 per cent of patients on ART survived more than one decade after the onset of AIDS (Poorolajal et al., 2016). In comparison, just 18 per cent of patients who did not receive ART survived six years and just over 50 per cent of those who did not receive ART survived less than two years after AIDS onset (Poorolajal et al., 2016).

## Life expectancy of people living with HIV compared to the general population

Interestingly, Van Sighem et al (2010), in comparing life expectancy estimates between recently diagnosed HIV-infected patients and age and sex-matched uninfected individuals from the general population projected that the life expectancy of asymptomatic HIV-infected patients who were still treatment-naive and had not experienced a CDC-B or C event at 24 weeks after diagnosis (baseline of the study) approached that of non-infected individuals (van Sighem et al., 2010). However, a significant limitation of the study was the short follow-up period (median of 3.3 years) used for the projection and the time the patients eventually started treatment was not controlled for.

The Antiretroviral Therapy Cohort Collaboration had also estimated that the life expectancy of a 20-year old person starting ART between 2008 and 2010, with a CD4 count of more than 350 cells per micro litre one year after starting ART, to be 78 years, close to the expected life expectancy of the general population (Antiretroviral Therapy Cohort Collaboration, 2017).

## Life expectancy of people living with HIV in low- and high-income countries

The above trends converge with a meta-analysis comparing life expectancy of people living with HIV after starting combination antiretroviral therapy in low/middle- and high-income countries. According to this study, life expectancy of people living with HIV after starting combination antiretroviral therapy improved over time although the gain in life expectancy in high-income countries was more than in low- and middle-income countries (Teeraananchai et al., 2017c). Nonetheless, studies in Thailand (Teeraananchai et al., 2017a) and Uganda (Mills et al., 2011) cohere with global evidence of increasing life expectancy related to being on ART. The study in Uganda showed that patients receiving combination ART were able to expect an almost normal life expectancy (Mills et al., 2011), with women having higher life expectancy compared to men. The Thai study also showed that HIV positive Thai women had a higher life expectancy compared with HIV positive men (Teeraananchai et al., 2017b). The life expectancy of HIV positive women was around 84 per cent of the general Thai female population (67.0 vs 80.0 years) and the life expectancy of HIV positive men was around 73 per cent of the general male population (53.6 vs 73.2 years) (Teeraananchai et al., 2017a). The Thai study attributed increased life expectancy to the effectiveness of combined ART as well as early initiation of treatment (Teeraananchai et al., 2017a).

## Benefits of early initiation of treatment: Increase in CD4 cell count and viral suppression

In addition to the benefits of increased life expectancy related to being on ART, evidence from a landmark study reinforced the benefits of early initiation of ART in HIV-positive adults (INSIGHT START Study Group, 2015). The INSIGHT START study demonstrated that early initiation of ART in HIV-positive adults with a CD4 count of more than 500 cells per cubic millimetre was significantly associated with a higher rate of increase of CD4 cell counts and lower serious AIDS-related and serious non-AIDS-related events compared to those for whom ART was initiated after the CD4 count had declined to 350 cells per cubic millimetre (INSIGHT START Study Group, 2015). Such a treatment strategy of initiating immediate ART across different regions in the world showed that the consequent suppression of viral replication and improvement in immune function occurred at no increased rate of adverse effects to the participants (Lundgren et al., 2015).

A similar finding of early ART initiation resulting in less AIDS progression with no increase in adverse events or loss of virologic response compared to deferred ART was also seen in another randomised strategy trial in the United States of America (Zolopa et al., 2009), while another nationwide study in Brazil revealed that viral suppression was achieved within the first 12 months of being on combination ART (Grangeiro et al., 2014). Similarly, the TEMPRANO clinical trial in Ivory Coast found that people living with HIV on the early-ART arm had nearly 50 per cent lower risk of death or severe HIV related illness (Danel et al., 2015). Importantly, a meta-analysis on the implications of rapid ART initiation (including same day initiation and initiation within two weeks) and comprising both clinical trials and observational studies also revealed that accelerated ART initiation could lead to improved clinical outcomes (Ford et al., 2018).

Other studies have found that early initiation of ART in subgroups without a history of Hepatitis B Virus (HBV) or Hepatitis C Virus (HCV) infection, drug/alcohol abuse, or smoking narrows the gap in life expectancy between people living with HIV and HIV-uninfected people, although an 8-year gap in life expectancy remains for HIV-infected compared with HIV-uninfected individuals (Marcus et al., 2016).

These findings complement the 2019 Cochrane review among people living with HIV in low- and middle-income countries which revealed a significant association between rapid initiation of ART (within a week of HIV diagnosis) and greater viral suppression, better ART uptake and improved retention in care at 12 months (Mateo-Urdiales et al., 2019).

Viral suppression refers to the reduction in a person's viral load (HIV RNA) owing to being on ART and is usually defined as having less than 200 copies of HIV per millilitre of blood (CDC, 2019). ART can even reduce viral loads to an undetectable level. Whereas persistent low-level detectable viraemia during ART has been found to increase the risk of virological failure and switch to second-line ART (Hermans et al., 2018), undetectable viral load has been significantly associated with the benefit of reducing the risk of transmission of HIV as borne out in the landmark studies by Rodger et al (2016 and 2019). The 2016 study revealed that among sero-discordant heterosexual and homosexual couples in which the HIV-positive partner was using suppressive ART (HIV-1 RNA load less than 200 copies per millilitre) and who reported condomless sex, during median follow-up of 1.3 years per couple, there were no documented cases of within-couple HIV transmission (Rodger et al., 2016). Similarly, the 2019 study also indicates that the risk of HIV transmission in gay couples is effectively zero through condomless sex when HIV viral load is suppressed (Rodger et al., 2019). Another study undertaken in 13 sites in nine countries with 1763 sero-discordant couples also showed that early ART was associated with a 93 per cent lower risk of linked partner infection than was delayed ART and no linked infections were observed when HIV-1 infection was stably suppressed by ART in the index participant (Cohen et al., 2016). These findings are significant since the global epidemic and that of Malaysia are driven by sexual transmission.

The undeniable evidence on the benefits of early initiation of ART is reflected in the WHO guidelines (since 2015) on when to start ART (World Health Organization, 2015). In the guidelines, ART is recommended to be initiated in everyone living with HIV at any CD4 cell count.

## Consequence of increased life expectancy

As early diagnosis and early initiation of treatment leads to improved CD4 count and suppression of viral replication is maintained, people living with HIV tend to manifest clinical conditions commonly associated with ageing such as cardiovascular disease, lung disease, certain cancers, HIV-Associated Neurocognitive Disorders (HAND) and liver disease (including hepatitis B and hepatitis C).

Together with the increased life expectancy of people living with HIV, other co-morbidities that would typically appear in older aged people have been observed in people living with HIV, at much younger ages (Brown and Qaqish, 2006, Chan et al., 2018, Guaraldi et al., 2011, Guaraldi et al., 2014, Hidalgo et al., 2018, Pelchen-Matthews et al., 2018, Ruzicka et al., 2018, Thrift and Chiao, 2018). These comorbidities include diabetes mellitus, cardiovascular disease, bone fractures, renal failure, hypertension and even other non-AIDS-defining malignancies. Chronic systemic inflammation and heightened coagulopathy occur in people living with HIV as a consequence of HIV infection (Deeks et al., 2013, Lederman et al., 2013). The chronic inflammation and coagulopathy are suggested to contribute to comorbidities and other non-AIDS complications such as cardiovascular disease (Farahani et al., 2017, Islam et al., 2012, McKibben et al., 2015, Shah et al., 2018) and cancer (Borges et al., 2013).

In studies around the world, co-morbidities in people living with HIV were consistently higher in comparison to non-HIV infected general population. Guaraldi et al's study comparing co-morbidities between 2,854 people living with HIV and 8,562 non-infected participants in Italy reported higher prevalence of renal failure, bone fractures and diabetes mellitus among people living with HIV, compared with controls (Guaraldi et al., 2011). A recent study in Australia of comorbidities in gay or bisexual men (median age 63 years old) reported that HIV positive men (compared to HIV negative men) were at increased odds of diabetes, thrombosis and neuropathy (Petoumenos et al., 2017). Althoff et al showed that people living with HIV from the Veterans Aging Cohort Study in the United States of America had higher incidences of myocardial infarction, end stage renal disease and non-AIDS-defining cancers (Althoff et al., 2015). A meta-analysis estimated that people living with HIV were at nearly a four-fold increased risk of renal disease compared to HIV-negative people (Islam et al., 2012). Importantly, the same study also showed that older people living with HIV (compared to younger people living with HIV), people living with HIV with lower CD4 cell counts, people with AIDS (compared to those still in HIV stage)

and people living with HIV on treatment (compared to people living with HIV who were treatment naïve) were at higher risk of renal disease.

The 'greying' of the HIV epidemic including increased life expectancy and new cases of older people living with HIV calls for a new understanding of the effect of HIV on the ageing process and the significance of ageing on people living with HIV (Harris et al., 2018).

## Benefits of ART treatment: lowered risk of comorbidities and non-AIDS related complications

At the same time, it has also been found that the benefit of ART treatment extends to lowering the risk of comorbidities and non-AIDS-related complications. ART also attenuates the advent of HIV associated neurocognitive disorders (HAND) (Heaton et al., 2011, McArthur et al., 2004). HAND is used to describe neurocognitive disorders (the most severe form being severe dementia) among people living with HIV treated with ART (Ahluwalia et al., 2015). Neurocognitive disorders (or cognitive impairment) can occur in up to 50% of HIV patients (Schouten et al., 2011). While the pathology of HAND is not fully understood, it has been hypothesised that HIV infection together with the subsequent host immune response and inflammation likely augment the development of HAND (Ahluwalia et al., 2015). Other studies measuring biomarkers in people living with HIV have shown that ART reduced systemic inflammation (Baker et al., 2011, Guaraldi et al., 2013, Sereti et al., 2017, Tomita et al., 2015) and coagulopathy (Sereti et al., 2017), but not to the extent of levels in HIV-negative individuals (Sereti et al., 2017). A significant consequence of systemic inflammation in people living with HIV is the development of non-AIDS-related co-morbidities (Sokoya et al., 2017, Appay and Sauce, 2008), further strengthening the association between ART, lowered systemic inflammation and lowered risk of comorbidities.

There is some, albeit limited evidence linking ART to better outcomes for non-AIDS defined co-morbidities in people living with HIV. Castillo-Mancilla et al.'s study (2018) demonstrated that higher adherence to ART corresponded to lower levels of inflammatory and coagulatory markers of people living with HIV in Uganda (Castillo-Mancilla et al., 2018). Al-Khindi et al.'s meta-analysis of 23 studies showed that ART was associated with some measures of neurocognition in people living with HIV and the extent of improvement correlated with CD4 cell count improvement following ART initiation (Al-Khindi et al., 2011). Al-Khindi et al.'s results suggested that improvement of cognition was linked to the integrity of the immune system.

Taking a different approach, investigators in the Strategies for the Management of Antiretroviral Therapy (SMART) study compared the episodic use of ART guided by CD4 cell count with continuous ART (Samji et al., 2013, Strategies for Management of Antiretroviral Therapy Study et al., 2006). However, in the SMART study, increased risk of liver, cardiovascular, renal and cancer events were found in the episodic ART arm instead. Deeks and Phillips suggest that the results from the SMART study showed that the risk of non-AIDS-related morbidity (liver, cardiovascular, renal and cancer events) and mortality were higher in untreated HIV infection (Deeks and Phillips, 2009).

The benefits of ART for people living with HIV extend beyond the management of HIV symptoms and progression. While ART controls the disease progression effectively, the HIV infection in itself carries long term consequences (accelerated ageing and increased risk of comorbidities) that are showing up in the people living with HIV who survived well with treatment. The evidence so far showed that people living with HIV on ART may also lower the risk of these consequences, compared to not being on ART



## Pre-exposure Prophylaxis (PrEP) for HIV-uninfected persons at substantial risk of HIV infection

A significant advance in relation to preventing HIV transmission has been the role of pre-exposure prophylaxis (PrEP). PrEP refers to the use of antiretroviral medications by HIV-uninfected individuals to prevent the acquisition of HIV. PrEP does not, however, prevent the transmission of other sexually transmitted infections.

In a recent population level study by Grulich et al (2018) in Australia, PrEP via co-formulated tenofovir disoproxil fumarate and emtricitabine given to a proportion of men who have sex with men was effective at reducing the number of HIV diagnoses in the community by 25 per cent (Grulich et al., 2018).

In an earlier randomised trial of oral ART as PrEP in 2012 (Baeten et al) among HIV-1-serodiscordant heterosexual couples from Kenya and Uganda where the HIV-1-seronegative partner in each couple was randomly assigned to one of three study regimens, namely, once-daily tenofovir (TDF), combination tenofovir-emtricitabine (TDF-FTC), or matching placebo and followed up for 36 months, it was found that TDF, combination TDF-FTC, both, were effective in protecting against HIV-1 infection (Baeten et al., 2012). Similarly, a review of 12 randomised controlled trials by Okwundu, Uthman, & Okoromah (2012) also showed that pre-exposure prophylaxis with TDF alone or TDF-FTC reduces the risk of acquiring HIV in high-risk individuals including people in serodiscordant relationships, men who have sex with men and other high-risk men and women (Okwundu et al., 2012).

A randomised clinical trial using a combination of daily, oral tenofovir disoproxil fumarate and emtricitabine as PrEP in the United States found that HIV transmission was extremely low among men who have sex with men and transgender persons, despite a high incidence of sexually transmitted infections (STIs) (Liu et al., 2016). Aligning with this study, the uptake of PrEP on men and transgender women who have sex with men also showed a reduction in HIV transmission related to the use of HIV pre-exposure prophylaxis (Grant et al., 2014). Likewise, experience with increasing PrEP use in a clinical setting showed that there were no new HIV infections despite high rates of STIs and reported decreases in condom use (Volk et al., 2015).

The above evidence on the effectiveness of PrEP is evidenced through a systematic review and meta-analysis which concluded that PrEP is protective against HIV infection across populations, presents few significant safety risks and there is no evidence of behavioural risk compensation. (Fonner et al., 2016). Behavioural risk compensation can be defined as an intentional increase in risk behaviours following the initiation of disease prevention modalities known to be effective.

The effectiveness of PrEP as an HIV prevention strategy is however contingent upon certain factors such as, adherence (Grant et al., 2014, Marrazzo et al., 2015), uptake, sexual practices, PrEP being made available free of charge by experienced providers (Grant et al., 2014) and availability of interventions that address racial and geographic disparities and housing instability (Liu et al., 2016).

Barriers to PrEP uptake include persistent concerns about side effects, the overly onerous clinical engagement that is required and importantly, stigmatizing or unfriendly health services for key populations (Eakle et al., 2019). Barriers cited by other researchers include side effects of the medication usually in the initial period of treatment, stigma, rumours and relationship difficulties related to being perceived as HIV positive, complexities of daily life, especially post-coital dosing adherence suffered from alcohol use around the time of sex, belonging to mobile population groups and engaging in sex work (Van der Elst et al., 2013). Finally, risk compensation (Jenness et al., 2017) was found to be another factor that compromised the effectiveness of PrEP. However, randomised placebo-controlled trials undertaken by McCormack et al (2016) and Mugwanya et al (2013) demonstrate that PrEP provided even higher protection against HIV than in placebo-controlled trials (McCormack et al., 2016) and did not bring about increase in incident sexually transmitted infections or pregnancy in spite of a significant increase in unprotected sex with outside partners (Mugwanya et al., 2013).

In 2015, the WHO recommended the use of daily oral PrEP as a prevention choice for people at substantial risk of HIV infection as part of combination prevention approaches (World Health Organization, 2015). The recommendations were based on a systematic review and meta-analysis of 11 randomised controlled PrEP trials containing TDF. The analysis demonstrated that PrEP is effective in reducing the risk of acquiring HIV infection across age, gender, regimen (TDF versus FTC + TDF) and mode of acquiring HIV (rectal, penile or vaginal). However, the level of protection appears to be strongly correlated with adherence.

## Role of adherence to treatment in maintaining improved health outcomes for people living with HIV

The above evidence indicates that subject to adherence to treatment, ART can significantly improve the overall health status, life expectancy and survival, economic status and quality of life of people living with HIV. In order to maintain good health and optimise medical costs in people living with HIV, access and adherence to ART are crucial factors, including to scale up prevention efforts.

Overall, the key to longer survival time is access and adherence to ART. The Cochrane review cited earlier (Mateo-Urdiales et al., 2019) reports that early initiation of treatment also had positive benefits on treatment adherence. However, factors affecting the access and adherence to HIV treatment are complex.

Barriers to access include (but are not limited to) stigma, poor disease knowledge, logistic issues, high treatment costs and lack of medical insurance (Ankomah et al., 2016, Dombrowski et al., 2015, Koirala et al., 2017, Yehia et al., 2015).

In a peer reviewed study, based on 15 programmes across Asia, Africa and South America with over 5,000 patients pooled for the analysis, higher probability of treatment drop-outs were found in fee-for-service programmes compared to free treatment programmes in developing countries (Brinkhof et al., 2008), although ARV is free in many countries. Financial cost is one of the main barriers to accessing HIV treatment and care. Systematic reviews on treatment adherence to ART have identified factors such as alcohol use, male gender, use of traditional/herbal medicine, dissatisfaction with healthcare facility and healthcare workers, depression, discrimination and stigmatisation and poor social support as significant in sub-Saharan Africa (Heestermans et al., 2016). Binford et al (2012) in reviewing evidence related to treatment adherence in people living with HIV with drug use found that directly administered antiretroviral therapy, medication-assisted therapy (MAT), contingency management and multi-component, nurse-delivered interventions provided short-term adherence and positive virologic outcomes only as long as the intervention lasted (Binford et al., 2012).

Thus, healthcare financing in relation to people living with HIV is an important component of access to healthcare, adherence to treatment and consequent accrual of the medical and health and economic benefits discussed above.

It is important to note however that a simulation study by Braithwaite et al. using data from Veterans Health Administration database in the USA demonstrated that regardless of adherence levels (ranging from 50 per cent to 100 per cent of dose consumption), early ART initiation still increased life expectancy for people living with HIV (Braithwaite et al., 2009).

## Evidence from Malaysia

Although data for Malaysia is sparse, a recent study by Ngah et al documented poor survival time of 1,295 AIDS patients whose records were extracted retrospectively from the Malaysian National AIDS Registry (Ngah et al., 2019). Median survival time (from diagnosis between years 2010 to 2014) was 11 months, with survival probabilities of 49.1 per cent, 47.8 per cent, 47.3 per cent, 47.0 per cent and 46.7 per cent in one-year, two-year, three-year, four-year and five-year periods respectively. Significant prognostic factors were age of 30-49 years, being male, unemployed and having HIV-TB co-infection. There was no mention of treatment status in this study although it is known that subsidised treatment was already available at this time in the country.

In contrast, other Malaysian studies on people living with HIV on ART treatment showed much higher survival time. Lubis et al's study (Lubis et al., 2013) was based on records of 845 patients living with HIV from a large teaching hospital in Malaysia from 1989 to 2009, among whom 74.1 per cent had been on ART with triple drugs or more (2 NRTI+1 NNRTI). This study reported that 72.7 per cent of the patients survived and the mean survival time was 130.9 months; while 64.5 per cent achieved VL $\leq$ 50 copies per millilitre. Significant independent predictors of death in HIV-infected patients on ART were an age of  $\geq$ 50 years, having at least secondary and tertiary education, unemployment, initial presentation of AIDS, starting ART with single or double drugs and inability to achieve viral load  $\leq$ 50 copies per millilitre. The difference in the survival may be due to the treatment effect of ART, as Ngah et al's study would have had patients who were not on ART as well as those on ART compared to the other Malaysian studies where all patients were on ART.

More significant was Mat Shah et al's retrospective cohort study which was the first attempt to evaluate the effectiveness of ART in Malaysia, based on records from the Infectious Diseases Clinic, Hospital Sungai Buloh from 1997 to 2008, which were then matched with the National Registration Department Death Records 1997 to 2008 and Selangor State HIV/AIDS/Death Surveillance database from 1997 to 2008. This study found that patients not on ART had a median survival duration of 19 months (Mat Shah et al., 2012). In direct comparison, 75 per cent of patients on ART were estimated to live for up to 11 years in comparison to 75 per cent of patients who were not on ART and were estimated to have a survival time of eight months. The ART group had a lower all-cause mortality rate and AIDS-defining events (Mat Shah et al., 2012).

More recently, Lee et al's retrospective cohort study (Lee et al., 2019) based on 339 people living with HIV patients at Hospital Sungai Buloh who had initiated ART between 2007 and 2016 reported overall survival rates of 95.9 per cent, 93.8 per cent, 90.4 per cent, 84.9 per cent and 72.8 per cent at six months, one year, three years, five years and ten years, respectively. Patient data (n=8,757) on baseline CD4 count at presentation to care of HIV patients from the same hospital (Hospital Sungai Buloh) showed that the proportion of late presenters (defined as CD4 cell count less than 200 cells per micro litre) had decreased throughout the years (from 57 per cent in 2007 to 44 per cent in 2016). However, the proportion of late presenters was still significant. Nonetheless, the earlier presentation to care and treatment may contribute to more favourable survival rates (Lim and Kumar, 2019).

Although the research on treatment outcomes for people living with HIV in Malaysia may not be as extensive, the emerging body of knowledge indicates that people living with HIV are able to achieve positive outcomes when they are on ART. Adopting WHO guidance and policy, the Ministry of Health Malaysia also recommends ART for all HIV-infected individuals, regardless of CD4 cell count, to reduce the morbidity and mortality associated with HIV infection and also to prevent HIV transmission (Ministry of Health & MASHM, 2017). In addition to the recommendations related to management of the clinical symptoms, the Malaysian Consensus Guidelines on ART 2017 also provides guidance to assess and provide support related to the psycho-social dimensions of illness and treatment and to support patient autonomy and participation in the treatment process. Acknowledging that more research on treatment outcomes for people living with HIV in Malaysia would bring about a more nuanced understanding of the issue, it can also be inferred that with robust access to treatment, early initiation of ART and the required support services, the prognosis for people living with HIV in Malaysia could be good, allowing them to live productive lives.

In one of the main teaching hospitals in Malaysia, a study comparing people living with HIV (n=336) and controls who were non-HIV infected members from the community (n=172) (Rajasuriar et al., 2017) mirrored findings from around the world (Althoff et al., 2015, Guaraldi et al., 2011, Islam et al., 2012, Petoumenos et al., 2017) where premature ageing and increase in non-AIDS related comorbidities were found in people living with HIV. In the Malaysian study, people living with HIV were found to have a higher burden of geriatric related conditions (Rajasuriar et al., 2017).

Malaysia contributed a significant number of patients (n>500) to a large multi-country observational registry of people living with HIV (TREAT Asia - Therapeutics Research, Education and AIDS Training in Asia). While not statistically significant, one of the studies conducted using data from TREAT Asia (which included data from Malaysian people living with HIV) had reported that the proportion of AIDS-related mortality decreased from 2007 to 2017 and the proportion of non-AIDS-related mortality increased from 2007 to 2017 (Jung et al., 2019).

Thus, the advent of combination ART has brought about a shift in the HIV epidemic, changing HIV from a fatal disease to a chronic condition that can be managed with appropriate medication and adherence.

## Treatment outcomes with regard to people living with HIV participants in the study

This similar trend was evidenced in the narratives and records of the people living with HIV who had been interviewed in this study. As mentioned earlier, 14 people living with HIV participated in the depth interviews. The earliest diagnosis was in 1994 while the most recent was a few months before the interview.

**Table 13** provides details of the study participants' year of diagnosis, CD4 count, viral load and treatment payment details.

► **Table 13. Treatment outcomes of people living with HIV interviewed in the study**

PLHIV	Year of diagnosis	CD4 at diagnosis	Viral load at diagnosis	Present treatment	Latest CD4	Latest viral load	Payment for treatment
R5	2009	>1000	NA	1st line	600+	Undetectable	Free
R6	1995	NA	NA	2nd line	NA	Undetectable	Self
R7	2018	200+	NA	1st line	400+	Undetectable	Free
R8	2014	175	High	1st line	NA	Undetectable	Free
R9	2014	200+	NA	2nd line	NA	Undetectable	Free
R10	2019	300+	NA	1st line	NA	NA	Free
R11	2017	356	1038	1st line	NA	Undetectable	Free
R12	2017	100+	NA	1st line	NA	Undetectable	Free
R13	2012	400+	NA	2nd line	NA	Undetectable	Shared
R14	1994	149	NA	2nd line	839	Undetectable	Shared
R15	2016	222	Millions	2nd line	NA	Undetectable	Free
R16	2008	7	284,000	1st line	886	Undetectable	Free
R17	2008	230	NA	1st line	660	Undetectable	Free
R18	2011	Normal	Normal	1st line	800+	Undetectable	Free

Note: NA = Not Available

All the interviewees were on treatment, with nine on first line ART and five on second line ART. The medication was taken either as a once daily or twice daily dosage.

Eight had CD4 levels below 300 per cubic mm on diagnosis, while three had symptoms of AIDS when starting treatment, like oral thrush or pneumonia.

Currently, 13 of the 14 people living with HIV interviewed had undetectable viral loads. Six had normal CD4 levels while seven more had not taken a CD4 test recently as the viral load was stable over a period of time, following the guidelines stated previously. The interview participant who was diagnosed recently had an initial CD4 of more than 300 cells per cubic millimetre and was awaiting the viral load test result.

In discussing their treatment experiences and treatment outcomes, the people living with HIV participants in the study raised many issues. Some of the significant themes that emerged included:

1. Side effects of medication.
2. Health status.

## Side effects of HIV medication

The side effects of HIV medication ranged from mild to severe. Most often, mild to moderate side effects resolved on their own. Where the side effects were severe, the physician usually changed the medication in keeping with the accepted practice that aligned with improvement in treatment.

Initially, three persons had side effects on first line medication. These side effects such as rashes or dizziness got resolved over a period of time. Three more reported that they had changed to a different first line medication because it was affecting the liver, kidney or nerves. Another five people changed to second line medication due to side effects like depression, allergic reactions or effects on the liver or kidneys. These side effects were either absent or stabilised after the change to second line medication.

Most people living with HIV interviewed had no or minimal side effects. When asked if he had experienced side effects with the first line medication he was taking, participants R7 replied that he didn't experience much except some dizziness if he stayed awake beyond 1 am. His activities before that were not affected.

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▶▶ Didn't have. Even at night, I play games, play badminton also, OK. Because I usually take the medicines at 10.30pm, that's when I start playing badminton. That's what I'm saying, I take the medicines but I don't feel anything. I play as usual. (R7)

Another study participant stated:

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▶▶ I consider myself very lucky, because I only had side effects for the first two to three weeks. With Efavirenz. Floating, dizziness, after two to three weeks, then it was OK. Only that. (R8)

Respondent R10 had some side effects affecting the digestive tract initially. These got resolved on their own. He also had some rashes that also resolved after a break in the first line medication for a week.

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There have been reactions to the drugs. I had bloating but it resolved by itself. It was for a week with not much appetite and diarrhoea. It wasn't serious. I still eat on time but didn't feel like eating a large portion. Prior to the diarrhoea and bloating, I also developed rashes. Doctor advised me to stop the yellow/orange pill for one week and then I started again. It's been fine until now. (R10)

Two study participants, however, had more severe side effects. These were mainly Stevens-Johnson Syndrome (SJS, a type of severe skin reaction), suicidal thoughts and depression. However, both evidenced improvement of the side effects after changing to second line ART. Interviewee R9 who had variously experienced gut symptoms, depression and SJS which all resolved with changing of medication, stated:

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My journey, taking the medication is not smooth. First, I was on Efavirenz, but I developed vomiting and nausea and most important, depression. So, I stopped it, then I felt OK. After taking Nevirapine, I was normal and discharged from psychiatry. But only for a week. After that I started to have a fever and rashes and they withdrew me from Nevirapine and discharged me with Raltegravir. Now OK, feels good. (R9)

R6 too, had a similar experience with second line ART. His physician had asked him to change medication as his cholesterol was increasing and he felt a big difference after changing the regime.

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So, I went on second line, I think early 2018. Almost two years now. Oh my god, what a great change it was. No side effects, oh my gosh, it's like eating Panadol. You know, I don't know how to explain it to people. It's like, the first line, is still something. I take it about 9pm and then you know, if I ever... Cos I also travel, flights and all. So difficult. There's always something. Dizziness, nausea, there's always something that comes. But, second line, it was nothing. (R6)

## Health Status

As **Table 13** shows, except for one person living with HIV who had only recently known his HIV status and was awaiting his viral load results, all the other people living with HIV study participants were adherent to treatment and had achieved viral load suppression.

Additionally, many of them stated that they were in much better health than before, with some admitting that the routine follow-up and testing which were part of the HIV treatment and care they were receiving, were significant factors in enabling them to maintain good health.

One study participant who stated that he remains healthy with no current side effects explained that he felt healthier as he had regular check-ups and had not gone on medical leave since his diagnosis two years prior to the interview.

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▶▶ I feel like I can live just like a normal person and in fact I think I am healthier because my health condition is monitored every 6 months - whether my sugar level is increased, or if my cholesterol is increased. So, the doctor is having all that data and is keeping us in check every step of the way. Every 6 months we have blood tests and meeting with the doctor. The good news is that was my last hospitalization (at diagnosis) and until today, I don't remember taking any medical certificate. (R11)

Another study participant who had switched to second line treatment also stressed that he felt healthier as he has regular check-ups and takes care of his health.

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▶▶ I exercise. I think people living with HIV are a lot healthier than those people who are not positive. Because you have medical check-up every half a year. You know what I mean right, because we know our condition, we have to take care of ourselves. We have to eat well, sleep well, exercise regularly. We know how to take care of ourselves. (R5)

# Annex 5

## ► Health expenditure for HIV

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### National health expenditures and financing for HIV

In South Africa, as in some other countries in Africa where there is a proliferation of private health insurance, government expenditure on health has remained relatively constant and consistently lower than the 15 per cent Abuja Declaration target of the African Union. When the share of health in the country's GDP rose marginally from 8.3 per cent in 1995 to 8.8 per cent in 2014, it was largely attributed to the increase in private health insurance coverage (Ataguba and McIntyre, 2018). As a source of healthcare financing, its contribution is 46.9 per cent of current health expenditure (WHO, 2016c). Currently, efforts are being made to reduce the role of the private sector in healthcare financing in South Africa as it prepares for a national health insurance scheme.

In Brazil, private health insurance coverage increased from 17.6 per cent to 24.8 per cent of the population between 2000 and 2014. However, it decreased to 22.8 per cent of the population in 2017 following dips in income and employment levels (Massuda et al., 2018). According to 2016 data from the WHO (WHO, 2016c), private insurance comprised 28 per cent of current health expenditure in 2016 (WHO, 2016c). The drop in unemployment rates and increase in the share of formal sector employment has been attributed to the increased role of private health insurance in healthcare spending in Brazil (Dmytraczenko et al., 2015).

In Kenya, the proportion of private health insurance in current health expenditure was 11 per cent (WHO, 2016c) and is concentrated in the affluent population group (Munge and Briggs, 2013).

In the Philippines, since the establishment of the Philippine Health Insurance (PhilHealth) which claims to cover 92 per cent of the population, Filipinos, especially the indigent, have other healthcare financing options. By introducing the "Sin Tax" in 2012 on tobacco and alcohol, the government raised more than US\$1.2 billion within the first year, allowing the enrolment of an additional 14 million families or about 45 million Filipinos into PhilHealth (Obermann et al., 2018). However, increasing by over 60 per cent between 2009 and 2014, (Dayrit et al., 2018), private health insurance accounted for 10.6 per cent of current health expenditure (WHO, 2016c).

In Malaysia, the WHO data in **Figure 1** puts the share of private health insurance at 10 per cent of the current health expenditure (WHO, 2016c). According to the Malaysia National Health Accounts, private health insurance comprises about seven per cent of THE and about 15 per cent of private sources of funding (Ministry of Health, 2019b)

On the other hand, private voluntary health insurance in Indonesia comprises 3.5 per cent of current health expenditure (WHO, 2016c), with its share in overall healthcare financing falling with the advent of the social health insurance programme, Jaminan Kesehatan Nasional (JKN) in 2014. However, employers contributing under the compulsory health insurance for corporations covering formal labour (Jamsostek) are allowed to opt out and buy private health insurance for the employee, as long as this process is efficient (Mahendradhata et al., 2017).

Similarly, in Thailand too, private health insurance contributes to 6.6 per cent of the current health expenditure (WHO, 2016c) and only covers around two per cent of the population, offering similar benefits to the three health financing schemes covering civil servants, private sector employees and the rest of the population which is covered by the Universal Coverage Scheme (UCS). Private health insurance, though, offers more choices of private hospitals in Thailand (Jongudomsuk et al., 2015).

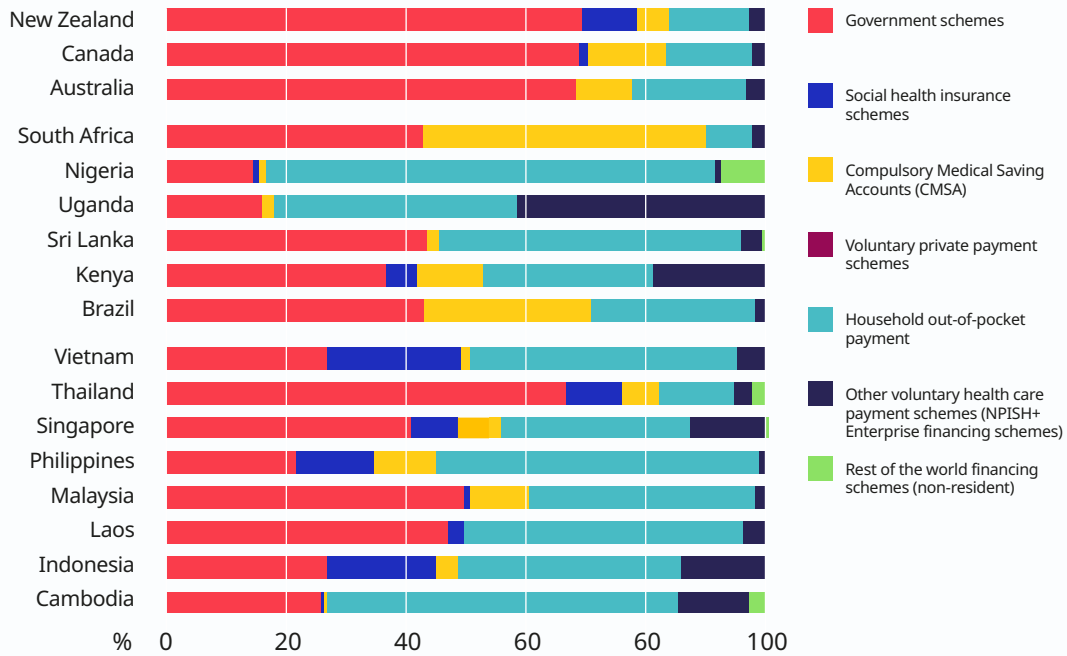


However, a major reform that Thailand undertook in terms of private insurance, in general, was to set up the independent state agency, Office of Insurance Commission (OIC) in 2007 under the 2007 Insurance Business Regulation and Support Act. The OIC is a juristic entity with a mission to regulate and develop insurance business and to protect the insurance benefits and rights of the people, similar to the Bank of Thailand and the Office of the Securities and Exchange Commission. The OIC has taken over the regulation of insurance business, which had previously been in the Department of Insurance of the Ministry of Commerce. It is tasked to facilitate market penetration for insurance companies and also protect the rights of consumers, particularly increasing access of low income and rural populations to insurance (Jongudomsuk et al., 2015).

Following suit, in Cambodia, after the closure of all private health insurance schemes under the Pol Pot regime, in 1992, the National Assembly adopted a law on insurance allowing a small number of insurance companies, mostly foreign owned, to operate. However, at 0.6 per cent of the current health expenditure, its coverage is insignificant (Annear et al., 2015). Here too as in Vietnam, social health insurance eclipses other forms of healthcare financing for the general population. In 2017, the Ministry of Health in Vietnam issued a circular to facilitate the management of antiretroviral (ARV) drugs that are procured using the Social Health Insurance (SHI) fund, with the first ARV drugs procured through SHI planned for early 2019 (USAID, 2018).

In high-income countries private health insurance is often acquired by those who can afford it and as an additional basket of benefits to those provided by public healthcare financing programmes (WHO, 2013).

► **Figure 4. Current health expenditure (CHE) in select countries by sources of financing (%), 2016**



Notes:

1. NPISH = Non-profit institutions serving households, refers to the funds allocated from government domestic revenues to financing schemes operated by institutional units other than government units.
2. Enterprise financing schemes primarily include arrangements where enterprises provide or directly finance health services for their employees (such as occupational health services), without the involvement of an insurance-type scheme.

Source: WHO Global Health Expenditure Database (<http://apps.who.int/nha/database/Home/Index/en> - (accessed 6 Dec. 2019)

What this indicates is that total health expenditures as a proportion of GDP and public health expenditures, in general, are higher in high-income countries with some exceptions like Thailand, which have significant levels of public spending on health. Most upper-middle-income countries such as Brazil, Malaysia, Singapore and Thailand are fully or nearly fully domestically self-financed for their overall healthcare needs while countries like Cambodia, Kenya, Nigeria and Uganda (Table 6) rely more heavily on external aid. In this context, as seen earlier, the private health insurance sector has a ubiquitous presence across low, middle- and high-income countries although its share in the current health expenditure (Figure 4) varies between countries. It also makes a noteworthy contribution to health spending in the respective countries. The comparable significant proportion of private health insurance in the current health expenditure in Malaysia (10.6 per cent) with countries such as Philippines (10.6 per cent), Kenya (11 per cent), or Canada (13 per cent) shown in Figure 4, cannot escape attention. However, overall, within countries in the ASEAN like Vietnam, Thailand and even the Philippines, social health insurance seems to be the dominant option to provide access to healthcare with financial protection. In fact, (see Figure 4), although the share of private health insurance in the overall health spending is higher in the Philippines (10.6 per cent) than in Malaysia (10.1 per cent) or Thailand (6.6 per cent), the market penetration rate of health insurance is higher in Malaysia and Thailand compared to Philippines, Indonesia or Vietnam, with

this association probably being a function of the country's economic development level (Chassat, 2013). Yet, as seen in the previous section, market penetration in Malaysia is far from optimal, indicating the lurking potential for expansion of private health insurance in the country. In middle- and low-income countries, private medical and health insurance seems to be focussed within the upper income and formal sector employment groups.

## Financing for HIV

With regard to the role of external aid in HIV financing, the pattern changes. Although external aid could be driven by economic and epidemiological reasons, analysing global trends in healthcare spending, Xu et al (2018) demonstrate that spending from external sources to combat HIV is not clearly related to national HIV prevalence or income with some middle-income countries oftentimes receiving more than low-income countries in aid for HIV (Bavinton et al., 2018).



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